TREATMENT OF PAIN AND SUFFERING IN THE TERMINALLY ILL

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INTRODUCTION

SECTION I -- PAIN
CHAPTER 1. PAIN IN THE TERMINALLY ILL

1.01 Pain in Cancer and Other Terminal Illnesses; Introduction

1.02 The Nature of Pain

1.03 Common Sites and Types of Non-Local Cancer Pain

   A. Pain of Neurological Origin
   
   B. Bone Pain
   
   C. Abdominal Pain
   
   D. Lesions of the Mouth

1.04 Pain as a Consequence of Surgery and Diagnostic Procedures

1.05 Pain in Patients With AIDS

1.06 Pain in Other Conditions

1.07 Pain in Special Populations

   A. The Elderly
   
   B. Children
   
   C. Minorities

1.08 Early Discussion of Pain Management with Family

1.09 Basic Information About Pain Therapy

1.10 Measuring Pain
1.11 Evaluating Pain; Form

1.12 The Pain Treatment Plan; Form

1.13 Overall Success of Pain Therapy

1.14 AHCPR (DHHS) Guidelines

1.15 AHCPR (DHHS) Statement on Patient Education

CHAPTER 2. PAIN THERAPY USING DRUGS

2.01 Drug Therapy of Pain; Introduction

2.02 The Ladder Approach

2.03 Non-Narcotics

   A. Aspirin and Acetaminophen

   B. Newer NSAIDs

2.04 Narcotics: In General

2.05 Routes of Administration

   A. Intravenous Injections

   B. Subcutaneous Infusion under the Skin

   C. Intramuscular Injections

   D. Oral Administration

   E. Buccal Mucosal Administration
F. Rectal Administration

G. Transdermal Administration

H. Nasal Administration

I. Administration into the Central Nervous System

2.06 Opioids in the Ladder Approach

2.07 Opioid Narcotics; Method of Action

2.08 Different Opioid Narcotics

2.09 Different "Potent" Opioid Narcotics

   A. Morphine
   
   B. Hydromorphone (Dilaudid)
   
   C. Methadone (Dolophine)
   
   D. Fentanyl (Duragesic or TDS-Fentanyl)
   
   E. Levorphanol (Levo-Dromoran)
   
   F. Meperidine (Demerol)

2.10 Patient-Controlled Analgesia (PCA)

2.11 General Principles of Narcotic Use

2.12 Dose and Choice of Narcotics

2.13 Side Effects of Narcotic Administration
2.14 Treatment of Narcotic Side Effects

A. Constipation

B. Nausea and Vomiting

C. Sedation

D. Mental Clouding

E. Respiratory Depression (decreased breathing)

F. Subacute Overdose

2.15 Influence of Concurrent Medical Conditions on Pharmacotherapy

2.16 Narcotic Tolerance and Addiction

2.17 Adjuvant Drug Therapies

A. Corticosteroids

B. Anticonvulsants

C. Antidepressants

D. Other Drugs

2.18 Reversible Medication Failures

2.19 Inadequate Pain Therapy/Health Care Providers

A. Educational Failures
B. Inadequate Pain Assessment

2.20 Inadequate Pain Therapy/Social Problems/Patients

A. Under-Reporting of Pain by Patients

B. Inappropriate Administration of Pain Medication

2.21 Inadequate Pain Therapy/Social Problems/Cultural and Religious

A. Misunderstanding of Religious Principles

B. Problems of Communication

2.22 Inadequate Pain Therapy/Social Problems/Cost-Containment

2.23 Inadequate Pain Therapy/Social Problems/Poor Communications

2.24 Inadequate Pain Therapy/Legal Problems

A. Threatened Recriminations

B. Practical Difficulties

2.25 Summary

APPENDIX

Table 1 NSAIDs

Table 2 Opioid Narcotics, Comparison of Methods of Administration
CHAPTER 3. MECHANICAL TREATMENT OF PAIN

3.01 Mechanical Treatment of Pain; Introduction

3.02 Tumor Surgery

3.03 Surgical Nerve Intervention and Anesthetic Blocks

3.04 Radiation

CHAPTER 4. ALTERNATIVE THERAPIES FOR PAIN

4.01 Physical and Psychological Modalities in Pain Relief; In General

4.02 Slow Rhythmic Breathing For Relaxation

4.03 Psychosocial Intervention

4.04 Cutaneous Stimulation

4.05 Exercise/Positioning

4.06 Massage Therapy

4.07 Acupuncture

4.08 Relaxation and Imagery

4.09 Distraction and Reframing
Treatment of Pain and Suffering in the Terminally Ill

4.10 Hypnosis

4.11 Pastoral Counseling

4.12 TENS Therapy

4.13 Peer Support Groups

SECTION II -- SUFFERING

CHAPTER 5. INTRODUCTION: SUFFERING IN THE TERMINALLY ILL

5.01 Suffering in the Terminally Ill; In General

5.02 Definition: What is Suffering?

5.03 Treating Suffering Related to Pain

5.04 On Death and Dying/Adapting to the Reality of Death

5.05 Suffering in the Terminal Illness and End-Stage Disease
   A. End-Stage Physical Suffering
   B. Mental Suffering
   C. Existential Suffering

5.06 Effects of Suffering on Others
CHAPTER 6. SUFFERING FROM PHYSICAL SYMPTOMS OTHER THAN PAIN

6.01 Physical Symptoms Other than Pain; In General

6.02 Symptoms Related to Digestion

A. Nausea and Vomiting
B. Constipation
C. Diarrhea
D. Loss of Appetite and Weight Loss
E. Trouble Swallowing
F. Dry Mouth
G. Nutrition and Hydration

6.03 Problems with Breathing and the Lungs

A. Shortness of Breath
B. Cough
C. Hiccough
D. Secretions

6.04 Neurologic Problems

A. Insomnia
B. Confusion, Delirium and Dementia

C. Terminal Restlessness

D. Seizures

E. Headache

6.05 Conditions of the Skin

A. Itching

B. Bedsores

C. Edema

D. Odors

6.06 Bladder Problems

6.07 Weakness and Other General Symptoms

CHAPTER 7. MENTAL SUFFERING IN THE TERMINALLY ILL

7.01 Frequency of True Mental Illness in the Terminally Ill

7.02 Specific Mental Conditions Related to Terminal Illness

A. Anxiety

B. Depression

C. Therapy of Depression

(i) Drug Therapy
(ii) Psychiatric Care

(iii) Family Care

7.03 Existential Suffering

A. Definition

B. Factors in Existential Suffering

C. Applicability of Medical Treatment to Existential Suffering

7.04 Specific Fears

A. Pain

B. Death

C. Physical Symptoms Other Than Pain

D. Being a Burden on Others

E. Family Desertion

F. Abandonment by Physicians

G. Loss of Standing or Status Within One's Profession, Family, and/or Community

H. Losing Mental Ability

I. Narcotic Addiction

J. Loss of Dignity During the Process of Dying
K. Being, Or Being Considered, A Worthless Individual

7.05 Other Causes of Existential Suffering

A. Inability to Obtain, Evaluate and Use Information

B. Loss of Ability to Control One’s Bodily Functions/Loss of Dignity

C. Loss of Ability to Maintain Access to One’s Family or Society

D. Loss of Ability to Control People Formerly Controlled by the Patient

E. Hopelessness

7.06 Stressing Past Accomplishments

7.07 Helping Establish Closure

7.08 Helping Patient with Unfinished Family Business

7.09 Being There

7.10 On Showing Compassion

7.11 Choosing Appropriate Caregivers to Question the Patient

7.12 Working Through Problems/The Physician’s Role

7.13 Specific Suggestions

A. Maintaining Appearance
B. Helping Maintain Function

C. Adding Meaningfullness to Life

D. Stressing Pleasure

E. Honoring Privacy

CHAPTER 8. SUFFERING AND THE PROVISION OF ARTIFICIAL NUTRITION AND HYDRATION

NUTRITION AND HYDRATION

8.01 Employment of Artificial Sustenance; Introduction

8.02 Nutrition and Hydration as Part of Dying Naturally

8.03 Methods of Artificial Nutrition and Hydration

8.04 Do Terminally Ill Patients Suffer Starvation and Thirst?

8.05 Considering Artificial Sustenance

A. Benefits of Forsaking

B. Emotional Aspects

C. Societal Aspects

D. Religious Aspects

E. Ethical Aspects

F. Legal Aspects
G. Traditional Medical Practice

H. Palliative Care Medicine

I. Feeding Tubes

8.06 Author's Opinion

8.07 Reaching a Decision

CHAPTER 9. ADDITIONAL ISSUES/SUFFERING AND THE TERMINALLY ILL

9.01 Family Issues/Family Suffering

A. Caregiver Burden

B. Family Showing of Compassion and Respect

C. Family Pressures and Dying at Home

D. Family Concerns Regarding Patient Suffering

E. Family Demands for Futile Therapy

F. Family Concerns in Stopping Aggressive Therapy

G. Family Requests for Assisted Suicide

9.02 The Signs of Dying

9.03 Physician Issues/Physician Suffering

A. Inadequate Training
B. Palliative Care as Non-Traditional Care

C. Death as a Failure

D. Recurrent Need to Deal with Death

E. Time Considerations

F. Specialization and Costs

G. Variability in Desired Treatment Philosophies

H. Dealing with Families in Conflict

I. Dealing with the Law

J. Miscommunications

K. Physicians Facing Their Own Mortality

9.04 Telling Patients the Truth

9.05 Desirability of Working with Patients, Not Surrogates

9.06 Balancing Symptom Relief and Sedation

9.07 Financial Issues

SECTION III -- HOSPICE AND ALTERNATIVES TO PAS

CHAPTER 10. HOSPICE
10.01 Hospice; Introduction

10.02 Hospice; History
   A. England
   B. America
   C. Home v. Institutional Hospice Care

10.03 Hospice Philosophy

10.04 Hospice Approach
   A. Primary Concern is Symptom Relief
   B. Interdisciplinary Team and Plan of Care
   C. Autonomy and Patient Communication
   D. Working with Family Caregivers
   E. Emphasis on Home Care

10.05 Hospice Experience

10.06 Medicare and Hospice

10.07 Hospice Cost

10.08 Problems with Hospice

10.09 Separation of Care

CHAPTER 11. DOUBLE-EFFECT AND PHYSICIAN ASSISTED
SUICIDE

11.01 Double-Effect; Introduction
11.02 The Principle of Double-Effect
11.03 Historical/Religious Development
11.04 Ethical Considerations
11.05 Legal Considerations
11.06 Clinical Effects
11.07 Double-Effect Versus Euthanasia

CHAPTER 12. TERMINAL SEDATION

12.01 Terminal Sedation; Introduction
12.02 Frequency of Need
12.03 Symptoms for Which Employed
12.04 Medications Used
12.05 Usual Period of Sedation
12.06 Patient Choice/AMD
12.07 Ethics of Terminal Sedation
12.08 Legal Aspects of Terminal Sedation
12.09 Clinical Implications of Terminal Sedation
12.10 Clinical Use of Sedation When Discontinuing Life-Support

12.11 Terminal Sedation Versus Euthanasia

CHAPTER 13. VOLUNTARY TERMINAL DEHYDRATION

13.01 Voluntary Terminal Dehydration; Introduction

13.02 Historical Development

13.03 Case Histories

13.04 Thirst and Hunger

13.05 Medical Aspects

13.06 Ethical Aspects

13.07 Legal Aspects

13.08 Practical Undertaking

SECTION IV -- RELATED ISSUES

CHAPTER 14. ADVANCE MEDICAL DIRECTIVES IN THE TERMINALLY ILL PATIENT

14.01 Advance Medical Directives; Introduction

14.02 General Values of Writing a Living Will
14.03 Common Law Living Wills

14.05 The Patient Self-Determination Act

14.06 Living Will Form Declaration When Terminally Ill

14.07 Form Notice to Health Care Provider

14.08 Health Care Powers of Attorney: In General

14.09 Pros and Cons of Designated Health Care Agents

14.10 Choosing a Health Care Agent

14.11 Determination of Competency/Capacity

14.12 Other Concerns of the Physician

14.13 Decisions of a Health Care Agent

14.14 Advantage of a Combined Document

14.15 Form: Durable Power of Attorney for Health Care

14.16 Do-Not-Resuscitate Orders: In General

14.17 Do-Not-Resuscitate Orders/Difficulties

14.18 Do-Not-Resuscitate Orders/Principles Guiding Decision-Making

14.19 Do-Not-Resuscitate/Hospital Forms

14.20 Do-Not-Resuscitate Orders for Use at Home
14.21 Do-Not-Resuscitate Orders/Special Considerations

14.22 Anatomical Gifts: In General

14.23 Anatomical Gifts; Surrogate Decision-Making

14.24 Anatomical Gifts: Form

CHAPTER 15. GRIEF, MOURNING AND BEREAVEMENT

15.01 Grief, Mourning, and Bereavement; Introduction

15.02 Anticipatory Grief

15.03 Grieving as a Normal Process

15.04 Responsiveness to Understanding

15.05 Timing

15.06 Stages of Grief

15.07 Symptoms of Grief

15.08 Grief Versus Depression

15.09 Grief Therapy

15.10 Shadow Grief/Grieving by Others [Burn-out]

CHAPTER 16. GRIEVING FOR PATIENTS WITH ALZHEIMER'S DISEASE

16.01 Patients with Alzheimer's Disease; Background
16.02 Natural History and Prognosis in Alzheimer's Disease

16.03 One or Two Individuals

16.04 Artificial Nutrition and Hydration in Alzheimer's Disease

16.05 Suffering and Grieving in Alzheimer's Disease

16.06 Grief Therapy for Relatives of Patient's Dying of Alzheimer's Disease

16.07 Institutionalization of the Alzheimer Patient

CHAPTER 17. SPIRITUALITY AND TERMINAL ILLNESS

17.01 Spirituality; Introduction

17.02 Spirituality; Definition

17.03 Spirituality as Different Than Religion

17.04 Uniqueness of Spirituality

17.05 Reasons for Trying to Understand the Patient's Spirituality

17.06 Promoting Spirituality

17.07 Efforts to Determine Spirituality

APPENDIX -- Issues Related to Spiritualism

I. Religion

II. Attitude Toward Self/Spirituality
III. Support Family/Friends

IV. Illness/Terminal Care
Treatment of Pain and Suffering in the Terminally Ill - Introduction

TREATMENT OF PAIN AND SUFFERING IN THE TERMINALLY ILL

by Alan D. Lieberson, M.D., J.D.

INTRODUCTION

Introduction/Personal
Introduction/Outline
Introduction/Highlights

Introduction/Personal

My wife cannot believe I am writing a book on care of the terminally ill patient. She was with me during the last few years of my medical practice when I stopped going to funerals simply because I couldn’t do it any more. Too often I had become the deceased’s "best friend" and confidant during the dying process. And too often they had joined mine. Too many "best friends" to mourn. Too many I thought -- mistakenly, I now realize -- I could not help. I would pull myself together to be with each through their death, but then there seemed to be nothing left in me to comfort the families at the funeral. Others would have to do that! What energy I had left I felt a need to preserve for the next patient who needed my support through the dying process.

Perhaps I was deceiving myself. Perhaps I just felt more comfortable treating the dying patient than consoling the family because I have personally always felt more deeply for the patient who "will not see another one," than for the families. Perhaps I just needed to be alone to think about and grieve for the friend who was gone instead of spending time with family members who I perceived as having the benefit of time to reassimilate into the world and enjoy the pleasures of living after their personal periods of grief had ended.

So how, fifteen years after leaving the practice of medicine, do I come to writing a book about care of the terminally ill? It took a circuitous path which I will summarize believing as I do that readers should know the probable viewpoints and biases of the writer before reading any non-fiction:

I grew up in Westchester County, the oldest son of a New York City internist who later spent the last twenty-two years of his life caring for the medical needs of the people in St. Thomas, U.S. Virgin Islands. After attending Cornell undergraduate school for three years, I entered Yale Medical School, graduating in 1962. Six years later, after four years of training at Indiana University Medical Center and two as a general medical officer in the Air Force, I joined three other internists at "IMA" (Internal Medicine Associates of Westport, Connecticut) where I practiced for the next sixteen years.
As to my personal experience with dying patient while practicing medicine at IMA, I should point out that, for various reasons, it was somewhat limited and quite different from most internists. First, because I was the youngest partner for most of my sixteen years at IMA and because it served an unusually "young" community, I had few of the older patients who usually make up most of the terminally ill patients in a physician’s practice.

Second, as a partner in IMA I dealt primarily with a highly motivated, well educated and financially secure population with the ready availability of specialists, transportation and home health care. At the time, the resultant lack of financial concerns gave me the opportunity to treat many more terminally ill patients at home than most other internists around the country. In addition, I must point out that from the beginning I tended strongly to think in terms of quality of life and not quantity, concentrating more on patient comfort and home care than the latest techniques to prolong life. Obviously, I would take a different approach if it was the wish of the patient that "everything be done," but when faced with such a patient, I would frequently ask the oncologist to basically take over active care in the hospital while I limited my own patient visits primarily to dealing with the patient’s non-medical concerns.

As a result, most of my practice dealing with end-stage care of patients dying of chronic disease was undertaken at home after caregivers had accepted limitation of therapy to comfort care. To the best of my memory, none of these patients received artificial nutrition or hydration once they were no longer able to take fluids by mouth. With liberal use of narcotics, sedatives for sleep and antiemetics to control nausea and vomiting, I do not remember any dying with significant pain or physical discomfort, although the mental suffering of patient, family and friends was, at times, overwhelming. Hopefully less evident was the suffering of their personal physician, but at times it showed through. I will never forget one young women with terminal breast cancer who caught my tears as I left her room five minutes before she died saying "It’s alright Alan. I’m just going to get there before you. I’m sure we’ll see each other again in the future."

There were, of course, some terminal patients who were treated in the hospital and received intravenous fluids while they were dying. In retrospect I think they suffered more than those at home, but I must admit this may be a chicken/egg issue. It may be it was because their suffering was harder to control which explained their being admitted to the hospital, and not because they were receiving fluids in the hospital that their suffering was worse. [Note: I realize this commentary is a little out of order, but I add it as background to explain my obvious bias in the book in favor of terminal care at home.]

Going back to my history, in 1984, after twenty-four years of patient care beginning in medical school, I quit the practice. How much of my decision to leave was due to the emotional drain of treating the terminally ill I do not know, but I know it was a significant part. Perhaps more important was the time commitment to the practice in general, with little if any left to be with my family, or just to think, read, research, and write. But what I do know is my leaving had nothing to do with the science of medicine, or the patients themselves.
To the contrary, I have always loved the study of medicine and the interrelationship with office patients. If I could have stayed in the office and cared for one patient after another from 7:45 A.M. to 6:00 P.M. each day I never would have left. Unfortunately, though, when the office was done, there were hospital rounds. And after that, records, reports and insurance forms. So one morning at two A.M., a moment I will never forget, while walking down a back flight of stairs in the hospital after trying to save a woman who had opted out of life with sleeping pills, I opted out of my life as it then existed too. In my own way, at my own time, while I still had time to find another method to fulfill my goals in life.

Obviously, the decision to leave clinical practice was not totally new. During the time I had thought about it I had not thought about going to law school, but having just remarried at the time, it was a natural thing to do. My new wife had just graduated from the University of Bridgeport Law School and I greatly enjoyed discussing legal issues with her. Law seemed to be an area of increasing influence on medical care and the thought of going back to school offered a refreshing break from the hectic years I had just experienced -- and it lived up to my expectations. It was fun. It was the easiest time of my life. I worked regular hours -- from the time my wife left to go to work till she returned -- and graduated first in my class at University of Bridgeport Law School (now the Quinnipiac School of Law) in December, 1986. Over this time, I spent two and a half years at my favorite pastime, learning. Just great. I recommend it for everyone. [Perhaps one of the reasons two of our four children are law school graduates, although they do not practice law.]

Contrary to my original intentions, following law school for a short time I joined a law firm headed by a close friend, Vincent Tirola. In addition to consulting on medically related issues, I worked primarily on projects involving research and writing. When one of the partners left the firm, I took on estate planning, researching the law and writing wills and trusts. As part of that project, I naturally became involved with advance medical directives and soon began writing a series of articles and books advocating that attorneys learn at least enough medicine to draft a clinically relevant living will -- not the traditional forms advocated by state statutes which clinicians routinely find to be worthless. Among my publications on the subject, the most extensive coverage was in a legal textbook, *Advance Medical Directives*, published by Lawyer’s Co-Op, a company which is now part of the West Group of legal publishers. Soon after this, I wrote another legal "text" on *Elderlaw*, actually one volume of a set -- Volume 18A -- in the "West's Legal Forms" series.

[Note: I actually believe advance medical directives should be drafted by physicians, not attorneys, because skillful drafting requires knowledge of both law and medicine -- and the law is much easier for doctors to learn than the reverse.]

As legal textbooks require yearly updates, publishing the legal textbooks requires me to take
on a yearly review of the literature, including and increasing so, the issue of physician assisted suicide (PAS).

Studying this recent commentary, it quickly becomes evident that most patients who ask about aid-in-dying are not really seeking death. What they truly seek is better, more comfort-related medical care. This, in turn, suggests an initial request for aid-in-dying should not be taken literally, but reinterpreted instead as a request for improved care, most notably in the area of pain management.

As I worked with these thoughts and how to incorporate them in the yearly update in *Advance Medical Directives* and *Elderlaw*, the question of pain management happened to be raised at a Norwalk Hospital Bioethics Committee meeting. It was about the time the U.S. Supreme Court reversed the lower appellate courts’ findings that terminally ill patients had a constitutional right to PAS. In response to these thoughts, as chairman of the committee I suggested we research how pain and suffering of the terminally ill was managed at our hospital.

In the resulting division of responsibilities, as others gathered information about pain control and hospital care of the terminally ill, I looked for materials in the literature on relief of suffering. This led me to reconsider my own experiences with dying patients. In retrospect, as difficult as it had seemed at the time, the treatment of physical symptoms in fact had not been hard. What had been difficult was dealing with my patient’s emotional suffering when faced with the reality their life was coming to an end. It was this process, now commonly referred to in the medical literature as "existential suffering," that had been the drain on my patient’s emotions.

I began to gather the research materials and to summarize them for the committee. Slowly, the computer filled until it occurred to me the various reports I had gathered needed to be merged and summarized in such a way as to make it more readable for others. And so, this book.

**Introduction/Outline**

I have divided the book into four sections. The first deals with pain, the second with suffering, the third with advanced methods of dealing with unresponsive pain and suffering during the end-stage of disease, and the fourth with a variety of related subjects.

The section on pain include an introductory chapter, which discusses the present status of pain therapy in the terminally ill and how it is limited by medicine’s own weaknesses, ethical considerations, legal constraints, cost-containment, and general misinformation of both patients and health care providers. It stresses that proper pain management can be almost one hundred percent effective and notes that well developed and accepted guidelines for pain therapy have been developed by numerous organization, including the World Health Organization’s "laddered" approach of analgesic therapies. This approach is then discussed at
length in the second chapter, which also addresses medical, legal, and ethical aspects of narcotic use in pain management stressing the need to overcome the unjustified reluctance of many patients and families to use high dose narcotics for pain relief. In few areas of medicine is misinformation so rampant and destructive of patient well-being.

The section on pain then continues with two chapters discussing the numerous alternative approaches to pain management which have been developed -- from the highly technical placement of catheters carrying narcotics directly into the central nervous system and surgical ablation of pain nerves throughout the body to alternative methods of pain control, such as acupuncture, massage therapy, distraction therapy and TENS.

The chapters on suffering also begin with an introduction stressing some of the specific problems facing the terminally ill patient. Unlike pain, which can almost always be successfully managed, other physical symptoms, the topic of the second chapter in the section, are likely to be more difficult, but not impossible, to treat. This chapter discusses such symptoms as nausea, dyspnea (shortness of breath), constipation, urinary incontinence, weight loss, fatigue, etc. and includes suggestions on how non-drug interventions by the patient or family can help along with prescription medications.

A separate chapter discusses the symptoms and treatment of psychiatric problems frequently seen in terminal patients --anxiety, confusion, delirium, and, most importantly, depression. Far too often these treatable symptoms are accepted as an inescapable part of the dying process when, in fact, they can be significantly ameliorated or reversed by proper drug and/or non-drug therapy.

This chapter also deals in detail with "existential suffering," a subject which tends to receive insufficient consideration in most discussion of terminal care, for this is probably the area in which families are most likely to be the primary therapist for the dying patient. In addition to discussing the various issues which the patient is forced to face once they realize their existence is about to cease, it notes a number of therapeutic approaches which have been developed to address specific problems of personal integrity, disappointments in life, remorse, death anxiety, and issues of hopelessness, meaninglessness and futility. Goals of these approaches include (1) giving the patient a sense of completing family, financial and community affairs; (2) obtaining a sense of appreciation of one’s self and one’s life; (3) experiencing love of others and reconciliation with those with whom there have been differences; (4) obtaining a sense of meaning about life in general and an acceptance of the finality of life; and (5) obtaining a sense of one’s own existence as an individual along with the need to surrender that life to the unknown -- commonly referred to as "letting go."

Two additional chapters in this section deal with the specific question of when and how to use artificial nutrition and hydration in the terminally ill patient and a series of additional issues related to suffering in the terminally ill patient.
The third section of the book deals with specific advanced alternative approaches that may be useful or required in the treatment of terminally ill patient as they approach the end stage of their illnesses. It begins with a chapter on hospice, discussing concepts of palliative care and how hospice came to be a late arrival on the scene of modern medicine -- one often seemingly at odds with mainstream medicine. This chapter stresses the need to merge the teachings of the two disciplines, even as hospice remains an alternative to aggressive terminal therapy. In doing so, it points out the inexplicable legal factors which limit hospice’s ability to help more of the needy, the requirement to obtain certification of a life expectancy of less than six months, the need to forsake concomitant active treatment of the underlying illness, and the shifting of medical responsibility away from the personal physician of choice to a hospice based physician.

An important ethical and legal aspect of palliative care is referred to as "double-effect" therapy, the subject of the subsequent chapter. Under this age-old theory, therapy which is known to risk a shortening of life is permitted both legally and ethically if the intent of the physician is not to hasten or cause death, but to treat symptoms of the patient’s disease. As well as this theory is accepted by law and ethics, it is widely misunderstood by patients, families and physicians. So important is this subject, it deserves a full chapter of discussion in any book attempting to help patients and their families minimize the pain and suffering of a terminal illness.

The next chapter deals with a now well accepted medical practice, actually an extension of the double-effect principal, referred to as "terminal sedation." Many symptoms of terminal illness such as pain, dyspnea, anxiety, and psychic distress, traditionally require therapy which employs analgesics like morphine and/or sedatives like barbiturates and tranquilizers. Although patient tolerance and careful manipulation of dosage will usually permit these medications to be administered so as to maintain the patient’s conscious stream of thought, at times, especially in the last few days of life, this is no longer possible. It is in such a situation that physician assisted suicide may be warranted if it were legal, but in the absence of legalization, terminal sedation -- keeping the patient asleep until death supervenes -- supplies a reasonable alternative.

Another legal alternative to assisted suicide receiving increased medical, legal and ethical support in the last few years and one which does not require physician participation is the subject of the last chapter in this section. Commonly referred to as "voluntary terminal dehydration," when employed, it is usually done so by patients who have slowly progressive terminal disease, have accepted the inevitability of their own death, and who have, with full mental capacity, balanced anticipated pleasures and burdens of continued life and found the prospect to be overwhelmingly negative. Having reached this conclusion, they announce to the world an intent not to partake in further nutrition or hydration. As harsh as this may seem to the average person, as explained in the chapter, medical science and history as well as law and ethics are highly supportive of this approach.
The final section of the book deals with ancillary considerations in dealing with the dying process. The first chapter discusses advance medical directives which permit patients to maintain continued control over their own care until the end of life. Additional chapters in this section deal with grieving, religion and spiritualism, and a chapter discussing some of the unusual aspects associated with family issues and the patient with Alzheimer’s disease, a subject of particular interest to the author.

Introduction/Highlights

Having given the reader a personal background and outline of the book, I will now follow the advice of an early teacher of mine who suggested when writing to always lay out what you want the audience to carry away from your writings up front -- so the reader can look for supporting evidence as they go through the materials. In thinking about this approach, I have come to also think in terms of an alternative reason for listing highlights -- to insure I have not totally forgotten to include thoughts I consider to be of high importance by mistake in the text. Here, then, are what I consider to be the highlights of what follows -- and what I would want the reader to "walk away with":

1. The best approach to the issue of physician assisted suicide is insuring competent, concerned care of the dying patient. When this occurs, few patients opt for suicide, most preferring to live their life as fully as possible to the end.

2. Most, but not all terminally ill cancer patients experience pain. Pain is also common in patients dying of AIDS, end stage kidney disease and, at a somewhat reduced frequency, in most other forms of terminal illnesses.

3. The pain of terminal disease can almost always be relieved by modern medicine with appropriate use of drug therapy and various anesthetic and surgical procedures to block nerve transmission of pain. Relief can also be achieved at least in part through alternative means of non-traditional therapy. In the rare situations in which pain ultimately becomes untreatable, both the law and medical ethics recognize the use of large doses of medicine even to the point of inducing persistent sleep as an alternative until death occurs, usually within a couple of days.

4. Failure to control pain in the terminally ill is usually not a result of the disease process but a combination of other potentially reversible causes. These include ineffective evaluation of pain severity, lack of knowledge on the part of physicians related to modern pain therapy, unwarranted fear by patients, families, and physicians of narcotic addiction, over-concern with potential ill effects of therapy, lack of financing for appropriate terminal care, the fear of litigation, abandonment of the patient by the medical profession, and patient-
5. Physical symptoms other than pain which frequently occur in terminally ill patients may be more difficult to treat than pain itself, but again can usually be controlled by modern medicine and appropriate supportive care. These symptoms most commonly involve shortness of breath, cough, nausea, itching, incontinence, and constipation.

6. Much can be done to help the psychiatric complications of terminal illness such as anxiety, agitation, confusion, and depression. It is a mistake to consider these clinical states to be a normal part of the dying process.

7. General symptoms of terminal illness such as weight loss, fatigue, weakness and troubled or prolonged sleep are difficult to treat toward the end of life, but are usually more troublesome to the family than the patient.

8. By far the most difficult suffering to deal with clinically is that which has come to be referred to as "existential suffering," the loss of the meaning of self, such as the feelings of abandonment, failure, guilt, fear, boredom, helplessness, dependency, hopelessness and anger. As suggested by a well-known physician/commentator on care of the terminally ill, dealing with these feelings requires the answering of such patient questions as "How will I die?" "Where will I die?" "Who will care for me?" "Will my pain be controlled?" "Will my values be preserved to maintain the quality of my life as it ends?" "What are my options for care and how will my care be paid for?" "Who will help the caregivers?" "Will my cultural, religious and spiritual beliefs be respected?" To the extent family and physician can give reassurance related to these questions, we can help relieve the loved one’s suffering.

9. To help the patient with existential suffering requires a consistent, repetitive and non-judgmental effort by family and friends to become aware of and to understand the personal concerns the patient is dealing with as he or she attempts to bring successful closure to life. Only with such knowledge, best shared by the various caregivers, can a supportive approach to the patient’s existential suffering be successfully undertaken.

10. The routine use of artificial nutrition and hydration in care of the terminally ill has been challenged by almost all clinical health care providers. There is little evidence that routine use of invasive procedures to maintain nutrition and hydration after the patient has voluntarily stopped their oral intake results in prolongation of life and abundant evidence it only causes or increases most symptoms in the dying patient.
11. For unexplainable reasons, palliative care, which addresses the symptoms of disease as opposed to the cause of disease, has largely developed by the hospice movement almost as an alternative medical modality instead of as part of traditional medicine. This split tends to force an unreasonable and uncalled for decision on patients -- whether they want treatment for cure or treatment for relief -- when in fact the two are not and should never be considered mutually exclusive.

12. In spite of increasing recognition of hospice principles, hospice itself remains a major, underused resource in the care of the terminally ill.

13. Unfortunately, there are problems with hospice which could be easily reversed by changes in the law or minor changes in the hospice approach. First, hospice requires the patient to choose between care aimed at cure and that aimed at relief. Second, hospice care usually requires a change of primary physician. Third, hospice care would appear to require the patient to accept that further care of the underlying disease is hopeless and they are going to die. Fourth, payment for hospice care requires two doctors to certify the patient is expected to die within six months, which enhances any feeling of hopelessness.

14. Because future development of aid-in-dying in the form of physician assisted suicide is likely to be hindered by difficulties in developing appropriate legal procedure, interest and discussion of alternatives has heightened as a result of the recent Supreme Court decisions denouncing a patient’s constitutional right to suicide.

15. One long standing alternative to aid-in-dying is based on the theory of "double-effect" therapy. It indicates the medical, ethical and legal acceptance of the high priority of treating symptoms in terminally ill patients even though the therapy carries a known potential risk of causing death or shortening life. A more advanced use of double-effect therapy involves prolonged and on-going sedation through the end-stages of a terminal illness ("terminal sedation") when other methods have failed to control symptoms.

16. Although the number of reported cases of patients who have voluntarily refused to take nutrition and hydration in order to hasten death are limited, these case reports suggest minimal associated discomfort. Other studies involving the discontinuation of nutrition and hydration also suggest the absence of significant suffering and an untroubled death.

17. Although many medical, legal, religious, and ethical commentators are against physician assisted suicide, only the most antagonistic fail to admit there
are times when it would seem to be appropriate for a physician to help a patient die. In many of these situations, the need for increasing medications to control suffering would appear to hasten the patient’s death, although, unlike assisted suicide, there is no direct intent to take part in a suicide. Alternatively, when the patient retains the ability to make medical decisions, "voluntary terminal dehydration" with appropriate therapy of resultant suffering, if any, would seem to be a reasonable consideration without significant opposition or the production of pain and suffering in the patient.

18. Pain and suffering is not confined to the terminally ill patient. It is important to realize that family, friends, and caregivers also suffer, and to make allowances for the effects of such suffering. Although we typically think of grieving as a process which occurs after death, this is not accurate, for much of the grief process, especially among the caregivers, occurs during the period in which the patient is terminally ill. Not infrequently, caregivers require help along with the terminally ill patient. Caregiving and grieving are particularly likely to co-exist when the terminally ill patient suffers from Alzheimer’s disease.

19. The place of spirituality in resolving existential issues is receiving increased interest in recent years. Caregivers are often unable to make use of spirituality in attempting to help the individual patient because spirituality is, in fact, so individualistic. Confusion between religious practices and spirituality is also likely to confuse caregivers, who are likely to have lived with the sick individual for many years without gaining a true understanding of his or her spirit. It is therefore essential to forget what one thinks one knows about the patient’s spirit and to listen carefully to understand his or her personal spirit, just as one must listen to understand the important issues in existential suffering.

Now, having reached these conclusions, I will set out to explain to the reader the basis for these statements, hoping thereby to facilitate an understanding between patient, family and health provider which will ensure the best possible care of the terminally ill patient. I suspect most of those who choose to read this book will be involved in the highly emotional state of caring for the terminally ill either personally or as a professional. I feel your pain, as well as that of the patient, and only hope that the information contained herein will be helpful in reducing that suffering at least a little. If so, it will please me greatly.

[Note: The author specifically exempts from copyright protection any forms he has developed and included in the book and notes that much of the quoted materials from the DHHS is also free of copyright protection.]
# Table of Contents

- Introduction
- Chapter 1
- Chapter 2
- Chapter 3
- Chapter 4
- Chapter 5
- Chapter 6
- Chapter 7
- Chapter 8
- Chapter 9
- Chapter 10
- Chapter 11
- Chapter 12
- Chapter 13
- Chapter 14
- Chapter 15
- Chapter 16
- Chapter 17
CHAPTER 1. PAIN IN THE TERMINALLY ILL

1.01 Pain in Cancer and Other Terminal Illnesses; Introduction

1.02 The Nature of Pain

1.03 Common Sites and Types of Non-Local Cancer Pain
   A. Pain of Neurological Origin
   B. Bone Pain
   C. Abdominal Pain
   D. Lesions of the Mouth

1.04 Pain as a Consequence of Surgery and Diagnostic Procedures

1.05 Pain in Patients With AIDS

1.06 Pain in Other Conditions

1.07 Pain in Special Populations
   A. The Elderly
   B. Children
   C. Minorities

1.08 Early Discussion of Pain Management with Family

1.09 Basic Information About Pain Therapy

1.10 Measuring Pain

1.11 Evaluating Pain; Form

1.12 The Pain Treatment Plan; Form

1.13 Overall Success of Pain Therapy

1.14 AHCPR (DHHS) Guidelines
1.15 AHCPR (DHHS) Statement on Patient Education

1.01 Pain in Cancer and Other Terminal Illnesses; Introduction

Cancer is diagnosed in over 1 million Americans each year, causing death in slightly more than half that number over the same period of time. This corresponds to twenty-three percent of all deaths nationally -- close to 1,400 deaths per day. At the same time, it also leaves close to 8 million Americans living at any one time to deal with either a previous history of cancer or with known residual disease. Worldwide, cancer incidence is somewhat lower, but it still constitutes approximately 10 percent of all deaths.

At the time of diagnosis, approximately one in three cancer patients experience moderate to severe pain, with close to ninety percent of those who are not ultimately cured or their cancer experiencing at least some pain during the course of their terminal illness. Fortunately, appropriate use of pain medication alone will now satisfactorily control pain in nine-tenths of these patients even in the final stages, with other more sophisticated methods being capable of achieving relief in an additional eight percent. This leaves only 2% of terminally ill patients who require more advanced clinical techniques as discussed later on in this book for pain control. As a result, the medical profession can be highly reassuring to cancer patients that they will not be forced to suffer from unrelieved pain unless they, their families, and/or society interfere in some way as to deny optimal care.

This statement may sound strange to the reader, but it is probably the most important message in this whole book -- one that will be stressed repeatedly in this introduction, this chapter and thereafter. There is no longer any need for a cancer patient to die in pain! There are many reasons why this still happens, but the reasons are social, not medical!

Pain in chronic diseases other than cancer is a little more difficult to characterize, but here, too, the modern use of pain therapies developed primarily for cancer patients has generally been found to be equally effective. For example, studies of AIDS patients have shown very similar pain statistics as do cancer patients. Thirty percent have pain as part of their initial symptoms and forty to sixty percent experience pain at any one time later in the course of their disease. Similarly, approximately two to four percent requiring the more advanced pain avoiding therapies available at the end of life -- as discussed at length later in this book.

These statistics should be reassuring to terminally ill patients, but the opposite perception, that many people are doomed to die with unrelieved pain, is hard to overcome for many reasons.

First, because our society relies so heavily for information on unverified media input which is often biased in favor of a specific group of potential beneficiaries, i.e., promoters of alternative medicine.

Second, because we are so ready to accept uncorroborated anecdotal stories told by individuals who are interpreting facts without confirming their completeness or accuracy. For example, I remember well a patient who was widely reported by friends to have died in unrelievable pain when, in fact, he had demanded that narcotics not be given to relieve the pain until the last two days before death.

Third, because many patients want to appear stoical before their physicians and therefore fail to report pain when it exists.
Fourth, and most unfortunately, because many physicians fail to apply the most appropriate means of pain therapy.

But fifth, and perhaps most importantly, because of misunderstandings of legal, ethical, medical and social concerns involved in pain therapy of the terminally ill patients, especially as it relates to tolerance and addiction.

These are the basic reasons why all the "good" statistics I have quoted above cannot overcome the perceived risk of having to die in pain. Because my statistics are based on ideal treatment, and many terminally ill patients do not receive the best pain management. Instead, many continue to suffer unnecessarily due to the multiple outside factors suggested above, only some of which can be blamed on medical providers.

The initial chapters in this book which address pain management are primarily intended to help keep this from happening to the reader or the reader's loved one by helping to insure proper pain management is provided. To do this, we will repeatedly stress the need for the patient, family, caretakers and providers alike to assume all pain can be controlled to the extent desired. At various times in the clinical course, a rational choice may be made not to seek total pain control -- but this should only occur by personal choice. This means, if you or a loved one is seeking pain relief in vain, you must assume something is wrong with the care being received and must seek additional help in determining where appropriate therapy has gone astray.

If anything comes up which makes you sway from this conviction -- that all pain should be considered relievable -- or if people tell you this is inaccurate, consider the following facts:

First, in the Netherlands where patients can obtain euthanasia on repeat request, although pain is the most common reason why an initial request for euthanasia is made, it is seldom a significant consideration at the time of the second and final request. The reason: once physicians are aware of how bad the pain has become, bad enough to prefer death, it can almost always be relieved.

[Interestingly, in the Netherlands approximately two percent of deaths involve euthanasia -- the same percent of deaths in this country involving the advanced methods of pain avoidance discussed later.]

Second, as discussed later in this book, hospice based physicians who specialize in treatment of terminally ill patients expect them to experience pain and to require a pre-planned approach to pain management, but they do not perceive pain management to be a difficult challenge. In contrast, other physical symptoms like nausea and shortness of breath produce far more difficult problems to overcome.

Third, for what it is worth, the author can honestly report he cannot remember any of his patients dying at home with unrelieved pain. Although some critics might say this is because I didn't end up caring for those patients with severe pain who end up being hospitalized, I think that is only a minimal truth. Far more important is the fact that being at home signifies an acceptance by all involved that the patient is terminal. Once this happens -- when physicians families and friends accept the inevitability of death and understand that further aggressive care will only prolong death, not life -- there is no longer resistance to effective total pain management.

Fortunately for the author, the writing of these initial chapters on pain has been greatly simplified by the recent interest in pain therapy arising out of the publicity surrounding physician assisted suicide. Especially helpful has been the release by the Agency for Health Care Policy and Research (AHCPR) of a summary of pain...
management under the title: "Management of Cancer Pain -- Clinical Practice Guidelines." This work, designated as Publication No. 94-0592 [March 1994], is available in its entirety [All 250+ pages] free of charge to clinicians, patients, and family members by calling the National Cancer Institute's toll-free number at 1-800-4CANCER. It is also available by writing to: Cancer Pain Guideline AHCPR Publications Clearinghouse P.O. Box 8547 Silver Spring, MD 20907. A shorter version is also available for physicians [No. 94-0593] and patients [No. 94-0595].

Note that in discussing pain, because the principles involved in non-cancerous conditions are generally similar to those in cancer, this book tends to emphasize therapy developed in treating cancer patients because it has been studied and reported on so extensively. At the same time, it is fair to assume our discussions are equally applicable to other diseases unless specifically noted otherwise in the text which follows.

While subsequent chapters deal more directly with the principles of pain relief and how families can help, this introductory chapter on pain looks in greater depth at pain itself and, more specifically, at the reasons why pain relief is frequently sub-optimal.

### 1.02 The Nature of Pain

Pain has been narrowly defined by *The International Association for the Study of Pain* (IASP) as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage." For the purposes of this book, however, the author takes a broader view of "pain." When the author speaks of pain herein I will be referring to any combination of an unpleasant nervous sensation from a part or parts of the body, combined with the resulting emotional experience which results. Unlike the narrower concept of the IASP, which seems to require transmission of a pain impulse along nerves containing specialized pain fibers, as used in this book pain only requires the patient's perception of such a sensation. In other words, "pain," as used in this book, reflects both the sensation produced by activity of the patient's nervous system and the many psychological, personal, and physiologic factors which may so predominate one's life as to produce the sensation of pain even in the absence of a noxious (pain-producing) stimulus.

Although we tend to think of physical pain as originating in the body and being perceived purely in the brain, recent understanding of pain transmission allows us to consider a third potential site for drug related pain therapy outside both the brain and the area of injury. This understanding has led us to realize that pain transmission is a two directional interaction between the brain and the nerves running in the spinal cord which normally relay pain impulses to the brain from the body. In this two directional system, not only are pain impulses transmitted from the body to the brain, but the brain also sends messages down to nerves in the spinal cord which influence how pain impulses from peripheral tissues are perceived and transmitted. These "descending pathways," as the nerves running from the brain to the spinal cord are called, can be influenced by drug therapy in such a way as to actually decrease the number of pain stimuli carried from the body to the brain. In fact, it has been speculated it is the activation of this system from the brain which explains how acupuncture or even placebos, with no active ingredients, can be helpful in pain therapies.

In considering the origin of pain in the terminally ill, our knowledge stems largely from its occurrence in cancer. Patients with cancer often have multiple types of pain stemming from various complications of the disease. Most commonly, 75-80% of the time, cancer pain is due to tumor progression, the growth of the tumor itself pressing on nerves carrying pain fibers to the brain or by stretching the covering of an organ or tissue which contains
similar pain-relaying nerve fibers. In another 15%-20% of cases, pain is the result of cancer therapy, either resulting from operations and other invasive diagnostic or therapeutic procedures or from the toxic side effects of chemotherapy. Less frequently, pain is the result of infections, common in patients receiving cancer chemotherapy, or due to muscle aches associated with limited physical activity. Of course, having cancer does not preclude all the other causes of aches and pains experienced by other people, some of which, like appendicitis, may be difficult to diagnose when the patient is receiving narcotics for cancer-related pain.

1.03 Common Sites and Types of Non-Local Cancer Pain

Most cancer pain is caused by the presence of the local tumor and is determined by the exact location of the tumor, its rate of growth, the proximity to pain nerves, etc. The following describe some common, specific types of pain often associated with cancer.

A. Pain of Neurological Origin

Some of the more difficult pain patterns to treat in cancer patients involve nerve junctions on both sides of the neck or in the area of the pelvis where the nerves to the arms and legs merge before entering or after exiting the spinal cord which lies within the spinal canal. These nerve complexes are referred to as the "brachial plexus" and "lumbar plexus" respectively. Pain from these sources is often felt both in the local area and either from the neck into the back of the head and arm or from the pelvis into the abdomen, buttocks and down the leg. In many cases, the patient also experiences numbness or weakness of the arm or leg as well. Neuropathic pains (pains originating in the nerves) involving these complexus are usually caused by local tumor, but it can be difficult to know for sure because it can also result from previous radiation, the ill effects of chemotherapy, or, less commonly, by stretching of the nerves during a previous operative procedure.

Peripheral nerve injury is also common during surgical procedures for cancer, in which case resultant pain which follows is often made worse by touching specific areas (trigger points) on the surface of the body near the surgical incision. Occasionally, pain is also felt to exist in extremities after they have been amputated (phantom limb pain) due to irritation of the nerves that previously served the amputated extremity. A more specific diagnosis of the pain origin can often be made using radiographic procedures, like CT or MRI scanning.

Another type of nerve pain originates in the peripheral nerves themselves, either secondary to chemicals released by a tumor or, especially in the presence of HIV infection, due to direct involvement of the nerve by a viral infection. Pain from peripheral nerve problems is usually constant, although it may come and go. It is usually described as piercing, like a tooth ache, or as burning. It is also frequently associated with sensory loss producing a tingling sensation, and/or is found in association with weakness of muscle movement in the fingers and toes if it involves the extremities.

This type of nerve pain is particularly important to recognize because it can be difficult to treat with the usual doses of narcotics, thus requiring significantly higher doses than most physicians are used to using when treating other forms of pain. In such situations, when pain originates in the nerves themselves, it may be wise to consider adding special medications developed specifically for the treatment of nerve pain as an alternative to increasing the dose of narcotics.

Nerve pain due to chemotherapy usually occurs in the absence of other nerve findings, and almost always occurs
on both sides of the body almost equally. Typically, it is first felt in the most distant parts of the body, the feet followed by the hands. It is most common with specific chemotherapeutic drugs, including vincristine (Oncovin), Cisplatin, and Taxol.

Another common source of nerve pain is shingles, a viral infection closely related to chicken pox, which commonly occurs in patients with all kinds of cancer but especially those with leukemias and lymphomas. Although pain from shingles occasionally occurs without a skin rash, most patients with shingles develop little fluid containing lesions (vesicles) on their skin similar to chicken pox but occurring in limited patches over or close to the same area where pain is felt. Although it may take months to clear completely, and may require large amounts of pain medication for awhile, the pain of shingles usually lessens over a few weeks and gradually goes away completely with time.

Although pain of peripheral nerve injury may be treated with both non-narcotic and narcotic drugs, many other approaches have been developed which act more directly on the nerve itself. These will be discussed in following chapters.

B. Bone Pain

Bone pain is most common in patients with cancer of the breast, prostate, or lung and is almost always due to spread of the original tumor through the blood into the bone. The most common sites of bone spread include the back, pelvis, upper leg, and skull. Because patients often have multiple sites of bone spread, multiple areas of pain are common. Pain is usually described as dull and aching in the area of spread and is frequently made worse by movement. When cancer spreads to the bone, complications such as fractures, compression of nerves as they leave the spine, and high blood calcium levels are common. Spread from the bones of the spine into the spinal canal pressing on the spinal cord is a dread complication of cancer, creating a true medical emergency which requires rapid diagnosis and treatment to avoid paralysis.

Pain resulting from cancer spread to the skull tends to be variable in its effect because so many of the nerves to the face and the sensory organs of the head run through openings in the skull. As a result, the patient may experience both pain and sensory changes in the face, trouble chewing, talking or swallowing, double vision, partial loss of vision, a drooped eye lid, nasal stuffiness, headache, pain when swallowing or upon moving the head in certain directions, etc.

Most spread of cancer to bone will be seen on routine x-rays or found by simple scans using radioactive materials in a procedure referred to as a "bone scan." Bone pain due to metastatic cancer is usually treated with radiation therapy, which tends to be quite successful.

C. Abdominal Pain

The diagnosis of abdominal pain in patients with cancer is likely to be particularly difficult when the patient is receiving narcotics, but once the cause of the pain is determined, it is not particularly difficult to treat. The reason for concern is that many of the complications of cancer which cause pain require surgical treatment, and patients with cancer also develop the kinds of emergency surgical problems which are common in patients who do not have cancer -- like appendicitis, infection of the gall bladder, and perforated ulcers. Among the causes of abdominal pain due to cancer itself are spread of the tumor to the liver or other organs, blockage of the
intestines, sudden interference with blood flow to the abdominal organs (the liver, kidney, spleen, or intestines), or direct spread of cancer to the "peritoneum," the inner lining of the abdominal cavity. This latter complication, spread to the peritoneum, is particularly common in women with cancer of the ovaries.

D. Lesions of the Mouth

A particularly distressing cause of pain occurring primarily in patients with cancers around the face is due to irritation of the inner linings of the nose, mouth, throat, and sinuses. Although it may be due to cancer itself, it is more often a result of radiation therapy and/or chemotherapy. Preexisting poor oral hygiene may contribute to the pain, which is often intense and interferes with oral intake of food, liquids, and medications. When caused by chemotherapeutic drugs, the discomfort usually begins 3 to 5 days after therapy is given, reaches its peak at 7 to 10 days, and then slowly improves over the next 5 to 7 days unless complicated by infection or bleeding. When caused by radiation, discomfort is usually first noted at the end of the second week of treatment, plateauing during the fourth week of radiation, and sometimes persisting for 2 to 3 weeks after the completion of treatment. In addition to changes in the lining, pain is often associated with the development of ulcers (deep holes going through the surface linings down into the muscles or other tissue below the mucus membranes).

Treatment of pain around the oral cavity often requires heavy use of narcotics and may require temporary use of artificial nutrition and hydration to get past the period of maximum pain and difficulty swallowing.

1.04 Pain as a Consequence of Surgery and Diagnostic Procedures

Surgical procedures can cause several different types of pain in addition to pain from the incision itself. Depending on the nature of the surgery and the specific tissues or organs removed, patients may experience deep wound pain from the beginning which is usually duller but more distressing, more difficult to treat, and longer lasting than pain from the incision. In addition, many patients experience a variety of conditions referred to as "chronic pain syndromes" after surgery, which may not emerge until weeks or months after the surgery has taken place. Treatment of this type of pain frequently requires pain medication for a period lasting into the months, but usually decreases slowly with time.

In addition to full surgical interventions, cancer patients frequently must undergo painful procedures for diagnosis, therapy, and supportive care, including lumbar punctures, bone marrow aspirations, and biopsies. Although simple injections and vein punctures for blood analysis or the insertion of intravenous catheters are minimally invasive and painful, their frequency and repetition become a major source of distress and apprehension for many patients, especially youngsters who may find them to be the most difficult part of having cancer.

It has been noted that when dealing with youngsters, because of the bonding of parent and child, it is particularly important that both have their questions answered prior to the undertaking of potentially painful procedures. Questions to be answered include:

Why is the procedure being performed?

What is the expected intensity of pain?
What is the expected duration of pain?

What is the expected intensity of anxiety?

What is the expected duration of anxiety?

How often will the procedure be repeated?

How do parents think their child will react?

What reaction do adults predict for themselves?

What is the meaning of the procedure for the patient and the family?

[Note these are also good questions for adults as well.]

Suggestions for dealing with these kinds of problems in children after going over the above questions include the following:

1. Treat anticipated procedure-related pain prophylactically prior to initiating the procedure.

2. If possible, administer drugs by a painless route, such as orally or through an existing intravenous line.

3. When possible, try to cluster procedures at a predictable time and frequency so the patient can expect definite blocks of time when no procedures are to be performed.

4. Be attentive to the environment and to privacy. For children, a room other than the child's room should be used whenever possible. Environmental factors, such as cold or crowded rooms or "beepers" on machines, can escalate distress.

5. After the procedure, review the experiences and perceptions of the effectiveness of pain management strategies with the physician.

6. For procedures that will be repeated, maximize treatment for the pain and anxiety of the first procedure to minimize anxiety before subsequent procedures. It may be reasonable to consider anesthesia or heavy sedation if skilled personnel are available to monitor the procedure.

7. Minimize delays to prevent escalation of pain and anxiety.

8. Ask questions about monitoring and resuscitative equipment if they have not been explained. They frequently are related to insure their will be no trouble from drugs used for sedation.

9. For children, it is usually wise to allow parents to be with the child during the procedure, if the
parent chooses to remain. The presence of a controlled parent is a source of great comfort for the child. Parents should be taught what to do, where to be, and what to say to help their child through the procedure. Parents should not be asked to restrain the child during the procedure.

10. Infants can benefit from sensory motor interventions (e.g., using a pacifier, touching, and patting). Potentially effective strategies for older children include distraction techniques such as music, hypnosis, play therapy, TENS therapy and counterirritants such as ice.

11. Remember it is frequently wise to overtreat the likely discomfort with narcotic analgesia and/or local or systemic anesthesia to maintain an appropriate working relationship.

1.05 Pain in Patients With AIDS

AIDS is commonly associated with specific types of cancer, such as Kaposi's sarcoma and beta-lymphoma of the brain, which can cause pain patterns of their own. But even in the absence of cancer, HIV infection alone is commonly associated with pain requiring the same aggressive style of pain therapy used in cancer. Unfortunately, this is seldom done.

Severe pain due to direct nerve infection with the HIV virus (HIV-related peripheral neuropathy) is a common condition affecting up to 30 percent of people with AIDS. It is typically characterized by a sensation of burning, numbness, or anesthesia in the affected extremity. Several antiviral drugs, such as didanosine (Videx) or zalcitabine (Hivid), chemotherapy agents used to treat Kaposi's sarcoma (vincristine-Oncovin), as well as phenytoin (Dilantin) and isoniazid (INH), all commonly used in AIDS patients, can also cause painful irritation of peripheral nerves producing almost identical symptoms of neuropathy.

Painful rheumatologic manifestations of HIV infection include not only direct involvement of the joint linings (painful articular syndrome) but infection of the joints (septic arthritis), psoriatic arthritis (associated with psoriasis, itself common in AIDS), vasculitis (inflammation of blood vessels), Sjögren's syndrome (joint pains associated with a lack of saliva, tears, etc.), polymyositis (inflammation of multiple muscles), zidovudine myopathy (AZT induced muscle disorder), and dermatomyositis (inflammation of skin and muscle). Reiter's syndrome, a reactive arthritis commonly associated with irritation of the eyes and a urethral discharge in addition to back and large joint pains, is also common early in the course of HIV disease.

Conditions associated with chronic or intermittent pain in AIDS include intestinal infections with Mycobacterium avium-intracellulare (bird tuberculosis) and cryptosporidium (a one celled parasite similar to amoeba), which cause cramping and intermittent abdominal pain. In addition, AIDS is often associated with hepatosplenomegaly (enlargement of the liver and spleen), which results in abdominal swelling and pain, as well as oral and esophageal candidiasis (monilia/yeast infection), causing pain while the patient is eating and swallowing, and inflammation of the brain (encephalopathy) causing painful muscle spasms throughout the body.

HIV-related conditions that cause acute pain in children include sinusitis and meningitis (infection of the covering of the brain), either of which can result in severe headaches; otitis media (middle ear infections); shingles; cellulitis and abscesses (local infections); severe candida (monilia/yeast) skin irritation; and dental caries.
Just as cancer patients with drug abuse disorders are at high risk of undertreatment of pain by physicians who are overly concerned with problems of drug abuse, so are those who suffer from AIDS. Nonnarcotic drugs should not be substituted for narcotics in these patients when severe pain is suspected just because of a known past tendency to abuse drugs or even because of a known present addiction problem.

Because patients with AIDS are usually less well established in life, and because society tends to shun them out of fear, discrimination and ignorance, AIDS patients typically face even greater stresses and depression during the course of their disease than patients with other terminal illnesses. This makes adequate pain control and a promise of adequate therapy in the future even more important in AIDS patients. In a study of pain in ambulatory HIV-infected patients, depression was significantly correlated with the presence of pain. In addition to being significantly more distressed and depressed, those with pain (40 percent) and those reporting inadequate social support were twice as likely to have suicidal ideation as those without pain, of particular importance because of the extremely high suicide rate in these patients.

The issue of drug abuse is also problematic in the pediatric HIV population. Many children with HIV infection live in families where intravenous drug abuse is or was a problem. Either they have parents who are actively using drugs or are recovered from drug abuse, or they live with extended family who have had experiences with their drug-abusing relatives. In these environments, questions arise about the safety of prescribing opioids for the child. Extended-family members are often anxious about the use of opioids for a child whose parent was a drug addict, fearing the child will also become addicted. These fears and concerns should be anticipated and discussed, and explicit plans should be put into place to minimize the risk of drug diversion.

The general management of pain in children with HIV is the same as for children with cancer. The assessment of pain in HIV-infected children may be complicated by the frequency of encephalopathy (brain dysfunction) and related developmental delays. It is often difficult to determine whether an encephalopathic (brain injured) infant or toddler who cannot talk is in pain. Observations of a child's response to a trial of pain medication may be the best means of assessing such a child's pain.

[Note: Many of these factors are further discussed below in the chapters on pain therapy and later in the chapters related to suffering.]

1.06 Pain in Other Conditions

Just as both cancer and AIDS patients commonly complain of sensory neuropathies resulting from nerve damage, similar pains of nerve origin are frequently noted in patients with kidney failure or long-standing diabetes.

Patients with heart failure may suffer from pains related to water retention, especially over the liver area at the bottom of the right side of the rib cage, while other patients with diseases of the blood vessels may develop pains in the abdomen or extremities because of a limitation of the blood supply.

Still other terminal illnesses, like strokes and neuro-muscular disorders, may lead to such joint immobilization that even such low level activity as turning over in bed or moving joints may cause pain, often without evidence of any local disease process.
1.07 Pain in Special Populations

Special attention may be required when treating pain in special populations, including the very young and very old, those who are confused or disoriented, and non-English-speaking persons. In these groups, uncontrolled pain can be particularly distressing because they are unable to rationalize any reason for the experience or to understand that the situation is temporary.

A. The Elderly

Elderly patients are often undertreated for cancer pain. Fortunately, because this has become so well appreciated, the attitude of health care professionals, the public, and patients toward pain is changing as we come to realize neither acute nor chronic pain is part of normal aging.

In some instances, pain is not assessed because the elderly patient is somewhat confused making it difficult to communicate their pain to health professionals or may be ignored by those who believe pain is normal with age. In other instances, clinicians have mistaken beliefs about decreased pain sensitivity and heightened pain tolerance in the elderly or of the ability of the elderly to tolerate narcotics, thus leading them to underprescribe analgesics. Often overlooked is the fact that elderly patients are more likely than younger patients to also have pains from non-cancer chronic illness which still require therapy to avoid the additive effect of multiple pains.

In addition, troubles are likely to be encountered with the use of pain measurement scales developed for younger patients, which function poorly in the presence of mental confusion or physical impairments with vision, hearing, or motor skills.

Such misinformation and testing problems are difficult to overcome, in part because of inadequate field research, routinely undertaken by pain clinics serving only the most mobile of the elderly, not those suffering from cancer. Furthermore, elderly patients are often excluded from research oriented rehabilitation or pain management programs, making them infrequent research subjects.

While it may be true that some of this concern with large doses of narcotics in the elderly is justified, it has to be individualized. The elderly are said to be more sensitive to the pain relief of opioids because they develop higher blood concentrations with delayed clearing of the narcotic from the blood, but this varies greatly from patient to patient. Initial doses suggested for "all elderly" may therefore be too low to obtain adequate pain relief in any one individual and may require additional dosing from the start. Again, because the elderly are known to frequently have decreased rates of drug metabolism, they are feared to be particularly vulnerable to drug accumulation, leading physicians to routinely lengthen the time between doses in addition to lowering the dose of narcotics given. If this approach is taken in an individual with a normal metabolic rate, however, periods of pain are likely to recur before the next due dosing. Only careful measurement and evaluation of pain can provide the information necessary to insure the proper dosing to prevent the continued presence of unrelieved pain.

Finally, the elderly are more likely to have other conditions which make them more susceptible to becoming delirious when given narcotics than younger patients, increasing natural reluctance of physicians to use these drugs to the full extent indicated or commonly given to younger patients.

B. Children
Recent use of highly aggressive chemotherapeutic approaches in children with cancer have increased survival rates markedly. Unfortunately, such regimens often involve treatment toxicity that results in painful conditions, most notably from infection, peripheral nerve damage, and severe irritation of the mucus membranes of the mouth and throat. Successful treatment of pain in this population involves a number of unique considerations.

1. Because a child is unlikely to accurately assess pain on request from a physician, treatment of pain in children requires knowledge of the person to whom the child is likely to have communicated about pain and the child's method of communicating, e.g., "hurt," "owie," "boo-boo."

2. Patient-controlled analgesia in which the child can trigger the release of additional pain medication should be considered even in young children. Most children over the age of 7 understand this concept, and sometimes even younger children can learn to use it successfully.

3. Pain control in children may be benefitted by the use of stimulants such as Ritalin and amphetamines, which are generally given at times of desired wakefulness, such as morning and midday. Unfortunately, their use in the drug culture [as "speed" or "meth"] often makes families reluctant to allow a trial of their use to the detriment of the child.

4. Unlike adults, young children have difficulty communicating symptoms like itching, nausea, constipation, and generally feeling bad. Their presence is often best indicated by increasing restlessness or irritability, which must be considered a sign of an unexpressed discomfort the nature of which needs to be determined.

5. Nonpharmacologic methods may be very helpful in children with pain, although little research has focused on their use. For example, distraction techniques might involve reading or telling a favorite story, talking about the story's characters, or playing video games. Preparation for painful events could involve the use of a puppet, a favorite cartoon character, or an animal. Stuffed animals with inserted audiotapes of stories or music may help to induce a state of relaxation. Something familiar to the child may facilitate participation in these non-pharmacologic strategies.

6. When a child is in pain, the presence of a parent is usually helpful. Other methods of psychological support include holding someone's hand, a stuffed toy, or favorite blanket; asking questions; using distraction; sleeping and resting; relaxing or using imagery; changing positions; and engaging in humor can have powerful effects. Although not well researched in child populations, measures such as physical therapy, TENS [electronic stimulation; described later], splinting a painful extremity, positioning, the application of heat or ice, and massage may help relieve pain.

7. Proper measurement of pain and evaluation of pain interventions as discussed in the next section is of utmost importance in children who are less able to indicate directly their level of pain and distress.

8. Any reservations the parents may have about the use of narcotics for pain relief needs to be
thoroughly discussed prior to their initiation except in an emergency.

C. Minorities

Minority patients are likely to receive less adequate cancer treatment than average. Indexing the adequacy of cancer pain management by WHO standards, a recent multicenter study found minority patients, African-Americans and Hispanics, with pain due to metastatic cancer were three times more likely to have inadequate pain treatment than those seen in non-minority settings. The reasons are unclear, but would seem to include less frequent follow-up care, more concern about the potential addiction both on the part of the patient as well as the physician, increased difficulty in obtaining narcotics from drug stores due to concerns about theft and violence, poorer financial payments for pain therapy, and less time spent by providers to ask about and evaluate the presence of pain.

1.08 Early Discussion of Pain Management with Family

Many problems of pain management arise when there is insufficient communication between health care providers and families in formulating a general plan of therapy from the beginning of an illness or at the first time it becomes apparent the patient suffers from a terminal illness. The number of possible considerations at this point are endless, but the basic decisions which must be made are how aggressively the underlying disease should be treated, how aggressively the pain is to be treated, what should be done if aggressive treatment of the illness is likely to produce additional pain, and how to approach a situation in which obtaining greater pain relief will reduce the patient,s awareness of and ability to relate to his or her surroundings.

Also basic is an understanding of the three stages of cancer therapy. In the first or active stage, which generally lasts until it is determined cure is not possible, most families and health care providers agree to do everything possible to obtain a cure, including such technologically advanced approaches as bone marrow transplantations when indicated. During this phase, the usual feeling is that pain should be endured in the hope of obtaining a prolonged meaningful life -- but this should not interfere with adequate pain therapy, unless doing so would interfere with the final results.

In the second stage, when the terminal nature of the disease is known but the patient can still enjoy life, therapies are undertaken or not (often referred to as "forsaken") based on a balancing test which tends to look at the quality of life as well as the risks and burdens of any procedure. During this period, surgery or chemotherapy that will make the patient miserable for ten days may be justified if it will add thirty days of quality life in the end, but is not justified if it will only add ten days.

Then, in the final stage, it is accepted the patient will, in fact, no longer have quality days, and everything done to prolong life will only delay death without benefit to the patient. At this point a consensus should be reachable that nothing will be done which is likely to cause pain, not even a needle stick to obtain a blood test, and all care will be directed solely at comfort. With this acceptance comes an appreciation that if pain relief requires interventions which might inadvertently shorten life, it will be given.

Two aspects of this type of staging is of particular interest to the author. The first is that we as physicians switch from stage one to two, and then two to three, very dramatically in time. A decision which is deemed as appropriate yesterday becomes inappropriate tomorrow, a difficult concept for the average layman.
The second aspect closely related to bioethics and decision-making is that the patient should be the one to decide when care should switch from stage one to two and two to three, but often the patient is not capable of doing so. In this situation, if there are many concerned family members and friends, there is usually a short period during which there is a difference of opinion among the surviving caregivers, with a little time being required to obtain agreement or near agreement. During this time, medical providers will invariably -- and wisely, I believe -- continue with the approach of the more aggressive stage knowing that within a few days, as the unconvinced witness progress of the disease, a consensus will be reached.

During this early discussion period, one of the most important goals is to reassure the patient and family of the intent and ability to make full use of pain therapies which can assure one hundred percent effectiveness if so desired by the patient. At this point, questions related to the use of narcotics and the potential for addiction and habituation are likely to be raised, at which point the patient and family needs to be reassured not only that this should not be a concern when dealing with a terminal illness, but that the physician does not intend to allow this fear to interfere with effective pain relief.

In fact, the family can and should be reassured that the need to closely balance pain relief against over-sedation or mental confusion seldom becomes a problem until the final stage of the illness is reached. By this time, past history has shown that everyone will tend to accept that there is no need to limit narcotic use except for specific purposes, such as temporarily improving mental function required to sign an important document or to visit with a particular individual of importance to the patient.

During this initial discussion, it is also important to point out the significant connection between the perception of pain and other aspects of cancer care. As noted by Drs. Carla Rimaponti and Eduardo Bruera, two leaders in the field:

"Pain is always subjective; it is what the patient says hurts. A patient's threshold of pain is an individual concept. It can be raised by adequate sleep, mood improvement, diversion, empathy, and understanding, while fatigue, anxiety, fear, anger, sadness, depression, and isolation can lower the pain threshold. The perception of the intensity of pain relates to the interactions of physical, psychologic, cultural, and spiritual factors rather than to the type or extension of the tissue damage. Thus, successful pain control requires a multidisciplinary approach to treatment that addresses all aspects of care and suffering."

This means that if other non-pain symptoms, such as physical incapacity, social isolation, fear, or hopelessness are not addressed, pain management will fail to impact on quality of life in a meaningful way and pain relief is likely to go unrecognized by the patient. Conversely, when little can be done to relieve physical pain without overly interfering with the patient's quality of life in other areas, one can still be helpful by intensely addressing other symptoms just as one would aggressively treat pain if possible. Management of other symptoms may be pharmacologic, but is more likely to be of a social or psychiatric type. Such approaches are discussed elsewhere in this book.

### 1.09 Basic Information About Pain Therapy

The Department of Health and Human Services guidelines suggest there are certain basic questions and concerns cancer patients and their families have which should be specifically addressed by physicians even if not asked.
These include:

1. **Should I only take medicine or other pain treatments when I have pain?**

   **Answer:** You should not wait until the pain becomes severe to take your medicine. Pain is easier to control when it is mild than when it is severe. You should take your pain medicine regularly and as your doctor or nurse tells you. This may mean taking it on a regular schedule and around-the-clock. You can also use the other treatments, such as relaxation and breathing exercises, hot and cold packs as often as you want to.

2. **Will I become "hooked" or "addicted" to pain medicine?**

   **Answer:** Studies show that getting "hooked" or "addicted" to pain medicine is very rare. [And is not particularly harmful when dealing with a terminally ill patient.] Remember, it is important to take pain medicine regularly to keep the pain under control.

3. **If I take too much medicine, will it stop working?**

   **Answer:** The medicine will not stop working. Sometimes your body will get used to the medicine. This is called tolerance. Tolerance is not usually a problem with cancer pain treatment because the amount of medicine can be changed or other medicines can be added. Cancer pain can be relieved, so don't deny yourself pain relief now.

4. **If I complain too much, will I be considered to be a poor patient?**

   **Answer:** Controlling your pain is an important part of your care. Tell your doctors and nurses if you have pain, if your pain is getting worse, or if you are taking pain medicine and it is not working. They can help you to get relief from your pain.

5. **Will I have pain from my cancer?**

   **Answer:** Not necessarily, although most patients do at one time or another. But remember there is a great deal we can do to relieve the pain if we work together to get it done.

6. **Is it necessary that pain be treated?**

   **Answer:** No, it is not required. Just as treating it early will not make it worse later on, failure to treat pain early will not influence the degree of pain days later, although early treatment may prevent worse pain a few hours later.

7. **Is it wise to treat pain early?**

   **Answer:** This is your choice, but there is little reason to delay treatment and there are potentially bad effects of remaining in pain. These include such things as limiting your activity, interfering
with your sleep, keeping you from enjoying family and friends, lessening your appetite, and causing fear and depression, as well as worrying and troubling your family and friends.

8. Will the treatment of my cancer pain influence the other pains I have from the past or in the future?

Answer: Cancer treatment is not likely to interfere with other diseases that might cause pain, but pain medication given for the cancer is also likely to reduce the pain you would have from other diseases. This is usually good, but may be troublesome if it interferes with your ability or the ability of your doctor to recognize other problems, such as appendicitis.

9. What can I do to help my doctors treat my pain?

Answer: The most important thing you can do is to be observant of your pains and to notify your physician when they change, when they get better and when they get worse or if you develop any problems which you think may be coming from the pain medication. It is also wise to tell your doctors if you are taking any medicines not known to him or if you plan to try any other medicines, if you are using any additional remedies for pain, if there are any pain medications that have been particularly helpful for you in the past, or have caused you any troubles in the past, including allergies. If your physician suggests the use of any medication or therapy which causes you fear, it should also be discussed before the treatment is tried.

You may want to fill out the form "Evaluating Pain: Form 1" below to help your physician at the time of his evaluation to develop a plan to treat your pain.

10. Will I have side effects from the medication?

Answer: All medicines can cause side effects, but not all people get them and, in fact, more often than not there are none. When they do occur some people have different side effects than others. Most side effects happen in the first few hours of treatment and gradually go away. Because of the variation from person to person, it is generally wise not to do anything special unless a side effect occurs. The one possible exception to this rule is undertaking preventive measures to avoid constipation when narcotics are given, such as drinking lots of water, juice, and other liquids, as well as eating more fruits and vegetables. Your doctor or nurse may also be able to give you a stool softener or a laxative.

### 1.10 Measuring Pain

Because pain is subjective (determined purely by the patient’s perception) there is no way for the severity to be determined by another party directly. This makes it essential to obtain information about its severity from the patient whenever possible and from the closest care-giver(s) when it is not. This has led to the development of a number of approaches which are intended to give the physician, who is only present intermittently, a better guide to the patient’s pain levels over a twenty-four hour or longer period.

Advances in pain measurement has pointed out that many patients with cancer experience many different pains...
at the same time, with the more severe pain often drowning out the lesser. As a result, upon successful treatment of the more severe pain, there is typically an increase in complaints about the less severe. To prevent this type of confusion, it is important that whatever pain scale is used, it needs to be applied individually to each individual pain perceived by the patient.

There are many scales and methods of recording pain in use, but most employ either a numerical rating, a visual scale, or a description of severity. A typical version referred to as a "Numerical Intensity Scale" asks the patient to assign a number to the intensity of each of his/her noted pains on a scale of 0 to 10; 0 reflecting "No Pain" and 10 reflecting the "Worst Pain Possible."

0-10 Numeric Pain Intensity Scale

Another typical version referred to as a "Visual Analogue Scale," asks the patient to put a slash mark on a line across a paper ranging at one end from "No Pain" to the other end, "Pain as bad as it could possibly be" for each pain being experienced or formally having been experienced.

Visual Analogue Scale

A simple "Descriptive Pain Intensity Scale" asks the patient to choose one of the following words to best describe each of the pains being experienced or formally experienced: "No Pain", "Mild Pain", "Moderate Pain", "Severe Pain", "Worst Possible Pain".

Simple Descriptive Pain Intensity Scale

The following form may also be used:

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Pain Intensity scale rating</th>
<th>Medicine I took</th>
<th>Pain Intensity scale rating 1 hour after taking the medicine</th>
<th>What I was doing when I felt the pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>1/3/94</td>
<td>2:35</td>
<td>6</td>
<td>2 aspirin tablets</td>
<td>3</td>
<td>Sitting at my desk and reading</td>
</tr>
</tbody>
</table>
In making measurements of pain, certain factors should be considered by patients, physicians and families:

1. People vary greatly in how they experience pain and probably in how they rate the same level of pain if experienced similarly, but are likely to rate equal levels of pain fairly equally from time to time. Results are therefore much more helpful in determining whether pain is getting better or worse than how bad the pain is to begin with.

2. One severe pain is likely to diminish the amount of attention given to a less severe pain. With improvement in the most distressing pain, the rating of lesser pains is likely to become more severe even if they have changed little.

3. Impairment of thought, (delirium and/or dementia) makes pain assessment much more difficult, as do impairments of vision, hearing, and motor function. Research on the nursing home population shows that many patients with impairments are able to report pain reliably at the moment asked, but are unreliable recalling pain which occurred in the hours or days before. Reports of present pain are therefore much more reliable then past pains. This suggests the need for more frequent evaluation in patients with these impairments.

4. Because pain is highly responsive to medication, social situations, and other forms of suffering, care should be taken to evaluate pain under similar circumstances and at similar times from day to day. It is also helpful to know if the pain is steady or varies through the day. If it varies, when is it the best and worst. How bad is it at its best and worst.

5. Patient,s families can be very helpful to physicians by taking on a large part of the day to day evaluation and measurement of pain. This is particularly helpful if the person performing the evaluation is not the person who is undertaking most of the care, because the latter is likely to be less objective. [The caregiver,s report is more likely to be influenced by his or her own state of mind.]

6. Because pain is so subjective, it is only reasonable to accept the patient,s evaluation of pain as controlling, without the family or physician trying to interpret how bad the pain actually is themselves.

7. The same measurements used to evaluate pain from day to day may also be helpful in determining how well a particular drug or other form of therapy is working. Repeated measurements over a few hours may be invaluable in determining the timing of doses required in the particular patient by the physician.
8. Development of a "new" pain not previously mentioned by the patient may be particularly important to the physician as a reevaluation of their total condition may well be required.

9. The decision as to whether hospitalization is required to evaluate a new pain is likely to be very complicated and best made by the physician after reviewing all the data available.

10. Knowing factors which aggravate or relieve pain helps clinicians to design a pain treatment plan.

11. The DHHS guidelines for doctors uses the mnemonic "ABCDE":

   A. Ask about pain regularly. Assess pain systematically.

   B. Believe the patient and family in their reports of pain and what relieves it.

   C. Choose pain control options appropriate for the patient, family, and setting.

   D. Deliver interventions in a timely, logical, and coordinated fashion.

   E. Empower patients and their families. Enable them to control their course to the greatest extent possible.

12. The best time to evaluate the effect of pain medication is usually at its peak effect. This is usually 15 to 30 minutes after injections and 1 hour after oral dosage.

13. At times, a patient may report much more severe pain than their attitude suggests is occurring. If pain medication is being limited, this may indicate a desire to receive more pain therapy than is required, but there are other reasons. For instance, if the patient is using distraction and relaxation techniques, they may still be experiencing severe pain from which they are being distracted.

14. It is wise to express the need for accurate reporting. Stress that being stoical may be appropriate in many situations if that is the patient's desire, but not at the time of pain evaluation and measurement. It just causes confusion.

15. If the patient is also suffering from conditions other than pain, they should be noted separately. Try to have the patient rate the pain independent of the other suffering.

16. The physician(s), and other health care providers should establish the roles of various personnel in pain management and who should be ultimately in charge. This responsibility is typically assigned to the clinician most knowledgeable, experienced, interested, and available to respond to patients' needs quickly. When pain is being managed at home, the family should know exactly what will be expected from them and what they can expect from the health care team.

17. Sometimes patient and family satisfaction with pain management does not follow the findings
on pain measurement scales. When this occurs, it is important it be discussed with the person in charge of pain management. Failure of the various parties to continue to agree on the goals of pain management is a frequent cause and may require a reevaluation of the overall treatment plan.

18. It is wise to decide beforehand when a routine review of pain management will occur, and what findings on measurement should trigger an early review, i.e. a new type of pain, or an increase of more than 2 on a 0-10 rating scale.

Physicians are also advised to assess many aspects of psychosocial importance. Frequently, families can be very helpful in aiding this assessment. The DHHS suggests the following are particularly important for the physician to know:

A. What are the effect and understanding of the cancer diagnosis and cancer treatment on the patient and the caregivers?

B. Does the pain have special meaning or produce specific concerns for the patient and the family?

C. Has the patient or family had experience with similar pain in the past?

D. How has the patient responded to incidence of pain in the past? Have they withdrawn? Have they become stoics? Have they underreported the pain they experience? Have they become depressed? etc.

E. Does the patient have specific knowledge of, curiosity about, preferences for, and expectations about pain management methods?

F. Does the patient have specific or unusual concerns about using narcotics such as opioids (morphine and derivatives), anxiolytics (tranquilizers), sedatives (barbiturates) or stimulants (caffeine, Ritalin, amphetamines)?

G. Are there economic fears or realities that are likely to interfere with the patient receiving appropriate pain management?

H. Have there been changes in mood that have occurred as a result of the pain (e.g., depression, anxiety)?

I. Has the pain influenced activities of daily living, including work and recreational activities, sleep patterns, mobility, appetite, sexual functioning, and mood?

J. How has the patient respond to treatment of pain in the past? Have any drugs been particularly effective or ineffective?

K. Are there specific cultural or family patterns which deal with the appropriateness of expressing
Dear Patient:

The key to getting the best pain relief is talking with your doctors and nurses about your pain. They will want to know how much pain you feel, where it is, and what it feels like. Answering the questions below may help you describe your pain. You may wish to write your answers in the space after each question.

1. Where is the pain? You may have pain in more than one place. Be sure to list all of the painful areas separately.

_______________________________________________________________________________

2. What does the pain feel like? Does it Ache? Throb? Burn? Tingle? You may wish to use other words to describe your pain.

_______________________________________________________________________________

3. How bad is the pain? You can also use a number scale and rate your pain from 0 to 10: 0 means no pain and 10 means the worst pain. You can also describe your pain with words like none, mild, moderate, severe, or worst possible pain.

