

Confronting Life-Threatening Illness

**Maintaining Control and
Establishing Positive Objectives**

John D. Whitacre

Based on a Survivor's Experiences

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CONFRONTING LIFE-THREATENING ILLNESS

by **John D. Whitacre**

You can be near death, but through your spirit light the way for yourself and others with whom you come in contact. Through the power of your spirit—through positive attitudes and actions—you assert who you are; assert *your* spirit with a touch of class. Strive for faith, hope, love, laughter, purpose, and festivity. Invoke forgiveness, charity, caring, compassion, and love both for others and yourself. Fill your day with these positive aspects of living.

So writes John Whitacre in *Confronting Life-Threatening Illness*. John knows; more than two years ago he was diagnosed as having terminal cancer. In the days that followed, he struggled both with his medical crisis and the need to get his personal, financial, and legal life "in order."

Confronting Life-Threatening Illness is meant for the patient and his or her family. It includes tips on: what to expect emotionally; how to deal with the medical community; how to handle pain; descriptions of legal documents that may be needed and appropriate; tips for family crisis management; tips on selecting help; and methods to enhance the quality of life for both the patient and his or her family.

Also included are a series of flow charts, check lists, and worksheets to help detail finances, key personal contacts, important documents, medical directive choices, and key items for the patient to emphasize, which will enhance quality of life and add joy to the days that lie ahead.

Among John's advice is: "Accept the diagnosis, but defy a bad prognosis." He did; and two years later, he has prepared this insightful guide based on both his very personal experiences as well as those of other seriously ill persons he has helped.

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DEDICATION

To those who love and care:
the patient, his family, his friends, and his caregivers.

To those who loved and cared for me, a terminal man:
Arlene, Michael, Nancy, Martha, family, and friends.

To the Contemplative Sisters of the Good Shepherd who provide hope
and comfort through prayer, especially Sister Mary Therese.

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FOREWORD

by Robert F. Todd, III

I first came to know John Whitacre in May, 1989, when, as a consulting medical oncologist, I had the unpleasant task of telling him that he had cancer and that his long-term prognosis was poor; i.e., that he would likely die within the ensuing 6-18 months. His initial response to this "bad news" was that he could come to terms with the likelihood of his imminent death and that his goal for the time that remained was quality of life "with dignity". To ensure the continuity of his medical care, he was anxious to know if I would serve as his primary physician. I told him that I would be delighted to be his doctor and that I would respect his wishes to emphasize quality over quantity of life.

Our initial meeting led to a 2.5-year doctor patient relationship in which I developed an enormous respect for John and his zest for life. In my experience as an oncologist, extreme adversity brings out an inner-strength of character in certain people (the result of "bad things happening to good people") and John's positive attitude toward his predicament was an uplifting experience for me. To avoid the fear of the unknown, he asked a lot of questions about what he could expect as his disease progressed and his condition deteriorated. We discussed symptom management and he generated a computerized list of his medications that was as helpful to me as it was to him. As I came to learn, he carefully planned and prioritized the events of his life striving to make the most out his "good days" and budgeting his strength. His organized efforts in achieving the maximum quality of life while preparing for death led to this book. In the chapters that follow, John describes the emotions that arise in individuals faced with life-threatening illness and outlines a cogent, detailed strategy for effective living with a potentially terminal illness. More than a "how to cope" book, it provides sound specific advice for dealing with doctors and other caregivers, family members and friends, and legal advisors. It offers a useful detailed outline of what plans to make in advance to ensure the emotional and economic well being of family survivors and tells how to stipulate to caregivers the wishes of the individual in providing terminal care. Since many people when faced with the emotional and physical demands of a catastrophic illness find it difficult to "get their lives in order", John's book offers an invaluable resource of information.

In John's own experience in confronting a life-threatening illness, a fortunate "twist of fate" has occurred: he didn't die. In fact, follow-up tests have failed to detect active cancer several years beyond his predicted survival (he is a statistical "outlier"). It was this positive turn of events that enabled John to write this book and, in so doing, provide other individuals with a guide to living while facing the possibility of death.

Robert F. Todd, III, M.D., Ph.D.

Professor and Associate Chairman, Department of Internal Medicine,
Division of Hematology/Oncology; and
Director, Tumor Immunology Program,
University of Michigan Cancer Center

PREFACE

by **John G. Pfaendtner**

John Whitacre often refers to his book, *Confronting Life Threatening Illness*, as a workbook. It is in fact a description of how he worked to organize his life when he was diagnosed terminally ill. Doctors gave him no hope of surviving for more than a few months. His life was instantly reduced to chaos. Every plan he had for the future was useless. Every aspect of his life had to change. He experienced the feeling that is felt by most people confronting a life threatening illness, the overwhelming feeling that they have suddenly lost control of everything in their life.

John's workbook offers an excellent method of regaining a feeling of control. It describes how to reframe the chaos into order and offers a way to find enjoyment and peace with the days that lie ahead. It offers a way to face the possibility of death with dignity while making the most of the time with your family and friends.

John G. Pfaendtner, M.A.
Marriage and Family Therapist; and
Clinical Member,
American Association for Marriage and Family Therapy

PREFACE

by **Francine Cimino Cole**

A bitter lemon can become sweet lemonade. John Whitacre's illness and terminal diagnosis was a bitter personal event. Yet he chose to sweeten his fate by creating order out of a potentially chaotic situation; in this book, John shares these experiences with us. In a timely and practical manner, this book provides a step-by-step guide that will help other persons who are facing life threatening illness, and their families, to find a sense of control in a potentially "helpless and hopeless" situation. John describes ways for the patient to care for his or her loved ones even when no longer capable of providing physical care; and to leave directions to govern future events when the patient can no longer make his or her own decisions.

In a deeper sense, John shares with us his appreciation for the simple "act of being." Through his experience, we begin to appreciate the fact that we are all terminal. Once this is truly understood, we can then begin to live authentically.

Francine Cimino Cole, D.O.
Adult and Geriatric Psychiatry

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First, the insights that are included with this book have been learned in part through my own, and my family's, hard experience with cancer; however, without the sharing, continued instruction, and encouragement by others who experienced their own life-threatening medical crises, it would only be a partial effort and may not have come to completion. A special thank you to the many exceptional people who have shared their experiences in managing life-threatening medical crises.

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Third, no set of acknowledgments is complete without mentioning the support of my family members, who have held my hand through the tough times and extended much help in the preparation of this book.

INTRODUCTION

This book is addressed to those of you who, like me, are facing a life threatening illness. Based on my own experience with the medical, financial, and legal aspects of a health crisis and its social/emotional impact on me and my family, I have attempted to assemble what I have learned into a book that hopefully will help other persons experiencing a similar event.

This book is meant for the patient facing a life threatening illness and his or her close support structure (e.g., family), but I have addressed it specifically to you—the patient.

Inside this book you will find tips on what to expect emotionally and how to deal with the medical community, tips on family crisis management, tips on selecting help, and tips on how to enhance the quality of life for you and your family. In addition, you will find descriptions of legal documents that may be needed and appropriate.

Also included are a series of flow charts, check lists, and work sheets to help you assemble essential personal information; you will derive a sense of satisfaction, comfort, and relief in knowing that this information has been identified, detailed, and consolidated in one place. These forms will help you detail your finances, key-person contacts, important documents, and medical directive choices. Furthermore, the forms will help you identify and prioritize key items to emphasize so that you can enhance your quality of life and add joy to the days that lie ahead.

CHAPTER 1: HINTS AT TIME OF CRISIS

MAINTAINING CONTROL—THE POWER OF CHOICE

Important Note:

If you do not have the time or are not able to read this chapter in its entirety, turn directly to "Check List no.1: Medical Crisis Check List" (in the Appendices). The "Medical Crisis Check List" briefly outlines many of the issues and tasks that you will need to address in the near future. Where possible, solicit help from others to assist you with these matters. Ask members of your close support structure to read this book and become familiar with the issues and tasks that must be addressed. Others can then help you facilitate these tasks when you have the time and/or are feeling able to personally handle them; or they can independently address these issues as required.

You have control over your medical treatment plan and your environment, within limits. The control is asserted by the choices you make and the attitude you maintain each and every day. You can dramatically affect your quality of life and maintain control over events to come by applying positive choices and attitudes today.

In fact, through your own power of choice you can stay in control throughout the total process of a life-threatening illness. Do not underestimate that power. At times, you, like all seriously ill patients, will feel that your life is out of your immediate control. This may be true because of an incapacity imposed by your illness. Also, you may feel completely powerless about your circumstances and physical setting. Medical settings intensify this feeling. Even under these conditions, you can remain in control of future events by the use of advance directives—instructions made in advance. You can also make positive choices about how you use and fill your time to maximize joy and quality of life.

The selection of your medical treatment path and the attitude you maintain toward yourself and your illness are where the first application of positive choices and attitudes is paramount. The key to making positive choices is in knowing what you want to do with your future time. When confronted with life-threatening illness, you must think through your definition of quality life and determine your goals. Positive choices and attitudes will then allow you to stay in control of your life and lead to the attainment of your objectives.

Throughout the period of a serious illness most patients must learn to give up some aspects of normal life activities. You may have to give up your mobility, your job, day-to-day business activities, handling your finances, and recreational activities that are beyond your capability. Whether and/or when you give up an aspect of your former life will be determined by your particular circumstances and the progression of your illness. No one can predict whether or when this time will come or the duration of the period. Some seriously ill patients remain competent to carry on most activities and are independent throughout their recovery or right up to the point of death.

At some point, other individuals will generally take over your personal care needs, including handling financial and medical decisions. You can prepare for this transition before it is forced on you (as a result of your own diminished capacity), by personally choosing your legal representatives and caregivers as early as possible. It is important to plan for your possible incapacity.

Consulting a lawyer about your legal needs and the appropriate legal documents to have in place will help you prepare to exercise your power of control and choice during your medical crisis. Legal documents such as a durable power of attorney and a living will can help you establish your wants and "people of choice" to handle your affairs while you are still living. Other legal documents will ease the lives of those you leave behind after you die; these documents are a will for distribution of major assets to heirs and a "codicil to will" or "memorandum to executor of estate" to distribute smaller, personal possessions to heirs. Alternatively, a living trust may be employed to accomplish these objectives. These documents are discussed later in this book.

Legal documents that delegate your choices and responsibilities to others are not to be taken lightly. The bond in many families includes deep trust of a spouse, child, or relative who can take over for you when required. Some of us are fortunate enough to have friends we trust who are near enough and involved enough with us to help.

Others are not so fortunate. When there seems to be no one you can trust with these delegated powers, talk to an attorney who can help you determine your best course of action. At some point, someone will make decisions for most severely ill patients. If you want to have control over your future, you must act while you can still competently choose your legal representatives and decision makers.

ESTABLISHING A SENSE OF SECURITY

You can expend a lot of time and induce stress by worrying about security. Your first and foremost concern will probably be to establish a sense of security—both financial and medical—for you and your loved ones. The Appendix includes a Medical Crisis Flow Chart, check lists, and worksheets to help you organize and establish this sense of security. See the Appendix Introduction for directions on how to use the Appendix section.

The Medical Crisis Flow Chart (Appendix item 1) will help you understand the dynamics of your crisis and establish priorities for action. Note that this chart has three loops that are marked with

dashed lines. These loops indicate areas where you and your family will expend the greatest amount of time and energy and endure the greatest amount of stress. It takes time to go through these loops and let facts develop so that you can make intelligent, instead of reactionary, assessments of your condition and needs and identify required actions.

Loop 1 depicts what happens in the hospital as your medical crisis evolves. Doctors will stabilize you, run diagnostics, treat your condition, and observe your response. More than one serious medical event may occur during your hospitalization. Finally doctors will state a diagnosis and prognosis. This process can take from a few hours to many weeks. The prognosis—the doctor's prediction of how you're going to do in the future—clarifies whether the medical crisis is "big" or "small." The prognosis should indicate if you are going to stabilize, recover, or die. Your doctor may try to quantify his long term prognosis with "chance" and "time" limits, such as "There is a 70 percent chance you will recover from the illness" or "There is a 70 percent chance you will die in the next two to twelve months." You should request that the doctor clarify his prognosis until you clearly understand what he is saying. Although the prognosis is your doctor's educated opinion, it is not an absolute predictor of future events!

Loop 2 depicts getting required legal work done. This is the first action you and your family should take that will provide security. Getting a durable power of attorney (or other legal device) completed for your financial needs (to carry on day-to-day business of handling expenses and receiving your income) will provide a sense of relief and security for you, your dependents, and close family members involved with your crisis. The durable power should include a "person of choice" to make your medical decisions in the event you are incapacitated by your illness. Finally you should communicate and preferably document how you want to be treated medically by having a living will or medical directive prepared (see chapter 7). It should take an attorney a day or two to prepare a durable power of attorney and living will. See chapters 8 and 9 about other legal tools and actions that you may need, along with tips on choosing your legal representatives and caregivers.

Loop 3 depicts the process of assessing your financial resources. This process can take from a week to several months. The first step in this loop is gathering together information and important documents. The difficulty in assessing your own and your family's financial security stems from estimating how your medical condition will impact the spending and income of resources. It will take time for this information to develop and for a sense of security to mature.

It is common for you and family members to be in all three loops at the same point in time during your first medical crisis. Serious stress and fatigue can result for you and your family. Read the following section on hints and methods for the patient, family, and caregivers to manage and reduce this stress.

HINTS FOR THE PATIENT, FAMILY, AND CAREGIVERS

Personal Care

You come first—take care of yourself. This may sound selfish, but it is good advice. The state of crisis constantly changes and places great demands on your energy and talents. To effectively manage crisis, you must conserve your energy and talents.

Sleep and Rest

You need to get adequate sleep and rest. Establish and maintain a regulated eating schedule. Take a break whenever you need one. Get out of the hospital room, leave the hospital, do whatever is necessary to retain your sense of balance. You must actually "make a break" for yourself. Get a doctor's help if you can't sleep or rest.

Screen Calls

Install an answering machine on your telephone at home. You must protect yourself from the constant bombardment of well wishing friends and those wanting information. Screen your calls and determine those that require immediate response. After a difficult visit or day at the hospital, you need time for yourself. Calls that are not urgent can be returned when you are rested or when your schedule permits.

Resume Daily Routines

Maintain as much routine and normalcy in your life as possible while balancing the demands of the immediate crisis. Any degree of established routine in your life will help. Getting up each morning at a scheduled time, taking a shower, shaving or putting on make-up, eating a regular breakfast, reading the morning paper—these are all important matters of routine!

Not All Crises Are Equal

Keep yourself in shape so that you can distinguish between "small" and "big" crises, problems, and decisions. Each crisis you face will be unique in intensity and importance. Big crises necessitate big changes in your lifestyle and living conditions. As you face each new situation, you experience a degree of uncertainty relative to its outcome. More facts become evident with time. With the facts come clarification and stabilization. Facts about each crisis enable you to determine if it is big or small and enable you to make intelligent decisions. Small crises entail little or no change in your life.

Blow Off Steam

When a crisis lasts more than a few days and becomes, instead, weeks with intense stress, you need to blow off some steam. You need a positive stroke. Try a complete change of environment. Go out to the zoo or to a museum. See a movie or a play. Read an entertaining and fun book unrelated to your personal crisis. "Reading can take you anywhere."

