

REFLECTIONS



A Guide to End of Life Issues
for You and Your Family

BY

Roger C. Bone, M.D.

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This book would not be possible without the inspiration and support of my wife and family, my colleagues, and my patients.

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Roger C. Bone, M.D., Ph.D. (hon), MACP, MACCP

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This book is dedicated to
my wife, Rosemary,
our daughter Mary Katherine and her husband Ron,
and our daughter Cynthia and her husband Todd.

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I N T R O D U C T I O N



“You and I Are Dying”

Dying is a biological fact. To many it is a religious symbol.

Dying is something we all do. But it is also something we only observe in others at a distance.

Dying can be a peaceful event or a great agony when it is inappropriately sustained by life support.

Dying is a subject in great novels and small poems.

Emily Dickinson wrote:

*Because I could not stop for Death—
He kindly stopped for me—
The Carriage held but just Ourselves—
And Immortality.*

I am a physician and I am dying of metastasis of renal carcinoma. As I write these words, I understand I may live a week, a month, a year—perhaps two. If I beat all the odds, I may live five years.

I have spent the majority of my adult life as a clinician, author, researcher, and professor. As a result, I have felt a strong impulse to write about the mental, spiritual, and practical aspects of the dying process. The *Journal of the American Medical Association* has published some of my thoughts in a series of personal commentaries entitled “The Taste of Lemonade on a Summer Afternoon,” “Another Taste of Lemonade,” “Lemonade—The Last Refreshing Taste,” and “Maumee: My Walden Pond.” In addition, I have investigated the topic of dying in great works of literature. My findings were detailed in “As I Was Dying: An Examination of Classic Literature and Dying” in the *Annals of Internal Medicine*, a professional medical journal.

Of course, dying is not a new subject at all. It is one of the oldest subjects known to humanity and certainly the first and greatest mystery of our existence. It is a topic familiar to almost every person. Though we seldom speak openly of dying, we all have been touched by death. A child’s grandmother dies when he is seven. A teenager’s best friend dies in an auto accident. A young woman’s favorite uncle dies of a heart attack. A colleague at work commits suicide.

Any death makes us sit up and take notice. A favorite movie actor dies of AIDS. A country’s president is assassinated. Some of us take a moment every day to scan the obituaries in the local newspaper for a

familiar name. At times death comes closer and we find we have certain social responsibilities. We must attend a funeral or cook a casserole for a wake.

Sometimes death strikes close to home and things get very, very personal.

We all think about our own death—or at least try *not* to think about it. In reality, few people actually spend much time under a death sentence. Most are unaware of their own deaths or only conscious of their fate for a short period. Individuals suffer from mortal heart attacks or strokes everyday. We often hear of tragic and sudden accidents where someone is perfectly healthy one minute and gone the next. Patients with a chronic or curable disease may experience medical complications and die for unknown reasons. Or, Alzheimer's victims who lose their mind and reason may not care that they are slowly slipping away from the world.

Yet, there are still many of us who know death is irresistibly approaching. In some ways, death is an intriguing topic. There was the mythic king who was so fascinated by death he ordered his own beheading and dictated that no one could save him. How would loyal subjects react to such a command? Obey their king and lose him or disobey his commandment and risk treason? A more important question is whether or not the king found what he was looking for.

I observed death every day for more than twenty-five years in a series of operating rooms and intensive care units, including a surgical field hospital in Vietnam. As a pulmonologist and critical care physician, I often was the patient's last ally in his or her stand against death. For many, many people, I was the last person they saw.

It occurred to me once: who will be the last person or persons I will see? I hope it will be my wife and my two daughters. That is a very personal and private goal. However, I have discovered that dying is not necessarily a private business. The nineteenth-century sounding phrase, "Setting one's affairs in order," is still full of meaning today.

This small book is intended for terminally ill individuals who are not going to be surprised by death. It is also a book we can share with family and friends who will survive us. Hopefully, these pages will help everyone understand what a dying patient experiences so they can both deal with the practical matters surrounding death comfortably. It is for all of us to make one last effort together with grace, humor, dignity, and courage.