_______________________________________________________________________________

4. What makes the pain better or worse? You may have already found ways to make your pain feel better. For example, using heat or cold, or taking certain medicines. You may have also found that sitting or lying in certain positions or doing some activities affects the pain.

_______________________________________________________________________________

5. If you are being treated for pain now, how well is the treatment working? You may want to describe how well the treatment is working by saying how much of the pain is relieved: all, almost all, none, etc.

_______________________________________________________________________________

6. Has the pain changed? You may notice that your pain changes over time. It may get better or worse or it can feel different. For example, the pain may have been a dull ache at first and has changed to a tingle. It is important to report changes in your pain. Changes in
pain do not always mean that the cancer has come back or grown. Describe how the pain was before and how it is now.

Children and others without the capacity to follow the regular pain scales for adults present specific problems. The following represent sources which may be helpful in advising the reader about pain measurement in children:


### 1.12 The Pain Treatment Plan; Form

When a patient with significant pain is being discharged from the hospital or any time when there is a change in the proposed plan for treating pain at home, it is advisable that a written treatment plan be implemented to insure against confusion on the part of the various caregivers. The following is a suggested plan form:

Pain control plan for

(Name)___________________________________________________________

1. At home, I will take the following medicines for pain control:

<table>
<thead>
<tr>
<th>Medicine</th>
<th>How to take</th>
<th>How many</th>
<th>How often</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>
2. Side Effect Medicine How to take How many How often Comments

<table>
<thead>
<tr>
<th>Side Effect</th>
<th>Medicine</th>
<th>How to take</th>
<th>How many</th>
<th>How often</th>
<th>Comments</th>
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</tbody>
</table>

3. Constipation is a very common problem when taking opioid medications. When this happens, do the following:

___ Increase fluid intake (8 to 10 glasses of fluid per day).

___ Exercise regularly.

___ Increase fiber in the diet (bran, fresh fruits, vegetables).

___ Use a mild laxative, such as milk of magnesia, if no bowel movement in 3 days Take ___________________________ every day at _________ (time) with a full glass of water.

___ Use a glycerin suppository every morning (this may help make a bowel movement less painful).

4. Nondrug pain control methods:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

5. Additional instructions:

________________________________________________________________________
________________________________________________________________________
6. Important phone numbers:

<table>
<thead>
<tr>
<th>Your Doctor</th>
<th>Your pharmacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>------------</td>
<td>---------------</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Your nurse</th>
<th>Your Emergencies</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

7. Call your doctor or nurse immediately if your pain increases or if you have new pain. Also call your doctor early for a refill of pain medicines. Do not let your medicines get below 3 or 4 days' supply.

The following advice may be given to the patient in writing:

If you are having trouble with your plan for the treatment of your pain, consider the following:

Some people find the first pain control plan does not work for them. You and your doctor or nurse can change your pain control plan at any time. Here are some questions to ask yourself about the pain plan:

Is the pain plan hard to follow?

Is there any part of the plan that is hard to understand?

Are you pleased with the pain control?

Are you having trouble getting the medicine?

Are you having trouble taking the medicine?
Are you having side effects from the medicine?

Is the medicine or the treatment causing a problem for you or your family?

Are the nondrug treatments working for you?

Write any other questions you have for your doctor or nurse below.

1.13 Overall Success of Pain Therapy

Experts in pain therapy believe the number of patients with unavoidable and intolerable pain is very small. It has been estimated that for 90 percent of cancer patients, drug therapy alone can alleviate pain and symptoms to an extent patients find adequate, and an additional 8 percent can be relieved with other approaches involving surgery and local interruption of pain through the use of nerve blocks, etc. It is therefore only two percent of patients in whom relief of pain requires heavy sedation to a sleeplike state at the end of life. While far from an ideal option, the choice of terminal sedation in these few is likely to be preferable to the patient experiencing severe pain and suffering at the end of life.

Undoubtedly, this report is optimistic when compared with what happens in reality because it is based on the experience of physicians who specialize in pain therapy and who practice in hospices where patients and their families have accepted the concept that treatment of pain and suffering is more important than a few extra days of life in misery. As we have discussed and will discuss further subsequently, this ideal situation can be undermined by many factors in society, but it is important for patient and family to know that unrelieved pain need not be part of the dying process. In fact, as we will see, adequate pain management seldom contributes significantly in shortening a patient’s life even when a very aggressive approach is taken.

1.14 AHCPR (DHHS) Guidelines

A major advance in reducing inadequate treatment of pain in cancer patients was the development of the AHCPR (Agency for Health Care Policy and Research) guidelines. The Agency was established in December 1989 "to enhance the quality, appropriateness, and effectiveness of health care services and
One of the first projects of the Agency was the release of Clinical Practice Guideline for the Management of Cancer Pain (AHCPR Publication No. 94-0592) in March 1994. The forward to and stated goals of these guidelines, which are freely available both by mail and on the Internet, is instructive in pointing out some of the obstacles to adequate pain relief. It reads as follows:

Cancer is increasingly prevalent in the United States, and the pain associated with it is frequently undertreated. Cancer is diagnosed in over one million Americans annually, of which one of five deaths, or approximately 1,400, die each day from cancer.

Patients with cancer often have multiple pain problems, but in most patients, the pain can be effectively controlled. Nevertheless, undertreatment is common because of a lack of knowledge by clinicians about effective assessment and management, negative attitudes of patients and clinicians toward the use of drugs for pain relief, and a variety of problems related to drug regulations and the cost of and reimbursement for effective pain management.

This guideline was developed by an interdisciplinary panel of clinicians, patients, researchers, and experts in health policy. The guideline provides a synthesis of scientific research and expert judgment to make recommendations on pain assessment and management. Approximately 470 health care professionals and 70 patients were involved either as consultants and peer reviewers or as participants in pilot testing.

The Clinical Practice Guideline for the Management of Cancer Pain was commissioned by the Agency for Health Care Policy and Research (AHCPR). It follows and makes reference to an earlier guideline on acute pain management after surgery or trauma, also commissioned by AHCPR. The cancer pain guideline includes a section on the management of HIV positive/AIDS-related pain because of similarities in the sources of pain and the management approaches. This guideline is designed to help clinicians understand the assessment and treatment of cancer pain and associated symptoms. It reflects a multimodal approach to the management of pain, and it emphasizes the need for careful and continuous assessment to match interventions to the sources of pain in individual patients.

The cost of cancer pain in suffering, disability, and quality of life is high. The guidelines recommend cancer pain be treated aggressively by pharmacologic and nonpharmacologic approaches. In most instances, pain can be treated effectively with relatively low-cost, noninvasive therapies. Given this evidence, health system barriers that interfere with effective pain management •• such as restrictive legislation regarding the uses of opioid analgesics and third-party payer practices that do not reimburse for less invasive interventions •• should be changed.

The guideline specifically notes ten goals:
n To inform clinicians and patients and their families that most cancer pain can be relieved by available methods.

n To dispel unfounded fears that addiction results from the appropriate use of medications to control cancer pain.

n To inform clinicians that cancer pain: (1) Accompanies both disease and treatment. (2) Changes over time. (3) May have multiple simultaneous causes. And (4) If unrelieved, can affect the physical, psychological, social, and spiritual well-being of the patient.

n To promote prompt and effective assessment, diagnosis, and treatment of pain in patients with cancer.

n To strengthen the ability of patients with cancer and their families to communicate new or unrelieved pain in order to secure prompt evaluation and effective treatment.

n To provide clinicians with a synthesis of the literature and expert opinion for application to the management of cancer pain.

n To familiarize patients and their families with options available for pain relief and to promote their active participation in selecting among these.

n To provide a model for cancer pain management to guide therapy in selected painful, life-threatening conditions such as AIDS.

n To provide information and guidelines on the use of controlled substances for the treatment of cancer pain that distinguish the use of these drugs for legitimate medical purposes from their abuse as illegitimate drugs.

n To identify health policy and research issues which affect cancer pain management.

The guideline set out to emphasize:

n A collaborative, interdisciplinary approach to pain control, including all members of the health care team, with participation of the patient and the patient's family.

n An individualized pain control plan developed and agreed on by patients, their families, and practitioners.

n Ongoing assessment of the patient's pain.

n Both drug and nondrug therapies to prevent and/or control pain.

n A formalized, institutional approach to the management of cancer pain, with clear lines of responsibility for pain management and for monitoring the quality of pain management.
An overview of the guidelines presented by the Agency listed the following as the most basic recommendations. I include them because they again serve to stress the importance of the patient, family, and physician interaction:

1. Clinicians should reassure patients and their families that most pain can be relieved safely and effectively.

2. Clinicians should assess patients and, if pain is present, provide optimal relief throughout the course of illness.

3. Curricula for health professionals should include sufficient content on pain to prepare clinicians to assess and manage pain effectively.

4. Clinicians should include patient and family education about pain and its management in the treatment plan and encourage patients to be active participants in pain management.

5. Federal, State, and local laws and regulatory polices should not hamper the appropriate use of opioid analgesics for cancer pain.

6. Clinicians should collaborate with patients and families, taking costs of drugs and technologies into account in selecting pain management strategies.

The guideline was specifically made part of the public domain, making it legal for commentators [like this author] to use the materials without infringing on the copyrights of the original authors. This has been done freely in the chapters which follow. Because the Agency is part of the Department of Health and Human Services, they are frequently referred to as the DHHS Guidelines.

1.15 AHCPR (DHHS) Statement on Patient Education

Knowing what physicians are being advised can be helpful to patients and their families. The following are the suggestions on patient education taken from the DHHS guidelines:

"Patient education entails giving patients and families accurate and understandable information about pain, pain assessment, and the use of drugs and other methods of pain relief, emphasizing that almost all pain can be effectively managed. It should also address major barriers to effective pain management, namely, patients' reluctance to talk about their pain with their care providers, their unfounded fears about becoming addicted to opioids, and their fears that the pain cannot be effectively controlled without unacceptable consequences. Patient education should address other misconceptions, such as the thought that pain medication should be saved for when pain is severe, or else it might not be effective. Some believe that analgesics might produce unacceptable side effects or that choices might have to be made between treating the disease or treating the pain.

"A goal of patient education is to involve patients in their pain management: one of the most important steps toward improved control of cancer pain is better understanding by patients of the nature of the pain,
its treatment, and the role that they need to play in pain control. Patients should be encouraged to report pain as active participants in their own care. To improve their understanding of drug therapy and its effects, patients should be told that:

- The use of opioid analgesics will not lead to addiction.

- Tolerance to opioid analgesics can be dealt with by upward dosage adjustments.

Many patients worry that, if they complain of pain, their health care providers might not think of them as "good" patients. Because of these concerns, some patients who are taking opioids and have been told to take them regularly may take them only when their pain is severe. Patients should be taught that the prevention of pain by the use of regularly scheduled analgesics is desirable. Because of the many misconceptions regarding pain and its treatment, education about the ability to control pain effectively and correction of myths about the use of opioids should be included as part of the treatment plan."
CHAPTER 2. PAIN THERAPY USING DRUGS

2.01 Drug Therapy of Pain; Introduction

2.02 The Ladder Approach

2.03 Non-Narcotics

A. Aspirin and Acetaminophen

B. Newer NSAIDs

2.04 Narcotics: In General

2.05 Routes of Administration

A. Intravenous Injections

B. Subcutaneous Infusion under the Skin

C. Intramuscular Injections

D. Oral Administration

E. Buccal Mucosal Administration

F. Rectal Administration

G. Transdermal Administration

H. Nasal Administration

I. Administration into the Central Nervous System

2.06 Opioids in the Ladder Approach

2.07 Opioid Narcotics; Method of Action

2.08 Different Opioid Narcotics

2.09 Different "Potent" Opioid Narcotics

A. Morphine
B. Hydromorphone (Dilaudid)

C. Methadone (Dolophine)

D. Fentanyl (Duragesic or TDS-Fentanyl)

E. Levorphanol (Levo-Dromoran)

F. Meperidine (Demerol)

2.10 Patient-Controlled Analgesia (PCA)

2.11 General Principles of Narcotic Use

2.12 Dose and Choice of Narcotics

2.13 Side Effects of Narcotic Administration

2.14 Treatment of Narcotic Side Effects

A. Constipation

B. Nausea and Vomiting

C. Sedation

D. Mental Clouding

E. Respiratory Depression (decreased breathing)

F. Subacute Overdose

2.15 Influence of Concurrent Medical Conditions on Pharmacotherapy

2.16 Narcotic Tolerance and Addiction

2.17 Adjuvant Drug Therapies

A. Corticosteroids

B. Anticonvulsants

C. Antidepressants
D. Other Drugs

2.18 Reversible Medication Failures

2.19 Inadequate Pain Therapy/Health Care Providers

A. Educational Failures

B. Inadequate Pain Assessment

2.20 Inadequate Pain Therapy/Social Problems/Patients

A. Under-Reporting of Pain by Patients

B. Inappropriate Administration of Pain Medication

2.21 Inadequate Pain Therapy/Social Problems/Cultural and Religious

A. Misunderstanding of Religious Principles

B. Problems of Communication

2.22 Inadequate Pain Therapy/Social Problems/Cost-Containment

2.23 Inadequate Pain Therapy/Social Problems/Poor Communications

2.24 Inadequate Pain Therapy/Legal Problems

A. Threatened Recriminations

B. Practical Difficulties

2.25 Summary

APPENDIX

Table 1 NSAIDs

Table 2 Opioid Narcotics, Comparison of Methods of Administration

Table 3 Table of Dose Equivalents for Opioid Analgesics
Table 4 Table of Adjuvant Drugs for Treatment of Pain

2.01 Drug Therapy of Pain; Introduction

Thirty years ago medicine sought desperately to develop new technologies to impart drug free relief of pain in the terminally ill considering surgical alternatives to be preferable to drug therapy. Although this search was highly successful and many of the methods developed remain clinically useful in specific situations, recent advances in the use of morphine and related narcotics (also commonly referred to as "opioids") have proven much more significant in our ability to control pain in the terminally ill. Based on these advances, drug therapy and not mechanical intervention has become the accepted cornerstone of pain therapy as it has proven to be effective, inexpensive, rapid in onset, and of relatively low risk. This does not mean the other modalities available to manage cancer pain are outdated, but that they tend to be limited to use when drug therapy is either unsuccessful or overly intrusive on the patient’s quality of life. The following are among the major factors which have made drug therapy so much more effective.

1. Acceptance of the need to individualize drug therapy (analgesia) for the patient suffering with pain in a step-wise fashion, commonly referred to as "laddering." The simplest drugs and dosage schedules involving the least invasion of the patient’s life style are used first, beginning typically with acetaminophen (Tylenol), followed by a group of drugs referred to as "NSAIDs," standing for "non-steroidal anti-inflammatory drugs." When pain persists or increases, a low-potency opioid (narcotic) is added, most commonly, codeine or one of its derivatives. When moderate or severe pain persists, treatment involves the use of increasingly potent opioids, most commonly, morphine, in increasing dosages.

2. Realization that the past practice of giving pain medication only when needed, ("PRN"), should be replaced with plans calling for routine dosing of pain medications "around-the-clock" with additional doses, if needed, being added "PRN." This method has been found to be far superior to only giving medication PRN and actually has been found to result in lower total dosage of narcotic used.

3. Acceptance of the "drug tolerance" and "physical dependence" associated with long-term use of opioids as an unavoidable, but relatively unimportant side-effects of usage, to be clearly distinguished from the problems of addiction. [See discussion below.]

4. The development of new, more convenient methods of drug delivery employing oral preparations, which have proven to be superior to injections because they are more convenient, less costly and provide smoother blood levels which improve the effectiveness of pain relief. When patients cannot take medications orally, narcotics can be given by skin patches which have also been proven to be very effective and well-tolerated in the treatment of severe pain. In rare instances, use of narcotics in rectal suppositories has also been found to be effective. These innovations in drug delivery have essentially replaced the time-honored practice of giving narcotics by injection, which has only been shown to be painful, inconvenient, and unreliable because of the variations of absorption of narcotics from the site of injection.

5. The development of what can be considered to be additional rungs on the ladder when conventional narcotic therapy fails to obtain or maintain good pain relief without unacceptable side-effects. These
added rungs consist of non-narcotic drugs which have been found to be additive in effect with the narcotic pain relievers. Among these drugs, the most commonly employed are drugs generally classified either as anti-depressants, tranquilizers, and a group of drugs medically designated to be "neuroleptics" which are specifically designed to alter the transmission of impulses in the brain, spinal cord, and/or peripheral nerves.

6. Progressive discontinuation of meperidine (Demerol) and pentazocine (Talwin), commonly used narcotics in the past, in favor of more appropriate narcotic choices for the treatment of chronic pain.

7. The development of patient controlled analgesia (PCA), an approach which allows self-administration of narcotics by the patient when it is felt to be required, an approach which surprisingly often reduces the amount of total dosage required.

8. The development of pain evaluation methods which make it easier for physicians to determine the effectiveness of drug therapy and to separate out the various "pains" suffered by the patient in a more organized manner.

9. The development of approaches specifically using written pain management plans, the avoidance of placebos, and the need for continuous monitoring of the effects of drug therapy. The best protection patients and their families have from inadequate therapy is being informed about pain management and speaking up clearly. In this way, they come to know what to expect, when to request additional therapy, and what sets the limits for effective pain management.

10. A change in the approach to narcotic side effects when the drug has been found to be effective in pain control. In this new approach, instead of discontinuing the "successful" narcotic, efforts are made to enable its continued use through manipulation of dosage schedules or the addition of specific therapy to control the side-effect(s). In some cases this involves anticipatory measures, most typically, starting stool softeners at the same time narcotics are started even before constipation occurs.

11. Closely related to #10 is advanced knowledge of how to switch narcotics of similar strength back and forth in an effort to maximize effectiveness of pain control while minimizing side-effects. One way this can be done is by taking advantage of the partial non-transferability of tolerance. This refers to the fact that although the patient will develop tolerance to all narcotics requiring increasing dosage with time, development of tolerance for one narcotic may not be completely transferrable to another narcotic. Therefore, a lower comparable dose of a new narcotic may be as effective in treating pain as a higher relative dose of the narcotic that has been in prior on-going use with less resultant side-effects.

12. Another possible method of taking advantage of the tolerance phenomena is related to the fact that pain relief and the production of side-effects are both subject to the development and loss of tolerance but not necessarily at the same rate. This means that a previously discontinued drug may later be found to be effective for pain relief in the patient at a dosage which does not cause side-effects. This happens if loss of tolerance for pain relief occurs faster than loss of tolerance for the side-effect.

13. Realization that the most feared and discussed complication of narcotics, depressed breathing, is actually uncommon with the modern "laddered" approach to pain therapy calling for slow increases in
narcotic dosages. Also, the fact that even if breathing is depressed, it can be quickly reversed with special drugs used to stop the narcotic effects. (naloxone/Narcan)

This chapter addresses the use of drugs in the treatment of pain more extensively. Other aspects of pain management are addressed more fully in later chapters.

2.02 The Ladder Approach

The ladder approach to pain therapy was pioneered by the World Health Organization in 1990. Under this plan, pain is managed according to its severity. Mild pain is initially treated with acetaminophen (tylenol) or aspirin with additional use of NSAIDs [see discussion below] as needed. Even though moderate symptoms are likely to require the use of mild (codeine, hydrocodone-Hycodan) or strong (morphine, fentanyl-Duragesic) narcotics, they are initially treated with the same drugs as mild pain which are then continued if and when the narcotics are added. When severe pain exists from the onset, the ladder approach recognizes that more rapid relief is required and treatment is usually initiated with long-acting strong opioid narcotics. Once pain relief is achieved, the milder medications may be added and the dosage of narcotic reduced. If relief is not achieved quickly, additional drugs which have been found to add to the effectiveness of the narcotic pain killers is added until relief is obtained. Severe pain almost always necessitates the use of long-acting strong opioid narcotics, often in association with additional drugs which have been found to add to the effectiveness of the narcotic pain killers.

The five essential principles of management according to the WHO ladder include:

1. Medications should be taken by mouth when possible.

2. Medications should be taken by the clock. Research shows patients generally require less analgesics when opioids are taken according to a set schedule.

3. Medications are escalated according to the rating of pain from mild, moderate to severe.

4. Medications are tailored to individual needs. The goal is always the most effective pain management with the fewest side-effects.

5. Pain is monitored and re-assessed regularly.

The ladder approach to pain accepts and encourages the use of additional non-pharmacologic methods of pain control including both physical and psychological means. The addition of heat, cold and massage can effectively relieve muscle spasm and tension. Physical therapy and range-of-motion exercises may help prevent muscle atrophy and other problems related to disuse of body parts. Acupuncture and transcutaneous electric nerve stimulation (TENS) can be very effective in the treatment of nerve and muscle pain. Additionally, techniques such as imagery, hypnosis, biofeedback, and relaxed breathing increase feelings of self-control and may promote healing. Psychosocial and pastoral support assist with both pain and suffering. [Many of these approaches are further discussed in subsequent chapters]
2.03 Non-Narcotics

A. Aspirin and Acetaminophen

Most of the non-narcotic pain relievers commonly used for initial pain therapy in terminal illness are from a group of drugs referred to as "NSAIDs." [Usually pronounced as two words, "N-SAIDS"] NSAIDs in general work by blocking the production or activity of chemicals called prostaglandins, which are produced in multiple organs of the body. Although the term NSAID is relatively new, we now know in hindsight that NSAIDS include many older drugs, such as aspirin and acetaminophen (Tylenol), as well as the whole series of related drugs released over the last thirty-five plus years beginning with Butazolidine, Indocin and Motrin.

In general, NSAIDs are considered to be useful in a wide variety of conditions involving mild to moderate pain both related and unrelated to cancer and other terminal illnesses. They are particularly useful because they have few side effects within approved dose ranges, but are limited in their effectiveness by having what is referred to as a "ceiling effect." This means that increasing the dosage beyond a certain level, the "ceiling" dose, does not increase their effectiveness, although it does increase the side-effects.

Aspirin has traditionally been the first drug used in the treatment of mild pain, but has largely been replaced in recent years by acetaminophen because it does not have aspirin’s tendency to cause bleeding both by irritating the stomach lining and by interfering with the coming together (aggregation) of blood platelets as required in the process of blood clotting. In spite of this potential problem, however, aspirin should not be forgotten because it is still relatively safe compared to other analgesics and is often found to be more effective than acetaminophen in relieving pain. [Note: many physicians believe that it is the effectiveness of Tylenol advertisements and not the superiority of the drug which has led to the recent diminished use of aspirin for pain.]

B. Newer NSAIDs

Somewhat more effective than aspirin and acetaminophen in general are the newer NSAIDs, including Motrin, Nalfon, Feldene, Toradol, Anaprox, Naprosyn, Orudis, Meclomen, and Ponstel among many others, but they, too, share aspirin’s effect on the stomach lining and on platelet aggregation and therefore constitute a risk for bleeding. Although NSAIDs have ceiling effects which limits the usefulness of dosing any one drug over recommended levels, changing to a different NSAID may still be effective when the approved dosage of one provides inadequate relief. NSAIDs are frequently used as initial therapy in mild pain even before aspirin or acetaminophen because they are effective, frequently available over the counter, relatively inexpensive, and have been found to be effective in combination with opioids which are commonly required later when pain gets worse.

Use of NSAIDs and narcotics together are often additive in effect, each being better when used in combination. This is in part because the NSAIDs work primarily in the local areas of inflammation while the narcotics work in the brain and spinal cord. In addition, that part of the action of the NSAIDs which does occur in the brain involves areas of the brain different from those affected by narcotics. As a result, concurrent use of an NSAID with an opioid is likely to produce better pain relief with lower dosages of
both drugs than would be required if either were used alone.

Unlike opioid analgesics, NSAIDs do not produce tolerance, physical, or psychological dependence. Like aspirin and acetaminophen, the newer NSAIDs also lower body temperature.

The major side effects of the NSAIDs, besides the inhibition of platelet aggregation noted above, is on the G.I. tract, occasionally producing gastric distress, heartburn, nausea, vomiting, loss of appetite, diarrhea, constipation, flatulence, bloating, epigastric or abdominal pain or discomfort, and, more rarely, causing bleeding, ulceration, or perforation of the stomach. NSAIDs may also cause dysfunction of the liver or kidney, but this is usually the result of long-term use greater than typically involved in terminal care.

Although this list of potential side-effects is long, the number of patients who are unable to tolerate any NSAID is small, and the incidence of the more serious side-effects like bleeding, liver or kidney failure is quite low unless there is preexisting disease of these organs. If long-term care is anticipated, routine checks of organ function by blood testing should be done on occasions. Because the damage to the liver and kidney caused by NSAIDs is gradual, such testing should avoid any significant risk of significant injury.

Most NSAIDs are available as oral tablets or capsules, and several are available as oral liquids. They are rarely used as rectal suppositories and only one, ketorolac, (Toradol) can be given by injection.

[For more information about these agents, see the table in the Appendix of this chapter]

2.04 Narcotics: In General

Pain which persists after the maximum dose of non-narcotics has been given or moderate to severe at the outset is normally treated with narcotics. Initial trial usually involves such drugs as codeine or hydrocodone (Hycodan) -- often referred to as mild opioids -- but if these fail or when they become ineffective over time, the more potent opioids, such as morphine (MS-Contin among many brand names), Hydromorphone (Dilaudid), methadone (Dolophine), fentanyl (Duragesic), or levorphanol (Levo-Dromoran), are prescribed as well.

Typically, initial dosing is fairly low, but rapidly increased to obtain control of pain as required. Usually dosages which are initially found to be effective need to be increased with time, experience showing that hesitating to make required increases only leaving the patient in unrequited pain without reducing the amount of drug that will actually be required in the end. Rarely, side effects of the narcotics will preclude obtaining adequate relief either from the beginning or as time progresses.

Most patients who require potent opioids for relief of pain will require simultaneous treatment with two different forms: a long-acting (basal) form administered around-the-clock and a short acting form, administered as needed (commonly referred to as "PRN").

Since most cancer pain is constant and unremitting, an around-the-clock schedule for the administration of a base level of narcotics is preferable to PRN administration, which is based on the presence of
perceived pain. This strategy, most commonly using oral morphine, oral methadone (Dolophine), or fentanyl (Duragesic) skin patches, avoids the "roller coaster" type of pain relief which is produced when drug is withheld until pain is felt and the patient then has to wait for the drug to be given and to take effect. In addition, prolonged use of PRN drugs often leads to a pattern of patient anticipation and memory of pain which produces a form of suffering even when drug therapy has been found to be effective.

Superimposed on the above "base" regimen, potent short-acting opioids such as immediate release morphine, hydromorphone (Dilaudid), or oxycodone (Percodan, Percocet, Tylox) are generally made available on a PRN basis, usually at intervals of two to four hours, for exacerbations of pain. Such exacerbations, referred to as "breakthrough pain," may be spontaneous, related to specific activities, or, if the dose of the basal analgesic is insufficient, may occur regularly just prior to the next scheduled dose. When specific pain producing activities has been identified, patients should be instructed to utilize PRN doses prior to activity. When the patient experiences end of dose failure, the dose of long acting analgesic should be increased.

Because narcotic therapy for pain is such an integral part of the medical treatment of terminally ill patients and so often causes concern by the patient and family and misunderstanding with medical providers, this book will now discuss in detail many of the factors involved in the use of narcotics in the terminally ill.

2.05 Routes of Administration

Traditionally, opioid narcotics were given by injection just beneath the skin (sub-cutaneous), or, less frequently, into the muscle or by vein. Because the early preparations were short acting, they required multiple (4 to 6 or more) injections a day, thereby necessitating the presence of nursing services or family members willing and able to give the injections.

Happily, these significant drawbacks were avoided when it became evident that proper formulation of morphine could be given effectively by mouth and, even more recently, with the development of "transdermal administration," using skin patches made with the potent narcotic, fentanyl (TDS-Fentanyl). Thanks to these advances making oral or patch administration the treatment of choice, pain can almost always be effectively controlled by informed members of a home support system even in the absence of continual medical supervision. In addition, alternative methods of administration have been developed which do not require continuous medical supervision if these more established methods fail, as discussed below.

The following compares the risks and benefits of the various routes of administration. In many cases, more than one route may be used at the same time in the same patient to treat different types of pain or pain of varying severity.

A. Intravenous Injections

Because it avoids the need for the drug to be absorbed, intravenous injection is the fastest means of obtaining narcotic pain relief. It is also associated with the most pain relief for the dose and, for most
preparations, is not excessively expensive. Although the intravenous route provides the most rapid onset of analgesia, the duration of pain relief after a single dose is shorter than with other routes, making it inappropriate as the primary route of administration in most patients who suffer persistent pain of moderate or greater severity. On occasions, however, if for instance there is another need for a continuous intravenous infusion line, a continuous intravenous drip of narcotics may be reasonable for persistent pain control. When, however, there is no real need for an intravenous line, oral or transdermal administration is clearly preferable as the I.V. line always interferes to some degree with the comfort of the patient.

B. Subcutaneous Infusion under the Skin

Many physicians find continuous administration of narcotics dissolved in very small quantities of salt water through a needle directly under the skin to be preferable to intravenous administration in the home unless there is an additional need for an I.V. line. Absorption of opioids from under the skin is rapid and blood stream levels can be quickly stabilized to give continuous pain relief. Morphine and hydromorphone (Dilaudid) are most commonly employed for subcutaneous infusions, usually in very high concentrations which may require only one or two ounces of fluid to be given each day.

C. Intramuscular Injections

Narcotic injections directly into the muscle is usually avoided because it tends to be painful and inconvenient, and absorption from muscle is not very reliable.

D. Oral Administration

Oral administration of narcotics is the preferred route whenever possible because it is the most convenient and cost-effective. Oral opioids, including morphine, are available in tablet, capsule, and liquid forms and in immediate and controlled-release forms. Controlled-release tablets become immediately released when crushed and are therefore not appropriate for long-term therapy in patients who are unable to swallow whole tablets.

While oral administration is preferred, in some patients it is not practical. This most commonly occurs when there is persistent nausea and vomiting, pain or disability with swallowing, fear that pills will "go down the wrong way" (be aspirated) into the lungs, when severe pain requires more immediate relief, or when the patient suffers from delirium, confusion, stupor, or other changes in the mental status.

E. Buccal Mucosal Administration

At the time of writing this book, attempts are underway to develop means of administering narcotics (morphine, fentanyl-Duragesic) through the lining of the mouth either by using a concentrated liquid (elixir) or lozenges to be held against the cheek or under the tongue. They may now be available.

F. Rectal Administration
The rectal route of administration using a narcotic suppository may be used when patients have nausea or vomiting or are fasting for surgery or special testing. It is not appropriate if there is irritation around the rectal area which can be made worse by placement of a suppository, if there is diarrhea, or if the patient is unable to insert a suppository himself or herself. Like oral administration, the absorption of the drug is less than total and must pass in the blood through the liver where it is partly inactivated to get to the rest of the body, so larger dosage must be used than when given intravenously. Like oral administration, this means is also inexpensive and most appropriate for long-term administration for stable pain, not for acute pain.

**G. Transdermal Administration**

Transdermal administration goes directly into the blood stream without going through the liver and therefore requires doses very similar to those used for injections. At present, fentanyl (TDS-Fentanyl) is the drug which is typically used with transdermal applications. Four patch sizes are available, made to provide absorption of 25, 50, 75, or 100 mgs per hour. The maximal recommended daily dose is 300 mg/hour. If this dose fails to relieve pain, it is suggested an alternative means of administration be tried. Patches are made to last 3 days. Absorption requires 12 to 18 hours to obtain adequate blood levels, so the patches are not appropriate if rapid pain relief is required. Transdermal fentanyl (TDS-Fentanyl) is therefore most appropriate when pain is relatively constant with infrequent episodes of breakthrough pain.

**H. Nasal Administration**

The transnasal route is an alternative delivery method that may be useful when patients are no longer able to tolerate the oral route. Unfortunately, the only commonly used narcotic formulated for nasal use is butorphanol (Stadol), which is rapidly absorbed from the nasal mucosa. Because it is not a full acting narcotic, it is not the best formulation for control of chronic pain, but may be particularly helpful for acute headache.

**I. Administration into the Central Nervous System**

Narcotics may be administered through catheters placed within the spinal canal or even directly into the fluid which bathes the brain (cerebro-spinal fluid). These methods are only used when pain cannot be controlled by oral, transdermal, subcutaneous, or intravenous routes or when side effects such as confusion and nausea limit the use of sufficient narcotics by simpler means to relieve pain. Administration through catheters is much more expensive and inconvenient to use, as they require experienced, meticulous technique, significant family and professional support systems, and sophisticated follow-up, which is not always available. Their use is also more likely to be associated with acute respiratory depression.

Once the narcotic administration through such catheters has been shown to be effective, a permanent device capable of delivering narcotics directly into the cerebro-spinal fluid can be implemented, thereby decreasing the need for constant medical monitoring.

Morphine is the most commonly used intraspinal drug. Alternative opioids such as hydromorphone
(Dilaudid), fentanyl (Duragesic), or sufentanil (Sufenta) have been used intraspinally to manage cancer pain and may be useful substitutes, especially when the patient experiences general side effects from morphine which is partially absorbed from the spinal fluid into the general circulation. Intraspinal use of narcotics tends to be most effective clinically when the patient’s pain is localized in the legs and lower part of the body. Introduction of narcotics directly into the fluid bathing the brain is most commonly used for severe headache or pains involving the neck area.

[For more information comparing the methods of administration, see the table in the Appendix to this chapter]

2.06 Opioids in the Ladder Approach

Narcotics, especially the less powerful ones such as codeine, are often used from the beginning for the treatment of moderate to severe pain. But even when initial pain therapy with non-narcotics is successful, this success is usually not lasting and narcotics are likely to be required for pain relief at some time before cancer reaches the terminal phase.

When narcotics are added to NSAIDs in the treatment of pain, the most effective NSAID is normally continued in the same dosage as was found to be maximally effective prior to the institution of the narcotic. The NSAID is not stopped.

When treatment with the NSAIDs is associated with insufficient relief of pain or is poorly tolerated, the addition of a member of the class of drugs referred to as the "weak opioids," such as codeine, or oxycodone (Percodan, Percocet, Tylox), or an "intermediate" opioid, such as hydrocodone (Hycodan, among others), is recommended. While there is probably no ceiling dose for the weak opioids themselves, because they are often prescribed as part of a combination analgesics with acetaminophen or aspirin, and because the dose of these additional components are limited, the dose of the total preparation is artificially limited. If this were not the case, the distinction between the so-called "weak" and "potent" opioids would probably disappear and the "weak" opioids would probably be used in larger dosage similar to the more potent opioids.

In general, because codeine is so constipating, oxycodone (Percodan, Percocet, Tylox) is a better choice among the "weak" opioids. It is also more readily available as a single drug preparation, making it easier to regulate dosage. While there may be legal pressure to use these drugs in increasing dosage because they are viewed to be less addicting, it may not be wise, as switching to a more potent opioid is likely to be a better course of action.

Note propoxyphene (Darvon) is purposely omitted from this scheme as not being an appropriate drug for the treatment of terminally ill patients.

2.07 Opioid Narcotics; Method of Action

Opioids relieve pain by a means entirely different from the NSAIDs, which are primarily effective in reducing local inflammation. The pain which is produced in the body by local inflammation and injury must ultimately be perceived by certain cells within the brain. For this to happen, the local inflammation...
or injury must initiate the passage of an impulse over a series of interconnecting nerve cells which run between the site of pain production and the pain receipting cells in the brain. Although passage of the impulse along the nerves acts more like an electric current, passage from cell to cell requires the release of certain chemicals (neuro-transmitters) from the surface of the previous cell in the line of transmission. These chemicals in turn activate specific areas on the surface of the next nerve cell (receptor cites) in the chain which then provides for further passage of the impulse down its length through the "electrical" current so as to cause the release of the chemical required to stimulate the next cell in the series. The point of action of the narcotic is at the specific receptor cite on the cell surface which perceives the presence of the chemical. Opioid analgesics work by blocking these specific receptor cites both within and outside the brain and spinal cord.

2.08 Different Opioid Narcotics

Many opioid narcotics are available, although morphine is by far the most commonly used. Although their mechanisms of action are similar, the dosage of the various chemicals varies considerably and one frequently will work when another has failed. A major difference among the various narcotics is that some are available only for injections or for oral use, while others are available in different types of preparations, giving the physician a wide choice of drugs to use in any one individual and at any one time. To avoid confusion, it may be important to understand the interaction of these drugs and the relative strength.

Most of the commonly used opioid narcotics belong to a class of drugs referred to as "full agonists" because they work directly on the receptor site. The full agonists include morphine, hydromorphone (Dilaudid), codeine, oxycodone (Percodan, Percocet, Tylox), hydrocodone (Hycodan), methadone (Dolophine), levorphanol (Levo-Dromoran), and fentanyl (Duragesic). This is only important to know because being of the same class of drugs, they do not antagonize each other and are additive in their effects. Full agonists are of particular importance in the treatment of cancer pain because they do not have a ceiling to their pain killing effect and therefore the dosage can continually be increased as long and as high as required.

Unlike the full agonists, narcotics such as pentazocine (Talwin), butorphanol tartrate (Stadol), dezocine (Dalgan), and nalbuphine hydrochloride (Nubain) are considered mixed agonists. These drugs are similar to the NSAIDs in having an analgesic ceiling above which additional dosages do not increase their effectiveness because they do not work on all receptors. In recent years, these drugs have not been widely recommended, in part because their use with the more common full agonists can cause interference with the effect of the full agonist precipitating a withdrawal syndrome and increased pain.

Morphine is the most commonly used opioid for moderate to severe pain for many reasons. First, because it can be administered by many routes. Second, because it is available in a wide variety of dosages, including long-acting preparations. Third, because it is so widely studied in the past making its actions extremely well known to the medical community. Fourth, because it is inexpensive. In contrast to morphine, which has continually gained increased popularity, Demerol and Talwin, narcotics widely used in the past, have become much less popular over recent years and should probably be avoided in most situations. An increasingly popular narcotic is fentanyl (Duragesic or TDS-Fentanyl) because of the ease with which it can be used in skin patches, a method now being advocated even before oral morphine.
2.09 Different "Potent" Opioid Narcotics

A. Morphine

Morphine is the most commonly used opioid narcotic, oral morphine being most physician’s drug of choice in the management of moderate or severe chronic cancer pain. Oral morphine comes in both short-acting (MSIR, Roxanol) and long-acting forms (MS Contin, Oramorph). The short-release tablets allow fast absorption, with peak blood levels (corresponding to maximum pain relief) appearing in 20 to 90 minutes and effective pain relief usually lasting approximately four to six hours, although this may vary considerably from patient to patient and may be even less than four hours. The amount of medication absorbed after an oral dose varies from about 35% to 75% of that given, making the oral dose of morphine approximately twice that of injectable forms. Morphine tends to be removed from the body more slowly in patients over 50 years of age, which may explain why older patients usually [but not always] require relatively lower doses of morphine for the same analgesic effect. Using slow-release tablets, morphine administration can be reduced to twice a day, although a few patients may require dosing every eight hours to maintain effective pain relief even with the long-acting preparations. In general, every 12-hour administration of slow-release morphine and every four-hour administration of short-release oral morphine provides similar analgesic efficacy and side-effect profiles in the treatment of chronic pain. Morphine also can be administered by rectal, subcutaneous, and spinal routes.

B. Hydromorphone (Dilaudid)

Dilaudid can be administered orally, rectally, and by intravenous or subcutaneous injection, but its main use is when it is desirable to give constant pain therapy through continuous infusion of a solution containing the drug under the skin. It is more potent than morphine and acts even more quickly, making it useful for acute, severe, breakthrough pain. It may also be useful in patients who fail to tolerate morphine well. Because of its short duration of action, administration is likely to be required every two to three hours.

C. Methadone (Dolophine)

Methadone is particularly useful because of its long acting effects, but, because it remains in the body so long, runs the risk of build-up and overdosing if too many doses are given in too short a time. This is made more likely to happen by the large variance in dose requirements experienced by different patients. Doses are usually given at eight hour intervals, but many physicians use six or twelve hour intervals, and this may vary from patient to patient. Methadone is also effective and well tolerated by rectal and intravenous administration, but should not be used under the skin.

When switching to methadone from other drugs, the dose required is often found to be considerably less than would be predicted from charts comparing the strengths of the various narcotic analgesics. Overall, Methadone has certain advantages over the other strong opioid analgesics: (1) it is much less expensive than the others, (2) it generally requires much less frequent administration, (3) it has a high potential to control pain which is unresponsive to morphine or other opioids because there is reduced cross-
tolerance, and (4) it has less problems with side-effects of break down products in the body. The main problem with Methadone is its lack of predictability because of the marked variation from patient to patient and the fact it is hard to determine its expected effect when switching from one opioid to another.

D. Fentanyl (Duragesic or TDS-Fentanyl)

Fentanyl is a synthetic narcotic approximately 75 times more potent than morphine and with characteristics that make it particularly good for use by administration in skin patches for chronic pain therapy. Fentanyl is especially useful in skin patches because of its high potency, skin compatibility, and small chemical size making for easy absorption through the skin. Patches are available in four doses set to release 25, 50, 75 or 100 micrograms per hour for anywhere for up to three days. In these doses, it is well tolerated, but higher doses are likely to cause side effects such as vomiting, sleepiness, and respiratory depression. Transdermal fentanyl (TDS-Fentanyl) is not appropriate for acute pain and breakthrough pain, but newer fentanyl tablets are being developed to be sucked on and absorbed through the lining of the mouth in order to meet the need for a rapid onset of pain relief.

E. Levorphanol (Levo-Dromoran)

Levorphanol resembles methadone (Dolophine), in that it is very long acting allowing dosing every 8-12 hours but, like methadone, is commonly associated with accumulation of drug and excessive sedation. It is more powerful than morphine and therefore is effective in lower dosage.

F. Meperidine (Demerol)

Although extensively used for postoperative pain, meperidine is not recommended for the treatment of chronic pain because chronic use leads to a build-up of breakdown products within the body causing tremors, muscle jerking and seizures, especially in patients with kidney problems.

2.10 Patient-Controlled Analgesia (PCA).

Patient controlled analgesia (PCA) is a major advance in pain control. It can be used orally by patient self ingestion of pills, but is more commonly employed using a special pump which is set to inject small quantities of narcotics through a catheter placed within a vein, under the skin, or within the spinal canal, in which case it empties directly into the spinal fluid. PCA was largely developed for use in postoperative patients, in which it is usually the only source of pain control. But in treating terminally ill patients it is usually used along with continuous around the clock narcotics orally or by patch, the patient supplementing the continuous medication with PCA when break-through pain occurs. The amount of extra pain medication self administered by the patient may also help indicate how much additional pain medication should be added to the around-the-clock dosages.

PCA has been found to be safe for both home and hospitalized patients, but should not be used for sedated and confused patients. It has not been found to increase the rate of development of tolerance or the total amount of narcotics given if good pain relief is obtained. Use of PCA is particularly satisfying because it helps maintain patient independence and control by matching drug delivery to the self-determined need for analgesia.
2.11 General Principles of Narcotic Use

1. Best results are normally obtained using continuous dosing. This is usually done by using a longer acting oral preparation such as morphine or by using a skin patch. Around-the-clock administration of narcotics allows each dose to become effective before the previous dose has lost its effectiveness and therefore avoids peaks and valleys with associated poor pain relief.

2. When pain is aggravated or is expected to be aggravated by a procedure or event, a single dose of short acting narcotic may be used in addition to the background long-acting medication. A patient may also be given PRN doses for the first 24 to 48 hours when a new drug is started to define the best daily dosing requirements for that individual patient.

3. Dosage typically requires adjustment over time as background pain levels vary and tolerance develops. Because of this variation and tolerance, daily doses of morphine ranging from 60 to 3000 mgms. may be required to adequately relieve cancer pain and should not be considered to be abnormal at either end. [Discussed below]

4. With the exception of fentanyl delivered by the transdermal route, there is no ceiling or maximal recommended dose for full opioid agonists, as discussed above. In fact, very large doses of morphine, e.g., well more than ten times the normal dose, may be needed for severe pain and is likely to be well tolerated if tolerance has developed over time.

5. Published tables vary in the suggested doses of other narcotics which are equivalent to morphine. This is in part because individual patients react differently to the different compounds. While the table can give a guide as to appropriate starting doses, clinical response must be monitored for each individual patient to actually achieve the appropriate dose.

6. When tolerance develops for one drug, there is also likely to be some tolerance for a different opioid narcotics, but not to the same extent as for the original drug. This means when shifting drug, a lower dose of the new drug is likely to be as effective as the higher equivalent dose of the original drug for which the body has developed tolerance.

7. It is usually advisable to try several different oral opioid narcotics before switching routes of administration. In most instances, failure of oral administration is next followed with the use of skin patches, or the patches may be used first or earlier in the sequence of drugs tried. Only when multiple failures have occurred does it become appropriate to try the more complicated invasive approach to relieve persistent pain. For example, patients who are too sleepy or who develop nausea when taking oral morphine should first be tried on another oral medication to see if pain relief can be obtained without the side effect. If this doesn’t work, a fentanyl skin patch may be tried. Because of individual variation in response, this is likely to find a drug which both works and does not cause unreasonable side effects.

8. Constipation is an almost universal complication of opioid use, and all patients should receive prophylactic stimulant laxative therapy unless otherwise contraindicated (e.g., if the patient has chronic diarrhea). Sedation is a frequent side effect of initial opioid use or following increased dosage, but
usually does not require treatment because the body quickly develops tolerance to their sedative effects.

9. Many people fear large doses of opioid narcotics will cause undue respiratory depression, but this is most unusual because large doses are always preceded by the use of smaller doses during which time the body develops tolerance to its respiratory effect. In patients with underlying respiratory disease, this concern may be more legitimate.

10. True hypersensitivity reactions to opioids are rare. If patients experience such reactions, it is often possible to administer a different opioid safely. For example, patients allergic to morphine are likely to tolerate fentanyl or methadone and vice versa.

11. All effects of opioid narcotics can be reversed by giving an opioid antagonist such as naloxone (Narcan). It should only be used in an acute emergency, however, because its use completely blocks the pain relief which is being experiencing and can cause excruciating pain and seizure.

12. Opioid tolerance and physical dependence do not equate with "addiction."

13. Whatever the cause, a change of opioids using equivalent doses may decrease side-effects while maintaining pain control in some patients. Opioid rotation often is necessary to obtain satisfactory long-term pain control in cancer patients.

### 2.12 Dose and Choice of Narcotics

The appropriate dose of narcotics is the amount of opioid that controls pain with the fewest side effects. The need for increased doses of opioid often reflects progression of the disease, as well as the development of tolerance. Either cause may lead to the need for more frequent administration as well as increased dosage. Some idea of the dosage which may be required can be gathered from a recent report by Dr. Portenoy, a well-known specialist in the treatment of cancer pain, who reports that while the average dose of morphine for cancer patients may be 100-200 mgms. per day, some patients may require over 1,000 mgms per day, the largest dose being noted to be over 35,000 mgms. per day.

An important part of finding the right dose is using slow titration. This means that until pain is relieved, the next dose is usually increased by about twenty-five percent over the previous dose. Points to keep in mind include:

1. **Titration.** Increase or decrease the next dose by one-quarter to one-half of the previous dose.

2. **Route conversion.** When changing from the oral to the rectal route, begin with the oral dose, then titrate upward frequently and carefully. Lower doses are required for parenteral (non-oral) routes but are similar when given into a vein, under the skin, or directly by injection into a muscle.

3. **Schedule.** Prevent recurring pain rather than having to subdue it. Give analgesics on a regular schedule to prevent a loss of effectiveness between doses.
n Tolerance. Assume patients actively abusing heroin or prescription opioids (including methadone) have some pharmacologic tolerance which will require higher starting doses and shorter dosing intervals.

n Cessation of opioids. When a patient becomes pain free as a result of cancer treatment or palliation (e.g., nerve destruction), gradually decrease the opioid to avoid the symptoms of withdrawal. [The speed of possible withdrawal varies from one narcotic to another.]

n Opioid therapy in special populations. Specific guidelines for opioid use should be used with the elderly, children, persons physically or cognitively impaired, and known or suspected drug abusers.

[See table in Appendix of this chapter for dose equivalents.]

2.13 Side Effects of Narcotic Administration

Treatment with opioid narcotics frequently causes side effects, but in most cases they are transient and manageable. Proper identification and therapy for these side effects is critical to effective pain relief, as they are too often viewed by the patient and family as immovable barriers to effective therapy. To the contrary, they should instead be considered temporary challenges to the creativity of physician and family to minimize their effects through tailoring of the pain management program to the needs of the particular patient. Of particular importance in this regard is the need to avoid a belief the patient is "allergic" to the drug, a rare occurrence which requires permanent discontinuation of the drug, as opposed to suffering one of the many common dose related side effects that can be managed by proper switching and dosing of drugs.

Constipation and sedation are the most common side effects associated with narcotics. Other common side effects include confusion, nausea and vomiting, depressed respirations (breathing), dry mouth, difficulties urinating, itching, muscle spasms, poor mentation, euphoria, sleep disturbances, sexual dysfunction, skin irritation with patches, and inappropriate secretion of ADH, a hormone which causes decreased urine production. Because constipation is so common, it is wise to act prophylactically to try to avoid its development. Because the other side-effects vary so much from patient to patient, they are best treated only when clinical observation shows them to be present.

2.14 Treatment of Narcotic Side Effects

A. Constipation

Constipation is a common problem associated with opioid administration. It is also frequently aggravated by other factors associated with terminal illness, such as decreased food and water intake and disease of the bowel itself. In addition, it may mask other important medical conditions such as bowel obstruction or fecal impaction, both of which may be aggravated by overly aggressive treatment of the apparent constipation. Mild constipation can usually be managed by an increase in fiber consumption and the use of a mild laxative such as milk of magnesia. These agents should be administered on a regular schedule, barring contraindications. Severe constipation occurs as a result of opioid induced slowing of intestinal contractions and can be treated with a stimulating cathartic drug, e.g., bisacodyl (Dulcolax), standardized senna concentrate (Senokot), or hyperosmotic agents (e.g., lactulose or sorbitol). Oral laxatives can be taken at bedtime, and rectal suppositories
can be used in the morning if needed. Stool softeners are of limited usefulness.

B. Nausea and Vomiting

Narcotic induced nausea is frequently relieved with the passage of time. It may also be treated with specific drugs such as Compazine or other phenothiazines, or with sea sickness medications. [Note: These drugs may cause increased sedation.]

C. Sedation

Sedation is common when opioid doses are increased substantially, but tolerance usually develops rapidly with relief of sedation within a week. Persistent drug induced sedation is usually best treated by reducing the amount of narcotic given in each dose and increasing the dosage frequency. In some patients switching to another opioid may reduce the sedative effects. CNS stimulants such as caffeine, amphetamines and Ritalin may be added to increase alertness if the above approach is ineffective in reducing sedation.

Persistent sedation unrelieved by dose manipulation and changing of narcotics may lead the physician to search for an alternative approach to pain relief using surgery or placement of catheters within the central nervous system for more localized administration of analgesics. At times, especially toward the end of life, permanent sedation may be desired and the narcotic effect welcomed by patient and family alike.

D. Mental Clouding

At times opioids cause mental changes more severe than sedation, better described as somnolence, confusion and/or delirium. Mild confusion is relatively common and usually acceptable during the period required for tolerance to develop, while severe delirium can usually be avoided if narcotic doses are not increased too rapidly. Even when this happens during initial therapy or in response to the need for an increased dose, withholding drug for a brief period usually leads to reversal. To the contrary, when the patient becomes rapidly confused or delirious while on base-line narcotics, it is suggestive of a process other than narcotic side-effect and must be evaluated for new problems either of the brain or other major organ system within the body.

E. Respiratory Depression (depressed breathing)

Patients receiving long-term opioid therapy generally develop tolerance to the respiratory depressant effects of these agents so treatment is seldom required. When it is required, the administration of naloxone (Narcan) is effective, but risks a rapid exacerbation of pain. Therefore, unless there is an acute emergency, it should initially be given in small doses.

F. Subacute Overdose

Far more common than acute respiratory depression, subacute overdose manifests as slowly progressive (hours to days) somnolence and respiratory depression. When this happens, the withholding of one or two doses will
usually reverse the symptoms. Medication can then be restarted at a lower dose, usually twenty-five percent less than the previous dose.

### 2.15 Influence of Concurrent Medical Conditions on Pharmacotherapy

The presence of other medical conditions in cancer patients and the medications taken for them may influence the best choice of narcotics to be used for pain management. Common medications or classes of medications that produce clinically significant drug interactions with narcotics include alcohol (as in elixirs) and other mental depressants such as phenytoin (Dilantin), as well as rifampin [an antibiotic mostly used for tuberculosis but also for some other infections] and certain antidepressants referred to as monoamine oxidase inhibitors. [Now largely replaced by the tricyclic and newer SSI antidepressants, Prozac, Zoloft, Effexor, Paxil, and Serzone discussed below.]

Coexisting conditions also may influence the type and doses of opioids administered. For example, patients with newly recognized cancer pain who have been recently treated with opioids for another reason, such as surgery, may require higher than the recommended starting doses because they are opioid tolerant. Blood clotting abnormalities, low white blood counts, and infection may contraindicate the use of spinal catheters or other regional anesthetic techniques because the risks of bleeding or "seeding" of infection are increased.

### 2.16 Narcotic Tolerance and Addiction

If there is one lesson to be learned from this book, the author would wish it to be the difference between the expected occurrence of narcotic tolerance and physical dependence, both of which must be anticipated as part of pain therapy with narcotics, and addiction, which is extremely uncommon in the setting of terminal illness. Failure to separate the two is undoubtedly the leading cause for unrelieved pain in the terminally ill, and also the major factor in producing the public’s distrust of the medical profession as it deals with the terminally ill patient.

The word "tolerance" refers to a time-related progressive resistance of the body to the effects of a particular drug such that increasing dosage of the drug is required to obtain the same effect previously achieved with a lower dose. Fortunately, the same process which requires increased dosage to obtain the same pain relief also occurs with side effects, so that the increased dosage required for pain relief usually does not result in increased side effects. This means as long as there is no ceiling on the amount of drug which can be given and as long as increasing dosage remains effective, the only significant problem resulting is a matter of how many pills must be taken and the associated increase in cost. Of course, progression of the underlying disease may also require an increased narcotic dose, in which case, because the increase is not based on tolerance, side effects are likely to increase along with increased pain relief.

A concurrent factor in narcotic treatment of pain is the development of physical dependence, which means the body’s metabolism has changed to expect the presence of the drug in the system and to react negatively if it is absent. Although such potential negative reaction must be expected with the long term use of narcotics for pain relief, the absence of any need to ever withdraw the drug from a terminally ill patient makes this potential problem irrelevant, provided the patient continues to receive proper medical attention.

In contrast, the term "addiction," refers to a state of mind in which there is continual craving for the medication.
leading to compulsive behavior to obtain the drug and an overwhelming involvement in drug procurement and use. Unlike tolerance and physical dependence, which routinely occurs when narcotics are used, addiction is extremely rare when opioids are used for relief of pain in the terminally ill. In one large study of cancer patients, only seven cases of addiction were found among 25,000 patients receiving narcotics. Of course, if the patient was a narcotic addict before they developed cancer, the addiction remains and only complicates the treatment.

When the body becomes dependent on a drug, its absence leads to certain symptoms referred to as a "withdrawal syndrome." The appearance of a withdrawal syndrome may occur as early as 2 weeks after the initiation of opioid therapy if narcotics are withheld and typically manifested itself as anxiety, irritability, chills and hot flashes, joint pains, tearing, running nose, sweating, nausea, vomiting, abdominal cramps and diarrhea. Although these symptoms are similar to those reported in narcotic addicts who have been denied drugs, it does not imply psychological dependence or addiction, for if the pain were to be miraculously relieved, once these initial symptoms were appropriately treated the patient would not seek out the drug and would not exhibit the loss of control and compulsive use patterns which characterizes narcotic addiction. This difference has been attributed to the fact that when treating the pain of terminal illness, there is no psychological dependence, only a reliance on the drug for pain relief. Although most patients with cancer take opioids for more than 2 weeks, it has been repeatedly shown when pain is otherwise relieved, patients almost never continue to seek narcotics once appropriate dose reduction has been undertaken -- a very simple process in the absence of pain. [Note: Recent experience with cancer patients undergoing bone marrow transplantation in which large doses of narcotics are often required for a prolonged period after transplant but can then be stopped has served to reassure the medical community such use of narcotics does not lead to the production of truly addicted individuals, even in the presence of tolerance and physical dependence.]

When cancer develops in a previously addicted individual, the difficulties of drug management are understandably complicated. In general it is believed the best course of treatment in this situation is to treat the claimed pain as real, recognizing pain to always be a perception and that the perception is likely to be real to the patient even if influenced by the body’s desire for more drug. As well stated by Dr. Foley, a world renowned cancer therapist at Memorial Sloan-Kettering in New York: "So what? Pain is pain and it should be relieved." After years of research in treating the pain of terminal disease her message is the opposite of Nancy Reagan’s, "Just say yes to drugs."

Of equal importance in pain relief is the avoidance of so-called "pseudo-addiction," in which inadequate treatment of true pain produces a situation in which the patient displays the same manipulative behavior normally associated with addicts in the search for adequate pain relief -- recurrent hospital E.R. visits, doctor-shopping, recurrent phone calls to doctors, and other apparently aggressive drug-seeking behavior. Unfortunately, this situation is highly likely to result from over concern by physicians who ask the patient to describe their experience of pain in detail and then, when the patients are highly graphic in their descriptions, react to them as being undue complainers.

In summarizing the issue of adequate pain relief and going even further than suggested by the DHHS, the Council on Ethical and Judicial Affairs of the American Medical Association in a report related to physician-assisted suicide in a 1994 journal, 10 Issues in Law & Medicine 91-97 (1994) wrote:

"The first priority for the care of patients facing severe pain as a result of a terminal illness or chronic condition should be the relief of their pain. Fear of addiction to pain medications should
not be a barrier to the adequate relief of pain. Nor should physicians be concerned about legal repercussions or sanctions by licensing boards. The courts and regulatory bodies readily distinguish between use of narcotic drugs to relieve pain in dying patients and use in other situations. Indeed, it is well accepted both ethically and legally that pain medications may be administered in whatever dose necessary to relieve the patient's suffering, even if the medication has the side effect of causing addiction or of causing death through respiratory depression."

This statement by the Council of the AMA does present an issue worthy of further consideration. Because narcotics are sedating and may further interfere with thought processes already limited by the cause of the terminal disease, it is wise for those who will be caring for a terminal patient to discuss preferences of the patient at a time when thought processes are clear. What will the patient want when pain progresses and greater narcotic use will be required for relief? When forced to choose between suffering from pain and being able to interact with friends and family members, how much sedation does the patient expect to want? Obviously, decisions made beforehand are open to change in the future, but it is much easier for physicians and family to agree on the appropriate level of pain therapy if and when the time comes if the patient’s own basic desires have also been made known beforehand.

Many patients will request doses of analgesics which do not control their pain fully in order to meet a goal of continuing to interact with their families. In such situations, physicians are more likely to consider other means of controlling pain, such as using adjuvant drugs or mechanical interventions for pain relief.

Caregivers should also discuss with patients how they would balance the value of obtaining more relief from higher doses of pain killers against the potential risk of respiratory depression. Although the development of tolerance is likely to prevent this from happening, it is worth discussing for the rare situation in which large increases in narcotic doses are required in the last stages of the illness outstripping the body’s ability to develop tolerance.

### 2.17 Adjuvant Drug Therapies

The terms "adjuvant drugs" or "adjuvant drug therapies" are commonly used to describe the use of certain medications which are not normally considered pain relievers along with either narcotic and non-narcotic analgesics because they have been shown to enhance the effective level of pain relief. [Note that medications which relieve side effects of analgesics, such as laxatives, could be considered adjuvant drugs because they permit higher dosing of narcotics, but the term is usually limited in use to those medications designed to treat co-existing symptoms which have been found to secondarily improve analgesia.] The groups of drugs most commonly used in association with pain therapy for terminal illness are (1) corticosteroids -- drugs related to the anti-inflammatory drug, cortisone; (2) anti-depressants -- which have their own specific effect on nerve transmission in the brain and which often enhances the effect of narcotics; (3) anti-epileptics -- drugs initially developed for the treatment of epilepsy, but which also have independent effects on nerve conduction in the brain; and (4) specific drugs used to interfere with nerve transmission and referred to as "neuroleptics."

In initiating adjuvant drug therapy, it must be remembered that unlike true pain relievers, the onset of analgesia may be delayed by days or even weeks after initiating therapy, and the quality of analgesia is less closely linked to dose increases. As a result, serial trials of each class of co-analgesics, and even of different agents within the same class, is often indicated.
A. Corticosteroids

The corticosteroids provide a wide range of potentially beneficial effects. These include mood elevation, interference with local inflammation, reduced nausea and vomiting, and appetite stimulation. They may also be used to reduce swelling of the brain and spinal cord, most commonly in situations involving increased pressure within the skull and spinal column. As such, they may be particularly helpful in the relief of headaches when they are due to tumors within the skull or in the relief of pain related to compression of the spinal cord within the spine.

Although corticosteroids are known to frequently be associated with severe side effects when used for extended periods in chronic illnesses, the doses required to improve the pain relief of narcotics and the short period of time for which it is likely to be required minimizes any worry about significant side effects when used in terminally ill patients.

B. Anticonvulsants

The anticonvulsants [carbamazepine (Tegretol), phenytoin (Dilantin), valproic acid (Depakene), and clonazepam (Klonopin)] and the more specific neuroleptics are principally used to manage pain of nerve origin, especially pains typically described as "shooting" or "burning" in nature. In addition, they may be helpful in other pains of nervous origin such as those caused by tumor invasion of the nerve, radiation nerve damage, surgical scarring of the nerves, Shingles -- a viral infection of the nerves, and similar conditions. Side effects of therapy can be serious, but these risks are generally low compared to the potential benefits in most terminally ill patients.

The most commonly used pure neuroleptic, methotrimeprazine (Levoprome) may be particularly helpful if the patient experiences narcotic induced constipation by reducing the required dose of the opioid. It may also be helpful in relieving nausea and anxiety.

C. Antidepressants

Like the anticonvulsants and neuroleptics, the tricyclic antidepressants [such as amitriptyline (Elavil), imipramine (Tofranil), desipramine (Norpramin), clomipramine (Anafranil), and nortriptyline (Pamelor)] are most useful in treating pain coming directly from nerve irritation. Although referred to as "anti-depressants," it is inappropriate to think of their use in the treatment of pain as requiring the presence of depression to be effective, for they have direct analgesic properties in addition to antidepressant properties. Even in the absence of clinical depression, they may increase the analgesic effects of opioids either by stimulating the pain inhibitory pathways discussed above or by increasing the blood levels of circulating opioids. The toxic effects of these drugs are important, for they are fairly common -- dry mouth, dizziness when standing, sleepiness and confusion, being among the most common.

Although less well investigated, there is reason to believe the newer group of SSI antidepressants, fluoxetine (Prozac), sertralin (Zoloft), venlafaxine (Effexor), paroxetine (Paxil), and nefazodone (Serzone), are also likely to be helpful in enhancing the action of opioids, although it is hard to tell how much of their effects relate to their anti-depressant action and how much they are truly adjuvants in pain relief.
D. Other Drugs

Many ongoing studies are investigating the use of other common drugs in the management of pain in terminal illness. One such group of studies is looking at derivatives of commonly used local anesthetics, such as lidocaine (Xylocaine) intravenously for relief of neurologic pain. Another group of studies is investigating the use of the new bisphosphonates, developed to prevent calcium loss from bones, in the treatment of bone pain associated with cancer.

Other drugs may also be helpful along with those listed above. Hydroxyzine (Vistaril, Atarax) is primarily an antihistamine which also is a mild anti-anxiety drug. With both sedative and analgesic properties, it may be particularly useful in treating the anxious patient with pain, and may also be helpful to relieve nausea. Additional help may be obtained from the use of psychostimulants, such as amphetamines and Ritalin, which may be used to relieve sedation.

[See table in Appendix of this chapter for adjuvant drugs used in the treatment of pain.]

2.18 Reversible Medication Failures

When we speak of "medication failures" we usually refer to situations in which appropriate medications fail to control the clinical process -- infections progress in spite of antibiotics, blood pressure remains high in spite of the use of anti-hypertensive, or cancer fails to respond to appropriate chemotherapeutic agents. In contrast, failure to control pain in terminal illness is usually due to inappropriate therapy, and by far the most common form of inappropriate therapy is undertreatment. This has led a recent widely quoted study to conclude: "the most common form of narcotic abuse in the care of the dying is the undertreatment of pain" leading to "psychiatric comorbidity, altered immune function, impaired function, diminished quality of life, loss of autonomy, ... suffering ... and suicide."

The most frequent causes of undertreatment of cancer-related pain have been said to be: (1) a discrepancy between patient and physician in judging the severity of the patient's pain, (2) the reluctance to prescribe opioid analgesics for fear of developing addiction, tolerance, and side effects, (3) the fact analgesic treatment is not of primary importance in the health care system, (4) the high cost of analgesic medications, which are nonrefundable and not readily available in some countries, and (5) the fact analgesic treatment often is considered only for advanced and terminal cancer patients.

In future chapters we will discuss true medication failures, situations in which the best of palliative therapy fails to adequately control pain. In the rest of this chapter we address situations in which inadequate therapy results from potentially reversible social factors involving physicians, patients, families, finances, and the law. These reversible factors are particularly distressing for they represent unwarranted causes of pain in the terminally ill, leading to depression, magnification of other symptoms, unrelenting suffering, and requests for euthanasia.

2.19 Inadequate Pain Therapy/Health Care Providers
A. Educational Failures

It is difficult to explain or justify the frequent failure of modern medicine to adequately treat pain in the terminally ill. Fortunately, recognition of this sad state of affairs has led many medical organizations to produce guidelines and educational materials for physicians stressing the importance of adequate narcotic pain therapy, the unwarranted over concern about its risks, and the frequency of inadequate treatment. Among these organizations are the World Health Organization, the American Pain Society, the American Society of Clinical Oncology, the Oncology Nursing Society, and the American Society of Anesthesiologists, as well as the guidelines discussed above from the Department of Health and Human Services, and the U.S. Agency for Health Care Policy Research.

Most commentators suggest the basic problem has been lack of physician education, pointing out the value of morphine for pain relief was better established as a mainstay of patient care at the end of the last century than now. This lack of proper education seems well documented. A recent report of the American Medical Association on medical education covering the years 1993 to 1994, showed only 5 of 126 medical schools in the United States required a separate course in the care of the dying. Of 7048 residency programs, only 26 percent offered a course on the medical and legal aspects of care at the end of life as a regular part of the curriculum. According to a survey of 1068 accredited residency programs in family medicine, internal medicine, and pediatrics as well as fellowship programs in geriatrics, each resident or fellow coordinates the care of 10 or fewer dying patients annually.

This lack of physician knowledge seems to have been further magnified in the recent past by lack of hospital commitments to the care of patients at the end of life and an unexplained separation of traditional hospital care and training from that potentially available in hospice program. For example, only 17% of schools offering students rotations in hospice care, and only half of these requiring such study of care for the terminally ill.

Another major cause for physician’s apparent lack of knowledge about pain relief would seem to stem from the late recognition of the effectiveness of oral narcotics in treating chronic pain and the misunderstanding within the profession itself of the differences between tolerance, dependence, and addiction. As late as 1971 the A.M.A. Drug Evaluation Manual considered morphine not to be effective when given by mouth, largely because early studies of its use orally employed inadequate doses.

Until recently, tolerance was considered to be a major drawback to the use of narcotics, but this misunderstanding failed to acknowledge that if (1) the same tolerance develops for side effects, (2) the cost of the drug is modest, (3) there is no ceiling on how much drug can be used, and (4) increased dosages do not lead to the behavior we associate with addiction, then tolerance is not necessarily harmful. In fact, because tolerance for one drug does not necessarily produce tolerance for another in the group, tolerance gives the potential for renewing the effectiveness of narcotics by switching, which would not be possible if the drugs just lost their effectiveness in the absence of tolerance.

Another failure of the medical profession has been its over concern regarding addiction. Almost forty years ago the author was told using narcotics over a short period for acute pain or post-operatively did not lead to addiction, but somehow the wrong message was emphasized. The important factor in this legitimate observation was not that the treatment was only confined in time, but that it was used specifically for pain relief and not to
relieve other forms of emotional suffering. Only recently has it become evident chronic treatment of pain with narcotics does indeed produce tolerance and physical dependency, but not addiction.

**B. Inadequate Pain Assessment**

Somewhat different from the physicians’ failure to properly evaluate the risk versus benefits of narcotics in the treatment of chronic pain has been the failure to properly measure pain and to recognize the numerous factors which obscure the adequate reporting of pain.

Take, for instance, the now evident connection between the perception of multiple pains. It has now been clearly shown when a patient has multiple pains, a mild pain is essentially blocked out by the more severe pain. This means if the patient has multiple pains and the physician asks how bad the pain is, the patient will answer relative to the most severe pain and not a lesser pain. In these circumstances, if the more severe pain is relieved, when asked how their pain is, the patient is likely to reflect the severity of the second most painful site -- but it is likely to be reported as more severe than it would have been reported in the continued presence of the more severe source of pain.

These factors were not understood until physicians started to chart pain severity routinely on a daily basis, each time asking the patient to evaluate each pain on some objective scale of one type or another. Doing this, it soon became apparent many different charts had to be kept, because most cancer patients who experienced pain did so at more than one location. Only when these separate charts were analyzed did it become apparent the reporting of overall pain was likely to be determined almost exclusively by the most severe, with little reference to the others. As a result, physicians were routinely led to both underestimate the severity of pain and also to underestimate the degree of pain relief experienced from increasing dosage of narcotics.

In addition, physicians were slow to realize the admission of pain by patients was made difficult by other psychic and social factors, leading to underestimation of pain, or by the patient’s lack of ability to express pain when also suffering from sedation or delusional thoughts. As these problems are most troublesome during short patient visits, it is not surprising recent studies of the phenomena of undertreatment repeatedly shows the assessment of pain severity by nurses and house officers varies significantly from that of the patient, often suggesting even greater levels of pain symptomatology.

### 2.20 Inadequate Pain Therapy/Social Problems/Patients

**A. Under-Reporting of Pain by Patients**

Many factors have been cited for patients’ failure to adequately report pain to their treating physician with resultant undermining of adequate pain therapy.

First, many patients are concerned that if they spend significant time discussing their pain with their physicians,
this will distract the physician from taking time to plan treatment for the underlying disease, a process the patient is likely to be more concerned about than the acute relief of pain.

Second, patients may be reluctant to be honest, for they suspect, but do not want to face the reality, that increased pain often indicates greater spread of the disease. By so doing, they discount the other common situation in which increased pain is the result of tolerance and not directly related to the spread of disease.

Third, many patients are preoccupied with being good patients, and are afraid they will be seen as bad patients by doctors and family if they ask for increased doses of narcotics. Others want to please physicians and family by giving the appearance they are improving by demanding less pain medication. Still others fear they are likely to be abandoned if perceived to be bad patients.

Fourth, many patients have misbeliefs about narcotics -- that taking the drugs will decrease the body’s ability to fight the disease, or that higher doses will invariably lead to additional side effects -- especially sedation and respiratory depression. They have heard the talk about narcotics hastening death, and fail to realize this is only likely to be true in the very end-stages when purposeful or required sedation leads to decreased fluid intake.

Fifth, many are afraid taking increased doses early is likely to lead to a situation in which narcotics will lose their effectiveness, not understanding this can be overcome by simply increasing the dose.

Finally, patients, like physicians, are likely to be overly concerned with the threat of developing an addiction, because the same opioids used by patient for pain relief are used by addicts for mood effects. It has been said the one most provable effect of the "War on Drugs" has been its ability to instill fear in the patient who legitimately requires narcotic use.

B. Inappropriate Administration of Pain Medication

Patients and their families often have trouble understanding and remembering the details of any proposed plan for managing pain -- best avoided using a written treatment plan. Instructions for pain relief should include the specific drugs to be taken; the type and purpose of each medication (for example, "for chronic pain," "for acute pain," "for anxiety," "for inability to sleep," "for anxiety," etc.), when the drug should be taken, whether it should be taken regularly or only when a certain type of pain is present, and the likely side effects of each drug. In addition, the plan should pay attention to the prevention or treatment of side effects, specific precautions to follow when taking a pain medication, and whom to notify about pain problems or concerns about the medication. [See the previous chapter for a suggested form]

2.21 Inadequate Pain Therapy/Social Problems/Cultural and Religious

A. Misunderstanding of Religious Principles

If asked to express themselves on these issues, most people would express a belief modern medicine is overly aggressive in treating terminal illness, but this belief is not uniform, with close to one third believing everything possible should be done to prolong life. Although this belief may be cultural or personal, it often stems from religious beliefs which may or may not be proper interpretations of the religious dogma on which it is thought to be based. If one believes erroneously that their religion requires prolongation of life whenever possible and
also believes the use of narcotics shortens life, it is understandable why a patient might fight total pain relief through their use.

The Roman Catholic Church and most mainstream Protestant denominations accept the principles of palliative care in treating the terminally ill, but many followers are confused by the subtleties used to express these beliefs. For instance, "the Church" in question may express the idea it is not necessary "to impose a heroic way of acting as a general rule," but at the same time might express the belief suffering may be a means of spiritual growth. How is the layman to interpret these two statements together?

While most religions accepts the concept of "double-effect," therapy in which medication required for pain relief may be employed even if it runs the risk of accelerating death [discussed in detail later] this is frequently unknown by its followers. In addition, while the religion might accept the practice of withholding burdensome or useless therapy from someone who is dying, it might not accept the concept that artificial nutrition and hydration is a burdensome therapy, thus leaving it to the individual patient to make such determinations.

Jewish law in particular is likely to produce confusion. On one hand Jewish law says human life has "infinite value," therefore one may not do anything to hasten death, including, at least in some orthodox interpretations, withdrawing or withholding artificial nutrition and hydration. On the other hand, under Jewish law one need not prolong the dying process, so if a therapy is not effective in prolonging life, it need not be offered, and palliative care, including hospice care, would therefore become acceptable.

**B. Problems of Communication**

Another increasing problem in America is the large number of patients who do not share a common language or culture with their health care providers. In the absence of a common language it is difficult to express the subtle differences between the severity of pain or the impact of other factors on its perception. And in the absence of cultural understanding, it is hard for providers to interpret the needs and concerns of the patient -- leading, invariably, to prolonged use of survival-based medicine with undertreatment of pain. One situation in which this is particularly common has to do with Asiatic and Hispanic cultures in which discussions normally occur more with family than with the individual patient, leaving physicians who have grown accustomed to dealing directly with patients at a loss as to how to proceed.

**2.22 Inadequate Pain Therapy/Social Problems/Cost-Containment**

Wide variations in the cost of pain management between different approaches and different drugs as well as poor coverage by many third party payers makes pain therapy in the terminally ill one of the most serious victims of modern cost-containment. It is therefore no surprise it has been shown low-income people experience greater pain and suffering from cancer than do other Americans, and a disproportionate share of people who are inadequately treated for pain are minorities.

Differences in insurance coverage is also likely to lead to inappropriate usage of different modalities of treatment. Medicare, for example, may not reimburse for outpatient oral narcotics but may reimburse for pain management in an inpatient facility. Thus, "a person may well have reimbursement for the $4,000.00 cost of patient controlled analgesia (PCA) morphine but will have no coverage for $100.00 of oral morphine solution."
2.23 Inadequate Pain Therapy/Social Problems/Poor Communications

Patients frequently have little knowledge of how to communicate their perceptions of pain. In spite of recent changes which give the patient increased control over his or her own care, most patients do not understand their right to refuse treatment, to demand that physicians withdraw burdensome treatments, or to direct an approach to therapy based on palliative care emphasizing pain relief over prolongation of life. Moreover, because few patients have written advance directives expressing their wishes and appointing appropriate agents to see they are carried out, once the patient loses the ability to make decisions, the patient’s desires no longer dictate the course of therapy. In short, there is an enormous need for both professional and public education to ensure patients fully understand their options for care at the end of life and to express these wishes both in writing and orally to their family and physicians.

One area of special importance relates to the proper use of emergency cardio-pulmonary resuscitation (CPR) in the terminally ill patient. While CPR has a good outcome in certain clinical situations, patients with severe underlying medical illness almost never survive to be discharged from the hospital even if resuscitation is initially successful. Despite this dismal outcome in the terminally ill, and even though survival often has no effect but to prolong suffering, absent a signed request by the patient not to have CPR performed, the law requires it be undertaken even when logic would say it should be refused. To prevent this from happening, a special do-not-resuscitate (DNR) order form should be used as part of routine palliative care for patients expected to die because such sudden arrests result in instantaneous loss of consciousness and leads to a peaceful death.

2.24 Inadequate Pain Therapy/Legal Problems

A. Threatened Recriminations

Unfortunately, the war on drugs has resulted in a number of both federal and state laws and regulations which are intended to reduce illicit drug consumption but have the unintended effect of limiting drug availability for terminally ill patients. These include such rules as requiring special prescription forms, limiting the number of pills prescribed per form or the dosage which can be prescribed, the number of refills allowed, the length of time for which the prescription is intended or requiring those taking strong opiates to register as drug users. Laws which restrict the amount of narcotic which can be ordered in a single prescription are particularly troublesome in situations in which a patient has developed considerable tolerance, thus requiring large doses of narcotics which may require multiple prescriptions in a single day.

Another growing problem is the expansion of laws requiring triple prescriptions for narcotics. A triple prescription has three copies -- one stays with the physician; one staying with the pharmacist, and one being forwarded by the pharmacy to the Drug Enforcement Administration (DEA). Triple prescriptions are aimed at procuring fuller monitoring of the prescribing habits of every physician by the DEA, but close oversight is threatening to physicians. Although passed with the best of intent as part of the war on drugs, the World Health Organization has observed that although multiple-copy prescription programs are intended to reduce careless prescribing, "health care workers may be reluctant to prescribe, stock or dispense opioids as they feel that there is a possibility of their professional licenses being suspended or revoked by the governing authority in cases where large quantities of opioids are provided to an individual, even though the medical need for such drugs can be proved."
The threat of malpractice leading to defensive medicine is well-known, but the threat of losing one’s license to practice medicine for over-prescribing narcotics is equally threatening, especially when the language used in state regulations is vague and the means to determine the appropriateness of use is ambiguous. As a result, just as physicians may order unnecessary testing to avoid malpractice, they may underprescribe narcotics using combinations of analgesics including weak opioids like codeine instead of morphine for fear of losing their licensure to practice medicine. As has been pointed out, "it can become a real challenge for physicians to treat pain adequately when, for instance, the back of every Ohio physician's license includes ten activities which may jeopardize his or her license, with six of the ten pertaining to activities of illegal prescription writing, mostly for narcotics."

**B. Practical Difficulties**

Practical difficulties may also arise once the appropriate prescription is written. Many pharmacies, concerned about crime, paperwork, and regulatory oversight, either do not carry narcotics or stock only a limited number of drugs in only a few dosage forms. Moreover, some state laws restrict prescribing controlled substances to addicts in such a way as to make it almost impossible for a physician to feel comfortable prescribing narcotics to known addicts who also suffer from cancer or similar pain-evoking diseases. Pharmacies located near or associated with cancer centers and hospices often are better stocked. In addition, many health maintenance organizations and government-funded hospitals restrict their patients to drugs from formularies which may be limited in the drugs or dosage forms available.

### 2.25 Summary

The following from Marilyn Webb’s book, *The Good Death: The New American Search to Reshape the End of Life*, (Bantam, New York, 1997) taken from various publications written by Dr. Foley strikes the author as an excellent summary of the factors related to the problem of undertreatment of pain in terminal illness:

1. "Don’t limit drugs for fear of an overdose." Junkies frequently overdose -- but they are seeking an immediate rush from one high-dose single injection and use materials of unknown concentration. In contrast, "proper treatment for pain is a steady dose of opioids, given around the clock, either orally, in a high-tech, continued-supply patch or pump, or in an IV drip. Tolerance to the drugs builds up, and the body safely adjusts."