Let Someone Else Do It

Do not assume responsibilities that are not yours, especially when there are caregivers responsible for the job, such as nurses in the hospital. If nursing services are inadequate tell your doctor. Doctors want the best medical care for their patients; they will make sure you get adequate attention if they are aware of shortcomings. Look to family members and friends for services that others don't give, such as true love and encouragement.

Get Help

Share, even delegate, as much of the crisis load as possible among family members and primary caregivers. When the need arises, do not hesitate to use professional advisors and service providers who are within your financial means.

If you are restricted to a chair or bed, you will need the help of others to meet your basic needs. They can provide basic home care needs such as meals, cleaning, and laundry, do the shopping, and supply transportation to doctors and required medical services. Some can pursue sources of help for you such as an attorney, financial counselor, nursing service, or hospice. In short, you can depend on others to keep work going, take care of the home front, and care for your important needs.

CHAPTER 2: WHAT TO EXPECT EMOTIONALLY— A SUMMARY OF STAGES

You can expect to go through at least six primary emotional stages during a serious illness. You will feel as if you are on an emotional roller coaster—a long, hard ride incorporating extremes of intense hope and despair and other powerful emotions, often occurring in a short timeframe.

These six stages are discussed in detail in Elisabeth Kübler-Ross' book *On Death and Dying*.¹ Descriptions of these stages, as listed below, are simplistic but nevertheless give you a good idea of what you can expect. These stages are not unique to a serious illness. They summarize the experiences of those who encounter a major, traumatic event.² Hence, they are experienced by family members, intimate caregivers, and everyone else who is intimately involved with the patient. These stages, which do not always follow a prescribed order, include: 1) denial and isolation, 2) anger, 3) bargaining, 4) depression, 5) acceptance, and 6) hope.

Denial and Isolation

When informed of a life-threatening illness, your first reaction may be to reject the diagnosis with thoughts like "This can't be right" or "There is a mistake in the diagnosis or prognosis." Persons confronted with traumatic news often deny the happening and isolate themselves while they ponder the event. This is true for both the patient and close family members.

Anger

The next reaction is usually a sense of anger. The anger can be diffuse and its source may not be identified by you or family members. However, there is a predictable interval where you are likely to feel anger and strike out verbally at those nearest to you. You will experience anger toward the pain and suffering you may have to endure. You will experience envy and even anger towards those around you who are "healthy." Even close family members can feel a diffuse or directed anger that is caused by the crisis being managed.

Bargaining

Often a stage of bargaining is reached in which you offer some life change, service, or gift to be "healed" or for your suffering to end.

Depression

Usually the negative stage that lasts the longest is depression. The experience of depression is associated with any major traumatic loss or change in life.

Acceptance

Acceptance is the most comfortable stage. At this stage, you acknowledge the reality of the illness and the possible outcome of death. Acceptance is generally followed by "getting on" with the process of living.

Hope

Hope is sprinkled throughout the stages—hope for maximum quality of life, hope for a cure, hope for minimal suffering.

EXPERIENCING ENHANCED EMOTIONS—FEAR, SORROW, JOY, AND COURAGE

A medical crisis enhances your ability to experience emotional extremes. Emotions are felt to a greater degree than before the crisis. Fear can become terror and joy can become ecstasy.

Fear

Many experience fear in varying degrees when facing the prospect of death because of all the unknowns. Fear comes from not knowing what comes next. "How long do I have to live?" "Will my doctors be able to control discomfort?" "What will the treatments be like?" "What will it be like in the afterlife?" "How will the bills get paid when I am no longer around?" The fears also include not knowing how your loved ones are going to get along in the future without you. Perhaps the two greatest fears are the anticipation of suffering and the loss of personal identity.

Sorrow

Sorrow is experienced as the result of missed opportunities in life, both past and future. Everyone wishes that he or she could have done better in life. When you find you may have a limited amount of time remaining, you become aware of all the things you want to do or could have done. During this stage, you also experience intense grief as a result of your anticipation of impending separation from loved ones and things.

Joy

Great joy is also experienced. Simple things—a flower, a leaf, an animal—are appreciated as never before. By facing the end or limit to our existence, the value of things that we earlier took for granted becomes heightened. We see beauty where before we saw nothing. This enhanced sensitivity applies to relationships as well as things.

Courage

In his book, *The Road Less Traveled*,³ Dr. Scott Peck defines courage as taking positive action in spite of fear. There are many fears that you must face. Despite these fears, know that most patients take positive action and make positive choices for the balance of their lives. They show great courage at the time of greatest crisis.

These actions may include facing and accepting a bad prognosis with all its ramifications, selecting your medical treatment plan, final goodbyes to friends and family, planning for the security of your loved ones, accepting the increasing limitations your illness imposes on you, reviewing or making a will, and taking other necessary legal actions. The list seems to go on and on. Preparing for the possibility of death requires a lot of "action" and work.

The Continuing Cycle

The above feelings are often experienced repeatedly and do not follow a prescribed order. On good days with few symptoms of the illness, you may experience only joy. On bad days you can experience one or more of the stages—fear, sorrow, denial, depression, isolation, anger, and bargaining.

Smoothing the Emotional Ride

Facing a medical crisis in a hospital setting is a lot like taking a car that needs an engine tune-up to a body shop. Only part of the problem is being dealt with intensely. The doctors, specialists, and nursing staff are busy getting the dents located and pounded out. They are not paying attention to the engine/mind state. They are primarily interested in intensive medical diagnostics and treatment procedures—in short, they are good "body" mechanics and technicians, but they are usually not holistic. That is, they do not attend to the total needs of the patient and certainly not those of the family. They are centered on fixing the body but not the mind. They ignore a person's emotional and spiritual needs.

The body/mind connection is often not addressed as a crucial part of the medical process. Illness affects the mind as well as the body. Dealing with the crisis is physically and mentally draining for all involved.

Denial, isolation, anger, bargaining, and depression—for all involved—are seen as normal occurrences and consequences when dealing with a serious illness. You need to work through these stages and the accompanying emotions so that you and your family can move to the more positive stage of acceptance.

Getting Emotional Support and Help

Seek professional guidance to help you and your family ease the emotional ups and downs during your medical crisis. Professional help can smooth out the extremes in emotional states. It is available from many sources.

One source of help is from religious organizations. For those with strong belief and religious systems, the ability to turn over problems to a "higher power" can provide an immense source of strength. Openness to prayer and the caring gestures of friends and family to relieve our uncertainties and discomfort is a great source of comfort to most individuals.

If you will find strength and emotional relief through the prayers of others, there are numerous organizations that will pray for your well-being. One religious order, which offered prayers for me, is The Contemplative Sisters of the Good Shepherd. Requests for prayer can be directed to them by telephone at (314) 837-1719 or by writing to The Contemplative Sisters of the Good Shepherd, 2711 Mullanphy Lane, Florissant, Missouri 63031.

Psychiatrists and psychologists can provide emotional support and counseling for you and your entire family. This type of support is appropriate to bring the family together and help sort out the many feelings you all are experiencing.

Medications are available through doctors to provide better sleep and periods of rest as your needs require. Medications can also help address any distressing symptoms that you experience.

Hospices offer a wide variety of help that includes doctor, nursing, emotional support for you and your family, and support with chores around the home.

The above sources of help can augment other sources of emotional support. Many patients receive excellent support through their family, friends, religious groups, and co-workers. You and your family should take advantage of all available support.

CHAPTER 3: IMPROVING QUALITY OF LIFE

LOVE SELF, OTHERS, LIFE

Perhaps the greatest gift and source of strength and comfort anyone can share during a time of crisis is true human love. Love is often confused with many different experiences. The definition that applies here, as derived from *The Road Less Traveled*, is "the will to extend one's self for the purpose of nurturing one's own or another's spiritual growth."⁴

To be open to spiritual growth, your basic personal and family needs—for food, shelter, and personal care—must be met. Providing for your basic needs can be a fundamental and key act of love. Those of you who are fortunate enough to have systems in place that provide these basic needs can have a very special spiritual experience through love at this time of crisis. By facing the possibility of death in this way, you can maximize the quality of your remaining life and achieve a new sense of fulfillment.

FORGIVE SELF, OTHERS

At some point you may have wronged yourself or others; or you may have been wronged by others. You need to forgive both yourself and others. By forgiving, you move away from the sources of negative emotions and attitudes—fear, anger, hate, panic, depression, and frustration. These emotions and attitudes, as well as the actions they promote, can spoil your quality of life and damage your health. It is important to forgive.

Most of us have a person in our lives with whom we have had a difficult or bad relationship. Resolve your unfinished business with that person. Forgive the hurt you feel that person has caused. If possible, contact that person and work through your relationship. Sometimes, you must come to a "one-way—self-resolution" if you are unable to resolve the relationship through personal contact. The key to a "one-way" resolution is forgiveness.

MOURN FOR LOSS OF SELF AND OTHERS

The greatest loss in life is the loss of self-existence that is associated with death. With death you must give up family and friends and all the activities and worldly goods you have come to love and associate with a full life. Above all, you face giving up yourself. Do not fear this process

of giving up; it is generally gradual and often you are not aware of the process. What you and your family will experience is the emotional suffering of acute sadness and deep sorrow, which is grief. This grief is enhanced by the crisis state that you and your family are managing. It is important to recognize the deep emotions that you feel. These emotions are legitimate. To achieve the more comfortable stage of acceptance, they must be worked through.

How do you "work through" an emotion? First, you must become aware of the emotion with which you are dealing and experience it.

KNOW AND EXPERIENCE WHAT YOU ARE FEELING

Be in touch with and experience your emotions fully and deeply. By knowing what to expect emotionally in each stage of your situation, you gain the power to better manage your emotional state throughout the situation. Negative emotions and stages cannot be avoided. They can be managed, however, so that you and your family do not become trapped by them. By managing your negative states you can move on to more positive ones.

You can promote certain emotions by controlling your thoughts (conscious or unconscious) and environment. One way you can do this is through the music you select. Consider the emotions that music can elicit. Music can literally bring you to tears of happiness or sadness. Listen to a selection of music that elicits the emotion you desire. You can then choose to replay the passage if it encourages desirable feelings or move on to another selection.

When you experience anger, joy, sadness, grief, and other emotions, consider the factors that have elicited these emotions. By identifying the factors, you can move away from the feelings or toward them to decrease or enhance your experience. You cannot avoid unpleasant emotional states such as anger, bargaining, and envy—but you can identify these emotions when you experience them, and you can gain control of them by manipulating your thoughts and environment.

CARING GESTURES OF FAMILY AND FRIENDS

Be open to the caring gestures of those who are trying to help during this time of crisis. It is important to recognize that most people you come in contact with will want to help now. Many extend themselves with gestures of friendship and support, often in the form of cards, notes, letters, visits, phone calls, flowers, and small gifts.

Many will offer prayers and other religious practices and rituals on your behalf. They will seek help from a higher source of power, one that they recognize in their lives. You may be uncomfortable with this type of support, but remain open to what these friends and family members are attempting to do. They are offering you help and strength in the sincerest way they know. It is not their intent to make you feel uncomfortable or hurt you.

BEGIN A NEW WAY OF LIVING

Take one day at a time. Live in the present, not the future or the past: the past is gone and the future is not here yet. You have the day you are in *now*. Concentrate on making today the best day of your life by filling your senses and time with pleasant feelings and events.

Seeing and hearing are two senses that can make your life pleasurable. At the same time, because of the discomfort with which you may contend, plan events for the future. Use these events to fill your time when you are feeling good enough to enjoy an activity. Match the activity to your capability. If you are limited to either a bed or chair, sight and sound can be used to fill your life with positive experiences.

Make a list of things to do for the categories of happy/joyful, special/memorable, and productive (see Appendix work sheets 7, 8, and 9). The list should include a large number of items that require various amounts of effort. This will enable you to select items that you are capable of performing on any given day.

Act Now

Do not put off a planned event or activity! When possible, complete unfinished business, make your bed, take a shower. Do what you can do. Get up; dress up. Do some laundry, empty the dishwasher. Pour your own glass of water if you are restricted to bed. These items are productive. Take that special trip you have been thinking about. If that is not possible and you are unable to travel, visit with your family and friends by phone. Consider these ideas for your special category. They may also apply to the happy/joyful category, as may reading, watching TV, listening to music—the list is endless. Buy that special item you wanted (within the limits of your financial resources). Force yourself to take actions. Push yourself! You maintain control and a sense of independence by persisting with the activities of life.

Use Your Sight

Prominently display pictures of loved ones, family, and friends. Include pictures, paintings, posters, poetry, a motto, and sayings that you enjoy. Place these next to your bed and near where you sit most of the time. You are on an emotional roller coaster as you experience the stages described earlier. You can temper your extreme emotional swings by concentrating on the positive things in your life. Collect sayings and quotes that give you comfort and help you to focus on the positive. Keep them posted and read them daily. This will help to keep you focused on the positive ways of living. Make a bulletin board and post well-wishing correspondence and notes from special friends on it. Fill an entire wall—make a rooting section for yourself. Read books you enjoy.

Use Your Hearing

Make pleasant music and story books that are available on tape a part of your life. Invest in a portable cassette player with an AM/FM radio. Use this to make time spent at the hospital, in waiting and treatment rooms, and at the doctor's office more enjoyable; wherever you go bring your music and entertainment with you. Tape record a collection of your favorite music. Begin collecting tapes that address subjects you like. Many famous people discuss interesting subjects. These discussions can also be found on tape. Books are available on tape. These varied sources of sound can help fill an otherwise long day with pleasant experiences.

Norman Cousins' book, *Head First—the Biology of Hope*, provides a comprehensive listing of humorous and other materials that are available.⁵ It is derived from Duke University's Comprehensive Cancer Center in Durham, North Carolina. Sources for the material include books, audio cassettes, and video cassettes.

Television and video tapes can fill a significant amount of time with pleasant experiences. Besides feature films there are nature, documentary, and "learning" video tapes that can entertain you.

Set Goals

If the doctors predict you have a limited amount of time, establish events such as a birthday, wedding, anniversary, holiday, or trip for which you will be around. Set important business or financial goals for yourself, such as qualifying for Social Security disability, Medicare, or retirement benefits. Set goals within and "beyond" the life span limits your doctor estimates.

Stretch your capabilities with goals. If your doctors predict a life span of two to twelve months, set important goals for two, six, twelve, and eighteen months in the future. You will reach some of your goals; you may reach them all. As time passes and you achieve a goal, set a new one and work toward achieving it.

Enjoy Infants, Children, and Pets

Sometimes young children can be a source of enjoyment. The time spent must be limited to the capabilities of the patient and the child. Children and the patient can spiritually grow from sharing time together.

If you do not want to be exposed to children, young animals are another source of comfort. Exposure to a kitten or puppy for short periods of time can light up your life. If you have a favorite pet, it can provide much comfort and joy.

DO THINGS FOR OTHERS NOW

Express your gratitude to those who have been, and continue to be, important in your life, **now!** Show your appreciation with a heartfelt hug and a verbal thank you for the support they have given you. Contact your parents, children, grandchildren, high school friends, and other special people in your life. Remember your caregivers, people of choice, doctors, nurses, and all those who have supported you. Write each a letter or note. Send a thank you card. Call them. Send a box of candy or a special book.

What you give does not have to cost a lot. Remember that the value lies in the meaning and not the material size of the gift. Perhaps you can only give a special message or note. Do not underestimate the value of this kind of gift!

Perhaps you would like to see special family heirlooms passed on to certain family members. Do it now. This is not advocating that you give away all your worldly goods, compromise your comfort, or the financial ability to pay your bills. Nevertheless, there probably are many possessions that you may want to pass on to your heirs which can be given before you die. Your heirs will benefit now and you will experience the special joy and satisfaction of giving.

BALANCE HOPE AND A BAD MEDICAL PROGNOSIS

Find a balance between hope and a bad medical prognosis. You can accomplish this by holding in mind two opposing possible outcomes for your situation and acting on both simultaneously. Do not give up hope for a good outcome; instead, foster it. Intense hope and known goals have sometimes led to medically unexpected results and remissions in illness.⁶

Concentrate intensely on maximizing the quality of your time. At the same time accept the "probability" of the outcome described by your doctors and prepare yourself and your family to meet it, even if that outcome is death. There is a serious chance that this outcome can occur.

We are all terminal. Terminal simply means you have a finite life span. At some point during a serious illness, your doctor may say, "It's time to get your affairs in order." He is telling you that your illness, based purely on statistical probability, may result in your death. Keep in mind that doctors think in terms of statistics and probabilities for many types of illness and treatments.

GO AGAINST THE ODDS: GO FOR A MIRACLE

Recognize the other possibilities. You may not be in the statistical norm with a bad outcome in terms of a prognosis. A prognosis is an educated opinion; it is not an absolute prediction of future events. You can be what the statisticians call an "outlier"—one who doesn't fit on the curve—and it can be to your good. You are an individual, not a number, and therefore your individual handling and response to illness can be exceptional, no matter what type of patient you are. Learn how to be with those who are exceptional both spiritually and medically.

LEAVE SOMETHING BEHIND—A TOUCH OF IMMORTALITY

What can you leave behind for a touch of immortality? You will live on in the memories of those hearts that you have touched. By leaving messages, you can continue to touch and affect the lives of those you love even after your death. The messages you leave go beyond the value of material things. They continue to affect the lives and spirits of your loved ones. Today's technology enables you to leave your message on video, or make tape recordings, as well as write personal notes and letters.

Other diverse options certainly exist. You can leave a personal or family portrait, make a donation to an organization you support, or establish a trust to provide continuing support for your loved ones. These gestures are consistent with the old adage: "What you do for yourself dies with you; what you do for others lives on." The more personal your acts, the more enduring the meaning.

An example of a letter that can hold long-term meaning for loved ones, follows. It was written by the author to his son to pass on important values and sources of understanding. It was not meant to place an emotional burden on his son, but to summarize important sources of inspiration and insight that the author found in his life.

Dear Michael,

In high school I was given an award for "qualities of leadership" from The Danforth Foundation by my teachers and peers. I have never felt that I have lived up to that honorary recognition. With the certificate I was given a book called *I Dare You*. In short, the book was to be physically passed on in life to challenge others to excel in their life—to "Dare Greatly .. Live Usefully .. and Share Freely all worthwhile things in Life."

I have never passed on that dare—although it is presumptuous to think any of us are not living our lives fully and getting and giving all we can from it, it is human nature for us to go for the "status quo" and resist change that is necessary for growth. I know I have resisted that change and as a result lost many battles for extended periods of time. It is time to pass on the text and the dare; however, the physical text was lost long ago during one of my many moves. I am replacing it, therefore, with this letter.

I Dare You Michael,

- To add spiritual growth to yourself and others during your life through love.

I recommend Dr. Scott's book *The Road Less Traveled* for the definitions of love and a reflection on your particular path.

- To recognize your common bond with your fellow man—regardless of race or religious creed—and help humanity through the charity you carry in your heart and the productive accomplishments and donations that you can produce in your lifetime.

Do not be overwhelmed by the above "dares." If you can truly love and affect the lives of just a "handful," positively, you will have done more for humanity than most people do in a lifetime. This handful should include your family and any children you have, if that is in your future.

Take time to view the video series *The Power of Myth* by Joseph Campbell to find the common link in the belief systems and religions of the world that bond us—encompassing from Australian aborigines, American Indians, Moslems, Hindus, Jews, Christians, and other peoples.

- To maximize your joy in life by "dancing, doing the laundry and eating chicken-fried steak" as described in the book *All I Need to Know I Learned in Kindergarten*.
- To continue to add to this list, at least once, before Nancy [my daughter—Michael's sister] graduates from high school, and upon her graduation, pass on this letter and "our" dare for her.

All the above materials and references are in our house and also are at your Aunt Gloria's. An outline and quick reference that I made for *The Road Less Traveled* are on the Macintosh computer along with this letter when, and if, you accept this dare.

I believe both you and Nancy have the qualities to excel in life.

Love,

Dad

Pass on you own insights and values. Create your own challenge for your loved ones. Pass on your advice for living by using one of the above methods. Share the important things you have learned in life.

Remember, even though you accept a bad prognosis and devote time and effort to preparing messages and extending other acts of kindness in anticipation of death, the prognosis may be wrong. You may have many days and years ahead of you. In this eventuality, you should derive satisfaction and comfort in knowing that you have used this time well; and those who have been the recipients of your acts will know how deeply you feel about them. These acts of kindness, compassion, and love during your medical crisis may bring you emotional relief and satisfaction, which may, in and of itself, contribute to your recovery and sense of well being. These activities will certainly occupy your time with positive and meaningful objectives.

CHAPTER 4: WHAT TYPE OF PATIENT ARE YOU?

There are three basic types of patients—assertive, passive, and resolved. Assertive patients tend to be more exceptional than passive or resolved patients. Nevertheless, all patients can be exceptional in terms of outcome for any given illness. Dr. Bernie Siegel discusses patient types in his book *Love, Medicine, and Miracles*.⁷

Assertive

The assertive patient demands to participate in the treatment process, often accepts responsibility for pursuing care, and becomes involved with the process. The assertive patient also asserts choices and is ready to make lifestyle changes to promote healing. Patients in the assertive group tend to accept the diagnosis, defy a bad prognosis,⁸ and be exceptional more than patients in other groups.

Passive

The passive patient turns over the responsibility of care and treatment to the doctors and medical team. A passive patient also expects to be healed by the medical team regardless of prognosis.

Resolved

The resolved patient accepts the prognosis as well as the statistical norm predicted by his doctor. The resolved patient tends to be a passive patient where the issue of responsibility for care and treatment is concerned.

All patients really represent a mixture of the above descriptions, to varying degrees and at different times. It is important to understand that primary patient type does not exclude you from being exceptional. You are an individual and as an individual your response to illness can be exceptional.

ON BEING AN EXCEPTIONAL PATIENT

Ask your doctor to describe the characteristics of the exceptional patients with your specific illness whom he has treated. If he doesn't know what you mean, tell him: Those who beat the odds. Those who are "outliers." Those who stand out. Those who live the balance of their lives completely.

Medically

It is possible to be medically exceptional—to follow a medically unexpected path—with respect to your response to a diagnosis and prognosis. We are all individuals, and no one can predict the future with absolute certainty. Doctors make their prognoses based on prior experience with illness. Simply put, a diagnosis and prognosis can be wrong. Even when the doctor is right in his diagnosis, some patients will respond to an illness in unexpected ways. Many patients will do better than expected. Some people recover from a terminal prognosis against all odds.

Spiritually

You can be near death, but through your spirit light the way for yourself and others who come in contact with you. It is through the power of your spirit, your positive attitudes and actions that you assert who you are—with a touch of class. Strive for forgiveness and charity towards both yourself and others; seek to fill your life with faith, hope, compassion, love, laughter, purpose, and festivity. Invoke these positive aspects of living each day.

CHAPTER 5: INTERFACING WITH MEDICAL CAREGIVERS

DEALING WITH DOCTORS

Doctors are not fortune tellers. They cannot tell you exactly what the progression of your illness will bring. They can only provide a "most probable or likely" scenario. The details and specific problems encountered with your illness, along with what is appropriate for medical treatment, are going to be unique. Perhaps this is the primary reason doctors are so uncomfortable in discussing what to expect during the progression of a life threatening illness. They simply don't know the specifics themselves. They are afraid to expose you to many unpleasant possibilities that may not occur.

Write Down Medical Needs and Questions

Make a list of your medical needs and questions before each visit with your doctor, whether in a hospital environment or the doctor's office. Give a copy of the list to your doctor and discuss each item on it methodically. Press for clarification of your questions until you understand the answers and have no further questions.

List Medications

Make a list of all the medications you are on. Be sure to include the dosage levels and the doctor's instructions for taking the medication. Let the doctor know how effective the medication is in treating the problem. You also need to inform your doctor of any side effects that may need to be addressed. For example, if you take medication to alleviate nausea and find that you cannot keep your food down or you experience some disequilibrium, then you need to inform your doctor. These problems may be controlled either by new medication or by a change in the amount taken.

Establish Partnership with Doctors

Establish rapport with your doctors. Strive for a partner relationship that is based on trust and caring. If you are not comfortable or your needs are not being met with one doctor, look for another. This is important. Assert your power of choice and maintain your power to control future events. Do not be intimidated; insist that your doctors respond to every need and question that you have.

TREATMENT PLANS

You should insist that the doctor disclose his proposed treatment plan. He should also inform you of alternative treatments and approaches to managing the illness. Questions that are appropriate for you to ask concern how to go for a cure, how to achieve maximum life span, and how to achieve maximum quality of life.

Many doctors are extremely uncomfortable when confronted with these questions. This is especially true if you want to pursue a cure and your doctor believes the illness is terminal. If your doctor tends to cut you short and be incomplete in his answers to your questions, be persistent; he owes you answers. He is being paid for sound, straightforward advice. Do not give up; insist that your medical questions be answered until you are completely satisfied.

INFORMED CONSENT

Remember—you and your proxy medical decision maker are entitled to enough information to make informed decisions. The law requires that you be given certain information—the expected outcome of the procedure, expected risks, benefits, and alternatives to all treatments and procedures, and the expected outcome if you or your caregiver refuses the treatment or procedure.

IDENTIFYING AND SELECTING YOUR PRIMARY CARE DOCTOR

Many patients are fortunate to have a general practitioner for a primary care doctor who will guide them through the maze of specialists they need, and will stick with them throughout the crisis. Others aren't so lucky.

Sometimes your primary doctor will refer you to another medical support group or system. This support group will provide services that your doctor cannot furnish. It is easy to get confused as to who your primary doctor is when this occurs. The fact is, there is a continual, ongoing selection process for primary doctor as you move from one medical group to another. You must put the doctors on the spot. Tell them to identify the primary doctor in charge of your medical treatment in each new setting. Some doctors will immediately assume the responsibility.

Pose the questions, "Are you going to stick by me, providing primary care until the end of this illness?" and "Where [physical setting] and how will you continue to support me?" The doctor's response will tell you if he is a temporary or permanent source of medical support.

MEDICAL SPECIALISTS AND CONSULTANTS

Medical specialists bring to bear skills that your primary doctor cannot provide. These specialists are the strength and bane of our medical system. They can apply their skills to often improve quality of life and comfort and also to extend your life span.

On the other hand, it is the rare medical specialist who isn't biased toward his own specialty. The typical specialist has a very narrow perspective. He will often push and sometimes cajole you or your proxy medical decision maker into doing his own procedure. The surgeon wants to cut. The oncologist wants to administer chemotherapy. The radiologist wants to use x-rays. Specialists rarely seem to consider your needs and wants beyond the narrow realm of their own specialties. Think through the procedure that the medical specialist recommends and make sure it agrees with your goals.

GETTING MEDICAL STATUS OF A PATIENT FROM DOCTORS

One of the most difficult tasks your family or proxy medical decision maker faces is staying abreast of your medical status. Because most doctors see you almost daily in the hospital, having a family member or medical decision maker present when the doctor visits is an almost impossible task. At times visiting hours are restricted when the doctors make their visits. Many times, too, the resources needed to have someone constantly present simply are not available.

Talk to the Patient

First, your family or caregiver needs to talk to you. The doctor will keep you informed. If you are alert and oriented you can pass the doctor's information on to your family or caregiver.

Arrange to Talk to the Doctor

When you are neither lucid nor competent to make your own medical decisions, your proxy medical decision maker will need to arrange private, ongoing meetings with your doctor. This is best accomplished by having a frank and honest talk with the primary doctor in charge of your care. A system is needed to keep your family informed of your progress. The doctor also needs your medical decision maker's consent to perform numerous diagnostic and medical procedures. Your caregiver cannot always be present at the hospital, so an agreeable arrangement needs to be worked out. Some doctors will provide medical status and communicate medical needs via telephone conversations during their office hours. Other possibilities are to arrange dates and times to meet at the hospital for periodic briefings. Meetings can also take place at the doctor's office on either a scheduled or as-required basis.

Remember, most doctors do not act like they get paid to talk. They act as though they only get paid to perform medical procedures and treatments. Therefore, doctors will tend to be as brief as possible with this aspect of your needs. You must be persistent and work out an agreeable arrangement with the primary doctor to get your information needs met. The fact is that doctors *are* paid to talk. They are legally required to provide information for "informed consent" in the treatment of your illness. They are obligated to provide all pertinent medical information and answer your questions. You have a right to this information. You are paying for it. Collect it!

DEALING WITH CHRONIC PAIN AND DISCOMFORT

Few factors in the management of a serious illness are more important than your comfort. Intense pain and discomfort compromise your ability to work through the emotional stages discussed earlier and to reach and maintain the stage of acceptance. If you experience pain and discomfort beyond your ability to cope, you tend to center on the stages of depression and anger. It is imperative that you find the best way to control your pain by determining the most effective medication and treatments. Also, you need to learn how to strike a balance between the uncomfortable side effects of medication and maintaining quality of life.

Discuss your medications with your doctor. Find out what can be done to improve the medication's effectiveness. How can side effects be reduced? For instance, is prophylactic use of pain medication appropriate? Prophylactic use of pain medication is the taking of medication at specified times during the day, whether you are in pain or not. Ask your doctor if a "Pain Clinic" assessment for you is appropriate. If you think it is, pursue it. A Pain Clinic is a medical clinic often associated with large hospitals that specializes in the control of pain and discomfort.

Talk to your doctor about reducing the amount of pain medication that you take. Learn to accept and bear some pain and discomfort within your capabilities. Once you accept some pain and discomfort you will find your tolerance increases and you will suffer less. Keep in mind that pain medications can have uncomfortable side effects such as severe constipation. Pain medication may also indirectly shorten your life and dull your consciousness.

Occupy yourself with things that give you joy and happiness—laugh and experience humor as much as possible. It is a proven fact that humor and laughter can reduce pain and they definitely improve quality of life.⁹⁻¹¹ Keep as busy and as occupied as possible.

Plan to take advantage of times of minimum pain and discomfort—do something special at those times. Plan the events ahead of time.

MEDICAL SECURITY

It is sometimes easy to feel that you are being abandoned by the medical community. You can experience a sense of becoming an object to the many medical specialists you are exposed to as you are referred from one doctor to another, from one medical support system to another.

Sometimes you are simply told you should seek a certain type of medical service, such as a hospice, without a referral. At this time it is especially easy to feel that you have been abandoned. What is really happening is that the services you need cannot be provided by your doctor. More than likely it is not included in his specialty. He either does not have the skills you need or he simply is not procedurally set up to support your foreseeable needs. It seems unconscionable that some doctors tell patients to seek other help without a referral, but it does happen. Put your doctor on the spot. Ask for a specific referral in your area of need. Let him know that you are feeling abandoned by his action. At this point it is important to assert yourself or pass the task of finding the required service on to your primary caregiver.