   "Pain acts as a brake. It stimulates the nervous system, greatly decreasing the chance of serious side effects like respiratory depression .... Those who are still fearful of an accidental overdose should know that doctors normally get ample warning preceding respiratory depression. If healthcare professionals are available, specific medications can be given that immediately reverse the problem."

2. "When narcotics are used for pain control, there is little risk of addiction." While narcotic use can cause physical dependence, similar physical dependence can also occur with other drugs -- narcotics are not unique in so doing. That’s why doctors need to taper off on drug dosages instead of stopping them abruptly when any drug is used that produces physical dependence. In contrast, psychological addiction -- which is what junkies have -- is a completely different story, requiring
far more than tapering when the drug is stopped.

3. "Believe the patient." A person in pain doesn’t always scream, writhe, cry, moan. Chronic (long-term) pain can show up as depression; it has gone on so long that life seems hardly worth living. Only those in acute pain (short-term, intense, recently acquired pain, e.g., the result of surgery) act the way most of us believe tormented people act. To find out how great someone’s pain really is, a complete pain assessment is necessary.

To help physicians, patients must learn to be more articulate about describing pain. (Is it dull? Burning? Stabbing?) Those differences indicate different sources of pain, which need to be differently treated. (Even if the source remains unknown, however, the pain should be treated.)

4. "Severe pain can occur for months or years before someone dies." It is acceptable to use narcotics for all of those months or years. Pain relief contributes to a human being’s ability to lead a normal life. Aside from the agony it causes, undertreated pain can interfere both with quality of life and with a patient’s ability even to try to fight off illness and heal.

5. "A patient need not forgo morphine or another narcotic now in the hope that it will still be effective when the pain gets worse. It will. Since there is no medical or legal ceiling on how much one can take, doses can keep being increased."

6. "Pain relief is always the objective when someone is dying, even if the high doses might have the unintended consequence of contributing to death." Sometimes, doctors increase the dose of narcotics to control the pain and the patient gets sleepy. Sometimes, a sedating medicine is used specifically to induce unconsciousness because there is no other way to get symptom relief. As long as this is done openly (that is, mentally aware patients and caregivers are informed) experts say this can be appropriate therapy at the end of life.

APPENDIX: CHAPTER 2. PAIN THERAPY USING DRUGS

Table 1 - NSAIDs; Taken from a report of the Department of Health and Human Services

<table>
<thead>
<tr>
<th>Drug</th>
<th>Usual dose for adults and children &gt; 50kg body weight</th>
<th>Usual dose for children {1} and adults {2} &lt; 50kg body weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acetaminophen and over-the-counter NSAIDs</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Drug</th>
<th>Dose Details</th>
</tr>
</thead>
</table>
| **Acetaminophen** {3}     | 650 mg q 4 h  
975 mg q 6 h  
rectal |
| **Aspirin** {4}           | 650 mg q 4 h  
975 mg q 6 h  
rectal |
| **Ibuprofen** (Motrin, others) | 400-600 mg q 6 h  
10 mg/kg q 6-8 h {5} |
| **Prescription NSAIDs**    |             |
| **Carpofen** (Rimadyl)    | 100 mg tid   |
| **Choline magnesium trisalicylate** {6} (Trlisate) | 1 000-1 500 tid  
25 mg/kg tid |
<p>| <strong>Choline salicylate</strong> (Arthropan) {6} | 870 mg q 3-4 h |
| <strong>Diflunisal</strong> (Dolobid) {7} | 500 mg q 12 h |
| <strong>Etodolac</strong> (Lodine)     | 200-400 mg q 6-8 h |
| <strong>Fenoprofen calcium</strong> (Nalfon) | 300-600 mg q 6 h |
| <strong>Ketoprofen</strong> (Orudis)   | 25-60 mg q 6-8 h |
| <strong>Ketorolac tromethamine</strong> {8} (Toradol) | 10 mg q 4-6 h to a maximum of 40 mg/day |</p>
<table>
<thead>
<tr>
<th>Magnesium salicylate (Doan's, Magan, Mobidin, others)</th>
<th>650 mg q 4 h</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meclofenamate sodium (Meclomen) {9}</td>
<td>50-100 mg q 6 h</td>
</tr>
<tr>
<td>Mefenamic acid (Ponstel)</td>
<td>250 mg q 6 h</td>
</tr>
<tr>
<td>Naproxen (Naprosyn)</td>
<td>250-275 mg q 6-8 h</td>
</tr>
<tr>
<td>Naproxen sodium (Anapro)</td>
<td>275 mg q 6-8 h</td>
</tr>
<tr>
<td>Sodium salicylate (Generic)</td>
<td>325-650 mg q 3-4 h</td>
</tr>
<tr>
<td><strong>Parenteral NSAIDs</strong></td>
<td></td>
</tr>
<tr>
<td>Ketorolac tromethamine {8}, {10} (Toradol)</td>
<td>60 mg initially, then 30 mg q 6 h</td>
</tr>
<tr>
<td></td>
<td>Intramuscular dose not to exceed 5 days</td>
</tr>
</tbody>
</table>

{1} Only drugs that are FDA approved as an analgesic for use in children are included.

{2} Acetaminophen and NSAID dosages for adults weighing less than 50 kg should be adjusted for weight.

{3} Acetaminophen lacks the peripheral anti-inflammatory and antiplatelet activities of the other NSAIDs.

{4} The standard against which other NSAIDs are compared. May inhibit platelet aggregation for ³ 1 week and may cause bleeding. Aspirin is contraindicated in children with fever or other viral disease because of its association with Reye's syndrome.

{5} Not FDA approved for use in children as an over-the-counter drug; has FDA approval for use in children as a prescription drug for fever. However, clinicians have experience in prescribing ibuprofen for pain in children.

{6} May have minimal antiplatelet activity.
7. Administration with antacids may decrease absorption.

8. For short-term use only.

9. Coombs-positive autoimmune hemolytic anemia has been associated with prolonged use.

10. Has the same GI toxicities as oral NSAIDs.

Additional Notes:

1. The ceiling dose in a given individual may differ from the recommended dose by up to two-fold. As a result, trial with larger than recommended dosage may still be indicated.

2. The selection of agent to be used should be based on the patient's prior experience, minor differences in toxicity if the patient already has specific problems, physician experience, scheduling of other medication, and expense. In general, the least expensive medications should be tried first as the more expensive are no more likely to be effective.

3. Acetaminophen and NSAID dosages for adults weighing less than 50 kg should be adjusted for weight.

4. It is impossible to predict which NSAID will be best tolerated by a particular patient; no particular NSAID has demonstrated superiority over others for pain relief.

5. Once an NSAID has been selected, the dose should be increased until pain has been relieved or the maximal recommended dose has been achieved.

6. Dosing intervals should be based on patient response and not necessarily on recommendations of the manufacturer as the metabolism of each drug is likely to vary from patient to patient.

7. The NSAIDs are particularly effective for bone pain and pain associated with inflammation.

8. Regular around-the-clock administration is most effective in using NSAIDs.

Table 2 Opioid Narcotics, Comparison of Methods of Administration; Taken from the report of the Department of Health and Human Services
<table>
<thead>
<tr>
<th>Method</th>
<th>Pros</th>
<th>Cons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transdermal opioids (fentanyl)</td>
<td>- Long duration of action (48 - 72 hours) from single patch.</td>
<td>- Side effects may not be as quickly reversible as in oral opioid administration.</td>
</tr>
<tr>
<td></td>
<td>- Allows use of a strong opioid (fentanyl) in outpatient settings for some patients who have not tolerated morphine and related drugs.</td>
<td>- Difficult to modify dosage rapidly.</td>
</tr>
<tr>
<td></td>
<td>- Many patients find them easy to use.</td>
<td>- Relatively slow onset of action.</td>
</tr>
<tr>
<td></td>
<td>- Provides continuous administration of an opioid without use of needles or pumps.</td>
<td>- Requires additional medicine for breakthrough pain.</td>
</tr>
<tr>
<td></td>
<td>- Can be administered by patient or family.</td>
<td>- Expensive.</td>
</tr>
<tr>
<td>Rectal opioids</td>
<td>- Relatively easy-to-use alternative route when the oral route is unavailable.</td>
<td>- Not widely accepted by patients or families.</td>
</tr>
<tr>
<td></td>
<td>- Other opioid suppositories available for morphine intolerant patients.</td>
<td>- Side effects may limit analgesic effectiveness.</td>
</tr>
<tr>
<td></td>
<td>- Can be administered by patient or family.</td>
<td>- Relatively slow onset of action.</td>
</tr>
<tr>
<td></td>
<td>- Less expensive than subcutaneous or intravenous infusions.</td>
<td>- Contraindicated if low white blood cell or platelet count (risks of infection, bleeding).</td>
</tr>
<tr>
<td>Subcutaneous infusion</td>
<td>- Can provide rapid pain relief without intravenous access.</td>
<td>- Only a limited volume of infusate can be administered (e.g., 2 to 4 ml/hour).</td>
</tr>
<tr>
<td></td>
<td>- Morphine or hydromorphone are the preferred drugs for this route when administered in the home.</td>
<td>- Induration, irritation at infusion site may be a complication.</td>
</tr>
<tr>
<td></td>
<td>- When used in PCA mode, allows for rapid individual dose titration and provides sense of control for patient.</td>
<td>- Requires skilled nursing and pharmacy support.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Often requires expensive drug infusion pump and recurring charges for disposables.</td>
</tr>
</tbody>
</table>
| **Intravenous infusion** | - Can provide rapid pain relief.  
- Almost all opioids can be given by this route.  
- Not limited by infusate volumes.  
- When used in P titration and provides CA mode, allows for rapid individual dose titration and provides sense of control for patient. | - Infection and infiltration of intravenous lines are potential complications.  
- Requires skilled nursing and pharmacy support.  
- Often requires expensive drug infusion pump and disposables. |
| **Epidural, intrathecal, and intracerebral ventricular routes [Through catheters in the spinal canal or around the brain]** | - Useful for pain that has not responded to less invasive measures.  
- Local anesthetics may be added to spinal opioids and may produce additive analgesia. | - Tolerance may occur sooner than with oral or rectal administration.  
- Infection at catheter site can produce meningitis and/or epidural abscess.  
- Pruritus and urinary retention are more common than with oral or parenteral opioid administration.  
- Contraindicated in presence of acute spinal cord compression.  
- Requires special expertise.  
- Requires careful monitoring, especially when therapy begins and when doses are increased.  
- May require expensive drug infusion pump, intervention fees, and recurring charges for disposables. |
**Table 3 Table of Dose Equivalents for Opioid Analgesics [in adults and children more than 120 pounds who have never received opioids/narcotics]; Taken from the report of the Department of Health and Human Services**

<table>
<thead>
<tr>
<th>Drug</th>
<th>Approximate equianalgesic dose {1}</th>
<th>Usual Starting dose for moderate to severe pain</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Oral</td>
<td>Parenteral</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Oral</td>
</tr>
<tr>
<td><strong>Opioid agonist {2}</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Morphine {3}</td>
<td>30 mg q 3-4 h (repeat around-the-clock dosing)</td>
<td>10 mg q 3-4 h</td>
</tr>
<tr>
<td></td>
<td>60 mg q 3-4 h (single dose or intermittent dosing)</td>
<td></td>
</tr>
<tr>
<td>Morphine, controlled-release {3}, {4} (MS Contin, Oramorph)</td>
<td>90-120 mg q 12 h</td>
<td>N/A</td>
</tr>
<tr>
<td>Hydromorphone {3} (Dilaudid)</td>
<td>7.5 mg q 3-4 h</td>
<td>1.5 mg q 3-4 h</td>
</tr>
<tr>
<td>Levorphanol (Levo-Dromoran)</td>
<td>4 mg q 6-8 h</td>
<td>2 mg q 6-8 h</td>
</tr>
<tr>
<td>Meperidine (Demerol)</td>
<td>300 mg q 2-3 h</td>
<td>100 mg q 3 h</td>
</tr>
<tr>
<td>Methadone (Dolophine, other)</td>
<td>20 mg q 6-8 h</td>
<td>10 mg q 6-8 h</td>
</tr>
<tr>
<td>Oxymorphone (Numorphan)</td>
<td>N/A</td>
<td>1 mg q 3-4 h</td>
</tr>
<tr>
<td><strong>Combination opioid/NSAID preparations {5}</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drug</td>
<td>Dose 1</td>
<td>Dose 2</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>--------</td>
<td>--------</td>
</tr>
<tr>
<td>Codeine {6} (with aspirin or acetominophen)</td>
<td>180 mg</td>
<td>130 mg</td>
</tr>
<tr>
<td></td>
<td>q 3-4 h</td>
<td>q 3-4 h</td>
</tr>
<tr>
<td>Hydrocodone (in Lorcet, Lortab, Vicodin, others)</td>
<td>30 mg</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>q 3-4 h</td>
<td></td>
</tr>
<tr>
<td>Oxycodone (Roxicodone, also in Percocet, Percodan, Tylox, others)</td>
<td>30 mg</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>q 3-4 h</td>
<td></td>
</tr>
</tbody>
</table>

Codes: q=every. N/A=not available. N/R, not recommended. IM=intramuscular. SC=subcutaneous.

{1} Caution: Recommended doses do not apply for adult patients with body weight less than 50 kg (110 pounds).

{2} Caution: Recommended doses do not apply to patients with renal or hepatic insufficiency or other conditions affecting drug metabolism and kinetics.

{3} Caution: For morphine, hydromorphone, and oxymorphone, rectal administration is an alternate route for patients unable to take oral medications. Equianalgesic doses may differ from oral and parenteral doses because of pharmacokinetic differences.

{4} Transdermal fentanyl (Duragesic) is an alternative option. Transdermal fentanyl dosage is not calculated as equianalgesic to a single morphine dosage. See the package insert for dosing calculations. Doses above 25 mg/h should not be used in opioid-naive patients.

{5} Caution: Doses of aspirin and acetaminophen in combination opioid/NSAID preparations must also be adjusted to the patient's body weight. Aspirin is contraindicated in children in the presence of fever or other viral disease because of its association with Reye's syndrome.

{6} Caution: Codeine doses above 65 mg often are not appropriate because of diminishing incremental analgesia with increasing doses but continually increasing nausea, constipation, and other side effects.

Table 4 Table of Adjuvant Drugs for Treatment of Pain; Taken from the report of the Department of Health and Human Services
| **Corti-costeroids** | Effective in pain associated with inflammatory component (e.g., bone pain).  
-Can produce cytotoxic effect against some tumors.  
-May be given orally or intravenously.  
-May increase appetite.  
-May produce euphoria in some patients.  
-May decrease pain associated with CNS and spinal cord tumors. | -Prolonged use associated with adrenal suppression, fluid and electrolyte disturbance.  
-Increases risk of gastritis.  
-Prolonged use may decrease cell-mediated immunity and increase risk of infection.  
-Some patients experience emotional instability or psychoses.  
-May suppress (mask) fevers associated with infections. |
| **Anti-convulsants** | -Useful for peripheral pain syndromes associated with neuropathic pain, especially lancinating or shooting pain. | -May increase sedation.  
-Monitoring required to avoid specific toxicities associated with increased serum levels.  
-Idiosyncratic or dose-related bone marrow suppression may limit usefulness. |
| **Anti-depressants** | -Useful in pain syndromes associated with neuropathic pain and with pain caused by surgery, chemotherapy, or nerve infiltration.  
-May promote sleep when taken at bedtime. | -May increase sedation.  
-Anticholinergic side effects of many antidepressants are distressing to many patients.  
-CNS, cardiovascular, and hepatic toxicities may limit usefulness. |
<table>
<thead>
<tr>
<th>Hydroxyzine</th>
<th>-When given in high dosages (100 mg), some antihistamines may produce additive analgesia with therapeutic doses of opioids.</th>
<th>-In high doses demonstrates a significant potential for causing respiratory depression which is additive to that of opioids, but not reversible with naloxone.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>-May be beneficial in patients with opioid-induced nausea and vomiting.</td>
<td>-Can cause significant sedation.</td>
</tr>
</tbody>
</table>
CHAPTER 3. MECHANICAL TREATMENT OF PAIN

3.01 Mechanical Treatment of Pain; Introduction

3.02 Tumor Surgery

3.03 Surgical Nerve Intervention and Anesthetic Blocks

3.04 Radiation

3.01 Mechanical Treatment of Pain; Introduction

In a majority of patients, pain medication along with physical therapy and supportive counseling adequately controls the pain of terminal disease, but at times it fails or produces unacceptable side effects. In the ten percent or less of patients in whom this happens, other more invasive interventions may be employed to relieve pain. Surgical procedures, for instance, may be used in selected patients to remove tumors of large size just to reduce the obstruction or compression produced by the tumor mass. Alternatively, neurosurgery is undertaken to interfere with or cut the nerve pathways which carry the pain sensations. More commonly, and increasingly in recent years, methods to implant devices for drug delivery in and around nerve structures are being used with great effectiveness by highly skilled anesthesiologists, who have tended to become the leaders in developing these approaches because of their knowledge about placement of needles and catheters within the body. Because these methods often involve considerable risk and require highly skilled providers, the availability of physicians with the appropriate expertise and the presence or absence of payment coverage frequently determine whether they are undertaken. Of course, even more important in this decision is the location and type of pain being experienced and the general condition and life expectancy of the patient.

3.02 Tumor Surgery

Surgery directed at tumor removal remains one form of physical intervention which may be helpful for pain relief even when total removal of the tumor for cure is not possible. Before such surgery is undertaken, however, it is important for everyone involved to clearly understand the limited objective of the undertaking, pain relief. This is particularly important when dealing with illnesses in which second surgical procedures may be appropriate on occasion in search of a cure, as discussed below.

In deciding to undertake a surgical procedure purely for pain relief, knowledge of the natural history of various cancers is critical. For example, a woman who previously underwent a lumpectomy for breast cancer may develop a recurrence of the cancer in the same breast or in the lymph nodes on the same side under the arm. In either of these situations, removal of the recurrent tumor with or without additional chemotherapy may still be attempted with the hope of achieving a cure. To the contrary, if the spread of the cancer was to the brain, even though surgery might be undertaken to remove the brain metastasis, it would not be undertaken with the hope of achieving a cure.
Under these two different circumstances, decisions regarding surgery are very different. First, when cure is still possible, highly aggressive surgery may be indicated, but when cure is no longer possible, less invasive alternative approaches are usually preferable. If, for instance, surgery for pain relief is going to be directed at decreasing tumor bulk, the ability to achieve this same goal through the use of radiation may well be preferable with less risk for the patient in most situations.

Second, even when cure is not possible and surgery is being undertaken purely for palliation, the surgeon should consider the potential for additional spread of the tumor and should remove as much of the tumor as can be safely accomplished to help decrease the risk of recurrent pain in the future.

Third, when surgery for palliation alone is being considered, rapid care may not always be in the patient’s best interest. If cure is not possible, it may be wise to delay surgical intervention as long as medication successfully controls pain, for such delay is likely to improve the immediate quality of life and may allow greater total benefit from the surgical procedure when it is finally performed.

Such a delay in surgical intervention is, in fact, somewhat of a shift in the course of suggested medical therapy. In the past when use of opioid narcotics was generally frowned upon, given a choice of surgical or medical intervention, surgery was often employed as a means of reducing the need for narcotics. Recently, however, as we have learned how to use narcotics more effectively in the treatment of cancer pain, this has reversed, surgery being delayed until drug therapy fails. Even more recently, this switch in medical theory has been further intensified with the increased use of methods permitting local use of narcotics through needles and catheters placed locally around tumors, within blood vessels, within the spinal canal, or in the brain itself. Employment of these techniques has greatly extending the usefulness of medicinal pain therapy further limiting the need for surgical pain relief.

3.03 Surgical Nerve Intervention and Anesthetic Blocks

In the past, peripheral neurectomy (surgery directly cutting pain carrying nerves) was common, but this approach has been largely replaced by newer drug therapies and/or surgical techniques designed to interfere with the transmission of the nerve impulses through the spinal cord to the brain. Neurectomy may, however, still be used in certain specific situations, such as tumors involving the chest wall or the face.

The most commonly used surgical procedure of this kind, commonly referred to as a "cordotomy," is most helpful with pain from the legs or lower body and involves cutting specific pathways in the spinal cord. It, like neural blockade discussed below, requires significant expertise and is quite expensive. Somewhat similar is a procedure which cuts not within the spinal cord but the nerve roots just as they enter into the spinal cord. This procedure, called a "dorsal rhizotomy," is usually used when pain is coming from an arm or leg which has already lost most or all of its function. Recently, new procedures have been developed which may permit these same procedures to be undertaken without actual surgical incisions, either through telescopic type surgery using radio frequencies instead of cordotomies, or by the...
Like the positioning of needles for chemical rhizotomies, many of the new approaches to pain therapy rely on placement of catheters in far corners of the body by radiologists or anesthesiologists with special expertise in these fields. These procedures, which allow the infusions of opioid narcotics or anesthetics within the fluids bathing the spine (intraspinal fluid) or the brain (intraventricular fluid) has the advantage of producing profound pain relief in properly selected patients without causing significant side effects or interfering with other nerve functions. In practice, use of such techniques usually involves continuation of the general pain killers by mouth or patch in addition to the local application, making coordination between the various physicians involved more complicated.

Similarly, in a procedure called "neural blockade," otherwise intractable pain may be relieved by the relatively brief application of a local anesthetic or nerve poison at crucial points in the nervous system. This procedure is most commonly employed in patients with cancers within the abdomen, such as the pancreas, when narcotics are unable to provide adequate relief without undue side effects. The procedure itself usually involves a trial in which a local anesthetic is injected through a needle into the area of nerve transmission to see if there is temporary relief of pain. If this occurs, and there are no apparent harmful effects, other nerve destroying chemicals, such as alcohol or phenol, may then be used to produce more lasting effects. Alternatively, a thin walled catheter may be left in the area through which pain medications can be repeatedly administered to block nerve transmission of pain sensations. Unfortunately, undertaking such procedures requires great expertise and is often an expensive undertaking at a time when life expectancy is short.

A less commonly employed technique for relief of generalized pain such as may occur from multiple bone metastases is destruction of the pituitary gland at the base of the brain. This can be accomplished either surgically or by local injection of chemicals like alcohol. This is a risky procedure with significant, unpredictable side effects, but one that may be used to avoid the necessity of sedation for pain relief.

As the reader should appreciate, use of these procedures can be highly limited by the need for physicians with great expertise in the precise placement of the needles and catheters, in addition to requiring the availability of special hospital units set up to undertake the procedures. As a result, many of these more sophisticated approaches to pain management are limited by lack of local expertise. Even more upsetting is the situation in which the expertise is available, but lack of financial backing causes the patient to suffer needlessly.

3.04 Radiation

The use of x-ray therapy to treat tumor pain has decreased along with recent developments enhancing the effectiveness of drug treatment and nerve blocks, etc., but remains an important part of pain relief, especially when it is caused by metastases to bone. In the presence of bone metastasis, radiation therapy is also likely to be helpful in preventing future fractures when x-rays and scans suggest a high risk for
fracture of the bone in the future. Fortunately the radiologic procedure referred to as a "bone scan" is easy to perform and is very reliable in identifying metastases, while also being highly predicative of the ability of radiation therapy to reduce bone pain and prevent fracture.

Radiation therapy is likely to also be helpful in shrinking large tumors which are causing pain by local pressure effects and in relieving pain which results from spread of cancer to nerve networks, such as at the "brachial plexus," a meshing of nerves at the base of the neck giving rise to the more peripheral nerves which provide sensory and motor function to the arms.

Although radiation can cause both early and late side effects, they are usually avoidable by careful dosing by skilled radiotherapists. Early side effects are usually very dose related and have the advantage of being short lived, so the patient typically only suffers for a short period of time even when side effects do occur. Late side effects usually take many years to develop, which is not of concern when dealing with terminally ill patients.

In addition to direct radiation therapy, many drugs have now been developed which carry radioactive material and localize in specific tumors, thus allowing direct radiation to the cancer itself. Such "radiopharmaceuticals," as they are called, are now being used under specific indications in at least thyroid, breast, and prostate cancers.
CHAPTER 4. ALTERNATIVE THERAPIES FOR PAIN

4.01 Physical and Psychological Modalities in Pain Relief; In General

4.02 Slow Rhythmic Breathing For Relaxation

4.03 Psychosocial Intervention

4.04 Cutaneous Stimulation

4.05 Exercise/Positioning

4.06 Massage Therapy

4.07 Acupuncture

4.08 Relaxation and Imagery

4.09 Distraction and Reframing

4.10 Hypnosis

4.11 Pastoral Counseling

4.12 TENS Therapy

4.13 Peer Support Groups

4.01 Physical and Psychological Modalities in Pain Relief; In General

As in all health care, many methods of therapy have been used to treat the pain of terminal illness outside the realm of traditional medicine. While many physicians frown on these techniques, others accept them gladly -- any help in dealing with this most difficult problem being welcomed by the clinician.

Without taking sides, the author suggests it is extremely important for patients and families to recognize the inherent difficulties physicians face when asked to recommend or comment on these alternative therapies. Because these alternative therapies by and large do not require government approval, they have not undergone the usual scientific studies typical of traditional medical approaches, thus leaving physicians without good evidence for or against their use. Thus, when asked "might so and so help?" the answer is likely to be "Yes, it might." At the same time, if the physician is asked "Do you recommend its use?" the answer is likely to be "No." This may make little sense to most laymen, but perfect sense to me.
As a physician, I have no scientific evidence it doesn’t work, so certainly it "might" help. I also have no scientific evidence it does work, so I see myself as not being in a position to recommend its use to my patients -- and that would be true even if I used it and believed in it for myself. People come to physicians for advise based on scientific evidence. They do not want advise based on the physician’s reading of ads from Madison Avenue or the unsupported claims of salesmen or writers in Prevention Magazine.

In the following I will try to separate what seems to be proven from that which is purely claims of those involved in the various forms of therapy. In trying to be fair, I draw heavily on the suggestions of the Department of Health and Human Services guidelines, although the guidelines do not correspond totally with my own views. The following are some of their overall recommendations regarding alternative medical care of pain in the terminally ill:

1. Stimulation techniques of the body surface, including applications of superficial heat and cold, massage, pressure or vibration, should be offered to alleviate pain associated with muscle tension or muscle spasm.

2. Patients should be encouraged to remain active and to participate in self-care when possible.

3. Clinicians should reposition patients on a scheduled basis during long-term bedrest and provide active and passive range-of-motion exercises. For a patient in acute pain, exercise should be limited to self-administered range of motion exercises.

4. Prolonged immobilization should be avoided whenever possible to prevent stiffening of joints, muscle wasting, cardiovascular deconditioning, and other untoward effects.

5. Patients who choose to have acupuncture for pain management should be encouraged to report new pain problems to their health care team before seeking palliation through acupuncture.

6. Psychosocial interventions should be introduced early in the course of illness as part of a multimodal approach to pain management. They generally should not be used as substitutes for pain medications.

7. Because of the many misconceptions regarding pain and its treatment, education about the ability to control pain effectively and correction of myths about the use of opioid narcotics should be included as part of the treatment plan for all patients.

8. Clinicians should offer patients and families means to contact peer support groups.

9. Pastoral care members should participate in health care team meetings that discuss the
needs and treatment of patients. They should develop information about community resources that provide the spiritual care and support of patients and their families.

10. Physical modalities for pain relief include stimulation of the body surfaces (cutaneous stimulation), exercise, immobilization, transcutaneous electrical nerve stimulation (TENS), and acupuncture. Their use may decrease the need for pain-reducing drugs, but they should not be used as substitutes for medication.

11. Physical modalities should be introduced early to treat or avoid generalized weakness and loss of conditioning as well as aches and pains associated with periods of inactivity and immobility caused by the underlying disease.

12. Other techniques commonly employed for pain relief include distraction with music, handicrafts or exercises, breathing exercises, relaxation techniques, visualization techniques, a technique referred to as "inner smile" and numerous approaches involving human touch.

4.02 Slow Rhythmic Breathing For Relaxation

In some patients slow rhythmic breathing may help them relax and thereby lessen the need for pain medication, especially when there are occasional episodes of worse pain which occurs in spite of taking around-the-clock medication. To do this, the following instructions may be given to the patient:

1. Breathe in slowly and deeply.

2. As you breathe out slowly, feel yourself beginning to relax; feel the tension leaving your body.

3. Now breathe in and out slowly and regularly, at whatever rate is comfortable for you.

4. To help you focus on your breathing, breathe slowly and rhythmically:

(a) breathe in as you say silently to yourself, "in, two, three";

(b) breathe out as you say silently to yourself, "out, two, three," or each time you breathe out, say silently to yourself a word such as "peace" or "relax."

5. Do steps 1 through 4 only once or repeat steps 3 and 4 for up to 20 minutes.

6. End with a slow deep breath. As you breathe out say to yourself "I feel alert and relaxed."
4.03 Psychosocial Intervention

Psychosocial interventions are an important part of an approach to pain management to be used in conjunction with appropriate analgesics for the management of pain. The fact they work, however, should not be held as an indication the pain was not "real," because relief of the underlying anxiety has a direct effect on the perception of pain. "How people think affects how they feel, and changing how they think about pain can change their sensitivity to it and their feelings and reactions toward it."

Psychosocial interventions are usually differentiated into cognitive or behavioral techniques and can be undertaken by general medical practitioners or specially trained psychiatric workers. Cognitive techniques are designed to influence how one interprets events and bodily sensations. Giving patients information about pain and its management and helping patients to think differently about their pain are both cognitive techniques. [Note: In some ways, this book is part of a cognitive technique.] Behavioral techniques, by contrast, are directed at helping patients develop skills to cope with pain and helping them modify their reactions to pain.

The therapist typically emphasizes the patient's past strengths, supports the patient's use of previously successful strategies for coping with problems, and teaches new coping skills. Studies have shown patients with cancer who receive active, structured psychological support report less pain and may even live longer. Psychotherapy is particularly likely to be helpful in patients whose pain is difficult to manage, those who develop symptoms of clinical depression, and those with a history of psychiatric illness, including drug addiction.

4.04 Cutaneous Stimulation

Cutaneous stimulation has been used for centuries to detract the patient from more worrisome internal pains. An early form of cutaneous stimulation was the use of "mustard plasters" which irritated the skin deflecting concern to a problem which the patient readily recognized as being unimportant. Present methods include the application of superficial heat (thermotherapy) and cold (cryotherapy), as well as massage, pressure, and vibration, all aimed at helping the patient relax or to distract them from their pain. These methods are noninvasive and usually can be easily applied by family caregivers if not by the patient himself or herself. Because there is no strong evidence these methods are actually beneficial in the treatment of pain, they should only be continued in patients who appear to obtain a benefit, and should be discontinued when they do not provide clinical relief. [This analysis may not be true if the underlying cause of pain is muscle spasms, for instance.]

Superficial applications of heat may not only act as a detractor, but may also increase oxygen and nutrient delivery to damaged tissues as well as decreasing joint stiffness by increasing the elastic properties of muscles. Superficial heat can be applied by hot packs, hot water bottles, hot and moist compresses, electric heating pads (dry or moist), commercially available chemical and gel packs, and immersion in water (tub, basin, or whirlpool). For all types of hot packs, care should be taken to wrap them well to prevent burns and to discourage patients from lying directly on them. In most cases, the
protection of one towel between the skin and the heating device is sufficient. If the patient has decreased skin sensation, is using an electrical heating device, or tends to lie on top of a hot pack, more layers of cloth are needed for skin protection and close monitoring of the skin condition is required. Heat should not be applied to tissue that has been exposed to radiation therapy.

In contrast to superficial heat, the recommendations of the DHHS suggests that means of delivering deep heat -- such as short wave diathermy, microwave diathermy, and ultrasound -- should be used with caution in patients with active cancer; they should not be applied directly over a cancer site.

Cold therapy is specifically recommended when superficial heat is ineffective in reducing muscle spasms. Ice packs, towels soaked in ice water, or commercially prepared chemical gel packs can be used. Cold packs should be sealed to prevent dripping, they should be flexible to conform to body contours, they should be applied so as to produce a comfortable and safe intensity of cold, and they should be adequately wrapped (e.g., in one layer of towel or pillowcase) to prevent skin irritation. The duration of ice application is shorter than that of heat, usually lasting less than 15 minutes; however, it produces a longer acting effect, provided the muscle is actually cooled.

Cold should not be applied to tissue which has been damaged by radiation therapy and is contraindicated for condition involving poor blood supply to an area of the body. In some patients, cooling painful joints will increase range of motion, but in others, this may increase joint stiffness and should therefore be avoided.

4.05 Exercise/Positioning

Exercise is frequently suggested for the treatment of subacute and chronic pain because it strengthens weak muscles, mobilizes stiff joints, helps restore coordination and balance, enhances patient comfort, and provides conditioning of the heart. These effects may be helpful in some forms of pain related to terminal disease, but may not be helpful in others. When patients are unable to maintain function, families should assist in simple range-of-motion exercises and massage to minimize discomfort and preserve muscle length and joint function during periods of decreased function and immobility if possible. Passive exercises should not be carried out if they increase pain. During acute pain, exercise should be limited to self-administered range of motion. All forms of exercise which involve weight bearing should be avoided when cancer related fractures are likely because of known tumor spread to the bones of the legs.

At times, exercise must be restricted in parts of the body immobilized to manage episodes of acute pain, allow fractures to heal or to prevent fractures at sites of bony metastases. When immobility is desired, supportive devices such as adjustable elastic or plastic braces can be used to maintain the desired body alignment.

Unlike exercise, which is only infrequently helpful in the actual management of pain, repositioning of the body frequently is helpful in reducing pain. Family members are wise to note such relief, for later in the
course of the disease process the patient may not be able to reposition himself or herself, but is still likely to obtain relief when repositioned by others.

### 4.06 Massage Therapy

Massage therapy is a comfort measure used to aid relaxation and ease general aches and pains, particularly those associated with periods of immobility. Massage may also decrease pain in a specific area by increasing superficial circulation. Common techniques of massage are stroking, kneading, and rubbing with rhythmic, circular, distal-to-proximal motions. An alcohol-free lotion can be used to reduce friction. The patient should be encouraged to choose movements which provide the greatest comfort. Massage cannot strengthen debilitated muscles, and it should not be used in place of exercise and activity for patients who are able to walk. Manual or mechanical vibration can also be used to increase superficial circulation.

A somewhat different use of massage is aimed primarily at enabling people to deepen spiritual contact with the dying patient. This often involves a visitor massaging the patient’s hands or feet instead of just sitting doing nothing while they talk, listen, or just share time.

Suggestions regarding massage include:

1. Massage (3 to 10 minutes) may consist of whole body massage or be restricted to back, feet, or hands. If the patient is modest or cannot move or turn easily in bed, consider massage of the hands and feet.

2. Use a warm lubricant, e.g., a small bowl of hand lotion may be warmed in the microwave oven, or a bottle of lotion may be warmed by placing it in a sink of hot water for about 10 minutes.

3. Massage for relaxation is usually done with smooth, long, slow strokes. (Rapid strokes, circular movements, and squeezing of tissues tend to stimulate circulation and increase arousal.) However, try several degrees of pressure along with different types of massage, e.g., kneading, stroking, and circling. Determine which is preferred.

4. Especially for the elderly person, a back rub which effectively produces relaxation may consist of no more than 3 minutes of slow, rhythmic stroking (about 60 strokes per minute) on both sides of the superficial part of the backbone (spinous processes) from the top of the head to the lower back. Continuous hand contact is maintained by starting one hand down the back as the other hand stops at the lower back and is raised. Set aside a regular time for the massage. This gives the patient something to look forward to and depend on.

[For more instruction on the use of massage as a means of communicating care and concern and breathing exercises, see Richard Reoch, *To Die Well: A Holistic Approach for the dying and Their*]
4.07 Acupuncture

Acupuncture is a technique which treats pain by the insertion of small, solid needles into the skin at varying depths, typically penetrating the underlying musculature. There are few controlled studies of its use and those that exist are inconclusive, making it difficult to suggest which specific types of pain problems are likely to be alleviated by its use.

When acupuncture is employed, it is important the physician know about its use because it may rarely cause pain through introduction of infection, or other means. The physician should also be made aware of any new pains before acupuncture is employed so they can be checked to make sure they do not indicate a change in disease status requiring additional medical intervention. Knowledge that acupuncture is being sought may also be helpful to the physician by indicating present medical management is not producing adequate pain relief.

4.08 Relaxation and Imagery

Relaxation techniques and imagery may be used singly or together to achieve a state of mental and physical relaxation. Mental relaxation means alleviation of anxiety; physical relaxation means reduction in skeletal muscle tension. Relaxation techniques include simple focused-breathing exercises, as discussed above, progressive muscle relaxation, meditation, and music-assisted relaxation. Simple relaxation techniques are most effective during episodes of brief pain, e.g., during procedures, as well as when the patient's ability to concentrate is compromised by severe pain, a high level of anxiety, or fatigue.

Pleasant mental images can be used to aid relaxation. For example, patients might be encouraged to visualize a peaceful scene, such as waves softly hitting the beach, or to take slow, deep breaths as they visualize pain leaving the body. Both pleasant imagery and progressive muscle relaxation have been shown to decrease self-reported pain intensity and pain distress.

Relaxation and imagery are particularly helpful because they are easy to learn, do not require special equipment, and are readily accepted by most patients. [Many tapes are available]

A suggested approach to relaxation and imagery, say:

Something may have happened to you a while ago that brought you peace and comfort. You may be able to draw on that past experience to bring you peace or comfort now. Think about these questions:

1. Can you remember any situation, even when you were a child, when you felt calm, peaceful, secure, hopeful, or comfortable?
2. Have you ever daydreamed about something peaceful? What were you thinking of?

3. Do you get a dreamy feeling when you listen to music? Do you have any favorite music?

4. Do you have any favorite poetry that you find uplifting or reassuring?

5. Have you ever been religiously active? Do you have favorite readings, hymns, or prayers? Even if you haven't heard or thought of them for many years, childhood religious experiences may still be very soothing.

6. Additional points: Very likely some of the things you think of in answer to these questions can be recorded for you, such as your favorite music or a prayer. Then, you can listen to the tape whenever you wish. Or, if your memory is strong, you may simply close your eyes and recall the events or words.

4.09 Distraction and Reframing

Distraction is the strategy of focusing one's attention on stimuli other than pain or the accompanying negative emotions. Distractions may be internal, for example, counting, singing mentally to one's self, praying, or making self-statements such as "I can cope," or external, for example, listening to music as an aid to relaxation, watching television, talking to family and friends, or listening to someone read. Distraction exercises often include repetitive actions or activities of thought, such as rhythmic massage or the use of a visual focal point. Distraction may be used alone to manage mild pain or along with analgesic drugs to manage brief episodes of severe pain, such as procedure-related pain.

A related technique, reframing, teaches patients to monitor and evaluate negative thoughts and images and replace them with more positive ones. For example, patients who are preoccupied with a fear of pain can be encouraged to use positive self-statements to facilitate coping (e.g., "I've had similar pain and it's gotten better"). Reframing can add to patients' feelings of control over their situations.

A suggested method of distraction:

Active listening to recorded music:

1. Obtain a cassette player or tape recorder (small, battery-operated ones are more convenient); earphone or headsets (these are more demanding stimuli than a speaker a few feet away, and it avoids disturbing others); and a cassette of music like you like (most people prefer fast, lively music, but some select relaxing music. Other options are comedy routines, sporting events, old radio shows, or stories.)
2. Mark time to the music, e.g., tap out the rhythm with your finger or nod your head. This helps you concentrate on the music rather than your discomfort.

3. Keep your eyes open and focus steadily on one stationary spot or object. If you wish to close your eyes, picture something about the music.

4. Listen to the music at a comfortable volume. If the discomfort increases, try increasing the volume; decrease the volume when the discomfort decreases.

5. If this is not effective enough, try adding or changing one or more of the following: massage your body in rhythm to the music; try other music; mark time to the music in more than one manner, e.g., tap your foot and finger at the same time.

6. Additional points: Many patients have found this technique to be helpful. It tends to be very popular, probably because the equipment is usually readily available and is a part of daily life. Other advantages are that it is easy to learn and is not physically or mentally demanding. If you are very tired, you may simply listen to the music and omit marking time or focusing on a spot.

4.10 Hypnosis

The hypnotic trance is a state of highly focused concentration which can be used to manipulate the perception of pain. In skilled hands, it is frequently effective in obtaining at least partial relief from cancer related pain. Often the problem is finding the appropriate person to undertake the therapy without producing a risk of danger, such as failure to recognize the presence of a new pain indicative of a medical emergency at a time when intervention would be desirable to prolong the patient’s life.

4.11 Pastoral Counseling

Having a terminal illness frequently raises issues for patients and their families commonly addressed by religion and/or spirituality. Questions related to the meaning of life, pain and suffering, evil, punishment, reconciliation, guilt, forgiving, afterlife, etc., all of which may be helped by pastoral counseling. The experience of pain can often lead patients to fear abandonment and to question meaning and the possibility of hope. Many religions address these concerns and provide highly skilled counseling services to terminally ill patients and their families even when they are not regular members of the congregation. As their training and approaches are likely to be effective and different from those normally employed by health care providers, it is important they be included in any multidisciplinary approach to pain management.

4.12 TENS Therapy

TENS (Transcutaneous Electrical Nerve Stimulation) therapy is a method of applying controlled, low-
voltage electrical stimulation to large peripheral nerves through skin electrodes as a means of relieving pain. Like acupuncture, TENS is believed to activate natural nerve pathways which change or limit the perception of pain. Whether this is in fact the correct explanation of the pain relief observed by many patients is difficult to know, as many studies also suggest most relief may in fact be due to placebo effect. Nevertheless, patients with mild to moderate pain may benefit from a trial of TENS which, if successful, should be continued as it is not prone to causing significant side effects.

### 4.13 Peer Support Groups

Self-help and mutual support groups for cancer patients and their families are widely available. Some enroll survivors of any type of cancer and their relatives. Others target specific cancers like breast, larynx and prostate. Many of the peer support groups work closely with health care teams who refer patients to them.

The experience and understanding of people who have experienced a disease can provide credible support to others with the same disease or problem and can help new patients learn to cope more effectively. Support networks can also help patients to maintain social identity and provide emotional support, material aid, and access to information. Obviously, these types of support groups are helpful in many areas involved with dealing with dying in addition to pain. The following are suggestions of how to find a support group.

1. Call the local unit of the American Cancer Society; see the phone book in the business white pages.

2. Contact the National Coalition for Cancer Survivorship: 1010 Wayne Avenue, 5th Floor Silver Spring, MD 20910 (301) 650-8868.

3. Call the National Cancer Information Service, 1-800-4-CANCER.

4. Call the State self-help clearinghouse; the American Self-Help Clearinghouse at (201) 642-7101 has information on State clearinghouses.

5. Call the local mental health department.

6. Call the local United Way office or other community fund offices.
CHAPTER 5. INTRODUCTION: SUFFERING IN THE TERMINALLY ILL

5.01 Suffering in the Terminally Ill; In General

5.02 Definition: What is Suffering?

5.03 Treating Suffering Related to Pain

5.04 On Death and Dying/Adapting to the Reality of Death

5.05 Suffering in the Terminal Illness and End-Stage Disease
   A. End-Stage Physical Suffering
   B. Mental Suffering
   C. Existential Suffering

5.06 Effects of Suffering on Others

5.01 Suffering in the Terminally Ill; In General

As much as physicians have been criticized for undertreating pain in the terminally ill, they have been criticized even more for their failure to appreciate the full extent of their patients’ suffering. To some extent this criticism is justified, but in many ways it is not, for physicians should only be held primarily responsible for dealing with certain types of suffering, and are often limited in what they can do even in these areas. The following chapters will explore and discuss suffering at the end of life with the goal of enabling patients and families to work more effectively with health care providers to obtain its relief.

In caring for the terminally ill, certain general concepts are best addressed and agreed upon by physicians, patients and families before specifics are addressed. To begin with, all should agree to work together to treat patients with unconditional positive regard, sharing responsibility for relieving both the patient’s physical suffering and the psychological distress which routinely coexists.

Next, although care must be primarily directed at the patient’s suffering, the psychological distress and fatigue in families and health care providers needs to be addressed along with those of the patient. To this end, respite care for family and appreciation of the emotional drain on health providers needs to be considered by the management team as part of the division of responsibilities. This means physicians and families must work together to set the goals of therapy appropriate for each stage in the terminal process. From the beginning the support team must plan ahead for the time when aggressive therapy aimed at cure is replaced with one aimed at prolonging meaningful life, realizing that this, too, will subsequently be
replaced by a third goal of maximizing comfort care and relieving terminal suffering. Failure to accept this anticipated progression or ambivalence in goal setting by the patient, family, or physician will invariably lead to needless suffering. To the contrary, by discussing beforehand the eventual need to make these goal transfers, the team will be well positioned to decide on the details of future plans as the need arises over the course of the disease.

Although physicians are generally held responsible to open discussions with patient and families about these goals and to try to obtain knowledge of the patient’s desires, the author suggests failure of physicians to fulfill this obligation is best handled by the patient or family taking the initiative to invite this discussion. Waiting until the physician approaches the subject is too likely to result in delay past the time when the patient can take an active part in decision-making. This will not do, for it leaves the health care providers unsure of what is wanted and the patient devoid of the needed reassurance that his or her wishes will be honored.

Such discussions about the various possible approaches to treating the patient should begin early in the course of care and should focus on such issues as the availability of help at home, religious and moral beliefs, financial considerations, and patient concerns in particular. Having such discussions at a time prior to a crises situation also permits the physician and family to discuss the strengths and limitations of modern treatment of terminal suffering and to obtain informed consent directly from the patient for potential future interventions.

In developing a strategy to approach terminal care, the team should appreciate that the inevitable sadness and distress associated with death frequently renders it difficult to obtain the "good death" promised by many commentators on the subject. Some have suggested substitution of the term "appropriate death" for "a good death," but it is hard for a physician to accept the concept that death is appropriate after all the efforts put forth by the patient, family, and health care providers to prevent it from happening. Perhaps it is best to just admit there are limits as to what can be done and to aim simply to optimize the care given, including (1) relief of physical and psychological symptoms; 2) maintenance of as high a level of patient functioning as possible within limits set by the stage of the disease; (3) maintaining the opportunity to resolve uncompleted life tasks and goals through reconciliation, resolution of conflicts, communication in significant relationships, and pursuit of remaining hopes; and (4) working through the necessity for the patient to yield control to others in whom he or she has confidence.

In introducing a discussion of care of the terminally ill, appreciation must be extended to the work of Dr. Elizabeth Kubler-Ross who first introduced the concept of the five stages of adaptation experienced by the dying person: shock and denial, anger, bargaining, depression and acceptance. Although usually referred to as normal "stages," experience has shown they may occur simultaneously, may fluctuate in intensity, may occur in any order, and may not be successfully dealt with in every individual.

Dealing with each of these stages is often referred to as "coping," and the degree to which the patient is able to maintain self-esteem and stability while dealing with these stages as the patient’s "ability to cope." Patients who are confronted with terminal illness generally resort to the coping mechanisms they
have used to maintain self-esteem and stability in the past. Coping mechanisms may include denial, the assumption of a combative approach, distraction through task-oriented activities, or resignation. These coping mechanisms are reflected in the dynamic and content of the physician-patient relationship and in patient decision-making. Denial, willingness to receive hospice care, resorting to unconventional therapies, or the desire to receive experimental therapies all reflect different coping strategies and should be accepted even if they are different than one would choose for oneself.

In developing an overall strategy to obtain "the good death," Marilyn Webb, in her book, The Good Death; The New American Search to Reshape the End of Life, suggests the following in conclusion:

1. **Open, ongoing communications.** Honest and coordinated discussion among doctors, the patient, and the family begins well in advance of the terminal stage of illness and addresses the chance of recovery, as well as the benefits and burdens of treatment, for both patient and family. Advance directives are reviewed and, if necessary, revised as the situation changes.

2. **Preservation of the patient’s decision-making power.** The patient is granted as much decision-making as she wants at every stage of her illness, and can be confident her wishes will be carried out even when she can no longer express them.

3. **Sophisticated symptom control.** Pain and other troubling or humiliating symptoms are managed aggressively and well. Narcotics are used without fear of addiction, and calibrated to balance what the patient determines to be good pain control with an acceptable level of sedation.

4. **Limits are set on excessive treatment.** Excessive treatment--defined as medical interventions that extend the process of dying longer than the person who is dying wants it extended--is not given.

5. **A focus on preserving patient quality of life.** Communication about treatment takes into account the patient’s autonomy and how he defines "Self," and weights both the physical and existential questions of life: What does he most value? When are pain and loss of function so great they become intolerable? What constitutes a meaningful life? What constitutes loss of Self for the person who is dying?

6. **Emotional support.** Psychological issues are addressed, especially those having to do with depression, sadness, and loss. Attention is also paid to finishing old business and family reconciliation.

7. **Financial support.** Decisions about palliative care, acute medical care, home care, or long-term care are not dictated primarily by financial considerations. Costs are adequately covered, whether by public or private health insurers.
8. Family support. Decision-making occurs within the context of a functioning family, with attention paid to the needs of the family and primary caregivers as well as to the patient. Support is given so the family is not torn apart, and is provided according to that family’s system of values. There is a recognition of the need for family strength, an understanding that the good or bad legacy this death creates will endure in family lore.

9. Spiritual support. Spiritual issues are considered regarding what it means to this person to have a meaningful, dignified, and peaceful closure. Physicians, medical and care personnel, relatives and friends are open to the spiritual needs of the individual patient, however the specific patient might define them.

10. The patient is not abandoned by medical staff even when curative treatment is no longer required. The dying person does not feel isolated, nor does she have to die alone. Doctors and other medical personnel are supportive even when a cure is no longer possible, helping to manage dying well, through to the end.

In addition, the author suggests the following Guidelines for Symptom Control taken from Cecil’s Textbook of Medicine’s 1996 edition may be informative:

1. "Nothing matters more than the bowels." Daily assessment needed.

2. Control of one symptom improves control of all symptoms.

3. Most symptoms are caused by multiple factors. Psychological distress may augment all symptoms.

4. "Assessment must precede treatment."

5. Rule out correctable factors underlying each symptom.

6. Clarify who is bothered by symptom: patient, family, or staff.

7. Give simple explanation for each symptom to patient and family. Diagrams helpful.


9. Discuss treatment options with patient and family and involve them in treatment planning where practical.

10. Determine what was helpful in the past.
11. Use a total-care approach employing nondrug, environmental, and other supportive measures.

12. If needed, use combination of pharmacologic agents when differing mechanisms of action and toxicity permit.

13. Prescribe drugs prophylactically in individually optimized, regular doses for persistent symptoms.

14. Never say "Nothing more can be done." Consult or refer if comfort is not achieved.

5.02 Definition: What is Suffering?

We frequently lump the terms "pain," and "suffering," but while pain is certainly a component of suffering, suffering is clearly more inclusive than pain alone. Similarly, we often find it difficult to differentiate suffering from distress. While few people who consider themselves to be suffering would not also say they were distressed, the opposite is not true. In health, distress need not produce a feeling of suffering. In the terminally ill, this is not likely to be so, the word "distress" usually being close to synonymous with "suffering," as they will be treated in this book.

Although it is hard to find a universally acceptable definition of suffering, the following references to "suffering" when thought of together should allow our readers to develop a reasonably similar concept of the topic of our discussion.

1. Suffering is a global experience of impaired quality of life.

2. Suffering is "the state of severe distress associated with events that threaten the intactness of the person." Intactness can relate to one’s very existence, one’s integrity, the ability to maintain one’s role in family and society, or one’s sense of self and identity.

3. "Suffering is the experiencing of severe psychological pain arising from medical or personal causes." Even more than with pain, an individual's experience of suffering reflects his or her unique psychological perception of reality. Because this experience is so subjective, people are often unaware of the causes or extent of another person's suffering.

4. "Suffering is the distress brought about by the actual or perceived impending threat to the integrity or continued existence of the whole person."

5. "Suffering denotes an extended sense of threat to self-image and life, a perceived lack of options for coping with symptoms or problems, a sense of personal loss, and a lack of a basis for hope."
6. "Suffering is the state of severe distress associated with events that threaten the intactness of the person." Suffering can include physical pain but is by no means limited to it. The suffering of patients with terminal cancer can often be relieved by demonstrating their pain truly can be controlled.

Together these definitions indicate that suffering (a) involves a perceived threat to the self which may involve the physical body, the psychic and social self, or both, (b) is inherently emotional, unpleasant, and psychological more than physical, and (c) constitutes an enduring psychological state, not a transient or fleeting experience.

Suffering in terminally ill patients typically results from multiple sources of diverse origins. Pain is likely to be a major factor, but the fear the pain cannot be relieved or the perception that it is indicative of a deteriorating physical condition may cause far more suffering than the pain perception itself. Biological signals of local distress is likely to cause much more suffering if it is perceived to indicate a worsening of the terminal illness as opposed to an unrelated cause.

Parts of a patient’s suffering almost always involve general symptoms unrelated to pain -- like weakness, excessive fatigue, sleep disturbance, loss of appetite and weight loss -- but frequently also involves other more specific physical symptoms like nausea, constipation, and shortness of breath. At the same time, suffering frequently results from distress of psychic origin --like guilt, anger, frustration, perceived loss or helplessness, threat to self-image or body image, or simply the awareness of the threat of death -- all of which may produce or exacerbate an underlying depression. Finally, suffering frequently results from social problems -- isolation or a sense of abandonment, loss of social status and/or social influence, and the loss of self-esteem which follows the loss of ability to work and earn an adequate income for oneself and one’s family. These latter types of psychological distress are frequently referred to in medical articles as "existential suffering," and will be addressed separately later in this book.

5.03 Treating Suffering Related to Pain

With the physical ability to relieve pain discussed in previous chapters comes the added potential for relief of much of the psychological suffering experienced by terminally ill patients related to pain. To accomplish this goal requires physicians and other health providers to specifically address by their actions and in their words many of the unfounded beliefs commonly held by terminally ill cancer patients.

Most terminally ill cancer patients suffer from the fear that medical care is generally unable to control pain related to cancer. This makes rapid, total relief of the first pains experienced by cancer patients essential, not only because it is the right approach to pain relief in general, but because it serves to reassure the patient that cancer pain, like others, can and will be aggressively controlled. In contrast, allowing initial pain to go unrelieved or undertreated simply because it is likely to be relatively mild is a mistake, for it produces unnecessary anxiety for the future, thus adding to the patient’s generalized
From a patient’s perspective, one of the worst aspects of cancer pain is that it is a constant reminder of the disease, its inevitable progression and the approach of death. This makes the prevention of pain through anticipatory use of routine narcotic doses even more effective in reducing patient suffering than relief of pain on a "PRN basis," after the pain is experienced.

Unfortunately, patients with cancer invariably tend to lose hope when pain emerges or increases, believing it indicates the inexorable progress of the disease and failing to consider the effects of drug tolerance. It is therefore wise to note from the beginning that the dose of narcotics is likely to require increases from time to time even if the disease is not progressing as the body builds up tolerance, but that this will not mean increased side effects as the body will become tolerant with regard to the side effects as fast as it becomes tolerant with regard to pain relief.

Chronic unrelieved pain tends to decrease the patient’s willingness to undergo active treatment programs, and, when severe or combined with depression, leads them to consider or to actually commit suicide. Because pain diminishes activity, appetite, and sleep, it can further weaken already debilitated patients while at the same time preventing patients from working productively, enjoying recreation, or taking pleasure in their usual role in the family and society.

To overcome these detrimental effects of pain and the fear of pain requires both aggressive therapy and active discussion of potential pain therapy between the physician, patient and family. If not previously addressed, the time of initial pain relief is often a good time for a heart to heart discussion between health care providers and the patient aimed at convincing the patient of a number of essential facts about pain management. First, that the physician not only has the ability to treat cancer pain, but that he or she intends to do so aggressively until the end-stages of the disease. [The patient must be reassured he or she will not be abandoned with pain.]

Second, that given proper use of modern pain therapies, even in the end stages of cancer, pain seldom becomes unrelieveable through modern pain therapy. And, even then, if the patient should happen to be one of the few whose pain cannot be relieved by traditional pain therapy, other ways short of assisted suicide have been developed to relieve their suffering.

Third, that narcotics are good, not bad. That there need be no fear of addiction. That the development of tolerance is not to be feared because dosage is unlimited and the development of tolerance in fact may tend to make treatment more effective. This should include the notion that proper narcotic dosing is unlikely to interfere with thought processes unless it is so desired by the patient.

5.04 On Death and Dying/Adapting to the Reality of Death

In 1969 Dr. Elizabeth Kubler-Ross, a Swiss born, U.S. educated psychiatrist working with terminally ill patients at the University of Colorado published On Death and Dying, a book based primarily on repeat
The first stage is characterized as "denial and isolation." Dr. Kubler-Ross describes this stage as follows:

"The patient’s first reaction may be a temporary state of shock from which he recovers gradually. When his initial feeling of numbness begins to disappear and he can collect himself again, man’s usual response is "No, it cannot be me." Since in our unconscious mind we are all immortal, it is almost inconceivable for us to acknowledge that we, too, have to face death. Depending very much on how a patient is told, how much time he has to gradually accept the inevitable happening, and how he has been prepared throughout life to cope with stressful situations, he will gradually drop his denial and use less radical defense mechanisms."

In characterizing this stage, Dr. Kubler-Ross notes the same reaction occurs if the patient is told straight out or if the patient comes to appreciate the reality of the situation over time. Although clearly a defense mechanism, initial denial "functions as a buffer after unexpected shocking news, [and] allows the patient to collect himself and, with time, mobilize other, less radical defenses." Although the predominant reaction in the early stages, the need to deny may come and go until the end -- meaning that a perceptive, sensitive listener will recognize denial when it exists and learn to accept it without forcing the patient to face reality until the passage of time makes it possible.

The second stage is characterized as "anger," and typically including rage, envy and resentment as well. Unlike denial, the stage of anger is difficult for the family to deal with, because the patient typically projects the anger in all directions, frequently striking out at anyone around as if they were the cause of the illness. "The visiting family is received with little cheerfulness and anticipation, which makes the encounter a painful event. They then either respond with grief and tears, guilt or shame, or avoid future visits, which only increases the patient’s discomfort and anger."

Patient’s in this second stage typically act to demand attention, raising their voices, making demands, loudly complaining as if to say, "I am alive, don’t forget that. You can hear my voice, I am not dead yet!"

In dealing with patients in this stage, Dr. Kubler-Ross suggests:

A patient who is respected and understood, who is given attention and a little time, will soon lower his voice and reduce his angry demands. He will know that he is a valuable human being, cared for, allowed to function at the highest possible level as long as he can. He will be listened to without the need for a temper tantrum, he will be visited without ringing the bell every so often because dropping in on him is not a necessary duty, but a
Stage three is characterized as a stage of "bargaining." In this stage, which is usually quite brief, the patient who was unable to face the facts in the first stage and found little gain in the anger of the second makes an effort to enter "into some sort of an agreement which may postpone the inevitable happening." It is as if the patient feels guilty about past ways and is now asking for time off for good behavior, usually offering to be good in the future and addressing the request for time in exchange in one way or another to God.

Stage four is characterized by Dr. Kubler-Ross as "depression," which she relates to two causes, "reactive" and "preparatory." The first type stems from reality and is easily recognized and understood, the need for treatments and hospitalization, the financial expenses, the loss of appearance, the loss of jobs and difficulty functioning. At times this type of depression can also be irrational, as when it is somehow related to guilt and/or shame.

In dealing with this reactive type of depression, it is reasonable to try to "cheer them up, to tell them not to look at things so grimly or so hopelessly. We encourage them to look at the bright side of life, at all the colorful, positive things around them. [Although] this is often an expression of our own needs, our own inability to tolerate a long face over any extended period of time ... [it] can be a useful approach when dealing with the first type of depression in terminally ill patients."

As to helping the patient who is going through the second type of depression, Dr. Kubler-Ross’s suggestions are very different:

"When the depression is a tool to prepare for the impending loss of all the love objects, in order to facilitate the state of acceptance, then encouragement and reassurances are not as meaningful. The patient should not be encouraged to look at the sunny side of things, as this would mean he should not contemplate his impending death. It would be contraindicated to tell him not to be sad, since all of us are tremendously sad when we lose one beloved person. The patient is in the process of losing everything and everybody he loves. If he is allowed to express his sorrow he will find a final acceptance much easier, and he will be grateful to those who can sit with him during this stage of depression without constantly telling him not to be sad. This second type of depression is usually a silent one in contrast to the first type, during which the patient has much to share and requires many verbal interactions and often active interventions on the part of people in many disciplines. In the preparatory grief there is no or little need for words. It is much more a feeling that can be mutually expressed and is often done better with a touch of the hand, a stroking of the hair, or just a silent sitting together. This is the time when the patient may just ask for a prayer, when he begins to occupy himself with things ahead rather than behind. It is a time when too much interference from visitors who try to cheer him up hinders his emotional preparation rather than enhances it."
Dr. Kubler-Ross goes on to suggest it is important this stage be recognized by the medical profession, so they can advise the family "this type of depression is necessary and beneficial if the patient is to die in a stage of acceptance and peace. Only patients who have been able to work through their anguish and anxieties are able to achieve this stage. If the reassurance could be shared with their families, they too could be spared much unnecessary anguish."

The fifth and final stage, which is to be sought prior to death according to Dr. Kubler-Ross, is "acceptance." In this stage the patient is neither angry nor depressed. He or she will have been able to express envy for the living, mourned the loss of people and places and contemplated the coming end with a certain degree of quiet expectation. He or she will be tired, quite weak, will doze off and sleep at intervals no longer to escape pain, discomfort or itching, but almost as a sign they have given up the fight.

In advising the family on dealing with this state, Dr. Kubler-Ross suggests:

Acceptance should not be mistaken for a happy stage. It is almost void of feelings. It is as if the pain had gone, the struggle is over, and there comes a time for "the final rest before the long journey" as one patient phrased it. This is also the time during which the family needs usually more help, understanding, and support than the patient himself. While the dying patient has found some peace and acceptance, his circle of interest diminishes. He wishes to be left alone or at least not stirred up by news and problems of he outside world. Visitors are often not desired and if they come, the patient is no longer in a talkative mood. He often requests limitation on the number of people and prefers short visits. This is the time when the television is off. Our communications then become more nonverbal than verbal. The patient may just make a gesture of the hand to invite us to sit down for awhile. He may just hold our hand and ask us to sit in silence. Such moments of silence may be the most meaningful communications for people who are not uncomfortable in the presence of a dying person. We may together listen to the song of a bird from the outside. Our presence may just confirm that we are going to be around until the end. We may just let him know that it is all right to say nothing when the important things are taken care of and it is only a question of time until he can close his eyes forever. It may reassure him that he is not left alone when he is no longer talking and a pressure of the hand, a look a leaning back in the pillows may say more than many "noisy" words.

In the following years Dr. Kubler-Ross expanded her initial five stages to encompass two more. The first she referred to as "finishing old business," during which one learned to finally drop one’s emotional baggage of jealousies or resentments and to make an intimate, heart-to-heart connection with love. In the second, referred to as "transcendence," the dying patient develops a kind of love that is not just one-on-one, but universal, encompassing the vastness of life and humankind.

How hard it can be for the family. How hard to accept that
a dying man who has found peace and acceptance in his death will have to separate himself, step by step, from his environment, including his most loved ones. How could he ever be ready to die if he continued to hold onto the meaningful relationships of which a man has so many? When the patient asks to be visited only by a few more friends, then by his children and finally only by his wife, it should be understood that is the way of separating himself gradually.

**5.05 Suffering in the Terminal Illness and End-Stage Disease**

Most people think of the terminal disease as spanning a time frame set in weeks, but that is only true if we define "terminal" so as to limit its scope to the truly end-stages of an illness. If, however, we define "terminal" as we do in this book, in terms of a "progressive and incurable" disease, the illness is likely to span months and even years, making it essential that we think in terms of relief of suffering in relation to a time continuum.

If, for example, an MRI or CT scan shows a newly discovered cancer is incurable from the time it is first diagnosed, we should not necessarily expect there will be a rapid progression of disease, for many tumors are slow growing. If this be the case, the presence of cancer may not even mean the patient will develop significant physical symptoms over a short period of time, for many cancer patients are symptom free for months to years. During this period, most patients are best thought of and related to as normal in order to minimize the non-physical "existential suffering" which accompanies the knowledge that one has a fatal illness.

What is equally true, however, is that once tumor growth reaches the point when the patient enters the phase of weight loss, weakness, and lethargy typical of end-stage disease, infirmity and dependence is likely to progress quickly and life expectancy is likely to be measured in a few months at most.

It is therefore important to differentiate what usually happens in the last few days of life from thinking about what happens during the earlier course of the "terminal disease process," prior to the events we typically associate with end-stage disease. As part of this, it is important to differentiate reports about symptoms during the last few days or hours of life, in which physical suffering is likely to be the major concern, from all the time between diagnosis and the terminal events, when most suffering is of a psychological nature.

**A. End-Stage Physical Suffering**
This over-all section of the book addresses physical suffering throughout terminal illness, but if we look more specifically at physical suffering during end-stage disease, we will find that the percentage of patients experiencing significant weakness, sleepiness and fatigue, has increased from approximately 50% to approximately 80%. During this period, a little over half experience significant pain, although few experience severe pain unresponsive to therapy. In the last few days, even when pain is generally well controlled, it is not uncommon for patients to suffer pain only on movement, even if deeply unconscious. At one time it was said that many patients died in a "crescendo of pain," but this does not seem to be true in modern medicine, perhaps because of the great improvements in pain management.

Shortness of breath is also common as a terminal event, occurring in approximately one quarter of patients during the last month of life. In the last few days, congestion of the lungs is also frequently evident even to visitors, typically producing a sound which has been called a "death rattle." Nausea and constipation are common throughout the last month, with dry mouth and difficulties in urination, either inability to urinate or inability to hold the urine, being more common in the last few days of life.

In spite of these considerable problems, the experience of hospice providers shows that even in the last few weeks and months of life, dying persons are much more commonly distressed by the same concerns they have earlier in the course of their terminal illness -- the fear of pain, loss of control, indignity, a weariness with life, the absence of self-worth when not being productive, and a desire not to burden family than actual physical or psychiatric symptoms.

B. Mental Suffering

Again looking more closely at the end-stage of disease, the typical worried anxiety noted to be present in approximately one quarter of patients in the earlier stages of a terminal illness is likely to be replaced during the last few days with symptoms more suggestive of agitated anxiety, such as restlessness, irritability, jerking, twitching, and plucking. Whether these symptoms are related to true anxiety or to chemical changes in the brain which cause such movements is typically hard to tell.

In addition, approximately 25% of patients experience at least intermittent confusion during the last month of life, with some increase in the last few days, especially when increased doses of medication may be required. In contrast, depression is much more common earlier in the course of terminal illness than in the final phases, when the typical patient has accepted the finality of approaching death.

Although not usually considered a mental illness, fear is probably even more common than anxiety, confusion, or depression during the final weeks of illness. Fears regarding loss of autonomy, disfigurement, being a burden to their family, letting the family down, facing the unknown, and loss of cognitive function which are likely to have appeared earlier are likely to continue into the final month of illness. As the end stage approaches, however, different fears are likely to become more important, such as having to experience pain, shortness of breath, nausea and vomiting, loss of appetite and isolation.

C. Existential Suffering
In trying to explain suffering in the terminally ill, commentators have carefully separated out the concept of "existential suffering" from both physical symptoms and mental illness, although they certainly have strong interactions. Those forces which are recognized to exert existential suffering have in common a challenge to "self," the patient’s actual or perceived threat to his or her own identity and integrity. Looked at another way, existential suffering calls into question the continuity of the "I" by which individuals refer to themselves. Frequently, as death approaches and comes to be "accepted," these major concerns of the previous period become less pressing, but in some patients they persist to the end.

Problems related to existential suffering are the most difficult for physicians to treat, for they require the most individualistic approaches. Unlike pain, nausea, shortness or breath, fear, anxiety, confusion, and depression, there are no medicines for a threatened loss of self-image, but there still remain proven approaches to be taken by caregivers to relieve or minimize the suffering. In general, such efforts can be summarized as undertakings to maintain the patient’s autonomy and to counteract the patient’s natural feeling of diminished control of one’s own life.

Discussing existential suffering, Courtney S. Campbell, a Professor of Ethics at Oregon State University stated [in Suffering, Compassion, and Dignity in Dying, 35 Duq. L.R. 109, 119 (1996)] says:

"It is through acknowledging existential suffering that society can make some sense of the lament, "my world is coming apart." This form of suffering seems to deprive the sufferer of all that is most humanly meaningful in life: relationships, memory, creativity, communication, a responsive body, autonomy; in short, precisely those characteristics that might well constitute an individual's sense of "dignity."

Existential suffering represents not only a threat to the autonomous self but also implicates the claimed liberty interest of terminally ill persons in a right to die.... "At the heart of liberty is the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life." In the ordeal of existential suffering, however, it is precisely an individual's concept of existence and understanding of meaning that is under siege. The individual's universe and world is conceptually "coming apart," and he or she has no answers for the mystery of his or her own life, let alone human life in general. The sufferer winds up asking ... "why these torments," and finding an answer equivalent to, "for no reason--they just are." Confronting this abyss of meaninglessness can be almost too intimate and personal for the patient to bear.

If such suffering could be relieved by medicine, of course, then all would be conducive to a peaceful and dignified death. What drug or medication is there, though, that can alleviate this rupture of an individual's self and world? Society needs to understand that while medicine certainly can prevent or remedy the occasions out of which suffering arises, the experiences of suffering, mortal or existential, are not so medically malleable. What is needed in these circumstances is a different kind of response, a human response that can be given professional direction; the response of compassion.
Common existential issues for patients with advanced disease include hopelessness, futility, meaninglessness, disappointment, remorse, death anxiety, and disruption of personal identity. Easily recognized sources of this suffering include losses of privacy, lifestyle and established routines; the destruction of one's sense of security and sense of normalcy; the painful awareness of one's former physical powers and present incapacities; the dreaded anticipation of future mental and physical deterioration; the loss of control over one's life and life plans; the unwanted dependence on machines and doctors; the loss of home and of social roles in the outside world brought about by institutionalization; the loss of hope, of optimism about the future, and of pleasure in life, and a realization one is destined "to witness and endure a final stage not as an effective agent, but merely a deteriorating object."

5.06 Effects of Suffering on Others

Terminal events can precipitate a kind of social death in which there is loss of contact with others, most notably at times, physicians. Isolation of the incurably ill, even in busy hospitals, is common. The desire for distance from the dying, doctors' priorities in caring for those with a reasonable chance for recovery, the monetary reward system, time pressures, and other personal and institutional factors all contribute to what one physician has called "a miserable job of caring for the dying" performed by the medical system.

Patients and their families also suffer the stress of mounting emotional and financial burdens. The wish to avoid depletion of family resources may motivate some to seek a quicker rather than slower death. Few mothers and fathers would want to leave behind an impoverished family. Many would also not want to feel responsible for ruining the quality of life of a family member who would have to serve as a caretaker during an arduous, chronic fatal illness.

Finally, people have an interest in how they will be remembered. The manner of one's death may overshadow other facets of one's life, to the point of haunting loved ones who witness an intolerable death. Justice Stevens, dissenting in the U.S. Supreme Court decision commonly referred to as "Cruzan," suggested this interest was of supreme importance by writing:

Nancy Cruzan's interest in life, no less than that of any other person, includes an interest in how she will be thought of after her death by those whose opinions mattered to her. There can be no doubt that her life made her dear to her family, and to others. How she dies will affect how that life is remembered. The trial court's order authorizing Nancy's parents to cease their daughter's treatment would have permitted the family that cares for Nancy to bring to a close her tragedy and her death. Missouri's objection to that order subordinates Nancy's body, her family, and the lasting significance of her life to the State's own interests. The decision we review thereby interferes with constitutional interests of the highest order.
CHAPTER 6. SUFFERING FROM PHYSICAL SYMPTOMS OTHER THAN PAIN

6.01 Physical Symptoms Other than Pain; In General

6.02 Symptoms Related to Digestion

A. Nausea and Vomiting

B. Constipation

C. Diarrhea

D. Loss of Appetite and Weight Loss

E. Trouble Swallowing

F. Dry Mouth

G. Nutrition and Hydration

6.03 Problems with Breathing and the Lungs

A. Shortness of Breath

B. Cough

C. Hiccough

D. Secretions

6.04 Neurologic Problems

A. Insomnia

B. Confusion, Delirium and Dementia

C. Terminal Restlessness

D. Seizures

E. Headache
6.05 Conditions of the Skin

A. Itching

B. Bedsores

C. Edema

D. Odors

6.06 Bladder Problems

6.07 Weakness and Other General Symptoms

6.01 Physical Symptoms Other than Pain; In General

Most physical symptoms in the terminally ill can be treated quite successful, although many pose more difficulties in management than pain. This chapter discusses some of the more common symptoms experienced by patients with terminal disease and what can be done to help. In many cases, successful therapy will depend on careful reporting of observers to a health care provider in order to allow appropriate adjustments of drug therapy. In other cases, suggested efforts by family members alone are likely to be at least as helpful as physician initiated interventions.

In treating physical symptoms of the terminally ill certain common factors are likely to be relevant:

(1) symptoms may be caused by drugs originally given for symptoms which no longer exist and should therefore be stopped;

(2) many suggested therapeutic approaches for one symptom may not be appropriate because of other existing problems, and (3) coexisting symptoms can frequently be effectively treated with the same medications or in the same manner. For example, many, but not all medications for nausea, are also helpful in the relief of anxiety and itching.

[Note: In the following text you will frequently see a reference to a group of drugs collectively called "steroids." These drugs are all chemically similar and closely related to the naturally occurring human hormone produced by the adrenal glands, named hydrocortisone. In general, these chemicals serve to decrease the body’s reaction to potential irritants of many kinds, making them useful in many different situations. Because they differ somewhat from each other, specific steroids tend to be used in slightly different situations -- but there is great overlap. Some of the commonly used steroids with names you might recognize besides hydrocortisone itself are cortisone, prednisone, prednisolone, triamcinolone]
A. Nausea and Vomiting

Nausea with or without vomiting is the most common digestive symptom and, after pain, the second most common symptom in terminally ill patients. Frequently it is caused by pain medications, both narcotic and non-narcotic, and can be relieved by changing the drug or dosage being used. Other drugs which frequently cause nausea include iron tablets, antibiotics, cancer chemotherapeutic agents, and, less commonly, steroids. [See brief discussion of steroids, above] Nausea may also be caused by a local tumor either in the abdomen or brain, or may be secondary to other problems such as constipation, kidney failure, excessive calcium in the blood and/or emotional problems.

If the physical cause of the nausea and vomiting cannot be relieved, it is still frequently responsive to medications, such as metoclopramide (Reglan), which can be given either orally or by injection; seasickness medications like merazine (Bonine), meclizine (Antivert), and hydroxyzine (Vistaril); minor tranquilizers like lorazepam (Ativan) and prochlorperazine (Compazine), low doses of major tranquilizers, like haloperidol (Haldol), chlorpromazine (Thorazine), and prochlorperazine (Compazine), and occasionally by steroids, like cortisone and prednisone (Deltasone, Meticorten), or by marijuana derivatives.

In addition to drug therapy, severe nausea may frequently be relieved temporarily by placement of a tube in the stomach to empty its contents. Occasionally, sucking on ice or sips of cola or ginger ale is found to be effective, as may the ingestion of crackers or popcorn. In some patients, the avoidance of odors may be important, as may the avoidance of specific foods such as those which are sweet, salty, fatty or spicy depending on the individual, or the avoidance of foods which are either very hot or cold. Providing distractions such as talking, music, electronic games, reading and using relaxation techniques such as rhythmic breathing and positive visual imagery may also be helpful.

B. Constipation
Treatment of Pain and Suffering in the Terminally Ill - Chapter 6

Constipation is frequently due to a combination of factors, but usually involves to some degree the use of narcotics. In fact, this side effect is so common that many physicians recommend preventive measures be undertaken as a preventative as soon as narcotics are started for pain. Antidepressant medication may add to the problem, as may calcium based antacids, tranquilizers and other medications. In addition to drug use, constipation may be aggravated by limited intake of fluids and bulk in the diet, inactivity, generalized weakness or by high levels of calcium in the blood due to cancer in the bone, especially when linked to lack of activity. Occasionally, a tumor may cause mechanical blockage of the intestines, but much more common than this is mechanical blockage from a fecal impaction (a hard lump of stool in the rectum which the weakened patient cannot pass). One further possibility that is easily relieved -- a patient who is bed ridden may purposely retain stool out of fear of soiling the bed.

Perhaps the most important approach to the treatment of constipation is the regulation of pain medications to the extent possible. Frequently a patient will experience less constipation from one narcotic preparation than another even at dosages which provide equal pain relief.

Maintenance of a satisfactory intake of roughage and fluids is usually advocated early in the course of the disease along with bulk type laxatives, such as Metamucil, Colace, and Senokot. If constipation still occurs, more powerful laxatives may be used, such as Milk-of-Magnesia, Peri-Colace, Doxidan and lactulose. Enemas may be required, as may be mechanical removal of a fecal impaction.

In addition to drug and dietetic therapy, the provision of privacy is often important, as well as arranging for the patient to assume an upright position for bowel movements, usually with the use of a bedside commode. Warm liquids may be helpful, as may a soft massage of the abdomen. Smokers may also be helped with a cigarette.

C. Diarrhea

Diarrhea is far less common than constipation in the terminally ill, but just as varied in causation. One frequent cause of diarrhea is liquid nutritional supplements released into the intestinal tract through feeding tubes. Other common causes are anxiety, previous radiation therapy to the abdomen, the use of antibiotics, and various infections of the intestines. A frequently overlooked and readily treatable cause is a rectal impaction (hard stool in the rectum), which commonly causes diarrhea like passage of loose stools if it does not completely block the intestinal tract causing constipation.

When possible, diarrhea should be treated by eliminating the cause -- changes or elimination of the food supplements being given by tube feedings, treatment of infection, or removal of a fecal impaction. At times, changing the narcotics to one more constipating may have the desirable side effect of eliminating the diarrhea. If these therapies do not work, use of typical drugs for diarrhea may be successful (Kaopectate, Lomotil, and Imodium, among others).

D. Loss of Appetite and Weight Loss
Loss of appetite (medically called "anorexia") and weight loss ("cachexia") are not usually present early in the course of cancer but are almost always present during the end-stages. Weight loss is also common during the end-stages of other terminal illness -- heart, liver, lung and kidney failure, as well as Alzheimer’s disease.

When intake of carbohydrates falls below a certain level, chemicals called "ketones" build up in the blood from the breakdown of body fats. These ketones further reduce food intake by interfering with the patient’s normal appetite producing a vicious cycle of decreased input, increased ketones, decreased appetite and weight loss.

When this happens early in the course of the disease, as the result of depression or of medical therapy for cancer, for instance, and the patient has a significant amount of time to live, it is important to take steps to prevent the malnutrition that will inevitably follow. When, however, this occurs as part of the dying process late in the course of the disease, health care providers are reluctant to interfere because doing so is likely to result in more patient suffering than relief of discomfort.

In addition to the ketone effect, it is now believed that the terminal loss of appetite in the cancer patient is closely related to various chemicals either released by the tumor itself or by the body in response to the tumor. This gives hope that a specific blocking agent may soon be found to reverse the process, but, unfortunately, none is presently available. Physicians are therefore generally left to make suggestions of limited value, such as encouraging menu variations, smaller meal portions, meals served in a room other than the patient’s bedroom, dressing the patient to eat, use of sherry or wine, selection of a preferred diet, family feeding, elimination of odors, food supplements, specific mouth care prior to eating, and dental consultations regarding dentures which have become ill-fitting due to weight loss.

Some drugs which are used to try to stimulate the patient’s appetite are steroids (most commonly Decadron and Medrol), derivatives of male or female hormones, metoclopramide (Reglan), Cyproterone and marijuana derivatives. [Note: another drug which has recently been suggested as potentially helpful in fighting weight loss in certain conditions is Thalidomide, which shares with marijuana a troubled past history.]