Not all doctors are cold or callused. If a doctor says you are terminal, you need to discuss how he will be able to support you throughout the course of your illness. Be up front and ask him if he will stick by you until the end or whether he will pass you to some other medical support group in the future. If he states he can only support you for a limited time, then you need to decide if this doctor is appropriate. It may be time to look for an alternate primary doctor and medical support system that will be with you until the end.

Also, it is important to discuss the setting in which the doctor will support you. You may have a preference such as your home, a specific hospital, or nursing home. Your doctor may be willing to support you only in specific settings, such as hospitals with which he is associated.

CHAPTER 6: SUPPORT SETTINGS

You can either let your support setting evolve naturally or you can choose to participate in the process. You will probably experience more than one of the settings described below. At times you will be independent, require only out-patient medical support, and be able to live at home. At other times, you may have to be hospitalized. This might be necessary to treat a specific symptom or provide a procedure that will extend your life or improve your comfort. You may also need a nursing home setting at different intervals when your basic care needs cannot be handled at home.

ACTIVE AND PASSIVE CHOICES

You can choose the support setting for your recovery or the final stages of your life. It is within your power to consider different support settings and work toward attaining your choice. You move toward the support setting you choose through your conscious actions and those of your family. By choosing your support setting, you and your family can remain in control of events.

There is no guarantee you will die in your support setting of choice. Your medical and tangible needs tend to determine the location; however, many persons who actively choose their setting attain their desired choice.

Making no choice is itself a passive choice—be assured a system of support will evolve to meet your needs. With a little thought you can envision to what this support system will probably evolve. It is strongly recommended that you make conscious choices to retain control in your life.

HOSPITAL

A hospital is a treatment-oriented facility. The down side of a hospital is that the environment may cause you to feel as though you are an object rather than a person. Hospitals will band your arm (a mark of possession), and may take away your clothes, restrict your visitors with visiting hours, and more. In short, they limit your free choices and your control of factors that affect your quality of life. A hospital is a busy place with many interruptions and it provides you with little emotional support. Perhaps one reason the hospital is selected so often today is because it is convenient for doctors. Hospitals also have other drawbacks; they are extremely expensive

and medical insurance will not always cover your needs until death. Fortunately, you can choose from other viable alternatives.

The Hospital Social Worker

A very important contact you establish in the hospital is with the hospital social worker. The social worker is responsible for seeing that the tangible assets you need to support your next physical move are in place. This includes identifying and lining up your next physical setting, be it home, hospice, or nursing home. The hospital social worker can also get a nursing service if you require one, arrange transportation to treatments (e.g., radiation and chemotherapy), and see that physical supplies are on hand. Assistance is also provided to help you identify financial and insurance resources.

NURSING HOME

A nursing home provides the best alternative for those who cannot take care of their basic personal needs and do not have an in-home support system. Different nursing homes provide for different levels of nursing care.

There are two basic types of nursing homes—skilled and unskilled. A skilled nursing home maintains special medical devices, such as feeding tubes and IVs, in addition to providing your basic food and shelter needs. An unskilled home provides the day-to-day necessities of meals, shelter, laundry, cleaning, and so on, but cannot maintain specialized medical devices that require a skilled nurse.

HOSPICE

A hospice is both a practical system of care and a philosophy. It is not necessarily a "place," although a hospital or physical location may be associated with the hospice when care is needed beyond what can be provided at home. A hospice is for patients with a limited life expectancy (estimated by a doctor). A doctor's referral is generally required for acceptance by a hospice.

First, a hospice is a system of patient and family support. Most hospices offer a variety of support: doctors who specialize in providing comfort for the patient, nurses who support in-home care, counseling for you and your family, and, in many cases, volunteers who visit two to six hours per week to help you and your family with everyday tasks.

Second, and perhaps more important, a hospice is a philosophy that centers on palliative care of the patient. Palliative care—the treatment of symptoms rather than the underlying cause of the illness—focuses on making death as comfortable and as symptom free as possible while at the same time maximizing the quality of your time. The hospice "affirms and cherishes life, helping us live each day to the fullest."¹²

Most hospices today support an in-home setting for dying. They generally require that you have a "primary caregiver." A primary caregiver is the person you choose who will be primarily responsible for providing your care. In most cases, a primary caregiver will live in your home for the duration of your illness.

A hospice can also be a source of continuing support as you move from one setting to another (i.e., from home to a hospital to a nursing home and back home again). Hospice support continues for your family up to thirteen months following your death.

HOME-SUPPORTED

Some doctors suggest a home setting that is supported only by nursing services. Exceptional doctors will make house calls to support you with this arrangement. Home nursing care can approach the hospice support system and philosophy. The quality of support with this approach depends on the doctor with whom you are working and the services he recommends and enlists for your support.

The primary advantage of a home setting is twofold. You are being cared for by loving people in an environment that is familiar to you. This setting offers you maximum potential for achieving unequalled quality of life.

HOME-UNSUPPORTED

At times you may elect no support system. This can be your desired choice or it can be a choice imposed on you by perceived financial and medical insurance limitations. You may find that these limits do not exist if and when you fully investigate the social service systems for medical and financial aid.

Home-unsupported is actually a passive choice; if you choose this route you fully intend to let your support system evolve naturally as a reaction to your developing needs for help.

CHAPTER 7: KNOW AND TELL YOUR DOCTORS AND CAREGIVERS HOW YOU WANT TO BE TREATED

You and your family must select your medical treatment path. You may elect extremes in your treatment path such as seeking maximum quality of life or maximum life span. You may elect to pursue a cure against all odds. Usually a compromise is sought in treating your illness. You can achieve a balance between quality of life and longevity. Concentrate on the goals of medical treatment rather than on the medical treatment itself.

The subject of "health care documents" such as the living will and medical directive is quite complicated. It is important enough that you should get the professional help of a doctor and a lawyer when preparing and executing these documents.

COMMUNICATING YOUR MEDICAL TREATMENT INSTRUCTIONS FORMALLY

Living Will

First, you should discuss your health care directly with your doctor as long as you are mentally and physically capable of doing so.

A living will is a formal, written statement that specifies how you want to be treated medically when you cannot communicate your wishes due to an incapacity imposed by your illness.

In some states a living will is considered an "advisory" document because it is not recognized by state statutory law. Many states do have laws that recognize health care documents. The law in this field is developing. Consult with your lawyer or call your state's attorney general's office to determine the details of the laws in your state.

In states that do not recognize a living will by statute, it is best to couple your living will with a durable power of attorney. In this case the instructions included in the living will should be referred to in the durable power of attorney. A durable power of attorney can designate your person of choice to make medical decisions. This person becomes your "proxy" medical decision maker during intervals when you can not represent yourself because of incompetence. Your power of attorney should state if you want the proxy's direction or your living will to take precedence in

your health care direction. An example of a designation clause appropriate for inclusion in a living will follows:

"Should I become comatose, incompetent, or otherwise mentally or physically incapable of communication, I authorize _____ (whoever you choose), residing at _____ (address), to make treatment decisions on my behalf in accordance with my living will declaration."

When using both legal devices, it is important that the living will instructions and the person responsible for approving your medical care (via a durable power of attorney) be in agreement. The best way to accomplish this is to clearly communicate your wants and agree on the instructions that your medical decision maker will give on your behalf.

It is important to specify in your living will the types of treatments you want or those to which you strongly object. A frank discussion with your doctor about what to expect during the progression of your illness is necessary. In this way you know what to expect and you know what treatments will be available. Without this knowledge you cannot make intelligent decisions about your own treatment. As a result, you cannot adequately convey your medical treatment directives to your caregivers and decision makers. (For a further discussion of living wills, please read chapter 8.)

Medical Directive

A medical directive is a formal health care document.

The Harvard Medical School Health Publications Group provides a medical directive form that you should consider using. (Copies of this form may be obtained from The Harvard Medical School Health Publications Group, P.O. Box 380, Boston, MA 02117 at 2 copies for \$5 or 5 copies for \$10; bulk orders also available.)

In this book, this medical directive shall be referred to as the "Harvard Medical Directive." The Harvard Medical Directive has been reproduced in full in the Appendices to this book, but with one very significant change from the original form. The original form is a three panel fold-out document that, when opened, measures 11" high by 25 1/2" wide. We have "sliced" that form into page units for printing in this book. Apart from this physical change, the content of the Harvard Medical Directive has been included in its entirety.

The Harvard Medical Directive contains a series of illness situations that include incompetence. You must consider the possible interventions and the goals of the medical treatments for each situation. One of the strengths of this medical directive is that it enables you to specify the "goal" of your medical treatment. It also includes a page for your personal statement and allows specifying preferences in care setting (i.e., home, nursing home, etc.) and organ donation.

This directive also incorporates a durable power of attorney for health care. It elegantly addresses many of the concerns noted above in the discussion of living wills.

The Harvard Medical Directive that is included in the Appendices to this book can be used as a work form and can be signed and witnessed for interim use prior to your receipt of the forms from The Harvard Medical School Health Publications Group.

Important Note

It is recommended that choices (each and every box selected by you) for your medical treatments in a medical directive be initialed by you rather than simply checked (or "X"d) by you. This will reduce the likelihood that the directive can be inadvertently modified contrary to your wishes and intent.

COMMON MEDICAL PROCEDURES

A Common Medical Procedures List is included below and a similar Common Medical Procedures Check List is included in the Appendix of this book; the Common Medical Procedures Check List is designed for you to take with you to your doctor's office. Its purpose is to expand your knowledge and enable you and your doctors to determine the types of medical treatments that are acceptable to you. The Common Medical Procedures Check List will also help you obtain information and make decisions relevant to completing a living will or medical directive.

It is strongly recommended that you discuss this list with your doctor on your next visit in the context of preparing a living will or medical directive. Also, once you create a document, such as a living will or medical directive, you should distribute it to your doctors and caregivers and discuss your feelings about the document with each person. Whenever you are hospitalized, your doctor should "flag" a copy of this document with your "chart" or medical records.

COMMON MEDICAL PROCEDURES LIST¹³

Antibiotics

Use of drugs to combat infection, by oral, intravenous (IV), or rectal application.

Artificial Hydration

Giving of fluids through a tube in the nose or stomach by nasal-gastric tube (NG) or in the veins by intravenous tube (IV).

Artificial Nutrition

Giving of nutrition through a tube in the nose or stomach by nasal-gastric (NG) tube or in the veins by intravenous tube (IV).

Blood or Blood Products

Giving blood transfusions through a vein by intravenous tube (IV).

Cardiopulmonary Resuscitation

At the point the heart stops beating, using artificial breathing, cardiac massage (compressing the chest), electric shock and drugs to restore the heart beat.

Chemotherapy

Use of drugs to fight cancer or other life threatening disease.

Invasive Diagnostic Tests

The insertion of an instrument such as a flexible tube scope to look into the throat or stomach or to take a bone marrow sample.

Kidney Dialysis

Removing wastes from the blood by machine or by passing fluids through the belly to filter body wastes from the blood.

Mechanical Breathing

Breathing aided by a machine.

Pain Medications

The use of medications to reduce pain. Such medications are often used even though they may indirectly shorten your life and dull your consciousness.

Simple Diagnostic Tests

Common, simple tests such as X-rays or blood tests.

Surgery, Exploratory

Major or minor surgery for diagnostic purposes that serve to identify the medical problem. The surgeon may also be able to correct the medical problem during the surgery.

Surgery, Major

Serious surgery not limited to removing an obstruction in the intestines, bile, or urinary tracts or appendix or the repair or replacement of a major organ such as the heart.

Surgery, Minor

Surgery that may include removing some tissue from an infected finger or installing catheters or other devices to restore the functions of vital organs or improve comfort.

Although you may have strong feelings about certain procedures, it is impossible to predict the future. The appropriateness of a given procedure usually cannot be known until the situation requiring that procedure actually takes place. Knowing health care goals will help clarify if specific medical treatments and procedures are appropriate.

When the doctor suggests the procedure, you will be asked to give your permission if you are lucid and competent. This above list is provided to let you know some of the more common types of medical procedures that you could be exposed to in the future. It may also help you think through options when doctors offer suggestions to improve comfort or extend life.

AN EXAMPLE OF INFORMAL WISHES

Your wishes regarding treatment can also be communicated informally, in writing or orally. In fact, you should always tell your doctors and caregivers how you want to be treated. You must make these wishes clearly understood by your whole support team of doctors, family, and other caregivers.

You will probably want as much enjoyment, happiness, and freedom from pain and discomfort as possible during your illness. You have your own set of choices to make based on the facts of your particular illness. If possible, outline your wishes in writing and distribute copies of them. For example:

TO WHOM IT MAY CONCERN:

A note to my doctors regarding my wishes and care during this illness:

My and, hopefully, my doctors' objectives:

1. Maximize the quality of my remaining time
2. Make each day count
3. Maintain my ability to make reasonable, rational choices throughout this illness in order to accomplish these objectives
4. Live a minimum of six months after date of surgery or chemotherapy
5. Maximize comfort either during terminal/final phase of illness or when quality of life has decreased
6. Minimize time required to die when either terminal/final phase is reached or quality of life has decreased; at this point do not employ life extending procedures other than those related to comfort
7. Allow a death with dignity, perhaps even with a little class

What a Death with Dignity and Class Means to Me

1. Make each day special
 - A. Do something fun
 - B. Do something special and memorable
 - C. Do something productive
 - D. Love each day
 - E. Be loving each day
2. Live each day one day at a time
3. Bear pain and suffering without an unreasonable amount of complaints passed on to my family and friends. Minimize complaining and grunts and groans
4. Maintain my ability to make reasonable, rational choices throughout my illness
5. Be a productive member of my family and household as long as possible
6. Allow my family enough closeness and distance at appropriate times in the process

Caution

Do not confuse this outline of informal wishes with the formal living will and medical directive previously discussed in this chapter. The formal living will and medical directive may be enforced in some states by statutory law, informal wishes will not. However, both formal and informal kinds of health care documents can play a significant role in communicating your treatment wishes.

CHAPTER 8: LEGAL DOCUMENTS YOU SHOULD HAVE REVIEWED OR MADE

The legal documents you have in place should be reviewed by a lawyer to determine if they are adequate and whether or not you will need to prepare any others. Listed below are a number of documents and items that your lawyer should discuss and explain to you:

- Power of Attorney—Durable/Limited/Broad
- Will
- Codicil to Will
- Memorandum to Executor of Estate
- Trust
- Living Trust
- Living Will/Medical Directive
- Designation of a Guardian (when minor children are involved)
- Guardianship/Conservatorship

Caution

Wills and trusts, etc., involve complicated legal, tax, and other problems. Different states have different laws governing these problems. Consult a lawyer when making or reviewing these documents. A lawyer can help you find and implement the best solutions for your needs.

For a discussion of estate planning and many of the above items, an excellent reference book is *The Living Trust*, by Henry W. Abts, III.¹⁴

Caution:

If you do not prepare a will, your state court will distribute your property to your heirs according to a statutory formula. Only a valid will (or living trust), properly prepared, signed, dated, and witnessed, will "remove" your estate from distribution according to this statutory formula. Why not prepare this document for yourself with a lawyer's help rather than letting the "system" determine what happens?