A major question in the treatment of the anorexia and weight loss seen in many terminal patients is the advisability of employing a feeding tube to bypass the need for oral intake of food. Only in America, where the dying process is not accepted as natural, do we tend to associate lack of food and fluid intake during the dying process with "starvation" and "thirst." This will be discussed further in the chapter discussing nutrition and hydration in relationship to suffering, but in brief it is fair to say that most physicians who are active in the field of palliative care do not believe that forced "feeding" through artificially placed tubes either prolongs life or reduces suffering.

E. Trouble Swallowing

Many diseases which involve multiple areas in the brain such as Alzheimer’s Disease and strokes are
associated with mechanical difficulties swallowing. Cancers around the mouth, including those of the
tongue, larynx, esophagus and stomach, may also cause similar problems. More frequently, however,
swallowing problems in cancer patients are due to irritation of the lining of the mouth as a result of
chemotherapy and radiation, vitamin deficiencies, dental problems such as infections of the gums, drug
side effects (tranquilizers, antihistamines, steroids, and antidepressants), poorly fitting dentures, and local
infection with fungus brought on by previous use of antibiotics and cancer chemotherapy. Other common
causes of difficulties swallowing relate to the general debility we associate with terminal disease --
generalized weakness, confusion, mouth breathing, and nausea.

Swallowing difficulties may be dangerous as well as causing malnutrition and dehydration. Most
frequently, it is associated with the development of aspiration pneumonia, a non-infectious chemical
irritation of the lining of the lungs which occurs when food and fluids, as well as saliva and regurgitated
stomach acid, are aspirated into the lungs instead of being swallowed into the stomach.

Treatment of swallowing difficulties should be directed at the specific cause whenever possible.
Although efforts are likely to be made to change the nature and consistency of foods and fluids offered
the patient, these changes seldom produce significant improvement and run a high risk of causing
pneumonia themselves. Depending on how long the patient is likely to be unable to swallow safely, a
decision is likely to be required as to whether and what artificial means of providing nutrition and
hydration should be employed. Fluids can easily be given by vein, but provisions of adequate nutrition
for any extended period of time requires either a feeding tube or placement of a large intravenous line in
one of the big blood vessels in the patients chest, a procedure which often leads to significant
complications itself.

Whatever the cause, when swallowing is difficult, medications should preferably be given by
suppository, patch or injection instead of by mouth. Care should be taken as to what foods are offered to
the patient and the form in which it is offered, although it is hard to determine without trying which form
is most likely to be well tolerated. Whatever the situation, forced feeding by mouth is seldom wise.
[Note: Jello is frequently tried in these situations but is notorious for causing aspiration pneumonia]

F. Dry Mouth

Although commonly attributed to lack of fluid intake, a complaint of dry mouth is less likely to result
from decreased fluid intake than other factors. Studies have shown, in fact, that a complaint of dryness of
the mouth or thirst is just as common in patients receiving plenty of intravenous fluids as in those
patients who are not, suggesting that the sensation is related to local factors and not the absence of fluids.
Common causes of dry mouth in these patients are the side effect of medications (including many
antidepressants), mouth breathing, the after effects of radiation to the mouth area and salivary glands,
local infections, most commonly due to a fungus following the use of antibiotics and cancer
chemotherapy, (monilia/thrush), and/or food debris and dried sputum that collects in the mouth as part of
the general state of weakness.
Most important therapeutic measure in dealing with dry mouth involves reversal of causes, but this may not be possible. Medications are not likely to be helpful, except for mouthwashes or similar therapies aimed at local fungus infections, usually monilia, which is often very responsive to mycostatin (Nystatin), fluconozole (Diflucan) or other anti-fungal medications.

In spite of the lack of specific therapy, local care is often very helpful in eliminating the "dry mouth" problem. This includes washing of the mouth with salt water, baking soda or peroxide every two hours, sucking on ice chips, frequent sips of water, sour candies, artificial saliva (Xerolube, Salivart), topical anesthesia (Viscus Xylocaaine or Dyclone), Vasel bland cream, buttermilk, yogurt, and cold fruit nectars. Humidification may also be helpful.

Unfortunately, while a "dry mouth" complain is likely to evoke a search for local causes to remedy, a complaint of "thirst" is likely to lead the caregiver to mistakenly think in terms of inadequate fluid input. This may inadvertently lead to consideration of a feeding tube being passed typically from the nose down the back of the throat into the stomach, a procedure which only aggravates the irritation of the mouth by encouraging mouth breathing and placing a foreign body up against the dry membranes of the throat.

[Note: This is not to imply there are never times when dehydration should be treated with fluids through a feeding tube. This may be perfectly correct when the local condition is temporary, such as immediately after radiation or heavy chemotherapy, when the patient is not in the end stages of the disease, and the rare time when "thirst" is truly caused by a lack of fluids (dehydration).]

G. Nutrition and Hydration

Problems with nutrition and hydration are almost universal in the terminally ill patient. Although they do relate to problems in the digestive tract, they will be discussed separately in a later chapter because the medical considerations are so overlapped by related issues -- ethical, legal, moral, social and religious.

6.03 Problems with Breathing and the Lungs

A. Shortness of Breath

Shortness of breath, medically referred to as "dyspnea," is probably the third most common symptom during terminal illness after pain and nausea. When experienced early in the course of a terminal illness it is usually due to a complication of the disease process itself or to a co-existing medical condition which may have been made worse by the effects of the terminal disease. In contrast, when it occurs in the last week of life, it is more likely to represent a combination of more general factors related to the terminal state -- muscle weakness, inability to maintain circulation of the blood, generalized infection, and poor general metabolism of the body. This type of shortness of breath is often characterized by the production of a sound deep in the chest and commonly referred to as a "death rattle."

When dyspnea occurs early in the course of a terminal condition, the exact cause should be sought and
attempts made to reverse the process. In this situation, a chest x-ray along with clinical examination is likely to be very helpful. Commonly, fluid is found in the chest (hydrothorax) or in the abdomen (ascites) which can be removed through a needle or with the temporary insertion of a tube (catheter). If pneumonia or other infection is found, treatment with antibiotics is indicated as long as other body functions are adequate to provide meaningful life for the patient in the future. If the patient has developed a wheeze due to spasm in the tubes leading to the lungs (bronchi), the same medication that benefit asthma are likely to be helpful. If the patient is anemic (low blood hemoglobin level), proper medication or transfusions may help. At times, therapy may be indicated to maintain a normal heart rhythm if there are irregularities in the heart beat.

Another common cause of shortness of breath in the terminally ill is the development of blood clots in the veins of the legs or pelvis which break off and flow through the blood stream to the lungs. Treatment of this condition, referred to as "pulmonary emboli," requires the use of "blood thinners," most commonly Heparin at the beginning followed by warfarin (Coumadin), to limit clot formation. On occasions, if the patient is very ill from the blood clots but not in the terminal stages of the disease, surgery or the placement of a special device in the large vein running through the abdomen (inferior vena cava) is also advisable to prevent sudden death.

On occasions, radiation or other cancer chemotherapy may be helpful if there is extensive metastatic cancer in the lungs, but this is in fact quite rare, the presence of tumor tissue in the lungs seldom being so extensive as to cause shortness of breath.

If the patient’s heart or kidneys are performing poorly, water is likely to build up in the lungs, in which case appropriate medications, including diuretics such as furosemide (Lasix), is likely to be helpful and well tolerated by the patient.

At times patients experiencing shortness of breath may also be helped by simple atmospheric modifications, like use of fans, nebulizing fluids for humidification, cooling a room, a change in position, or simply teaching the patient to breath through pursed lips creating a little back pressure in the lungs. Although most people think in terms of using oxygen, this rarely reverses a downward course of the disease over a short period of time and tends to be destructive of the patient’s ability to enjoy life because oxygen therapy is difficult to stop once started. Continuation of oxygen then requires the patient to be "hooked-up" to some apparatus greatly limiting mobility and quality of life for the short time remaining.

[Note: As with artificial feeding and hydration, this is not to set a general rule that oxygen has no place in the relief of shortness of breath in the terminally ill, but only to suggest oxygen tends to be over used, in large part in response to the expectations of the family, with minimal true benefit to the patient.]

In contrast to dyspnea early in the course of illness, dyspnea appearing in the very terminal stages of the disease process requires a very different approach in which a determination of the exact cause is not likely to be helpful. In this situation, primary concern should be comfort, not cure, and the inevitability of death accepted as no longer an enemy. In fact, because severe dyspnea is so distressful -- often the most
difficult of all symptoms to treat -- many patients at this point in the course of this disease look to death as a potential friend, not an enemy at all.

By far the most important treatment of terminal dyspnea, as in the treatment of pain, is the proper use of morphine and its derivatives. And, as in the treatment of pain, it is important to consider the interplay of tolerance, the need for symptom relief, and the potential of suppressing respirations. When a patient is truly oxygen deprived and there is hope of reversing the disease process, it is reasonable to avoid a drug which reduces respiration and might cause death. When, however, there is no chance of reversing the disease process and the potential risk of causing death would be either accepted or welcomed by the patient and family, this fear is no longer reasonable. To the contrary, as with pain relief, because these patients have almost routinely developed tolerance to the effects of narcotics, there is little risk of suppressing respiration, but it is still reassuring to know that even if suppression were to occur, it would only result in a mixed blessing.

[Note: Some people will resist the concept of accepting the risk of potentiating death in the treatment of distress, even though it is well accepted by ethicists, legal scholars, medical leaders, palliative care specialists, and even by most religions. "Double-effect therapy," as it is called, is discussed at length later in this book, and actually stems from early Greek medicine through the middle-age teachings of Catholic theology.]

At this very late stage, if oxygen is available, it may be reasonable to try its use, because many patients perceive it to be beneficial and the threat of interfering with mobility no longer exists as the patient is now likely to be essentially bed-bound. In reaching the decision to use oxygen, however, two thoughts should be kept in mind.

First, while patients with terminal shortness of breath may feel better when given oxygen, there is no proof it is medically beneficial, so its use should thus be based on the patient’s perception of benefit, not specific medical indications.

Second, keep in mind that the sound of a "death rattle" does not indicate physical distress to the patient, but that the sound itself may either go unnoticed or be psychologically very upsetting to the patient. This means, if the patient is not upset, nothing need be done. But if the sound itself upsets the patient, efforts to relieve the rattle are justified. One way to relieve this distress may be to give oxygen, not for its therapeutic value but because doing so makes noise from the delivery system, thus reducing the patient’s awareness of the sound. If this fails or if oxygen is not easily available, drugs which dry up secretions can also be used, although they all run risks of side effects. These include scopolamine, atropine sulfate, and antihistamines like Benadryl. [Note: use of these agents for relief of family anxiety is not justified, for they may negatively effect the patient, who’s well-being should be the primary concern.]

Finally, it is worth noting that the most common symptom leading to the use of high doses of sleeping medication to induce continual sleep [discussed in a later chapter under the designation of "terminal sedation"] is unrelieved dyspnea.
B. Cough

Cough is another frequent symptom associated with terminal illness. Early in the course of the disease, it is likely to be due to a specific condition like bronchitis, pneumonia, heart failure, or blood clots, in which case specific medical therapy aimed at the particular cause is indicated. Late in the disease process it often accompanies the same causes as those producing shortness of breath. In this case, it is often suppressed by the use of narcotics for relief of pain or dyspnea independent of the cough. If not, it may be helped by removing irritants, such as odors or cigarettes, by oral moisturization and mouth care, and by humidification.

Another common cause of cough in the debilitated patient that should be considered is aspiration of food and fluid. This may be readily apparent when there is a close time relationship between the cough and eating or drinking, but the cough may also be produced by resultant inflammation within the lungs in which case the timing is not apparent. When delayed, a chest x-ray is likely to be suggestive of recurrent aspiration.

C. Hiccough

Hiccough may be a surprisingly persistent problem in terminally ill patients. Unlike typical hiccup, which lasts for only a short period of time, hiccup in the terminally ill may be persistent for days and weeks in spite of medical therapy. Persistent hiccup in this situation is usually indicative of either direct pressure on the diaphragm by a tumor in the chest cavity or an enlarged abdominal organ below the diaphragm. Alternatively, it may be due to a process in the chest, often the tumor itself, irritating the phrenic nerve as it passes through the chest to innervate the diaphragm from its origin in the spinal cord of the neck. When triggered by irritation instead of the normally conducted impulse from the brain, the diaphragm contracts suddenly instead of in the normal sequenced order typical of normal breathing thus producing hiccup.

One fairly common cause of hiccup that is easily relieved is upward pressure on the left side of the diaphragm due to a collection of gas in the stomach. When this is not relieved by the simple process of the patient belching, the gas can be removed by passing a tube from the nose to the stomach which allows the gas to escape and relieves the hiccup.

Occasionally hiccup can be relieved by eating raw sugar or using common antacids like Mylanta. If this does not work, physicians will often pass a tube through the nose into the back of the throat which somehow causes a nerve reflex relieving the hiccup.

Some of the drugs commonly used to try to control hiccup include tranquilizers like Thorazine or Haldol, regulators of stomach action like Reglan, steroids like Decadron, or drugs used to control seizures, like Dilantin.

When uncontrollable by these maneuvers and medications, persistent hiccup may require
neurosurgical techniques which block the phrenic nerve as it travels from the neck through the chest to the diaphragm. This is most commonly required in patients with cancer involving the chest cavity pressing directly on the left or right phrenic nerves which serve the respective side of the diaphragm.

D. Secretions

Most people are not aware of the large quantity of fluids normally produced each day by the body in the sinuses, salivary glands, lungs, and stomach and which passes into the digestive tract only to be reabsorbed and returned to the blood stream from the intestines. In illness, this unrecognized internal flow of fluids is often interrupted and the liquid, commonly referred to together as "secretions," then become a problem of significance. Obviously, anything which blocks the passage of these secretions will cause an accumulation above the block typically resulting in regurgitation and vomiting and frequently causing aspiration into the lungs. Even without blockage, trouble swallowing may similarly lead to accumulation of secretions above the throat which eventually finds its way "down the wrong pipe" into the lungs. In the presence of such mechanical problems, an exact determination of the cause and direct therapy is likely to be necessary if the patient still maintains a significant quality of life. Although some medications may be employed to decrease the amount of normal secretions, this approach is not likely to be successful to any significant degree.

In some patients, increased secretions may be due to infection, while in others, generalized weakness may make it difficult for the patient to cough and swallow effectively. When infection is present, antibiotics may be helpful, but it is difficult to treat the generalized weakness making the repeat suctioning of excess secretions from the back of the throat required for comfort. If the patient is near the end of life, the patient is likely to request only minimal quantities of fluids by mouth, which tends to help reduce secretions. If this occurs, use of artificial hydration with intravenous fluids is only likely to cause increased problems with secretions.

6.04 Neurologic Problems

A. Insomnia

Insomnia in the terminally ill is commonly the result of sleeping during the day and minimal activity, but is frequently made worse by inadequate treatment of physical symptoms and mental distress. Poor planning of medication dosing which requires the awakening of the patient should be an easily remedied cause of insomnia. A surprising number of patients experience night sweats which interfere with sleeping both because they wake the patient and because they leave the patient to lie in water soaked bedclothes.

Although it is hard to force a terminally ill patient to be more active or to stay awake during the day when there is little meaningful distraction, it is not hard to insure that symptoms like pain, nausea, and dyspnea have been adequately treated. In addition, sweating can often be relieved using anti-inflammatory medications like steroids, so-called NSAIDs (Non-Steroidal Anti Inflammatory Drugs) like Naprosyn, Indocin or Motrin, or with small doses of major tranquilizers like Thorazine.
When such methods fail to help the patient sleep, small quantities of alcohol at bedtime, traditional sleeping pills, or increased dosage of a longer acting narcotic at bedtime is likely to be helpful and justified. On other occasions, patients may be greatly helped by efforts to decrease noise and activity within the room at night or by providing background activity such as a "white noise-maker," television or radio to help distract the patient from his or her other thoughts.

**B. Confusion, Delirium and Dementia**

Confusion and delirium are essentially the same condition characterized by abnormal changes in thought processes, although laymen tend to refer to confusion while physicians tend to use the word delirium. Characteristically, delirium is rapid in onset, over hours or a few days, and is potentially reversible without lasting effects. Typically, it is caused by processes going on outside the brain, such as fever, drug reactions, alcohol abuse, or problems with the circulation, respiratory system, liver or kidneys.

In contrast to the terms confusion and delirium is the term "dementia," which is more universally accepted as suggesting progressive mental difficulties which are not only irreversible but due to disease which directly affects the brain. Because dementia is usually the result of a slowly progressive process -- either Alzheimer’s disease or the result of multiple strokes -- we traditionally do not consider dementias to be terminal illnesses, but this is truly an aberration of our present thinking which is likely to change in the future as Alzheimer’s disease becomes even more common with the aging of our population and an ever increasing cause of death in the United States.

A major difference between delirium and dementia is that delirium is usually a symptom of another condition while dementia is usually a disease process of its own. This means that when delirium co-exists with a terminal illness, it is usually due to that illness, whereas when dementia co-exists with another terminal illnesses, they should probably be thought of as two separate disease processes.

The symptoms we associate with delirium usually indicate a widespread failure of brain function which is likely to include disturbances of consciousness, attention, thinking, perception, memory, psychomotor behavior, emotion, orientation, and the sleep-wake cycle. Also typical of delirium is a tendency of symptoms to fluctuate up and down in severity, often with surprisingly abrupt changes in level of brain function over a very short period of time from minutes to hours.

When delirium is pronounced, it is quite easy for the patient’s family to recognize and the physician to confirm. Unfortunately, when the symptoms of delirium are less pronounced, it is very common that both the patient’s families and the patient’s physician fail to recognize its presence, especially in situations when there are likely to be so many other reasons for mental abnormalities.

Among the many early signs that are likely to go unrecognized as indicative of delirium are the following, which I list not to make the reader an expert in the diagnosis, but only to suggest they may indicate a failure in brain function secondary to a reversible general medical condition outside the brain. These symptoms include: restlessness, agitation, trouble focusing, difficulty with language, sudden
profound weakness, loss of orientation to time and place, loss of attention and memory, disruption of sleep patterns, repetitive purposeless behavior -- like groping and plucking, unexplained attempts to get out of bed, jerky uneven movements, hitting at nonexistent objects, ransacking of bedclothes, pulling out of catheters, frightening and vivid hallucinations, suspiciousness, hostility and combativeness, mumbling and shouting, jerky muscle movements, shakes, or weird movements of whole extremities.

Having determined that the patient is delirious, a physician has many potential causes to consider, some of which can be easily treated while others are not. As with shortness of breath in terminal illness, the physician should first determine if the delirium is a complication of a specific disease process or is actually a sign that the patient is truly entering the most terminal stages of the primary disease before deciding how great an effort should be put forth to determine the cause.

Some of the more easily treated causes of delirium are drug reactions or overdoses caused by pain medications, tranquilizers, antidepressants, alcohol, sleeping pills, and cimetidine (Tagomet), among others. Kidney, lung or liver failure are fairly common causes of delirium which are easy to diagnose and are frequently related to reversible infections, such as pneumonia or urinary tract infection. Changes in blood chemistry, including low sodium, magnesium, or blood sugar and high blood calcium are also frequent treatable causes of delirium which are fairly common in terminally ill patients.

In contrast to such physical causes of delirium, it is surprising how often delirium results from a simple transfer of physical location in the terminally ill, especially if it is superimposed on some level of existing dementia. If such happens, improvement can be expected when the patient becomes more familiar with his or her new surroundings. Unfortunately, delirium-like symptoms may also be caused by irreversible changes in the brain, as may happen when cancer metastasizes to the brain or when the patient starts developing ministrokes.

In most cases primary therapy of delirium is directed at its underlying cause, by changing medications, treating infection, correcting blood abnormalities, etc. If, however, no cause is found or if treatment is not effective, other maneuvers may still be helpful in reversing the process. If, as is frequently the case, the patient has been relocated or left alone, stimulation with familiar faces, voices, and objects, large readable room clocks and calendars, photographs, night lights, and increased attention by all staff members can be quite effective in re-orientating the patient. If possible, drugs which cause sedation, including pain medications, should be reduced in dosage unless it results in increased suffering. Verbal reassurance from close relatives and friends that things are "okay" and "will get better" may be very helpful. In addition, when these modalities fail, tranquilizers like Haldol and Thorazine derivatives like methotrimeprazine (Levoprome) and midazolam (Versed) may be effective. Restraints should generally be avoided if at all possible, as they are likely to increase patient agitation.

Successful treatment of delirium is particularly important because delirium increases the patient’s sense of helplessness and loss of control, feelings frequently mentioned by patients who seek or actually undertake suicide. Patients exhibiting minor levels of delirium are particularly likely to react negatively to episodes of confusion or hallucination which can result from the use of narcotics, as they tend to foster...
the perception that they are losing control of their minds. This may produce the difficult situation in which sedation with tranquilizers or sleeping medications (hypnotics) are used to treat delirium and at the same time frequently produce episodic periods of increased delirium.

It has been reported that as many as 10% to 20% of patients experience delirium at the very end of life requiring heavy sedation using narcotics, tranquilizers, or sleeping medications, but that percentage seems high to the author. Looked at from a different viewpoint, many practitioners suggest that delirium should be considered a part of the dying process which does not produce suffering and need not be treated at all unless required for the comfort of the family. [See further discussion below in the chapter on terminal sedation.]

C. Terminal Restlessness

Although terminal restlessness may occur as part of delirium, it sometimes occurs alone or only in association with such other symptoms as agitation and wandering. If the patient is mentally unable to express discomfort in general, restlessness may be the only clue that there is an undiscovered problem which is causing the patient distress, such as the inability to urinate, the presence of unrelieved pain, lung problems leading to low oxygen in the blood, constipation, high blood calcium levels, or a drug reaction, among others.

When no cause is found for the restlessness, one must consider a psychological problem which may be relieved by increased family contact and conversation, massage therapy, etc. At times, medications can be helpful -- tranquilizers, sedatives or increased doses of narcotics -- especially when wandering puts the patient at risk for serious injury.

At other times restlessness may be difficult to differentiate from muscle twitching, which is also fairly common in the terminally ill. Such twitching may be part of the very terminal stage of the disease when the body’s metabolism is failing, but is often due to drugs and is therefore potentially reversible if the drug causing the problem can be identified and stopped. If no drug can be found that is causing the twitching, tranquilizers, narcotics or anticonvulsants may be used to try to control it, but only if it is bothering the patient.

D. Seizures

Seizures are common in the terminally ill, usually indicating spread of cancer to the brain or changes in the blood as a result of failure of other organs in the body. If the cause is spread of cancer to the brain, the seizures will be treated with medications similar to those used for naturally occurring seizures along with therapy, usually steroids and radiation, directed at the cancer itself. If the seizures are due to problems with other organs in the body, such as the lungs, kidney or liver, therapy will be directed at the exact cause when this is possible. If not, adequate doses of seizure medications are usually effective in achieving control, although it may require doses which tend to cause significant sedation.
E. Headache

Headache is common in the terminally ill patient either related to complications of the terminal illness or part of a pre-existing condition which the patient may have suffered for years. If it is part of an old problem, the patient can probably tell caregivers what has given relief in the past -- a good clue as to what is still likely to be effective. When headaches are new and the patient has cancer, spread of cancer to the brain must be considered likely and appropriate tests done to find out if metastases are present unless death is imminent.

If it is decided not to actively pursue the cause of headaches, it is important that the patient decide how aggressively he or she wants them treated, for there is a great variation in desires. Some patients do not find the headache particularly distressful and would prefer not to experience the sedation or mental disorientation caused by increased dosages of narcotics. For others, headaches are extremely distressful and require increased doses of narcotics even to the point of producing near total sedation. When pain requires increased narcotics for relief, attempts to reduce the pressure within the skull are usually employed. Most commonly, this involves use of radiation to the brain, but before this is done, doctors are likely to attempt to lessen pressure within the skull by using large doses of steroids, most commonly with the drug Decadron.

6.05 Conditions of the Skin

Three diverse skin problems are especially troublesome in the terminally ill -- itching, bedsores, and odors. In addition, many common skin conditions occur with increased frequency in terminally ill patients, among them, skin allergies from the use of multiple drugs and Herpes Zoster (Shingles), along with multiple skin conditions which are peculiar to AIDS.

A. Itching

Itching may be caused by specific terminal illnesses like lymphomas (cancers of the lymph glands and organs [spleen]) and diseases of the liver. It is also frequently due to drug allergies, including local reactions to medications applied directly to the skin. Because their skin is constantly in contact with sheets, patients who are bed-bound are also prone to develop reactions to chemicals used in cleaning of bed cloths and to dry skin in general. Frequent use of antibiotics may lead to fungus infection of the skin (monilia), especially in patients who also suffer from diabetes.

Treatment of itching in the terminally ill naturally is highly dependent on the cause. When narcotics cause the skin allergy, substitution of a different narcotic may be helpful in eliminating the itching, as may the discontinuation of other drugs causing the skin reaction. Moistening agents such as Eucerin may be helpful when the cause of itching is dry skin, while substitution for products which had been applied to the skin may reverse associated itching. At one time low-phosphate detergents used in the cleansing of sheets were particularly prone to cause itching, but they are seldom used today. Still, using a neutral soap instead of other cleaning agents for bed clothes may be helpful in the treatment of itching, as may
substitution of cotton bedclothes and pajamas for other materials.

If itching is caused by liver disease, a specific medication, cholestyramine, is likely to be helpful. Otherwise, various drugs may be tried, including antihistamines and both the minor and major tranquilizers. When simpler medications are not successful, cortisone-like steroids are likely to be effective, both when applied locally to the skin and when taken by pill.

[Note: be sure to keep nails trimmed to reduce the harmful effect of scratching itself.]

B. Bedsores

When patients lie in bed for a long time without getting up and around it is common for those areas of the skin which bear the body’s weight on the bedsheets to undergo changes which cause a breakdown of the skin. This is particularly likely to happen when there is reduced movement of the body, as most commonly occurs in patients who have neurological diseases of the brain or spinal cord, including strokes, multiple sclerosis, Alzheimer’s disease, Lou Gehrig’s Disease (amyotrophic lateral sclerosis) or secondary to trauma. When these changes occur, the covering skin is actually lost producing what is referred to as a "superficial ulcer" or "bedsore" in which either muscle or bone can be seen at its base. Because there is no skin to keep out bacteria, these superficial ulcers are always infected and are particularly dangerous because they allow bacteria access directly to the blood stream in a way normally prevented by the skin.

Unlike itching, which is primarily an annoyance, bedsores are both dangerous and a difficult medical problem which can severely limit the patients quality of life through the terminal phase of an illness. That is why it is so important to try to prevent bedsores in situations in which they can be expected to develop. Foremost among the preventive measures that need to be taken are (a) frequently changing the position of a patient who spends a great deal of time in bed, (b) making sure the bed remains dry because wetness encourages skin breakdown, (c) increased time sitting instead of lying, (d) careful choice of an appropriate mattress and covering (air mattress with lamb’s wool covering, for instance) and (e) maintenance of nutrition through earlier stages of the disease process.

Much preventive effort has gone into developing methods to reduce pressure points, such as the use of special cushioned fabrics to place under the body and the use of water beds or air mattresses to spread the weight more evenly. Early treatment of skin breakdown with various anti-infectious creams is standard therapy, as is early removal of dead tissue (debridement) from bedsores when they develop. Not infrequently, the use of oral antibiotics or antibiotics by injection is also required.

C. Edema

Although not truly a disease of the skin, edema is a condition which often makes its initial appearance as swelling of the skin of the lowest part of the body, the legs or buttocks, depending on whether the patient is in a somewhat upright position or lying flat in bed. For the most part, edema of the skin which results
from excess body water is not a significant medical problem in itself, but it does suggest the likelihood of other possible complications, such as water in the lungs and/or brain. In the absence of other water accumulations, edema need not be treated aggressively, but its presence in the lungs and brain are more serious and require aggressive therapy.

When edema occurs in the terminally ill patient, it is frequently related to heart, kidney or liver failure, but it may just be part of the general process of dying related to poor nutrition and failing circulation. Treatment is usually quite successful and involves the use of specific drugs (diuretics) most commonly, furosemide (Lasix). At times when a specific cause is found, other methods of therapy may be tried, but if the patient is in the final stages of disease, treatment with diuretics is usually the only drug therapy undertaken.

Other than drugs, use of elastic stockings may limit the amount of swelling which occurs in the legs, along with efforts to keep the legs from constantly being positioned below the rest of the body. To the contrary, when water accumulates in the lungs causing shortness of breath or in the brain causing lethargy, placing a lying patient in the sitting position and lowering the legs is often helpful in relieving the symptoms --better the water be in the legs than in the lungs or brain. [Note: Care should be taken when using elastic stockings or similar mechanical devices that they be applied evenly so as to avoid a tourniquet-like effect which traps water below.]

Most families have a natural tendency to limit salt in patients who have edema. Doing so is theoretically helpful and at times may be appropriate, but doing so is often not necessary when diuretics are being given and may restrict one of the last remnants of the patient’s quality of life -- the ability to enjoy eating.

**D. Odors**

Odor is frequently due to skin problems such as intertrigo, a skin infection primarily involving skin folds under the arm, in the groin, and under the breasts. Treatment usually requires the use of creams or ointments with antibiotics and anti-fungal agents, often with the addition of a steroid to decrease local irritation. Bedsores are a frequent cause of odors as well, and should be treated as noted above. A third common cause of odor in the terminally ill involves patients who have had to have a surgical procedure on the bowel, commonly referred to as an "ostomy," resulting in stool collection in a bag. Surprisingly, the resultant odor is often quite treatable by adding certain chemicals to the bag, including charcoal, aspirin, or a drug named Nilodor. Others have suggested that intake of cranberry juice may prevent the odor.

When other methods fail, room deodorizers may be helpful, the odor from infected bedsores or other wounds may be decreased by applying yogurt, or Oil of Wintergreen may be helpful when thinly spread on bedsheets.

**6.06 Bladder Problems**
Problems of urination are common in the terminally ill, especially in the last few days of life related to the patient’s general debility. Earlier in the course bladder problems are more likely to be related to infections or obstruction, especially after medical procedures which require passing a tube or instrument into the bladder.

Infection is typically associated with frequent urination, pain on urination, difficulty in controlling urination and odor of the urine. When these symptoms are noted, evaluation of the urine under a microscope will make the diagnosis and an appropriate medication can be given. Less commonly, these symptoms do not occur and the only symptoms are abdominal pain, fever, or rapidly increasing debility. In these situations, unfortunately, there is a frequent delay in looking at the urine and making a correct diagnosis so proper treatment is delayed.

Late in the course of the disease, men are particularly likely to develop symptoms of urinary obstruction causing pain low in the abdomen, difficulty passing the urine and a very weak urinary stream. In this situation it is common for the patient to continually pass very small quantities of urine without any apparent control, in which case a quick medical examination by a physician will easily reveal the enlarged bladder. It may also reveal a very large mass of stool in the rectum (fecal impaction) which can also be a cause for difficulty urinating. If there is hard stool, it needs to be removed by enemas or manually. If there is urinary obstruction, placement of a catheter in the bladder is likely to be required. Because "urinary retention," as it is called, frequently occurs at a time when life is very short, in most cases no effort is made to remove the catheter until death ensues.

In women the most common urinary problem in the days before death is incontinence (an almost constant release of urine) although they, too, may be unable to pass urine with the development of a large bladder and pain in the abdomen. As in the men, when either incontinence or obstruction occurs in the very end stages of disease, placement of a permanent catheter in the bladder is common, although at times use of one of the new protection garments to soak up the urine in women with incontinence is sufficient and may avoid the problems associated with the permanent placement of a catheter.

6.07 Weakness and Other General Symptoms

Almost all patients complain of weakness at some time in the dying process. Although the emotional effects of existential suffering are likely to be difficult to separate from physical causes, when this complaint occurs early in the disease process, one commonly finds a specific cause which can be rectified. As death approaches, however, weakness is likely to be more related to the underlying disease or a combination of irreversible factors than any single treatable problem.

Common causes of weakness in the terminally ill patient are poor nutrition, dehydration, anemia, pain or pain therapy, fever, postsurgery effects, chemotherapy, radiotherapy, prolonged bed rest, and changes in the blood, such as low potassium, sodium, and/or magnesium or high calcium. Specific therapy for weakness depends on the cause, but late in the course of the disease efforts to reverse the weakness may cause greater suffering than the weakness itself, i.e., attempts at forced feeding or artificial hydration.
may be just as likely to cause suffering as to reverse the weakness. When physical therapy is applied in
an attempt to reduce weakness or limitation of motion, it should be aimed more at keeping the condition
stable than rehabilitation, an unattainable goal in the later stages of disease.

If it is decided that no specific intervention is warranted, it is important for families to understand why
that decision has been made, for they are frequently as distressed or even more distressed than the patient
about the weakness. This discussion should, of course, take place outside the hearing of the patient, and
the family should be advised not to stress it in the patient’s presence, as the patient is already likely to
view it as a prelude to helplessness, dependency, and impending death.

Closely related to weakness is fatigue, a common complaint which can be characterized as exhaustion of
physical, emotional, spiritual, financial, familial, communal, or other resources. Other typical symptoms
occurring in terminal illness include tiredness, loss of appetite, weight loss, general aches and pains, as
well as psychiatric symptoms, such as depression.

As with weakness, the decision to attempt therapy of these symptoms should be preceded by an
understanding of the goals of treatment for the individual patient independent of the desires of the friends
and family. Agents which may increase activity may also increase agitation. Drugs which increase
wakefulness may interfere with the patient’s desire to sleep through suffering. And attempts at reversing
weight loss may only serve to increase discomfort.

Blood transfusions are usually inappropriate in an attempt to reverse anemia unless a specific goal, such
as remaining alert enough to converse with a specific important person, may be met by such support. As
disability increases, assistance offered to the patient should be limited so as not to overwhelm the patient
with his or her loss of physical independence.

It is natural for families to consider nutrition an important part of improved life expectancy and quality of
life, but very good controlled studies have suggested that aggressive nutritional therapy in cancer patients
has no impact on tumor response to therapy, its effect on quality of life or survival. Contrary to the
thoughts of families, many physicians believe that increasing nutrition actually enhances tumor growth
more than maintaining normal tissue and may therefore be counter productive. While the author has often
used this suggestion when families seemed overly concerned with forcing foods on patients who no
longer desired to eat, he admits this belief is unproven, but continues to believe it is at least as reasonable
as the belief that forced feeding is beneficial.

In order to improve appetite and nutrition, patients are frequently given appetite stimulants. Steroids may
have a significant appetite-stimulating effect that is accompanied by increased oral intake, but their effect
appears to be short in duration and is not accompanied by any significant change in nutritional status.
Occasionally, female hormones will have a beneficial effects on appetite, food intake, and overall
nutritional status, especially if they are also found to decrease nausea in the particular patient. It is
questionable, however, how much is gained when it is not intended to produce other beneficial effects,
such as relief of nausea. Small quantities of alcohol may be helpful as an appetite stimulant, but it is hard
to verify its effectiveness. Another drug frequently tried in nausea related weight loss is metoclopramide (Reglan), with fair success.

It is the authors considered opinion that use of drugs for the treatment of nutrition in patients who are in the end-stages of their disease should be used primarily for the treatment of specific symptoms, like nausea, and not for nutritional goals. Nausea deserves treatment as an unwanted symptom. If this is helped, the drug should be continued with or without weight gain. Using weight gain as a goal is too likely to be impossible to measure, for increased in poundage is more likely to be related to the weight of the tumor or accumulated water than actual increase in body muscle and fat, for instance.

Going one step further, many families request something even more dramatic be done in the form of placing feeding tubes of various kinds within the patient’s body. This question is addressed at greater length later in this book, but in summary should only be undertaken to achieve a short range goal and not with the hope of improving quality of life or survival in end-stage cancer patients and should be used in other patients only with their knowledge and general approval.
CHAPTER 7. MENTAL SUFFERING IN THE TERMINALLY ILL

7.01 Frequency of True Mental Illness in the Terminally Ill

7.02 Specific Mental Conditions Related to Terminal Illness

A. Anxiety

B. Depression

C. Therapy of Depression
   (i) Drug Therapy
   (ii) Psychiatric Care
   (iii) Family Care

7.03 Existential Suffering

A. Definition

B. Factors in Existential Suffering

C. Applicability of Medical Treatment to Existential Suffering

7.04 Specific Fears

A. Pain

B. Death

C. Physical Symptoms Other Than Pain

D. Being a Burden on Others

E. Family Desertion

F. Abandonment by Physicians

G. Loss of Standing or Status Within One’s Profession, Family, and/or
Community

H. Losing Mental Ability

I. Narcotic Addiction

J. Loss of Dignity During the Process of Dying

K. Being, Or Being Considered, A Worthless Individual

7.05 Other Causes of Existential Suffering

A. Inability to Obtain, Evaluate and Use Information

B. Loss of Ability to Control One,s Bodily Functions/Loss of Dignity

C. Loss of Ability to Maintain Access to One,s Family or Society

D. Loss of Ability to Control People Formerly Controlled by the Patient

E. Hopelessness

7.06 Stressing Past Accomplishments

7.07 Helping Establish Closure

7.08 Helping Patient with Unfinished Family Business

7.09 Being There

7.10 On Showing Compassion

7.11 Choosing Appropriate Caregivers to Question the Patient

7.12 Working Through Problems/The Physician,s Role

7.13 Specific Suggestions

A. Maintaining Appearance
Treatment of Pain and Suffering in the Terminally Ill - Chapter 7

B. Helping Maintain Function

C. Adding Meaningfullness to Life

D. Stressing Pleasure

E. Honoring Privacy

7.01 Frequency of True Mental Illness in the Terminally Ill

Mental problems are normally differentiated as being psychotic, neurotic, or based on a personality disorder. Terminally ill patients may manifest these same types of psychiatric disorders, either as a residuary from the past or as a result of stresses related to the terminal illness, but the very presence of the illness and its overwhelming effect on the patient,s mentation makes it much more difficult to determine the presence of a co-existent mental disorder. Instead, we tend to look at changes in the thinking of terminally ill patients not in terms of a separate disease process but as the result of the patient,s response to the realities surrounding approaching death. And, because there are such great differences in how patients face death, we accept almost any response as being within the limits of normal and not indicative of a separate psychiatric illness.

When looked at more closely, however, studies conducted primarily on terminally ill patients with cancer suggest that approximately fifty percent also suffer from a separate diagnosable psychiatric illness, but this is of little help to the clinician. For example, patients with associated psychiatric disease are said to be more likely to report severe pain than those who are judged to be free of psychiatric illness, but it is unclear whether they suffer greater pain because they are also mentally ill, or whether they are more likely to show signs of mental illness because they have more severe pain.

The most difficult problem when trying to evaluate mental illness in the terminally ill relates to "depression." Most layman and many physicians, tend to consider "depression" and "unhappiness" to be essentially the same, but most psychiatric practitioners tend to look on them as different. They tend to separate the two by relating "unhappiness" to sad feelings based on a realistic evaluation of one,s situation, while limiting the use of the term "depression" to those situations in which the sad feelings come primarily from within, either unrelated to outside reality or significantly out of proportion to reality. Based on this differential, to determine when sadness qualifies as depression requires a determination of what is the natural degree of sadness one would expect from learning one is shortly going to die -- clearly, a most difficult determination.

Fortunately, trying to make this differential has become less important in recent years with the development of newer anti-depressant medications which, unlike the older drugs, tend to act as mood elevators in patients who are technically "unhappy" as well as those who are "depressed." If, however, we use this broader definition of depression to also include "unhappiness," it is fair to say that close to ninety percent of patients will suffer from a depressed state at some time during their terminal illness.
We should not, however, get caught up in the question of definitions. The exact frequency of mental illness in the terminally ill is unimportant. Of primary importance must be attempts to prevent or minimize its occurrence, by avoiding drugs with unwanted mental side effects when possible, by recognizing drug effects early when they are used, and, most of all, by treating pain aggressively so as to avoid the mental effects which result from living with chronic pain.

In this chapter we will discuss some of the specific mental conditions frequently seen in the terminally ill, stressing in particular those types which stem naturally from having to deal with the reality of approaching death. Such mental suffering is commonly referred to in the medical literature as "existential" in origin because it relates to the end of mortal existence.

7.02 Specific Mental Conditions Related to Terminal Illness

A. Anxiety

Anxiety can be thought of as an inner feelings of tension, apprehension, and/or worry. It commonly causes symptoms such as restlessness, sweating, trembling, overactivity, over awareness of one’s environment, trouble sleeping, frequent distractions, shortness of breath, tingling and numbness, especially in the hands, arms and face. Because symptoms of anxiety can be caused by physical problems common in the terminally ill, these need to be considered and evaluated before it is assumed the symptoms of anxiety are related to a mental condition. Some of the physical problems which are likely to cause symptoms suggestive of anxiety include hypoxia (decreased oxygen in the blood), infection, blood abnormalities, bleeding, drug reactions, and drug withdrawal, especially the withdrawal of pain medications and steroids. In addition, inadequately treated pain or uncontrolled shortness of breath very commonly cause anxiety for which increased narcotics is usually the best and most effective treatment.

Terminally ill patients understandably become anxious as a result of persistent symptoms, the need for constant medical care, the recurrent crises which arise around new symptoms, problems in arranging care, and the uncertainty and fear about the process of dying and how it will be handled. A certain level of anxiety should therefore be expected and the patient given time to work through the realities. Patients who continue to experience high levels of anxiety for weeks or months, however, should be offered the possibility of therapy, either through referral to a psychiatrist, psychologist, psychiatric nurse, or psychiatric social worker, or with the use of anti-anxiety (tranquilizer) drugs.

In many cases, family members can also be very helpful in exploring and relieving many of the patients, concerns, acknowledging the uncertainties of the situation, and reassuring the patient they and the health care team will be there to support them through the end-stages of their disease. When drug therapy is used, it most commonly involves the use of the so-called "minor tranquilizers" of the benzodiazepine family, such as lorazepam (Ativan), alprazolam (Xanax), and oxazepam (Serax). On occasion, when oral medication cannot be tolerated, diazepam (Valium) can be used as a rectal suppository for the control of anxiety, restlessness, and agitation. If simple tranquilizers are not appropriate or helpful, major tranquilizers like haloperidol (Haldol) or anti-depressants [discussed below] may be effective.
B. Depression

Sadness is understandably common in patients who learn they have a terminal disease, making it difficult to determine when medical intervention in the form of psychiatric referrals or drug therapy for depression is indicated. This is also a matter in which individual patients, families and physicians are likely to have great variance of opinions, as many people consider it advisable to "work through" the difficult times associated with impending death, while others take the attitude that when life is short, rapid improvement of mood should be sought without worrying about the working through of problems.

In order to determine when intervention is appropriate, many health care providers try to differentiate minor from major depression, the same as they would in physically healthy individuals, but this often fails in the presence of a newly diagnosed terminal illness. Experience with cancer patients indicates that with the initial diagnosis, patients often respond with either shock and disbelief or with denial of the diagnosis. Subsequently, patients frequently experience sadness or depressed moods along with anxiety, at which time they may be expected to suffer the usual symptoms of anxiety and depression -- changes in appetite and sleep patterns, agitation, loss of interest in daily activities, complaints of tiredness, feelings of guilt, inability to concentrate and recurrent thoughts of death or suicide. Most typically, these symptoms decrease over a period of two to three weeks once the patient is receiving treatment for the underlying disease and/or has adjusted to his or her situation, but may recur at times of increased stress when undergoing therapy or when recurrences of cancer are found.

Such mental reactions to the knowledge of a limited life expectancy are generally viewed as indicating normal adjustment problems under the circumstances and not requiring medical intervention, but when symptoms persists or seem to get worse with time, psychiatric evaluation is often felt to be advisable.

In order to speed up the determination of when psychiatric intervention is indicated, many attempts have been made to separate the normal from the abnormal process in the terminally ill patient. As a result, investigators have determined that while certain symptoms tend to overlap the normal and abnormal, others are particularly likely to be present with an abnormal, true depression. Common symptoms of depression which are likely to be unreliable in the terminally ill include agitation, complaints of fatigue, loss of appetite, sleep disturbances, weight loss, decreased concentration and social withdrawal. In contrast, a prolonged feeling of hopelessness and despair usually suggests abnormal depression, as does a feeling of helplessness, worthlessness, loss of self-esteem and guilt. Likewise, the desire to commit suicide, unlike just thinking about suicide, is likely to be associated with significant degrees of depression even in terminally ill cancer patients.

Other clues may also be helpful in separating normal unhappiness from abnormal depression in the terminally ill. The unhappy patient typically tends to exhibit sadness and grief but there are interrupting moments of more normal feelings and even of pleasure at times depending on the happenings of the moment. In contrast, the truly depressed patient tends to have an all pervasive, unrelenting quality of sadness unchanged by ongoing events. Patients who are truly depressed more frequently give a personal or family history of depression or substance abuse. Finally, potential clues to depression include
complaints of pain or other symptoms which seem excessive to the observer along with a history of poor cooperation with planned treatment plans for the same symptoms.

The delayed thinking processes we normally associate with depression may be particularly troublesome in the terminally ill because this is often a time when important decisions must be made in a timely manner. As a result of the depression, the patient's awareness and reasoning is likely to be influenced by a resultant unrealistic low self-regard, feelings of being deprived and rejection (even in the face of bountiful affection), and a tendency toward self blame with no logical basis. Moreover, patients suffering from depression are not only likely to be delayed in decision-making, their decisions are likely to be systematically biased against interventions of any sort. When seriously or terminally ill and depressed, a patient's reasoning process is thus impaired so as to deny the patient the ability to make well-considered life-and-death decisions. Furthermore, this tendency toward guilt and lack of self-assurance are likely to make the terminally ill patient more vulnerable to the suggestions of others, thereby increasing the potential for abuse.

One added difficulty in evaluation of a terminally ill patient for depression relates to thoughts about suicide. In physically healthy depressed patients, thoughts about suicide are considered indicative of more severe disease, but this may not be true in terminally ill patients since almost all terminally ill patients at least think about suicide at some point in the course of their illness. These thoughts can therefore be considered almost normal, considering the overwhelming sense of hopelessness or helplessness typical of terminal illness. In fact, for some patients consideration of the suicide option may provide a much desired sense of control -- a "way out" if things get too bad. Fortunately, when offered personal support and palliative care, most patients adapt and continue life in ways they might not have anticipated, often finding remaining days more precious as they become less numerous.

Confusing the issue even further are financial consideration which may surreptitiously undermine the patient's thinking about terminal care, often giving a false impression of having given up on life. Reality confirms that death is cost-effective, leading many terminally ill patients to refuse expensive care for themselves in order to avoid a depletion of assets to be left their family after death. Because they realize explaining their reasons for refusing care is likely to upset their families, such patients are likely to mislead the family with false information, often suggesting the refusal is closely related to depression.

C. Therapy of Depression

The following discusses potential therapy for clinical depression among patients who are terminally ill. As indicated above, it is often difficult to differentiate true mental depression from the sadness we associate with the realities of approaching death. The following therapies, although always discussed in terms of depression, may, in fact, be equally effective in helping patients who are justifiably unhappy.

(i) Drug Therapy

Before drug therapy is undertaken for depression in the terminally ill, care must be taken to exclude the
possibility there is a physical cause for the symptoms of depression, such as poor oxygenation of the blood or thyroid problems. In addition, one must be sure the depression is not a reaction to drugs such as steroids, cancer chemotherapeutics, cimetidine (Tagomet), indomethacin (Indocin), and sedatives like phenobarbital.

Patients displaying continued symptoms of despair and depression should probably be given the benefits of at least a trial with anti-depressant medication. In the past, the most commonly used antidepressants were from the group referred to as "tricyclics," including amitriptyline (Elavil), imipramine (Tofranil), trazodone (Desyrel) and doxepin (Adapin, Sinequan) among others. More recently, patients have generally been given drugs from a class referred to as "SSRIs," such as fluoxetine (Prozac), sertraline (Zoloft), paroxetine (Paxil), and bupropion (Wellbutrin-a slightly different class of drugs) which have the advantage of acting more quickly with fewer side effects and perhaps greater effect in patients who would be more properly classified as unhappy than depressed. On occasion, drugs which primarily stimulate the body may be effective. These drugs include dextroamphetamine (Dexedrine), methylphenidate (Ritalin), and pemoline (Cyclert). A third group of anti-depressants, the MAO-inhibitors, should not be used in patients receiving narcotics and are therefore seldom used in the setting of terminal illness, although they may be effective in certain specific situations.

Although it is often hard to determine the effectiveness of antidepressant therapy in terminally ill patients, it has been stated that marked improvement is likely to occur in approximately one-quarter of users.

(ii) Psychiatric Care

Although psychiatric referral is frequently undertaken in terminally ill patients, time factors and general debility of the patient usually tend to a preference for at least a trial of drug therapy first. To the extent sadness relates to the realities of the dying process, the most effective psychotherapy is generally thought to be time -- not the passage of time, but time given by the psychiatric team to the patient and family to help them deal with the emotional and spiritual aspects of their impending loss.

When the patient is preparing to die, there usually comes a time when the patient wants to forget the struggle to live a few extra days to concentrate on emotional problems inherent in death. At these times, providers trained in psychotherapeutic techniques can be most helpful. Members of the health professions as well as families should be aware of this particular stage undergone by most terminally ill patients, and should also try to help the patient deal with the discrepancies and conflicts which can exist between the patient and the rest of the world. Physicians and families should realize these types of distress are a necessary and beneficial part of the dying process if the patient is to die in a state of ultimate acceptance and peace. Most patients who work through their anguish and anxieties are able ultimately to achieve a state of passive resignation. In addition, when the process is understood, it can be of great comfort to families, sparing them unnecessary anguish.
(iii) Family Care

Initial sadness in the terminally ill usually stems from realities closely aligned to the situation itself -- the need to endure pain and disfigurement, the costs, the loss of financial income, etc. This type of sadness should usually be addressed by the family in a reassuring manner, by trying to get the patient to look at the brighter side of life, and offering what reasonable hope can be given without making false promises that all will be well.

As time goes on another type of sadness develops in most patients which is not related to immediate changes but is more an anticipation of what is to come as the patient prepares a final separation from the world. The patient is in the process of losing everything and everyone he or she loves, and it is only natural such a threat should evoke sadness. At this time, quiet reassurance of love and an intention to remain available to help becomes the most important aspect of therapy.

7.03 Existential Suffering

A. Definition

The term "existential suffering" is a relatively new term being used extensively in both medical and psychiatric articles to indicate a form of mental suffering which is now considered to be both normal and treatable. In its simplest terms, it refers to the suffering which the terminally ill individual experiences when faced with the reality that his or her existence in this world is about to end. A famous scholar on these issues, E.J. Cassell, defined "existential suffering" as "involving a perceived threat to the integrity of the self, helplessness in the face of that threat, and exhaustion of psychosocial and personal resources for coping." Surprisingly, even though this definition seems more complicated than one would like, other authors continually refer back to Cassell's definition, which does seem to encompass the basic factors involved -- (1) the realization the self is about to end as an entity, (2) the inability to avoid this loss of the individual self, and (3) the inability of many to accept that one can no longer control one's own existence. Among those feelings expressed by terminally ill patients which are commonly included as part of existential suffering are hopelessness, futility, meaninglessness, disappointment, remorse, death anxiety, and disruption of personal identity.

Existential suffering is particularly important in the context of this book because it not only leads to
suffering in the patient, but is also a frequent cause of frustration in the family. As the patient’s suffering becomes increasingly evident, family members tend to look to health professionals for help, which is often not forthcoming. At this point, the resultant frustration in watching a loved one suffer leads to a tendency to blame the medical profession for its failures to meet the needs of their dying loved one, which then leads to increased anger and frustration. To avoid the disruption of patient care which is likely to result, certain truths need to be accepted, even if they are difficult for most families to accept.

First, existential suffering is normal and need not be totally controlled. In fact, over control can lead to increased suffering if the patient is not allowed to work through his or her problems related to death.

Second, there is no effective drug therapy for existential suffering. Because it frequently occurs with and is made worse by pain, physical symptoms, anxiety, and depression, adequate treatment of these attendant symptoms may greatly decrease the level of suffering, but will not remove the realities each individual must face.

Third, recognition that the patient’s existential suffering also causes suffering and frustration in health care providers as well as the family is essential in working together in trying to help the patient cope with his or her reality.

Fourth, recognition of the factors that add to the patient’s suffering is often helpful in planning an appropriate approach to fulfillment of the patient’s needs.

Fifth, most means of relieving patient suffering are equally valid for family and health care providers. Rarely are the means of helping solely within the sphere of medical expertise, although the authority of the physician may be of particular importance in lending credibility to reassurances offered the patient.

Sixth, when dealing with existential suffering, one needs to recognize the difference between fears of the dying process and fears related to being dead. As caregivers, we must determine which of these fears is actually being expressed by the patient in order to be effective in diminishing the patient’s suffering. While the position of professional caregivers tends to give them credibility when discussing the dying process, it does not give them expertise regarding what it is like for the individual after death occurs.

**B. Factors in Existential Suffering**

Among the causes of existential suffering, fear is certainly a major, if not the major, contributor. Fear of pain. Fear of physical distress and suffering. Fear of becoming a burden to others. Fear of family desertion. Fear of abandonment by physicians. Fear of losing one’s standing or status within one’s profession, one’s family, or one’s community. Fear of losing one’s mental function. Fear of becoming addicted to narcotics. Fear of losing one’s dignity in the process of dying. Fear of being, or of being considered, a worthless individual. And fear of death itself.

Outside of fear, many consider the leading contributor to existential suffering to be loss of personal
control. Loss of the ability to obtain, evaluate and use information. Loss of the ability to express choices among options and to see they are followed. Loss of the ability to control one's body in such a way as to preserve one's own dignity. Loss of privacy. Loss of the ability to maintain access to one's family or society. Loss of the ability to control the people who formerly fell under the patient's control.

Another major contributor to existential distress involves the reality that time is short and one's accomplishments in life are about over. This leads to a natural tendency to try to catalogue one's success and failures in life and, inevitably, to the need to accept one's failures -- financial, occupational, societal, and interpersonal.

C. Applicability of Medical Treatment to Existential Suffering

It is much easier for health providers to treat physical or even mental symptoms than to help a person hold together when everything in life seems to be falling apart -- to help maintain or restore a person's self when faced with irreversible illness and the approaching loss of "self" as thought of among the living. To achieve this latter goal requires supreme efforts on the part of all those involved in caring for the terminally ill patient and the ability to overcome one's own feelings of suffering and frustration when dealing with the dying patient.

When healthy people think of death, they typically think in terms of what it will be like after they die. Some think in terms of heaven and hell, others of nothingness, but their thoughts typically involve the absence of life and not the dying process itself. In contrast, studies have shown that when terminally ill patients think about death, they predominately think about the dying process itself. Fears are likely to revolve more around pain, physical suffering, loss of dignity and control, abandonment at the end of life, etc. than what it will be like to be dead.

What then can we do? We can begin by trying to understand the patient's individual concerns apart from our own, or what we assume our own concerns would be, for they are likely to be very different. The big need is taking the time and being an active listener, for once the concerns are identified, the potential solutions, if they exist, are usually readily apparent. Just as important, when there are no solutions, this is also readily apparent, a great benefit for the caregiver who may now be able to escape the guilt felt when unable to relieve a loved one's suffering.

The rest of this chapter considers the various factors discussed and what can be done once those playing a part in the individual's existential suffering have been identified.

7.04 Specific Fears

A. Pain

Fear of pain is perhaps the most universal factor causing existential distress in the terminally ill patient, even more than pain itself. Such patients need to be reassured pain will be controlled even to the end of
their life. This is primarily the role of the physician, but the family also has a critical role, to

(a) point out to the physician the need to reassure the patient initially and whenever the fear is expressed by the patient, even if this is frequent and suggests lack of trust in what has previously been said,

(b) learn the basic principles of pain management and accept that relief of pain is even more important than prolonging life, and

(c) reassure the patient the family and the involved physicians have agreed to honor the patient's wishes regarding pain management in the future.

Remember, although physicians recognize that reassurance is part of their role and expect the issue to be raised, they may be reluctant to be the one to raise the issue for fear of producing more concern on the part of the patient. Remember also that the best time for the patient or family to raise the issue may not be the best time for the physician. The physician asking the patient "what are your thoughts about what the end will be like?" or "what are your fears about how the end will be like?" is likely to lead to a time-consuming discussion which should only be initiated by a physician who has time to respond at length. If initiated by the family at a time when the physician does not have time to follow through on the resultant discussion, it is only likely to lead to increased anxiety for the patient.

Fortunately, because of the major advances in treating the pain of terminal illness, given the necessary time, a knowledgeable physician will almost always be able to honestly reassure the patient his or her fears about pain are unjustified. Simple reassurance from a physician with a statement like: "My job is to make sure you remain comfortable and will not have to suffer bad pain," has been repeatedly shown to be remarkably effective in relieving this fear in both patients and families, although repetition is frequently required.

At times, however, even with repetition, patients fail to accept reassurances about pain, often expressing their continued anxiety by claiming they had heard of a case when pain, shortness of breath, or some similar condition went unrelieved at the end. When this happens, physicians must be prepared to take the time to convince the patient this will not be the case. Physicians know such stories are almost always the result of misunderstanding, that they lack some important details, but arguing about the story is seldom productive. Instead, it is usually wiser for the physician to admit failure to control symptoms with traditional therapy can occur, but even when specific symptoms may escape control, there are means to control the overall situation by giving enough medication to induce a kind of continuous dream sleep which makes the patient unaware of the symptom.

If family or friends are aware the patient intends to challenge the physician with a story of unrelieved pain, it is wise to warn the physician. When this is done, the physician and the family can discuss the possibility of terminal sedation [discussed later in this book] in those rare instances when traditional therapy is ineffective in controlling symptoms before taking this discussion to the patient. Having this chance to discuss terminal sedation with the family first makes it easier to reassure the patient knowing
there will not be later disagreements with the family if it needs to be instituted. Then, discussing it with the patient can produce a three way agreement of what can and will be done at the end if required, thus avoiding the later appearance that terminal sedation amounts to abandonment.

Having given the patient reassurances about pain relief in end-stage disease, it becomes imperative for the health care team to react quickly to relieve symptoms which do arise to insure credibility be maintained. For this reason, many palliative care specialists recommend overtreatment of pain at the beginning even if it produces sedation which requires subsequent lowering of dosage just to impress the patient with the physician,s ability to control pain when required.

At the same time, such reassurances can be undermined by anything which causes the physician,s loss of credibility. To prevent this from happening, families should make efforts to keep health care providers aware of new or increasing pain so appropriate pain therapy can be planned and undertaken in a timely manner, while physicians need to show interim pain can be controlled if the patient so chooses. Patients may choose to suffer some pain in order to remain more alert, but when more pain relief is requested, it should be given quickly to retain confidence in the patient/physician relationship.

Families must also act to maintain the physician,s credibility by not making disparaging remarks about health care providers in front of the patient. Telling the patient the physician has not returned four phone calls about the potential need for vitamin supplements will only lead the patient to worry later phone calls requesting pain relief will also go unreturned.

[Note: To maintain credibility, both families and physicians need to continue to recognize that many patients who appear to be in coma are not. Although their eyes are closed, they can hear what is being said. This may allow thoughts to purposely be expressed to comfort the patient, but unless carefully orchestrated, is more likely to lead to overheard conversations which should have been held in private.]

B. Death

We all think at times throughout our life of what it will be like to be dead. For some, faith in an afterlife is very reassuring, but for most of us, even those who consider themselves religious, there remains fear of the unknown and nothing is as unknown as what it is like after death.

One of the major causes of existential suffering is the inability to escape these thoughts. When we are healthy, we normally think periodically about death only to dismiss the thoughts for later consideration. This becomes ever more difficult to do when the time remaining is clearly running out. When one is dying, it is hard to repress thoughts about what lies ahead.

For caregivers, fears related to being dead are particularly difficult to relieve. Unlike the process of dying, where much is known and we can speak reassuringly about symptom relief without losing credibility, the fact that no one has verified knowledge regarding life after death denies the credibility needed for patient reassurance. Accepting the reality of death is a lonely battle for each individual. One
that may be helped by skilled intervention by pastoral care or gifted counselors, but one fraught with difficulty when undertaken by physicians or family members.

C. Physical Symptoms Other Than Pain

Fear of physical distress from symptoms other than pain, such as nausea and shortness of breath, require similar reassurance from physicians that relief will be available if and when it is needed. Again, to maintain credibility, palliative care must be initiated promptly when symptoms do occur. In these situations, as well as in therapy for pain, terminal sedation may also be suggested as an alternative if required.

At times patients with great fear of discomfort in the end stages of their disease will raise the question of physician assisted suicide. If families are aware that this may be mentioned or is being considered by the patient, they should tell the attending physician and discuss his or her thoughts on how to aid the patient if required through the end stage of disease. Some of the alternatives are discussed later in this book. If the patient truly wants to control the end of his or her life, the possibility of voluntarily stopping food and fluid intake can be discussed with the patient after the family and physician agree to accept the patient's desire to do so. Frequently, an explanation of how the concept of "double-effect therapy" legalizes relief of symptoms can be reassuring to the patient who fears legislation limiting assisted suicide limits the ability of the physician to relieve symptoms. This may also be a time for discussion of the possible use of terminal sedation if required for terminal symptomatic relief.

D. Being a Burden on Others

Many patients refuse help from family and friends wanting, and claiming, to be independent. This is fine and should be encouraged as long as the patient is capable, but at some point in the course of most terminal illnesses, this capacity is lost. When this occurs, remember the fear of burdening others often relates to not feeling worthy of other people's time and efforts, even though in reality it is often the people who have done the most for others who feel the least worthy and vice versa. Do not assume the patient who has been giving all their life understands they are due help now. Instead, remind them it is a privilege to return some of the aid they have given you and others in the past.

When a patient expresses concern about being a burden on others it is important to respond in such a way as to minimize the reality -- but do not deny it. More importantly, as previously mentioned, point out that responsibility can be a privilege when it relates to someone you love or to whom you owe a great deal. A chance to pay back what is owed for all they have done in the past. "You fed me when I was young and again whenever I was sick. This gives me a chance to pay you back. It is a privilege, not a burden." "You were there for me and my children when we needed you. Now I can be there for you. I consider it a privilege, not a burden." "We've worked it out Mom. I'm going to do A, Michael will do B, the kids will do C, and Bob and Louise are coming to stay for a few days the first of next month to give us a little break. We're all happy to work together to help you in your time of need. You were always there for us." "Don't worry Dad. If it gets to be a little too much for us we can always get an aide to help, but right now
we don't think that will be necessary. We want to do it ourselves. It's a privilege, not a burden."

During such a discussion it is also wise to discuss certain parameters, certain limits on what can and what cannot be done for them. Like certain hours in the week when the caregiver cannot be available for other reasons or certain services that cannot be considered for financial reasons.

During such discussions, be prepared for the patient to raise the question of physician assisted suicide for the desire not to be a burden physically or financially is one of the most common concerns leading patients to consider ending their life. If the patient mentions suicide, listen closely for a discussion of the patient's reasoning, for it may give clues to other concerns of the patient over and above the question of burdens or worthiness.

E. Family Desertion

Families must constantly remind themselves that patients are likely to be much more concerned about how they will die than about what it will be like to be dead. A major fear of many terminally ill patients is that they will die alone, deserted by family and friends. Failure to address this fear when it exists leaves the patient in a precarious position. Afraid that complaining will be seen as being an ungrateful patient and drive their family away, they fail to complain about symptoms that should be relayed to health professionals for evaluation and therapy. Afraid they will be too demanding, they bear discomfort which can often be ameliorated by simple turning or by use of a bedpan. Afraid any previous love shown was only there for what the family could get in return and not out of true love, they strive to find new ways to continue to give to family members as a means of "buying" reassurance they will not be deserted. Afraid that it is not in the nature of their family to cope with someone who is ill, they fear and fight short-term hospitalization or placement in a nursing home out of fear no one will ever come to take them home.

Unfortunately, at times physicians are aware these fears are justified, making reassurances to the patient difficult. At other times, patients are so overly demanding, even truly caring family members believe the patients should do more for themselves. And at times, the truth is the patient was not there or was unable to be there for the family in the past making the family justifiably resistant to giving as much as is requested --not feeling that giving back is a privilege.

Some patients have been overly controlling in their family relationships and fear revenge will play a major part in how they will be cared for in their final days, a feeling which may or may not be justified. Some families realistically lack appropriate caregivers, or members who are available, or those who care enough about the patient to make the often extensive efforts required to aid in the process of terminal care.

In dealing with patients who express or suggest anxiety about family desertion it is important for the potential health care team -- family, friends and health care providers -- to come up with an overall plan to present to the patient instead of doing it piecemeal. Frequently, discussion with the patient will allow a determination of when the patient feels comfortable caring for himself or herself in the absence of active
care by others or to a realization and acceptance by the patient the time has come to arrange for a paid aide to cover periods when family and friends are not available or need respite relief. In contrast, if the patient doesn’t know what to expect, he or she is likely to consider any failure of the family to do what the patient desires to be an early sign of desertion.

In addition, while developing a strategy for home care, it is important to define when hospitalization, nursing home care, or hospice care may become a more desirable option. This is best done in consultation with physicians and, when finalized, conveyed to the patient so if and when the future hospitalization or admission to a nursing home materializes, it will not be taken by the patient as a sign of abandonment.

In developing a plan, honesty is essential. A person who must run from the site of blood may be limited in the roles he or she can undertake in the scheme of care, but certainly should still take part in the overall plan. A person with lots of family commitments or who lives at a distance may not be as active an everyday participant, but can make the most of visits if they are planned ahead of time and are accompanied by a bright appearance. On occasions, such infrequent visitors should be given the task of asking directed questions, for they are often better positioned to ask about the patient’s concerns than those who are direct caregivers, for they may not be as threatening to the patient who is worried about family desertion.

F. Abandonment by Physicians

Just as terminally ill patients fear family desertion, they also fear abandonment by "their doctor." Limiting this fear is likely to require not only the loyalty of the physician, but understanding on the part of the patient and family as to some of the realities of medical care.

First, physicians practice medicine as an occupation. Because present reimbursement policies frequently deny payment to two physicians of similar sub-specialties at the same time and because most terminally ill patients are being followed by a true specialist as well as a primary physician, the primary physician is often in a position in which he or she cannot bill for time spent with the patient.

Second, physicians often become the patient’s "closest friend" at the end of life -- the person with whom they share their innermost concerns. In a way this is to be encouraged, for the physicians is often best situated to lead the health care team and develop strategies to meet the patient’s needs, but it also places a major emotional burden on physicians who may be following many dying patients at the same time and who are repeatedly forced to suffer with "close friends" far in excess of others in society. For their own protection, especially at times when they are hurting emotionally for other reasons, physicians are likely to purposely avoid repeated serious conversation of emotional problems with certain patients. During these periods, they are likely to concentrate instead on strictly mechanical problems, such as changing drug dosages or the contents of fluids to be administered to the patient.

Third, specialists who care medically for terminally ill patients under present health care systems frequently lack the knowledge of the patient’s personality and the existing family structure required to
deal with their existential problems. In such situations, physicians are likely to resent -- and therefore avoid -- being asked to deal with existential problems which can be handled just as well or better by family members. When this happens, the family may feel annoyed, but any annoyance toward the doctor for not undertaking a suggested action or not offering to intercede in dealing with an existential problem should not be communicated to the patient in order to avoid the misperception that the physician is in fact abandoning the patient. Such non-medical problems should be handled by caregivers other than the physician, as others are at least as well positioned to know and deal with these issues as is the physician(s).

Fourth, at times, physician will want to talk privately with the patient or with only a single, trusted family member being present. If the conversation is with the patient alone, it occurs within the patient/physician zone of privacy, meaning the physician may not be able to further discuss this conversation with the family even if he or she would want to do so unless the patient specifically agrees to such a further conversation with the family. If there is only one family member present, it generally becomes his or her duty to discuss what was said with other family members, although such further conversations may be limited by the patient,s expressed wishes during the initial conversation.

Fifth, at times physicians will want to talk separately with family members without knowledge of the patient, but this should be limited, for subsequent awareness of such discussions is likely to threaten the patient,s confidence in the patient-physician relationship. [Such meetings are likely to suggest either a breach of confidentiality or a conspiracy to the patient.]

Sixth, there are many parts of patient care which only a physician can or should handle, like ordering tests, interpreting test results, developing a diagnostic or therapeutic approach to a problem, discussing and arranging the undertaking of a new therapeutic approach, and keeping the family aware of what is happening with the patient. Because these tasks fall almost exclusively on physicians, they have a tendency to look on these aspects of care as their responsibility, while expecting other caregivers to handle those aspects which can be handled by more than one member of the health care team. An important aspect of this split in responsibilities involves physician/family communications. The physician,s role requires him or her to explain to the patient and/or family what is happening and what therapeutic plan is suggested, but this requirement is only for one telling -- not to each family member individually.

An important method to deal with the last three issues is for the patient and family to agree upon a representative to act as spokesman for the family to receive communications from providers on one side and concerned family and friends on the other. Concerns of family and friends can thus be limited and prioritized for discussion with health care providers and the providers, information can be limited to a single discussion, saving time and limiting the chances for none agreement over what was said.

Obviously, there are times when the physicians is likely to want to talk to various family members or to all at once, but when time is limited and decisions relatively unimportant, limiting the discussion to a single spokesperson leads to efficiency, making the interaction much more pleasant for the physician. [Remember, physicians are human. They are more likely to choose to spend more time in pleasant
interactions than in situations which are likely to prove unpleasant or confrontational.\[Note: The author remembers his first chief resident during his internship explaining how he forces a large family to choose a representative for him to speak to. "I just go out of the intensive care unit, face all the people sitting around in the waiting room, and ask for the family member responsible for the patient,s bill to step up to speak with me." There should be a better method of choice, but I do think the choice of a representative is important, especially when dealing with the multiple issues which are likely to be involved when dealing with a prolonged term terminal illness. Witness the movement toward suggesting that patient appoint health care agents.\]

G. Loss of Standing or Status Within One,s Profession, Family, and/or Community

Terminal patients fear the loss of relevance in the world. Even though they are troubled by their own problems, family and friends should continue to seek out the patient,s advice about issues with which they have traditionally been involved in the past. Being asked for advice supports the patient,s belief they are still relevant to the family and is not likely to be considered a burden, just as asking them to do things within their continued ability is likely to improve relationships, not make them worse.

As part of maintaining this self-worth, terminally ill patients should be encouraged to continue their work and their relations with family and community to the extent desired as long as the patient expresses a desire to do so. Although this may require greater effort than taking over previous duties of the patient at work, maintaining the patient,s involvement is likely to help avoid the existential suffering associated with faltering abilities. At the same time, enabling the patient,s continued involvement with family and community will help reduce existential suffering by maintaining the patient,s self-worth and feelings of self-control in life.

In addition, family efforts to help maintain the patient,s status in family and society is likely to be seen by the patient as a sign of appreciation of the patient,s previously established role, thus fortifying positive feelings about the patient,s achievements in these fields during earlier stages of life.

H. Losing Mental Ability

Many people are extremely fearful of losing their own mental ability. One cannot be totally reassuring this will not happen, because depressed mental function is almost the norm at the very end of life.
Nevertheless, it is fair to say that most patients with cancer, for instance, only lose mental function during the very last few days of life unless they have tumor in the brain itself. This is also true of most other terminal illnesses, except those which are primarily diseases of the brain, such as strokes, encephalitis, multiple sclerosis or the progressive dementias, like Alzheimer's disease.

To the extent that patients fear loss of control over their own medical care at the end of life, advance medical directives can be reassuring and effective if properly explained and written, especially when the cause of the terminal disease and its likely clinical course are already known. Use of specific advance directives in these situations is terribly underutilized because it does not conform to those legal documents which appear on typical forms advocated by the states -- but they are just as legal as the so-called "statutory forms." [See chapter on advance directives later in this book]

Because patients frequently equate taking increased amounts of pain medications with loss of control, they may refuse to take appropriate doses of narcotics. Patients should be reassured the same process of developing tolerance which leads to their needing larger doses to control pain also effects their mental tolerance for pain medication. Upward adjustment of doses for pain relief should therefore have no more effect on their mental function than the lower dose did previously.

I. Narcotic Addiction

The author remembers vividly talking with fellow interns in the early nineteen sixties about the use of narcotics in dying patients. At the end of our discussion, we would all agree in a rather flippant manner that all cancer patients should die addicted. Thirty-five years later, the terms have changed but the concept remains valid. Today we recognize the difference between tolerance and addiction and realize when narcotics are given for relief of physical pain, addiction almost never results. Tolerance, yes, but not addiction.

Thus, today we would still treat the patient as we advocated then, but would view it differently. We would say there is no reason not to give as much narcotic as necessary to overcome both the tolerance and the pain because any stigma which attaches to the word "addiction" has no place in the reality of death and dying. It is just an unfortunate coincidence the same family of drugs used by terminally ill patients to relieve physical pain are also used by people with addictive personalities to blunt their psychic problems leading to narcotic addiction. If it wasn't for this coincidence, patients would not fear "addiction" to pain medication any more than they fear addiction to medication to relieve diarrhea. In fact, paregoric, another member of the same family of opioid drugs and occasionally addictive in itself, has been used for a century to treat diarrhea without producing any general fear of addiction.

No terminally ill patient should think less of themselves because life has burdened them with a painful disease requiring relief from narcotics, but that is much easier to say than it is to accomplish. If nothing else, reading this book may produce an equally important goal -- to convince the family not to fear addiction -- for it is frequently the family and non-physician health care providers who subconsciously fight the use of adequate narcotics to control pain in the terminally ill because of their notoriety related to
addiction.

**J. Loss of Dignity During the Process of Dying**

One cannot assure a terminally ill patient they will not have any loss of dignity during in the end stages of their disease, but it is possible to show the patient that as a present caregiver you are concerned about dignity by arranging for personal privacy and hygiene, respecting requests intended to preserve dignity, and by indicating an awareness that loss of dignity is likely to be a concern of the patient in the future.

In general, a patient's dignity is preserved by continuing to work when possible, by remaining part of the community, by taking pride in grooming, by taking part in conversations, by continuing to help others, and by remaining as much the person they were before they were ill as possible.

By continuing to treat the patient with dignity, being graceful when illness temporarily intrudes on their dignity, and promising to continue to treat the patient with dignity to the end, caregivers also reassure the patient that future lapses in dignity will be accepted without reflection on the bigger picture of who they were throughout a lifetime.

**K. Being, Or Being Considered, A Worthless Individual**

Fear of being considered a worthless individual is very similar to loss of dignity, but actual fear of being worthless is different. In a highly materialistic world, a patient is likely to think of his or her worth in terms of wealth or the ability to accumulate wealth. A terminal patient is therefore likely to feel worthless if there are few assets to pass on to children -- but this author at least believes the worth of a person's life is better evaluated based on sayings we find on mugs, or wall hangings, or a greeting card, or in book passages that talk about "success."

From a coffee mug:

"That Man is a Success who strives quietly to make his corner of the world a little better. That man is a success who brings out the best in others and gives the best of himself."

Also consider the beautiful thoughts of the following excerpt, which may serve well to reassure a loved one of the value of their life:

**AUTHENTIC SUCCESS**


Authentic success is having time enough to pursue personal pursuits that bring you pleasure, time enough to make the loving gestures for your family you long to do, time enough to care for your home, tend your garden, nurture your soul. Authentic success is
never having to tell yourself or those you love, "maybe next year." Authentic success is knowing that if today were your last day on earth, you could leave without regret. Authentic success is feeling focused and serene when you work, not fragmented. It's knowing that you've done the best that you possibly can, no matter what circumstances you faced; it's knowing in your soul that the best you can do is all you can do, and that the best you can do is always enough.

Authentic success is accepting your limitations, making peace with your past, and reveling in your passions so that your future may unfold according to a Divine Plan. It's discovering and calling forth your gifts and offering them to the world to help heal its ravaged heart. It's making a difference in other lives and believing that if you can do that for just one person each day, through a smile, a shared laugh, a caress, a kind word, or a helping hand, blessed are you among people.

Authentic success is not just money in the bank but a contented heart and peace of mind. It's earning what you feel you deserve for the work you do and knowing that you're worth it. Authentic success is paying your bills with ease, taking care of all your needs and the needs of those you love, indulging some wants, and having enough left over to save and share. Authentic success is not about accumulating but letting go, because all you have is all you truly need. Authentic success is feeling good about who you are, appreciating where you've been, celebrating your achievements, and honoring the distance you've already come. Authentic success is reaching the point where being is as important as doing. It's the steady pursuit of a dream. It's realizing that no matter how much time it takes for a dream to come true in the physical world, no day is ever wasted. It's valuing inner, as well as outer, labor, both your own and others. It's elevating labor to a craft and craft to an art by bestowing love on every task you undertake.

Authentic success is knowing how simply abundant your life is exactly as it is today. Authentic success is being so grateful for the many blessings bestowed on you and yours that you can share your portion with others.

Authentic success is living each day with a heart overflowing.

Authentic success is to have written on your epitaph, as was written on a gravestone back in 1820: "The only pain she ever caused was when she left us."

When patients begin to express thoughts of their own worthlessness, find similar passages which fit their life history to read aloud together in order to fortify an image of success in life as being something other than monetary status.
One additional thought when dealing with a patient who suggests he or she is worthless. Consider the possibility that they are thinking they owe it to their family to die. Be ready to reassure them they should not question the expending of their money on their own behalf and that those who would inherit the money would feel bad if everything possible was not done to preserve and insure any meaningful life they might have. Alternatively, if this feeling is based on perceived failures of their own, it may be helpful to introduce the concept of forgiveness and to give permission for self forgiveness.

7.05 Other Causes of Existential Suffering

A. Inability to Obtain, Evaluate and Use Information

Different patients desire different information, and in an age of communication there is almost no limit on how much can be made available to them even at home -- through television, the Internet, or from rental libraries in the form of videos as well as books. Arranging these services may require some effort on the part of caregivers, but is worthwhile not only for the information it provides, but also to help the patient retain his or her personhood. Realistically, at some point the patient will reach the stage when they can no longer partake of the information directly themselves, but even then it is important to try to supply requested information through caregiver intermediaries.

Of course, obtaining the information is only part of the process. The patient is also likely to need and greatly appreciate someone to discuss it with, and someone who takes the responsibility to transmit the patient,s thoughts to other parties directly or through written communication. Offers to do these types of things for the patient and a plan which includes caregivers willing to do such things on a routine basis can be highly beneficial in reducing existential suffering.

B. Loss of Ability to Control One,s Bodily Functions/Loss of Dignity

There is an old truism in medicine -- physicians cannot stand to deal with stool, but have no trouble dealing with sputum (fluid coughed up from the lungs). By contrast, nurses have a great deal of difficulty with sputum, but are not bothered by stool. Why do we mention this? To point out that people differ when it comes to which duties are difficult and which are not. Much discomfort is caused by a patient having to rely on others to move them, feed them, wash them, fetch things for them, and to take care of body excretions when they can no longer be controlled by the patient.

As part of the plan of care for a terminally ill patient, it is important to determine which of these various tasks should be undertaken by which potential participant -- one who does not find the specific act required objectionable. If the person undertaking the task does not find it objectionable, the patient is much less likely to feel it to be a burden. In many relationships, it is correct and appropriate to say: "you did it for me, now I will do it for you." How better to show love?
C. Loss of Ability to Maintain Access to One's Family or Society

At some point in the course of most terminal disease the patient loses the ability to personally arrange and maintain access to his or her family and society. For a period, help from family and friends in the form of provided transportation is likely to delay this process, but eventually the patient must rely on family and society to make the effort to come to him or her instead of the reverse. At this point it is often the patient who must reach out to appreciate the difficulties experienced by others when coming to see a terminally ill patient in their home.

Some friends and relatives will not appear at the bedside either because of an inability to make arrangements or a personal choice against doing so. For many this will represent a simple desire to remember a loved one when they were happier or more vibrant, while for others it might just be too painful to endure, as it is likely to create recall of painful past memories best forgotten. The desire to avoid visiting a former patient may be particularly strong among physicians, who are likely to fear the creation of their own feeling of guilt, which would make it more difficult to continue a life devoted to helping others.

Whatever the case, the patient is wise not to complain about the absence of any visitor in the past, for there is nothing which prevents a revisit as much as hearing a complaint that a previous absence has been interpreted by the patient as an abandonment. True family and friends tend to visit as much as their schedules and personhood allows. The patient's best means of insuring this access if it is important to them is to make each visit as pleasant and comfortable for the visitor as possible.

D. Loss of Ability to Control People Formerly Controlled by the Patient

Many people are naturally so controlling of their lives and people around them they have seemingly lost the ability to relinquish their control even when they are dying. When such individuals continue to try to maintain control at a time when they are no longer capable of doing so, conflict is likely to be the result.

Many emotions are involved. The family is likely to desire that everything possible be done, which often requires them to try to vest control from the patient. The patient, seeking to maintain self-sufficiency, is likely to be angered when his or her desires are seemingly undermined by the family. The physician may find it easier to work through the family than the patient, but is likely to recognize that doing so undermines the patient's self-esteem, maintenance of which is likely to be far more important than having specific directives of the physician followed to the letter. It can be a baffling problem in which communication between family and health care provider is pivotal, setting on goals critical, and separating of fact from fiction essential.
Take, for instance, the value of nutrition. The family is likely to be upset the patient isn't eating enough. The patient finds eating more than desired to be uncomfortable. The family thinks the patient is failing to take adequate care and wants to intervene. The patient considers efforts on the part of the family to force additional food to constitute loss of control over his or her life. What should be done?

Another example. The patient is given a bottle of pills to take for nausea with instructions to take four a day, but he often forgets. As a result, the patient commonly complains of an upset stomach, yet doesn't want to give the control of pill taking over to the family. The family gets tired of hearing the complaints about the stomach. What should be done?

In both of these and in similar situations, the author would suggest that whether caregiver intervention is appropriate can only be determined by knowing the seriousness of a failure to follow physician directives, and it is frequently only the physician who can make that determination. Before taking away a patient's autonomy or self-control, it should be determined that failure to do so is likely to cause significant harm to the patient. Otherwise, it is wisest to leave the patient in control.

If the decision is made to "take control," it then becomes important for the family and physician to sit down with the patient and make it clear his or her care from here on in must be a combined effort, one in which the patient's duties in the overall scheme will be to accept that others are required to maintain adequate care during the terminal stages of the disease.

To summarize. Patient's often try to remain independent as long as possible even when their capability to do so is limited. Because the right and ability to control one's own life is so important in maintaining self-esteem, removing this right adds significantly to existential suffering. Therefore, it is important not to intervene unless and until there is firm evidence intervention is required to prevent significant physical harm to the patient.

During this process it is well to remember the desire to maintain control may well be based on concerns which reach beyond the simple desire to do for one's self. For many, allowing others to do for them interferes with their dignity, while for still others it represents loss of control. For others, simply admitting they have cancer may risk in their minds being stigmatized as a "cancer sufferer," with a resultant change in personal relationships even amongst long-standing acquaintances. Going one step further and giving up control only adds to their suffering.

To allay these fears, it is important to reassure the patient they will continue to make most decisions for themselves and they will certainly be consulted on all. That intervention will only be undertaken in specific situations, such as with the particular problem at hand. Similarly, as discussed further below, it is important to allow the patient the right to choose when to inform others in society about their illness, for this, too, is likely to threaten the patient who wants to continue life as before with a loss of control.

Remember also that with loss of control comes an additional fear, revenge. Although unspoken, many dying patients who question their own relationships with family fear revenge -- that the spouse, child or
other relative they controlled or neglected during life will use this time of helplessness to "get even." And, at times it would appear the fear is justified. When revenge is intentional, little can be done, but when the appearance is inadvertent, simple awareness of this potential problem is likely to suggest methods of reassuring the terminally ill there is no ill will intended when caregivers are unable to fulfill the patient’s wishes. There are no grudges for past acts which would lead one to want to get even. To the contrary, there is only appreciation for what has been done in the past, but circumstances are such there are realistic limits on what can be done for the patient. Any failure to meet all the patient’s desires stems from reality, not revenge.

E. Hopelessness

Many terminally ill patients find the most difficult emotion to deal with to be hopelessness. This has long been recognized by the medical profession and is undoubtedly the reason why over the centuries leading up to the last few decades, physicians routinely kept knowledge of the terminal nature of a disease from the patient. It may also explain at least in part the reluctance of many physicians to recommend hospice care, for one requirement of hospice is that the physician judge and note in writing that the patient’s life expectancy is less than six months.

The fear of fostering hopelessness may also explain physician reluctance to discuss with patients the advisability of discontinuing aggressive medical care even when the physician knows it will be futile. Knowing it is time to limit future care to comfort related measures does not always justify such a changed approach, for doing requires the obtaining of the patient’s approval, which is likely to enhance the hopelessness of the situation.

How carefully the plans must be made to present the switch in treatment philosophy to the patient without eliminating hope. No wonder so many physicians and families, after discussing and agreeing on the futility of future therapy, still continue to go ahead with therapy even knowing the risks far outweigh any potential physical benefit. [Note: The author considers continuing such care appropriate even if it is futile, as long as it does not present a significant risk to the patient and is not associated with significant suffering.]

Even those patients who come to fully accept they have an untreatable illness which will cause their death find ways to maintain hope. At times this can take the form of hoping to live to see a particular event, to be released from the hospital, to achieve the resolution of a particular problem, or to achieve a less troubled place in the world to come. At other times even the most realistic patients talk about the possibility of finding a cure for their disease, as if they need a glimmer of hope to maintain them through the final days, weeks or months of suffering -- some hope which justifies their need to endure, a spirit which also requires the presence of "a little" denial.

Somewhere in this consideration of truth and hopelessness we must also face another reality. During a terminal illness, patients are often forced to make many decisions about therapy and therapeutic approaches to their conditions. Patients with higher expectation for the future routinely choose more
aggressive care than those with lower expectations, and half-truths or outright lies intended to foster hope are also likely to foster a personal choice for more aggressive care. At times this is what the treating team desires and feels justified to have happened. At times it is not, and greater honesty may be required.

### 7.06 Stressing Past Accomplishments

It has been said that everyone,s life deserves an autobiography. As the terminally ill patient faces the finality of death, it is natural to look back over and catalogue his or her accomplishments and failures in life, financial, occupational, societal, and interpersonal. Invariably, each individual will fall short of what they wished to achieve no matter how successful their life may seem to others. It is hard to predict how each individual will act. Will they feel good about their accomplishments or will they dwell on their perceived failures? How helpful it would be to the family who wish to support the patient through this time of existential suffering to know what the patient is thinking.

A classic way of achieving this goal, commonly referred to as a "life review technique," involves a review of the patient,s life in order to place the current illness in a personal context. It is often accomplished by helping the patient recount his or her history as if to facilitate the writing of a book, even if it is only memoirs for the family. The book itself may be unimportant, for the goal of the undertaking the review is in fact not the book but a means to pick up from the patient,s recitation of life those happenings which are viewed as successes and those which are viewed as failures. Based on this input, further conversations can be directed at stressing the positive memories which remind the patient of success and avoiding those memories which call up feelings of failures. In addition, knowing the patient,s deemed failures in life can be of particular help if they are potentially reversible either before or after death. In the former case, efforts should be made to address issues of patient concern in a positive manner. In the latter, it is important to assure the patient the matter will be dealt with after his or her death.

Other ways of obtaining information about the patient,s thinking include asking such questions as "How would you like to be remembered?" and "Looking back, what do you consider to be the most important events in your life?" Of course, the most important part of this exercise is likely to be the second question: "Why do you look at that as being such an important event?"

### 7.07 Helping Establish Closure

An additional concern for terminal patients is the need to bring closure of existing issues. Frequently, this will require the help of one or more consultants as well as family members chosen to address specific topics with the terminally ill patient. At times it is difficult for caregivers to raise specific issues because it may appear to be self-serving, but doing so early in the course of the disease is likely to avoid significant soul-searching on the part of the patient later in the course of the disease when understanding the issues and making decisions will only be more difficult.

One method of avoiding the problem of appearing to be self-serving is to use one of the many existing
lists of suggested issues to be discussed with terminally ill patients, especially if the list is produced by a reputable organization looked on favorably by the patient.

The following list taken largely from the chapter on pre-death planning in the author's book on Elderlaw and published by West Legal Publishers may serve as a starting point. Naturally, many of the suggested issues for discussion will be known not to be relevant to the particular patient and can be skipped:

I. Estate Planning:

1. Is there a will? Where is it? Who is named the executor or executrix (personal representative)? How recently was it written? Are there any known desired changes? Should it be reviewed? Should the executor be brought in to discuss it or would the patient rather discuss it with someone else? [Note: Because of the rapid changes in estate tax law, any estate with total assets over $650,000 should probably be reviewed if saving taxes is important to the patient. Even if a consultant is not desirable, a will should be reviewed to make sure time has not made certain provisions obsolete, like the sale of a described car and purchase of another.]

2. If there is no will and the patient has the capacity to execute one, should an attorney be brought in to discuss it with the patient? Should the family accountant be consulted?

3. Are there any personal assets which would be better distributed before death to avoid delayed use during probate?

4. Are the presently named beneficiaries on a life insurance policy, IRA, pension remainder, etc. as the patient would want them to read? Are the names on real estate deeds and money accounts as the patient would like? Should a consultant lawyer or accountant be asked about these matters?

5. Are there any assets which the family may not know about or any "hiding" places for documents which may be unknown to the proposed executor.

6. Are the locations of all keys known? Combinations on any vaults, etc.?

7. Is the patient worried about the availability of sufficient finances to cover family needs in the first few months of probate? If so, can something be done to transfer funds in such a way as to make them more readily available to the family until the probate is completed?

8. If the nature of disease is likely to lead to a prolonged period of incapacity, should special durable powers of attorney be executed to cover the pre-death period?

9. Is the patient owed any money by friends, family members, or business acquaintances?
Are these debts in writing? If so, where are the promissory notes and how should the debts be handled after death -- should they be forgiven or attempts made to have the debts collected? If collected, would this best be done before death? [Note: if there are large debts involved, it may be wise to check with an appropriate professional to determine how they should be handled to the best tax advantage.]

10. Does the patient have debts the family is not aware of?

11. Might the patient have insurance which is unknown to the family? Mortgage insurance, for instance.

12. If funds are short, consider the possibility of a reverse mortgage or pre-payment of insurance benefits to avoid undue financial pressure on the patient and family.

13. Has the patient made any transfer for assets in the last few years which could be questioned by the IRS after death. If so, what are the particulars. If significant amounts of money are involved, should a proper consultant be contacted for an opinion on how it should be handled?

14. Does the patient have any valuable but difficult to value collections? If so, would the patient want to consider a sale prior to death to maximize value instead of relying on the executor? How can this be arranged?

15. If any normal heir is not covered in an existing will, are they aware and do they understand the reasons? If a normal heir is not going to receive any gifts, does the executor know why? [Note: It is usually not wise to put reasons in the will, but it is good for those probating the will to know the reason.]

16. Are there any potential beneficiaries of the will who may be hard to find? If so, does the patient know anything about their whereabouts?

17. Is the patient concerned about others learning about his or her estate after death? If so, consider the use of a living trust prior to death to minimize the exposure of documents during probate.

18. If there will be significant estate taxes, the patient might want to consider making gifts of up to $10,000 to multiple individuals prior to death. These gifts will not effect estate taxes after death. The patient might also want to consider prepayment of tuition for beneficiaries or beneficiaries' children or making charitable gifts prior to death as a further means of decreasing taxable assets.

II. Planning for Terminal Care:
1. Does the patient have an advance medical directive? A living will? A durable power of attorney for health care?

2. If the patient has an advance directive, suggest it is probably advisable to review it with the attending physician to see if it covers the likely expected events based on the nature of the patient's disease and to make appropriate additions if required. [Note: If the patient wants to retain control of future care, a new advance directive with far more specificity than previously signed form documents is likely to be required.]

3. If the patient has named an agent under a durable power of attorney for health care, be sure the choice is still the desired choice and that the individual named is still willing and able to fulfill the responsibility. Ongoing talks between the patient and named agent through the period of increasing disability may prove invaluable in assuring the patient his or her wishes will be honored in the end.

4. If the patient does not have an advance directive, suggest the patient either write down or have a family member write down how they want their terminal care to be handled. Have this reviewed with the physician and then structured into either a living will or as an instructive directive in a power of attorney for health care by an attorney.

The most important questions to address are likely to be:

(A) whether the patient wants to be kept alive as long as possible using modern technology or wants to be allowed to die if the disease causes him or her to lose the ability to think and make personal decisions;

(B) whether the patient wants to name a specific person to make decisions for them if and when they lose the ability to make decisions for themselves;

(C) whether the patient wants to be treated at home even if this means less can be done to prolong their life; and

(D) whether the patient would want to be given nutrition and hydration through a feeding tube in order to prolong their life.

5. Would the patient want to be an anatomical donor of body organs if the nature of the disease permits it?

III. Business Issues:

1. Is there a personal business that will become an asset of the estate after death? If so,
have arrangements been made to insure it will be managed appropriately during the probate of the estate? Would it be better off sold before death? Would it be wise to arrange for it to be sold immediately after death for tax purposes?

2. If there is a personal business which will require management that has not been planned for, what does the patient want to happen? Who does he or she want to manage the business during probate? Who should be brought in to make appropriate arrangements through a trust or appointment of officers, etc.? Who does the patient want to be the beneficiaries of the business profits during this time? Is this well documented in the will?

IV. Family Issues:

1. Are there any members of the family the patient has not seen for a prolonged period who he or she would want to see before death?

2. Are there any members of the family the patient has not talked to for a prolonged period who he or she would want to talk to before death?

3. Are there any members of the family whose relationship with the patient is troublesome? If so, why is it troublesome and would the patient want it to be different? If they would want it to be different, would the patient mind if the interviewer made some efforts to reconcile the trouble?

V. Personal Issues:

1. Discuss the contents of any safe deposit boxes and determine who will have access after death. Should any documents be removed and given to specific individuals? Should any be removed so as to avoid them becoming part of probate?

2. Discuss the contents of any safe and determine who else has access. To insure contents do not disappear, make copies of all important documents.

3. If the patient has any significant monetary funds which are not in safes or accounts, does the patient feel comfortable they will be appropriately distributed after death? If not, what should be done?

4. Consider the various roles played by the patient in life, such as a trustee in a trust or an officer of an organization. Should resignation occur? Should a successor be named? Should the organization be told of the patient,s state of health? Does the patient want to make a last appearance or write a note to the organization?

5. How does the patient feel about his or her religious affiliations? Is there a desire for
communication with the congregation? With any individuals in the congregation? With any priest, minister or rabbi? How could this best be arranged?

VI. Issues Related to After Death Events

1. Does the patient want to be buried or cremated? Where would the patient want to be buried or the ashes placed? Is there any specific desire about a headstone?

2. What religious or other memorial service is desired? Is there anyone in particular the patient would like to have speak at a funeral or memorial service?

3. How would the individual want to be remembered in an obituary, a eulogy, etc.? And, how would the individual prefer those left behind handle the mourning period?

4. Does the patient have any specific thoughts about funeral expenses or organization? Any one person who would be preferred to handle the arrangements?

5. How does the patient feel about an autopsy?

6. Have there been arrangements made for a burial plots, cemetery contract, monument preparation, trust fund to construct burial vault or to maintain the burial site.

7. If the patient's death will leave behind a spouse, how would the patient feel about a remarriage. Are there any concerns about finances and the children if there should be a remarriage. [Author's Note: In my experience, most terminally ill patients would want the spouse left behind to find a new mate, but many are concerned a new mate might "take" assets earned by the two together away from the children. Knowing this about a deceased spouse often makes it much easier for the second spouse to date without guilt and also to make certain requests of a future spouse as it relates to financial planning.]

VII. Papers to Accumulate

1. Will

2. Advance medical directives

3. Passport

4. Insurance Contracts

5. Birth Certificate
6. Financial Power of Attorney

7. Anatomical Gift Form


9. Funeral Plans/Burial Arrangements

10. People the Patient would want Notified

11. Specific Requests

7.08 Helping Patient with Unfinished Family Business

A task of great importance to many dying patients is the need to bring closure to family disagreements which may have occurred over the years and never been resolved. This can be a curious phenomena. Within all families there are at least occasional disagreements which are not dealt with immediately but only resolved with time. Resolution may be the result of mutual agreement made when the issue is less heated or may be resolved by unspoken actions which negate the premise on which the original conflict was based. Just as some conflicts are resolved with time, others remain unresolved, either fading into oblivion because they are too unimportant to be remembered, or continually constituting an obstacle to better relations yet being judged to be too controversial for either party to risk addressing for fear of producing even greater animosity between them.

All this can change when time is running out. Many of those disagreements which previously "could wait" cannot wait any longer. The time has come for both parties to decide whether the issue should wait forever, or whether a resolution should be sought in spite of the high risk of pain and further distancing during the terminal disease state. When we think about it, we all know people who have chosen to go to their graves with important unresolved family issues, and, just as importantly, we all know people who live wishing an issue with a now expired person had been resolved prior to his or her death. What we don't know is whether either would be happier if the issue had been addressed.

As caregivers, one should give great deference to what the patient wants in these situations, unless it is quite clear the healthy party wants to seek resolution and is willing to go more than half way in achieving that result. Even so, it may be difficult to know what the patient wants. Perhaps a question, "Would you like to see so-and-so" or "would you like to talk with so-and-so" would be helpful. Alternatively, maybe so-and-so should be called and asked similar questions. Then the patient can be asked, "would you like to see or speak to so-and-so? I know he or she would like to see or hear from you."

Another way of trying to find out what is on the patient's mind is to ask them to list what they would do if they had ten years to live; five years; one year; three months; or less. Alternatively, one can ask more
directly if the patient feels he or she has any unfilled obligations to family or friends they want to deal with? Conversations they would like to have? Messages they would wish to convey? Objects, feelings, or thoughts to share with others before they die? Personal desires from the past they would like to fulfill? A debt to repay? A writing or recording to leave for posterity? Information about one's own religious or moral beliefs to be shared with others?

One may also try to learn what concerns the patient by asking specific questions related to personal desires surrounding death. How do you want people to treat you when you are close to death? Is there anything you would specifically want done? That you would not want done? Are their any religious practices you would want observed? Is there anything which is normally done which you do not want? Is there anything you would specifically want done for people you love?

7.09 Being There

First and foremost, families should maintain presence with the patient even when there is little specific which needs to be done. This allows the patient to initiate conversation when desired and avoid the fear of abandonment -- probably the most pervasive worry of most terminally ill patients once the fear of terminal pain has been removed. In this situation, "presence" need not be continual, but may involve no more than looking in on a patient at frequent known intervals. Just knowing someone will be coming to answer questions and deal with complaints if necessary is the essential value of presence. One of the most difficult problems in dealing with the dying patient is the need to reassure the patient that as a caregiver you are not becoming resentful of the time required to meet the patient's needs. This may be made much easier when presence is not continuous, but intermittent.

Remember also the presence of complaints does not necessarily indicate something need be done in the absence of a direct request of the patient to do so. In many cases, the complaint is just being registered to be heard and not with the expectation something can be done. More important than doing things is listening to hear what is really bothering the patient, to give little bits of support, to listen without judging, and to give him or her a chance to work through the problems which must be faced during the dying process.

7.10 On Showing Compassion

Webster's dictionary defines compassion as a "deep feeling for and understanding of misery or suffering and the concomitant desire to promote its alleviation." In many ways, it is more important to express compassion than to actually achieve relief of suffering for the terminally ill patient, for this goal may be unobtainable, while the expression of compassion is always possible. Compassion requires a bond between individuals that cannot be conveyed by the offer of a technological fix for terminal illness. Instead, promising a fix when none is obtainable only suggests a desire to avoid dealing with the patient's suffering, a sign of abandonment.

Compassion is a virtue which involves assuming the burden of another's suffering as one's own.
Compassion thus requires that caregivers suffer with patients rather than express moral or theological judgment. It thus requires presence rather than abandonment, and the recognition and appreciation of the particular nature of suffering, especially existential suffering.

Each individual will make of suffering what he or she will make of it. To show compassion requires acceptance of this individual nature of suffering. Making statements like "I know how you feel," is not only inaccurate but demeaning to the individual. Such words only isolate the suffering individual by suggesting the listener has the power to understand the patient,s most private thoughts without even hearing them expressed. This leaves the patient powerless, with no reason to even attempt to put his or her individual thoughts into words and thus robbing the listener of an understanding of the problems which need to be faced. To avoid this from happening, the compassionate individual must accept a position of relative weakness by acknowledging the difficulties facing the patient while continuing to express an interest. Obtaining a better understanding of the particulars will enable the caregiver to be in a better position to help.

7.11 Choosing Appropriate Caregivers to Question the Patient

When dealing with a patient,s existential suffering, the first step is often to create an atmosphere in which the patient is willing to discuss his or her concerns. Health care providers and family members may convey either implicitly or explicitly that they are uncomfortable discussing such issues. If one feels uncomfortable and is not adept at hiding the discomfort, it is wise not to address the issues in the absence of someone trained to deal with resultant answers, such as a competent social worker, pastoral or grief counselor, or clergyman. The designation of the appropriate person to do so may in fact bring about the recognition of similar fears held by family members which should also be addressed.

7.12 Working Through Problems/The Physician,s Role

While the family must usually carry the major burden in dealing with a patient,s existential distress, the physician generally carries the major role in preventing intrusion on this ongoing interplay by insuring other symptoms are well controlled. When other symptoms are poorly controlled, efforts to deal with existential problems are constantly interrupted with the reality of pain and distress sapping the patient,s time and strength and making it unavailable for efforts to express gratitude, forgiveness, promise, peace, or hope between patient and family.

7.13 Specific Suggestions
A. Maintaining Appearance

Patient's concerns for their own physical integrity can be helped by efforts to improve their own appearance in their own minds. One method of helping is therefore to enhance the patient's appearance by attention to grooming, purchase of new clothes, alteration of clothing for appropriate fit, and use of cosmetic prostheses when appropriate.

B. Helping Maintain Function

Attention should be addressed to maintaining patient function even when its maintenance may be more difficult than performing the function for him or her. This may require purchase of devices, such as hearing aids or artificial limbs, the reason for undertaking the expense being more for maintaining the patient's integrity than the ability to function.

C. Adding Meaningfulness to Life

Meaninglessness of life is a major component of existential suffering, especially in people with high achievement levels in the past. An important approach to this issue requires the identification of short-term achievable goals whose fulfillment could preserve a sense of self-worth even if the benefits of fulfilling the goal may be minimal. Meeting with a religious counselor may also be very effective in providing short-term spiritual goals which may be accomplished even in the presence of severe physical incapacity.

Some methods of adding meaningfulness may be the taking up of a handicraft the patient was always too busy to undertake in the past. Another can be as simple as learning to scan the Internet for information of particular interest to the patient.

D. Stressing Pleasure

Throughout life, we constantly balance risks and pleasures. We limit the pleasure of foods in the newborn in the hope of avoiding allergies in the future. We accept the side effects of medications in the hope they will prolong our lives. We give up the pleasure of smoking for the same reason and undertake serious studies in the hope the knowledge obtained will make life more fulfilling in the future.

But when a patient is terminally ill, all this changes. There are no long-term risks and even the short-term risks are likely to be dominated by the fact that most of remaining life is likely to be very limited in pleasure. This dramatically changes the balances we normally make over a lifetime.

If the patient wants to do something that will give him or her pleasure it is probably warranted even if it risks an earlier death. For example, consider a terminally ill patient who wants to go on a cruise or visit a specific place where medical care is likely to be highly limited. Do it. The worst that can happen is that
the patient will get sicker and die, but they are about to die anyway. And sudden death is likely to be considered better by the patient than living through the end-stages of the terminal illness.

Similarly, don't worry about narcotic addiction (tolerance). If full relief of pain makes life more pleasurable, support it. We do not have to worry about the risk of addiction in the future. And for heaven sakes, if the patient still wants to smoke or wants to take it up again, encourage them to do so if they find it pleasurable. [I know there will be arguments about this statement.]

And keep in mind the fact the patient has little time to give to non-pleasurable efforts. Time spent getting to, in, and returning from a doctor's office or a hospital to obtain chemotherapy and then living through any period of ill-effects thereafter is dear to the patient. In many, using that time to enjoy life as best they can better serves the patient than spending time in pursuit of a few more weeks of life.

Similarly, undertaking therapeutic regimens which interfere with active use of time in pursuit of pleasure is likely to be contraindicated. Medications which produce depression or sleepiness should be avoided. Procedures with require time in a hospital should be limited as narrowly as possible, unless the patient happens to be one who enjoys being there as a setting for social interaction.

E. Honoring Privacy

Largely as a result of advancing technology, cancer is being diagnosed much earlier than it has been in the past. This has allowed some improvement in the cure rate, but has also produced many more patients who suffer a "terminal illness" for many months and years before physical deterioration becomes evident. During this interim period, between the original diagnosis and the onset of generalized physical deterioration, patients are likely to react very differently with regard to discussing their disease with family, friends and acquaintances.

Some patients may choose to bring up and discuss their illness with almost everyone. A casual observer might suggest the patient is looking for sympathy -- "woe is me" -- but this may be unfair, for it is likely the patient is just using these conversations as a way to work through the various stages of coping with death by seeking methods of accepting their life is ending.

Other patients may also be comfortable discussing their illness with others if the issue is raised by the friend or family member in a way which suggests a desire to understand the patient's thoughts either as a caregiver or just for their own interest. Sharing one's thoughts in an almost random fashion may make it easier for caregivers to know what the patient desires without the need for a direct request or may just indicate the patient wishes to share experiences as a lesson for others who are certain to face similar experiences in the future.

In contrast, however, many patients express a strong desire to keep any knowledge of their condition personal. They fear the stigma of being a cancer victim and want to avoid any change in their relationship with the world for as long as possible. Eventually, physical effects of the disease or of concomitant
chemotherapy will become so evident the truth will have to come out, but until that happens, they do not want to be denied the chance to work, communicate, and enjoy life as they have in the past by well-meaning, but intrusive outsiders.

At times it is difficult for those in attendance to deal with the approach chosen by the patient, but we must remember each person deals with the acceptance of death in their own way. The same information or incident may be described repeatedly to sequential visitors until we are tired of hearing it, but the patient who is seeking varied responses in the hope of finding a means to deal with his or her problem in an acceptable way should be encouraged to do so. Alternatively, the patient who is repeating the story simply out of the desire to continue to be a helpful person in society by sharing an experience others have never known should similarly be commended for their effort, not criticized.

Conversely, as caregivers we must respect the patient who has chosen not to routinely reveal or discuss his or her illness for personal reasons even though it may make it more difficult to fulfill our own roles. At times, when the requirement for caregiving makes other routine chores or habits of the caregiver impossible, it may become necessary to reveal facts which we have been asked to keep secret, but this should only be done out of need and with a request that the information not be passed beyond the person who "has to know."
CHAPTER 8. SUFFERING AND THE PROVISION OF ARTIFICIAL NUTRITION AND HYDRATION

8.01 Employment of Artificial Sustenance; Introduction

8.02 Nutrition and Hydration as Part of Dying Naturally

8.03 Methods of Artificial Nutrition and Hydration

8.04 Do Terminally Ill Patients Suffer Starvation and Thirst?

8.05 Considering Artificial Sustenance

A. Benefits of Forsaking

B. Emotional Aspects

C. Societal Aspects

D. Religious Aspects

E. Ethical Aspects

F. Legal Aspects

G. Traditional Medical Practice

H. Palliative Care Medicine

I. Feeding Tubes

8.06 Author,s Opinion

8.07 Reaching a Decision

8.01 Employment of Artificial Sustenance; Introduction

Many terminally ill patients go through periods when illness temporarily interferes with the desire or ability to eat and drink. Among the most common causes are the side effects of cancer chemotherapy and reversible physical abnormalities involving the mouth, throat, esophagus, stomach, or intestinal tract. During such periods, artificial nutrition and hydration by feeding tubes or by intravenous fluids is clearly
justified. In contrast, artificially maintaining of sustenance (nutrition and hydration) on a permanent basis through the end-stages of a terminal illness is a totally different issue involving major potential conflicts between patients, physicians and caretakers involving a combination of medical, legal, moral and ethical concerns.

Many of these concerns were addressed in a 1990 article in the Lancet Medical Journal with the enticing title: "The Sloganism of Starvation." [Ahronheim JC, Gasner MR, 335 Lancet 2/3/1990 278-279] In this article the authors stressed that the use of the word "starvation" to express "inadequate nutrition" and "thirst" to express "under-hydration" were provocative terms but did not accurately reflect what happens when these conditions occur during the end-stages of terminal illness. They noted that until the end of this century, people who grew too old, too disabled, too weak, or too sick to eat and drink died without artificial nutrition and hydration. That the natural tendency of sick people to reject food and fluids should be considered a natural part of the illness and the dying process. According to the authors, it is the technology of supplying nutrition and hydration to the terminally ill patient who forsakes food and fluids which is unnatural and artificial, while it is the rejection of food and fluids which is natural. And that the provision of artificial nutrition may in fact be better viewed as forced feeding, frequently resisted by the patient through the only remaining mode of expression, struggling to pull out the tube.

According to the authors, the cruelty and abandonment implied in the word "starvation" was not relevant to the dying patient. Indeed, requiring artificial feeding to be continued itself was viewed as potentially cruel. In their view, and the view of most clinical physicians involved in palliative care of the terminally ill patient, it is indeed the artificial feeding and hydration, not its withdrawal from debilitated patients, that is gruesome, cruel, and violent in nature.

Because of its importance, the question of patient suffering and the decision to forsake artificial nutrition and hydration is being addressed in two separate chapters in this book. In this chapter I address the use of artificial nutrition and hydration when the patient can no longer maintain an adequate intake on his or her own, the feedings being intended to prolong life. In the later chapter we will discuss the patient,s right to refuse nutrition and hydration as a means of controlling one,s own death. In neither chapter am I referring to the situation in which the use of artificial nutrition and hydration is undertaken as a temporary medical measure during a reversible condition which is expected to get better or in which there is hope the patient will improve and regain the ability to eat and drink.

8.02 Nutrition and Hydration as Part of Dying Naturally

Throughout history, natural death from chronic illness was accompanied by dehydration and malnutrition because of the natural tendency of terminally ill patients to stop eating and drinking. In retrospect, it is likely dehydration frequently played a major role in the final event. This, however, changed with the advent of intravenous fluid therapy. Once developed, I.V. fluids became a routine part of terminal care for all hospitalized patients, thus ending the effects of dehydration on the dying process. For better or worse, two different patterns came to exist side by side. Death itself didn,t change, just the particulars of the dying process, by dehydration at home, by other means in the hospital.
In more recent years, as more patients come to die in hospitals and intravenous therapy is increasingly used in the home care setting, even fewer patients are dying without I.V. fluids, but there is little, if any, evidence this is for the better. In fact, there is abundant evidence the reverse is true, that dehydration is a kinder death than others. This has led those medical providers and facilities most closely related to palliative care in the dying patient, the hospice movement, to routinely forsake artificial hydration in the final stages of terminal illness whether in the home or in an inpatient facility.

The major issues in the terminally ill patient has thus changed from whether nutrition and hydration can be adequately maintained to whether or not it is desirable to employ these techniques in the delivery of care.

8.03 Methods of Artificial Nutrition and Hydration

The frequent need to maintain patients through periods of reversible illness when oral food and fluids were either impossible or harmful to the patient's condition has led to extensive development of techniques for artificial maintenance of nutrition and hydration. All of these techniques, developed for use in non-terminal situations, can also be applied in the case of the terminally ill patient if so desired. The following discusses the major methods employed:

1. Hypodermoclysis. Many years ago it was common in both hospitals and nursing homes for fluids to be given to the patient by hanging a bottle of water containing a little sugar and/or a little salt and attaching it to a needle placed under the skin of the upper legs through a tube with a mechanism to regulate the rate of flow. This method was actually quite effective in maintaining body fluids and is still used at times, but tends to cause more problems with infection than properly employed intravenous fluids discussed next. This process, hypodermoclysis was essentially limited to provision of fluids, not nutrition, and is not appropriate for the delivery of most medications.

2. Intravenous Fluids. The device used in supplying intravenous fluids is similar to that used in hypodermoclysis, but the needle is typically placed within a vein running beneath the skin of the back of the hand or lower arm. It, too, contains salt or sugar water and is essentially limited to supplying fluids and not nutrition, although approximately five hundred calories in sugar can normally be given through an I.V. every 24 hours. Intravenous "lines," as they are frequently referred to, have the added convenience of allowing the administration of many different medications, including antibiotics, narcotics, tranquilizers, sedatives, etc. Thanks to years of observations, studies, and advances in technology, the techniques of supplying intravenous fluids have improved markedly over the years with far fewer complications.

One major problem, however, remains, the resultant lack of mobility. A patient receiving I.V. fluids is essentially tied to the bottle. Methods have been devised to allow a basically healthy individual to get up and around in spite of the I.V., but these methods are seldom appropriate in the setting of a terminally ill patient whose mobility is likely to be highly restricted when on I.V. fluids.
3. Naso-gastric feeding tubes. Naso-gastric (N/G) feeding tubes are thin tubes passed through the nose and down the esophagus into the stomach or further on into the beginning of the intestines. In most patients, placement of the tube is relatively easy and it can remain in place for long periods of time, especially in situations involving an unconscious patient. When patients are conscious, however, the tubes tend to cause discomfort in the nose and throat and may lead to vomiting, bleeding, and ulcerations. It is also common for the tubes to be improperly placed or dislodged by movement of the patient so fluids that are intended to go into the stomach actually end up going into the lungs and causing aspiration (non-infectious) pneumonia, which then often goes on to become infected.

Because of the distress caused in the nose and throat, after a short period of time N/G tubes are normally replaced with a surgical tube if artificial nutrition and hydration is to be continued. (PEG or PEJ discussed below.) Naso-gastric tubes also have the disadvantage of keeping the junction between the stomach and esophagus open and providing a mechanism for fluids from the stomach to find their way up into the lungs by the same mechanism as water tends to run up the sides of a glass. N/G tubes can be used to supply all required nutrients and can also be used to administer medications, but has the disadvantage of not being able to employ solid foods. Unfortunately, the fluids which are normally administered through naso-gastric tubes which are enriched with nutrients to maintain nutrition usually cause diarrhea and/or an over accumulation of body water.

4. Total Parenteral Nutrition (TPN). Total parenteral nutrition is a procedure in which a mix of the total required body nutrients can be given through a vein using a relatively large catheter (thin-walled tube) placed through the skin into a major vein in the center of the chest. The advantage of TPN lies in the fact that unlike I.V. fluids using small arm veins, with TPN the fluid is actually discharged into a large vein which is not irritated by the addition of nutrients to the fluid given. As a result, unlike I.V. fluids which can only be used to maintain hydration, TPN can also be used to maintain nutrition.

It sounds good, but there are many complication when TPN is used besides being quite expensive. Infection is a particularly important problem because when it occurs, it can go straight to the heart, lungs and other important organs in the body.

5. Surgically implanted tubes (PEG,s and PEJ,s). Modern technology now allows surgeons to implant tubes into the stomach (PEG) or the beginning of the intestines (the jejunum -- PEJ) directly through the abdominal wall without requiring general anesthesia. These approaches are fast, simple, and can be undertaken with minimal risk, and are certainly preferable to long term use of either a naso-gastric tube or TPN. Although a major medical advance when dealing with potentially reversible conditions, their use to maintain artificial nutrition and hydration in a terminally ill patient is much more questionable and revolves almost exclusively around issues involving quality of life. Among the potential complications of PEG,s and PEJ,s are local perforation of the stomach or intestines and blockage of the intestinal tract, but more commonly the ill-effects are likely to come from the fluids introduced into the tube, either causing diarrhea or traveling back up the esophagus from which they are aspirated into the lungs.

8.04 Do Terminally Ill Patients Suffer Starvation and Thirst?
All of us have experienced hunger pains and the distress of thirst. Although these are often decreased during times of illness, they still exist and can be remembered as particularly troublesome if the disease process makes normal eating and drinking impossible, as with a bad sore throat. In addition, we have all witnessed movies or actual events on television depicting the horrors of terminal thirst or starvation, but this evidence associating starvation and thirst with suffering is not necessarily applicable in case of the terminally ill patient. In fact, there is overwhelming medical evidence the two are not associated -- that lack of food and fluids does not cause significant suffering in this situation.

The reason for lack of hunger in the terminally ill patient who has stopped nutritional input appears easy to explain and is similar to the reason why people on very low calorie diets do not experience true hunger. In order to avoid the breakdown of fats in the body, there must be an intake of approximately 100 grams (just over three ounces) of carbohydrates (sugars or starches) each day. Because there is such limited storage of carbohydrates in the body, this input must occur on a near daily bases. If this input or carbohydrates is inadequate, once the meager stores in the body are utilized, fats begin to be broken down within the body to produce the required energy.

For reasons involving the biochemistry of metabolism, in the absence of adequate carbohydrates, this process results in the release of certain chemicals called "ketones" into the blood which have a tendency to cause a loss of appetite. Once this occurs, the patient no longer feels hunger.

Although loss of appetite and hunger typically takes three to four days to occur when food intake ceases in a healthy person, most terminally ill patients experience this process -- decreased carbohydrates -> ketone production -> loss of appetite without it being obvious to observers, who just report the final loss of appetite without understanding its basis. [Note: If carbohydrates are given in typical amounts used in I.V. fluids, the 100 gram threshold for preventing ketones is likely to be met and hunger is likely to persist or recur. Thus, patients on I.V. fluids are likely to experience hunger while those without I.V.,s are not.]

The exact reason for the absence of thirst in the terminally ill patient is more difficult to explain than the absence of hunger. In part it may be related to the fact that most terminally ill people are older, and older people are less likely to experience thirst than young people. In addition, it may be explained in part by the fact thirst is normally experienced when the amount of salt in the body is high compared to the amount of water, whereas terminally ill patients are likely to be as depleted of salt as they are of water.

Whatever the cause, what is known is that terminally ill patients who complain of "thirst" are usually complaining more about having a dry mouth than lack of fluids. Thus, relief is not likely to occur as the result of the patient being given fluids either by mouth or I.V., but as the result of effective local care of the mouth -- like sips of water or ice, cleaning of the teeth and mouth, etc. When handled this way, lethargy and sleepiness are likely to result, but basic mental function is normally maintained even in the absence of fluid intake until the very last day or two of life when mental cloudiness is likely to supervene.
Although patients do not seem to suffer from starvation or thirst when artificial sustenance is withheld, it is worth recognizing that withholding artificial sustenance is likely to result in a change of terminal event. Those who have forgone artificial sustenance are more likely to exhibit signs of fluid deficit, like dryness of the skin and mucous membranes, poor circulation to the extremities, decreased urinary output, restlessness, muscular irritability, and sleepiness. They may also be more prone to fall when walking, the development of bedsores and problems with blood clots as circulation fails. In contrast, those who receive food and fluids by tube may exhibit the same signs, but are more likely to experience others, like shortness of breath, coughing, choking, nausea, vomiting, cramps, swelling of the extremities, loss of urinary control, and recurrent oral secretions requiring suctioning.

Those who have not received artificial nutrition and hydration are also more likely to appear comfortable, in part because dehydration has an unexplained tendency to cause at least mild euphoria with increased tolerance for pain, and to more peacefully slip into a final comatose state. Death occurring in the absence of fluid therapy frequently involves irregular heart beats, infection, and circulatory collapse as terminal events, all of which tend to be rapid and, ideally, not associated with perceived discomfort by the patient.

In trying to balance the merits of artificial nutrition and hydration in the terminally ill patient, numerous studies have been done comparing the suffering of patients who receive artificial nutrition and hydration by tube with those who do not. Not surprisingly, symptoms varied, but overall those without artificial feeding and hydration fared better, mostly because they suffered less from lung complaints, such as cough and shortness of breath, and from intestinal complaints, such as nausea and diarrhea. Interestingly, those who did not receive supplements were no more likely to complain of hunger, thirst, or dryness of the mouth, the latter being common in both groups of patients with or without artificial fluids being given.

[Note: The author has accumulated over 90 articles from the medical literature overwhelmingly supporting the view that suffering is not relieved in the terminally ill patient by giving artificial nutrition and hydration beyond that which is naturally desired by the patient. Whether artificial nutrition and hydration actually prolongs life is uncertain, and even then, the question remains whether the potential extension of life with its accompanying pain and suffering justifies the disadvantages of feeding tubes and intravenous lines in the end-stages of most terminal illnesses.]

8.05 Considering Artificial Sustenance

A. Benefits of Forsaking

The natural tendency of terminally ill patients to discontinue food and fluid intake produces many beneficial side effects which should be considered when deciding on whether or not to employ artificial nutrition and hydration. Reduced fluid intake means reduced urine output, thereby reducing incontinence (the uncontrolled leaking of urine) and the need for urinary catheterization. It also means reduced fluid in the stomach and intestines, with resultant reduction in vomiting and diarrhea, and reduction of lung secretions which tend to cause cough, shortness of breath, choking, a sensation of drowning or
suffocation, and a need for recurrent suctioning of the back of the throat. Reduced fluid also means less fluid swelling (edema) which may be particularly beneficial if the patient experiences headaches or confusion related to swelling of the brain. Lack of food and fluids together cause a build-up of toxins and changes in body chemistry which might normally be considered deleterious, but are an advantage in the terminally ill, for they result in increase in the natural production of endorphins which act like morphine and reduce the need for pain medication. In addition, the production of ketones, break-down products of fat, produces suppression of hunger, while changes in body chemistry add to lethargy and the gradual production of coma -- welcomed end points in the terminally ill.

B. Emotional Aspects

It has been said:

As infants we were given food and drink when we were too helpless to nourish ourselves. Because of this early psychological connection between feeding and loving and the on-going connections between nutritional satisfaction and emotional satisfaction throughout life, it is hard for the family to forsake artificial nutrition and hydration without feeling they are abandoning the patient. Not to provide food and water is as if one has cruelly and for selfish reasons decided against providing basic life-support measures, and to precisely those to whom we owe our own life and well-being. Although few of us may know what it feels like to undergo cardiopulmonary resuscitation or heart transplantation, we all know what it is like to be hungry, or thirsty. How can we wish those experiences on this poor, defenseless person who we profess to love? Is it not true that if there is any way in which the living can stand by those who are not yet dead, it would be through the continued provision of food and drink even when the struggle against disease has been lost? To continue to nourish the life of one who had been defeated in that battle is the best evidence we can offer that we are more than frontrunners, that we are willing to love to the very point of death.

No one is comfortable with the thought a loved one may "die of thirst" or "starve to death." But as noted above, we must not allow ourselves to feel guilt simply because of the terms "thirst" and "starvation." Studies tend to show patients who have the capacity to decide usually refuse artificial feeding when they are near death or severely debilitated with little hope of recovery. They also show when patients are asked about the discontinuation of various forms of medical treatment, most consider the discontinuation of artificial nutrition and hydration to be much the same as discontinuing a respirator or kidney dialysis and more appropriate than discontinuing medications like antibiotics.

C. Societal Aspects

In our society, food carries high symbolic value, representing comfort and nurturance. Feeding is one way we express love and caring. The first thing the mother does for a newborn child is to suckle it, providing food and hydration. When a child is sick, the family,s role is classically to be sure he or she
remain fed and receives "lots-of-fluids." Even as adults, we worry when illness causes a loss of appetite or decreased fluid intake. And when we care for others, one thing we all feel comfortable in addressing is the provision of adequate food and fluids for the patient.

Even when we go beyond family, the feeding of the hungry, whether because they are poor or because they are physically unable to feed themselves, is one of the most fundamental of all human relationships. It is the perfect symbol of the fact that we as humans are inescapably social and communal. We cannot live at all unless others are prepared to give us food and water when we need them, and just as we look for help from others in our needs, we look to help others in theirs. Even in third world nations where various tribes go on killing each other decade after decade, the outside world emphasizes the need for provision of nutrition as the primary goal of support.

Given this general feeling of society, that provision of food and fluids is a basic right of all, it is not surprising families usually become the strongest advocates of artificial nutrition and hydration during terminal illness. A recent study among hospice nurses found seventy-six percent of families were very concerned about weight loss compared with only twenty-six percent of patients. As to the nurses themselves, ninety-five percent felt aggressive nutritional support did more harm than good.

In fact, among hospice nurses it is thought that provision of artificial nutrition and hydration to the terminally ill by medical professionals is primarily a method to support the family which desires that everything possible be done and in disregard to the patient's desires or best interests. As they perceive the situation, undertaking such provision is a relatively easy, inexpensive way for health care providers to show compassion and concern. To the contrary, many palliative care specialists sarcastically point out that providing artificial sustenance is in fact a way for physicians to avoid the more difficult tasks of dealing with the patient's existential problems -- they are too busy working with the manipulation of nutrition and fluids to spend their precious time talking to the patient and family.

D. Religious Aspects

From a religious standpoint, the provision of artificial nutrition and hydration to the terminally ill patient is a controversial area, although most denominations seem to be increasingly receptive to the idea that nutrition and hydration may at times be considered unnecessary forms of therapy.

Those religious groups which do not support the discontinuation of nutrition and hydration believe life should be prolonged at all costs and every step toward shortening a life diminishes its value in the collective mind. Advocates of this pro-life position are likely to claim we are morally mandated to provide fluid to all terminally ill patients to prevent "suffering" by painting a gruesome picture of dehydration: a parched, skeletal victim, burning with fever, convulsing, and retching from a dried-out stomach. Although this may be an accurate picture based on studies of healthy people deprived of fluids who commonly complain of headache, abdominal cramps, nausea, vomiting, and dry mouth, it is not
what is witnessed in terminally ill patients who suffer natural dehydration as part of the dying process.

On the other side, many religious leaders believe that allowing the dying process to occur without interference is not immoral, and people are not obligated to endure treatments they consider burdensome in order to prolong life. Religious leaders of this philosophy acknowledge that "Nature itself has made provision to render more bearable the moment of death...," [citing the Declaration on Euthanasia, Vatican Congregation for the Doctrine of the Faith, June 26, 1980.] This, in fact, corresponds quite closely to present legal concepts discussed below.

Unfortunately, in addition to these highly competing views common in different religious circles, there is a great deal of public misunderstanding which revolves around a now outdated concept of "ordinary" and "extra-ordinary" care.

Beginning with St. Thomas Aquinas and remaining part of Catholic doctrine into the not too distant past, there was a theory of medical care that in caring for the terminally ill patient it was an obligation of the medical profession to supply "ordinary care," but no obligation to supply "extra-ordinary" care. Under this division, provision of food and fluids were considered basic, ordinary care and was therefore required in all cases. The development of modern medical technology in the last forty years has, however, led to the official abandonment of this approach many years ago as it provided numerous situations in which separating ordinary and extra-ordinary care no longer proved appropriate. Official abandonment by the Church, however, has not erased the concept amongst the public, who continue to refer to this differential as if it were still accepted theological theory. As a result, feeding and providing fluids to sick patients is still routinely evaluated as being "ordinary," and thus equated to a moral necessity.

Even if we were to consider the provision of food and fluid to be a moral necessity, there are numerous arguments against applying this approach to artificial nutrition and hydration. First, while feeding by mouth is ordinary, "artificial feeding," by definition, is not. Second, ordinary feeding by mouth can be refused by the patient by simply not swallowing, this is not true of artificial feeding. Third, ordinary feeding is pleasurable, artificial feeding is not. Fourth, ordinary feeding is not normally associated with risks to the patient, but artificial feeding is. Fifth, ordinary feeding by mouth takes time and is associated with a touching/feeling type of relationship, while artificial feeding is not.

E. Ethical Aspects

Ethical theory related to forsaking of nutrition and hydration in the terminally ill revolves heavily on the concept of autonomy, the right of the individual patient to decide what care he or she wishes to undergo. As stated in the guidelines established by the President,s Commission for the study of Ethical Problems in Medicine and Biomedical and Behavioral Research in its 1983 report, "discontinuing medical hydration is ethically acceptable when, from the patient,s point of view, it is more burdensome than beneficial. Burden or benefit from the patient,s point of view is determined by the decision-maker utilizing the patient,s stated desires or, if the patient,s desires have not been stated, deciding what would
be in the patient,s best interest." [Note: This statement of ethics as put forth by the Commission closely parallels the now existing legal stance on the use of artificial sustenance in terminally ill patients. For further considerations of the decision in competent patients, see chapter on voluntary forsaking of sustenance, below.]

In keeping with the Commission,s guidelines, additional ethical commentary can be summarized as accepting the patient,s desires as controlling, and then going on to add that when the patient,s desires are not known, artificial nutrition and hydration in the terminally ill is ethical to prolong life only if the genuine well-being of the patient is being served. If treatment is continued merely based on motives which are outside the expected quality of the life of the individual person, such treatment cannot be considered to be at the service of that individual,s life and should not be undertaken. In such situations, there still exists a duty to make food and fluid available to the patient upon request and a frequent suggestion that food and fluid be left at the bedside as an almost symbolic gesture that food and fluid are still being provided.

Two special ethical considerations should be noted. The first relates to determining a patient,s desires. Artificial sustenance is frequently begun in patients at the request or with the approval of family members when the patient has limited ability to express his or her wishes. Under these circumstances, it is common for the patient to physically remove the tube or to fight to have it removed in such a way that the patient must subsequently be placed in restraints to prevent the repeated removal of the tube. This leads to an ethical dilemma -- should the repeated attempts of a patient to remove a feeding tube be considered a decision on the part of the patient not to have the tube continued? There are, of course, differences of opinion, but most ethicists presently argue that in the absence of any hope the underlying condition will improve, these gestures by the patient should be interpreted as saying "No" to the tube and a legitimate expression of the patient,s wishes. Even those ethicists who would suggest leaving the tube in would frequently recommend it not be left if this required the use of restraints -- better to go ahead and put in a PEG or PEJ which is more difficult for the patient to dislodge.

The other highly divisive ethical issue related to the provision of artificial sustenance involves patients with progressive dementias, as typified by Alzheimer,s disease. Most patients with dementia eat well until the disease is far advanced, but eventually are unable to maintain adequate nutrition and hydration by mouth. This most commonly occurs when the brain destruction causes an inability to swallow correctly causing the "swallowed" food and fluids to "go down the wrong way," into the lungs and not the stomach. In this situation, interventions, such as placement of a feeding tube, can be anticipated to (1) inflict at least some level of discomfort, (2) fail to improve the underlying progressive dementia, but (3) will prolong life.

Traditionally in this country, but not in Europe, for instance, patients with end-stage dementia who reach this stage of their disease are given artificial nutrition and hydration through surgically implanted feeding tubes. But is this ethical? Again, there is the expected difference of opinion. Many ethicists support the maintenance of the patient,s life through the use of an implanted tube, but others say progressive dementia should be considered a terminal condition similar to incurable cancer. Taking this latter view, a hospice type treatment approach which emphasized maintenance of patient comfort instead of preventing
death at all costs would be appropriate, especially if this was a choice previously requested by the patient.

In a much quoted 1984 article on this subject in the New England Journal of Medicine, noted medical ethicist Dr. Bernard Lo stated:

"When demented patients stop eating and cannot be fed by hand, physicians and family need to discuss the goals of care and the benefits and burdens of tube feedings. If feeding problems are temporary, tube or even intravenous feedings are appropriate. Long-term tube feedings are indicated in a patient who has no irreversible life-threatening problems, whose quality of life is acceptable, and whose family wants such feedings. However, tube feedings are not indicated when life-threatening medical problems are irreversible, the quality of life is poor, and the family agrees that the appropriate goal is to provide comfort rather than deliver calories or try to prolong life."

To many ethicists, even fifteen years later this would appear to be an appropriate summation of present thinking on the subject.

F. Legal Aspects

Although there have been few legal cases involving the discontinuation of nutrition and hydration in patients who are close to death, there have been many involving patients who suffered from illnesses which robbed them of any significant quality of life while allowing them to be kept alive for long periods of time with artificial nutrition and hydration. As a result of these cases, the law is now pretty well established, although there is still some variation from state to state. The following summarizes where the law stands in most states, although it may not be the law in the particular state in which any particular patient is being treated.

1. The patient with decision-making capacity has the clear choice of whether he or she wants to be given artificial nutrition and hydration.

2. If a patient with decision-making capacity chooses to refuse artificial nutrition and hydration, this choice must be honored. Failure to do so may make the health care provider legally responsible for damages based on pain, suffering, and additional expenses.

3. A patient has the right to refuse artificial nutrition and hydration in an advance directive even if the state statute would suggest they cannot.
4. If there is a difference of opinion as to whether artificial nutrition and hydration should be undertaken or continued, the patient's decision should control, not the family's or the physician's.

5. Most, but not all states have accepted the concept that it is acceptable to withdraw medical nutrition and hydration when the appropriate decision-maker for the patient determines the burdens of the treatment outweigh the benefits from the patient's point of view.

6. In most states, a decision by someone other than the patient to use or forsake artificial sustenance should be based on the patient's wishes, if known. In a minority of states, the preference is to make this decision based on what is thought to be in the patient's best interest.

7. Even when nursing home regulations appear to require the use of artificial nutrition and hydration in all patients, this does not prevent the patient and/or next of kin from refusing this therapy.

8. In most states, but not all, artificial nutrition and hydration is considered to be a medical treatment and thus may be withheld or withdrawn according to the same procedures and standards as other life-sustaining medical treatments.

9. There is legally no difference between stopping artificial nutrition and hydration and deciding against beginning it.

10. When a patient dies after the discontinuation of a life-sustaining treatment, such as artificial sustenance, the death is considered to result from the underlying disease and not the discontinuation of treatment.

11. Under the theory of "double-intent," [discussed in a separate chapter below] death which results from the discontinuation of artificial sustenance is not considered to be due to an illegal act as long as the intent of the physician and family is to benefit the patient, not to cause the patient's death. This is true even if the physician and family know it will result in the patient's death.

[Note: In spite of all these legal concepts, if the family strongly disagrees with a patient's request that artificial nutrition and hydration be stopped, physicians are unfortunately likely to follow the family's wishes]

G. Traditional Medical Practice
For reasons which are difficult to determine, many health care professionals go along with the "right to refuse treatment" until it comes to nutrition and hydration. Although the pendulum is swinging back to the natural state of dying without tubes, some physicians and medical commentators continue to espouse the moral need for continued care. Their arguments usually suggest stopping sustenance is different from stopping other medical treatments for the following reasons:

1. Finality. The denial of food and fluids is different than forsaking medical or surgical therapy in that it is "final." At times, we can choose to stop other therapy, like a respirator or antibiotics, and the patient will still live, but stopping food and fluids will always lead to death.

2. Universality. The need for food and fluids is universal. Stopping food and fluid would cause the death of all human beings, while stopping other medical or surgical therapies would only cause the death of a few individuals. Indeed, as recently as the 1940s such medical and surgical therapies were unavailable. Food and fluids are universal human needs; modern medical and surgical therapy are not.

3. Expectations. Few patients form the physician/patient relationship expecting to be dependent on the physician providing technical life-support, but they do expect their health care providers to supply nourishment.

4. Non-therapeutic. Provision of food and water can not be considered medical treatment because so doing will not overcome disease or restore health. Thus nutrition and hydration should be provided as part of a patient,s normal care, even if provision of such care requires medical technology, unless or until the benefits of nutrition and hydration are clearly outweighed by a definite danger or burden, or they are clearly useless in sustaining life.

5. Simplicity. Frequently, artificial nourishment may be provided in a simple, non-invasive manner, particularly in instances where use of a nasogastric tube is adequate. Therefore there is little reason to stop it.

6. Independent cause of death. To withdraw nourishment is to cause death by a means independent of the underlying illness. When one dies because of the withdrawal of other medical interventions, the individual dies because of their underlying disease.

7. Suffering. To withdraw food and fluids produces suffering, as we are all aware from the living of life.

It might be helpful to consider a few other reasons which are not likely to be voiced by the health care provider.

1. Clinician,s lack of knowledge. The provision of nutrition and hydration in terminally ill patients is often initiated because of clinicians, fears that malnutrition and dehydration are painful and engender significant suffering. In addition, physicians frequently provide sustenance because they consider such action ordinary care which expresses compassion and concern, because they want to avoid being
contributors to death, and because they perceive the provision of food and fluid as symbolic treatment that averts familial confrontation and condemnation.

2. Convenience. Although it is claimed physicians continue therapy to increase billing and to avoid potential law suits, there is little to support these beliefs. In contrast, convenience and time, two interrelated factors, probably do account for much of medical decision-making to undertake tube feedings. It is convenient and efficient to order an NG tube because nurses can insert the tube, give and monitor the feeding, and replace the tube when necessary. Even placement of a PEG or PEJ is an easy procedure to order and undertake.

3. Lack of Clinical Experience. Probably in part as a result of their lack of experience treating terminally ill patients, surgeons and anesthesiologists are much more likely to employ artificial nutrition and hydration than are general practitioners and internists.

[Note: In spite of the reluctance of many medical practitioners to forsake nutrition and hydration in the terminally ill, several national professional organization have stated it can be medically appropriate to forsake this type of medical care along with other non-comfort care under selected circumstances. These groups include the American College of Physicians, the American Dietetic Association, and the American Medical Association.]

H. Palliative Care Medicine

In contrast to traditional medical providers, health care providers specializing in palliative care of the dying patient are the leading proponents of limiting intake to what the patient desires and takes by mouth. They stress the fact that most patients require very little food and fluids as they approach death, that the patient’s hunger and thirst should determine how much food and fluids are given, and that the family should be discouraged from force-feeding or over-hydrating the patient. They note thirst can usually be relieved by ice chips or a few sips of water, and dehydration, while not producing true thirst, may in fact be beneficial in reducing unwanted body secretions into the lungs and intestinal tract. In addition, dehydration may result in mild loss of kidney function which tends to produce a welcomed type of sedation.

I. Feeding Tubes

In many cases the patient makes the final decision regarding the placement of a feeding tube, but family decision-making is also common. Because the patient is likely to have experienced starvation and thirst but not likely to have much experience with the treatment of terminally ill patients, asking the patient whether artificial feeding should be instituted without explaining the risks and benefits will almost always lead to a "yes" answer, unless the patient is specifically aware of the recent controversy surrounding its use.

When a decision is made to begin artificial sustenance in a conscious patient, it is wise to consider the
advisability of using a PEG or PEJ from the beginning, unless the feeding is expected to be of short duration. In close to fifty percent of naso-gastric tube placements, patient attempts to remove the tube resulting in the need for the use of physical restraints, a most undignified way to end one's life.

8.06 Author's Opinion

Unless there are specific reasons otherwise, such as the possibility of improvement, once a decision is made to limit care to concern for patient comfort, there is no reason to undertake artificial sustenance. If we are limiting our concerns to providing pleasure and eliminating suffering, whatever the patient desires becomes the appropriate foodstuff to supply. And if the patient is suffering from untreatable nausea or has no desire to eat, nothing may be the most appropriate offering, for there is no need to treat hunger which does not exist.

As discussed fully above, discontinuation of fluids in the terminally ill patient seldom leads to significant distress, and when it does, it is short lasting and easily treated. In the previous chapter we describe some medical considerations and treatments related to the dry mouth which is frequently attributed to "thirst," but which is probably more properly attributed to other factors involved in the dying process. In addition, discomfort from dry mouth can be relieved for one to several hours with sips of the patient's favorite beverage, ice chips, lip moisteners, cleansing and swabbing of the mouth, use of "viscous lidocaine" (a local anesthetic), a water spray to the mouth, room humidification or sucking on hard candies. Meticulous mouth care, including removal of debris with frequent water and peroxide rinses, may be helpful. Brushing of the gums, teeth, and tongue with a soft toothbrush, if the patient can tolerate it, may also help. To the contrary, artificially loading the body with undesired water serves only to increase breathing problems, usually the most distressing symptoms of the dying process.

8.07 Reaching a Decision

Unfortunately, the decision to institute artificial sustenance often falls on a surrogate decision-maker. Deciding to go ahead when a loved one is unable to decide for himself or herself in the hope of prolonging a life associated with unavoidable suffering can be a most difficult, trying choice. It is not a time for emotions to get in the way of doing what is best for the patient, but it has to be among the most emotional choices one must make in life.

Health care professionals may opt to supply artificial nutrition and hydration almost as a reflex, without fully considering whether they are performing a truly caring act. When this happens, it becomes the duty of the appropriate decision-maker to stand back and make a carefully considered decision. If the artificial sustenance and the technology used to make it possible is more of a burden than a benefit to the patient, a request should be made to the physician to have it stopped.

Hopefully, this chapter will serve to help the decision-maker. Because the author's personal experience treating terminally ill patients led him to prefer home health care without "tubes," there is a certain risk of bias in what has been said above, as well as in the following summary of thoughts put forth in this
1. The decision to undertake artificial nutrition and hydration in the end-stage terminally ill patient deserves careful consideration and should not be undertaken "routinely."

2. In years past most patients with terminal illness died at home without food or fluid beyond that which they voluntarily took by mouth. This is still the usual practice in most European countries and under hospice care, but not in American institutions.

3. When a patient is in the end-stages of dying from cancer, there is no evidence artificial nutrition and hydration prolongs life. This is not necessarily true of other diseases in which it may extend longevity.

4. For many reasons, some unexplained, the absence of food and fluids does not produce significant hunger or thirst in the late stages of terminal illness.

5. When a patient is in the end-stages of dying from cancer, there is no evidence artificial nutrition and hydration prevents suffering. In fact, it may add to unpleasant symptoms experienced by the patient.

6. The use of artificial nutrition and hydration may counteract some of the lethargy often experienced by the dying patient. This effect may be beneficial, but may also increase the burden of living in the very end-stage of the illness.

7. The only common complaint of patients who are not given artificial nutrition and hydration is dryness of the mouth. This can be effectively treated with local measures. It cannot be effectively treated with artificial hydration.

8. Many emotional, social, religious, legal and ethical issues revolve around the question of forsaking artificial nutrition and hydration in the terminally ill. In recent years there has been a tendency for all of these disciplines to accept a concept in which (A) the choice of a competent patient prevails and (B) when the patient does not have the capacity to make personal decisions, a surrogate decision is made based on the relative benefits and burdens artificial sustenance would bring to the patient.

9. Patients who have the capacity to decide usually refuse artificial feeding when they are near death or severely debilitated with no hope of meaningful recovery.

10. The final decision regarding the institution or continuation of artificial nutrition and hydration is best made between the patient, family and physician after an open discussion of the potential benefits and burdens.
11. Providing food and fluids orally upon request can be an effective means of fulfilling a patient's wishes. Some families feel better if they continue to give small amounts of foods which are meaningful within their family tradition.

12. The patient with dementia who has never voiced his or her wishes about artificial sustenance can present a most difficult social/ethical problem when oral feeding is no longer possible. Those who must make decisions are wise to consider a benefits/burden test limited to concerns of the patient. In this situation, standard therapy in America is to place a PEG or PEJ. In Europe, artificial sustenance is generally not undertaken.

13. If a decision is made not to use artificial sustenance, most ethicists suggest leaving food and fluids at the bedside to be given to the patient on request.
CHAPTER 9. ADDITIONAL ISSUES/SUFFERING AND THE TERMINALLY ILL

9.01 Family Issues/Family Suffering

A. Caregiver Burden

B. Family Showing of Compassion and Respect

C. Family Pressures and Dying at Home

D. Family Concerns Regarding Patient Suffering

E. Family Demands for Futile Therapy

F. Family Concerns in Stopping Aggressive Therapy

G. Family Requests for Assisted Suicide

9.02 The Signs of Dying

9.03 Physician Issues/Physician Suffering

A. Inadequate Training

B. Palliative Care as Non-Traditional Care

C. Death as a Failure

D. Recurrent Need to Deal with Death

E. Time Considerations

F. Specialization and Costs

G. Variability in Desired Treatment Philosophies

H. Dealing with Families in Conflict

I. Dealing with the Law

J. Miscommunications
Caring for a terminally ill patient places heavy burdens on the family. According to the SUPPORT study, a huge survey of terminal care undertaken by a team of Harvard researchers in a number of upstate New York hospitals, 34 percent of terminally ill patients require large amounts of caregiving assistance from another family member, 20 percent require another family member to quit work in order to give care, 29 percent involve loss of family income, in 31 percent most of the family savings are spent, in 17 percent there is a forced major upheaval in family plans due to financial changes, and in 12 percent other members of the family become unable to function because of emotional effects.

In an article on the management of pain and symptoms in the dying patient [J Pain & Symptom Management, p. 295, 1991], Kathleen M. Foley, a well-known physician specializing in palliative care noted:

The dying process can become extremely long and arduous for all concerned. Limited patient resource, limited physician input, family financial concerns, family fatigue, and psychiatric disturbances in the family can all lead the patients to think that it would be better for everyone, if they were dead. These aspects of exhaustion and fatigue appear to be the crowning blow to the patient and family, who have previously coped relatively well but become overwhelmed by poorly controlled pain and the depletion of financial resources.

There are many considerations:

1. Planning the care of a terminally ill patient requires a financial evaluation of available resources and open discussion between family members and health providers. Unfortunately, finances may realistically limit potential approaches to care, especially as it relates to institutionalization.
2. The availability of family members willing and able to partake in care may determine whether it is practical to undertake the normally preferred home care and whether or not to request help from hospice, which usually requires the ready availability of personal aid.

3. When care is likely to take place over an extended period, vacations for primary caregivers becomes a necessity to prevent "burn-out." Recognition of this need is now so well established that hospice routinely provides for and is paid by Medicare for brief in-patient care of terminally ill patients in order to provide respite for home care providers.

4. Early recognition that certain family members are psychologically unable to take an active part in care or are limited in how much of the burden they can undertake is crucial to avoid distressing situations for the patient.

5. Caregivers must recognize each other's psychological needs as well as those of the patient. Family, friends, and providers are all likely to be in the process of working through their own related suffering in their own ways.

6. Members of the caregiving team must strive to achieve an integrated approach to care to present to the patient, but must recognize that the overall plan will have to take into account difference in opinions regarding appropriate care among the team members.

7. Caregivers must have an opportunity to obtain a reasonable amount of rest so they do not become sleep deprived. This often requires a second person be available to care for the patient's emergency needs through the night.

8. In many situations, caregivers must be willing and able to accept the unaccustomed need to evaluate pain and other symptoms and to determine when additional medication must be given.

9. Because caregiver fear often leads to undermedication of patients, these fears must be addressed and overcome by careful instructions from physicians. This is particularly true at the end-stage of disease when it is necessary to stress that no "harm" will come from over medication -- the worst potential effect being almost synonymous with the best -- death without further suffering.

10. If a caretaker is unable to make decisions knowing they could hasten death, they deserve to be replaced by professional aids.

Of necessity, concern for family suffering must be accepted by health care providers as part of medical care of the patient. If family members are distressed because the patient's symptoms are poorly controlled, greater intervention is required to obtain patient relief. If their distress is due to the physical requirements of caregiving, additional help in the home must be arranged. If distress is related to emotional aspects of caregiving, supportive psychotherapy should be considered. Through telephone calls, home visits, and occasional clinic visits, the health care team needs to monitor the well-being of the
patient's family as well as the patient and to take part in planning and arranging for relief of their symptoms. Conversely, it is the duty of the caregivers to make these needs known to other members of the team so alternative arrangements can be met without adding to the patient's suffering.

B. Family Showing of Compassion and Respect

The showing of compassion repeatedly comes back to the issue of presence, the willingness to listen and the acknowledgement that what is happening to the patient is of critical importance to the family as well. The critical factor in presence is listening without minimizing the significance of what is happening to the patient, what is troubling the patient, what is important to the patient, and doing so in a non-judgmental way. Simply communicating with dying patients serves multiple purposes. It reaffirms their ongoing worth as living human beings, conveys compassion and care, and presents the opportunity to identify concerns and problems which can and should be addressed.

Family members should be given the opportunity to be present during the period prior to death. Visits from children reinforce the continuity of the personhood of the dying patient and are a potential source of significant consolation and pleasure. Many people are antagonistic to allowing young children to be around terminally ill patients, but most careful observers suggest that not allowing a child who wants to see a grandparent to do so because the grandparent is sick or dying is more harmful to the child than permitting the visit(s). This suggests the best rule is to ask the child what he or she wants to do. And, of course, the visits are likely to be very welcomed by the patient. [Note, most careful observers also believe it should be the child's decision, not the parents, whether they view the body of a deceased relative.]

In many ways, the problem becomes harder when the patient is comatose, unresponsive, or delirious -- situations in which the chance for any meaningful communication does not exist. Under these circumstances, many relatives and friends are likely to express a desire not to see the terminally ill patient in a state of distress, preferring to remember him or her for the rest of their lives in a more pleasant state. It is hard to advise how this situation should be resolved, as many people who choose not to see a loved one before death later resent that choice, while most tend to look back on it as the best for their own personalities.

Patients who have strong family ties generally cope much better with terminal illness than those who do not. One of the great accomplishments in life as viewed by a terminally ill patient is likely to be their role in producing a loving, caring family -- one "to be proud of." For patients who hold such patriarchal or matriarchal goals, it is important for the family to appear in harmony to the end. It is most unfortunate
when the tribulations necessarily associated with the dying process is allowed to falsely undermine the patient,s perception of harmony within "the family," especially when in fact the evident disharmony arises out of each family member,s desire to do more.

The family needs to remember to be cheerful. Dying persons have no desire for depressed and doleful company. If caregivers, moods are going up and down, as they almost must during the periods of grieving which inevitably accompany the care of a dying loved one, excuses should be found for short term absences from direct patient care or contact. At the other extreme, inappropriate flippancy or frivolity that is insensitive to the mood and situation of the patient can increase a dying person,s feelings of isolation. Joking may be good distraction from the patient,s suffering, but should not be undertaken without considering how it will be interpreted by the patient.

Consistency and perseverance in fulfilling promises are important to relieve the dying patient,s fear of potential abandonment and isolation. Regular visits or telephone contact provide reassurance of continued support and concern. When they are interrupted, however, remember lapses will be much less threatening if explained beforehand to the patient, who is likely to be understanding and thus less threatened by the fear of abandonment. If absence cannot be anticipated, an honest explanation should be given, or an acceptable excuse made if the truth would upset the patient too deeply.

C. Family Pressures and Dying at Home

When asked, almost all patients express a preference to die at home once they are assured they will receive adequate pain management even when they are told home care means forsaking other advanced technical care. Those who prefer hospitalization usually do so not for the purpose of obtaining more sophisticated care, but out of a desire to avoid being a burden on the family.

For most, dying at home is seen as providing the best opportunity for quiet and privacy, dignity, and the family closeness that may make death easier for the patient and provide consolation for the bereaved. Assuming a stable and caring home environment exists, emotional and physical comfort is usually greatest in this setting with family and friends nearby. At times, however, it is not ideal.

When contemplating the best place for terminal care, the following issues should be considered:

1. Who are the present inhabitants of the home? Are they of an age and physical ability to meet the needs of the patient? Will the patient,s presence cause too much of a burden physically or emotionally on the occupants? Is there any impediment to home care through hospice, and would this meet the patient,s needs? Should care at home be considered an interim action with further placement in a nursing home anticipated or to be considered at a later date depending on the patient,s course?

2. Who would be in charge of decision-making at home? In other potential places? Would this be in fitting with the patient,s nature? Have there been successful and/or unsuccessful
relationships between the patient and the would-be primary decision-maker in the past?

3. Are the facilities at home such that they can be adapted to meet the patient’s needs? Is there an appropriate room with available bathroom facilities? Would there be a place for others to come and visit? How difficult would this be? How expensive? Might a different room arrangement become more appropriate as the terminal illness progresses causing progressive weakness, etc.?

4. Do the people at home support the patient’s views as to what future medical care is advisable? Would being at home lead to a situation in which the caregivers are unwilling to follow the patient’s wishes?

5. Will being at home interfere with certain people visiting the patient? Would their loss of attention be felt negatively by the patient?

6. What special skills, equipment, or training will be required in the home or of people in the home? Will a hospital bed be required? Special mattresses to prevent bedsores? A bedside commode? A wheelchair? A rolling bedside table? A television, stereo, computer hook-up etc.? A method of getting up and down stairs? Can they be arranged for and managed?

7. Are there special parameters which should be set before the patient is brought home? For example, certain potential future conditions which would require the patient to be moved to a nursing home? If so, should this be discussed beforehand to avoid the appearance of abandonment?

8. Does the potential primary caregiver at home have too many other responsibilities to undertake the primary care? If so, how important are these other responsibilities? Can they be suspended for awhile? Can other potential caregivers be relied on to help relieve either the old or the new responsibilities? Are they willing to do so?


10. Can part of the weaknesses in home care be covered by professional employees? Are there funds to make this possible? Can they be arranged through hospice care or other home health-care agencies in the community?

**D. Family Concerns Regarding Patient Suffering**

The suffering of a terminally ill patient may be evaluated very differently by the family and health care
provider. The patient may be calm when the physician appears after being restless all day by chance, due to medication schedules, or out of a desire to be a "good patient." The patient may choose to complain much more bitterly of pain or suffering to family than to physicians based on existential reasons not known to either the physician or family -- and maybe even the patient. In any of these situations, the family is in a position to pass this information on to the physician, who should take it seriously and not view it as initiated by a complaining caregiver(s).

At the same time, health care providers frequently fail to consider that families are likely to perceive a loved one,s actions as indicative of suffering when the physician, having greater experience, would not under the same circumstances. The physician is likely to walk out of a sick room in which the patient is lying eyes closed waking only to answer questions and think the level of sedation is perfect, while the family perceives the lack of ability to enjoy conversation to be a form of suffering. Tubes, I.V. lines, monitoring instrumentation, etc. are so routinely used in medical situations physicians may not even notice their presence, yet these various apparatuses are likely to be seen as major bodily intrusions by the patient,s family. Skin lesions such as sub-cutaneous bleeding are likely to be quickly dismissed by physicians, while families view them as serious complications of medical therapy. Under such circumstances, the patient,s family may not express their concerns, even though they should. At the same time, a thoughtful physician can so easily relieve the family,s distress with just a few well chosen words: "I think the level of sedation is just right," "I,m glad that feeding tube doesn,t seem to be bothering your mother," or "we frequently see that kind of bleeding under the skin in patient,s who are taking steroid medications. It does not mean there is a high risk of bleeding internally."

Differences between family and provider perceptions of suffering may also lead to significant problems related to the forsaking of non-comfort care, especially as it relates to artificial sustenance. If relatives perceive the level of patient suffering as significant, they are likely to find it difficult to accept forsaking of sustenance. In this situation, convincing the family the patient is not suffering or that any present suffering is only transient and can be relieved by pain medications, etc. may be an important part in maintaining harmony with and within the family.

E. Family Demands for Futile Therapy

Many factors, most of them related to "trust," seem to be combining to produce an increasing demand for futile therapy by families. In particular, the belief medicine is becoming too commercial is difficult for physicians to counter, for the basic premise is probably true, even though it is unusual for physicians to abandon therapy unless they truly believe it to be futile.

Another frequent factor which leads to demand of futile therapy is guilt. When family members feel guilty about past relationships with the dying patient or have reason to believe something they have done may have contributed to the death, they are likely to want to continue care to the very end. In such situations, it is important the family not be asked by the physician "what do you want me to do?" but to ask instead "what would your father want done?" Asked in this way, the person who feels guilty about not doing what the father wanted done in the past is likely to honor the patient,s wishes ahead of his or
At least at the beginning, family demands for futile therapy should probably be honored by physicians. An attempt should be made to determine the basis of what appears to be unreasonable demands without specifically trying to change family opinion. Written documentation that therapy is being continued at the family's direction based on certain family beliefs is desirable, along with a statement that the providers do not expect a positive outcome. When this is done, as long as the family has not lost trust in the providers and given time to observe that continued therapy fails to reverse the patient's downhill course, the family will invariably recognize the presence of continued suffering without visible improvement and will come to a consensus in favor of forgoing non-comfort care. [Note: Legal decisions have repeatedly backed family demands for futile care even when the scientific evidence is overwhelming the care will not benefit the patient.]

Of course, comfort care is never futile and is always appropriate. Therefore physicians should not say "there is nothing more we can do for him or her," but should suggest instead that from here on care should be directed at maintaining comfort instead of prolonging life.

F. Family Concerns in Stopping Aggressive Therapy

The time of switching from aggressive care aimed at prolonging life to an approach aimed purely at providing comfort is an important point in the physician/family interaction. Ideally, it will have been discussed at least initially at some point prior to the time the decision is made, but it is still likely to be difficult for the family to accept. One issue which should be considered is the question of how to maintain at least some level of hope when everyone, including the patient, knows that care is no longer being aimed at prolonging survival. Another is how to explain to those caregivers who were not part of the decision-making team what is happening and why.

As part of the comfort-only approach, removal of unnecessary equipment which may impair the patient's appearance gains increased importance, along with removal of any undesired restrictions on visiting, the elimination of unnecessary procedures or investigations, and the determination and fulfillment of the needs of the family collectively and individually.

Another important consideration is removal of unnecessary drugs, often a welcomed event for family members who are concerned with the number of different medications the patient is receiving. Instead, emphasis is now focused on those drugs which are specifically meant to increase patient comfort, such as analgesics and sedatives. Of course, it is also a time to stop all diagnostic evaluations as well, unless they are undertaken relative to pain relief. This may also be a time to encourage the patient and family to communicate, touch and deal with "unfinished business," and to address issues involving the family unit as a whole.

G. Family Requests for Assisted Suicide
Families are unlikely to request a physician to assist the patient to commit suicide unless it has been brought up by the patient in private communications with the family. When a family member is acting as an intermediary for the patient, it is important to let the physician know it is the patient’s wishes which are being communicated and that they are allowing this to happen because they think the physician should know the patient’s thoughts, even though the patient is too embarrassed to raise the issue personally. By so doing, the family member permits any further discussion related to physician assisted suicide to occur directly between the patient and physician, the only appropriate relationship in which such a discussion should take place.

Another advantage of telling the physician even though the physician is prohibited from complying legally, is that the request is likely to be taken by the physician as a silent request for additional relief of pain or suffering.

9.02 The Signs of Dying

The final stage of the dying process can produce great anxiety among family members who do not know what to expect.

Weakness and diminished intake of food or fluids, either abrupt or gradual, are common manifestations of the patient entering the dying trajectory. These changes frequently seem to occur as part of an overall disengagement process in which the patient withdraws on a physical, emotional and social level. At this time, less communication takes place, but an awareness continues and, in fact, hearing may become more acute. There is often a focus on important objects in the person's life: a person, a pet, a particular food. Overall, there is a tendency to lethargy, somnolence and a quiet resignation.

At some point, these more general signs give way to others which are more specific. L.H. Herbst, et al., suggested the following information about the symptoms of death developed by the San Diego Hospice Corporation be given families about what to expect in an article entitled: What Do Dying Patients Want and Need?, Patient Care magazine, Feb. 28, 1995. In the article, the authors also note great variability, any one patient potentially experiencing all or none of the anticipated symptoms.

1. The patient’s arms and legs may become cool to the touch, and the underside of the body may darken in color as peripheral circulation slows down. Arm blankets will help prevent the patient from becoming too cold.

2. The dying patient will gradually spend more and more time sleeping and at times may be difficult to arouse as metabolism decreases. The family should plan to spend more time with the patient during times when he or she is most alert.

3. The patient may become increasingly confused about time, place, and the identity of people nearby. Family members may need to remind the patient what day it is, what time it is, and who is in the room.
4. Urine and bowel incontinence is often not a problem until death is imminent. If needed, pads should be used to keep skin clean and dry.

5. Oral secretions may become more profuse and collect in the back of the throat. Most people are familiar with the term "death rattle," a result of a decrease in the body's intake of fluids and inability to cough up normal saliva. Tilting the head to the side and elevating the head of the bed with pillows or obtaining an adjustable hospital bed will make breathing easier. Swabbing the mouth and lips with lemon-glycerine swabs also provides comfort.

6. Clarity of hearing and vision may decrease. The patient may want the lights on in the room as vision decreases. The family should be aware that hearing is often the last of the five senses to be lost, and they should not assume that an unresponsive patient cannot hear them.

7. The patient may become restless or have visions of people or things that do not exist. These symptoms may be a result of a decrease in the oxygen circulation to the brain and a change in the body's metabolism. Talk calmly and assuringly with the confused person so as not to startle or frighten him further.

8. Patients will have decreased need for food and drink. Food supplements may be helpful in maintaining nutritional status, but it is unwise to push the patient to eat.

9. Breathing may become irregular, with periods of 10-30 seconds of no breathing. This symptom is very common and indicates a decrease in circulation and buildup of body waste products. Elevating the head of the bed sometimes relieves irregular breathing patterns. It is not a symptom that requires specific treatment.