If you do not have someone legally capable of handling your medical care decisions and/or property, a representative called a guardian or conservator might be appointed by a court if you are determined to be "incompetent." You have no control over who this person is. The guardian or conservator is appointed by a court as a result of a competency hearing. A guardianship or conservatorship can be expensive. Fees for a lawyer, the court, and the guardian will be paid from your assets. This procedure might not be bad, however, if you do not have someone whom you can trust with the advance directives discussed below.

ADVANCE DIRECTIVES

Advance directives are tools that guarantee you a voice in future events. These directives are documents that tell others how to care for you and your property. Using these tools can keep a guardian or conservator from being appointed to handle your affairs.

Power of Attorney

A power of attorney can be very flexible and tailored to meet your specific needs. It is a document that allows the person you choose to handle, receive, and dispose of your assets—such as through receiving and paying bills. The person to whom you give a power of attorney does not have to be a lawyer; he or she can be any highly trusted adult. That person's signature is as good as your own on any document within the scope of powers you give. In effect that person "stands in" and is your proxy on any matter covered in the power of attorney document. This power can include the power to make decisions about your health care and medical treatments.

Durable Power

Patients with a life-threatening illness should have a durable power of attorney. A durable power includes a clause similar to the one that follows:

"This power of attorney shall not be affected by disability or incapacity of the principal."

A power of attorney document without a durable clause becomes null and void when you are determined to be incompetent. A durable power continues in force to cover your needs when you become incapacitated.

Limited Power

A power of attorney can be limited, empowering your person of choice to handle a specific need. For example, it can be limited to handling one or more bank accounts, real estate, stocks, or other assets that you specify. The limited power can be durable at the same time.

Sometimes a durable but limited power of attorney is needed to select a person to make medical decisions only, when financial needs are being taken care of by some other legally acceptable procedure.

Broad Power

A broad power of attorney allows one person to handle all of your worldly assets and medical treatment decisions.

Whether limited or broad, a power of attorney can be supplemented with a living will or medical directive (with a designation clause) providing more detail and specific instructions for medical treatment, as mentioned in chapter 7.

You need to recognize and accept that you may lose certain capabilities as your illness progresses. It is not easy to turn over the control of your life to others. You must think hard and take a second look at all advance directive documents before you sign them. In short, you are placing your faith and trust in others to handle your assets and medical "life and death" decisions in your best possible interest. To do that you must select those you can trust and set up the legal mechanisms that will allow them to act on your behalf and in your best interest.

Caution:

Any type of power of attorney can easily be abused. Be certain that you are selecting honest, trustworthy people when using these legal devices.

Living Will

For a definition and further description of a living will see chapter 7.

In most cases, when a living will is prepared, it leaves room for others to interpret (most specifically doctors administering treatment) what a "comfortable" death is.

Some cancer patients die of starvation. They reach a state where they cannot take food or liquids. Some doctors consider the discontinuation of intravenous feeding to be "uncomfortable" and

continue the process, which can prolong the process of death for months. Please note that there is a difference between providing "nourishment" and "fluids." Most hospices agree that continuation of fluid to prevent dehydration is a comfort measure. On the other hand, the continuation of intravenous nourishment (when you can no longer eat) is a life extension measure that may not provide you with additional quality time.

Doctors may also continue to administer vital medications for the heart and other vital organs that extend life. Sometimes, for instance, procedures such as surgery for a blocked urinary or intestinal tract are performed because in the doctor's mind death otherwise would be uncomfortable. The result is that life and suffering may be significantly extended for many weeks, sometimes months. You must make your own set of "hard choices" on what specific medical treatment you want as you face each unique medical crisis.

Unfortunately, what actually occurs even with a specific set of directions in a living will is often different than what you intended. The root of this problem is the discretion of the doctor who is providing treatment and the pressure that is put on either you or the person designated to approve medical procedures. Many doctors truly believe that death is the enemy and that they have failed if you are not "cured." Using broad requests like "comfortable" and "no heroic measures" can result in life-extending treatments. Many small diagnostic measures and "little" treatments added together and viewed as a whole can be interpreted as "heroic." These actions can extend life and the suffering associated with the final stages of dying.

Living Trust

A living trust is a form of advance directive that can be established to take care of your financial needs while you are living. If you do not have someone whom you trust or if you do not want to burden someone with receiving your income or paying your bills, a living trust is a viable alternative to a durable power of attorney. A living trust can be administered by an impartial party such as a bank.

A living trust can also provide an alternative to a will. The primary advantage of a living trust is that it can avoid the process of probate associated with a will. Estate assets can typically be passed to your heirs within a few weeks of your death; this is usually a relatively simple process with a living trust.

Probate is a process overseen by the court system. It is required for all estates with or without a will for any assets outside of the control of a living trust. The probate process can take a minimum of six months but it averages eighteen months before proceeds are distributed from an estate. It can take literally years to probate an estate. During that time some or all of the estate assets are tied up by the probate process. Probate can also be an expensive process, usually costing over five percent of the gross value of the estate. A typical will costs between \$100 to \$500 upfront to prepare. A living trust will cost between \$900 to \$2,000 upfront to establish, but can also have significant tax advantages along with conserving the estate assets and reducing hassles for heirs.

OTHER LEGAL TOOLS

Will

If you have not established a living trust, a will is required to ensure the distribution of your "major" assets to your heirs or others according to your intent after your death. If a will is already completed it should be reviewed. You need a lawyer to prepare or review this document. You should make sure your will is made and properly signed and witnessed before you lose the capacity to prepare this document.

Codicil to Will

A codicil to a will revises the will. A codicil to will can supplement the will or change directions given in the will and still retain validity of the unchanged content of the initial will itself. If this revision creates an ambiguity in the will, or codicil to will, or both, you run the risk of nullifying both documents, in which case your estate is distributed according to your state's statutory formula. You should consult a lawyer in making a will or a codicil.

Memorandum to Executor of Estate

A "Memorandum to Executor of Estate" is a written statement giving directions to your estate executor. If you do not want to mention small items in a will or codicil, then mention a "Memorandum to Executor" in your will. Tell your executor how to distribute those small items in that memorandum. The memorandum should be kept up to date with your will. Although such a memorandum is not binding on the executor it is highly likely to be honored. The executor will most likely comply with your wishes if possible (i.e., if the item has not been lost, etc.). If the distribution of small items is very important to you, it is best to specify your wishes regarding these items in the will or codicil.

The memorandum to your executor can avoid major squabbles in families where children and friends are involved with the estate. The distribution of simple items like a piece of furniture or a camera can split a family and result in hurt feelings.

Trust

A trust can also be established by action of your will to handle the distribution of your assets to your heirs or others after your death. A trust is especially appropriate if minors are involved as heirs. This type of trust would receive your assets after the probate process and distribute them—or the income they generate—according to the terms of the trust, which usually lasts several or many years.

INSURANCE RELATED ISSUES

Where to Get Medical Insurance Help

There are many sources that help determine the extent of your medical insurance benefits. First and most obvious, but often used as a last resort, is the insurance provider. To begin, review your policy and any literature you have regarding your insurance. Call a representative of your insurance company and discuss any questions you have.

Doctors, medical specialists, hospitals, hospices, and nursing services often offer a good source for determining what is and is not covered by a particular insurance plan. As a provider of medical services they are familiar with the specifics of many plans. They want to get paid and will often check directly with your insurance company to make sure you are covered for a given treatment or service. Do not overlook these sources; however, remember to check with your insurance company for a final determination of your specific benefits.

Life Insurance Policies—Review and Update Beneficiaries

Be sure to consult each life insurance company with which you hold policies to make sure the beneficiaries are specified per your intent. Insurance policy payouts are given directly to the beneficiary declared on the policy. They do not normally go through probate (unless you make a policy designation that the payout is to be part of your estate). It is important to check these details. An attorney will generally recommend contacting each insurance company with which you have a policy and redesignating beneficiaries for each policy to make sure they are up-to-date and there is no error.

CHAPTER 9: SELECTING HELP AND SERVICES

KEY REPRESENTATIVES—PEOPLE OF CHOICE AND OTHER HELP

We've already discussed why it is important to plan for the time when others may be needed to handle your business affairs and medical needs. As you've seen, in order to assert your power of control and choice, you need to "take this action" in the event that you become totally disabled by your illness. Choosing your legal representatives is a serious undertaking—one that is not to be taken lightly. You are trusting those you select to act in your best interest with your financial resources and medical decisions. You are literally putting your life in their hands.

In addition to choosing legal representatives many other services may be required. How do you go about selecting these individuals and services? How do you select professional help when required? To whom should you turn?

KEY CHARACTERISTICS FOR REQUIRED SERVICE PROVIDERS

First, you must look for key characteristics in the person or service.

Trustworthiness

Most important, you are looking for a person who possesses a reputation for honesty and integrity. Your primary caregiver or legal representative is, after all, the person who may be entrusted with your life, death, medical decisions, and financial decisions.

Capability

Next, the medical and legal representative must be capable. Find someone with prior experience in handling another person's affairs and medical direction. You might consider someone who has been an executor of a will in the family and has demonstrated his competence and trustworthiness in his performance of duties. You may not always be able to find a primary caregiver or legal person of choice who is qualified by prior experience. Many times the person of choice will be new to the experience, such as a spouse or other close family member. What is most important is that the person have the ability and qualities necessary to meet your needs and complete required tasks. The person you choose or service you hire must be capable and competent.

Caring

Selecting a truly caring person whose personality is compatible with yours is your next consideration. A caring and sensitive individual will be alert to your needs and will not resent filling those needs in the manner you wish.

Beware of "co-dependents," people whose self-worth and self-esteem are dependent primarily on helping others. These people will appear to be (and are) caring at first. As pressures build and time passes, however, they can come to resent the help they provide and become "persecutors" of the person they are helping.

Commitment

One of the worst experiences you can have is getting a commitment from someone to do a task that never gets done or gets done poorly. Some people either over commit or falsely commit to a task. To avoid this pitfall clearly explain to the service provider the specifics of what you are asking and when the service must be completed to meet your needs. Ask for a commitment for completion of work.

The primary caregiver needs to state the time and the resources he can expend to address your needs. Optimally, he should be physically located nearby; ideally, he should be living in the same household so as to be available on short notice and at times of crisis.

Qualifications and Experience

When choosing professional services such as a lawyer, doctor, or nursing care, you must consider their qualifications and experience. When you need professional service, you expect it to be done right the first time. Ask for references from professional service providers and check them out.

Affordability

The individual(s) who meet the key characteristics listed above may not be able to devote the time required to help you if they are not compensated for their time. You will have to pay for legal, medical, and financial care. You may also have to hire someone to act as your primary caregiver. The services you enlist must be within your financial capabilities. When asking for help or a service you should ask yourself several questions: What is reasonable compensation for the service provided? How much will the service cost? Can I afford this service? If you determine that the service is not affordable, you must develop an alternative plan to meet your needs. Be sure to investigate various sources of financial aid before making your decisions. Do not deny yourself services based on a perceived lack of resources.

Accountability

It is important to ensure that your "people of choice," caregivers, and hired services remain accountable for the services they provide. This is especially true of those you choose to handle your financial assets and medical decisions. Consider appointing an alternate for these

responsibilities in a durable power of attorney. Designating an alternate protects you in two ways. First, if your primary person of choice is disabled, your alternate can still act on your behalf. Second, a good "alternate" will stay abreast of and evaluate events and represent you if abuses are taking place. As you are able, evaluate what has taken place with your finances and medical decisions when others have acted on your behalf. Assess your help whenever possible.

OTHER IMPORTANT CHARACTERISTICS

Independence

The person or service you choose must be adept at independent action. First of all, if you are disabled, that person must be able to act on your behalf independently. When you are ill you want to be left alone as much as possible to pursue your quality of life factors without being interrupted by details. To choose someone who must constantly consult with you in order to accomplish a known or specified need or task is self-defeating for you.

Willingness to Travel

Service providers must be able to go to the place of need. As an example, you may not be able to go to a lawyer's office to discuss your legal needs. You should ask your prospective lawyer if he will come to the hospital or your home if he needs information or documents signed and witnessed. If he says "no," avoid him.

Responsiveness

Those you ask for help must complete the necessary work at the agreed and required times. It is imperative that essential tasks be completed on time. The bills must be paid when they are due. Legal documents must be given to you while you can still sign them. If you are incapacitated when legal forms arrive, it is too late and the effort has been for naught. If a medical decision must be made on your behalf the person must be available so that he can make that decision in a timely manner.

Your caregivers should want to help you and perform tasks when required. They should be self-motivated. If you choose people who are not truly "willing" and motivated to help you, you will not have your needs met.

CONSOLIDATE YOUR HELP—INVOLVE AS FEW PEOPLE AS POSSIBLE

Limit the number of people involved with your care to the absolute minimum. This is especially important with respect to legally assigned duties such as making your medical decisions, receiving your income, paying your bills, and handling your assets. If at all possible limit these responsibilities to one individual (with one specified alternate). Limit a durable power of attorney to one primary person. Select one primary caregiver. This eliminates the possibility of confusion

as to who is doing what for you. It also reduces the possibility of conflicts between caregivers or abuses in the handling of your affairs.

This is also true for doctors and all types of medical care. The more cooks who are involved the more likely the soup will be compromised. This is not to advocate that medical specialists other than your primary doctor not be involved. When your doctor makes a recommendation for a service, pursue it. Try to return to the same service provider each time, however, unless your needs are not being met.

TYPES OF HELP YOU WILL PROBABLY NEED WHEN DISABLED

The help and services you need may vary at different times during your illness. Select your sources for help early. Do not wait too long to identify these sources. At some point in time you may need help from someone to fulfill the following services:

- Receive your income and pay your bills legally
- Direct and monitor your medical care legally
- Administer medications
- Monitor and maintain special medical devices and needs
- Call for appropriate help when needed
- Provide for your personal comfort
- Take care of hygiene needs
- Provide your meals
- Do household cleaning
- Take care of the laundry
- Provide for transportation

WHERE TO LOOK FOR KEY SERVICE PROVIDERS

You should consider someone with whom you feel comfortable, preferably a person who knows you well, to handle your medical decisions and financial responsibilities. People to consider are your spouse, a grown child, a close relative, other family members, friends, or other alternatives such as agency assistance, a bank official, or a lawyer.

A primary caregiver such as your spouse or grown child may not be the optimum person to handle your affairs. A close family member may be so involved with giving you physical and emotional support that the additional responsibilities of handling your affairs might reduce his or her ability to provide tender loving care to you. Also, the person simply may not be fully capable of handling all the responsibilities.

When you involve your children you must choose carefully. To avoid hurt feelings and family squabbles consider the option of a living trust administered by a bank to handle your assets and pay your bills.

PROFESSIONALS YOU MAY NEED

You should pursue professional help for legal, financial, and medical support. A list of the types of professionals that you may need is given below.

Legal

Attorney

Financial

Certified public accountant
Bookkeeper and "check writer"
Financial counselor or advisor
Investment advisor
Broker

Medical

Doctors
Medical specialists
Visiting nurses
Nursing home
Hospice services for terminally ill

METHODS OF FINDING HELP

You can find help in many ways. The most common is by referral from another professional or friend. Do not overlook your prior contacts—people and services that have proven themselves with reasonable prices and good quality work. Commercial advertising should not be overlooked when pressed for time. When choosing services, remember to get references and check them out! In summary, sources of leads may include friends, acquaintances, other professionals, other service organizations, the Yellow Pages, and radio/TV programs and commercials.

CHAPTER 10: ON FACING DEATH

DEATH AS FRIEND AND MOTIVATOR

There is nothing like a deadline (no pun intended) to get one motivated. When you have a time limit, you tend to rise to the occasion and complete your goals. As Dr. Scott Peck says, "If we can live with the knowledge that death is our constant companion, 'traveling on our left shoulder,' then death can become, in the words of Don Juan, our 'ally,' still fearsome, but continually a source of wise counsel."¹⁵ The time limit that death imposes may be the driving force that enables you to achieve your maximum capabilities.

As you face the possibility of death, all things in the meaning of life are brought together. As an example, consider the contrast of opposites in life involving our senses. Salt and pepper used with food add contrast in the flavor. Death, which is the loss of our senses as we know them, highlights the flavor of life. The state of your emotional senses is enhanced as you approach possible death. As a result, your capacity to appreciate your existence and that of others is expanded.

This is eloquently stated by Dr. Peck:

"[i]t may seem to many—to give up one's self and one's life—represents a kind of cruelty on the part of God or fate, which makes our existence kind of a bad joke and which can never be accepted. This attitude is particularly true in Western culture, in which the self is held sacred and death is considered an unspeakable insult. Yet the exact opposite is the reality. It is in the giving up of self that human beings can find the most ecstatic and lasting, and solid, durable joy of life. And it is death that provides life with all its meaning. This 'secret' is the central wisdom of religion."¹⁶

DEATH WITH DIGNITY—A TOUCH OF CLASS

Not only must you learn to live a full life, you must also prepare for the eventuality of death. One of the greatest fears in facing death is that you will be forgotten as the human being that you are now, that you will become an object for the medical system to toy with, and that you will become an object in the eyes of your loved ones rather than the person they now know. You must define what it will take to maintain your dignity in this crisis—what will give you a touch of class in life and death. Then you can invoke these definitions in your remaining life.

NEAR-DEATH EXPERIENCES

Much research has been done in the last ten years on near-death experiences. In the United States, a significant number of people—nearly one in ten—have had a close encounter with death. Of that number, nearly one in ten has had a "near-death experience." That is, they report similar and pleasant experiences with one or more of the traits noted below.¹⁷ Perhaps this research can provide some insight into what you can expect at the time of death.

Near Death Traits Experienced

The following list comprises the perceptions most frequently reported by persons who have had a near-death experience.

- Activities and events going on around them
- Being in another world
- Being out of body
- Bright light(s)
- Passing through a tunnel
- Pre-cognition--awareness of events to come in future
- Presence of being
- Re-examination of one's life
- Sensations and feelings
- Total sense of peace and painlessness

Raymond A. Moody, Jr., has written a series of books that document the characteristics or traits encountered in a near-death experience.¹⁸⁻²⁰ In his books, significant details on each specific trait are noted and described by those who have experienced the phenomenon.

NOTES

1. Elisabeth Kübler-Ross, *On Death and Dying*. (New York: Macmillan Publishing Co., 1970), 38-156.
2. M. Scott Peck, *Going to Omaha*. (Simon & Schuster Audioworks, 1989).
3. M. Scott Peck, *The Road Less Traveled*. (New York: Touchstone, 1979), 131.
4. Peck, *The Road Less Traveled*, 81.
5. Norman Cousins, *Head First - the Biology of Hope*. (New York: E.P. Dutton, 1989), 150-53.
6. Bernie S. Siegel, *Love, Medicine & Miracles*. (New York: Harper & Row, 1986), 3-45.
7. Siegel, 22-27.
8. Norman Cousins, *Head First - the Biology of Hope*. (New York: E.P. Dutton, 1989), 79-96.
9. Cousins, *Anatomy of an Illness*. (New York: W.W. Norton & Co. Inc., 1979), 39-40.
10. Cousins, *Head First - the Biology of Hope*. (New York: E.P. Dutton, 1989), 125-53.
11. Allen Klein, *The Healing Power of Humor*. (Los Angeles: Jeremy P. Tarcher, 1989), xx-xxi.
12. Hospice Education Institute, *Competence, Compassion, Communication...The Hallmarks of Hospice Care*. (Hospice Education Institute, Essex, CT: Hospice, 1990), 4.
13. This procedures list is based in part on the following article: Linda L. Emanuel and Ezekiel J. Emanuel, "The Medical Directive: A New Comprehensive Advance Care Document," *Journal of the American Medical Association* 261 (9 June 1989): 3288-293.
14. Henery W. Abts, *The Living Trust*. (Chicago: Contemporary Books, 1989), 31-33, 152-53.
15. Peck, *The Road Less Traveled*, 133-34.
16. M. Scott Peck, *The Road Less Traveled*. New York: Touchstone, 1979. p. 72.
17. Gallup Poll, "Death," 10-13 August 1979. Data provided by The Ropper Center, Storrs, Connecticut.
18. Raymond A. Moody, Jr., *Life After Life*. (Covington: Mockingbird Books, 1975), 21-78.
19. Raymond A. Moody, Jr., *Reflections on Life After Life*. (St Simons Island: Mockingbird Books, 1977), 9-28.
20. Raymond A. Moody, Jr., *Light Beyond*. (New York: Bantam Books, 1988) 6-20.

BIBLIOGRAPHY

Abts, H. W., III. *The Living Trust*. Chicago: Contemporary Books, 1989.

This book discusses estate planning with the emphasis on the living trust as the recommended way to pass along your estate to your heirs. Included in the book are complete discussions of other legal documents such as a will, living will, durable power of attorney, the process of probate, and much more.

Cousins, Norman. *Anatomy of an Illness*. New York: W.W. Norton & Co., 1979.

Anatomy of an Illness is the story of Norman Cousins and his successful fight against a crippling disease. It is the story of a partnership between a physician and a patient in beating back the odds. The doctor's genius lay in helping the patient use his own powers—laughter, courage, tenacity. The patient's talent was in mobilizing his body's own natural healing resources—in proving what powerful weapons all the positive emotions can be in the war against disease.

Cousins, Norman. *Head First - the Biology of Hope*. New York: E.P. Dutton, 1989.

Norman Cousins, after ten years as a communicator and researcher in the medical community, describes his exciting quest to find the proof—or help create it—that positive attitudes are not merely "moods" but biochemical realities. Medical research has shown that panic, depression, hate, fear, and frustration can have negative effects on human health. This book presents the rapidly mounting scientific evidence that hope, faith, love, will to live, purpose, laughter, and festivity can help combat serious disease. Most important, such attitudes can enhance the environment of medical treatment.

Klein, Allen. *The Healing Power of Humor: Techniques for Getting through Loss, Setbacks, Upsets, Disappointments, Difficulties, Trials, Tribulations, and All That Not-So-Funny Stuff*. Los Angeles: Jeremy P. Tarcher, 1989.

Klein centers on the theme that humor is a key to the control and reduction of suffering in life. You may not be able to avoid pain but you can reduce suffering through humor. He provides techniques for getting through loss, setbacks, upsets, and related challenges. The book is written in good humor and will make you laugh.

Kübler-Ross, Elisabeth. *On Death and Dying*. New York: Macmillan, 1970.

This book is one of the first clinical works on the study of death and dying. Kübler-Ross includes sections on the fear of death, personal and societal attitudes toward death and dying, and the stages of dying: denial, anger, bargaining, depression, acceptance, and hope.

Moody, Raymond A., Jr. *Life After Life*. Covington: Mockingbird Books, 1975.

For this original book, Moody studied more than one hundred subjects who had experienced "clinical death" and been revived. The book provides a narrative of their experiences. Aspects of the different experiences are summarized and grouped according to similarity: such as a feeling of peace and quiet, unique noises, a dark tunnel, out of the body, meeting others, the being of light, the review, the border or limit, and coming back.

Moody, Raymond A., Jr. *Light Beyond*. New York: Bantam Books, 1988.

This companion book to *Life After Life* and *Reflections on Life After Life* expands and consolidates Moody's studies of the Near Death Experience (NDE). At the time this book was first published, Moody had studied more than a thousand case histories of adults and children who have clinically reached the point of death and survived. He again includes a summary of stages or elements of the near death experience, a section on child experiences, how the experience changes lives, why NDE intrigues us, and who the NDE researchers are, plus more information on NDE.

Moody, Raymond A., Jr. *Reflections on Life After Life*. St Simons Island: Mockingbird Books, 1977.

In this companion volume to *Life After Life*, Moody includes more evidence that suggests life after death really exists. He expands on the stages or elements of the death experience of patients from his previous work, provides historical examples, and answers questions generated by readers of his previous book.

Peck, M. Scott. *Going to Omaha*. Simon & Schuster Audioworks, 1989.

This audio cassette deals with the meaning of death. It also discusses Kübler-Ross' six stages of dying and why the stages are experienced for any traumatic event.

Peck, M. Scott. *The Road Less Traveled*. New York: Touchstone, 1979.

Confronting and solving problems is a painful process that most of us attempt to avoid. The very avoidance, however, results in greater pain and an inability to grow both mentally and spiritually. Drawing heavily upon his professional experience, Peck, a practicing psychiatrist, suggests ways in which confronting and solving our problems—and suffering through the changes—can enable us to reach a higher level of self understanding. Peck discusses the nature of loving relationships: how to recognize compatibility, how to distinguish dependency from love, how to become one's own person, and how to be a more sensitive parent.

Other topics Peck discusses pertinent to the patient with life-threatening illness are how the possibility of death brings meaning to life and can be a motivator to live life to the fullest. Peck bridges the science of psychology and religion with his philosophy of life expressed in this book. He equates mental growth with spiritual growth and defines love as the acts of an individual in doing the hard work of expanding his own or another human's spiritual self.

Pierian Press. *Directory of National Helplines*. Ann Arbor, Michigan: The Pierian Press, 1990.

This is a directory of national toll-free helplines for various services and information. It is updated annually. The current directory includes information on more than 500 services.

Siegel, Bernard S. *Love, Medicine & Miracles*. New York: Harper & Row, 1986.

Siegel is a surgeon and teaches at Yale University. This book takes note of the mind/body connection in dealing with disease. Siegel provides examples of how patients have defied the convention that a biopsy and prognosis are the determining factor in an individual's future survival and health. He also describes techniques he utilizes to identify the mind/body connection of his patients and how he educates them concerning the characteristics of exceptional patients.

SOURCES OF TOLL-FREE TELEPHONE ASSISTANCE

The following information on organizations that provide national toll-free assistance is derived from the Pierian Press publication, *Directory of National Helplines*, which covers more than 500 helpline services.

AIDS:

Aids Clinical Trials Service 1-800-TRIALS-A

Available 8:00-7:00 ETZ, M-F. Sponsored by the National Institute of Allergy and Infectious Diseases, which maintains a database on AIDS clinical trials. The helpline operators provide information on the location of AIDS trials, criteria for inclusion or exclusion, and related assistance. Brochures will be sent on request. Spanish-speaking operators available.

AIDS Hotline 1-800-342-6514

Available 24 hours. Sponsored by the American Social Health Association. Answers questions on AIDS and provides basic information. Offers referrals to local organizations.

National AIDS Hotline 1-800-243-7889

Available 10:00-10:00 ETZ, M-F; TTY accessible. Sponsored by Centers for Disease Control. Offers referrals to local hotline and service organizations. AIDS brochures available.

National AIDS Hotline 1-800-342-AIDS
(MI) 1-800-872-2437

Available 9:00-9:00 ETZ, M-Sat, 9:00-6:00 Sun. Offers counseling on AIDS and AIDS-related issues. Provides referrals to physicians, support groups, self-help groups, legal help, housing agencies, hospices, and home care services. Publications on AIDS available.

National SIDA Hotline 1-800-342-SIDA

Available from 8:00 A.M.-2:00 A.M.; recording from 2:00-8:00 A.M. Sponsored by Centers for Disease Control. Offers referrals to local hotline and service organizations to the Hispanic caller. AIDS brochures available.

Palmetto AIDS Life Support (PALSS) 1-800-868-7257

Available 24 hours. Provides emotional support for HIV-infected persons. Brochures available.

Cancer:

AMC Cancer Information and Counseling Line 1-800-525-3777

Available 8:30-4:30 MTZ, M-F. Sponsored by AMC Cancer Research Center. Answers inquiries about symptoms of cancer, prevention, methods of detection and diagnosis, treatment and treatment facilities, and rehabilitation. Literature will be mailed upon request.

The American Institute for Cancer Research Nutrition Hotline 1-800-843-8114
(D.C.) 1-328-7744

Available 8:00-6:00 ETZ, M-F. Provides nutrition information and sets appointments to speak with a dietician. Also refers callers to programs that offer treatment and transportation in their areas. Pamphlets and a newsletter for children available.

Cancer Information Service 1-800-422-6237
(HI) 1-800-524-1234

Available 9:00-5:00 EST, M-F. Nonprofit organization. Sponsored by National Foundation for Cancer Research. Conducts scientific studies on various types of cancer. Answers callers questions on cancer research. Provides referrals to other cancer organizations. Offers booklets and pamphlets that contain cancer information.

National Foundation for Cancer Research 1-800-321-CURE

Available 9:00-5:00 ETZ, M-F. Non-profit organization. Sponsored by National Foundation for Cancer Research. Conducts scientific studies on various types of cancer. Answers callers questions on cancer research. Provides referrals to other cancer organizations. Offers booklets and pamphlets that contain cancer information.

Y-ME Breast Cancer Support Group 1-800-221-2141
(Ex IL) 1-312-799-8228

Available 9:00-6:00 CTZ, M-F. Offers counseling with other cancer patients. Provides medical information on treatments dealing with cancer, such as chemotherapy, etc. Annual report and pamphlets are available.

Heart:

Heartlife 1-800-241-6993
(AK, HI, GA call collect) 1-404-523-0826

Available 24 hours. Provides information about heart disease, pacemakers, medication, exercise, and nutrition. Publications available.

Hospice:

HOSPICELINK (Ex CT) 1-800-331-1620

Available 9:00-5:00 EST, M-F; answering machine after hours. Sponsored by Hospice Educational Institute (HEI) and supported by private funds and some corporate contributions. Provides information on hospices and referrals to local hospices. Also offers "supportive listening." Books, brochures, and newsletters available. Polish- and French-speaking operator available.

APPENDICES

INTRODUCTION

This appendix includes a medical crisis flow chart and a series of check lists and work sheets to help you establish priorities and objectives and assemble important records and documents that may be needed during your health crisis.

Note:

The important information you need to assemble and record may exceed the capacity of the attached check lists and work sheets. It is recommended that as many copies of the appropriate forms be made as you may require, and that the original sheets in this booklet not be used. As a result you will always be able to photocopy more if and when they are needed. Photocopiers usually can be found in local libraries, post offices, and businesses.

Medical Crisis Flow Chart

The flow chart depicts a medical crisis and a patient's support systems. The flow chart is annotated to show the points at which the check lists and work sheets in this appendix apply.

Please note the feedback loops indicated by dashed lines in the flow chart. It is at these points in the crisis process that great amounts of stress is encountered and much time and energy are expended by the patient and his or her family.

Check List no.1: Medical Crisis Check List

The most important points discussed in this text are summarized in this check list. Included are items that require attention during your health crisis.