10. If the patient has a catheter in place, the amount of urine will decrease as death approaches. Irrigation to prevent blockage may become necessary.

In addition:

Family members should be aware of the following signs of death:

* No breathing

* No heartbeat
* Loss of control of bowel or bladder
* No response to verbal commands or shaking
* Eyelids slightly open
* Eyes fixed on a certain spot
* Jaw relaxed and mouth slightly open


The family should know whom to call when death occurs. If death is expected and a decision has been made to limit treatment to comfort care, the family should not call 911 or an emergency phone number. Instead, they should call their hospice or physician. A family member should write down the physician’s name and phone number, the patient’s full name, mother and father’s name, mother’s maiden name, Social Security number, and place and date of birth.

9.03 Physician Issues/Physician Suffering

For families to successfully deal with the needs of the dying patient they must interact successfully with the medical profession just as much as the reverse. This requires a certain level of compassion and understanding for health care providers just as providers are asked to consider the needs of the family. In a survey of 81 French general practitioners, 86% endorsed the assertion that encounters with death were a cause of physician suffering. The specific elements contributing to physician distress were reported to be the end of the doctor/patient relationship (58%), feelings of uselessness (55%) and failure (38%), increased awareness of their own mortality (49%), and the presence of "questions without answers." (31%) At the bedside of the dying patient, the most commonly reported feelings described by these physicians were sadness (94%) helplessness (89%), failure (61%), disappointment (59%), and loneliness (51%). Interestingly, physicians who specialize in palliative care of the dying patient find it much less stressful than those who only do so in patients they have failed to cure.

Physician problems are understandably aggravated in this country where, much more than elsewhere, the public has become so cynical about other people’s merits, be they politicians, attorneys, physicians, journalists, or clergymen. If the family enters the patient/physician relationship questioning the provider’s concerns for the patient, his or her financial value system, or commitment to the ethics of the profession, conflict is almost certain to ensue, to the detriment of the patient.

Consider the many following factors which can negatively influence the patient/physician relationship through the period of terminal care.
A. Inadequate Training

Many physicians are undertrained in care of the terminally ill. As a general rule "in teaching hospitals most patients are no longer seen by medical students or residents when the decision is made to treat them with comfort care. It is felt to be a waste of the trainee,s valuable time when they are OEnot going to do anything., OENot doing anything, translates into not undertaking traditional, disease-oriented medical treatments; but by implication it devalues the many complex medical options still available to help comfort the terminally ill. The clear message is given that caring for the dying has less importance than caring for those who will use medical technology to fight for life." [Quoting Quill, Death and Dignity, (W.W. Norton, New York, 1993) at p. 99]

As of 1993, only four percent of the nation,s medical schools has a separate course required on death and dying and only 26 percent of all medical residency programs offered instructions on end-of-life issues, although most programs offered some training as part of other programs.

Not only is training inadequate, the usual reference materials used by practicing physicians is also inadequate. The two most commonly referred to textbooks of medicine -- Cecil,s and Harrison,s -- are totally inadequate in the area. In the 1992 "Cecil,s," out of 2300 pages of text, only five discuss pain and three discuss the treatment of terminal illness. "Harrison,s" has even less coverage. The first modern textbook on palliative care, The Oxford Textbook of Palliative Medicine, wasn,t published until 1993, [Note: Updated by Oxford University Press, 1998] with the first guidelines on the treatment of pain in terminal illness being published for the first time in the late 1980s.

In most medical specialties when a physician finds himself or herself undertrained in a particular area, referral is made to an appropriate specialist. This is much more difficult when it comes to palliative care of a terminally ill patient, for there are so few specialists available and because doing so is likely to be considered a form of abandonment by the patient and physician alike.

Patients are likely to be unaware of this weakness in physician,s education, and physicians are likely to be more aware of the importance of an on-going relationship with the patient and family than they are aware of their own inadequate knowledge of the vast advancements which have been made in terminal care over the last ten years.

B. Palliative Care as Non-Traditional Care

For unexplained reasons, palliative care for terminal illness has largely developed outside of traditional medicine, only adding to the physician,s lack of knowledge. Although relief of suffering was a classic
concern of traditional medicine back to the Oath of Hippocrates, the twentieth century has seen such emphasis on technologic developments in the prevention and cure of disease that palliative care has failed to receive its just consideration until the last decade. Instead, physicians who specialized in palliative care and most of the research on such care developed largely in the hospice system [discussed in a separate chapter below] independent of traditional medicine. As a result, much of the information which can be found in the literature on hospice care has not been fully incorporated into traditional care.

In fairness to doctors, it should be pointed out that acceptance of hospice care by the individual patient requires three very difficult sacrifices which make it particularly difficult for the average physician. First, it requires the patient to forgo any care which is aimed at cure or extension of life, thus limiting care to concerns related to comfort. Second, hospice essentially requires the patient to accept total care from hospice-based physicians, thus forcing a split in the ties with the former primary care physician. Third, because third-party payment to hospice requires a physician statement that the patient is anticipated to have less than six months to live, physicians are reluctant to make such referrals until the terminal nature of the disease process is evident to the patient. To most doctors trained with a belief that terminal patients at least deserve hope, such a declaration to enable acceptance to hospice care is distasteful, for it is seen as nullifying any chance of hope for the patient.

C. Death as a Failure

Physicians are trained to make all efforts to prolong life and the patient,s quality of life. People make fun of the fact physician,s tend to look on death as a failure, but I have personally made it known to others that, "when I,m sick, I want a physician who thinks of death as a failure." I recognize such doctors may want to avoid significant contact with dying patients, but I am willing to accept that in return for the best efforts to keep me alive and well as long as possible.

D. Recurrent Need to Deal with Death

By the nature of their occupations, physicians are forced to deal personally with many more dying "friends" than most other members of society. It,s surprising how often the physician becomes the terminal patient,s best friend during the last few weeks of life. Terminal patients often require multiple visits over a short period of time through this period, and physicians frequently become the patient,s confidant during this process. Patients with whom there has been little exchange of personal philosophy over years of intermittent care all of a sudden find the physician the one person with whom they can share their most intimate fears and concerns. The compassionate physician listens nonjudgmentally, but after awhile it becomes harder and harder.

When the physician,s own weariness becomes evident to the patient,s family, it may be appropriate to ask the physician how he or she is doing. The answer may be strictly medical and related to the patient, but do not be surprised if the answer is more personal, such as feelings of sadness, compassion, loss, frustration, guilt, anger, anxiety, doubt, failure, depression, and helplessness. At times, if the dying process is being handled well with the maintenance of dignity, the physician may respond in a way
reflecting an inner feeling of empathy, caring, closeness, love, joy, or hope, but such feelings may not be expressed for fear they will be misunderstood by the family.

[Note: The author well remembers the day he called a family to tell the parents their daughter, who had been injured in an automobile accident, had died after ten days in coma. I was crying so hard they offered to come over and console me. I went to the funeral, but soon thereafter stopped. I had gone to too many. And, to relieve my own guilt for non-attendance, I reasoned if I continued to go, I wouldn’t have enough empathy left to sit and talk with my next dying patient.]

E. Time Considerations

To most physicians, time appears to be an extremely precious entity, a problem presently aggravated by managed care with its emphasis on bottom line values. This at times may be a blessing, for physicians train themselves to be very efficient in the use of time. If problems are presented to them in an organized way, they can be handled very quickly, but this means pre-planning by the family and other providers. In order to make the best use of physician time, it is helpful to establish a priority of questions before the doctor appears. Determine who will ask the questions and distribute the answers to the other concerned individuals. At times you may deem it harder for you to get an answer to a question by calling the insurance company or hospital than by asking the physician, but remember relying on the physician for all answers may shorten the time you have to ask other questions which only the physician can answer and thus deserve greater priority.

If there are many questions, prepare a well organized list. This is likely to save considerable time as many may be answerable together quickly and with the production of less ambiguity. If there are questions which do not require an explanation, consider faxing them to the office in such a way a nurse or assistant can obtain the answers and return the "call" without trying to establish phone contact with the physician.

F. Specialization and Costs

A frequent complaint leveled at physicians is the fact primary care physicians often stop visiting terminally ill patients in the hospital or at home on a routine schedule. As we have noted above, this can cause significant aggravation and a feeling of abandonment, especially when the physician has essentially become a family member during the patient’s terminal illness.

If such happens, some leniency should be allowed considering the present scheme of payment for
physician services. While it is true that payment shouldn’t be everything, physicians are in practice at least in part to make money. And when insurance companies or the government refuses to reimburse primary care physicians for their time once the patient is also being charged by a specialist [similar to coverage for hospice care] one might better understand the physicians, reluctance to maintain previous responsibilities.

G. Variability in Desired Treatment Philosophies

Physicians are often unaware of the desired approach to care of patients and families, especially when there are multiple physicians involved and many family members making different decisions. Absent specific agreements between the patient, family, and physician, suggested medical care is always likely to appear inappropriate to some. How much care should be addressed to the remote chance of cure? How much to prolongation of life? How much to maintaining the patient’s ability to communicate with family and friends? How much to relief of suffering? How much money is available to cover uninsured care? And how would the family feel if the patient were to die as a result of therapy addressed to relieve pain or suffering?

This last question, which will be dealt with more extensively in the chapter on double-effect therapy, is of particular importance. A recent, much quoted study of the attitudes of health care providers to terminally ill patients among doctors, nurses, and residents, showed that the vast majority thought terminally ill patients were generally overtreated, but they were undertreated for pain. The main reason for undertreatment was fear of causing an earlier death, largely stemming from uncertainty about the family’s potential reaction if this were to happen. As will be mentioned many times throughout this book, an understanding between health care providers and family related to the balance of aggressive therapy and comfort care, between the values of continued life and prolonged suffering, may be the most issue to be addressed by families who seek better care of their dying relative.

H. Dealing with Families in Conflict

Physicians find it extremely difficult to deal with families in conflict. They fear secondary agendas in issues raised and are often led by compassion for the dying person who is placed in a position of having to try to avoid family squabbles while dealing with his or her own existential concerns. This does not mean physicians wish to avoid bona fide medical questions, even if they are presented as involving a disagreement between family members, but when this happens and they are asked to help in decision-making, they are particularly prone to get angry when their advise is countermanded as part of the family squabble.

For example, the physician tells the family the patient is no longer taking enough food and fluids to maintain nutrition and hydration, a feeding tube will have to be placed. The family cannot decide whether to go ahead or not and the physician is asked his opinion. His opinion is that placement of a tube would just be prolonging death, not life, for the patient will never regain the ability to think. The family continues to disagree with the minority threatening to bring a law suit if the physician goes along with
the majority who wish to refuse artificial sustenance. [Note: if the family had decided either way before or after asking his opinion, their decision could probably be followed without difficulty -- physicians are only advisors, the final decisions rest with the patient and the next-of-kin. But if the caring physician accepts this request to essentially make the final decision and then has it thrown back, one can only anticipate a tendency for the physician to withdraw in the future.]

I. Dealing with the Law

Physicians do not know the law and are very antagonistic to getting involved with legal matters. When in doubt, it is much easier for the physician to just continue than to forsake aggressive care. This is another problem which is likely to be aggravated by the presence of family conflict.

J. Miscommunications

There is always a potential problem of miscommunication between patients, families and health care providers, but the recent legal requirement that providers discuss advance medical directives with patients and families at the time of admission to hospitals and other facilities has created a new type of misunderstanding. Because of this recent awareness of patient's rights, physicians are increasingly desirous of documenting where patient's stand regarding terminal care. To obtain this information, they may come to push for decisions on the part of the patient and family too early in the course of a disease process, giving the impression death is imminent or medical situations irreversible when they are not.

Too often I have recently been asked by families whether they should go along with the physician's suggestion to write a DNR order [discussed below] or to forsake care in a situation in which the patient may be perfectly capable of speaking for himself or herself, or in situations which are clearly reversible. When I ask why the doctor thinks the DNR order or discontinuation of aggressive care is advisable, I find out it has not been truly advised, just mentioned as a possible course of treatment for the patient and family to consider.

It is important for families to separate the two -- the one, an actual suggestion from the doctor to limit care to comfort measures and the second, a legal requirement on the part of health care providers to discuss with the patient their right to direct their own care through a terminal illness.

K. Physicians Facing Their Own Mortality

Each time a physician deals with death, he or she is forced to face personal mortality. Doctors react differently, creating different responses to patients and families. Most commonly they withhold personal feelings from the dying patient and family, often with purposeful intent -- "the physicians's role is a port in the storm, not to show emotions." In contrast, many other physicians believe in a sharing of feelings and openness when dealing with emotions. Occasionally physicians do neither, either by denying their own feelings or by dealing with the situation "as a learning experience."
Most medical commentators suggest it is best for physicians to share their own feelings with patients and families, but many fine physicians are unable to do so and will persist in choosing an alternative approach.

### 9.04 Telling Patients the Truth

One area of great potential disagreement both among providers and families is the necessity of telling patients the truth about their illnesses. Thirty years ago it was standard procedure for physicians to keep a poor prognosis secret unless specifically asked by the patient in a serious and repetitive manner.

As the medical profession came to increasingly accept the concept of autonomy, there came a greater need for informing the patient, but clinical practitioners were slower to move to open communication than were theoretical scholars who came to feel the patient's "right to know" constituted an obligation on the part of the physician to tell all.

In retrospect, it is still hard to know the relative merits of telling everything and limiting what is told to that which is asked. Most physicians believe patients who do not ask directly are still aware when they are terminally ill but purposely choose not to ask in order to maintain their inner desires to deny reality. Recognizing that once stated, the facts cannot be denied, most doctors still tend to resist total honesty as long as that appears to be the wishes of the patient, unless there is a clear need to tell in the patient's best interests.

Remember, the need to tell is seldom an emergency. If the patient asks, I believe law and ethics requires the patient be told. In the absence of questions, however, I still believe as others trained at my time were taught that as long as the family is well aware that death is approaching and sees no need they be told, there is no inherent need to go beyond answering those questions which the patient chooses to ask to make the full situation known. [clearly, others would disagree with this approach.]

At the same time, I believe that if the family believes the patient should be told and prefers the doctor tell the patient in private, that is the doctor's duty. Before doing so, I would suggest the physician discussed it with the family to obtain information about the patient's religion or spiritualism, the availability of related resources in their life, and a basic understanding of the family's feelings about terminal care, including their personal cultural and psychological attitudes about death. This will put the physician in a far better position to answer the patient's questions after he or she is told that life is coming to an end.

[Note: In the past, physicians may have even been reluctant to share the truth with the family. This no longer seems to be the case once the diagnosis is clearly established. In contrast, because of the great variability in disease progression in various patients, most reasonable physicians remain reluctant to give a time prognosis or to try to prognosticate what symptoms are likely to appear in any individual case.]

[I cannot leave this topic without mentioning a situation I was put in some twenty years ago by the wife of a man with rapidly progressive malignant melanoma which had just been diagnosed by liver biopsy.]
Because death was anticipated in less than a month and because he had business arrangements I knew he would want to make, I agreed with his wife he should be told he was dying even though he hadn’t asked. [I suspected he had figured it out already] As always under the circumstances, I offered to tell him. The wife said she certainly wanted me to do so, "but tell it to him softly, so it doesn’t hurt." Her request in fact hurt me deeply. I really cared for the man. I told him, but there was no way to honor her second request. I couldn’t even find a way to do so without hurting myself.]

9.05 Desirability of Working with Patients, Not Surrogates

A further outgrowth of the modern trend to autonomy is a growing desire on the part of the physician to work with the patient as opposed to the family in determining appropriate terminal care. In some ways this new direction tends to complicate communications with families, who in the past were given much more of a final say than is now the case. Remember when dealing with physicians that when the desires of the family and patient are at odds, it is the physician’s obligation to follow the patient’s directives even if the family’s would seem more in keeping with the patient’s best interests. Remember also that as long as the patient retains decision-making capacity, the physician must check with the patient before significant changes in approach to patient care are undertaken -- and that even if the patient has lost decision-making capacity, the family cannot direct the forsaking of non-comfort care as long as the patient, competent or not, directs such treatment be continued.

In large families in particular, the physician can be greatly helped in such situations by the patient naming a representative spokesperson either by orally telling the physician or through a written durable power of attorney for medical decision-making.

9.06 Balancing Symptom Relief and Sedation

Because many of the drugs used to relieve pain, shortness of breath, anxiety, depression, nausea, itching and similar symptoms produce sedation, there is frequently a trade-off which has to be anticipated between symptom relief and sedation. Obviously, the patient is the person who should make this choice, but this produces two common problems. First, it is not always easy for the physician to regulate the medications to achieve the balance desired by the patient, the dose required to relieve the symptoms often producing sedation greater than the patient would want. Second, attempts at minimizing medication, especially for pain, is likely to leave the family in the position of having to suffer along with the patient even though it may be at the patient’s direction.

9.07 Financial Issues

It is an unfortunate truth that the United States remains one of the few nations in which terminally ill patients must worry they will not receive the best available terminal care for financial reasons. At the same time, it is important to put this reality in the appropriate perspective. Although everyone may not want to pay for the most exotic care or be able to do so, it is great to be treated in America where the best of care is at least available if the choice is to spend all available resources to obtain such care. At the
same time, it is reassuring to know the mainstay of terminal therapy, drugs like morphine, are relatively inexpensive and Medicare has slowly been expanded to cover such important aspects of terminal care as hospice. In addition, as of 1996 Medicare has established a specific billing code for palliative-care hospital admissions which is making coverage for such care easier in the present than it has been in the past. This leaves the major problem of financing terminal care the cost of home-care, which is not covered by Medicare or most insurance. This in turn provides an incentive to hospitalize patients even those this is likely to lead to more aggressive care than would be deemed appropriate in the home care setting.

Because the patient himself or herself is likely to be concerned about expenses, it is wise for the family to try to find out just which expenses will be covered by Medicare, personal insurance, a Managed Care Plan, or other potential sources of private or public financing in anticipation of the cost of terminal care even if the patient makes no efforts in this regard. In addition, it is wise for the family to come to some agreement about what is reasonable under the family’s general financial circumstances. In reaching decisions, be aware the patient may be even more worried about unwarranted costs of treatment depleting assets than are the family members who stand to inherit those assets. This may lead the patient to make up excuses for refusing specific care when, in fact, it is the cost that has fostered the decision. This is particularly distressing when, in fact, the care in question would be covered by third party insurers but this is unknown to the patient who does not want to broach the subject for fear of disclosing his or her personal reasons for trying to reduce costs.

The inroads of managed care on medical practice and the threatened extension of managed care to many Medicare recipients poses a particular problem in the near future. A recent advertisement for such company boasted that they had cut the costs of care in the last year of life by twenty-five percent. How much of this cost reduction was based on decreased payment for undesired care, for treatment undertaken in an attempt to reverse treatable disease, or for treatment aimed at improved comfort was not addressed in the claim. Until this is determined, it is hard to say how much cost reduction is desirable. What is evident is an increased need on the part of families to be vigilant, and to complain loudly when palliative care of a terminally ill patient is denied or under-utilized.

Keep in mind that although physicians are supposed to tell patients when more effective care than is being offered could be available outside the insurance system, this does not always happen. Because of this, it may be wise for family members to ask the physician at times if additional care is possible, even if it has to be paid for out-of-pocket. And always remember, the squeaky wheel gets the grease -- repeated request and demands from managed care companies often lead to re-evaluation of circumstances and fee coverage.

Family decisions regarding the financing of care should be made known to health care providers who are likely to be considering health insurance coverage in planning terminal care. If family finances are limited and health care coverage poor, the physician should know that exhaustion of finances in a vain attempt to maintain patient’s unwarranted hopes in the early course of disease may leave the patient unable to pay for much needed palliative care later in the illness.
Note one area in which a conflict is particularly likely to arise is in the payment for so-called "patient controlled analgesia" (PCA) which requires rather expensive equipment to allow the patient to self-determine the timing of additional doses of morphine or other narcotics. Similarly, some insurance plans provide payment for morphine in an institution, but not at home.

This is not to say more expensive care is necessarily better. To the contrary, in most cases the most meaningful care is probably among the most inexpensive, care by family members in one's own bed at home receiving oral morphine on a regular basis to relieve constant symptoms and additional morphine as needed by injections given with the help of hospice care providers and family members as desired by the patient.
CHAPTER 10. HOSPICE

10.01 Hospice; Introduction

10.02 Hospice; History

A. England

B. America

C. Home v. Institutional Hospice Care

10.03 Hospice Philosophy

10.04 Hospice Approach

A. Primary Concern is Symptom Relief

B. Interdisciplinary Team and Plan of Care

C. Autonomy and Patient Communication

D. Working with Family Caregivers

E. Emphasis on Home Care

10.05 Hospice Experience

10.06 Medicare and Hospice

10.07 Hospice Cost

10.08 Problems with Hospice

10.09 Separation of Care

10.01 Hospice; Introduction

It is a sad commentary on American medicine that hospice care of the terminally ill comes to be presented as part of a separate chapter in this book -- as if it were an alternative means of therapy and not a normal subspecialty of traditional medicine. In some areas of the country and with some health care
providers, the term "hospice care" may in fact be used synonymously to mean "palliative or comfort care," but in others it still represents more of an alternative to traditional medicine than an accepted component of terminal care.

In retrospect, it is hard to say how this divergence in care came about, but that is unimportant. For the purposes of this book, the important short term goal is making the presence of a less aggressive, more comfort oriented approach to terminal care known to the reader. As for the long term goal, the aim of the book would be to find a way to incorporate the best methods of both hospice and non-hospice palliative care into a single system for the benefit of all patients.

10.02 Hospice; History

A. England

The term "hospice" originated in the middle ages to signify "havens" where weary travelers could find hospitality and care. Although the term may have first been applied to care of the terminally ill in Ireland in the late 1800's, credit for founding the modern hospice movement is generally given to Cicely Saunders, a nurse, social worker, and physician who was instrumental in opening St. Christopher's Hospice, the first modern day, free-standing hospice of our time, in London, England, in 1967. For this service, she was later named Dame of the British Empire by Queen Elizabeth in 1980.

Although originally trained as a nurse in a traditional medical setting focusing primarily on cures and prolongation of life, Saunders believed what mattered most at the end of life was pain control, dignity in dying, and help addressing the psychological and spiritual pain of death itself. As a result, at St. Christopher's she emphasized the need for effective symptom control, care of the patient and family as a unit, and the development of a multidisciplinary team approach, using volunteers, a continuum of care which included the home setting, and follow-up with family members after the patient's death.

B. America

The first hospice in America, the Connecticut Hospice, was opened with Dr. Sylvia Lack, who had trained at St. Christopher's under Dr. Saunders, as its medical director in 1973 in Branford, Connecticut. Funded in part by the National Cancer Institute, it was originally home-care based, but later expanded to include a free-standing, in-patient facility. It purposely chose not to incorporated with other medical facilities and in many ways held itself out in opposition to established medical care, positioning itself as a direct rebuke to the way pain was managed in conventional settings.

Unlike the original English hospices, American hospices generally developed primarily as home based institutions, thus evolving more as a concept of care rather than a place for care.

As a home based care service, hospice was viewed as a potential cost-saver, leading the government to authorize a national study of hospice care which evaluated more than 1,700 patients undergoing terminal
care along with their families. When this study showed that satisfaction with hospice was at least comparable with that of conventional care at lower costs, Congress authorized Medicare to reimburse hospices for the care of terminally ill patients who met specific criteria. As will be discussed below under "Problems," these specific requirements have been a major stumbling block to further expansion of hospice care, two-thirds of which is presently paid for by Medicare.

In spite of its limitations, hospice use has steadily increased. Studies have shown 300,000 patients and their families were served by hospice in 1994 compared with just over 200,000 in 1990. Of these patients, seventy-five to eighty percent have a diagnosis of cancer and the other twenty to twenty-five percent are mostly suffering from AIDS or end-stage kidney, heart and lung failure. The average case load of any single hospice facility is eighty patients and the average length of stay is about forty-two days. There are presently almost 3,000 hospice programs with at least one in every state. Approximately half of these programs are independent community programs, approximately one quarter are hospital-based, and most of the remainder are affiliated with home-health agencies or nursing homes.

Medicare expenditures for hospice coverage, which amounts to approximately two-thirds of total receipts, rose from $2 million in 1984 to almost $1.2 billion in 1994, but this still represented less than 1% of total Medicare benefit payments in that year. Because hospice is an optional Medicaid service, hospice comprises only 0.1% of total Medicaid payments.

**C. Home v. Institutional Hospice Care**

Initially, hospice programs as developed in England emphasized residential facilities using a multi-disciplinary approach in the care of the terminally ill. Today, most hospices are solely or primarily home-care programs with more than 85% of their enrollees being served at home, with few free-standing in-patient facilities, but increasing numbers of in-patient units in nursing homes or hospitals.

**10.03 Hospice Philosophy**

Hospice philosophy is said to be based on three basic principles, openness of mind, friendship of the heart, and freedom of spirit to listen to patients "as they search for the meaning of their own spirituality." This latter is said to require an affirmation to patients that regardless of their sex, race, lifestyle, religion, or disease, hospice accepts them as human beings and cares about their suffering.

These principles are further said to be based on several concepts:

1. Death is a natural part of the life cycle. When death is inevitable, hospice will not seek to hasten or postpone it.

2. Pain relief and symptom control are clinical goals.

3. Psychologic and spiritual pain are as significant as physical pain, and addressing all
three requires the skills and approach of an interdisciplinary team.

4. Patients, their families, and loved ones are the unit of care.

5. Bereavement care is critical to supporting surviving family members and friends.

6. Care is provided regardless of ability to pay.

"The goal of hospice is to promote an alert, dignified, and pain-free life for its patients in a manner respectful of their individual needs."

10.04 Hospice Approach

A. Primary Concern is Symptom Relief

The overriding characteristic of hospice care is addressing the need to relieve suffering and emphasizing quality of life. In hospice care the patient's symptoms, including pain, are aggressively treated to make the patient as comfortable as possible, but efforts to extend the patient's life are usually not pursued. This emphasis tends to stress a low technology environment suitable to the alleviation of patients' fears of an undignified, lonely, technologically dependent death.

Hospice is said to focus on the physical and emotional symptoms of the patient and family rather than on the terminal disease. In addition to controlling symptoms, its intent is to help the patient and family confront the issues which accompany approaching death. An emphasis on "total" pain control, including physical, mental, social, and spiritual aspects, is said to exemplify the concept of total patient care. Pain control as well as the management of other symptoms comprises the primary and ongoing focus of care based on each patient's needs.

As a result of this approach, hospice tends to emphasize the aggressive use of narcotics as needed for pain control even if such treatment requires heavy sedation and secondarily shortens patient survival. Hospice does not advocate cardio-pulmonary resuscitation (CPR) and believes all unwanted medical interventions, including artificial nutrition and hydration, should be removed, although this is not universal -- some hospices accepting artificial sustenance if it would produce a significant time in reasonable comfort for the patient. Hospice also believes anorexia (loss of appetite) should only be treated when it holds promise of significantly improving the quality of life, for it has not been shown to produce clinically significant weight gain, enhanced quality of life, or prolonged survival.

B. Interdisciplinary Team and Plan of Care

A major difference in hospice care is reliance on a written plan of care developed by an interdisciplinary team for each individual as opposed to the attending physician directing the over-all approach to the patient. This team is typically comprised of the patient's attending physician, hospice physicians with
palliative care training, nurses with specialized training and experience with pain and symptom management as well as in physical assessment of patient suffering, social workers with clinical experience appropriate to the counseling and casework needs of the terminally ill, spiritual counselors with education and experience in pastoral counseling, a volunteer coordinator with skills in organization and communication, and trained volunteers. Additional professionals, such as dieticians, pharmacists, nursing assistants and various therapists may also be involved. Part of the work of the team is to help and encourage the patient and family to develop and maintain a patient-directed, individualized plan of care addressing the physical, social, religious, and cultural differences and needs of the patient and family.

This approach is often referred to by hospice as continuing care or supportive care. Its goals are said to be relief from pain and other distressing symptoms, psychological and personal support for the patient and family, and assistance to help the patient maintain his or her daily activities, independence, and dignity. Unlike traditional care, hospice care is intended to emphasize psychosocial and spiritual support and counseling for the patient and family to cope with the various problems presented as the patient's illness progresses. In spite of these stated differences in intent, actual differences in practice from traditional medicine may not be as great as suggested.

One major difference in the hospice approach to care is the reliance on volunteers, usually family members, as part of the caregiving team. Although this reliance frequently serves the patient well, the need for constant availability of the family for hands-on caregiving often puts undue stress on family caregivers which can easily undermine the best intent of the overall system of care.

C. Autonomy and Patient Communication

Hospice supporters tend to promote its stress and support of "autonomy," the right of the individual and family to make medical decisions, the use of advance medical directives, and the refusal of unwanted life prolonging therapy including refusal of artificial nutrition and hydration. They also stress hospice's stated dedication to the importance of honest and open discussion with the patient and family as a means of facilitating communication. At the same time, in spite of their stated stance in favor of autonomy, hospice supporters have been strongly antagonistic to the acceptance of physician assisted suicide, stressing in particular the fear its legalization would cut off interest in developing better palliative methods of care in this country.

In some ways the antagonism of hospice workers to assisted suicide is reminiscent of the physician's reluctance to accept the restrictions of non-comfort based care proposed by hospice. To the physician, the acceptance of inevitable death is viewed as a failure of medicine. To the hospice supporter, the patient's desire for physician assisted suicide is viewed as a failure of palliative medicine to provide adequate relief of pain and suffering.

D. Working with Family Caregivers

As noted above, hospice relies heavily on family caregivers. Family members are instructed on methods
to minimize the patient's distress, organize the house, administer medications for pain and nausea, and accompany the patient throughout the peculiarities of the disease. At the same time, hospice also emphasizes the needs of the family for support through such efforts as vacations from the responsibility of patient support (respite care) and the need of the family for bereavement care during and after death.

E. Emphasis on Home Care

Most patients prefer to die at home and away from the high technologic approach of medical institutions. In keeping with this desire and the requirements of Medicare for reimbursement, over 85% of hospice care is given at home. Because of this emphasis and the high level of reliance on family members as caregivers, hospice has developed special expertise in advising families how to set up the home for ease of meeting patient care needs and specific needs of the caregivers as well.

In general, patients are encouraged to stay at home as long as possible, but services can generally also be provided in nursing homes, assisted-care facilities, and some hospitals. In most cases, acute in-hospital care can lead to discharge home, but all too often, it is the absence of family caregivers and hospice's reliance on continual care by the family which combines to force ongoing institutionalization of the patient until death.

10.05 Hospice Experience

In general, patients experiencing hospice care prefer it to traditional medical care, but this may well be a matter of initial choice -- those who want care limited to palliation at home choosing hospice and therefore preferring its approach, while those patients who want to hold on to the possibility of prolonging life tend to choose more aggressive in-hospital care and not hospice. Either way, it would be fair to say most patients treated in any plan with a strong emphasis on terminal palliation die with comfort and dignity.

In one well-controlled study in which half the patients received hospice care and half traditional medical care, the satisfaction with the two systems was very equivalent, but those receiving traditional care did so at a hospital which may have placed more emphasis on symptom relief than the average facility. Other studies of pain relief have found the best results when hospice care was combined with in-hospital care. Still other studies suggest hospice treated patients may have a better quality of life, but only during their last three days.

10.06 Medicare and Hospice

Acceptance and reimbursement of hospice by Medicare has been a major factor in its growth and acceptance, but the specific requirements have also produced major stumbling blocks in its development. These specific requirements include:

1. Physicians must certify a patient's life expectancy is less than six months;
2. The patient must waive all rights to routine Medicare payments for services which are related to active, non-comfort related treatment of the terminal condition; and

3. Continued care of the patient by the patient,s own personal care physician needs to be coordinated through the hospice care program.

As a result of these requirements, many patients do not receive hospice care because of the difficulty physicians have in predicting when a patient has less than six months to live and the fear that if it is instituted too early, the patient will end up being denied Medicare coverage for health care required for specialized end-of-life care. In addition, the need for physicians to work only through the hospice coordinators and the need to tell patient,s they will have to give up all active care aimed at curing the disease are both difficult steps for physicians to recommend, especially as they see doing so as taking away the patient,s last rays of hope.

Under Medicare financing, hospices receive a set fee per day for home services and must provide the basic outline of the services required in federal and state guidelines. Within the daily reimbursement, hospice programs are to provide all home-support services, medications, case-management, and bereavement services to the family. The daily rate must also cover all intensive treatments related to the primary diagnosis including radiation therapy, chemotherapy, infusion therapies and others. Separate rates are available for continuous care and inpatient-care days, but still under a single payment per day, which has been set quite low in general to encourage home care. Payment to attending physicians remains outside the rate.

10.07 Hospice Cost

Although hospice care remains costly, approximately $100 per day at home, it is clearly less expensive than other approaches to terminal care. In one study the cost of hospice care proved lower than conventional care by over $4000 per enrolled patient for home-care hospice than for traditional home health care, and $1300 lower for hospital-based hospices. Most of the cost savings were associated with the last month of life, when conventional care costs accelerated more rapidly than those of hospice care.

10.08 Problems with Hospice

Many of the problems commonly associated with hospice care have already been mentioned -- the difficulty of determining that life expectancy is less than six months, the feeling of hopelessness which may result when the patient is told no further cure is possible, the likelihood of failure when attempting to integrate previous attending physicians into the patient,s care during the terminal stages, and the need for the patient to give up Medicare coverage for certain types of medical care in order to receive hospice care. But there are many more.

First, a problem which could easily be rectified is the ambiguity as to how Medicare handles situations in
which patients outlive the anticipated six months of need. Individual experiences note continued payment for additional six-month periods extending as long as three years, but the lack of accepted procedure to obtain such extensions leaves physicians reluctant to refer patients early out of fear that coverage will not be available later in their course of illness if the patient survives longer than expected.

Second, hospice care as presently constituted requires the availability of voluntary home caregivers preventing its use for people who do not have family members or other unpaid, supportive persons available around the clock in the home. Alternative payment schemes could be devised to cover these situations.

Third, the artificial separation of hospice care from traditional medicine, whatever its origin, undermines the fact that palliative care methods should be employed in traditional medical care settings along with standard therapy aimed at cure and/or prolongation of meaningful life.

Fourth, and conversely, hospice care should recognize that modern technology has a lot to offer the terminally ill patient in the way of symptom relief. At times, as with AIDS, it may also hold the promise of reversing what appears to be a terminal situation, making a trial of experimental drugs appropriate even in a hospice environment.

Fifth, hospice care requires a stable home setting in which it is safe to bring narcotics.

Sixth, insurance coverage for hospice care is spotty and often follows the requirements of Medicare, thus eliminating the same potential patients less than 65 years of age from coverage.

Finally, hospice services currently do not cover patients with Alzheimer disease and their families who could benefit from its insights and support. Although predicting life expectancy with Alzheimer patients may be extremely difficult, those who have reached the advanced stages of the illness should be considered in a terminal condition similar to incurable cancer. A hospice treatment option which emphasized maintenance of patient comfort instead of preventing death at all costs should be available to such patients.

Many of these problems are nicely summarized by Joanne Lynn, M.D. in a 1995 article in the Journal of the American Geriatric Society as follows:

In public and professional media alike, an odd misstatement of the mission of medicine in caring for dying persons has become commonplace. We are said to turn from cure toward care, or to move from aggressive, life-sustaining care to palliative care. There are imagined to be two kinds of persons: ordinary persons who when sick are best served by aggressive care and dying persons who are best served by symptom management. This image profoundly disserves us. All persons, even ordinary sick persons, do not want to suffer unnecessarily and would prefer symptom management at all times, unless tolerating a symptom provides a much improved outcome. Furthermore, persons expected to die soon
are not often eager to die and would prefer life-sustaining treatment, provided that the life to be led thereby is reasonably comfortable and meaningful. In sum, what we want when close to death is not different from what we want from medical care in all circumstances: to have the care that enables the best possible life, given the limitations of the circumstances, as evaluated from the patient's perspective. We want, at all times in our lives, the mix of curative, preventive, rehabilitative, and palliative care that enhances our lives.

**10.09 Separation of Care**

In spite of the fact that hospice and traditional medical care learn from and accept each other to a degree, they tend to remain separate, somewhat competitive elements in the health care system. As a result, only one-third to one-half of patients with cancer and AIDS receive hospice care, mostly in the last one to two months of life. For other terminal illnesses, hospice care is even less common, with only an approximate 17% to 20% receiving any level of hospice care. This percentage may have increased under a new federal law which went into effect in 1995 requiring hospital discharge planners to inform all terminally ill patients about hospice services, but statistics are not readily available as yet to show any change. It may also increase in the future as cost-conscious managers press to decrease the percentage of patients dying in hospitals and nursing homes, which presently stands around 62% and 17% respectively.

Although both traditional and hospice care providers should clearly learn from each other, whether the two can, or should be combined is more problematic. To integrate the two would require overcoming numerous problems, many of which would be difficult to compromise.

First, whereas traditional medicine assumes cure is the primary goal, hospice assumes palliation is primary. Undoubtedly, over the course of most terminal illnesses, there are long periods of time when these two approaches can reasonably co-exist, but there are times when they cannot. As long as hospice remains resistant to maintaining therapies aimed at cures and traditional medicine refuses to give up even a negligible chance of cure or remission in favor of better palliation, the two must inevitably come into conflict. [Note that many hospitals are initiating programs in palliative care either with or without associated hospice participation.]

Second, the hospice approach is more sympathetic to subjective phenomena than the curative model. For example, hospice is much more concerned with the treatment of pain despite the fact it cannot be verified and at times cannot even be explained. Treating pain without such an explanation would be difficult for traditional medicine to accept, especially if more specific therapies would be available once a more exact diagnosis is made.

Third, hospice care is more tolerant of incomplete medical knowledge and accepting of medicine,s limitations than is traditional medicine. Diagnosis is not a goal in itself. Rather, it is pursued only if doing so conforms to patient-determined goals of palliative medical care. Similarly, a specific treatment is regarded as appropriate only if it is worthwhile from the patient,s immediate wish to avoid pain and
suffering, in contrast to traditional medicine's more long term approach.

Fourth, hospice does not equate death with defeat. To the contrary, it accepts death as the natural conclusion of life, while traditional medicine looks closely at deaths and tries to figure out how they can be avoided in the future.

Fifth, hospice care takes an approach which tries to tailor a plan specifically to each patient according to the patient's personal values and preferences. This approach contrasts with the curative model, in which the appropriate treatment is considered a scientific question best decided with longevity and cure in mind.

Sixth, traditional medicine stresses a need for continued hope in the dying process, while hospice care stresses acceptance of death. In fact, this process tends to set up a circular effect. In holding out hope, traditional medicine tends to give optimistic assessments of prognosis, which tends to lead patients to accept more aggressive therapy not acceptable to the hospice approach.

Seventh, because hospice care relies heavily on its own doctors, nurses, aides, facilities, reimbursement plans, etc., its initiation tends to undermine continuity of care and carries the potential of producing a major psychological stress at a most inopportune time in the dying process -- when the inevitability of death is newly established and must learn to be accepted by all.

Eighth, the unwarranted association of hospice care with the concept of "holistic medicine" identifies it with other modalities of limited appeal to traditional medicine.

Ninth, hospice has frequently appeared to take a stand negative to technologic advances, while traditional medicine stresses the development of new technologies which it views as being beneficial in controlling pain and suffering.

Tenth, hospice tends to believe its primary appeal is to patients who want to escape from the traditional medical system, which it proclaims undervalues the importance of palliative care. This is reflected in many physicians, belief that hospice's role begins when traditional medical care has nothing more to offer, and with the belief among many hospice workers that physicians look to hospice as a dumping ground when they are no longer interested in caring for the patient.

Eleventh, traditional care physicians have little knowledge of the workings of hospice. It has been estimated only 17% of medical training programs use hospice rotations, and only half of these are required. In addition, only 9% of the programs have a resident or fellow serving as a member of a hospice team.

The following excerpt by P. Wilkes, taken from a July 8, 1997 New York Times Magazine article entitled "Dying Well Is the Best Revenge," suggests some of the antagonism medicine holds for hospice and the need for better communication and greater mutual respect for each other's goals in therapy:
"The passion of hospice people is admirable, but their arrogance is irritating," Murphy [a traditional physician] said as we talked in her office at the end of one of her typically busy days. She had been Mike,s regular doctor for many years. "They view themselves as the champions on white horses riding in to save the day. The hospice approach often is too rigid, expecting -- even demanding -- that death be this fantastic event when all relationships are mended and life is neatly wrapped up. It,s as if they know it all and we ordinary practitioners know nothing about this patient we,ve been seeing for years. I,ve heard families complain that hospice simply took over, forced themselves in and began directing how their loved one ought to die. Let,s face it, the majority of deaths are painful, difficult, unfortunate, inglorious, and you have to accept this.

As a result of these conflicts, the benefits of hospice, when available and requested, are usually limited to a few weeks of life, perhaps two to eight. In many ways this reflects the natural history of cancer. Except for periods of medical treatment, cancer usually allows long periods of functional stability or slow decline, followed by dramatic losses over a relatively short period before death. It is usually only this "failing" phase which triggers consideration of enrollment in a hospice program. For many, this may in fact be most appropriate, but for others, treatment based on hospice principles becomes appropriate much earlier in the course of the disease.
Slowly in the course of a terminal illness the body weakens and its reserves dwindle. Frequently as this happens the mind becomes less active and less tormented -- more accepting of the reality of death. At the same time, pain and other symptoms may also decrease, and the last few days of life may be totally devoid of significant suffering up until the time, as usually happens, the patient falls into a deep sleep or coma which quietly precedes death.

At other times, however, death is not so benevolent. Pain and other symptoms like nausea and shortness of breath may continue and even get worse requiring increasing medical intervention to obtain relief. When this happens, physicians are forced to make a difficult decision -- as body strength falters it becomes less and less tolerant of high doses of drugs, but as pain and suffering increase, adequate treatment requires ever increasing amounts of medication. Eventually a point is reached at which further increases in drug dosages to adequately control pain or other symptoms may be beyond the limit of body tolerance and could easily result in death.

The question this dilemma raises is when does the known risk of death from giving medications sufficient to control symptoms become potential manslaughter if death should occur? This chapter on the theory of "double-effect" discusses this issue. In reading the chapter it is important to keep in mind the use of the double-effect theory almost always relates to a situation involving an end-stage terminal illness at a point in time when essentially everyone involved in the patient’s care has accepted that death is no longer the patient’s enemy, but would be a welcomed, if not sought after, event.

It is also well to keep in mind how common double-effect therapy is in the last few days of life. In the Netherlands, where euthanasia has been practiced openly for years, a recent very well researched report noted less than four percent of deaths occurred as a result of active euthanasia, but 17.5% were probably
hastened by the giving of drugs to relieve terminal suffering.

11.02 The Principle of Double-Effect

"Double-effect" has been defined as "the administering of opioids or sedative drugs to relieve pain and suffering in a dying patient with the incidental consequence of causing either respiratory depression or extreme sedation or both, resulting in the patient’s death."

For an action leading to a patient’s death to be held to be both ethical and moral based on this concept, it must conform to the following four legal requirements:

1. the action itself must be good or indifferent;

2. the good effect and not the evil effect must be the one sincerely intended by the agent;

3. the good effect must not be produced by means of the evil effect; and,

4. there must be a proportionate reason for permitting the foreseen evil effect to occur.

Applying these requirements to the situation of the suffering, terminally ill patient:

1. the action must be undertaken with a reasonable chance of reducing pain and/or suffering;

2. the action must be primarily intended to relieve pain and suffering, not to produce death;

3. the action cannot be undertaken with the intent of producing death as a means of achieving relief from pain and suffering; and

4. there must be enough reason to undertake the action, such as increasing the dosage of morphine as needed to control pain, to risk the foreseeable chance of producing death.

The general principle of "double-effect" therapy was well summarized by Dr. Timothy Quill in a 1995 article in the Archives of Internal Medicine entitled "You Promised Me I Wouldn't Die Like This! A Bad Death as a Medical Emergency":

The doctrine of double effect relies on a sharp distinction between intentions and consequences. Interventions that are intended to have a "good" primary purpose, such as the relief of suffering, can be justified even if they have unintended "bad" consequences, such as contributing to a patient's death. Such bad effects can even be anticipated as long as they are not intended. This distinction has freed physicians to provide high doses of opioid analgesics to patients who are dying in pain, even if this intervention indirectly
contributes to an earlier death. In practice, one can frequently find a pain regimen that provides sufficient relief without compromising the patient's consciousness of life span, but here again data are lacking. Double effect has recently been extended to treat patients who are tormented in dimensions other than pain. The primary intent of this intervention is to relieve suffering, and the sedated patient is then allowed to die of his or her disease, the barbiturates, pneumonia, and/or dehydration since he or she can no longer eat or drink. To remain within the confines of the double effect, death in these extreme circumstances may be foreseen, but must not be intended.

To keep double-effect therapy within medically accepted boundaries, one must be able to say the patient died from a disease and not from the intended effects of the medication. It must be a rational statement to say death occurred as the result of the combined physical effect of the disease process and the medications which were required to treat the disease.

Although double-effect therapy is often considered to be quite different than other therapies because of ethical and legal considerations, it is not very different medically. Whenever a medical intervention is undertaken, there is always some identifiable and foreseeable risk to the patient, and often at least a minimal risk to the patient’s life. In every case, the physician is expected to evaluate the risks and benefits of treatment, to recommend a course of treatment, and to provide treatments chosen by the patient or a surrogate speaking for the patient.

Thus, in a sense, the principle of double-effect comes into play every time a clinician chooses an antibiotic or chemotherapy regimen and weighs the desired outcome against predictable toxicity; every time a surgeon and patient discuss the pros and cons of extensive surgery, life-threatening or not. Looked at in reverse, double-effect therapy is no different from any other medical therapy, the only difference being it is undertaken in a situation in which the risk of death is high but the risk worth taking because death is close at hand and in the absence of symptom control, there will be no pleasure in life prior to its occurrence.

11.03 Historical/Religious Development

The concept of double-effect can be found in the writings of Hippocrates, but is generally traced back to Aristotle through the thirteenth century teachings of St. Thomas Aquinas who invoked the principle of double-effect to justify a killing in self-defense. In his discussion, Aquinas stated: "The act of self-defense may have two effects, one is the saving of one's life, the other is the slaying of the aggressor. Therefore, this act, since one's intention is to save one's own life, is not unlawful." If, however, the act was undertaken with the intention of taking the other's life, the description of the act could no longer be one of "self-defense" but rather one of "killing." St. Thomas then went on to say that even if an individual foresees the appropriate force used in self-defense will definitely result in death, this would not imply the individual's intention, and therefore it would not be a killing.

More recently the Catholic Church has applied the concept of double-effect to medical care, the classic
case being one in which a pregnant woman develops cancer of the uterus. In this situation the death of
the unborn child resulting from the performance of a hysterectomy is held not to be a killing under the
theory of double-effect as long as the four usual limitations are fulfilled. First, the action causing the dual
effect must be good -- the removal of a cancerous uterus saves the life of the mother. Second, the good
effect must not be obtained by means of the evil effect -- in this case, saving the mother is not the direct
result of ending the life of the unborn child. Third, sufficient reason exists for permitting the unsought
evil effect -- in this case, saving the life of the mother justifies the unavoidable death of the child. Fourth,
the evil effect is not intended in itself, but is merely allowed as a necessary consequence of the good
effect -- the object is not to kill the child but to save the mother.

In applying these principles to the question of double-effect therapy to the treatment of the terminally ill
patient, the 1994 Catechism of the Catholic Church in § 2279 reads:

> Even if death is thought imminent, the ordinary care owed to a sick person cannot be
> legitimately interrupted. The use of painkillers to alleviate the sufferings of the dying, even
> at the risk of shortening their days, can be morally in conformity with human dignity if
death is not willed as either an end or a means, but only foreseen and tolerated as
> inevitable. Palliative care is a special form of disinterested charity. As such it should be
> encouraged.

**11.04 Ethical Considerations**

The religious formulation of the rational for double-effect therapy is closely followed by medical
ethicists, again listing the necessary limitations as requiring that (a) the action is good in itself; (b) the
intention of the act to be solely to produce the good effect; (c) the good effect is not achieved through the
bad effect; and (d) there be sufficient reason to permit the bad effect.

As in the religious considerations, the ethical validity of the principle of double-effect requires a close
look to insure the proper primary intent of the action because of the ethically significant distinction
between foreseeing a potential undesired effect and intending an unavoidable maleficent outcome.

This difference between intended and unintended but foreseen consequences of medical treatment was
well addressed by the first President’s Commission for the Study of Ethical Problems in Medicine and
Biomedical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment in 1983 which
concluded the relevant moral issue "is whether or not the decisionmakers have considered the full range
of foreseeable effects, have knowingly accepted whatever risk of death is entailed, and have found the
risk to be justified in light of the paucity and undesirability of other options."

**11.05 Legal Considerations**

Theoretically, the "double-effect" doctrine may conflict with the usual legal definitions of reckless
homicide or involuntary manslaughter, which could lead to prosecution of the physician if he or she was
held to have consciously disregarded "substantial and unjustifiable risk to human life." Fortunately, the legal system in every state in America has refused to take this approach and has uniformly accepted the concept of double-effect therapy.

Some states, including Indiana, Iowa, Kentucky, Michigan, Minnesota, Ohio, Rhode Island, South Dakota, Tennessee and Washington specifically mention it in their statutes, while others, including Maine, New Mexico, South Carolina, and Virginia specifically permit patients to sign health-care directives in which they authorize pain treatment even if it hastens death. In the remaining states, the same acceptance of double-effect therapy as relieving physicians from prosecution has been routinely upheld, even in the case of Dr. Jack Kevorkian, whose lawyer argued his intent in assisting "his" patient’s suicides was to relieve suffering -- death being a necessary collateral consequence.

The question of double-effect therapy has produced some interesting comments in the legal literature. In a famous Dutch case referred to as the "Postma decision," the court found a woman guilty of killing her mother when doses of narcotic intended to relieve her pain were all given at once with the intent of causing her death even though the mother was terminally ill. The court said if the doses had been given as ordered to relieve pain and the mother had died, the woman would not have been guilty of any wrongdoing.

In the recent U.S. Supreme Court decisions involving physician assisted suicide, the Court clearly differentiated and essentially approved the double-effect principle noting "when a doctor provides aggressive palliative care; in some cases, painkilling drugs may hasten a patient's death, but the physician's purpose and intent is, or may be, only to ease his patient's pain."

The New York Task Force set up by then Governor Cuomo in a report under the title: "When Death is Sought," stated: "It is widely recognized that the provision of pain medication is ethically and professionally acceptable even when the treatment may hasten the patient's death, if the medication is intended to alleviate pain and sever discomfort, not to cause death."

Finally, the Select Committee On Medical Ethics of the British House of Lords addressed the question of the need to rely on physicians to determine the intent of giving medication with the following statement:

In the small and diminishing number of cases in which pain and distress cannot be satisfactorily controlled, we are satisfied that the professional judgment of the health care team can be exercised to enable increasing doses of medication (whether of analgesics or sedatives) to be given in order to provide relief, even if this shortens life. The adequate relief of pain and suffering in terminally ill patients depends on doctors being able to do all that is necessary and possible. In many cases this will mean the use of opiates or sedative drugs in increasing doses. In some cases patients may in consequence die sooner than they would otherwise have done, but this is not in our view a reason for withholding treatment that would give relief, as long as the doctor acts in accordance with responsible medical practice, with the objective of relieving pain or distress and with no intention to kill.
11.06 Clinical Effects

The acceptance of the concept of double-effect has freed physicians to provide high doses of narcotic pain relievers to patients who are dying in pain, even if this intervention indirectly contributes to an earlier death. In medical practice the physician can usually find a therapeutic pain-relief regimen which provides sufficient relief without compromising the patient's consciousness, but it is not always possible and it is certainly unpredictable. If the physician had reason to worry each time a large dose of narcotic was given to a weakened patient, his or her ability to control pain and other symptoms would be very compromised.

Although double-effect therapy is most frequently considered when dealing with pain, it has recently been extended to treat patients who are tormented in other dimensions as well. As long as the primary intent of the intervention is to relieve suffering, whether the suffering is in the form of pain, shortness of breath, nausea, or any other form, it doesn’t matter. Morally, ethically, legally and medically, whether the patient dies of his or her disease, the medications, pneumonia, and/or dehydration since he or she can no longer eat or drink, it is considered to be death by natural causes. All that is required is that the physician remain within the confines of intending the relief of suffering and not death itself -- death in these extreme circumstances may be foreseen, but must not be intended.

11.07 Double-Effect Versus Euthanasia

Some commentators suggest double-effect theory is just a charade for euthanasia, used purely to legitimize the prevalent use of excessive morphine which is administered by physicians who know or suspect it will cause death. At times, as in the case of Dr. Kevorkian, it is hard to argue with this opinion, but many physicians say this is fine. They suggest that although they are antagonistic to legalizing euthanasia because of the potential for abuse, they like knowing if a patient is truly suffering, they do not have to worry even if they know the level of medication ordered will almost certainly result in the patient’s death.

The same report of the House of Lords quoted above also addressed this problem saying:

Some witnesses suggested that the double-effect of some therapeutic drugs when given in large doses was being used as a cloak for what in effect amounted to widespread euthanasia and suggested that this implied medical hypocrisy. We reject that charge, while acknowledging that the doctor's intention, and evaluation of the pain and distress suffered by the patient, are of crucial significance in judging double effect. If this intention is the relief of severe pain or distress, and the treatment given is appropriate to that end, then the possible double effect should be no obstacle to such treatment being given. Some may suggest that intention is not readily ascertainable. But juries are asked every day to assess intention in all sorts of cases and could do so in respect of double effect if in a particular instance there was any reason to suspect that the doctor's primary intention was to kill the patient rather than to relieve pain and suffering. They would no doubt consider the actions...
of the doctor, how they compared with usual medical practice directed towards the relief of pain and distress, and all the circumstances of the case. We have confidence in the ability of the medical profession to discern when the administration of drugs has been inappropriate or excessive.
CHAPTER 12. TERMINAL SEDATION

12.01 Terminal Sedation; Introduction

12.02 Frequency of Need

12.03 Symptoms for Which Employed

12.04 Medications Used

12.05 Usual Period of Sedation

12.06 Patient Choice/AMD

12.07 Ethics of Terminal Sedation

12.08 Legal Aspects of Terminal Sedation

12.09 Clinical Implications of Terminal Sedation

12.10 Clinical Use of Sedation When Discontinuing Life-Support

12.11 Terminal Sedation Versus Euthanasia

12.01 Terminal Sedation; Introduction

This book repeatedly emphasizes that in the vast majority of patients, pain and other symptoms can be relieved by proper palliative care without producing undue sedation, but this is not always the case. On some occasions, symptoms cannot be relieved in such a way as to permit the patient to maintain active communication with the world. When this happens and persistent symptoms remain unrelieved, something more has to be done.

One approach is to accept the use of symptom-relieving drugs in spite of their heavy sedative effects or, at times, even with the intent of producing a continuous state of sleep until death occurs. This process is referred to as "terminal sedation," although some suggest it would more properly be called "sedation in the imminently dying," because it is almost always undertaken at the very end-stage of a terminal illness.

Usually, the decision to employ terminal sedation is reached only after the patient,s clinical course evolves into such a state. As described by one palliative care specialist:
The intent of the team was to reduce the patient's perception of suffering until the end thus allowing the patient to have a good quality of life in his own home surrounded by his relatives. The result that we sought, but which was not always possible, was the elimination of pain and other symptoms while keeping the patient alert until the onset of metabolic and biochemical phenomena that alter sensory capacities. In some situation, the progressive increase of the dosage and the combining of different drugs to control symptoms did end by sedating the patient. Death occurred some time later, in a quiescent patient who reacted to external stimuli only if provoked.

All patients were cared for at home until death. We did not consider the possibility of hospitalization for the patients with unendurable symptoms because, according to our experience, there are no differences in symptom control between the home and hospital setting. Moreover, the quality of life is much better for patients cared for at home than for those in the hospital.

At other times a more planned approach is taken. The suffering patient, along with his or her caretakers, decide collectively that trying to maintain the patient in a state of wakefulness is so dominated by suffering that the patient would reasonably prefer to sleep until death intervenes. In this situation, terminal sedation can be said to be voluntarily initiated at a particular time, as opposed to the first situation in which it gradually comes into being as part of the process of treating terminal illness.

It can be a difficult decision. As viewed from the side of the physician specializing in palliative care, terminal sedation would have to be characterized as a strategy of last resort for relief of otherwise unrelievable suffering. In deciding a symptom is refractory to regular treatment, the clinician should decide further invasive and noninvasive interventions are (1) incapable of providing adequate relief, (2) associated with excessive and intolerable acute or chronic morbidity, or (3) unlikely to provide relief within a tolerable time frame. Those who argue against terminal sedation are likely to argue that, "the moment of death is certainly a profound spiritual, psychological, and philosophical event. Complete obliteration of consciousness at this time may therefore be a serious disservice to some patients." Both sides are worth consideration, but in the end, it is the patient's choice.

12.02 Frequency of Need

Because most chronically ill patients with terminal illnesses are receiving medications which are at least somewhat sedative at the time of their death and most are asleep in the hour or more before death, it is hard to know how many should actually be considered to undergo terminal sedation. Palliative care experts tend to believe the number in which unavoidable and intolerable pain requires terminal sedation is very small, but this number is probably limited to those in whom terminal sedation is specifically planned. In contrast, many traditional medical reports suggest close to half of all terminally ill patients die in a state of sedation in part as relief for terminal suffering.

Perhaps it would be fair to estimate from the literature that one patient in four purposely receives
medications to help them sleep through the terminal event, but that is high in the author,s experience.

12.03 Symptoms for Which Employed

The three common symptoms requiring terminal sedation are shortness of breath, delirium, and unrelieved pain, with a fourth, vomiting, also occasionally requiring its use. Other psychological symptoms, like anxiety, depression and existential distress are also occasionally listed as a reason for terminal sedation, but they are relatively uncommon.

Delirium is more likely to require terminal sedation in an institutional setting than at home, where patients are usually better able to maintain their orientation and where their agitation, confusion, hallucinations, and wanderings are less likely to cause trouble with other patients and caregivers.

12.04 Medications Used

When terminal sedation is the result of gradually increasing use of palliative medications, narcotics like morphine are likely to be a major component of the drug regimen used. When terminal sedation is undertaken by mutual decision, the major drugs used are likely to be true sleeping medications, like barbiturates, or tranquilizers similar to valium. On rare occasions, true anesthetics may be used to induce a deep state of sleep.

12.05 Usual Period of Sedation

Terminal sedation is usually undertaken at home, for patients in whom it is appropriate seldom require medical surveillance or intervention except to maintain their sleep state. Because they are asleep they do not eat or drink and because there is no intent to try to reach a time when they can be awakened, there is no justification for using artificial nutrition and hydration. As a result, life expectancy is typically limited to approximately ten days, although most reports suggest death most commonly occurs within two or three days.

12.06 Patient Choice/AMD

Clearly it is preferable for the patient to make the choice to undergo terminal sedation and not to leave this most difficult decision for surrogates after the patient losses decision-making capacity. In an ideal world, the patient should always be asked if they would want terminal sedation if required early in the course of the disease. This will avoid any misinterpreting of the patient,s wishes which might occur later on when they patient is likely to be confused. In addition, asking early when symptoms are well controlled will make it easy for surrogate decision-makers to so decide without feeling they need to clear it with the patient, a process which would be seen as telling the patient they are about to die.

One way to accomplish this goal is to bring up the question of terminal sedation at a general discussion of advance medical directives, DNR orders, the use of artificial nutrition and hydration, preference for
home or hospital care, the naming of an agent for decision-making, etc. Because patients who decide in advance they would want to be sedated rather than suffer through the last days of life have been found to maintain that choice, a request for terminal sedation if needed in an advance directive should be honored if the patient subsequently loses the ability to make medical decisions.

12.07 Ethics of Terminal Sedation

Use of terminal sedation is ethically based on the twin concepts of autonomy and the principle of double-effect. Under the concept of autonomy, the patient has a right to choose between various medical approaches to relieve his or her pain and suffering provided the approaches are legal and provided they are made aware of the potential risks and benefits to each individual approach. As terminal sedation is both legal and an accepted approach to the relief of terminal distress, it is a choice which should be given every patient facing this possibility at a time when they have the ability to make a decision.

Unfortunately, patients are often not asked what they would want before they lose the ability to make a proper decision. When this happens, others (surrogates) must make the decision for the patient. Although this is more difficult, it is certainly acceptable for such decisions to be made by surrogates, although there is frequently a delay until the clinical course proves the necessity to all those involved in the decision-making process.

Ethically, the use of sedating medications in this setting meets all of the four conditions for the principle of double-effect therapy discussed previously:

* the treatment is at least neutral (if not beneficial), but may have untoward as well as beneficial consequences.

* The clinical intent is the beneficial outcome (relief of suffering), but the foreseen untoward outcome (e.g. potentially foreshortened survival) may be unavoidable.

* The untoward outcome is not necessary to achieve the desired beneficial outcome (relief of suffering does not require death).

* Adequate relief of unendurable symptoms is an appropriately compelling reason to place the patient at risk of the untoward outcome.

12.08 Legal Aspects of Terminal Sedation

Sedation of the terminally ill as therapy for otherwise unrelievable symptoms has been routinely held legally to fall within the reaches of double-effect therapy, and is therefore within the law. When terminal sedation is undertaken in conjunction with the stopping of nutrition and hydration, it is usually the stopping of sustenance which is questioned legally, as discussed in the chapters on nutrition and hydration. [Chapters 8 & 13.]
In contrast, when sedation is given along with stopping life-support systems such as a respirator the concurrent use of sedation is frequently questioned legally because the medication also suppresses breathing. In this situation many ethicists and legal scholars believe giving sedatives to the person in whom the respirator is being removed is taking away their last chance to survive. Normally, when patients are on a respirator they are "weaned off," a little at a time to give the body a chance to learn to breath on its own again. If we just stop the respirator without weaning and in addition give medications which stop this relearning, critics say it is like killing the patient.

To a large extent, the legal status of giving sedation to a patient coming off a respirator is dependent on the exact circumstances. The most common situation in which this becomes a question is when a patient who is paralyzed and known to be dependent of the respirator to maintain breathing directs it be removed and requests to be sedated when it is done. In spite of the objections noted above, courts routinely accept the use of the sedative to relieve anxiety even though in a sense they help insure death will occur.

In another common situation, the patient is known to have a terminal illness which will cause death soon after removal of the respirator even if death is not immediate. In this situation, courts are almost sure to accept the use of sedatives if the patient is alert and can direct that the medications be given, but are likely to be reluctant to do so if the patient,s wishes are unknown.

Of even greater trouble is the situation in which the patient has no proven terminal illness and has never expressed his or her wishes, the decision being made by a surrogate based on a belief stopping the respirator is in the patient,s best interest. In this situation, the court is very likely to require the patient at least be given a chance to survive by not employing sedatives.

12.09 Clinical Implications of Terminal Sedation

Use of terminal sedation should always be offered directly to the patient and not to the family if the patient is capable of making a medical decision. It is often appropriate to offer its use as an empathic acknowledgment of the severity of the patient,s suffering even at a time when the patient is expected to refuse primarily to reassure the patient it can be done upon request if desired in the future. At the same time, the offer should not be made unless the family and caregivers are willing to go along if the patient accepts the offer. If the patient declines but suggests the offer might be accepted in the future, it is wise to find out what would lead the patient to desire sedation in case the patient is no longer able to make decisions for themselves in the future.

Use of terminal sedation is likely to require:

1. The patient,s condition to be determined to be truly terminal, with no further hope for remission and with death considered likely to occur within hours or days;

2. The family members and the patient to clearly understand the seriousness of the
condition and the risks and benefits of using terminal sedation;

3. That after appropriate counseling, an informed consent be obtained to write a "do not resuscitate" order;

4. All family members be in full agreement with the intended therapy without reservation; and

5. Someone from the family or among close associates be present at the bedside at all times to assist the nursing staff in the continuous observation and monitoring of the patient.

In an extensive paper on the use of terminal sedation, it was reported: (1) all patients died; (2) All experienced improved relief from long-standing and increasingly severe symptoms near death; (3) All were permitted to have control in the final days and hours of their lives, and (4) all maintained personal dignity and autonomy with the assistance of the immediate family, the physician, and the nursing staff.

12.10 Clinical Use of Sedation When Discontinuing Life-Support

Withdrawal of life-sustaining treatment such as kidney dialysis, blood transfusions, antibiotics, and medications regulating blood pressure frequently occurs in the hospital without any resultant pain or discomfort to the patient. At times, however, as with the discontinuation of a respirator, the patient may experience severe air hunger and anxiety when therapy is stopped. At these times, it is important that active measures be taken to ensure the patient is kept comfortable.

Unfortunately, many physicians are reluctant or even unwilling to give sufficient sedation when stopping a respirator. It this is their personal belief, it must be accepted and a decision made to either accept this approach or to transfer care of the patient. If, however, it is out of fear that it is unaccepted, the consensus among ethicists, physicians, and the courts that it is morally permissible to provide this palliation should be pointed out.

When any question of survival exists and the patient is competent to make decisions, the problem can usually be handled simply by telling the patient the sedation will probably destroy any chance of survival and giving the patient the option to accept or reject it. When the patient cannot make decisions and there is a chance of survival, the question becomes much more complicated and sedation should probably be avoided until and unless the patient begins to show symptoms of distress, at which time short acting drugs can be given intravenously.

12.11 Terminal Sedation Versus Euthanasia

It is unfortunate in a way that euthanasia advocates maintain there is no difference between a doctor's intention in sedating dying patients and in deliberately ending patients' lives. Although their intent is to
further extend some of the concepts we accept regarding terminal sedation to euthanasia, many antagonists to any physician aid-in-dying use their arguments to also fight the acceptance of terminal sedation. Certainly, terminal sedation can and is used as a covert form of euthanasia by a few doctors who believe in euthanasia, but there is no evidence this approach is common or true for most doctors who see it as the only remaining way to legally relieve the pain their ethics requires them to treat.

In fact, while situations in which terminal sedation is employed are frequently those which suggest the appropriateness of euthanasia, this is not an appropriate argument. Most situations in which terminal sedation is used involves only a few days of therapy, which is generally very successful in relieving the patient's suffering, thus eliminating any need for euthanasia or assisted suicide. Certainly most on both sides of the euthanasia argument would agree it is better for the patient to continue to receive palliative care based on medicine's duty to relieve pain and suffering than to open up the possibility of improper use of euthanasia.

[Note: The author does not mean by this to imply he is against euthanasia in all situations, but only that its appropriate use, if any, is not in situations in which short term sedation for a few days can serve a similar purpose with far less attention and with fewer legal, moral, and ethical concerns.]
CHAPTER 13. VOLUNTARY TERMINAL DEHYDRATION

13.01 Voluntary Terminal Dehydration; Introduction

13.02 Historical Development

13.03 Case Histories

13.04 Thirst and Hunger

13.05 Medical Aspects

13.06 Ethical Aspects

13.07 Legal Aspects

13.08 Practical Undertaking

13.01 Voluntary Terminal Dehydration; Introduction

A previous chapter discusses the use of artificial nutrition and hydration in the end-stages of terminal illness. This chapter addresses a different, but related, subject -- the voluntary forsaking of sustenance as an alternative to physician assisted suicide (PAS).

Unlike PAS, voluntary terminal dehydration (VTD) is perfectly ethical and legal even when initiated by the patient relatively early in the course of a terminal disease simply to avoid living through the dying process. To this extent, unlike terminal sedation which only involves the final few days of life, VTD is much more consistent with the goals of a patient who might ask for physician assisted suicide (PAS) but who knows PAS remains illegal.

Due to the overlap, many of the issues discussed in the previous chapter on nutrition and hydration will be repeated in this one, but in a somewhat different context. In the previous chapter emphasis was on the use of artificial means of maintaining sustenance when the patient was no longer able to take oral food and fluids. In this chapter, we address the situation in which the patient remains capable of taking oral sustenance but voluntarily chooses not to do so in order to achieve an earlier and more controlled death.

Before discussing VTD, it is well to review some of what has been said about care in end-stage situations, especially as it relates to the discontinuation of artificial nutrition and hydration.

Summary of previous chapters related to voluntarily foregoing artificial sustenance:
1. Discontinuation of nutrition does not lead to hunger except in the first few days before and until chemicals called ketones build up in the blood.

2. Discontinuation of hydration does not produce true thirst, although a sensation of dryness of the mouth often is reported as "thirst." The evidence this is not true thirst is extensive and shows the ill feeling is not relieved by giving fluids intravenously but is relieved by wetting the tongue and lips and proper care of the mouth.

3. It is both ethical and legal for physicians to treat any suffering the patient might experience after choosing to voluntarily stop eating and drinking without requiring the patient to take nutrition orally or artificially. Not to do so would in fact be morally unjustified.

4. It is both ethical and legal for physicians to treat any suffering the patient might experience after choosing to voluntarily stop hydration without requiring the patient to take fluids orally or artificially. Not to do so would in fact be morally unjustified.

5. In addition to causing a dry mouth, dehydration is likely to cause the patient to become confused and then to slip into a comatose state before death. This is not specifically associated with pain or suffering and is generally accepted as a peaceful way to die.

6. Most health care providers who have extensive experience in treating dying patients report death due to dehydration tends to be less troubled and less symptomatic than death in a patient receiving artificial fluids.

7. The methods of giving artificial sustenance are all associated with potential risks in the form of pain and suffering. These are not so great as to preclude their use when otherwise indicated, but do give reason for the patient to decide against their use in the final hours and days of life.

8. In the end stages of terminal illness, there is little reason to believe artificial sustenance prolongs life. This is in contrast to VTD in which patients choose to voluntarily stop sustenance early in the course of a terminal illness specifically to cause a quicker, controlled death.

9. Foregoing of artificial sustenance by a patient’s family is emotionally very difficult. In contrast, when asked, most end-stage terminally ill patients do not choose artificial sustenance if the risks and benefits are adequately explained.

10. Society values the preservation of other’s lives and tends to treat the provision of food and fluid as basic rights of the patient. This tendency, however, is in conflict with more modern theories which stress autonomy, the right of the patient to make decisions for
himself or herself.

11. Traditional religions have tended to support the need for artificial sustenance for the incapacitated patient in the past, but in recent years have come to accept the right of the individual or a surrogate to forego its use. [Note, this may or may not be true with regard to the patient’s right to refuse oral food and fluids, in which case religions tend to vary a great deal.]

12. From an ethical point of view, foregoing artificial sustenance is not a problem. When a patient has the ability to make decisions and requests it not be employed, it would be unethical to insist on its use.

13. Legally, the competent patient has a clear right to refuse artificial sustenance.

14. Legally, if the patient loses the ability to make decisions, those people who are responsible to take over decision-making should follow the previously expressed wishes of the patient. This is best done through an advance medical directive.

15. Medically, many health care providers still resist foregoing artificial sustenance. This probably stems primarily from misinformation about the resultant suffering and about its legal acceptance.

13.02 Historical Development

Over the years, individual patients have occasionally refused to take food and water at various stages in the course of a terminal illness on a voluntary basis. At times families and the medical profession have fought these refusals with forced feeding or involuntary insertion of feeding lines. At other times the patient’s desires have been honored without hostility, but without much fanfare lest the caretakers be held accountable for not doing more to prevent an earlier death. In the last few years, however, and with the increasing discussion of PAS, a number of reports, many very well written, have been published describing voluntary refusal of food and fluids as an alternative to suicide.

Two articles of particular importance appeared in the medical literature in 1993. The first was in the April issue of a relatively new and at that time obscure journal, the Journal of General Internal Medicine with the title "Accepting Death Without Artificial Nutrition or Hydration." It was written by Robert J. Sullivan [8 J Gen Intern Med 220-224 (1993)] from the Duke University Medical Center and reported the history of a 78 year old woman with cancer of the uterus who refused surgery for a blockage of her intestines and later refused to take food or fluids by either natural or artificial means. She repeatedly asked for physician help in dying, but this was refused. Fourteen days after stopping intravenous fluids she requested narcotics to "relieve boredom and help her sleep," although she made no claim of experiencing pain. The medication was given until she died fifteen days later, although at no time did she complain of pain or any other discomfort.
In the discussion which followed the report, the author noted dehydration in the dying patient typically induces few neurologic symptoms initially, but eventually leads to confusion, weakness, and lethargy, which then eventually progresses to obtundation and coma. "Experience suggests that these patients slowly sink into unconsciousness over a period of days without complaining of pain or discomfort .... One recurrent physical complaint related to the absence of oral fluid intake is a dry mouth, which can be relieved with swabs, sips of fluid, or sucking on ice chips. Thus, from the available data, it appears that systemic dehydration induces little pain or discomfort provided the mouth is kept moist."

Sullivan also noted "[i]n contrast to the intense discomfort associated with semistarvation, total starvation is associated with euphoria. Instead of pain, food deprivation may induce analgesia. Mental function is maintained throughout a fast, with lethargy, apathy and irritability encountered only in the terminal phases."

The article concludes with the following observation:

Based upon the case presented and upon the available literature, it is possible to predict with some assurance the clinical course of an individual dying with dehydration and starvation. The majority of persons who embark on this course will be debilitated from an underlying illness that has robbed them of bodily fat reserves and thus reduced their ability to survive. Even then, death may not come quickly. By utilizing water generated in the metabolism of remaining adipose (fat) tissue, they may sustain circulatory function for a remarkable period of time. When significant adipose stores are present and renal (kidney) function is well preserved, as can be encountered in healthy individuals who suffer a massive stroke, survival without food or water can continue for weeks.

Fasting individuals will not be likely to experience pain induced by fluid or food abstinence. Indeed, mild euphoria can be anticipated, accompanied by an increased tolerance for pain. Absence of oral fluid intake will produce a dry mouth, which can be relieved with ice chips or swabs. Problems with excessive secretions, edema, or incontinence may be alleviated.

Worthy of particular attention is the potential for inadvertent induction of discomfort through amelioration of ketonemia. (Acids in the blood produced by carbohydrate withdrawal) The administration of even small amount of carbohydrate can block ketone production and rekindle hunger. Intravenous mixtures of 5% dextrose (sugar) and water provide amply carbohydrate to cause this metabolic shift. It is senseless to continue fluids after a decision has been made to discontinue food. If any sustenance is provided by vein or by feeding tube, it should be tailored to the full nutritional requirements of the patient and constantly monitored to ensure comfort.

In the setting of dehydration and starvation, death can occur from a multitude of causes. Arrhythmia (irregular heart beat), infection, and circulatory collapse due to volume...
depletion are common terminal events. The clinical course of each should be rapid and, ideally, not associated with perceived discomfort by the patient.

Based on this clinical report and a review of the literature, it is likely that prolonged dehydration and starvation induce no pain and only limited discomfort from a dry mouth, which can be controlled. For individuals carrying an intolerable burden of illness and disability, or those who have no hope of ever again enjoying meaningful human interaction, the withdrawal of food and fluid may be considered without concern that it will add to misery.

Later in December of the same year an article was written by Drs. Bernat, Gert, and Mogielnicki in the prestigious Archives of Internal Medicine entitled "Patient Refusal of Hydration and Nutrition; An Alternative to Physician-Assisted Suicide or Voluntary Active Euthanasia." In this article the doctors suggested that "educating chronically and terminally ill patients about the feasibility of patient refusal of hydration and nutrition can empower them to control their own destiny without requiring physicians to reject the taboos on PAS and VAE (voluntary active euthanasia) that have existed for millennia."

In this article the authors stated:

1. "There is no disagreement that physicians are morally and legally prohibited from overruling the rational refusal of therapy by a competent patient even when they know that death will result."

2. "There is also no disagreement that physicians are allowed to provide appropriate treatment for the pain and suffering that may accompany such refusals. In other words, physicians are morally and legally required to respect the competent patient’s rational refusal of therapy, and they are morally and legally allowed to provide appropriate treatment for the pain and suffering involved. Physicians also are morally and legally required to abide by such refusals given as advance directives."

3. In differentiating VTD from euthanasia, "[p]atient refusals must be honored when they represent the rational decisions of competent patients even when physicians know death will result. There is no moral requirement to honor patient requests when physicians know death will result and there may be legal prohibitions against doing so."

4. The authors maintained "a preferable alternative to legalization of PAS [and euthanasia] is for physicians to educate patients that they may refuse hydration and nutrition and that physicians will help them do so in a way that minimizes suffering."

5. "The failure of the present debate to include this alternative may be the result of ... an erroneous assumption that thirst and hunger remain strong drives in terminal illness, and a misconception that failure to satisfy these drives causes intractable suffering."
6. It is the consensus of experienced physicians and nurses that terminally ill patients dying of dehydration or lack of nutrition do not suffer if treated properly.

7. "Caregivers experienced psychological distress due in part to the failure to understand the distinction between killing and letting die, and the social implications of withdrawing or withholding food and fluids, particularly because of its symbolism as communicating lack of caring. However, if the distinction between killing and letting die is based as it should be on patients’ requests vs patients’ refusals, these latter considerations lose their force."

8. Clinical experience with severely ill patients suggests the major symptom of dry mouth can be relieved by ice chips, methylcellulose, artificial saliva, or small sips of water insufficient to reverse progressive dehydration.

9. Unlike PAS and euthanasia, VTD "is recognized by all as consistent with current medical, moral, and legal practices. It does not compromise public confidence in the medical profession because it does not require physicians to assume any new role or responsibility that could alter their roles of healer, caregiver, and counselor. It places the proper emphasis on the duty of physicians to care for dying patients, because these patients need care and comfort measures during the dying period. It encourages physicians to engage in educational discussions with patients and families about dying and the desirability of formulating clear advance directives."

10. "The patient who refuses hydration and nutrition clearly demonstrates the seriousness and consistency of his or her desire to die. The several-day interval before the patient becomes unconscious provides time to reconsider the decision and for the family to accept that dying clearly represents the patient’s wish. Furthermore, the process can begin immediately without first requiring legal approvals or other bureaucratic interventions. Thus, it may allow the patient to die faster than PAS or VAE (voluntary active euthanasia), given the delays intrinsic to bureaucratic process."

11. "The most pressing need is to dispel the myths about suffering caused by dehydration and to publicize as widely as possible to both physicians and their terminally ill patients the availability of PRHN (VTD) as a means of shortening the dying process. Educational efforts should be directed to physicians, who are often ill-informed on this matter, as well as the general public. The emphasis on research and education on symptomatic treatments to relieve suffering during dying is fully compatible with the traditional and appropriate role of the physician as caregiver and comforter."

One year later, in the July 20, 1994 edition of the Journal of the American Medical Association, Dr. David M. Eddy, a superb writer, beautifully described "A Conversation with My Mother," a woman who chose to end her life at age 85 by voluntarily refusing to take nutrition and hydration. Although not
suffering from a terminal illness, she had had a wonderful life and faced many problems ahead. She didn’t want to suffer through her future and didn’t want to be remembered in her suffering. Instead, she wanted to control her death, and, with the understanding of her family, she did. In describing the self-termination of her life, Dr. Eddy concluded his article saying:

I had always imagined that when I finally stood in the middle of my parents' empty house, surrounded by the old smells, by hundreds of objects that represent a time forever lost, and by the terminal silence, I would be overwhelmingly saddened. But I wasn't. This death was not a sad death; it was a happy death. It did not come after years of decline, lost vitality, and loneliness; it came at the right time. My mother was not clinging desperately to what no one can have. She knew that death was not a tragedy to be postponed at any cost, but that death is a part of life, to be embraced at the proper time. She had done just what she wanted to do, just the way she wanted to do it. Without hoarding pills, without making me a criminal, without putting a bag over her head, and without huddling in a van with a carbon monoxide machine, she had found a way to bring her life gracefully to a close. Of course we cried. But although we will miss her greatly, her ability to achieve her death at her "right time" and in her "right way" transformed for us what could have been a desolate and crushing loss into a time for joy. Because she was happy, we were happy.

"Write about this, David. Tell others how well this worked for me. I'd like this to be my gift. Whether they are terminally ill, in intractable pain, or, like me, just know that the right time has come for them, more people might want to know that this way exists. And maybe more physicians will help them find it."

Maybe they will. Rest in peace, Mom.