Check List no.2: Selecting Help and Services

This check list summarizes the services you may need, key characteristics to seek in service providers, and how to find and evaluate these services.

Check List no.3: Common Medical Procedures

This check list is to be used to expand your knowledge and awareness of common medical procedures that you may be offered in the treatment of your illness. The list is meant to be used to take personal notes on medical treatments during the context of a discussion with your doctor. The list will help you obtain information and make decisions relevant to completing a medical directive or living will (read chapter 7).

Harvard Medical Directive

The Harvard Medical Directive that is included in this book can be used as a work sheet to draft your choices. It can also be executed (properly filled out with final choices, signed and witnessed) for interim use prior to your receipt of the forms from The Harvard Medical School Health Publications Group. You should, if possible, complete the form in the context of a discussion with your physician. Consider using Check List no.3: Common Medical Procedures, during this discussion to take notes (read chapter 7).

Work Sheet no.1: Medication Summary

The purpose of the Medication Summary Work Sheet is to consolidate information on all medications you are taking. It is important to revise or make a new list every time your medications are changed. This work sheet provides a space for you to note effectiveness of the medications taken and any side effects. Provide a copy of this work sheet to your doctor on all doctor visits.

Work Sheet no.2: Medical and Home Support Contacts

The purpose of the Medical and Home Support Contacts Work Sheet is to consolidate information on your medical and home support group contacts. A copy of this work sheet should be provided to your primary caregiver.

Work Sheet no.3: Legal, Business and Financial Contacts

The Legal, Business and Financial Contacts Work Sheet will help you consolidate information on important business and legal contacts. A copy of this work sheet should be provided to your spouse and the executor of your estate.

Work Sheet no.4: Important Document Summary

The Important Document Summary Work Sheet will help you consolidate information on significant personal documents and their location. A copy of this work sheet should be provided to your spouse and the executor of your estate.

Work Sheet no.5: Draft Memorandum to Executor

The purpose of the Draft Memorandum to Executor Work Sheet is to help you draft your wishes regarding the distribution of minor possessions that you want distributed to specific heirs or other persons that are not mentioned in your will or codicil to will. Making this memorandum can avoid hurt feelings and squabbles between heirs and others when your minor possessions are distributed.

Caution:

This is only a DRAFT. You need to write a memorandum to your executor of estate, and sign and date it, to formally pass on these wishes to your executor. Also, the memorandum is not binding on your executor, although it is very likely to be honored. If you have strong feeling about passing certain minor possessions to heirs or others, you should include those directions in a properly prepared will or codicil (read chapter 8).

Work Sheet no.6: Assets and Liabilities Summary

The purpose of the Assets and Liabilities Work Sheet is to help you prepare a consolidated list of your assets and liabilities and their location. A copy of this work sheet should be provided to your spouse and the executor of your estate.

Work Sheet no.7: Things to do List—Happy, Joyful Objectives

Work Sheet no.8: Things to do List—Special, Memorable Objectives

Work Sheet no.9: Things to do List—Productive Objectives and Accomplishments

The Things to Do List Work Sheets are included to help you make lists of things that will improve your quality of life. Happy/Joyful things are to be done today. Special/Memorable things consist of objectives for tomorrow or a future date. Productive Objectives and Accomplishments should be listed for each and every day.

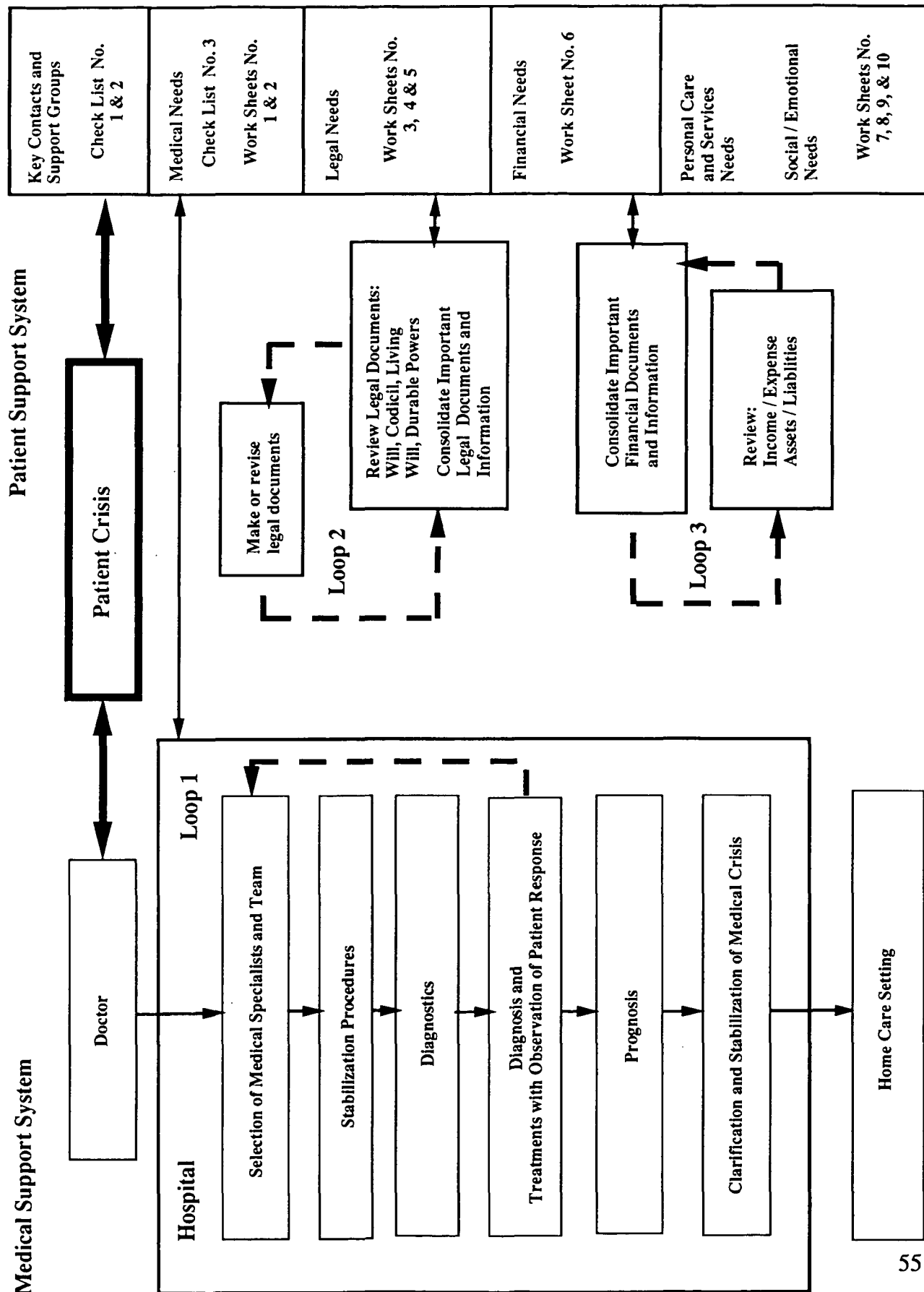
Work Sheet no.10: Social and Emotional Support Contacts

The Social and Emotional Support Contacts Work Sheet will help you consolidate information on those persons with whom you seek to maintain contact for emotional support.

Work Sheet no.11: Important Information for:

This supplemental work sheet can be copied and used in conjunction with other work sheets provided in this book.

Medical Crisis Flow Chart



Check List No. 1: Medical Crisis Check List

(page 1 of 3)

I. Select Medical Team and Medical Treatment Goals and Plan.

- ☐ Establish partnership with doctors
 - ☐ Make list of your medical needs and questions and discuss with doctors
 - ☐ Get facts for your particular illness
 - ☐ Discuss what to expect with progression of illness with medical team
- ☐ Make list of all medications you are taking. Discuss with doctors. (Work Sheet No. 1)
 - ☐ Dosage levels
 - ☐ Instructions for taking
 - ☐ Make personal assessment of effectiveness for purpose taken
 - ☐ List any side effects you need addressed
- ☐ Discuss available treatments with medical team. Determine your goals.
 - ☐ How to go for a cure
 - ☐ How to go for maximum life span
 - ☐ How to go for maximum quality
 - ☐ Determine the best action or compromise for you
- ☐ Make medical/home support key contacts list (Work Sheet No. 2)
 - ☐ Emergency
 - ☐ Doctors
 - ☐ Caregivers
 - ☐ Nursing services
 - ☐ Nursing home
 - ☐ Pharmacies
 - ☐ Medical supplies
 - ☐ Hospitals
 - ☐ Ambulance
 - ☐ Hospice
 - ☐ Other

II. Review/Make Key Legal Decisions and Get Legal Documents Reviewed/Prepared with Attorney.

- ☐ Designate proxy medical decision maker, your person of choice
 - ☐ Durable power of attorney (Harvard Medical Directive or other)
- ☐ Document/communicate how you want to be treated medically
 - ☐ Living will/medical directive (Harvard Medical Directive or other)
- ☐ Designate/provide for handling of finances, a proxy financial representative, your person of choice
 - ☐ Living trust
 - ☐ Durable power of attorney

Other Important Legal Actions to Consider.

- ☐ Select how you want to distribute major assets in event of your death
 - ☐ Will/codicil/living trust/trust
 - ☐ Designate guardian for minors
 - ☐ Establish trust for minors/others if desired
- ☐ Select how you want to distribute minor assets and possessions to family and others to avoid squabbles and hurt feelings
 - ☐ Will/codicil
 - ☐ Memorandum to your executor of estate (Work Sheet No. 5)

Check List No. 1: Medical Crisis Check List

(page 2 of 3)

III.

Make List for Key Legal, Business, and Financial Contacts (Work Sheet No. 3).

- ☐ Attorney
- ☐ Accountant
- ☐ Stockbroker
- ☐ Investment adviser
- ☐ Bank officers
- ☐ Guardians
- ☐ Life insurance
- ☐ Medical insurance
- ☐ Home/rental insurance
- ☐ Auto insurance
- ☐ Banks
- ☐ Social Security
- ☐ Work
- ☐ Other

IV.

Consolidate Important Documents in One Location (Work Sheet No. 4).

- ☐ Will
- ☐ Codicil to will
- ☐ Memorandum to executor of your estate
- ☐ Letter of instructions
- ☐ Living will
- ☐ Durable powers of attorney
- ☐ Birth certificates
- ☐ Insurance policies
- ☐ Stocks
- ☐ Bonds
- ☐ Titles
- ☐ Deeds
- ☐ Mortgages
- ☐ Loan records
- ☐ Tax records and tax documents
- ☐ Other important and other legal papers

V.

Establish Sense of Financial and Medical Security for Self and Family (Work Sheet No. 6).

Determine financial/medical support systems available.
Understand personal assets and benefits available to you.

- ☐ Financial
 - ☐ Income—all sources
 - ☐ Earned
 - ☐ Work sick leave
 - ☐ Retirement
 - ☐ Investment/interest
 - ☐ Social Security
 - ☐ Disability insurance
 - ☐ Other
 - ☐ Expenses—all sources
- ☐ Assets—all sources
 - ☐ Bank accounts
 - ☐ Safe deposit box
 - ☐ Stocks
 - ☐ Bonds
 - ☐ Property
 - ☐ Business
 - ☐ Other
- ☐ Liabilities
 - ☐ Mortgages
 - ☐ Loans
 - ☐ Credit cards/accounts
 - ☐ Other
- ☐ Medical
 - ☐ Details of medical insurance plan
 - ☐ Medicare
 - ☐ Medicaid
 - ☐ Other

Check List No. 1: Medical Crisis Check List

(page 3 of 3)

VI.

Choose Caregivers and Proxies [note: One person can fill all these roles] (Check List No. 2).

- ☐ Proxy medical decision maker
- ☐ Proxy financial representative
- ☐ Primary caregiver—medical/home
- ☐ Guardian for minors
 - ☐ Close family member
 - ☐ Other relative
 - ☐ Friend
 - ☐ Other legal choices

VII.

Select Techniques/Methods to Maximize Quality of Time Left.

What's important to you (within abilities/constraints of your illness). Items that enhance quality of life and provide hope.

- ☐ Happy, joyful objectives (Work Sheet No. 7)
- ☐ Special, memorable objectives (Work Sheet No. 8)
- ☐ Productive objectives and accomplishments (Work Sheet No. 9)

VIII.

Make List of Contacts for Social/Emotional Support (Work Sheet No. 10).

- ☐ Close family member
- ☐ Other relatives
- ☐ Friends
- ☐ Work associates
- ☐ Other

IX.

Select Setting and Support System for Recovery or Possible Death.

- ☐ Hospital
- ☐ Nursing home
- ☐ Hospice
- ☐ Your Home—supported
 - ☐ Doctor/Nursing
 - ☐ Hospice
- ☐ Your Home--unsupported

X.

Make List of Contacts to be Notified at Time of Death.

- ☐ Close family member
- ☐ Other relatives
- ☐ Friends
- ☐ Work associates
- ☐ Other legal/business/and financial key contacts
- ☐ Insurance companies
- ☐ Social Security
- ☐ Funeral home
- ☐ Cemetery
- ☐ Other

XI.

Make Funeral/Memorial Service Decisions.

- ☐ Select funeral home
- ☐ Method of body disposal—burial/cremation
- ☐ Select grave site/location/method to scatter ashes
- ☐ Document/communicate any special wishes for services (special readings, music, etc.)

Check List No. 2:

(page 1 of 1)

Selecting Help and Services

<p style="text-align: center;">Desireable Characteristics for Person or Service</p> <div style="display: flex; justify-content: space-around;"> <div style="text-align: center;"> <p>Key Characteristics</p> <p>Trustworthiness Capability Caring Commitment Qualified/Experienced Affordability Accountability</p> </div> <div style="text-align: center;"> <p>Other Important Characteristics</p> <p>Independence Willingness to Travel Responsiveness Self-motivated</p> </div> </div>		
People and Service Needs	Where to Look	How to evaluate
<p>Professional Help and Services:</p> <p>Medical Legal Financial Nursing Hospice Home help</p>	<p>Professional Help and Services:</p> <p>Prior contact Word of mouth/referral Family, friends, acquaintances, other professionals Ads Papers, magazines Yellow pages Radio/TV</p>	<p>Professional Help and Services:</p> <p>Prior experience, yours and other references Better Business Bureau Get other opinions on work done</p>
<p>Primary Caregiver and Other Help:</p> <p>Make your medical decisions legally (Durable Power of Attorney) Receive your income and pay bills legally (Durable Power of Attorney or Living Trust)</p> <p>Administer medications Monitor and maintain special medical devices and needs Call for appropriate help when needed Provide for your personal comfort Take care of hygiene needs Provide your meals Household cleaning Laundry</p>	<p>Primary Caregiver and Other Help:</p> <p>Close family member Relative—near/distant Friend Hired professional help</p>	<p>Primary Caregiver and Other Help:</p> <p>Personal assessment Listen to other people's opinions Legal advice Better Business Bureau Get other opinions on work done</p>

For: _____

Date _____

Antibiotics

Use of drugs to combat infection, by oral, intravenous (IV), or rectal application

Notes: _____

Artificial Hydration

Giving of fluids through a tube in the nose or stomach by nasal-gastric tube (NG) or in the veins by intravenous tube (IV)

Notes: _____

Artificial Nutrition

Giving of nutrition through a tube in the nose or stomach by nasal-gastric (NG) tube or in the veins by intravenous tube (IV)

Notes: _____

Blood or Blood Products

Giving blood transfusions through a vein by intravenous tube (IV)

Notes: _____

Cardiopulmonary Resuscitation

At the point the heart stops beating, using artificial breathing, cardiac massage (compressing the chest), electric shock and drugs to restore the heart beat

Notes: _____

Chemotherapy

Use of drugs to fight cancer or other life threatening disease

Notes: _____

Invasive Diagnostic Tests

The insertion of an instrument such as a flexible tube scope to look into the throat or stomach or to take a bone marrow sample

Notes: _____

Kidney Dialysis

Removing wastes from the blood by machine or by passing fluids through the belly to filter body wastes from the blood

Notes: _____

Mechanical Breathing

Machine aided breathing

Notes: _____

Pain Medications

The use of medications to reduce pain. Such Medications sometimes may indirectly shorten life and dull consciousness

Notes: _____

Simple Diagnostic Tests

Common, simple tests such as x-rays or blood tests

Notes:

Surgery, Exploratory

Major or minor surgery for diagnostic purposes that serves to identify the medical problem. The surgeon may also be able to correct the medical problem during surgery

Notes:

Surgery, Major

Serious surgery not limited to removing an obstruction in the intestines, bile, or urinary tracts or appendix or the repair or replacement of a major organ such as the heart

Notes:

Surgery, Minor

Surgery that may include removing some tissue from an infected finger or the installation of catheters or other devices to restore function of vital organs or improve comfort

Notes:

Other Procedures:

Treatment 1

Description:

Notes:

Treatment 2

Description:

Notes:

Treatment 3

Description:

Notes:

Discussed With:

Doctor:

Address:

Phone

Date:

* Based, in part, on Linda and Ezekiel Emanuel, "The Medical Directive," *Journal of the American Medical Association*, June 9, 1989. See footnote No. 13. This check list is not intended to function as a Medical Directive. However, it can be used to expand your knowledge regarding medical treatments which will help you when preparing a Medical Directive.

The Medical Directive

Introduction. As part of a person's right to self-determination, every adult may accept or refuse any recommended medical treatment. This is relatively easy when people are well and can speak. Unfortunately, during serious illness they are often unconscious or otherwise unable to communicate their wishes — at the very time when many critical decisions need to be made.

The Medical Directive allows you to record your wishes regarding various types of medical treatment in several representative situations so that your desires can be respected. It also lets you appoint someone to make medical decisions for you if you should become unable to make them on your own.

The Medical Directive comes into effect only if you become incompetent (unable to make decisions or to express your wishes), and you can change it at any time until then. As long as you are competent, you should discuss your care directly with your physician.

Completing the Form. You should, if possible, complete the form in the context of a discussion with your physician. Ideally, this should occur in the presence of your proxy. This lets your physician and your proxy know how you think about these decisions, and it provides you and your physician with the opportunity to give or clarify relevant personal or medical information. You may wish to discuss the issues with your family, friends, or religious mentor.

The Medical Directive contains six illness situations that include incompetence. For each one, you consider possible interventions and goals of medical care. Situations A and B involve coma; C and D, dementia; E, chronic disability; E and F, temporary inability to make decisions.

The interventions are divided into six groups: 1) cardiopulmonary resuscitation or major surgery; 2) mechanical breathing or dialysis; 3) blood transfusions or blood products; 4) artificial nutrition and hydration; 5) simple diagnostic tests or antibiotics; and 6) pain medications, even if they dull consciousness and indirectly shorten life. Most of these treatments are described briefly. If you have further questions, consult your physician.

Your wishes for treatment options (I want this treatment; I want this treatment tried, but stopped if there is no clear improvement; I am undecided; I do not want this treatment) should be indicated. If you choose a trial of treatment, you should understand that this indicates you want the treatment *withdrawn* if your physician and proxy believe you would have agreed that it has become futile.

The Personal Statement section allows you to mention anything that you consider important

to tell those who may make decisions for you concerning the limits of your life and the goals of intervention. For example, your description of insufferable disability in the Personal Statement will aid your health-care team in understanding exactly when to avoid interventions you may have declined in situation E. Or if, in situation B, you wish to define "uncertain chance" with numerical probability, you may do so here.

Next you may express your preferences concerning organ donation. Do you wish to donate your body or some or all of your organs after your death? If so, for what purpose(s) and to which physician or institution? If not, this should also be indicated in the appropriate box.

In the final section you may designate one or more proxy decision-makers, who would be asked to make choices under circumstances in which your wishes are unclear. You can indicate whether the decisions of the proxy should override, or be overridden by, your wishes if there are differences. And, should you name more than one proxy, you can state who is to have the final say if there is disagreement. Your proxy must understand that this role usually involves making judgments that you would have made for yourself, had you been able — and making them by the criteria you have outlined. Proxy decisions should ideally be made in discussion with your family, friends, and physician.

What to Do with the Form. Once you have completed the form, you and two adult witnesses (other than your proxy) who have no interest in your estate need to sign and date it.

Many states have legislation covering documents of this sort. To determine the laws in your state, you should call the office of its attorney general or consult a lawyer. If your state has a statutory document, you may wish to use the Medical Directive and append it to this form.

You should give a copy of the completed document to your physician. His or her signature is desirable but not mandatory. The Directive should be placed in your medical records and flagged so that anyone who might be involved in your care can be aware of its presence. Your proxy, a family member, and/or a friend should also have a copy. In addition, you may want to carry a wallet card noting that you have such a document and where it can be found.

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An earlier version of this form was originally published as part of an article by Linda L. Emanuel and Ezekiel J. Emanuel, "The Medical Directive: A New Comprehensive Advance Care Document," *Journal of the American Medical Association* 261:3288-3293, June 9, 1989. It does not reflect the official policy of the American Medical Association.

MY MEDICAL DIRECTIVE

This Medical Directive expresses, and shall stand for, my wishes regarding medical treatments in the event that illness should make me unable to communicate them directly. I make this Directive, being 18 years or more of age, of sound mind, and appreciating the consequences of my decisions.

1. Cardiopulmonary resuscitation

(chest compressions, drugs, electric shocks, and artificial breathing aimed at reviving a person who is on the point of dying), **or major surgery** (for example, removing the gall bladder or part of the colon)

2. Mechanical breathing (respiration by machine, through a tube in the throat), **or dialysis** (cleaning the blood by machine or by fluid passed through the belly)

3. Blood transfusions or blood products

4. Artificial nutrition and hydration (given through a tube in a vein or in the stomach)

5. Simple diagnostic tests (for example, blood tests or x-rays), **or antibiotics** (drugs to fight infection)

6. Pain medications, even if they dull consciousness and indirectly shorten my life

THE GOAL OF MEDICAL CARE SHOULD BE (*check one*):

SITUATION A

If I am in a coma or a persistent vegetative state and, in the opinion of my physician and two consultants, have no known hope of regaining awareness and higher mental functions no matter what is done, then my wishes — if medically reasonable — for this and any additional illness would be:

I want	I want treatment tried. If no clear improvement, stop.	I am undecided	I do not want
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		

___ prolong life; treat everything

___ choose quality of life over longevity

___ provide comfort care only

___ other (*please specify*): _____

SITUATION B

If I am in a coma and, in the opinion of my physician and two consultants, have a small but uncertain chance of regaining higher mental functions, a somewhat greater chance of surviving with permanent brain damage, and a much greater chance of not recovering at all, then my wishes — if medically reasonable — for this and any additional illness would be:

I want	I want treatment tried. If no clear improvement, stop.	I am undecided	I do not want
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		

- ☐ prolong life; treat everything
☐ attempt to cure, but reevaluate often
☐ choose quality of life over longevity
☐ provide comfort care only
☐ other (please specify): _____

SITUATION C

If I have brain damage or some brain disease that in the opinion of my physician and two consultants cannot be reversed and that makes me unable to recognize people, to speak meaningfully to them, or to live independently, *and I also have a terminal illness*, then my wishes — if medically reasonable — for this and any additional illness would be:

I want	I want treatment tried. If no clear improvement, stop.	I am undecided	I do not want
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		

- ☐ prolong life; treat everything
☐ attempt to cure, but reevaluate often
☐ choose quality of life over longevity
☐ provide comfort care only
☐ other (please specify): _____

SITUATION D

If I have brain damage or some brain disease that in the opinion of my physician and two consultants cannot be reversed and that makes me unable to recognize people, to speak meaningfully to them, or to live independently, *but I have no terminal illness*, then my wishes — if medically reasonable — for this and any additional illness would be:

I want	I want treatment tried. If no clear improvement, stop.	I am undecided	I do not want
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		

___ prolong life; treat everything
 ___ attempt to cure, but reevaluate often
 ___ choose quality of life over longevity
 ___ provide comfort care only
 ___ other (please specify): _____

SITUATION E

If, in the opinion of my physician and two consultants, I have an incurable chronic illness that involves mental disability or physical suffering and ultimately causes death, and in addition I have an illness that is immediately life threatening but reversible, and I am temporarily unable to make decisions, then my wishes — if medically reasonable — would be:

I want	I want treatment tried. If no clear improvement, stop.	I am undecided	I do not want
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		

___ prolong life; treat everything
 ___ attempt to cure, but reevaluate often
 ___ choose quality of life over longevity
 ___ provide comfort care only
 ___ other (please specify): _____

SITUATION F

If I am in my current state of health
(describe briefly): _____

_____ and then have an illness that, in the opinion of my physician and two consultants, is life threatening but reversible, and I am temporarily unable to make decisions, then my wishes — if medically reasonable — would be:

I want	I want treatment tried. If no clear improvement, stop.	I am undecided	I do not want
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		

- ___ prolong life; treat everything
 ___ attempt to cure, but reevaluate often
 ___ choose quality of life over longevity
 ___ provide comfort care only
 ___ other (please specify): _____

Copyright 1990 by Linda L. Emanuel and Ezekiel J. Emanuel. The authors of this form advise that it should be completed pursuant to a discussion between the principal and his or her physician, so that the principal can be adequately informed of any pertinent medical information, and so that the physician can be appraised of the intentions of the principal and the existence of such a document which may be made part of the principal's medical records.

This form was originally published as part of an article by Linda L. Emanuel and Ezekiel J. Emanuel, "The Medical Directive: A New Comprehensive Advance Care Document" in *Journal of the American Medical Association* June 9, 1989; 261:3290. It does not reflect the official policy of the American Medical Association.

Copies of this form may be obtained from the Harvard Medical School Health Publications Group, P.O. Box 380, Boston, MA 02117 at 2 copies for \$5 or 5 copies for \$10; bulk orders also available.

MY PERSONAL STATEMENT

(use another page if necessary)

Please mention anything that would be important for your physician and your proxy to know. In particular, try to answer the following questions: 1) What medical conditions, if any, would make living so unpleasant that you would want life-sustaining treatment *withheld*? (Intractable pain? Irreversible mental damage? Inability to share love? Dependence on others? Another condition you would regard as intolerable?) 2) Under what medical circumstances would you want to *stop* interventions that might already have been started?

Should there be any difference between my preferences detailed in the illness situations and those understood from my goals or from my personal statement, I wish my treatment selections / my goals / my personal statement (*please delete as appropriate*) to be given greater weight.

When I am dying, I would like — if my proxy and my health-care team think it is reasonable — to be cared for:

- ☐ at home or in a hospice
- ☐ in a nursing home
- ☐ in a hospital
- ☐ other (*please specify*): _____

ORGAN DONATION

(please check boxes and fill in blanks where appropriate)

__ I hereby make this anatomical gift, to take effect after my death:

- I give ☐ my body
- ☐ any needed organs or parts
- ☐ the following parts: _____
- to ☐ the following person or institution: _____
- ☐ the physician in attendance at my death
- ☐ the hospital in which I die
- ☐ the following physician, hospital storage bank, or other medical institution: _____
- for ☐ any purpose authorized by law
- ☐ therapy of another person
- ☐ medical education
- ☐ transplantation
- ☐ research

__ I do not wish to make any anatomical gift from my body.

DURABLE POWER OF ATTORNEY FOR HEALTH CARE

I appoint as my proxy decision-maker(s):

Name and Address

and (optional)

Name and Address

I direct my proxy to make health-care decisions based on his/her assessment of my personal wishes. If my personal desires are unknown, my proxy is to make health-care decisions based on his/her best guess as to my wishes. My proxy shall have the authority to make all health-care decisions for me, including decisions about life-sustaining treatment, if I am unable to make them myself. My proxy's authority becomes effective if my attending physician determines in writing that I lack the capacity to make or to communicate health-care decisions. My proxy is then to have the same authority to make health-care decisions as I would if I had the capacity to make them, EXCEPT (*list the limitations, if any, you wish to place on your proxy's authority*):

Should there be any disagreement between the wishes I have indicated in this document and the decisions favored by my above-named proxy, I wish my proxy to have authority over my written statements / I wish my written statements to bind my proxy. (*Please delete as necessary.*) If I have appointed more than one proxy and there is disagreement between their wishes, _____ shall have final authority.

Signed:

Signature

Printed Name

Address

Date

Witness:

Signature

Printed Name

Address

Date

Witness:

Signature

Printed Name

Address

Date

Physician (optional):

I am _____'s physician. I have seen this advance care document and have had an opportunity to discuss his/her preferences regarding medical interventions at the end of life. If _____ becomes incompetent, I understand that it is my duty to interpret and implement the preferences contained in this document in order to fulfill his/her wishes.

Signature

Printed Name

Address

Date

Work Sheet No. 1: Medication Summary

For: _____ Date: _____
(page ____ of ____)

[illegible]

(page 2 of 2)

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Work Sheet No. 3: Legal, Business and Financial Contacts

Category	Last Name	First Name	Phone	Address	City	St	Zip	Remarks/Pol #
Attorney								
Accountant								
Investment Advisor								
Stock Broker								
Guardians:								
1								
2								
Life Insurance								
1								
2								
3								
4								
Medical Insurance								
1								
2								
3								
Home/Rental Insurance								
Auto Insurance								
Banks:								
1								
2								
3								
4								

(page 2 of 2)

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Work Sheet No. 4: Important Documents Summary

(page 1 of 2)

Item	Description	Where located?	Remarks
	Durable Power of Attorneys		
	Living Will / Medical Directive		
	Will / Living Trust		
	Codicil to Will		
	Trust		
	Memorandum to Executor		
	Birth Certificates		
	Letter of Instructions		
	Personal Notes		
	Insurance Policies		
1			
2			
3			
	Stocks		
1			
2			
3			
	Bonds		
1			
2			
3			
	Titles		
1			
2			
3			
4			

(page 2 of 2)

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(page ____ of ____)

Date: _____

Last wishes of: _____

Caution—This is not binding on your executor of estate

[illegible]

Work Sheet No. 6: Assets and Liabilities Summary

(page 1 of 2)

Item	Description	Where located?	Remarks
Liquid Assets:			
Bank Accounts			
1			
2			
3			
4			
5			
Safe Deposit Box			
1			
2			
Cash			
Stocks			
Bonds			
Fixed Assets:			
Property			
1			
2			
3			
Business			
1			
2			
3			
Other Assets			
1			
2			

[illegible]

(page ___ of ___)

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(page 2 of 2)

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[illegible]