More recently, Lori Montgomery, reporting in the Detroit Free Press on November 20, 1996 [as circulated on the internet] noted that voluntary refusal of food and water was being advocated by a small, but growing number of hospice leaders as "an option desperate people can exercise now, without a court ruling and without a prescription."

Explaining the process as a combination of medically accepted legal rights, including the right to obtain medical treatment for any experienced suffering, she went on to note potential drawbacks, such as reluctance of caregivers to take part and the time requirements of one to two weeks.

But hospice workers were more enthusiastic, noting the lack of suffering and the tendency to produce "the kind of gentle, peaceful passing that so many people say they seek."

In the article, the author quotes the executive director of Hospice of Boulder County, Colorado, Connie Holden, as saying: "I would like to see us promoting this as a better and more autonomous option" to
lethal prescriptions. "I've been around a lot of people who have chosen it and it's not painful. The main thing people have is thirst. But you can counter that with ice chips."

As to the time requirements, she noted "[t]he Hemlock people groan when you say this takes a couple of weeks, but that might not be any slower than trying to find a doctor" who will help a patient who wants to die.

Noting Eddy had received over 100 letters from people who read the article about his mother discussed above and then worried his mother’s experience may have in fact been somewhat unique, the article goes on to quote Ira Byock, a Missoula, Montana, specialist in end-of-life care writing in the American Journal of Hospice & Palliative Care that "[v]irtually any patient with far-advanced illness can be assured of dying -- comfortably, without any additional distress -- within one or two weeks simply by refusing to eat or drink."

In the same article, Byock reported on 32 hospice patients who chose to stop eating and drinking. Of these, one-third said they never felt hungry or thirsty. Another third said they felt hunger, but it quickly subsided. Two-thirds felt thirsty, with 38 percent saying thirst plagued them throughout their final days, but all reported relief through oral care and small sips of fluids.

In the end, research shows the dehydrated patient's organs fail, leading to dizziness, confusion and a "deepening somnolence with the person often described as having ‘slipped away.’"

13.03 Case Histories

The two cases discussed above by Drs. Sullivan and Eddy are not unique. The following discussion of cases, often unidentified, may also be helpful to the reader.

In one, reported by Dr. Rousseau in a 1993 article in Clinical Geriatrics entitled "Dehydration and Terminal Illness in the Elderly" the author describes an 88-year-old man with inoperable lung cancer who requested that no artificial sustenance be given when he lost the ability to take oral fluids. The patient was noted to complain of hunger for five days after cessation of oral intake, beyond which his desire for food subsided. His main complaints were of mild nausea and dry mouth, which was relieved with ice chips, and sips of water. Two weeks later, he lapsed into a coma and died.

In a second case reported by a group of doctors headed by Dr. M. Andrews in another 1993 article, this in Postgraduate Medicine, and entitled "Dehydration in Terminally Ill Patients; Is it Appropriate Palliative Care? [93 Postgraduate Med 1:201-208 (1993)] the authors describe a 64 year old man with extensive cancer of the neck, larynx, and tongue who had previously undergone radical surgery. He was awake, alert and oriented upon admission to the hospice but was in constant pain and had difficulty breathing because of marked secretions from the sinuses and fluid swelling the tissues around his trachea. Eighteen days after admission he voluntarily stopped food and fluid therapy. Shortly thereafter the secretions from the sinuses diminished and the fluid swelling around the trachea decreased making
breathing less difficult. Discontinuation of food and fluids also appeared to decrease the level of pain, which could now be easily controlled with narcotics. He died quietly with no signs of discomfort 27 days after discontinuing food and fluids.

Somewhat different but also instructive is a description of the death of Bobby Sands, the first Irish Republican Army hunger striker to die. Bobby’s 65-day ordeal was noted to go from pangs of hunger to extreme nausea to loss of eye control, repeated vomiting, rambling, incoherence, convulsions, and coma while he and the other hunger strikers consumed water. A few days after they were no longer able to drink, their symptoms abated and "the doctors noticed a remarkable improvement. The retching stopped. The hunger strikers were able to hold down other fluids. As a result, they seemed more lucid and demonstrated signs of recovery." After they began taking water again, however, their untoward symptoms recurred.

Noticeable in all of these accounts is the relationship of symptoms and time to death after water intake ceases. Starvation without water deprivation requires many months to produce death and produces significant suffering. In contrast, patients who stop all fluids are likely to live approximately ten to fourteen days without significant suffering unless their previous care had produced increased amounts of edema (body fluids). Because these excess body fluids are reabsorbed once the patient stops taking in water, death is delayed in proportion to the amount of excess water in the body when intake is stopped.

**13.04 Thirst and Hunger**

The absence of significant thirst or hunger is not as well documented in patients who voluntary stop food and fluids in order to control death as in those who stop as part of the end-stages of a terminal disease, but reports like those above tend to show an absence of significant suffering.

Although most people who voluntarily undertake starvation do not stop fluids, the history of total starvation for weight control supports the findings in terminally ill patient that hunger ceases with the build-up of ketones after three or four days of starvation and with little if any effect on mentation.

Surprisingly, what evidence we do have about voluntarily stopping fluids seems to be similar to that experienced when the patient and family choose to forego artificial hydration -- continual "thirst" responding well to local mouth care -- suggesting the symptom experienced does not represent true dehydration and is wrongly being described as "thirst."

**13.05 Medical Aspects**

Medical acceptance of VTD stems from a series of principles developed in relation to other medical issues but which are also applicable to the situation which arises when a patient chooses to forego sustenance as a means of controlling his or her own death. Luckily, none of these factors are likely to conflict with existing ethics and none require the physician to participate in an act which is outside the law.
Most of these principles derive from basic ethical principle of autonomy, which gives to the competent patient the right to accept or refuse medical treatment based on his or her own personal evaluation of quality of life and the value of prolonged survival. Notably, autonomy does not begin when the patient has a terminal illness nor does it end at any particular stage of illness. The patient is always the final decision-maker. Competent patients ultimately have the right to refuse therapies which physicians recommend for them, even if death will be the result. In addition, competent patients also have the right to make decisions about what they would want done even after loss of decision-making capacity through advance medical directives. [Discussed at length in Chapter 14 of this book]

In fulfilling the patient’s right of autonomy, the physician is obligated to play many roles, and also has the right to set some limits.

First, it is the physician’s obligation to give symptomatic relief of pain and other forms of suffering to the full extent possible, in order to minimize patient stress that would lead them to consider methods of ending their life.

Second, it is the physician’s obligation to inform the patient in understandable terms about his or her diagnosis, prognosis, risks, benefits, and consequences of the full range of possible available medical interventions, in addition to the likely results of refusing any form of therapy. After so doing, it is also the physician obligation to work together with the patient to establish an overall treatment plan with mutually agreed upon goals derived from the patient’s own value systems.

A third factor in the medical approach to VTD is acceptance of the provision of nutrition and hydration as a form of medical therapy which can be refused by the patient. This has been clearly stated by such prestigious bodies as the American Medical Association's Council on Ethical and Judicial Affairs, Code of Medical Ethics, 1997, and by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.

A further medical consideration regarding VTD is acceptance of the physician’s role in relieving the suffering of a patient even when the patient has chosen to follow a course of treatment different from that recommended by the physician. The fact the physician may consider food intake to be the best treatment for hunger early in the course of VTD does not mean the physician is relieved from the duty to help relieve hunger by other means if so requested by the patient. In addition, this acceptance of the patient’s right to choose therapy implies the physician should try to avoid the giving of carbohydrates which would inadvertently reverse the ketone production the patient is relying on to reduce hunger.

Fifth, after having provided the patient with information required to obtain an informed consent, it then becomes the physician’s duty to assess whether the patient has adequate decision-making capacity to make the specific decision at hand. This assessment may, but need not, involve an appropriate consultation depending on the exact situation and whether there is disagreement as to the patient’s mental capacity among health care providers or the patient’s family members. If there is a legitimate question, critical elements of decision-making capacity which should be evaluated include (1) the ability to
understand the medical information presented; (2) the ability to reason and consider this information in relation to the patient’s own personal values and goals, and (3) the ability to communicate meaningfully.

More specifically with regard to patient capacity to decide to undertake VTD, some of the factors which are likely to be taken into consideration are the state of the disease process, if full relief from pain and suffering has been achieved, and the realization that a decision to stop food and fluid, unlike a request for PAS, is so readily reversible, thus allowing the patient to change his or her mind if suffering were to occur.

One factor which should not be considered in determining decision-making capacity is the decision itself, the refusal of food and fluid. Patients should not be judged as lacking decision-making capacity based on the view that what they decide (a request for support in undertaking VTD) is unreasonable. People are entitled to make decisions which others think are foolish without being held to have lost decision-making capacity as long as their choices are arrived at through a competently reasoned process and are consistent with their personal values.

[Note: This mirrors the argument some people make that a patient asking for physician assisted suicide proves the patient is mentally incapacitated.]

Although physicians are obliged to honor a patient’s directives to forsake life-support therapies, they also have the right to try to influence the patient in a direction different from the one chosen, as long as it is done with respect for the patient’s autonomy and not by coercive or manipulative means. In addition, it is ethical for providers to leave food and water at the bedside of a patient who has voluntarily chosen to refuse sustenance and to continue to encourage its intake, unless the patient asks the physician not to do so. In fact, many commentators believe this should be done to document the continuing voluntariness of the patient’s actions.

13.06 Ethical Aspects

It is hard for many healthy people to accept that a chronically or terminally ill patient might choose to die rather than continue life, but the rapidly increasing acceptance of PAS by the public bespeaks an increased acceptance of such a choice. For many reasons, the ethics of VTD is still easier to accept than that of PAS.

First, unlike PAS, VTD avoids the requirement of any active outside intervention. This means it can be realistically viewed in its entirety as a suicide which itself is neither unethical or illegal. VTD thus avoids the difficult ethical/legal issue of whether it is improper for one person to help another commit suicide.

Second, because the patient has a prolonged period in which to change his or her mind, one avoids the possibility the decision was made in a moment of irrational thinking, for it gives ample opportunity for reflection and retraction.
Third, it sets up a situation of refusal as opposed to a request for intervention. Physicians are not obliged to meet every request of a patient for intervention if the physician believes it is against the patient’s best interest, but they are obliged to honor a patient’s refusal of care.

Fourth, because physicians do not have to take part in the actual process of death, the medical ethics of assisted suicide is not involved. Instead, physician involvement, if any, relates only to their responsibility for carrying out the patient’s request in a humane and compassionate manner. To this end, the patient’s pain and other suffering, including dyspnea, can be relieved by administration of sedatives, analgesics, anti-nausea medications etc. in dosages which are not likely to be causally related to the patient’s death from the underlying disease and dehydration.

Fifth, based on the findings of the President’s Commission for the study of Ethical Problems in Medicine and Biomedical and Behavioral Research, discontinuing medical hydration is ethically acceptable when, from the patient’s point of view, it is more burdensome than beneficial.

Sixth, just as it is not morally permissible for physicians to force-feed a patient who has made a rational valid refusal to eat, it is also not morally permissible to feed and hydrate such a patient when he or she becomes incapacitated. If this intent has been clearly stated by the patient, his or her prior rational refusal continues to be decisive.

Seventh, an argument the physician who abides by the patient’s rational refusal of treatment "allows the patient to die" is significantly misleading for it implies a physician decision, when it is in fact a patient decision.

### 13.07 Legal Aspects

The patient’s legal right to make decisions about his or her medical treatment is clear, grounded both in common law and the constitutional right of privacy. This right also clearly involves the right to refuse life-sustaining treatment even when the patient is not terminally ill, as long as the decision is made with proper informed consent, is made at a time when the patient is mentally capable of decision-making, and is done without adverse coercion from others.

Although the extension of the right to refuse life-support systems to include nutrition and hydration has been challenged frequently, whenever it has been addressed by the highest court of a state it has been upheld within the common law rights of autonomy and self-determination except for two unusual situations -- when the decision is being made by a prisoner in protest over prison conditions and when parents of specific religious persuasions are making the decision for a child.

In addition, numerous courts have been asked to directly rule on the question of whether medications can be given to relieve the suffering of a patient who directs medical providers to forsake life-support systems, including nutrition and hydration. Invariably, the courts have found giving medications to these patients to be legally permissible as long as they are given with the intent of relieving suffering and not
causing death.

13.08 Practical Undertaking

Some practical considerations:

First, it is important for the patient to clearly express to family and caregivers the reasons he or she is choosing to voluntarily stop eating and drinking. The patient should make it clear the decision has been thought through and reached after finding the perceived future with continued sustenance will be more burdensome than beneficial for the reasons stated. This gives the caregivers an opportunity to change the circumstances to the benefit of the patient in the hope of changing the final decision and also gives them a chance to argue for alternative approaches before the decision is carried out. Doing so will help maintain others support through the days and weeks following discontinuation of sustenance.

Second, caregivers should be made aware the only likely complaint will be that of "dry mouth," or "thirst." Such a complaint should not be taken as a desire to drink unless the patient specifically asks to be given water or fluids. Instead, such complaints should be attended to by the use of mouthwashes, removing of mouth debris, brushing of the patient’s tongue, gums, and teeth with a soft toothbrush, the offer of ice chips or small sips of favorite fluids, treatment of local infections of the mouth, and use of protective coatings like Chap Stick.

Third, a pact should be made by the patient with his or her physician to use appropriate therapy to minimize suffering during the dying process and to remain available to comfort the patient by physical presence as well as treatment of symptoms, including pain, dyspnea, and dryness of the mouth. This discussion should include making everyone aware small amounts of food and fluids beyond sips of water or wetting of the mouth are inappropriate and will only increase the patient’s suffering.

Fourth, care must be taken to insure forced or artificial feedings will not be initiated after the patient loses decision-making capacity. This should be done both through direct discussions with physicians and other caregivers and through the use of written advance medical directives. [See Chapter 14]
Chapter 14. Advance Medical Directives in the Terminally Ill Patient

14.01 Advance Medical Directives; Introduction

14.02 General Values of Writing a Living Will

14.03 Common Law Living Wills

14.04 Common Law Living Wills

14.05 The Patient Self-Determination Act

14.06 Living Will Form Declaration When Terminally Ill

14.07 Form Notice to Health Care Provider

14.08 Health Care Powers of Attorney: In General

14.09 Pros and Cons of Designated Health Care Agents

14.10 Choosing a Health Care Agent

14.11 Determination of Competency/Capacity

14.12 Other Concerns of the Physician

14.13 Decisions of a Health Care Agent

14.14 Advantage of a Combined Document

14.15 Form: Durable Power of Attorney for Health Care

14.16 Do-Not-Resuscitate Orders: In General

14.17 Do-Not-Resuscitate Orders/Difficulties

14.18 Do-Not-Resuscitate Orders/Principles Guiding Decision-Making

14.19 Do-Not-Resuscitate/Hospital Forms

14.20 Do-Not-Resuscitate Orders for Use at Home
All patients have the legal right to direct their own medical care. Such directives are normally given orally by the patient to the physician after discussing the potential risks and benefits of recommended care, but all too often the terminal disease process makes this impossible, either by intruding on the patient’s ability to understand the situation or to communicate decisions to the physician(s). When this happen, the legal right to make decisions remains, but it is forfeited unless the patient has acted beforehand to insure his or her wishes continue to be known to health care providers.

Advance medical directives (hereinafter, "AMD") are legal documents specifically designed to preserve the patient’s right of self-determination in health care even when the patient is no longer able to make and communicate decisions. They do this in one of two common ways, although a combination of the two is becoming ever more popular.

The first means is usually referred to as a "living will" or an "instructive directive." In a living will, the individual, referred to by the legal term, "declarant," provides a series of written directives to physicians telling them what care is wanted under various conditions if the declarant has lost the capacity to make medical decisions. By so doing, the declarant, who is usually healthy at the time the living will is written, not only preserves the right to continue to control his or her own personal care in case of incapacity, but also avoids burdening loved ones with unwanted decision-making. This prevents many of the social pressures which tend to foster aggressive medical care far beyond the wishes of most patients.

It sounds easy, but it isn’t. Because most living wills are written by patient’s who are healthy, they have little ability to predict the conditions which are likely to surround their own death. The best they can do is to try to cover most of those conditions in which mental function is disturbed early, long before death is likely to occur, for these are the situations in which the patient would be deprived of their right and ability to personally direct care for significant periods of time. The conditions in which this is most likely to occur are progressive dementias, like Alzheimer’s disease, strokes, brain tumors, permanent unconsciousness, and a few uncommon conditions of the brain, like encephalitis and multiple sclerosis. Unfortunately, these conditions are not covered in most presently available living will forms, leaving most written living wills ineffective in the clinical setting.

The other common type of an AMD is the durable power of attorney for health care (DPAHC). Unlike the living will, which is based on the legal principle of autonomy [the patient’s right to direct medical care], the durable power of attorney for health care is based on a very different legal principle -- the right of an
individual, legally called the "principal," to name another individual, called the "agent," to make decisions on behalf of the principal.

Unlike the living will, the DPAHC does not require declarants to make statements about their wishes in various clinical situations, but only requires the principal to name specific agents to make decisions for them if they lose the ability to make medical decisions for themselves. This is very easy -- all one has to do is write down: "If I should lose the capacity to make medical decisions, I name (Name of Agent) to be my attorney-in-fact for health care decisions including the right to direct the discontinuation of non-comfort care. Signed: _____________ (Signature of Principal)"

Because appointing an agent through a DPAHC is much simpler than writing a living will, they are very popular, but they are not the best means of protecting the rights of the terminally ill patient. In fact, the best way to protect the rights of the terminally ill individual is to write a combined document. One which combines a living will [now usually called an instructive directive] along with naming an agent to be sure the patient’s directives are carried out.

Unlike the advance directives discussed so far, when drafting living wills or combined documents for patients with a known terminal illness one takes a very different approach. When the principal has a known terminal condition, directives like those discussed above addressing conditions other than that already diagnosed in the principal are usually minimized, while more specific directives are given relevant to the likely terminal events which are likely to occur with the principal’s specific condition. This generally turns out to be far easier than drafting a living will for a healthy patient, but there are unfortunately no forms readily available to use in this situation.

Without a form to follow, one must be at least a little creative. This begins by discussing the patient’s prognosis with the physician to find out what is likely to happen toward the end stages of the disease at the time when the patient is likely to lose the ability to make and relay decisions. Working with the physician, a series of medical decisions which are likely to be required can be developed and discussed with the patient. These, then, become the issues which are addressed in the living will document. [Note: Suggestions for the actual writing of this document are included below.]

14.02 General Values of Writing a Living Will

The value of writing a living will goes far beyond the mere expression of one’s continued right to direct one’s own health care. More importantly, it serves the purpose of fostering the patient’s existential desire to continue to control life. In addition, it is of tremendous help to caregivers who are likely to be forced to make decisions for the terminally ill patient who has subsequently lost decision-making capacity.

Making decisions for family members who can be kept alive but not returned to a meaningful way of life through the use of modern technology is difficult, but it is made much easier when the patient has made their desires known beforehand. And, because people find it easier to forsake their own undesired treatment than to make the same decision for others, living wills tend to minimize unwanted therapy while removing the family from emotion-laden decision-making. This in turn serves to minimize the unwarranted guilt
frequently engendered by family members by even the most logical decision to stop a loved-one's therapy.

Physicians also gain the same benefit of guidance, but, in addition, are aided by the living will changing the standard of care upon which they would be judged if they were later confronted by a claim of having given inappropriate care. Without direction from the patient, standard medical care is skewed to the maintenance of life. When directed otherwise by the patient, however, this standard of care changes to require the physician to honor the patient's wishes, thereby eliminating the requirement for "standard" (aggressive) care. Because malpractice litigation requires a finding the physician deviated from standard medical care, substituting this new minimally aggressive standard allays the physician's fear of legal or professional repercussions for withholding or withdrawing therapy. Without this protection, physicians may feel forced to continue treatment whenever the patient is incapable of refusing its continuation.

Another advantage of writing a living will is that it gives the patient an ideal opportunity to initiate a discussion with his or her physician about issues involving death with dignity. Such discussions are usually worthwhile and welcomed by both parties, although seldom initiated by either out of fear of embarrassing the other. By initiating such discussions, the declarant can find out if his or her physician has moral objections to withholding or withdrawing therapy in specific situations and such differences in philosophy can be discussed while the patient still has options available. If unresolvable conflicts of belief incapable of compromise are revealed at this time, the patient retains an option to choose another physician who is more compatible with his or her views before a decision requiring situation arises.

### 14.03 Common Law Living Wills

Unfortunately, most people, including physicians and attorneys, have come to associate the concept of a living will with a specific statement which is suggested in the written laws of the state and commonly referred to as the state "statutes." These "statutory living will forms" are developed by the state legislature and are intended for use by all residents of the state. But statutory living wills are only half of the whole. Living wills can also be drafted under what is referred to as the "common law" of the state -- that law which has been developed by the state courts as opposed to the state legislatures. Under state common law, the individual or patient, by writing and executing a written living will document, can refuse any medical care under any situation imaginable -- far beyond the scope of the typical statutory living will document. In addition, the individual can request any medical care, although unlike refusals, physicians need not honor a request if it is felt to be unethical or illegal. For example, the physician need not honor a request for assisted suicide even though he or she must honor a refusal to allow the giving of artificial nutrition.

Most carefully drafted living wills contain both the statutory provision of the state and additional common law provisions which further identify the patient’s wishes as to desired treatment if and when they lose the ability to make medical decisions for themselves.

### 14.04 Terminating Care Under the Common Law

Although most state statutes only authorize discontinuing aggressive medical care under narrow situations, the common law accepts the patient’s right to refuse any life-support systems in any situation as long as the
decision is made at a time when the patient has decision-making capacity. Because the common law also accepts the right of the patient to pass on directions through a living will, the common law also provides a way for the patient to refuse any life-support system in any situation even after the patient has lost decision-making capacity.

In the usual living will written by a healthy principal, the provisions which are most important are those which come under the common law part of the document, for the state statute coverage is usually very limited. With few exceptions, these state forms only cover "terminal illness" and "permanent unconsciousness," which, because of the way they are defined, are highly limited in clinical applicability. In contrast, it is the common law coverage for such conditions as Alzheimer’s disease and other dementias, brain infections, tumors, and strokes that are likely to be clinically controlling.

In contrast, when we are dealing with patients who are in the end stages of a terminally condition, the statutory part of the living will may in fact be important. But even when dealing with a known terminal illness there are many situations in which it is the common law provisions which are clinically controlling, especially when it comes to nutrition and hydration. This is particularly so because under many state statutes the living will is not empowered to allow the patient to direct the forsaking of artificial nutrition and hydration, while under the common law this right is almost universally upheld throughout the states.

14.05 The Patient Self-Determination Act

Many patients and their families have recently complained about being coerced over (or into) signing an AMD upon admission to a hospital or nursing home. This is unfortunate, for the government’s requirement that AMD be discussed at the time of admission to an institution is not intended to force the signing of an AMD in any way. In fact, it is generally thought not to even be the most appropriate time for initiating a discussion, but was chosen simply because it is the one time when the administrative procedures of an institution invariably comes in direct contact with the patient and/or the family.

As to being inadvertently coerced into signing a living will, the patient can and should refuse to sign, unless he or she has previously considered and discussed advance directives and decided what is desired. On the other hand, if the patient feels coerced into executing a power of attorney for health care because it is the easiest way "to get it over," this is, in the opinion of the author, still worse, as discussed below.

But before getting too upset at the Patient Self-Determination Act and its funny timing, consider the following. Although the Act has had little effect on the execution of AMD and their clinical use, the very fact the Act exists has had a powerful positive influence on physician acceptance of the patients’ rights to control their own care. It is hard to characterize or prove, but almost all people working in Bioethics have concluded physicians are becoming more responsive to the directions of the patient even at a time when other changes in health care delivery are increasingly interfering with patient autonomy.

In addition, consider that the routine introduction of the issue of AMD by uninterested third parties in an admission office can often serve to initiate badly needed discussions between the patient, family and caregivers in a much less threatening manner than when introduced by the physician or a family member.
Such non-threatening opportunities to find out what the patient is thinking come few and far between in many family settings when patients are not the type to freely share their thoughts with others.

14.06 Living Will Form Declaration When Terminally Ill

The following is a suggested form which can be used by a terminally ill patient who wants to leave directions about future medical care. Commentary on the reasons behind many of the entries is included as notes following the section. At the end is a provision for naming an agent to help see the patient’s wishes are followed. There are also specific provisions to be added related to other aspects of terminal care discussed in this book. Note that the notice provision at the beginning of the document and the first article are not actually part of the living will proper, but are suggested by the author to inform a physician or other responsible person who reads the document in the future of the circumstances under which the living will was written. This helps insure the health care provider will honor the directives contained in the body of the document.

Note that in the form, I have used (parenthesis) to indicate information which should be inserted; [brackets] to suggest possible additions, and [brackets separated by a slash]/[] to indicatesome potential choices. I have capitalized enclosed words where the words to be added should be capitalized. At the end I have used the legal witnessing procedure suggested in Connecticut. The procedure prescribed in the state in which the living will is being executed should be substituted if known. If not known, it can be signed just the way form is written. Because living wills are good evidence of the patient’s desires, it will almost certainly be followed under the common law even if it isn’t signed exactly as the state statute directs.

LIVING WILL FORM DECLARATION

NOTICE TO DECLARANT

THIS IS AN IMPORTANT LEGAL DOCUMENT. BEFORE EXECUTING THIS DOCUMENT, YOU SHOULD BE AWARE OF THESE IMPORTANT FACTS:

(a) THIS DOCUMENT IS INTENDED TO GIVE SPECIFIC GUIDANCE TO POTENTIAL DECISION-MAKERS, YOUR FAMILY, AND HEALTH CARE PROVIDERS AS TO THE KINDS OF MEDICAL TREATMENT YOU WOULD WANT EMPLOYED OR FORSAKEN UNDER SPECIFIC MEDICAL CIRCUMSTANCES IF YOU ARE NO LONGER ABLE TO MAKE SUCH DECISIONS FOR YOURSELF. IF YOU SO CHOOSE, THIS DOCUMENT ALSO GIVES YOU THE OPPORTUNITY TO DESIGNATE A HEALTH CARE AGENT WITH SPECIFIC POWERS TO MAKE ADDITIONAL HEALTH CARE DECISIONS ON YOUR BEHALF IF REQUIRED. DIRECTIVES MADE HEREIN ARE INTENDED TO SERVE BOTH AS A SOCIAL AID TO THE DECISION-MAKERS AND AS A LEGAL DOCUMENT TO ASSURE YOUR CONTINUED RIGHT OF SELF-DETERMINATION IN HEALTH CARE TO THE EXTENT ALLOWED UNDER THE LAWS OF THE STATE IN WHICH YOU WILL RECEIVE THERAPY.

(b) IF YOU DESIGNATE A HEALTH CARE AGENT IN THIS DOCUMENT AND THAT PERSON
AGREES TO SO SERVE, THAT PERSON IS EXPECTED TO ACT CONSISTENT WITH YOUR WISHES AS EXPRESSED HEREIN. IF YOU FAIL TO EXPRESS YOUR WISHES WITH REGARD TO PARTICULAR CIRCUMSTANCES HEREIN, YOUR AGENT SHOULD FIRST MAKE HEALTH CARE DECISIONS IN ACCORDANCE WITH HIS OR HER KNOWLEDGE OF YOUR BELIEFS FROM THE PAST AND, IN THE ABSENCE OF SUCH KNOWLEDGE, TO ACT IN YOUR BEST INTERESTS. IF YOU CHOOSE NOT TO NAME A AGENT, UNDER YOUR RIGHT OF SELF-DETERMINATION IN HEALTH CARE YOUR HEALTH CARE PROVIDERS WILL HAVE A DUTY TO ACT CONSISTENT WITH YOUR INSTRUCTION HEREIN EXPRESSED TO THE EXTENT PERMITTED BY LAW. IF THEY DO SO, THEY ARE ALSO HEREIN PROVIDED WITH IMMUNITY FROM CLAIMS OF MALPRACTICE OR PROFESSIONAL MISCONDUCT FOR HONORING YOUR DIRECTIVES. IT IS IN YOUR BEST INTEREST TO DISCUSS YOUR DESIRES AND BELIEFS WITH A PROPOSED DESIGNATED HEALTH CARE AGENT BEFORE NAMING SUCH AGENT TO BE SURE THE AGENT IS WILLING TO UPHOLD YOUR WISHES. IT IS ALSO DESIRABLE TO DISCUSS THIS DOCUMENT WITH YOUR PHYSICIAN TO BE SURE HE OR SHE DOES NOT HAVE ANY PERSONAL CONFLICT WITH FOLLOWING ITS DIRECTIVES.

(c) THIS DOCUMENT WILL REMAIN VALID AND IN EFFECT UNTIL AND UNLESS YOU AMEND OR REVOKE IT. YOU MAY AMEND OR REVOKE THE DECLARATION AT ANY TIME BY DEFACING (AND REPLACING, IF DESIRED) THE ORIGINAL COPY AND NOTIFYING YOUR DESIGNATED HEALTH CARE AGENT, IF ANY. THIS IS DONE BY CROSSING OUT THE FRONT SHEET AND SIGNATURE PAGES, WRITING ON THE SIGNATURE PAGE "I REVOKE" AND SIGNING THE REVOCATION.

(d) YOUR NAMED HEALTH CARE AGENT WILL BE GIVEN THE SAME RIGHT AS YOU HAVE TO EXAMINE YOUR MEDICAL RECORDS AND TO CONSENT TO THEIR DISCLOSURE TO OTHERS FOR PURPOSES RELATED TO YOUR HEALTH CARE OR INSURANCE UNLESS YOU LIMIT THIS RIGHT IN THIS DECLARATION.

LIVING WILL DECLARATION

OF

(NAME IN CAPS)

I, (NAME), with a present address of (Address), being of sound mind and after considering the notice above and other due consideration, do make, publish and declare this to be my Living Will Declaration, hereby revoking any previous living will made by me.

ARTICLE FIRST

PERSONAL STATEMENT REGARDING MY LIVING WILL

I am aware of the strengths and limitations of living wills and the fact that they serve as evidence of my
desires even when their legality is not guaranteed by a living will statute.

I therefore make the provisions included in this document to give clear and convincing evidence of my desires to my family, physicians, a court, or any other person or facility responsible for my care so they shall not have to question what I would choose for myself if I were still able to do so. By so doing I hope to also relieve any guilt those close to me might feel in permitting or choosing to discontinue therapy which I would perceive as only prolonging my death, not my life.

Although recognizing the social goals, I do not want to diminish the legal aspects of this document. As an individual I am entitled to the right of self-determination in health care under the constitutional right to privacy and the common law right of informed consent in addition to rights granted by state statutes. This right is not extinguished by incapacity. I therefore demand that the directives contained herein be respected by my physicians, family, and the courts to the full extent possible under the existing law at any time that I shall be unable to make such decisions for myself as if they were my own decisions made at that time.

[Note: The "notice to declarant" and "Article First" are not primarily intended for the declarant's initial benefit, but to insure health care providers the declarant had been adequately informed of the significance of the living will before it was executed.]

ARTICLE SECOND

DIRECTIVES/STATUTORY TERMINAL CONDITIONS

The directive in this article shall be operative if the time comes when my attending physician determines (a) I am no longer capable of making and communicating decisions regarding my own medical care and (b) I am eligible for coverage under the living will statute of the state in which I am receiving treatment.

DOCUMENT CONCERNING WITHHOLDING OR WITHDRAWAL OF LIFE SUPPORT SYSTEMS.

If the time comes when I am incapacitated to the point when I can no longer actively take part in decisions for my own life, and am unable to direct my physician as to my own medical care, I wish this statement to stand as a testament of my wishes.

"I,......................... (Name), request that, if my condition is deemed terminal or if it is determined that I will be permanently unconscious, I be allowed to die and not be kept alive
through life support systems. By terminal condition, I mean that I have an incurable or irreversible medical condition which, without the administration of life support systems, will, in the opinion of my attending physician, result in death within a relatively short time. By permanently unconscious I mean that I am in a permanent coma or persistent vegetative state which is an irreversible condition in which I am at no time aware of myself or the environment and show no behavioral response to the environment. The life support systems which I do not want include, but are not limited to:

Artificial respiration

Cardiopulmonary resuscitation

Artificial means of providing nutrition and hydration

(Cross out and initial life support systems you want administered)

I do not intend any direct taking of my life, but only that my dying not be unreasonably prolonged."

Other specific requests:

"This request is made, after careful reflection, while I am of sound mind."

................................................ (Signature)

........................ (Date)

[Note: The above is the prescribed statutory statement for the State of Connecticut, the author’s residence. If the living will is being executed in another state which authorizes a similar declaration, substitute the authorized statement regarding terminal illness and/or permanent unconsciousness for the above statement.]

ARTICLE THIRD

DIRECTIVES/NON-STATUTORY TERMINAL CONDITION
The directive in this article shall become operative if the time comes when my attending physician determines (a) I am no longer capable of making and communicating decisions regarding my own medical care and (b) I am in a terminal medical condition as defined below but not under the definition of a living will statute in the state in which I am receiving treatment.

If the time comes when I am incapacitated to the point when I can no longer actively take part in decisions for my own life, and am unable to direct my physician as to my own medical care, I wish this statement to stand as a testament of my wishes.

Should I have a terminal medical condition as defined below, I direct that life support systems be withheld or withdrawn and I be allowed to die and not be kept alive through their use.

"Terminal condition" means an incurable or irreversible medical condition which, within reasonable medical judgment, 1) would produce the patient's death without the application of life support systems and 2) even with the use of life support systems, precludes the patient from (a) ever regaining decision-making capacity or (b) ever regaining decision-making capacity without unacceptable pain.

[Note: Article Third is intended to be used when the state does not have a specific living will declaration covering terminal illness or when the nature of the patient’s illness does not qualify under the state statute. It would normally not be required in patients who have cancer unless it involves the brain. It would be reasonable to include in any living will written by a patient who has a terminal disease other than cancer to be sure the living will covers their condition.]

ARTICLE FOURTH

DIRECTIVES/CHRONIC, PROGRESSIVE, IRREVERSIBLE CONDITION

The directives in this article which specifically address my diagnosed illness shall only become operative if my attending physician determines I am no longer capable of making or communicating decisions regarding my own medical care. Any directives in this article shall be additive to previous directives in this declaration in Articles Second and Third and shall be subject to interpretation by my Health Care Agent, if I have named one below.

Statement: As of this date, ________________, ____, (Date) I, ___________________________, (Name) have been diagnosed by my physician, ____________________________ (Name of Physician), of __________________________________________ (address) as having the following disease or condition which I understand to be chronic, progressive, and irreversible, even though progression may not be observable from day-to-day: _____________________________________

(Name of Disease or Condition).
At the present time I am capable of making my own health care decisions, but I fear my condition or some intervening complication or condition shall make me unable to direct such care either because of (i) mental incapacity or (ii) the physical inability to make my directives understood or to insure they are honored.

I am particularly worried because I understand the disease or condition I suffer with can lead to a situation in which further medical care will only prolong my death without the hope of returning me to what I consider to be a meaningful way of life.

I, ____________________________,(Name), do therefore direct that life support systems be withheld or withdrawn and I be allowed to die in peace if I am no longer able to make and communicate decisions for myself and my attending physician and one other physicians trained in _______________________ (Fill in name of appropriate specialty) determine there is no reasonable chance that use of such life support systems would allow me to regain decision-making capacity.

ARTICLE FIFTH

ADDITIONAL DIRECTIVES

The following directives shall apply if any of the above Articles Second, Third or Fourth are in effect.

5A. I direct that under this article the term "life support system" or similar term shall include not only mechanical or other artificial means to sustain, restore, or supplant a natural vital function, but shall also include the following initialed items:

( ) transfusions, antibiotics, heart regulators, anti-cancer drugs, anti-inflammatory medication, or any other drugs administered to control a disease process;

( ) nutrition and/or hydration given intravenously, through a tube or any other means other than voluntarily taken by mouth;

( ) Emergency resuscitation for heart or lung failure;

( ) Surgery;

( ) Invasive or investigational procedures, including intubation and needle punctures.

[Note: Most people believe that once life is meaningless, all care should be stopped, making it appropriate to initial all of these statements. Some people, however, have specific feelings about stopping certain types of therapy, like antibiotics, blood transfusions, or artificial nutrition and hydration, in which case these provisions should go uninitialed.]
5B. I realize some of the terms used in this article may be difficult to interpret. For this reason I direct that if I have appointed a Health Care Agent in Article Sixth of this living will declaration, his or her interpretation of any term shall be held conclusive of my meaning and beseech physicians, family, friends, guardians, and administrators of any health care facility in which I reside to honor my directives and those of my agent named herein. In the absence of such a named agent, I request physicians and surrogate decision-makers to act in good faith in following the most probable meaning of my directives.

5C. I direct that any legal requirement that I receive comfort care under any statute shall be limited to pain medication and such other therapy or procedure which clearly is required for my observable personal comfort, not the comfort of those around me.

5D. I do not intend any direct taking of my life, but only that my dying not be prolonged. Nevertheless, nothing in this document should be interpreted to preclude my physicians from undertaking medical or surgical treatment primarily intended for the relief of my pain or discomfort, even if such treatment runs a significant risk of hastening the specific time of my death.

The following are suggested provisions the patient might want to add depending on the specific circumstances:

5E. I direct that if at all possible, I would like to live the rest of my life and to die at home. If this is not possible and hospitalization is required or if I must be treated in a nursing home, I request that no additional therapy be undertaken except to relieve my pain or suffering.

5F. I direct that if at all possible, I would like to live the rest of my life and to die at home. If this is not possible and institutionalization is required, I would prefer being treated at a [hospital]/[nursing home]/[hospice] facility, preferably [fill in if desired.]

5G. [I know that I am pregnant]/[I believe I might be pregnant]. Even so, I still want life support systems to be withheld or withdrawn [unless a medical evaluation determines the fetus is viable and could, with a reasonable degree of medical certainty, develop to live birth with continued application of such life support systems.] [Note: there are many alternative provisions that might be appropriate. See the authors text, Advance Medical Directives, published by The West Group of legal publishers.]

5H. I would not want any health care provider to worry about being sued for following my directives. I therefore hereby bind myself, my heirs and any personal representatives to indemnify all participants in the making of this directive or in honoring its directives, whether it be a health care provider, my spouse, a relative, friend or any other person, including a member of an emergency response team, against any responsibility in any form, legally, professionally or socially, for complying with my expressed wishes.
5I. I direct my health care providers to specifically ignore the desires of (Name) who does not share my wishes about how I should be treated when I am no longer able to make decisions for myself.

5J. I request this document be given consideration equal to that of a regular will and testament distributing assets. Unless my health care agent or my attending physician can verify I have revoked this document orally or in writing, it should be held as valid upon its presentation.

5K. If under the terms of these directives it would be appropriate to withhold life support systems, I request a letter to that effect be left at my bedside by the attending physician with a copy of this living will to inform any medical emergency personnel of the situation and to assure them all the immunity possible under the laws of the jurisdiction for following my directives in good faith.

5L. I request the holder of this declaration or the holder of any copy of this declaration carry the moral obligation to give such document to any physician in charge of my care who is not aware of its existence.

5M. I hereby make known a general desire to be allowed to die at home. Please honor any future request to be discharged from a facility at a time when I am dying even if my decision-making capacity is limited as long as my family is willing to provide required comfort care. [Note: The declarant may want to indicate a desire to be placed under hospice care at home to help insure more aggressive palliative care.]

5N. I do not want to be physically restrained even if this may result in some risk of falling or otherwise being injured. Under these circumstance, those tending to me shall not be held responsible for any ill effects that may result.

A patient with AIDS might consider the following provisions:

5O. If my attending physician, after obtaining appropriate consultation, concludes I am unlikely to ever leave the hospital, I request that all life-support systems be discontinued and care be limited to providing for my comfort.

5P. If I am receiving hospice care and a new method of therapy is made available which holds the promise of reversing my mental incapacity, I request it be given to me within the hospice if possible. If not possible, please have me moved to an alternative facility where I may receive the new therapy.

A patient who is considering the authorization of the use of terminal sedation should consider the inclusion of the following provisions:

5Q. I do not want to end my life in pain or with severe suffering. I have discussed this with
my family and my health care providers and expressed acceptance of the concept of terminal sedation if required. I therefore direct if the time comes that my health care provider(s) believe the only way to control my pain and suffering is to keep me asleep with medications, I direct that it be done.

5R. If a decision is made in the course of my therapy that the only way to effectively treat my pain and/or suffering is to keep me asleep with medications, I direct that after this is undertaken and I have subsequently lost the capacity to make medical decisions, no relative, agent, health care provider, or other individual shall make or enforce a surrogate’s decision to stop terminal sedation.

A patient who is considering voluntary terminal dehydration should consider the inclusion the following provisions:

5S. If I have made a decision to voluntarily stop taking oral nutrition and hydration as a means of controlling my life expectancy, and have acted in accordance with that decision, I direct no effort be made to force oral nutrition and hydration or any form of artificial nutrition and hydration, including intravenous fluids or any form of tube feeding.

5T. I direct if food and water are left at the bedside and I do not voluntarily attempt to swallow them at a time I am capable of doing so, that this action should be taken as a decision on my part to voluntarily refuse nutrition and hydration.

5U. If I have voluntarily refused nutrition and hydration, at no time should I be given small quantities of food or fluids beyond that required to care for my mouth locally. No action on my part shall be viewed as indicating thirst or hunger other than a request on my part for food or fluids.

5V. If as a result of my refusal of oral nutrition and hydration I lose my capacity to make medical decisions, I direct my rejection of food and fluids be honored by my family, friends, health care providers and agents, if any.

ARTICLE SIXTH

DESIGNATION/HEALTH CARE AGENT

A. I hereby authorize my [(relationship)]/[friend], (NAME)

with a present address of (address) as my Health Care Agent, to implement this, my Living Will Declaration, and to accept, direct responsibility for, and/or refuse hospitalization and/or treatment on my behalf if I am incapable of so acting for myself.

B. In addition, I request my Health Care Agent be recognized as the individual responsible to act on my
behalf in all health related matters including, but not limited to, all of the following:

[Note: Generally include all the following unless there is a specific reason not to.]

1. Serving as final decision-maker regarding any uncertainties or ambiguities which may exist in or related to this declaration.

2. Taking primary responsibility for making this document immediately known and available to any physician who is in charge of my care wherever care is being given.

3. Acting as the final arbiter of fact if any other person suggests I may have rescinded this document.

4. Serving as the designated guardian or conservator of my person if one is required.

5. Accepting the responsibility to see that the physician and facilities involved in my care honor my directives herein to the full extent provided under statutory or common law, including the right to transfer my care to alternative physicians or facilities, within or without the state.

6. Deciding if I would have wanted those life support systems herein addressed or any additional systems not specifically enumerated herein withheld or withdrawn under circumstances not specifically covered by my living will declaration.

C. If the person I have named above refuses or is unable or unavailable to act on my behalf, or if I revoke that person's authority to act as my Health Care Agent, I authorize as his or her replacement my [(relationship)]/[friend], (NAME) with a present address of (address) to implement my Living Will Declaration as my substituted Health Care Agent and to act in his or her stead and with the same powers conveyed.

D. I understand the full import of this designation of a Health Care Agent, and am emotionally and mentally capable of making this declaration. It is my intention this appointment shall be honored by designated alternative health care agents, my family, relatives, friends, physicians, attorneys and in all court proceedings as the final expression of my legal right to refuse medical or surgical treatment, and I accept the consequences of such a decision.

E. I understand I have the right to revoke the appointment of the persons named above to act on my behalf at any time by communicating that decision to the agent and/or my health care provider. If that is my intention, if I am still capable to do so, I will cross out and initial this article in the original living will document which can be identified because it is signed in colored ink.

F. If I am being treated in a state which does not recognize my directives herein in the form of a living will but does recognize the power of an attorney in fact to direct the forsaking of non-comfort directed medical
care, the above appointment of a designated agent shall serve as the appointment of an attorney in fact with authority to make health care decisions including the withholding or withdrawing of life support systems based on my desires as indicated in this declaration.

G. If I have named a physician as my agent, I direct if this conflicts with the law of the state in which I am being treated, he or she shall [act as my agent and transfer my care to other physicians for medical decision-making]/[continue to care for me as a physician and have the next alternative act as my agent].

[Note: Even if the state AMD statute does not provide for the naming of a health care agent as part of the document, it will still almost always be valid under the common law.]

It is important the person designated to help interpret the directives have a knowledge of the declarant's desires and share their general beliefs about health care at the end of life. If there is no one on whom they can rely to fulfill this function, the declarant may be better off relying on the medical profession to honor the directives than designating a health care agent.

Even though many states refuse to allow the attending physician to act as a health care agent, most do allow this to happen if the physician turns over primary care of the patient to another physician.]

IN WITNESS WHEREOF, I have subscribed my name to this my LIVING WILL DECLARATION, [including the designation of a HEALTH CARE AGENT] in the presence of the persons witnessing it at my request this (#)th day of (Month), (Year), at (#) [a]/[p].m. at (Name of Town or City and State)

Sign in colored ink. ____________________________

Copy only in black.

____________________________
Typed Name of Declarant

____________________________
Typed Name of Person

Signing for Declarant (If any)
WITNESSETH:

The foregoing instrument was signed published and declared by (NAME OF DECLARANT), the declarant, to be [his]/[her] Living Will Declaration, in our presence, and we, at [his]/[her] request, and in [his]/[her] presence and in the presence of each other have hereunto subscribed our names as witnesses this (#)th day of (Month), (Year), at (Name of Town or City and State).

Witnesses sign here indicating their residency:

___________________________ residing at ________________________
Town or City/State

___________________________ residing at ________________________
Town or City/State

AFFIDAVIT

STATE OF (STATE) )
) ss: (Name of Town or City) (Month, Day, Year)

COUNTY OF (COUNTY))

Then and there personally appeared the within named (Name of First Witness), (Name of Second Witness) and (Name of signer of Oral Declaration for Declarant, if any) who being duly sworn, individually depose and attest that:

(1) The declarant is personally known to them and they believe the declarant to be at least 18 years of age and of sound mind;

(2) They are at least 18 years of age;

(3) To the best of their knowledge, at the time of the execution of this living will declaration, they:

(A) Are not related to the declarant by blood or marriage;

(B) Would not be entitled to any portion of the declarant’s estate by any will or by operation of law under the rules of descent and distribution of this state;
(C) Are not the attending physician of declarant or an employee of the attending physician or an employee of the hospital or skilled nursing facility in which declarant is a patient;

(D) Are not directly financially responsible for the declarant's medical care;

(E) Have no present claim against any portion of the estate of the declarant; and

(F) Are not a designated agent under the declaration;

(4) That they witnessed the execution of the within Living Will Declaration by the within named Declarant [or signer for an oral declarant]; that said Declarant subscribed said Living Will Declaration and declared the same to be [his]/[her] Living Will in their presence; that they thereafter subscribed the same as witnesses in the presence of said Declarant, and in the presence of each other and at the request of said Declarant; that the said Declarant appeared to them to be of full age and of sound mind and memory and that they make this affidavit at the request of the said Declarant, (DECLARANT'S NAME)

Witness 1: _____________________________

Witness 2: _____________________________

Signer for Declarant, if any: _____________________________

{Appropriate language indicating the swearing to the above affidavit as is customary for notarization in the state in which the document is to be signed}

Seal:

Subscribed and sworn to before me

this # day of (Month) , (Year).

__________________________________

Notary Public

FOR USE IN A NURSING HOME OR OTHER EXTENDED CARE FACILITY:

I hereby witness this living will and attest that I believe the declarant to be of sound mind and to have made this Living Will Declaration willingly and voluntarily.
Witness ____________________________ *

*Medical director of skilled nursing facility, staff physician not participating in care of the patient, or chief of the health care facility.

The original signed declaration will be kept at: (place). Copies will also be given to: (Names of people).

[Note: If for some reason it is difficult to have the living will witnessed or notarized, have it executed without the witnesses and/or Notary Public’s signature. You may have it witnessed later by just indicating to the witnesses that it is your signature and having them sign. If it is never witnessed, it is still likely to be valid under the common law as indicating your desires.]

14.07 Form: Notice to Health Care Provider

When an AMD is written, it is important to notify health care providers of its presence. The following form may be used to do so.

NOTICE TO HEALTH CARE PROVIDER

To: (Name of Health Care Provider)

Address: (Address)

From: (Declarant's name)

Date: (Date)

This is to inform you I have recently executed a [Living Will]/[Power of Attorney for Health Care]/[Do-Not-Resuscitate Order]/[Designation of Anatomical Gift] a copy of which is enclosed for your records. [We have previously discussed my desires to execute such document(s).]

As part of this document, I have appointed the following Agent to speak for me if I am unable to make decisions for myself:

Name of Agent: (Name)

Address: (Address)

Telephone Number(s): (Work and home numbers)

I would appreciate your reviewing the enclosed and contacting me directly if you would have any difficulty
honoring my requests in a situation addressed by the document.

Although I would not hold you legally responsible, I do ask if the time comes when you are aware I am or am likely to become incapable of making medical decisions for myself, that you will give a copy of [this]/[these] documents to my attending physician [if that is other than yourself.]

Sincerely,

(Name)

14.08 Health Care Powers of Attorney: In General

As mentioned in the introduction, every state has passed a special law which allows one person, called the "principal," to execute a legal document, called a "power of attorney," which designates another person, called the "agent" or "attorney in fact," to make decisions for the principal. Once being granted the power of attorney, decisions of the agent are legally viewed as the principal's decisions.

A traditional power of attorney, however, is limited in that it only allows the agent to make decisions the principal could make if present. Therefore, if the principal loses the capacity to make decisions, the agent's power also ceases. This makes traditional powers of attorney inappropriate for medical decision-making because the agent would lose power to make decisions at the same time the principal lost decision-making capacity.

To correct this problem, laws have been passed which allow the agent to maintain decision-making powers even when the principal loses the ability to make decisions. Such documents are called "durable powers of attorney," because the power endures incapacity of the principal, the agent maintaining decision-making authority when the principal becomes incapacitated. [But not after death.] These durable powers of attorney are usually used for financial purposes to allow agents to continue the work of the principal after they have become incapacitated.

Although durable powers of attorney may be expanded by state law to allow the agent named in the document to also make health care decisions, most states prefer a separate document called a "Durable Power of Attorney for Health Care (DPAHC) be used. In this case, the person named is then usually referred to as a "Health Care Agent."

For many patients using a DPAHC seems like a much easier way of dealing with decisions about life support systems than writing a living will, but there are many problems even when used by patients who are known to be terminally ill. That is why the author prefers use of a living will, often with a provision naming an agent to see the desires of the patient be carried out, as provided in the form above.
14.09 Pros and Cons of Designated Health Care Agents

Many commentators believe powers of attorney for health care are preferable to living wills. They tend to point out the following:

1) An agent is likely to be better informed about an exact clinical situation requiring a decision than is the principal, who has to make decisions days, weeks, or months before the exact situation arises. This theoretically means the agent’s decision should be better because it is made at the time it is required than a decision previously written by the principal which had to have been nased on incomplete information.

2) Naming an agent prevents critical decisions from being made by a relative whom the principal considers untrustworthy or uncommitted to advancing the principal’s own values and desires.

3) Physicians relying on health care directives of a personally designated and legally recognized agent will be less worried about legal reprisals or questions of professional misconduct than when dealing with a living will.

4) Naming an agent resolves uncertainty about who is authorized to consent for the incapacitated patient, thereby eliminating the physician's problem when relatives are in disagreement or when the family disagrees with the physician(s).

5) Naming an agent gives doctors someone to talk to, someone who is empowered to make decisions, surmounting the problem of interpreting by guesswork the often vague terms of a living will.

6) Naming an agent allows decision-making even when the patient's desires were ambiguous, inconsistent, or otherwise not clearly expressed or did not take into account unforeseen developments.

[Note that while all of these may be true, they are also true of a combined document as suggested above in which the agent acts in compliance with the patient’s stated directives.]

A seventh advantage which may not fit with a combined document is that under the law, a patient needs less mental capacity to name an agent than to write a living will.

This may be an advantage if the patient’s capacity is in question. The theory is that it is much easier for the patient to remember which relative or person he or she has trusted over a lifetime than to deal with new specific medical conditions and therefore the naming of an agent requires less mental ability than writing a living will.

Those who, like the author, question the use of a "naked" DPAHC; i.e., one without an instructional directive, point out the following in favor of a living will or combined document:

1. In many situations, the power of attorney grants life and death decision-making to an agent who stands to
gain from the self-interested exercise of power. Such conflicts of interest are against general legal ethics.

2. Family members who are likely to be named as agents are frequently overwhelmed by grief or responsibility and unable to make decisions. This is particularly troublesome because agents have no requirement to act under the law of agency. This makes it very difficult for physicians when the named agent becomes indecisive. In contrast, the directives in a living will are to be followed by all physicians, thus allowing substitution for an undecisive decision-maker.

3. Studies have shown that in the absence of an instructive directive, families are very poor predictors of what a patient would decide. Therefore, even though the agent’s decision is legally binding because it is considered that of the patient, the physician is likely to be directed to take action different than what the patient would have wanted.

4. Family members are more reluctant to terminate a relative’s care than they are to terminate their own care. Relying on an agent is more likely to result in more aggressive and more prolonged [probably unwanted] care than use of a carefully written living will directive.

5. Many people do not have an individual relative or friend they would be comfortable with as an agent to make health care decisions.

6. The fact an agent’s decisions are considered those of the patient relieves legal liability, but does not conform to the concept of self-determination in health care. Naming an agent without giving direction essentially waives this right.

7. An agent may not be available in time of need.

8. A patient who has designated and instructed a proxy agent may undergo a change of heart and find it emotionally difficult to communicate this desire to make a revocation. Changing a living will would not evoke the same emotional problems.

9. A person who is under coercion when designating an agent may find it more difficult to revoke than a living will executed under coercion because the latter can be done in private.

10. Because the DPAHC is so easy, it gives the principal a false sense of security and accomplishment relieving him or her from undertaking the difficult task of deciding what would actually be desired in various clinical situations. While this may seem favorable for the principal, it actually results in loss of autonomy, for it fosters continued care whenever a difficult decisions must be made.

11. DPAHC’s are likely to place guilt on a single individual, often the one the principal would least like to hurt. This is much less likely to happen if decisions are made by consensus of the interested parties -- family, friends, and health care providers.

12. The execution of a DPAHC can produce family conflict. What happens within the family when the
named agent is a different sibling than the one who is the primary care giver? When two of three siblings are named to be co-agents? When a husband or wife names a child to be the agent and not the spouse?

13. Agency can produce major problems for the physician who firmly believes the decision made by a single agent is wrong. It is much easier to accept a "wrong" decision agreed to by multiple members of a patient’s family and friends.

14. In the absence of an instructional directive, if family members disagrees with an agent’s directives, they are likely to challenge the agent’s decision in court. [Argument for combined document.]

[Note: For a more thorough discussion of problems which result from durable powers of attorney for health care, the reader can refer to the author’s article in The Quinnipiac Probate Law Journal 12:3:305-342 (1998).]

14.10 Choosing a Health Care Agent

Based on the considerations noted above, reliance on sympathetic family members as agents may not be the most appropriate. The primary role of the agent is to assist the principal to maintain both dignity and autonomy. To do this, the agent may be required to review medical records, obtain a physician qualified to give a second opinion, delay procedures when informed consent is in doubt, delay undesired hospital discharge, and forbid any unwarranted use of the patient for experimental or teaching purposes without the patient’s specific knowledge and permission.

Such a person should be someone who will not be intimidated in the health care setting, someone known well by the principal, someone who is aware of the principal’s values, and who is not afraid to speak up and be assertive on the principal’s behalf. The agent must be comfortable abiding by the principal’s wishes, and prepared to carry them out without imposing his or her views.

In addition, the following qualifications should be considered before choosing an agent, for it requires a certain nature and ability to act objectively and effectively. Most importantly, an agent should be a person who is capable of acting when decisions must be made and one who would be able to direct the discontinuation of life support systems without fearing later guilt for making this most difficult decision on the principal’s behalf.

An initial factor which is likely to influences the appropriate choice of an agent is whether the agent is going to be making new decisions (DPAHC) or whether the agent is going to be primarily empowered to see to it the principal’s decisions are followed (combined living will with agent document).

First, unless specific guidance provisions are to be included, the principal must expect the final decisions made will tend to reflect the agent's own biases, prejudices, and psychological agendas even more than the principal’s. Therefore, an appropriate agent in these circumstances should share the principal's basic approaches to quality of life issues.
Second, because incapacitated persons are likely to be emotional and financial burdens on their family, potential agents may experience a conflict of interests. Unless the principal's goal is to reduce such burdens on others, choice of a person who would not bear direct financial burdens may be more appropriate.

Third, making life and death decisions for another person is psychologically stressful. As a result, agents may subconsciously try to avoid the moral and psychological responsibility for forsaking care. As they are only given the power, but not the duty, to act, the result may be prolonged, agonizing indecision. An appropriate agent should therefore be decisive and both willing and capable of accepting the emotional burdens which may ensue.

Fourth, principals should remember that other family members, especially those of a younger generation, are likely to underestimate the functional status or quality of life of the older individual. Those who have never suffered adversity are unlikely to understand the pleasures in living which still exist under physical limitations. A person whose enjoyment in life is largely physical or comes largely from activities which are not of interest to the principal may not be an appropriate agent.

Fifth, potential agents should always be asked if they would be willing to serve and would respect the principal's wishes. The desire of a spouse or adult child to decline to be designated as an agent because, "I can't be the one who pulls the plug," should be fully appreciated.

In contrast, when the agent is primarily responsible to see that the principal’s directives are carried out, proximity to the place where care is to be undertaken is very important. In addition, the ability to communicate with health care providers is highly desirable. Also, the need to be forceful in seeing to it the principal’s directives are being followed.

14.11 Determination of Competency/Capacity

AMD do not become operative as long as the patient is capable of decision-making. Therefore, before a clinician considers the directives in a living will or follows the directives of a health care agent, someone must determine the patient has lost decision-making capacity and to determine the capacity is not likely to return quickly. Although this frequently causes a major problem when trying to implement a traditional living will, it is less likely to cause problems when dealing with a terminally ill patient in whom improvement is not considered a likely possibility.

[Note this is not strictly true legally. In theory, the agent can direct care even if the patient is capable of decision-making, but, in fact, physicians will always follow the directives of the patient if there is a conflict assuming that the objection of the patient to the agent’s decision essentially revokes the appointment of agency. In the absence of a terminal illness, this is more likely to be a problem during times of temporary loss of decision-making capacity if the agent chooses to direct the discontinuation of life-support systems.]

Fortunately, courts and the legal system have been moving away from the old concept of "competency," which requires a court determination and evolving toward a new concept of "capacity," which does not require court action. Instead, capacity is determined by the current ability of the individual to make and
communicate specific decisions based on personal values and goals. As a result, physicians need not take a broad view of the patient’s competency to make decisions in general, but can limit the determination of when an agent gains authority based on the patient's present understanding of his or her situation and the risks and benefits of a specific form of therapy being suggested. Appropriate criteria for the determination of capacity are whether the individual possesses sufficient mental function to understand in a reasonable manner the nature, extent, character, and effect of his or her illness and the proposed act or transaction which is contemplated. If the physician believes the patient is capable of making and communicating such a decision, the patient’s current directives should be followed. If the patient is unable to make the decision, the directives in a living will or those made by the agent should be followed.

14.12 Other Concerns of the Physician

It is important to consider the concerns of physicians when drafting an AMD to try to anticipate and incorporate in the document information which will make it easier for the physician to honor the principal’s directives. As with the question of capacity, these concerns are often simplified when dealing with an AMD written after the patient has developed a terminal illness.

The following are some of the medical concerns about living wills which should be considered:

1. Coercion. Physicians may worry the patient has written an AMD under pressure from family to do so, but this is unlikely to be a problem when the patient has been communicating with health care providers on a regular basis before the document is written. In fact, the most likely coercive force is the patient’s own desire to preserve assets for the family, which may be a justified reason for trying to limit expenses for prolonging a life considered meaningless by the patient.

2. Informed consent. Physicians frequently question whether a patient who has written a general living will understood the significance of what they were writing at the time it was written. This is not likely to be a problem if the physician has taken part in the discussion prior to the writing of a living will for a terminally ill patient. [The major reason for including the notice provisions and article 1 in the living will form above.]

3. Conflict with family desires. A special concern for physicians arises when the family does not agree with the directives of a now incapacitated patient. The law would dictate that if the patient has left specific directives, the directives should be followed and not the family’s desires. The more specific the directive, the easier it is for the physician. The more ambiguous, the harder it is for the physician to follow the patient’s wishes, especially if the family threatens a law suit if their wishes are not followed.

4. Inappropriate directives. Unfortunately, because most general living wills do not address the important disease states -- dementia, strokes, brain tumors and other derangements of the brain -- most living wills do not give clear directives when hard decisions about stopping care must be made. This is not likely to be a problem when dealing with patients with known
terminal illness who have written living wills specifically addressing the issues of their predicted future care.

5. New therapies. Physicians may be more likely to try to keep a patient alive in the hope some new medical advance will reverse a previously untreatable disease than a directive would indicate. In the case of AIDS, for instance, this may in fact be quite rational, but there are few other conditions in which this would be reasonable.

6. Paternalism. Unfortunately, physicians may be reluctant to honor patient directives out of paternalism, a personal belief that the directive does not comply with the patient’s best interest. Again, this is not as likely to be a problem when the patient has a known terminal illness and it has been discussed with the patient before the living will was written.

The following are some of the medical concerns about powers of attorney which should be considered:

1. Physicians worry that agents will be difficult to convince time must pass before a decision to stop therapy is appropriate. In the absence of agency, the physician normally decides when to discuss discontinuation of aggressive care with the patient or family. An agent appointed to make sure a patient's wishes are followed may feel impatient to honor the patient's expressed wishes that care not be unreasonably prolonged.

2. Physicians may fear the long-term effects of forcing the agent to make the final decision to forswear therapy for a loved one. As a family member the decision can be shared. As the agent, it is one person's to bear. This may lead either to an inability to make decisions or to guilt when a timely decision is made.

3. Physicians fear the legal power of an agent who may have personal reasons for directing the discontinuation of care.

4. Physicians fear that absent an obligation to make decisions, agents will waffle between the desire to follow the principal's wishes and the pressures of other family members and the potential for guilt. During such periods of non-action, treatment will be uncertain and will have to be continued against the wishes of the patient.

The best way around all of these problems is the inclusion of a comprehensive informational directive along with the naming of a health care agent.

14.13 Decisions of a Health Care Agent

Most principals executing a power of attorney for health care believe the agent they appoint is likely to make the same decision they would make in the same clinical situation. There is little evidence to support this belief. The kind of medical decisions which must be made when a patient is irreversibly incapacitated are likely to be determined as much by the agent's values and personal evaluation of quality of life as by the
nature of the illness, and research indicates family members are generally unreliable in assessing a patient's quality of life. Although agents and principals are likely to evaluate the health issues similarly, significant discrepancies are likely to exist between their evaluation of the patient's emotional health, with spouses and children routinely underestimating a patient's satisfaction with life.

Similarly, studies continue to suggest agents and surrogates [decision-makers named by law in the absence of a designation by the principal] cannot predict patients' preferences for life-sustaining interventions. Agreement may be high when considering interventions for the patient's current health, but in the presence of dementia, or after a stroke, when the agent would have to make the decision for the patient, agreement is much less common. Indeed, in many studies selections made by appropriate agents are no closer to those which would be made by the principal than would be expected by random chance. [As reported by Emanuel and Emanuel, Proxy Decision-making for Incompetent Patients, 267:15 JAMA 2067-71 (1992). Also see discussion in Lieberson, Advance Medical Directives, (Clark/Boardman/Callaghan -- now part of the West Group of Legal Publishers, Rochester N.Y. 1992) §20:5 and (Supp. 1997) §21:14.]

Principals should therefore be advised that while their legal right of self-determination will be maintained by the naming of an agent, they should not expect this process to result in the same approach to medical care as they would have chosen for themselves.

14.14 Advantage of a Combined Document

Many commentators on advance directives, including groups like AARP, have concluded the main shortcomings of living wills would not exist if declarants took the time to write directives specifically addressing the various important clinical situations. If this were done, it would eliminate the supposed advantages of designated agents. At the same time, they believe if an appropriate agent is available, designating that agent to assure the declarant's wishes are followed is advisable. This general agreement has led to the introduction of combined documents, as are advocated in this book.

14.15 Form: Durable Power of Attorney for Health Care

The following is a suggested form durable power of attorney for health care. Like the living will form, it contains many provisions which are more instructive for the principal writing the document and for the physicians who will be asked to honor it than is required. There are also a number of provisions which should be considered for addition depending on the patient’s specific circumstances.

The form does not contain provisions for signing and witnessing. As these vary from state to state and change frequently, the specific requirements of the state about witnesses, notaries, etc. should be checked and included in the document. As DPAs are purely statutory and not validated by the common law, it is much more important that they be signed and witnessed as direct by state statute than living wills.

DURABLE POWER OF ATTORNEY FOR HEALTH CARE

WARNING TO PERSON EXECUTING THIS DOCUMENT
THIS IS AN IMPORTANT LEGAL DOCUMENT. BEFORE EXECUTING THIS DOCUMENT, YOU SHOULD KNOW THESE IMPORTANT FACTS:

1. THIS DOCUMENT GIVES THE PERSON YOU DESIGNATE AS YOUR AGENT, THE "ATTORNEY IN FACT," THE POWER TO MAKE HEALTH CARE DECISIONS FOR YOU. YOUR AGENT MUST ACT CONSISTENTLY WITH YOUR DESIRES AS STATED IN THIS DOCUMENT OR OTHERWISE MADE KNOWN.

2. YOU SHOULD DISCUSS THIS DOCUMENT AND YOUR DESIRES WITH THE PERSON YOU WANT TO APPOINT TO BE YOUR HEALTH CARE AGENT. IT IS ALSO ADVISABLE TO DISCUSS THIS DOCUMENT WITH YOUR PHYSICIAN OR OTHER HEALTH CARE PROVIDERS BEFORE YOU SIGN IT TO MAKE SURE THAT YOU UNDERSTAND THE NATURE AND RANGE OF DECISIONS WHICH MAY BE MADE ON YOUR BEHALF. IF THERE ARE ANY LEGAL ISSUES IN THIS DOCUMENT THAT YOU DO NOT UNDERSTAND, YOU SHOULD ASK A LAWYER TO EXPLAIN IT TO YOU.

3. EXCEPT AS YOU OTHERWISE SPECIFY YOUR DESIRES HEREIN, THIS DOCUMENT GIVES YOUR AGENT AUTHORITY TO CONSENT, TO REFUSE TO CONSENT, OR TO WITHDRAW CONSENT TO ANY CARE, TREATMENT, SERVICE, OR PROCEDURE TO MAINTAIN, DIAGNOSE, OR TREAT A PHYSICAL OR MENTAL CONDITION, INCLUDING TREATMENT SPECIFICALLY UNDERTAKEN TO EXTEND YOUR LIFE. YOU MAY STATE IN THIS DOCUMENT ANY TYPES OF TREATMENT THAT YOU DO NOT WANT YOUR AGENT TO AUTHORIZE, SUCH AS VOLUNTARY INPATIENT MENTAL HEALTH SERVICES, CONVULSIVE TREATMENT, PSYCHOSURGERY, STERILIZATION, OR ABORTION. UNLESS YOU OTHERWISE SPECIFY IN THIS DOCUMENT, YOUR AGENT WILL ALSO BE GIVEN THE RIGHT TO EXAMINE YOUR MEDICAL RECORDS AND TO CONSENT TO THEIR DISCLOSURE AND, AFTER YOU DIE, TO (1) AUTHORIZE AN AUTOPSY, (2) DONATE YOUR BODY OR PARTS THEREOF FOR TRANSPLANT, THERAPEUTIC, EDUCATIONAL, OR SCIENTIFIC PURPOSES, AND (3) DIRECT THE DISPOSITION OF YOUR REMAINS.

4. NOTWITHSTANDING THIS DOCUMENT, YOU HAVE THE RIGHT TO MAKE MEDICAL AND OTHER HEALTH CARE DECISIONS FOR YOURSELF SO LONG AS YOU CAN GIVE INFORMED CONSENT WITH RESPECT TO THE PARTICULAR DECISION. IN ADDITION, NO TREATMENT MAY BE GIVEN TO YOU OVER YOUR OBJECTION AT THE TIME, AND HEALTH CARE NECESSARY TO KEEP YOU ALIVE MAY NOT BE STOPPED OR WITHHELD IF YOU OBJECT AT THE TIME.

5. YOU HAVE THE RIGHT TO REVOKE THE AUTHORITY OF YOUR AGENT BY NOTIFYING YOUR AGENT OR YOUR TREATING DOCTOR IN WRITING OR BY ORALLY NOTIFYING YOUR TREATING PHYSICIAN, WHO SHOULD THEN NOTE THE REVOCATION IN YOUR MEDICAL RECORD. SHOULD YOU REVOKE THE AUTHORITY OF YOUR ATTORNEY IN FACT, IT IS ADVISABLE TO DISTRIBUTE COPIES OF THE REVOCATION WHEREVER COPIES OF THIS DOCUMENT ARE LOCATED. IF YOU APPOINT YOUR SPOUSE AS ATTORNEY IN FACT, YOU
MAY STATE THAT YOUR APPOINTMENT DISSOLVES ON DIVORCE. IN ADDITION, A COURT CAN TAKE AWAY THE POWER OF YOUR AGENT TO MAKE HEALTH CARE DECISIONS FOR YOU IF YOUR AGENT (1) AUTHORIZES ANYTHING THAT IS ILLEGAL, (2) ACTS CONTRARY TO YOUR KNOWN DESIRES, OR (3) WHERE YOUR DESIRES ARE NOT KNOWN, DOES ANYTHING THAT IS CLEARLY CONTRARY TO YOUR BEST INTERESTS.

6. THIS DOCUMENT PERMITS, BUT DOES NOT IMPOSE A DUTY ON YOUR AGENT TO EXERCISE GRANTED POWERS. THIS MAY CAUSE PROBLEMS IF THE AGENT IS INDECISIVE.

7. YOUR AGENT MAY NEED THIS DOCUMENT IMMEDIATELY IN CASE OF AN EMERGENCY THAT REQUIRES A DECISION CONCERNING YOUR HEALTH CARE. COPIES SHOULD BE GIVEN TO YOUR ATTORNEY IN FACT AND YOUR PRIMARY CARE PHYSICIAN. YOU SHOULD INDICATE ON THE DOCUMENT ITSELF THE PEOPLE AND INSTITUTIONS WHO WILL HAVE SIGNED COPIES.

8. MOST STATES DO NOT ALLOW THIS DOCUMENT TO BE CHANGED OR MODIFIED. IF YOU WANT TO MAKE CHANGES YOU MUST EXECUTE AN ENTIRE NEW DOCUMENT.

9. DIFFERENT STATES HAVE DIFFERENT REQUIREMENTS FOR SIGNING AND WITNESSING THIS DOCUMENT. IF YOU HAVE BEEN IN AN INSTITUTION RECENTLY, YOU SHOULD HAVE BEEN GIVEN INFORMATION ABOUT HOW IT SHOULD BE SIGNED ON ADMISSION.

General Statement

As of this date, (Month and Day), (Year), I, _______________ ________________ (Name) have been diagnosed by my physician, ______________________ (Name of Physician), of _________________ _________________ (Address) as having the following disease or condition which I understand to be chronic, progressive, and irreversible, even though progression may not be observable from day-to-day:

_____________________________________

(Name of Disease or Condition).

I, (Name), being of sound mind, voluntarily execute this document with the intent of creating a durable power of attorney for health care. Nevertheless, I expect to be fully informed about and allowed to participate in any health care decision for myself to the extent I am able.

After careful consideration, thought and discussion, I have chosen my attorney in fact (hereinafter referred to as my "Agent") to make health care decisions on my behalf based on his or her understanding of my concerns, directives, values and goals. No competing interests of other family members or third parties shall interfere with or compromise his or her decisions. If asked to make decisions covering areas we have not
discussed, I will rely on and vest decision-making solely with him or her rather than in some other party or group of parties in order to minimize confusion and simplify decision-making.

In exercising this authority, my Agent shall attempt to reach the decision I would have made under the circumstances, based [first on any instructional directive(s) I have left and second] on his or her understanding of my preferences and values. If my Agent determines he or she does not have enough information to reach the decision I would have made under the circumstances, my Agent shall make a decision based on what he or she believes to be in my best interests. In either event, my Agent has discretion to choose among a wide range of reasonable choices[, including both traditional and experimental medical treatment or procedures] as he or she sees fit.

For the purpose of this document "health care decisions" mean consent, refusal of consent, or withdrawal of consent to any care, treatment, service, or procedure to maintain, diagnose, or treat an individual's physical or mental condition.

For the purpose of this document, I direct that wherever I have referred to "Life Support Systems" I intend to include not only mechanical or other artificial means to sustain, restore, or supplant a spontaneous vital function, but shall also include the following items:

A. transfusions, antibiotics, cardio-vascular regulators, cancer chemotherapeutics, anti-inflammatory medication or any other drugs administered to control a disease process;

B. nutrition and/or hydration given intravenously, by nasogastric or gastrostomy tube or any other means other than voluntarily taken by mouth;

C. cardio-pulmonary resuscitation;

D. surgery; and

E. invasive or investigational procedures, including intubation and needle punctures.

[Note: Any of the provisions A through E can be removed if desired.]

I specifically request if I or my Agent direct that I not be given nutrition and hydration, this shall be interpreted to include both oral and artificial food and fluids.

I specifically authorize my Agent, after obtaining appropriate information from my physicians and after making reasonable efforts to communicate with me, to demand that life support systems be forsaken or discontinued if doing so is consistent with my directives in a valid living will or as otherwise known by my agent to be my updated wishes.

I recognize this authorization may exceed the powers granted under a statutory durable power of attorney or a durable power of attorney for health care in the state in which I am being treated. If such is the case, I
direct this authorization be honored as an exercise of my rights to exercise self-determination in health care under the United States Constitution, the Constitution and the common law both of the state of my domicile and state in which I am receiving care, and any other federal or state laws, rules, regulations and decisions, judicial or administrative.

I request this document be assumed to be valid unless my health care agent herein named or my attending physician can verify I have revoked this document orally or in writing.

1. Appointment

I, (NAME OF PRINCIPAL), with present address of (Address), do hereby appoint [(NAME OF AGENT)][(my relationship), (NAME OF RELATIVE or FRIEND),] with present address of (Address) [and telephone number (number)] my true and lawful Attorney in Fact for Health Care, hereinafter referred to as my "Attorney in Fact" or "Agent," to make health care decisions on my behalf. If my said Attorney in Fact ceases to serve, then I appoint (my relationship, if any),(NAME OF SUCCESSOR ATTORNEY IN FACT) of (Address) [and telephone number (number)], my true and lawful Attorney in Fact.

THIS POWER OF ATTORNEY SHALL NOT BE AFFECTED BY MY SUBSEQUENT DISABILITY OR INCAPACITY

[Note: Some state statutes provide specific language which only grants decision-making power to the Agent after the Principal becomes incompetent or incapacitated. This may be beneficial, but may require court intervention.]

2. Powers Regarding My Personal Care

The scope of authority granted in this durable power of attorney for health care is limited to matters set forth herein, but includes powers reasonably necessary to carry out the intent of this instrument. With respect to my personal care, my Agent shall have the power:

(a) To request, review, and receive any information, verbal or written, regarding my physical or mental health, including medical and hospital records, and to execute any releases or other documents which may be required in order to obtain this information.

(b) To employ and discharge physicians, psychiatrists, dentists, nurses, therapists and other professionals as my Agent may deem necessary for my physical, mental, and emotional well-being, and to pay them or any of them reasonable compensation.

(c) To give or withhold consent to my medical care, surgery, or any other medical procedures or tests; to arrange for my hospitalization, convalescent care, or home care; and to revoke, withdraw, modify, or change consent to my medical care, surgery, or any other medical procedures or tests, hospitalization, convalescent care, or home care that I or my Attorney in Fact, as my Agent, may previously have allowed or consent to which may have been implied due to emergency conditions. I ask my Agent to be guided in making such
decisions by what I have told my Agent about my personal preferences regarding such care. Based on those same preferences, my Agent also may summon paramedics or other emergency medical personnel and seek emergency treatment for me, or choose not to do so, as my Agent deems appropriate given my wishes and my medical status at the time of the decision. My Agent is authorized, when dealing with hospitals and physicians, to sign documents titled or purporting to be a "Refusal to Permit Treatment" and "Leaving Hospital Against Medical Advice" as well as any necessary waivers of, or releases from, liability required by the hospitals or physicians to implement my wishes regarding medical treatment or non-treatment.

(d) To consent to and arrange for the administration of pain-relieving drugs of any type, or other surgical or medical procedures calculated to relieve my pain even though their use may lead to permanent physical damage, addiction, or even hasten the moment of (but not intentionally cause) my death. My Agent may also consent to and arrange for unconventional pain-relief therapies such as biofeedback, guided imagery, relaxation therapy, acupuncture, skin stimulation or cutaneous stimulation, and other therapies I or my Agent believes may be helpful to me.

(e) To exercise my right of privacy to make decision regarding my medical treatment and my right to be left alone even though the exercise of my right might hasten death or be against conventional medical advice. My Agent may take appropriate legal action, if necessary in the judgment of my Agent, to enforce my right in this regard.

(f) To insure any legal requirement I receive comfort care under any statute shall be limited to pain medication and such other therapy or procedure which clearly is required for my observable personal comfort, not the comfort of those around me.

(g) To insist nothing in this document should be interpreted to preclude my physicians from undertaking medical or surgical treatment primarily intended for the relief of my pain or discomfort, even if such treatment runs a significant risk of hastening the specific time to my death.

(h) If I am cared for at home, to arrange for such home care and pay all said costs, without incurring personal financial liability, including the expenses of round-the-clock nurses or the equivalent, the rental or purchase of hospital type furniture, medical equipment and supplies (including special beds, wheelchairs, tables, bathroom fixtures, elevators, stair glides and ramps) as well as the temporary or permanent installation of such equipment in any home or homes owned or rented by me, my spouse or both of us, including necessary structural alterations.

3. Third Party Reliance

No person who acts in reliance upon any representation made by my Agent as to the scope of authority granted under the document shall incur any liability to me, my estate, my heirs, successors or assigns for permitting my Agent to exercise any such power, nor shall any person who deals with my Agent be responsible to determine or insure the proper applications of funds or property.

4. Determination of Incapacity
(a) For purposes of this document, "incapacity" exists if my attending physician signs a certification in my medical records which specifically expresses the opinion that I have a condition which makes me unable to receive and evaluate information effectively or to communicate decisions to such an extent that I lack the capacity to manage my health care decisions.

5. Revocation

This durable power of attorney for health care may be voluntarily revoked only by me at any time by (i) my written revocation delivered to my Agent; (ii) my written revocation delivered to my attending physician; or (iii) my oral declaration of revision given to my attending physician and recorded by him or her on my medical records.

6. Effect if Attorney in Fact Unavailable or Unwilling to Act

If no Agent designated herein is available or willing to act as directed, I request my health care providers to consider the information about my desires expressed herein to carry the same force and effect as any other written advance medical directive maintaining the declarant's right of self-determination in health care.


If a Guardian, Conservator of the Person, or similar fiduciary is to be appointed for me, I nominate the following individual to so serve:

_____________________________________________________

Insert name and address of person nominated as Guardian/Conservator of the Person.

8. Informational Provisions:

The following informational provisions are included for the benefit of my Agent with the understanding my care will be directed accordingly.

[Note, most of the general provisions in the living will form document above are also appropriate for inclusion as information provisions in the DPAHC. The following may also be considered for inclusion as informational provisions:]

1. I direct that if at all possible, I would like to live the rest of my life and to die at home. If this is not possible and hospitalization is required or if I must be treated in a nursing home, I request that no additional therapy be undertaken except to relieve my pain or suffering.

2. I direct that if at all possible, I would like to live the rest of my life and to die at home. If
this is not possible and institutionalization is required, I would prefer being treated at a hospice facility.

3. I would not want any health care provider to worry about being sued for following my directives. I therefore hereby bind myself, my heirs and my agent herein named to indemnify all participants in the making of this directive or in honoring its directives, whether it be a health care provider, my spouse, a relative, friend or any other person, including a member of an emergency response team, against any responsibility in any form, legally, professionally or socially, for complying with my expressed wishes.

4. I direct my agent to specifically ignore the desires of (Name) in reaching any decisions as he or she does not share my wishes about how I should be treated when I am no longer able to make decisions for myself.

5. If under the terms of these directives it would be appropriate to withhold life support systems, I request a letter to this effect be left at my bedside by the attending physician with a copy of this living will to inform any medical emergency personnel of the situation and to assure them all the immunity possible under the laws of the jurisdiction for following my directives in good faith.

6. I request the holder of this declaration or the holder of any copy of this declaration carry the moral obligation to give such document to any physician in charge of my care who is not aware of its existence.

7. I hereby make known a general desire to be allowed to die at home. Please honor any future request to be discharged from a facility at a time I am dying even if my decision-making capacity is limited as long as my family is willing to provide required comfort care.

8. I do not want to be physically restrained even if this may result in some risk of falling or otherwise being injured. Under these circumstance, those tending to me shall not be held responsible for any ill effects which may result.

A patient with AIDS might consider the following provisions:

9. If my attending physician, after obtaining appropriate consultation, concludes I am unlikely to ever leave the hospital, I request all life-support systems be discontinued and care be limited to providing for my comfort.

10. If I am receiving hospice care and a new method of therapy is made available which holds the promise of reversing my mental incapacity, I request it be given to me within the hospice if possible. If not possible, please have me moved to an alternative facility where I may receive the new therapy.
A patient who is considering the authorization of the use of terminal sedation should consider the inclusion of the following provisions:

1. I do not want to end my life in pain or with severe suffering. I have discussed this with my family and my health care providers and expressed acceptance of the concept of terminal sedation if required. I therefore direct that if the time comes when my health care provider(s) believe the only way to control my pain and suffering is to keep me asleep with medications, I direct it be done.

2. If a decision is made in the course of my therapy that the only way to effectively treat my pain and/or suffering is to keep me asleep with medications, I direct that after this is undertaken and I have subsequently lost the capacity to make medical decisions, no relative, agent, health care provider, or other individual shall make or enforce a surrogate’s decision to stop this therapy.

A patient who is considering voluntary terminal dehydration should consider the inclusion the following provisions:

3. If I have made a decision to voluntarily stop taking oral nutrition and hydration as a means of controlling my life expectancy, and have acted in accordance with that decision, I direct no effort be made to force oral nutrition and hydration or any form of artificial nutrition and hydration, including intravenous fluids or any form of tube feeding.

4. I direct if food and water are left at the bedside and I do not voluntarily attempt to swallow them at a time I am capable of doing so, that this action should be taken as a decision on my part to voluntarily refuse nutrition and hydration.

5. If I have voluntarily refused nutrition and hydration, at no time should I be given small quantities of food or fluids beyond that required to care for my mouth locally. No action on my part shall be viewed as indicating thirst or hunger other than a request on my part for food or fluids.

6. If as a result of my refusal of oral nutrition and hydration I lose my capacity to make medical decisions, I direct my rejection of food and fluids be honored by my family, friends, health care providers and agents, if any.

7. I specifically affirm my belief in the good advise of my physician, (Name). I therefore request my agent to consult with, (Name) M.D., presently of (Address) with telephone number (telephone number) prior to making a decision to forsake life support systems if possible.

8. [I know that I am pregnant]/[I believe I might be pregnant]. Even if this is so, I still want life support systems to be withheld or withdrawn unless a medical evaluation determines the
fetus is viable and could, with a reasonable degree of medical certainty, develop to live birth with continued application of such life support systems.

14.16 Do-Not-Resuscitate Orders: In General

Do-Not-Resuscitate (DNR) orders are medical orders left on the patient's chart by an attending physician which instruct other health care providers not to use or order specific methods of therapy, collectively referred to as "cardio-pulmonary resuscitation," or "CPR," on the particular patient.

CPR includes those emergency medical treatments employed when a patient experiences sudden loss of oxygen supply to the brain, either because of inadequate oxygen uptake from the lungs or inadequate blood flow required to carry oxygen from the lungs through the heart to the brain. The need for CPR always arises in an emergency situation because loss of oxygen supply to the brain quickly results in death. To the contrary, not all emergencies are referred to as CPR. Only those which relate to the lungs, heart and circulation are referred to as "cardio-pulmonary arrest" triggering the need for CPR.

Common methods employed as part of CPR to restore oxygen supply to the lungs include 1) artificial respiration, either by breathing into the patient's mouth, forcing air into the lungs with a simple balloon type device, or physically expanding the chest to produce a vacuum and draw in air; 2) placing a tube in the trachea to supply oxygen to the lungs (intubation); 3) use of mechanical respirators [also referred to as "ventilators"]; 4) removal of foreign material from the bronchi (airways leading to the lungs), a condition referred to as "aspiration"; 5) use of air mixtures with increased oxygen content; 6) placing an opening directly into the trachea (tracheostomy); 7) forcibly expelling a foreign body from the larynx (the Heimlich maneuver) and 8) supplying oxygen under increased pressure directly to the lungs )"positive pressure breathing").

Common methods employed to support a failing heart and circulation include 1) shocking the heart to stop abnormal rhythms (defibrillation); 2) pumping on the heart; 3) using an internal or external pacemaker to induce a regular heart beat; 4) use of medications to stimulate the heart to pump or pump harder; 5) use of a mechanical pump to drive the circulation; 6) use of chemicals to reverse acidity of the blood; 7) use of drugs which increase blood pressure; and 8) mechanically pumping the heart with a hand.

CPR is time-consuming, expensive, highly intrusive, and of highly limited success, but can produce many years of meaningful life in selected patients. Because it always arises in an emergency, the decision to employ CPR should be made in advance. In the absence of a DNR order, CPR is automatically undertaken. In most hospitalized patients CPR is appropriate, but in many, including most patients suffering from terminal illness, it is not. Situations in which CPR is not warranted require a DNR order, or CPR will automatically be started.

Although AMD which are intended to forsake all care other than that used to comfort the patient should include a DNR order, the reverse is not necessarily true. In many situations in which improvement is still possible, it would be appropriate to continue aggressive care of the underlying disease yet the patient and/or the family might consider the possible benefit of further care to be so remote that if a "natural death" were to
occur, they would not want the medical team to attempt a resuscitation. This is particularly true when the cardio-pulmonary arrest itself is likely to make the underlying condition much worse.

14.17 Do-Not-Resuscitate Orders/Difficulties

Do-not-resuscitate orders are a special kind of AMD. Instead of telling doctors when the patient wants to forgo further medical care to keep them alive, the DNR order tells the doctor that if the patient experiences a natural death through stoppage of the heart or lungs, the patient doesn’t want the doctor to attempt to return him or her to life.

Unfortunately, making this decision is much more complicated than it seems for many reasons.

First, we often think of attempts to resuscitate a dying patient as being very complicated medical procedures which are highly invasive of the patient and undignified at a time when a peaceful passing is desired, but this is not necessarily the case. While resuscitation may relate to half an hour of invasive tubes, pushing, prodding and broken ribs, to the contrary, on many occasions it only requires removing a piece of food from the patient’s throat or giving the patient one electrical shock through a paddle placed on the chest for a total of fifteen seconds.

Second, because the public thinks resuscitation is highly successful, there is a strong tendency to decide to go ahead and attempt to resuscitate a patient when in fact only a vary small percentage of patients in whom resuscitation is attempted every live to leave the hospital.

Third, cardio-pulmonary resuscitation was originally developed with the idea it would only be undertaken in those clinical situations in which the physicians thought there was a reasonable chance the patient would respond and get better. It was the evolution of the law which now forces physicians to undertake resuscitation efforts in the absence of a written DNR order even when they feel it is inappropriate or futile.

Fourth, because physicians seldom talk to patients about their desire to be resuscitated or not, the decision most often has to be made by a family member, not the patient himself or herself.

Fifth, because the law in Connecticut, for instance, requires a surrogate decision-maker to make decisions based on the known wishes of the patient and most patients haven’t discussed their desires regarding resuscitation, it is hard for relatives to direct resuscitation not be attempted.

14.18 Do-Not-Resuscitate Orders/Principles Guiding Decision-Making

In spite of these problems, there are some general principles which may be helpful in dealing with do-not-resuscitate orders in the terminally ill.

First, it is much better when the decision to forego possible resuscitation is made by the patient than when it has to be made by a family member. Although physicians may be reluctant to ask the patient out of fear the patient will take it as a sign of hopelessness, family members may be in a position to introduce the question
as a show of concern for the patient’s interest without producing such fear, for they are not seen by the patient as an ultimate source of knowledge. Once the patient’s position is known, it can then be passed on to the physician to arrange for an appropriate order to be written after he or she checks with the patient to be sure the decision was correctly communicated.

Second, in terminally ill patients who have reached a point in their disease where life is no longer enjoyable, there is little reason to attempt a resuscitation absent hope for better days ahead.

Third, in making a decision to have a patient undergo resuscitation it is well to begin with an understanding of the rule of thirds. Of patients dying in a hospital, in a little over one third, resuscitation is attempted; in approximately one-third of those in whom it is attempted, it will be successful and of these, approximately one third will go home. This means that among all patients who experience cardio-pulmonary arrest, about 3% end up going home as a result of attempted resuscitation. Most patients who are terminally ill are among the two-thirds in whom resuscitation is not attempted. And when it is attempted, their chance of going home is significantly less than the average patient -- almost certainly, less than one percent.

Fourth, the above statistics relate to patients in the hospital where medical specialists and equipment is readily available. The success in nursing homes, at home, or in the community is far lower than in the hospital -- essentially nil.

Putting this information together, it is reasonable to say that early in the course of a terminal illness, the question of whether a do-not-resuscitate order should be written is best determined by the physician directly with the patient because it depends on how long the patient has to live, how much discomfort is faced, how much meaning life still has in store for him or her, and how likely resuscitation would be successful without destroying any remaining quality of life. At this point in time, it is very difficult for a surrogate to balance the pros and cons and it is ethically wrong for that decision to be made by anyone other than the patient if the patient is able to make it himself or herself.

In contrast, when the terminally ill patient’s underlying disease has progressed to the point where it has robbed the patient of decision-making ability, it is almost always appropriate to forego cardio-pulmonary resuscitation.

### 14.19 Do-Not-Resuscitate/Hospital Forms

The execution of a DNR order is almost always initiated by the attending physician, frequently as part of protocols or guidelines developed by the individual health care facility. Such protocols or guidelines vary greatly between facilities, in large part because there is an ongoing battle between those administrative forces which want complete documentation of patient wishes and clinical providers, who realize an emergency team called to undertake resuscitation do not have time to read through a long form document. The clinicians tend to prefer a form similar to that provided by Michigan state statutes for out-of-hospital DNR Orders illustrated below. The following form reproduced with the permission of the Milford Hospital, Milford, Connecticut, is typical of a standard form used in a hospital setting at a time when completeness is being stressed.
DO-NOT-RESUSCITATE ORDER FORM

"1. Is the patient capable of understanding the nature and consequences of health care decisions? Yes___ No___

Does an Advance Directive exist? Yes___No___

Is the patient in a terminal condition? Yes___ No___

Is the patient permanently unconscious? Yes___ No___

Comments:_______________________________________________

"2. If the patient is capable, a discussion should be held and documented in items 4 and 6, and orders should be placed in item 5 that are consistent with the Advance Directive.

"3a. If the patient is incapacitated and there is a reliable Advance Directive in the medical record, check here ___, and enter orders in item 5 that are consistent with the Advance Directive.

"3b. If the patient is incapacitated and there is no Advance Directive in the medical record, or the Advance Directive needs clarification, check here ___, and contact the Conservator of the Person/Health Care Agent/Next of Kin/or other appropriate person regarding prior written or oral expression of the patient's wishes. Document the discussion in items 4 and 6, and place orders in item 5 that are consistent with the discussion. If the wishes of the patient are unknown, proceed to item 3c.

"3c. If the patient is incapacitated and has never expressed any written or oral wishes, check here ___. A discussion regarding limitation of treatment decision should be held with a substitute decision-maker. Consent for limitation of treatment may be given by one of the following in order of priority: (Circle one): Conservator of the Person; Spouse; Adult Child(ren); Parent(s); Adult Sibling(s); Grandparent(s); Other (Specify) _____________. Proceed to items 4,5,6.

"4. On _____________(date), a discussion was held between ________ (Attending MD) and _____________________ (Patient, Other -- specify relation to patient: _______________ ________________) regarding limitation of treatment for the patient.

"5. Order-specific measures/procedures to be performed or withheld/withdrawn per wishes of the patient or substitute decision-maker. (This section must be completed in entirety.) To
change an order, please initial and date the change, and document your reasons.

Perform Withhold
Withdraw
Chest Compression _____ _____
Intubation _____ _____
Mechanical Ventilation _____ _____
DC Countershock _____ _____
Pressor Agents or Cardiac Stimulants _____ _____
Intravenous Antiarrhythmics _____ _____
Transfer to the Intensive Care Unit _____ _____
Major Surgery _____ _____
Invasive Line (A-line, Swan-Ganz, Central line) _____ _____
Dialysis _____ _____
Transfusion of Blood Products _____ _____
Antibiotics _____ _____
Artificially-Provided Nutrition _____ _____
Artificially-Provided Hydration _____ _____
Other_________________ _____ _____

"6. Documentation of summary of discussion of: treatment options and risks and benefits of such options; that the patient's wishes have been considered; and that the decision is
consistent with the physician's best medical judgment:

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

Signed: Date: Witnessed by:

14.20 Do-Not-Resuscitate Orders for Use at Home

DNR orders have their greatest use in terminally ill patients and because most terminally ill patients die in hospitals, we generally think of DNR orders in terms of hospitalized patients. But with the modern trend toward home care of terminally ill patients, there is a need for DNR order forms which match the needs of such patients being treated at home. In this setting, the most important issue deals with providing emergency "911" personnel with legally binding directives not to resuscitate the patient.

In general, because of the exceedingly low survival rate after attempted resuscitation of terminally ill patients at home, a decision against further hospitalization should lead to the execution of a bedside DNR order as developed within the particular state. As important is an understanding of all the people in the home that whatever happens, all calls for help should be directed through the office of the attending physician and not through calling 911.

As an example of a home DNR order, the following form is suggested by the Michigan statutes for home care use:

**DO-NOT-RESUSCITATE ORDER**

I have discussed my health status with my physician, ____________________. I request that in the event my heart and breathing should stop, no person shall attempt to resuscitate me.

This order is effective until it is revoked by me.

Being of sound mind, I voluntarily execute this order, and I understand its full import.

__________________________________________  _________________
(Declarant's signature) (Date)
ATTESTATION OF WITNESSES

The principal (or surrogate) who has executed this order appears to be of sound mind, and under no duress, fraud, or undue influence. Upon executing this order, the principal has (has not) received an identification bracelet.

__________________________________________  ________________________
(Witness signature) (Date) (Witness signature) (Date)
14.21 Do-Not-Resuscitate Orders/Special Considerations

One area of special concern regarding DNR orders in terminally ill patients relates to the standard practice in hospitals of routinely cancelling DNR orders when the patient is taken for surgery or for special diagnostic or therapeutic procedures.

In a way it is understandable. During surgery and during certain procedures such as colonoscopy or invasive radiologic procedures there is an increased risk of the patient undergoing a cardio-pulmonary arrest and dying. The doctors undertaking these procedures are likely not to know the patient well and do not want to feel responsible for the patient’s death. They also feel if they must honor a do-not-resuscitate order, they may undertreat the patient and are likely to point out that because they will be there tending to the patient at the exact time the arrest occurs, it is very likely resuscitation will be easy and successful.

This makes sense in many cases, but it doesn’t make sense when the terminally ill patient is suffering, has no hope of getting better, and is undergoing surgery or another medical procedure purely for relief of pain. Under these circumstances, the patient’s desire not to be resuscitated if death occurs should be honored.

To achieve this goal, some hospitals have initiated procedures whereby the surgeon or special medical operator must ask a patient who has a DNR order whether it should be continued during the procedure, but many hospitals do not and the order is automatically cancelled. If the patient and/or family has clearly made a decision they don’t want resuscitation undertaken under any circumstances, this desire should be made known when any special procedure is being considered.

The following is a form that can be used to insure resuscitation is not attempted:

Special Consent Form for Use in Operating Room

Special Consent Form: Operative Do Not Resuscitate

Clarification {1}

Hospital Heading

[I]/[We] understand that the above named patient has been designated as DO NOT RESUSCITATE (DNR) by a physician order.

This patient is going to surgery for the following procedure:
This patient desires that the DNR order in place be followed in the Operating Room and Post-Anesthesia Care Unit. The patient understands that clinical events believed to be temporary and reversible will be treated and standard anesthesia procedures will be employed.

The patient desires that full resuscitative measures be employed in the Operative Room and Post-Anesthesia Unit in all clinical situations.

Date:

Time:

Signature:

Signature of Responsible Party:

14.22 Anatomical Gifts: In General

In the past, organ and tissue transplantation has largely been undertaken using donors who have died from acute causes of brain death, like automobile accidents, shootings, or hemorrhage within the skull. In the future, however, especially with the use of newer techniques to preserve organs and with a tendency toward using ever older donors, donations by terminally ill patients are likely to become an increasingly important source of transplantable body organs.

Although patients dying of cancer, AIDS or other infections are likely not to become potential donors, patients dying after strokes, heart problems, and Alzheimer’s disease may become potential candidates in the future even when death is associated with heart stoppage and not brain death.

With this in mind, it is important to find out how a terminally ill patient thinks about giving a "gift of life," by permitting use of his or her organs by another after death.

14.23 Anatomical Gifts; Surrogate Decision-Making

Both dying patients and potential recipient’s of human transplants are repeatedly hurt by surrogate decision-making. There is strong evidence many more people would agree to be an anatomical donor themselves than would be willing to make that decision for someone else, which means failure to ask a dying patient about anatomical gifting markedly decreases the availability of donor organs. In addition, because families frequently refuse to honor the wishes of a deceased person for their own convenience thinking the deceased person "will never know," they deprive the spirit of the deceased the right to do a terminal good at the end of life.

And, unfortunately, although the Uniform Anatomical Gift Act of each state directs the wishes of the...
deceased should control even if there are family objections, the fear of law suits leads most physician’s to honor the family’s wishes even when all legal and ethical positions support the right of the patient’s autonomy in anatomical gifting.

14.24 Anatomical Gifts: Form

The following form is recommended for use by the Uniform Anatomical Gift Act of 1987, which is now being followed in most states:

ANATOMICAL GIFT BY A LIVING DONOR

Uniform Anatomical Gift Act (1987)

Pursuant to the Anatomical Gift Act, upon my death, I hereby give (check boxes applicable):

1. [ ] Any needed organs, tissues, or parts;

2. [ ] The following organs, tissues, or parts only

   _______________________________________________________________________

3. [ ] For the following purposes only

   _______________________________________________________________________

   (transplant-therapy-research-education)

   ________________ ____________________________

   Date of Birth Signature of Donor

   ________________ ____________________________

   Date Signed Address of Donor

INSTRUCTIONS

Check box 1 if the gift is unrestricted, i.e., of any organ, tissue, or part for any purpose specified in the Act; do not check box 2 or box 3. If the gift is restricted to specific organ(s), tissue(s), or part(s) only, e.g., heart, corneas, etc., check box 2 and write in the organ or tissue to be given. If the gift is restricted to one or more of the purposes listed, e.g., transplant, therapy, etc., check box 3 and write in the purpose for which the gift is made.
For those who do not wish to donate:

Pursuant to the Anatomical Gift Act, I hereby refuse to make any anatomical gift.

_____________________ ____________________________
Date of Birth Signature of Declarant

_____________________ ____________________________
Date of Signing Address of Declarant

For attachment to a driver's license:

Print or Type Name of Donor

Pursuant to the Anatomical Gift Act, upon my death, I hereby give (check boxes applicable):

1. [ ] Any needed organs, tissues, or parts:

2. [ ] The following organs, tissues, or parts only _____

3. [ ] For the following purposes only:

(transplant-therapy-research-education)

Refusal:

4. [ ] I refuse to make any anatomical gift.
For anatomical gift by another:

**Anatomical Gift by Next of Kin**

**or Guardian of the Person**

Pursuant to the Uniform Anatomical Gift Act, I hereby make this anatomical gift from the body of _______________________________ Name of Decedent

who died on _____________________ at ____________________________ Date Place

in _______________________________. City and State

The marks in the appropriate squares and the words filled into the blanks below indicate my relationship to the decedent and my wishes respecting the gift.

I survive the decedent as [ ] spouse; [ ] adult son or daughter; [ ] parent; [ ] adult brother or sister; [ ] grandparent; [ ] guardian of the person.

I hereby give (check boxes applicable):

1. [ ] Any needed organs, tissues, or parts;

2. [ ] The following organs, tissues, or parts only ________________

3. [ ] For the following purposes only ________________

Date Signature of Survivor ______________________________

Address
Grief has been described as "an intense emotional and physical reaction to a loss, real or imagined, sudden or anticipated." Although in this book we will speak of grief as it relates to the loss of a loved one, the same term can be applied to many other losses, such as the loss of mortality (being diagnosed as having a fatal disease), the birth of an impaired child, a debilitating stroke, infertility, disfiguring injuries, loss of status, or esteem. Although the terms "mourning" and "bereavement" may be used almost interchangeably with "grief" or "grieving" when dealing with the loss of a loved one, the term "mourning" is more generally used to describe the social expression of grief and the terms "bereaved" and "bereavement" to describe the individual who is suffering the loss and the overall process of grief and mourning respectively.

Unlike psychiatric illnesses which share many of the symptoms of grieving, grief and mourning are considered normal, inescapable, and beneficial mental processes through which the survivor reconciles the loss of a loved one and breaks the emotional ties to the deceased. In fact, failure to mourn is often considered an invitation for ongoing pathologic forms of grief produced by the bereaved’s failure to separate from his or her loss so as to go on to new activities and relationships. Looked at in this way,
grief and mourning become a difficult and painful, but psychologically necessary, task. As Sigmund Freud claimed, only by working through the grieving process can the bereaved be set free to invest emotional energy in new directions.

Many authorities have looked to understand grief and mourning as attempts to reconcile "separation" and "attachment." On the one hand, reality requires the bereaved person to accept the loss in order to achieve a healthy adaptation to continued life in the real world in which the deceased is absent. On the other hand, psychological needs of the bereaved requires a certain maintenance of the previous relationship in spite of the absence of the deceased, the process of attachment. This dilemma requires each survivor to work through a balancing of the needs of separation and the desire to maintain an appropriate attachment depending on the unique circumstances of previous and ongoing relationships. The former demand, accepting the loss, is likely to generate intense anxiety; the latter demand, maintaining features of the relationship, usually provides comfort, but can interfere with future relationships if too much attachment is maintained because of the comfort it provides.

### 15.02 Anticipatory Grief

We tend to think of bereavement and mourning as beginning after death, but this is inaccurate when dealing with a loved one who suffers through a prolonged terminal illness. In this situation, often in conjunction with helping the patient deal with his or her existential suffering, the family is likely to be thrust into the grieving process long prior to death. This "premature" introduction of issues related to separation and attachment when undertaken prior to death is referred to as "anticipatory grief," and may produce a profound influence on both the family and the patient’s care during the final stages of life. It is because of the effect of this anticipatory grief on care of the terminally ill that we address the topic in this book. The following therefore addresses a series of issues related to anticipatory grief. Hopefully, this will give caregivers a better understanding of the interplay between their own grieving and how it influences their caregiving.

First, it should be known that anticipatory grief is the rule and not the exception. Of three hundred fifty subjects studied during the bereavement period, two hundred five (59%) stated they began grieving before the death, a percentage just slightly less than the percentage of patients dying from chronic illness as opposed to an acute event.

Second, in most cases therapists consider beginning the work of grieving prior to the loved one’s death to be beneficial and likely to shorten post-mortem mourning. This is especially true to the extent it allows and encourages the patient and family to work through "unfinished business," problem issues which become difficult to approach after death.

Third, it is important to recognize symptoms of anticipatory grieving in the care provider because, like the symptoms of post-mortem grief, simple understanding of the emotional bases of existing problems, as discussed below, are likely to be highly therapeutic.
Fourth, although working through anticipatory grief is often beneficial in reducing post-mortem grief, this is not always the case. At times, separation phenomena are worked through too early and a process of withdrawal develops which interferes with the mourner’s ability to provide ongoing care. At other times, the development of attachment comes too early so as to create a bond with an aspect of the terminally ill patient which then dies along with the patient’s death. [See, for instance, the discussion of double-grief in caring for sufferers of Alzheimer’s Disease.]

15.03 Grieving as a Normal Process

In mourning the loss of a loved one, it is essential survivors understand that grieving is a normal, necessary process of dealing with unresolved issues, not one to avoid or of which to be ashamed. Each of us who live a normal life span will have losses and will be forced to grieve, in our own way and on our own schedule. And because each of us and each relationship in this world is unique, the process of mourning is also likely to be unique, with no need to conform to a pattern urged on us by others. Each of us will be best served to live through our losses in our own unique way so as to get fully in touch with the lived experience, to accept the sorrow of the loss, and to reestablish the presence of others to help fill the resultant voids. This helps us not only through our bereavement, but through other problems we encounter in the future taking the place of the loved ones we have lost.

15.04 Responsiveness to Understanding

Because grieving is a normal psychiatric function and not an illness, bereaved individuals can usually be helped a great deal by learning from friends, books, or organized peer groups without having to rely on either medical or psychiatric therapists. In fact, most grief therapists try to avoid becoming involved with survivors in mourning unless there is an associated depression or it becomes unduly prolonged, as they fear early intervention will only serve to incorrectly suggest the problems being experienced by the individual are abnormal. In avoiding the direct care of the grieving individual, therapists typically make it a point to pass on specific information such as the following as a means of assuring the sufferer what they are experiencing is normal.

First, they note it is common for the grieving person to "hear" or "see" the deceased person as part of normal grieving and that it is often helpful to discuss such occurrences with people who can be trusted to accept it as normal.

Second, they warn the individual that holidays, birthdays, weddings, funerals, and other anniversaries are likely to be difficult, with certain ones being particularly hard because of past shared experiences. That a worsening of grief at these times should not be considered abnormal but as a part of the normal grieving process.

Third, they warn that guilt related to past events needs to be worked through as part of the grieving process, but there is no room for guilt related to reestablishing relations with others. New relationships will only help cement the appropriate separation and attachments established earlier in the course of
grieving. In other words, "it is okay to love again." Freedom from grief, or guilt, is not abandonment of what has been lost but rather affirmation of the ability and need to function in society and to share with others.

15.05 Timing

It has been said that most peoples’ problems with grief and mourning are not caused by abnormal responses to loss, but by other people’s desire "to get mourning over with." Society pressures us to mourn quickly so we can return to the mainstream of life. But others suggest "to mourn what has passed is to affirm life. To grieve well is to value what has been lost. When you value even the feelings of loss, you value life itself, and you begin to live again." By taking the time to grieve fully, one can then value life more.

Grieving is a process often said to take at least 6-12 months, but this is probably an unfair statement when one is referring to loss of a close relative like a spouse, child, or parent. In these instances, it is probably fairer to say grieving will last a lifetime, but tends to lessen with time, the first time through a birthday or anniversary tending to be worse than the next and the next and so on.

In general, it is hard to tell how well a survivor is doing with the grieving process for the first month following a death because the required activity associated with funeral and estate arrangements and the tendency of friends and relatives to be present to help during this time tends to cover up the severity of grief. In contrast, the second month often gives a better indication of the true severity of the bereaved’s grief, with some improvement usually being noted as one goes into the third month and more definite improvement by month six to seven.

In judging improvement, an outsider is likely to be misled by asking the bereaved directly. More accurate is an objective evaluation of how the individual is functioning, both as it relates to the demands of daily living, and as it relates to the ability to communicate with others, to hear what others have to say without the bereaved retreating into his or her own thoughts. Studies have shown individuals who have experienced anticipatory grief are more likely to consider themselves over the grief process earlier, sometimes as early as two months, but the number who feel this way is small, around eight percent. To the contrary, many who experience anticipatory grief are very close family members who are also likely to grieve for the longest periods of time.

15.06 Stages of Grief

Just as Dr. Kubler-Ross broke the acceptance of death into stages, so, too, is the grieving process delineated. Some commentators characterize these stages as being the same: denial, anger, bargaining, depression and acceptance, but others have taken varying approaches, with all recognizing the great variability from person to person. One such model employs a three step approach, consisting of (1) initial shock, disbelief, and denial; (2) an intermediate period of acute discomfort and social withdrawal; and (3) a culminating period of restitution and reorganization.
According to these theorists, the **shock and denial** phase is characterized predominantly by disbelief and numbness. The funeral, the gathering of friends, and other mourning rites help survivors accept the loss in a supportive environment. Viewing of the body is usually encouraged as a further means of overcoming denial. As numbness turns to intense pangs of separation, various searching behaviors, such as pining, yearning, and protest, generally take over.

The next phase, **acute anguish**, which typically lasts a few weeks or months, predominates once the searching for the deceased individual fails. Erich Lindemann has characterized six components of this acute anguish:

1. Intense somatic distress, occurring in waves for periods of twenty minutes to an hour, and manifested by a tight throat, choking and sighing, an empty feeling in the abdomen, weakness, tenseness, and mental pain. He notes in particular that because visits may bring on those somatic disturbances, withdrawal from friends, relatives and others is common.

2. Preoccupation with thoughts of the deceased.

3. Guilt thoughts leading survivors to accuse themselves of having mistreated or neglected the dead.

4. Irritation and anger being directed at themselves, the deceased, friends, relatives, doctors, the world, or God.

5. Restlessness, agitation, aimlessness, and lack of motivation accompanied by the abandonment of the survivor’s usual habit patterns.

6. Identification phenomena leading to the adoption of traits, behaviors, or symptoms of the deceased (especially those of the final illness), which can occasionally reach pathological proportions.

Finally, during **restitution** and **reorganization**, the bereaved recognizes the extent of loss and realizes grieving has been accomplished. Attention shifts to life apart from the deceased. The hallmark of restitution is the survivors’ recognition they can return to work, resume old roles, acquire new ones, experience pleasure, and seek companionship and love.

**15.07 Symptoms of Grief**

It is not surprising symptoms associated with mourning are many and varied, as each individual takes a unique course through the stages of denial, anguish, and restitution. Although the following discussion of symptoms may suggest their occurrence is likely to be related to grieving, it must be emphasized many of these symptoms may also suggest physical or psychiatric illness for which proper medical evaluation and
treatment is required and should be undertaken before assuming all is related to grief.

In the early stages of a normal grieving pattern, the mourner repeatedly reviews memories of the deceased only gradually realizing (or accepting) that these memories no longer corresponds to a real, living person. During this period, the griever is likely to suffer from irritability and restlessness, along with denial, a generalized feeling of anger and self-blame, often centering on some relatively minor act of omission or commission toward the deceased. Anxiety is likely to be heightened by the realization that the survivor no longer has the chance to be forgiven by the deceased.

Grieving persons are likely to present themselves as sedentary and withdrawn, having forsaken most activities and socialization. They often describe themselves as tired and not interested in physical exercise. Other common characteristics of the grief state include decreased appetite, a disturbed sleep pattern (frequent napping or dozing throughout the day), and lack of any interest in sexuality. Those who have lost a mate are often totally uninterested in a relationship with someone else and are offended at being asked about this.

A special kind of self-reproach referred to as "survivor’s guilt" may occur especially after a prolonged illness when survivors recognize they experienced a sense of relief when the deceased died. Sometimes the survivors feel they should have been the persons to die. Later, as the survivor makes new emotional attachments, another form of guilt appears -- a sense of betraying a former spouse in particular. Many bereaved persons go through a period of time when anger becomes a significant part of their grief. The anger may be felt toward the deceased person for unhealthy ways of living or as a legacy or anger about the relationship. Usually, the anger is felt as a response to being abandoned and left in the lurch. As time goes on, the anger may be redirected away from the deceased toward others, the deceased’s physicians, God, fate, society, or at their family or friends. In addition, they may feel envious of those who still have the type of relationship they have lost.

Frequently there are intrusive voices or images which force their way into the mind of survivors, often occurring as distressing instant replays of the circumstances of the death. As these are likely to occur at a time when the survivor is also experiencing fluctuating states of turmoil associated with the unpredictable states of emotional and cognitive thoughts, they may feel overwhelmed, out of control, and as though they were going crazy. This may be particularly distressing for healthy, generally adaptive people who never before have experienced such an emotional roller coaster and may be particularly disconcerted be their inability to assert control over their own internal lives.

At times mourners appear to purposely take on new personalities in an attempt to ease the pain of the grieving process. These strategies may include avoidance of reality, rationalization, attempts at humor, involvement with new types of friends, passive distraction (such as immersion in television) and indulgence in food, alcohol, tobacco, or sex. Many persons cite belief in God as helping them cope and find meaning in death even when they have not appeared to be religious previously. On occasions the mourner may chose to embellish the previous relationship instead of separating from it by maintaining and building symbolic, internalized ties, which tends to increase the deceased’s participation in the
bereaved person’s life through imaginings, symbols, legacies and memories. Efforts to perpetuate the lost relationship may be evidenced by so-called "linkage," an investment in objects treasured by the deceased or that remind the grief-stricken persons of the deceased. Alternatively, the survivors may take on the qualities, mannerisms, or characteristics of the deceased person, apparently as a means of perpetuating the person in some concrete form, or may develop physical symptoms similar to those experienced by the deceased or symptoms which suggest the illness of which the deceased died. Unfortunately, these strategies to avoid pain only serve to maintain the previous relationship, thus indefinitely blocking restitution which requires the previous process of separation to occur.

Alternatively, the grieving process may produce such insight into the weaknesses of former relationships the mourner actually comes out of bereavement much stronger than they were initially. This is particularly likely to happen when wives who have previously relied heavily on their husbands are surprised by their own capacity to tolerate grief, to carry on, and even to find new approaches to life, leading to an evolving sense of strength, autonomy, and independence appears. Having mastered acute grief, the survivors may then experience existential growth and may become more compassionate, patient, and balanced than they were before the loved one’s death.

15.08 Grief Versus Depression

As we have discussed previously, the layman tends to think of depression as being the same as unhappiness, but the physician does not. The same can be said about grief. Many layman will refer to others undergoing the grief process as being depressed whereas therapists and physician are likely to view the unhappiness as a normal psychological state naturally related to the death of a loved one.

Nowhere is this distinction more important than in dealing with grief, for a number of reasons. First, because when grief leads to clinical depression, it is far more likely to lead to suicide, medical illness, and psychiatric disabilities. Second, because the treatment of the unhappiness we associate with grieving and the modern treatment of depression with medications are so diametrically opposed to each other. And, third, because failure to recognize that grief is not the same as depression can lead to inadvertent drug therapy which may interfere with the grieving process. It is therefore important to try to differentiate normal grieving from depression, recognizing it is not always easy and that the two may come to co-exist, especially in individuals who have a history of previous depressive episodes.

In trying to differentiate the two, the one overriding difference between grief and depression as stressed by most commentators relates to loss or retention of self-esteem. In differentiating the two conditions, they point out that the predominant emotions in grief are sadness and a yearning for the return of what has been lost, accompanied by a sense of emptiness and lack of existential meaning, but without a loss of self-esteem. In contrast, the predominant emotions in depression are self-deprecation and overwhelming guilt, which reflect loss of self-esteem.

Another common difference is that with grief after the loss of a loved one, dreams of the deceased person and visualizations of other similar illusions are common, while they are not typical of depression. To
further differentiate the two conditions, some commentators suggest grief tends to interrupt the individual’s usual state of functioning, whereas in depression the individual continues to function but does so in an inappropriate manner. [The author admits he finds it somewhat difficult to make this differential.]

Factors which have been found to be associated with the development of depression during the grieving process include youth, poverty, low initial self-esteem, difficult parental relationships, multiple prior losses, neuroticism, and poor physical or mental health. Complicated grief patterns are more likely to occur following sudden death, a homicide or suicide, when it involves a missing person, or a situation in which the bereaved was partially at fault for the death. The presence of certain symptoms that are not characteristic of a normal grief reaction may be helpful in differentiating bereavement from depression. These include the survivor (1) feeling guilty about actions unrelated to the deceased’s death; (2) thinking about death in ways other than feeling he or she would rather be dead or should have died with the deceased person; (3) exhibiting marked preoccupation with worthlessness; (4) showing marked slowing of thought processes; (5) exhibiting prolonged and marked inability to function appropriately; and (6) having true hallucinations beyond just thinking he or she heard the voice of, or transiently sees the image of, the deceased person.

15.09 Grief Therapy

As mentioned earlier, a major element in "grief therapy" is reassuring the individual his or her feelings are normal, transient, beneficial, and do not require specific psychiatric or drug therapy. Another important element is discussing the process with the grieving party early during the terminal illness to help the sufferer recognize their own anticipatory grief and its potential effects on their own caregiving.

Although little is written specifically related to the treatment of anticipatory grief, there is little reason why suggestions related to dealing with mourning after death would not apply even earlier. The following are typical suggestions given to those who are in a position to help the bereaved. Knowledge of what health care providers are advised to do should be helpful for the individual griever to gain the understanding necessary to work through the mourning process. The following suggestions come from various sources addressed to physicians, nurses, grief therapists, clergy, hospice workers, etc.

1. Advise the mourner to avoid making significant personal decisions or lifestyle changes during this difficult time.

2. Acknowledge the stress the individual is going through and reassure them it is normal. Remember most bereaved persons do fine on their own without specific treatment. When additional help seems needed, a mutual-support group is usually beneficial. Such a group is efficient and both cost and clinically effective.

3. Suggest the need for rest, solid nutrition, diversion, the need to identify new activities, and routine meetings with others who share their distress.
4. Suggest concentration on the positive aspects of the deceased, not the negative.

5. Stress the uniqueness of the grieving process and accepting that a unique response may be perfectly appropriate for the individual. For example, a child going for a long ride on a motorcycle right after the funeral.

6. Recognize the early mourning period is a time to show love and appreciation and not to deal with specific issues. For example, by saying "I’m sorry about your loss" or, if you know the departed well enough, "I’m sorry about your mother."

7. Reassure the bereaved that a feeling help is needed is not a sign of weakness.

8. Later on in the course, mentioning that eventually the bereaved is likely to feel a desire to explore possibilities for new intimate relationships and that this would be normal and desirable if and when it occurs.

9. Minimize anti-depressant medication therapy if possible, except in the presence of a true clinical depression.

10. Many people write letters to the deceased during the grieving process. Consider doing this while the patient is still alive, first writing the letter as if the patient had died, then rewrite it maintaining those issues which the survivor feels can be addressed with the patient and omitting those that seem too stressful.

11. Encourage the grieving party to discuss their "unfinished business" with a terminal patient as well as encouraging the patient to address their own unfinished business.

12. Suggest that any unusual physical symptoms be discussed with the griever’s physician before assuming it is related to the grieving process.

When professional therapy is required for grief therapy, setting time-limits is often wise, for brief therapy is usually sufficient. Characteristics of such therapy usually involves (1) an educational component, helping the bereaved know what to expect; (2) encouragement for expressing the full range of bereavement emotions and affects through evocative techniques; (3) attempts to help the bereaved come to peace with their new relationship with the deceased; (4) attempts at helping the bereaved establish a new identity; and (5) focusing on an integrated self-concept and a stable world view.

Early in the grief process, when the prevailing forces are likely to be hopelessness, helplessness, inadequacy, and loneliness, the therapist aims at maintaining and communicating a conviction about the bereaved person’s adaptive capacities. Later, as the bereaved person emerges from the period of intense regression, the therapist may play a role in supporting the survivor’s efforts to try out new behaviors,
explore new relationships, expand attitudes, and grow through the experience.

In an advisory journal to nurses the following was suggested:

1. Obtain an in-depth personal history of an individual. Understand what unique losses the person sustained, the meaning of those losses to the individual, the strengths a person brings to the situation, what that person values in life, and how grief is unique to him or her.

2. Develop a relationship which encourages openness. Remember "to be open is to be vulnerable, an important characteristic of humanness." To be vulnerable is often to suffer. We tend to avoid suffering, and yet avoidance of suffering may deter movement to higher levels of consciousness. Suffering offers us the opportunity to transcend a particular situation.

3. Understand the inexpressibility of many emotions and experiences. This inability to express feelings, however, only denotes the importance of being there for the individual in "disciplined presence."

4. Acknowledge that missing is likely to be the theme or sentiment the bereaved will want to talk about. It is this unfolding recital of history that is likely to be meaningful to the bereaved individual.

5. Notice that seeking help may indicate that the bereaved needs to be comforted. "The need is to let go, embrace prior experiences and allow the expansion of consciousness to unfold."

6. Understand the premise that pain and hurting of the bereaved are being openly acknowledged. In witnessing and being present to another’s pain and hurt, it is important that we identify our own personal patterns of pain and hurt. Self-awareness is essential. In forming a "shared consciousness" with the one who is grieving, it is possible that the nurse may "revisit" a personal loss.

7. Anticipate a client holding onto memories, moments, and an identity as part of grieving. Confusion and mixed emotions can be manifestations of "holding on." Insight into the fact that this confusion is a normal part of the grief work is gained through nurse-client interaction. What the individual wants to do about holding on will become apparent as the grieving pattern emerges.

8. Understand that all societies define expectations of how one should grieve. Inform people, however, that each person’s lived experience of loss is unique -- each of us has our own natural life rhythm, and it is important to let this life rhythm guide our actions and
grief work. All of us must give ourselves permission to grieve.

9. Accept what the client is valuing in their life. This valuing shapes present experience and is an indicator of the significance of loss.

10. Recognize that change occurring in bereavement is unique to each individual. The nurse cannot assume that similar losses will reproduce like changes. Each has a unique pattern of response.

Before attempting an in depth approach to helping a bereaved person, it is recommended the "therapist" attempt an in-depth evaluation of the mourner. Critical to this effort is determining who the loved one was, what the person meant to the survivor, how they lived together, what their shared dreams and hopes were, and the nature of the events surrounding the death. The following are a few questions which have been suggested as a means to that end:

"How was the death for you?"

"Were you ready to let go?"

"Was there a sense of relief when your family member died?"

"Did you feel an empty space?"

"What are the memories of your family member, both before or after the illness?"

In evaluating the depth of grief for later comparison, it is wise to organize the patient’s responses or behaviors (markers of the intensity of grief) into five or six categories, commonly including socialization, physical exercise, occupational activities, appetite, sleep and sexual interest.

15.10 Shadow Grief/Grieving by Others [Burn-out]

When dealing with a prolonged terminal illness, it is not unusual for non-family members to become involved in the process of anticipatory grief. This can be especially devastating for a nurse or similar care giver who repeatedly deals with terminally ill patients. The following symptoms are said to be common in "shadow grief," as it is called, but the list may also be helpful in recognizing the symptoms of anticipatory grief in family caregivers.

* loss of energy, spark, joy, and meaning in life;

* more frequent times of fatigue;
* detachment from surroundings;

* feeling powerless to make a difference;

* not speaking up even when you feel strongly about an issue;

* increased smoking or drinking;

* drug abuse;

* physical illness, insomnia, weight change;

* unusual forgetfulness;

* constant criticism of others, especially managers;

* consistent inability to get work done;

* self-doubt;

* uncontrolled outbursts of anger;

* emotions out of proportion to the circumstances that caused them;

* talking about patients and their families as objects;

* giving up hobbies or interests.

In the same article listing these symptoms, the following list of suggestions is made to help the caregiver cope.

* When you recognize "shadow grief" let it come out, jot it down, let it enter your consciousness. Put it in a journal."

* Do "purge writing." Give yourself five minutes to write down whatever comes to your mind.

* Get physical. Exercise.

* Take time to cry -- with and for your patients.
* Ask colleagues to help you perform tasks. You might be feeling inadequate when in fact the job you’ve taken on is difficult or impossible to handle alone.

* Connect with your place of worship.

* Look for joy in you work and with your colleagues.

* Create a caring circle of friends.

* Seek professional counseling as needed.

* Listen to music. Ask if you can play soothing music in the unit while you work.

* Express your artistic side.

* Find other ways to give yourself comfort. Sit quietly for a few moments in a lounge or empty conference room or carry a photo of a favorite vacation spot on your clipboard.
CHAPTER 16. GRIEVING FOR PATIENTS WITH ALZHEIMER'S DISEASE

16.01 Patients with Alzheimer's Disease; Background

Caregiving to patients with Alzheimer's Disease (AD) is an area of particular interest to the author. My interest in part results from drafting living wills and writing about advance medical directives in which the primary concern of most serious individuals is to insure they will not be artificially kept alive for prolonged periods after they lose their ability to communicate with the world. In another part it results from the fact that since leaving the active clinical practice of medicine, it is the area of care in which my advice has most often been sought. In still another part, it relates of my interest in drug development, with AD probably being the most common disease in which we have failed to make significant advances over the last forty years in spite of the reasonable potential to do so. And finally, it stems in part from my intrigue with the "one or two" philosophical argument discussed below which questions how society should view a presently highly demented patient who was previously quite intelligent -- should we consider the present patient as if he or she is a new individual demented for life or should we continue to think in terms of a previously intelligent person who suffers from severe destruction of the brain.

16.02 Natural History and Prognosis in Alzheimer's Disease

Forty years ago, "senility," as it was called, was considered to be due to "hardening of the arteries," assumed to be common in the elderly. Alzheimer's disease was considered to be a totally different entity striking younger individuals in their early sixties and producing a somewhat different clinical picture, although in retrospect the clinical differences were found to be explained not by differences in the patients, but by differences in the normal activities of sixty year-olds and eighty year-olds to which the patients had been compared.

The problem with maintaining the split senility/Alzheimer theory was that on pathologic examination,
most patients with "senility" had no more hardening of the arteries to the brain than patients without senility. And, on closer microscopic examination of the brain, most had the same strange plaques of protein-like materials and knotting of nerve cells seen in patients with AD. This, however, was not universally true. Perhaps twenty percent of patients with dementia did not have changes of AD but did show evidence of multiple strokes and severe disease of the blood vessels. Thus what had previously been called "senility" was now redesignated to be either "Alzheimer's dementia" or "multi-stroke dementia," depending on the appearance of the brain. [Note: Only later with CT scans and MRIs was it recognized a still smaller group of demented patients had what has come to be called "low-pressure hydrocephalus," a condition in which blockage of fluid flow within the brain causes progressive damage to brain cells.]

Even though the incidence of these disease entities in the older population probably has not changed, the percentage of people in these age groups has greatly increased, making dementia a much more common disease. Nearly ten percent of Americans over 65 now suffer from Alzheimer type dementia [including multi-stroke and low-pressure hydrocephalus], and another 10% of the elderly population are caregivers to those who have it. Its incidence increases with age, from 1% at age 65, to 7-10% at age 75, and 20 to 25% at age 85.

Early complaints of patients with Alzheimer's disease are usually vague, including anxiety, diminished energy, loss of interest in hobbies and other favorite activities, and mood swings. Typical of this early phase is a "loss of recent memory," typified by an inability to remember what they ate for dinner the night before, although memory of events earlier in life remains fairly normal. Later, as the disease continues and general loss of cognitive thoughts occurs, the patient typically progresses from occasional loss of recognition of loved ones, to a state in which loved ones are only recognized occasionally, and then on to the time when all recognition is lost. At the same time, the patient's ability to communicate with the world and partake of any enjoyment in living progressively deteriorates, but at variable rates from person to person. In some, withdrawal from all worldly experiences tends to predominate leaving the patient lying and staring at a blank wall, while others maintain an ability to sit oblivious to the world but still able to enjoy music, television, or similar entertainment.

Unfortunately, even when the progressive mental loss allows a diagnosis of Alzheimer's to be made, it is difficult to predict how quickly any specific patient will deteriorate, or whether they will be able to maintain any enjoyment in life as the disease progresses. At the same time, it is probably fair to say that once deterioration has occurred, it is unlikely to reverse significantly in the future. This is important because while it would appear that some of the medications now being tried and developed to treat AD are somewhat effective in delaying deterioration, there is little evidence to suggest significant improvement of previous mental loss or hope for its reversal in the near future. This means once the patient's thought processes are lost and there is no significant quality of life, it is probably unrealistic to maintain the patient's life purely in the hope of breakthrough therapy in the near future.

In addition to the above, when considering care and grieving in Alzheimer's disease, it is well to remember that it is a progressive disease which in and of itself leads to death. This fact seems to be
largely overlooked, for even though it is one of the most common causes of death in America, most people fail to think of it as being a terminal illness. This probably is so because AD is usually so slowly progressive and because so many patients with AD are old and die of other causes before the AD reaches an end-stage itself. As a result, most people also fail to think of caregiving for patients with AD as involving terminal care with associated anticipatory grief, mourning and bereavement even though these processes are likely to play a major role in adding difficulties and complications to the relationship between the AD patient and caregivers.

16.03 One or Two Individuals

For those who are philosophically inclined, the following gives a brief account of the "one or two individual" issue alluded to as causing a major discussion in the world of ethical commentators in the introduction.

The issue, first raised by a famous ethicist, Rebecca Dresser, is whether an individual who has developed advanced dementia should be considered to be the same individual he or she was before becoming ill or a new individual within the same body -- similar to the question raised years ago as to whether a person with total and permanent amnesia of past events is the same or a different person than they were before for purposes of criminal sentencing.

In the field of ethics, the question typically addressed is whether autonomy requires that decisions made by the individual before they become demented which were based on their then existing relationship with society should continue to control what is done after they have lost any relationship with that society. Alternatively, should the now demented patient be given autonomy through a surrogate decision-maker as if they were a person who never had the capacity to make decisions, for in fact, without the ability to relate to society, decisions would be made very differently. For example, should artificial sustenance be withheld from a patient who wrote a living will forsaking artificial food and fluids if they develop Alzheimer's disease in order to save money for their children, when the patient no longer knows what "money" is, or whom their children are, but now appears to be able to enjoy life sitting and watching television or listening to music?

The law, of course, tends to say it is one and the same individual, but it, too, has trouble, because the law in different states provides for different methods of surrogate decision-making. In some states surrogates must make decisions based on a "substituted judgment," i.e. what the patient has said in the past. In this case the living will and the decisions made by the intelligent person in the past would seem to control. In others, the state requires decisions be based on the patient,s present "best interests," in which case the more reasonable decision would seem to be to ignore the money -- which holds no present interest for the patient -- and base decisions on the patient,s present ability to enjoy life. Putting it in the context of the patient with amnesia, what advantage is there of putting a murderer in jail for life when the person as they now exist has no memory of the past, the murder, the events, the motive, or the person killed?

Medicine, too, must deal with this issue. A common recent issue in medical decision-making as it
struggles with advance directive and physician assisted suicide relates to the question of death with dignity. But how does this get applied to a patient with Alzheimer's disease? Whose dignity needs to be considered? The patient's or the family's? And if it is the patient's, which patient -- the former patient when he or she was clear thinking and was disgusted by dirt, or the patient as he or she now exists, who doesn't even recognize what urine or feces is?

Consider, for example, a previously fastidious individual who now is of limited physical ability (and without a sense of smell) who has decided to keep twenty cats and, because she is occasionally unable to let them out, ends up living with cat droppings and noxious odors in the house. Relatives find it undignified for the individual to live in such a house, but as long as the individual does not find it undignified and maintains decision-making capacity, clearly the law would not support any relative who wants to force a change for the sake of what they perceive to be the individual's dignity. The patient with decision-making capacity would be given the right to control.

But what if the individual has early AD and can still live alone with a little physical support from neighbors and family members a couple of times a week. If the original person would have found it undignified to live among the cat litter but the present person doesn't, should the fact the former person would object enable a relative to force the ouster of the cats? And should the relative be legally allowed to claim it is unhealthy as a socially acceptable reason for getting rid of the cats without proving it to be unhealthy? And even if it could be proven to be unhealthy, what value should it be balanced against considering it is the cats which make life worth living for the patient?

Of course, medicine's main concern is not cats. The big problem is how to make decisions for patients with AD who now readily accept living in social situations they would previously have found to be undignified, even disgusting. Is it really appropriate to make decisions based on what the individual said in the past, or should we base decisions on their present best interests. And should medicine accept the legal division of state on the issue as determining its medical ethics?

In Connecticut, for example, with its total reliance on a substituted judgment standard, this is a particularly difficult problem. Legally, decisions must be made based on the previously stated desires of the patient. Any present communication, coming from a person lacking mental capacity, would not be appropriate for consideration. Thus, we are forced in the direction of following the wishes of the "previous" person or finding an excuse for failing to honor such directives.

In other states where more credence is given to the best interest standard, there is more choice. Under this standard, the decision-maker is free to make a decision based on what he or she thinks is best for the patient, recognizing the previously stated desires of the patient made at a time the patient had a normal relationship to society is entitled to carry considerable weight in the decision-maker's final decision. But at least under the best interests standard it becomes possible to evaluate the present patient's apparent desires independent of old statements and old thoughts related to dignity by just asking, "given X's ability to relate to the world and his or her apparent joys in life, would he or she want to be allowed to live with the cats, or to be institutionalized, or treated medically, or artificially kept alive by artificial
feadings at this point in their life?"

Applying this now to our subject, when we think in terms of mourning and terminal care, I wonder whether the same issues unconsciously occupy the minds of family members who become caregivers to loved ones with AD. Do some grieve the loss of the intellectual person and subconsciously consider the existing body to now house a new individual who is no longer the relative they used to be? Do some then end their grieving before death and no longer grieve the loss of a "stranger." When this occurs, does the caregiver feel they are caring for an individual they no longer love or respect? And do some grieve twice, first for the loss of the intellectual being, then the physical being?

Lots of questions with few answers. Maybe some of the readers have thoughts on the subject. I would like to know them if you do.

16.04 Artificial Nutrition and Hydration in Alzheimer's Disease

Eventually, most patients with AD reach a point where they are unable to swallow without food going into their lung, a situation which leads to repeated attacks of potentially fatal chemical (aspiration) and/or infectious pneumonia. This often becomes a defining moment for surrogate decision-makers who must decide for or against the initiation of artificial nutrition and hydration. Unfortunately, even though it is known that placement of the new forms of feeding tubes (PEGs and PEJs) is relatively easy, the decision-maker also realizes that by so doing they are committing to a long term process of maintaining an individual with the most minimal quality of life and at the same time depriving their loved one of one of the few remaining pleasures, the taste of food. And all in the hope of preventing a fatal terminal pneumonia.

Obviously, the question of whether to initiate artificial feeding in patients with AD is easiest if there has been previous input from the patient, but this seldom happens unless the issue has been raised by a skillful attorney when drafting an advance directive. In the absence of such direction, while trying to help the decision-maker decide it is often helpful to consider that in Europe and almost all other countries in this world, even in situations in which socialized medicine covers the cost of tube feedings, artificial sustenance of patients with AD is unusual. In contrast, here in America where the very lack of social financial support leads to guilt when it is not undertaken, tube feeding is usually employed. To many this suggests the decision is largely determined by guilt, the decision-maker not feeling free to say "no" based on the best interest of the patient.

16.05 Suffering and Grieving in Alzheimer's Disease

Early in the course of their illness, patients with AD experience and are typically upset by their waning capabilities and memory difficulties. But as the disease progresses, most patients enter a state in which they are no longer aware of their own failures, no longer worry about death, and no longer relate to the concept of "dignity." At this point further emotional difficulties are experienced far more by the family than the patient, thus altering greatly the normal need to address existential suffering in the patient while
increasing the need to address the suffering of the caregivers.

Similarly, to understand the family's grieving for an AD patient one must begin by recognizing that during the course of the illness, family members are forced to deal simultaneously with the loss of support and companionship previously provided by the patient and with a complex grieving process involving both the loss of the individual as he or she existed in the past and with the further mourning accompanying the loved one's actual death. To further complicate this problem, the long period of slow deterioration normally associated with Alzheimer's only adds to the likelihood and extent of anticipatory grief occurring at a time when home care becomes progressively more difficult, leading to increasing internal pressures within the family to institutionalize the patient. This in turn is often associated with guilt, especially when it is known that the patient has previously expressed a desire not to be institutionalized.

Recent commentaries have noted a difference in how families deal with grieving for patients with AD and other diseases. Studies of families who have cared for patient's with AD suggest the irreversible deterioration accompanying the disease places a caregiver in the agonizing position of watching a loved one lose independence, personhood and human dignity inch by inch independent of thinking in terms of physical death. This series of losses can initiate caregiver grief associated with feelings of a gradual but uncontrollable process of separation and detachment -- a long, drawn-out process of mourning the loss of the previously competent individual which is often described by the caregiver as "saying goodbye for a long time." Strong feelings of powerlessness and ambivalence, wanting to hold on and wanting to let go, are common, and not dissimilar from the same process of grieving which normally occurs after a loved-one's death.

Caregivers of family members who were still able to respond to affection and with whom some meaningful communication was still possible tend to experience less detachment prior to death with continuation of the grieving process after death much more in keeping with traditional anticipatory grieving merging with post-mortem grief.

In contrast, caregivers who had lost all meaningful communication with their family member prior to death were more likely to report crying, intense sadness, and grief during the caregiving periods, especially when the family member had not recognized the caregiver for some time and when they had not responded to affection or with meaningful communication for ages. In this situation, more than half the survivors said the period of greatest grief was during the caregiving period. Among this group too, family members frequently reported having grieved to the point of establishing the necessary detachment normally associated with the bereavement process and to even admitted that they prayed their family member would die without resulting guilt feelings or lingering sorrow after death. For these individuals, a brief period of intense grief immediately following death was common, as if the full grief process was nearly finalized before death occurred.

The high frequency with which grieving takes place during the care of Alzheimer's patients is suggested by the following report of statements made by those bereaved by an Alzheimer related death:

1. "I couldn't cry." (23%)

2. "I mourned for months before s/he died." (39%)

3. "I was ready to let him or her go." (77%)

4. "The death was a relief." (77%)

5. "There was grief, but it was different." (23%)

6. "I was ready to get on with life." (31%)

7. "I kept praying that he would die." (23%)

8. "The death was a relief, but I felt guilty." (31%)

Although most survivors followed the above patterns, other families fail to follow either of these patterns for a myriad of reasons. In some, the patient's loss of intellect which interfered with the bereaved's ability to work through problems prior to death caused anger in the survivor which was difficult to forgive after death. In others, an overly strong new relationships with the new, now dependent, incompetent patient develops as a substitute for the loss of the competent individual leaving the bereaved with the loss of a whole new relationship to mourn without enough surviving energy to work it through.

**16.06 Grief Therapy for Relatives of Patient,s Dying of Alzheimer's Disease**

A summary of a recent paper on grief therapy of caretakers for family members with Alzheimer's disease may be helpful to the reader in dealing with the problem. It suggests the need for completing two specific tasks in each of two phases as follows:

**Phase I: Reminiscence**

In this phase, relatives are encouraged to "tell the story" of their relationship with the patient suffering dementia as he or she existed at a previous time. While listening to the client, the therapist endeavors to facilitate the two tasks encompassed by this phase: making the loss real and encouraging the expression of the bereaved's resultant affect.

**Task 1; Making the loss real.**

In instances of "psychic loss," in which the individual remains alive but the relationship is profoundly altered as a result of the illness, the sense the loss is unreal and is fostered by its insidious and often
cyclic nature. Relatives of persons with severe dementia often perceive glimmers of the ill person's former self, which renews undue hopes for a cure and denial of the illness.

In this situation, the therapist should listen intently as the client relates his or her story of the past for specific meanings of the loss to the individual and to encourage acceptance that this loss is final and must be dealt with as such.

Task 2: Encouraging expression of overt and latent affect.

Many affects, including sadness, anger, guilt, anxiety, loneliness, helplessness, and relief, occur as part of a normal acute grieving process, but also occur in instances of psychic loss, and need to be recognized as part of a grieving process which has begun even prior to death.

Phase 2: Readjustment to loss.

A problem-solving approach is used to engage clients and to encourage them to consider all possible ways of meeting the unmet needs deriving from the profound changes in their relationship with their demented relative. In this process the therapist helps the client avoid premature closure or editorializing before generating a thorough list of solutions.

Task 3: Accommodating to the loss through relationships with others.

Relatives of persons with severe dementia tend to seal over the loss by denying their emotional needs in many relationships, not just in the relationship with the demented ill person. The therapist and client may begin the task by examining whether the loss has somehow been generalized to other relationships. "Given the closeness you once had with your father, I'm wondering whether you have gotten all the closeness that you could in other relationships and, if not, whether you have thoughts about how to get more of this feeling with other people?"

Task 4: Accommodating to the loss through the relationship with the demented person.

Unlike the loss by death, in grieving the loss of a person to Alzheimer's disease one must detach both from the original form of the relationship and the new form of relationship based on the relative's being regressed, passive or oppositional, and in embracing a new way of relating. Rather than saying "goodbye," the client is helped to say "hello" to the healthy partial self which exists in all demented persons.

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Many relatives entering grief therapy appear to be resigned to the idea they can never expect much emotional sustenance from their ill relative.... Clients report they rarely share with their demented relative their own worries or hopes, apart from those directly relating to the care of the ill relative.
"A primary goal in this task is to help the client embrace the idea that all [demented] persons still have a healthy aspect, or partial self. For some clients, particularly those with frequent contact with their ill relative, this task involves helping them make an alliance with their relative's healthy partial self.... Other clients simply may need a readjustment in the way they think of their ill relative."

For many clients, grief therapy appeared to enrich their relationship with their demented relative, perhaps by helping them to overcome the defenses of denial and intellectualization that had buffered the acute pain of loss.

16.07 Institutionalization of the Alzheimer Patient

Many older people express a desire, often in writing, to remain at home with their family and not be placed in a nursing home, but to do so has many potential shortcomings. First, staying home may become unsafe for the individual, placing extreme pressure on caregivers to insure safety. Second, it may produce tremendous time demands on the family, interfering heavily on their own ability to enjoy life -- a result not in keeping with the patient's wishes in most cases. Third, especially when one has lost the ability to even recognize the home or a relative, it is hard to understand the desire to stay therein and hard to believe it would still be the wish of the patient who is now demented. Fourth, it produces great guilt in the caring family members when a decision is finally reached to go against the wishes of the individual and have them institutionalized.

This problem has been addressed in many studies. In general, caregivers who have managed to keep their family member at home until the end were less likely to have feelings of guilt, but often at a significant psychic loss. In contrast, individuals who have chosen to put loved ones in nursing homes have often experienced great guilt prior to and at the time of institutionalization, but this guilt usually is short lived when the loved one is found during later visits to have accommodated nicely to the nursing home and to appear safer in day to day living.
CHAPTER 17. SPIRITUALITY AND TERMINAL ILLNESS

17.01 Spirituality; Introduction

17.02 Spirituality; Definition

17.03 Spirituality as Different Than Religion

17.04 Uniqueness of Spirituality

17.05 Reasons for Trying to Understand the Patient’s Spirituality

17.06 Promoting Spirituality

17.07 Efforts to Determine Spirituality

APPENDIX -- Issues Related to Spiritualism

I. Religion

II. Attitude Toward Self/Spirituality

III. Support Family/Friends

IV. Illness/Terminal Care

17.01 Spirituality; Introduction

As modern medicine comes to accept that care of the terminally ill extends far beyond medical therapy, it is forced to try to understand and integrate treatment plans with forces such as religion and spirituality. It is not easy. Physicians as a group are not particularly religious and generally have been trained not to insinuate their own religious beliefs on patients who may very well hold very different beliefs. Fortunately, most patients who are religious have other support mechanisms through clergy or religious organizations to fulfill these needs, but that is not as true of the newer concepts of individual beliefs and concerns which have come to be designated as "spirituality."

Because of the huge diversity in religious beliefs surrounding death and dying, this book, like the medical profession, will generally leave it to others to discuss in detail. At the same time, while recognizing we are not up to the task, it would be inappropriate, even disrespectful, not to recognize the
tremendous importance of religious teaching in allaying the fears of the dying. Undoubtedly, it is those who truly believe in God and religion that most readily accept death, their beliefs providing a framework of acceptance based on faith, a divine presence and an understanding of the afterlife which supports a continued coherence of the individual, and establishing values, directions and procedure which relieves the individual from having to decide what should be done. In addition, religious practices such as prayer and religious attendance can be wonderfully beneficial in coping with the stressors of daily living, while many rituals provide a framework for relaxation. Participation in a religious community, or simple awareness of an on-going relationship with a higher power, may afford comfort in contrast with the alienation which is so prevalent in the rest of our society.

So, too, may spirituality support acceptance of death through the support it gives us in dealing with the unknown. As an area of considerable recent discussion which now appears to be moving toward a consensus, this chapter will attempt to clarify its part in comforting the terminally ill patient.

17.02 Spirituality; Definition

If we are to talk about the relationship of spirituality to care of the terminally ill patient, we need to start by trying to develop a mutual understanding of what spirituality is in the context of this book. In trying to develop a workable, informative definition, most commentators stress its uniqueness to the individual, its broad base in individual thoughts about life, its influence on the individual’s relationships to other people, the unknown and the world in general, and its existence outside the realm of tangible things and events. Some examples may be helpful:

"Spirituality can be defined as a belief system focusing on intangible elements that imparts vitality and meaning to life’s events."

"Spirituality is viewed as the unifying force or vital principle that integrates all manifestations of a human being." [Webster’s Dictionary]

"Spirituality is defined as ‘an individual’s inner resource and the basic value around which all other values are focused and which guides a person’s conduct.’” [The 1971 White House Conference on Aging]

"Spirituality is defined as the essence of the person or an expression of his or her central source. Spirituality forms who we are."

"Spirituality is not a separate part of an individual but rather embodies the individual’s entire being. The spiritual dimension integrates and transcends both biologic and psychosocial nature. The term transcendental refers to that which exists apart from the material world, beyond the limits of possible human experience or knowledge, a power beyond the natural and rational, or a force that unites all beings with the universe."
"Spirituality is the life principle that pervades a person’s entire being, including volitional, emotional, moral, ethical, intellectual, and physical dimensions, and generates a capacity for transcendent values."

"Spirit refers to humanity’s inner resources especially ... its ultimate concern, the basic value around which all other values are focused, the central philosophy of a life which guides a person’s conduct. This ultimate concern is a generic or basic faith that positively affirms life, as distinguished from tradition or particular faith with its doctrine, dogma, and rituals."

The spiritual dimension is "the part of a person that allows God-consciousness and the possibility of relatedness to God, however God is defined."

"Most conceptualizations of spirituality posit an energy, or spectrum of energies, unrecognized by modern scientific methods, that can be accessed to affect physical events. Called by such names as life force, pana, chi, or ruach, this energy exists in the individual and in the cosmos and in the relationship between them. Wellness depends on, and is a manifestation of, the proper balance of this energy, whereas illness and disease reflect imbalance or blockage in the affected individual’s normal energy flow."

"The spiritual dimension transcends the individual and provides a common bond with all humans. The concept of transcendence is inherent in most forms of spirituality and takes on particular importance as one approaches the end of life. It is transcendence that restores wholeness to an individual after personal suffering. As a result of suffering, the individual comes closer to identifying meaning in life through sharing in the human experience."

"Spiritualism relates to human capacities to conceptualize and experience transcendence. Transcendence is human capacity to go beyond the physical into a spiritual world."

"The wholesomeness of one’s spirit can be considered spiritual well-being just as wholeness of body or mind is considered a state of well-being. More formally, spiritual well-being is defined as ‘the affirmation of life in relationship with God, self, community and environment that nurtures and celebrates wholeness.’"

In trying to encompass the above formulations, the author likes the following analysis, although it seems to understate the importance of relationships, relatedness, connectedness, and relational values with other individuals, such as love, justice, compassion, and integration as part of spirituality:

The spiritual dimension has been characterized as involving four aspects. First, the spiritual dimension is a unifying force that integrates and transcends the physical, emotional, and social dimensions. Second, it enables and motivates one to find purpose and meaning in life and to relate to God, however God or an Ultimate Other is defined. Third, because the spiritual dimension transcends the individual, it provides a common bond between individuals, enabling them to share themselves with others. Fourth, the spiritual dimension is based on individual perceptions and beliefs that will guide behavior.
Thus spirituality can be considered a conscious or unconscious belief that relates the individual to the world and gives meaning and definition to existence.

### 17.03 Spirituality as Different Than Religion

The terms "religiousness" and "spirituality" are often used interchangeably. One of my advisors in writing this book made a point that the original use of the word "spirituality" to express the concept developed above was a poor choice for this very reason. Another told me no matter what I say in the book, most readers will still think of spirituality as another word for religion. I hope not, for the author believes it would be misleading to infer that spirituality is based on an adherence to any set of beliefs and practices set forth by an organized church or religious institution. At the same time, one can admittedly define religion much more broadly, so as to encompass the individuals unique formulation of thoughts about living, be they social, cultural, theological, developmental, relational etc., which make up the essence of spirituality. Looked at in this extreme, it would be reasonable to consider spirituality to be an individual’s religion, be the individual a believer, atheist, agnostic, or secular humanist.

As has been noted, physicians tend to dismiss spirituality, in spite of the fact their very choice of education and occupation evidence a spirituality based on caring for others and the role of giving in this world. Because they often fail to perceive the relevance of individual spirituality to patient care, the clergy also invites problems when it equates it to religion. By so doing, clergy have repeatedly tried to force discussion of spirituality back into religious molds which frequently do not fit the beliefs of the patient, thus only adding to his or her distress.

Just as it is important for family members to support the terminal patient’s religious beliefs, it is also important to support his or her unique spirituality and not to assume the two are the same. To prevent this from happening, family members of a terminally ill patient should take time to consciously evaluate, or, more properly perhaps, reevaluate, the patient’s spirituality as it exists and evolves through the dying process. In doing so, one should recognize this is likely to be a time of intense devotion to spiritual matters by the sick individual occurring during a period of increasing dependency, when the individual must increasingly rely on others to obtain desired source materials and to arrange meetings with other individuals for conversational purposes. Similarly, it is likely to be a time when the individual is likely to share thoughts and beliefs which have remained private for much of a lifetime.

To avoid overemphasizing either the religious or the spiritual, it is well to keep in mind that most patients fall into one of four groups. The first of these group are those true believers who are both inwardly and outwardly religious, accepting of its dogma, procedures and rituals as the way to live and die, in whom religion and spirituality tend to merge. On the other extreme are those who profess no association with organized religion but choose to relate to their own basic elements of humanity and humanness as being their spirituality, natural spirit or personal religion. Third are those who consider themselves to be more or less religious through life, who have outwardly partaken of most religious protocols and dogma, but who have inwardly relied, often subconsciously, on individual beliefs to fill in perceived holes in religion and to have thus developed their own spirituality in relating to life. Finally there are those who believe in
religious teachings and feel close to their religion but have turned against organized religious expression in life.

It is failure to recognize these last two groups which is likely to be destructive in dealing with the terminally ill patient. If family members consider the patient to be fully accepting of religion, they may fail to take account of the patient’s personal spirituality and, like the clergy, try in vain to limit their search for spiritual questions to religious teachings. Alternatively, if family members take prior lack of ongoing involvement in religious practices during life to indicate the lack of interest in religion, the potential benefits of the patient partaking in religious counseling may not be recognized or suggested.

17.04 Uniqueness of Spirituality

An underlying, almost unifying principle of spirituality is its uniqueness. In the absence of accepted ritual, one area of uniqueness is the extent of its expression, with some people talking openly and repeatedly about their beliefs as being spiritual in nature, and others choosing to keep their beliefs private or not suggesting that their beliefs have taken on a spiritual nature within. This tends to change, however, as one faces death. At this time, most people tend to search their inner self for appreciation of their own life and, with this, find a desire to discuss that uniqueness of self which has led them to behave as they have throughout life.

For those who want to help loved-ones through their suffering and quest for meaning in having lived, it is not time to question the individual’s unique spirituality any more than it is time to question their religion. It is time to accept it’s uniqueness and to help the individual find solace in dealing with it as it exists, accepting that almost anything can have tremendous spiritualistic meaning, from desires of universal recognition to appreciation of a particular symphony.

17.05 Reasons for Trying to Understand the Patient’s Spirituality

Patients may look at spirituality as a means of advancing their own physical well-being, but the absence of generally accepted scientific evidence to support significant effects of spirituality on mortality makes it hard for physicians to accept such claims.

At the same time, there is ample evidence that fulfilling one’s spiritual goals in life leads to a general sense of well-being and relief of existential suffering during the terminal phase of illness. As has been said, "spirituality provides a sense of coherence that offers meaning to one’s existence as a human being. The experience of personal meaning, purpose, or truth brings integrity to the individual’s sense of self and the world. This aspect of spirituality is particularly significant in the face of uncertainty and change, as typified by the terminally ill patient.... Through transcendence the ill person experiences a ‘rising above’ limiting conditions, which are often a cause of suffering; the person feels part of a greater whole, nature, cosmos or higher being. Such an experience may provide much more than a temporary respite from cares and worries of our daily life. Sometimes, in revealing a whole new order of things, it profoundly transforms life."
In contrast to those who believe spirituality actually prolongs life and minimizes physical illness, many believe spirituality is a co-existent factor among others which effect patient wellness during terminal illness, helping them to feel whole. For them, being spiritual is significantly related to a decreased fear of death, decreased discomfort, and a positive perspective of death among the seriously ill.

In conformity with this belief it has been noted:

> Although the fighter and the optimist have been championed in the literature as dealing effectively with cancer, the situation may be that such persons have a social support system that buffers against stress and facilitates their access to medical care. Their attitude may have nothing to do with their illness but everything to do with seeking friends to support them during a difficult time.

Similarly, it has been said:

> Spiritual interventions frequently stimulate patients to experience and express their illness in new ways. The person feels "healed" but not "cured," and may experience a profound sense of psychologic and spiritual well-being and wholeness, even if disease persists. Additionally and importantly, the incorporation of spiritual healing modalities into an overall treatment plan is not intended to replace traditional biomedical interventions, but to complement them. Many patients feel that by infusing a "secular" modality with spiritual content the latter can enhance the impact of the former.

**17.06 Promoting Spirituality**

The challenge for families as well as health care providers is to recognize the spiritual component of the patient, both as personally developed over a lifetime and as it relates to cultural and religious forces in his or her life which create differences in attitudes toward illness, suffering, and death. Failure to discuss these beliefs and practices explicitly may lead to incomplete personal assessments which preclude the ability to make appropriate additional resources available to those terminally ill individuals who desire them.

By addressing spirituality in a nonjudgmental way, family and health care providers "legitimizes" for the patient the importance of spirituality as well as religion, and confirms their relevance in the medical and home setting. When appropriate, the providers can make suggestions regarding the utilization of spiritually based supports.

When trying to help a terminally ill patient reach spiritual satisfaction in life, remember the patient’s likely concerns: "Did I love well, did I live fully, and did I learn to let go?" Loving well asks the patient to reflect upon whether he or she placed love of family, friends, and community above material possessions and whether the love was offered unconditionally. Living fully centers on the preciousness
of life, an appreciation of the beauty of nature, and an openness to experiencing all life has to offer without being limited by material attachments. Letting go, which is also the central theme in many religious practices, asks the patient to place trust in a greater force, to accept life’s challenges with wisdom and compassion, and to forgive without judgment.

These themes echo the spiritual needs of the dying, which have been identified as the need to find personal meaning in life and death, the need to give and receive love, the need for a sense of forgiveness, and the need to maintain hope. For the terminally ill, the aim is to find spiritual meaning in illness and suffering. This means forsaking the answer to the question "Why did this have to happen to me?" for one which answers the question, "Now that the tragedy has happened, what am I going to do about it?"

In attempting to help a patient achieve religious and/or spiritual wholeness, one should evaluate potential obstacles: lack of structure, lack of access to clergy or appropriate therapists, lack of privacy, and reluctance on the part of caregivers to address spiritual issues. In this approach, lack of structure refers to the lack of required ritual or spiritual practices which would provide closure or reconciliation for the dying patient. Lack of clergy or therapists is related not to the number of personnel but rather to the lack of understanding, compassion, and acceptance of the dying patients, among pastoral and other workers. Too often, ritual and rote prayer or approaches are used by clergy and therapists as a means of avoiding real communication with the patient. Lack of privacy speaks to the fact that most individuals still die in the hospital, surrounded by machinery and isolated from family and loved ones. The quiet and privacy needed for spiritual reflection are difficult to obtain in the hospital setting because of the high level of activity and frequent interruptions as well as semi-private and ward accommodations which do not allow well for private conversations. Reluctance on the part of caregivers to address spiritual issues is frequently a result of caregivers’ discomfort with or failure to be in touch with their own spirituality.

17.07 Efforts to Determine Spirituality

Because spirituality is so unique and so personal, a caregiver interested in helping the patient obtain spiritual satisfaction at the end of life must first determine the patient’s beliefs as they relate to his or her remaining life and impending death. Appendix A, which follows immediately, may be helpful in suggesting issues which may fit the particular situation with any one particular patient.

APPENDIX A

I. Religion

1. Does the patient belong to a religious community? If so, how would they identify it in their own words?
2. What religious practices has the individual undertaken in the past? Does he or she undertake prayer or meditation? Have they been found to be beneficial? Are they important to the individual? Does the patient wish to continue them?

3. How important is religion and religious identification to the individual? Why is the religion important? Why is the identification important? Do they rely on religion for faith? For hope? If yes, how does this come about?

4. What is the patient’s belief in God or a Higher Power? What role does God or the Higher Power play in their life? How significant is such belief in God or a Higher Power? Do they worship the entity? How? Why?

5. Does the individual rely on religious or spiritual text materials? Prayers? Symbols or practices?

6. Has being sick made a difference in the individual’s religious practices? In their practice of praying? With what results?

7. What aspects of their religion would the patient want known to their physicians? caregivers? friends?

8. Does the individual believe in a life after death? If so, what is it like? What determines if they will be allowed to partake in that life?

**II. Attitude Toward Self/Spirituality**

1. Does the patient belong to a spiritual community?

2. How important is spirituality and spiritualistic identification to the individual? Why is the spirituality important? Why is the identification important? Do they equate spirituality to religion?

3. Does the individual rely on spirituality for faith? For hope? If yes, how does this come about?

4. What spiritualistic practices has the individual undertaken in the past? Have they been found to be beneficial? Are they important to the individual? Does the patient wish to continue them?

5. What does the individual consider to be his or her prime values in life? Has being sick changed these values? In what way?
6. Does the individual think at all in terms of their life experiences as being related to rewards or punishment? Do they think of their terminal illness as being related to rewards or punishment? In terms of justice?

7. Does the individual consider himself or herself to have been ethical in dealing with society? If so, how? If not, how not?

8. Does the individual rely on spiritual text materials? Symbols or practices? Would they desire more materials? More opportunity for expression?

9. What aspects of their spirituality would the patient want known to their physicians? caregivers? friends?

10. Does the individual see any purpose in living through a terminal illness? Does it give them additional understanding of the world and humanity? Do they welcome the opportunity to wind-up various loose-ends in their life or would they rather have died suddenly?

11. Does the individual feel any guilt about how they lived their life? Do they consider themselves to be evil? Do they consider their illness to be at all related to their guilt-producing actions in the past?

12. Does the individual consider there to be any benefits from suffering? If so, what benefits? Does it bring them closer to God? Does their ability to handle suffering reflect on their own value in life?

III. Support Family/Friends

1. Who is the most important person in the individual’s life?

2. Is this the person the individual turns to when he or she needs help? If so, is/are they available? In what ways do they help? If not, what individual do they turn to? What source do they turn to? How helpful is this person or source?

3. What or who does the individual consider his or her major source of strength and hope to be? Does this source alleviate the individual’s fears? Their need for special help? How?

4. Is there anything which is especially frightening or meaningful to the individual?

5. Looking back in retrospect over their life, how does the individual view their
relationship with their spouse? Their children? Their family? With society in general? With friends?

IV. Illness/Terminal Care

1. What aspect of being sick has bothered the individual the most?

2. What changes in the individual’s life has bothered them the most? Why?

3. What does the patient think is going to happen?

4. Has being sick made a difference in how the individual feels about God? About religion? About spirituality? About their own religious beliefs? About their own spirituality beliefs?

5. What religious or spiritual meaning has the individual taken away from suffering through their terminal illness so far? Do they have any expectations regarding additional meanings in the days ahead?