CHAPTER ONE



“Getting a Grip”

The English historian Arnold Toynbee wrote: “Ideally, every human being ought to live each passing moment of his life as if the next moment were going to be his last. He ought to be able to live in the constant expectation of immediate death and to live like this, not morbidly, but serenely.” The inevitability of our own death is with us from a very young age. However, most individuals usually ignore or repress this knowledge. Going about life’s work takes a tremendous amount of effort and standing around contemplating our mortality will not help pay the bills, rake the leaves, or lower our golf score.

I realized I was going to die on a beautiful October day in a medium-size Midwestern town. Although I am a member of the medical community, I learned of my prognosis like any other patient. My physician “got the x-rays back” and there was “bad news.”

My “bad news” actually began twenty-two months earlier when an accidental fall in my home at Christmas led to the discovery that I had renal cancer. An operation for the removal of my right kidney, which contained an encapsulated tumor larger than an orange, was completely successful. I was discharged from the hospital after a week and returned to my position as President and Chief Executive Officer of the Medical College of Ohio four days later.

Nevertheless, my experience had changed me. I became more appreciative and reflective of the world around me. I shared my revelations during a speech at the Fall Convocation for incoming medical students. I advised them to balance the scientific with the humanistic. Students, like many of us, are caught up in the pressures of daily life and do not take time to savor the present much less contemplate death. I urged them to maintain close relationships with family and friends, to enjoy a Beethoven symphony, to read a good novel, and to take pleasure in a fine dinner.

But, on this October day, I learned from my physician that I had metastasis to both lungs and a positive bone scan. As a clinician and cancer survivor, I was always aware of this possibility; however, the reality was not easy to accept. There is denial, anger, and a sense of great loss.

I had to realize the observations I made to the students were still true:

1. Good health is often taken for granted; however, it is the most precious commodity one possesses.
2. One’s spouse, children, family, and friends are the essential ingredients that allow one to endure a serious and unexpected illness.
3. When faced with death, one realizes the importance of God and one’s relationship with God.
4. The things one does through one’s life that seems so urgent are, most of the time, not so important.

The day my metastasis was confirmed was, of course, very traumatic. The initial shock created anxiety and caused a flurry of activity among my business

associates and office employees. What should they do?! What needed to be done and when?! Finally, I politely called a halt to all activity for the day. I told them I wanted to go home so I could simply sit and look at the river and spend time with my family.

Which is what I did.

Our house sits on a rather steep bluff and the Maumee River curves around a wide bend below us. The yard slopes gently to the edge of the bluff then descends through wildflowers and bushes to the banks of the river. Birds, squirrels and chipmunks populate this slope of land. On a quiet day, you can hear the rustling of the animals in the grasses. Occasionally, there will be a bird's song.

It was a perfect October day—the weather was sunny, the temperature measured 70 degrees, and a gentle breeze was in the air. The trees on both sides of the river were mostly green with only a hint of autumn reds and yellows. The river sparkled when stirred by the wind, and its course flowed in such a way that the sun seemed to set exactly on the water. It gave the appearance of a great fire being extinguished by the cool water.

I sat on a lawn chair and laid my suit coat and tie on the green grass beside me. At that moment, time stopped. My life--past, present, and future--was compressed into that second of time.

Time slipped past again and I looked up and saw my wife, Rosemary, standing next to my chair with a glass of lemonade for me; our daughter had just made a pitcher. I tasted the sweetness of the drink. The wind suddenly stirred the grass. A bird chirped. A small boat appeared far off in the river and became clearer as it made its way upstream.

I took Rosemary's hand and we stayed there a moment longer looking at the world passing before us.

Life has been good to me.

The American writers Thornton Wilder and Henry David Thoreau observed that most men and women lead frantic and desperate lives, seldom pausing to reflect on their activities. I am happy the initial diagnosis of renal cancer made me think anew about life and, therefore, consider the contemplative philosophies of both Wilder and Thoreau. One activity that has brought me peace is spending quiet time alone surrounded by nature similar to, I imagine, Thoreau contemplating Walden Pond.

Thoreau went to Walden Pond to search for his soul. There, in communion with nature, he found serenity and obtained fulfillment. He recognized and recorded for us a state of being in which one can come closest to the unity between nature and creation.

Thornton Wilder, nearly a hundred years later in his play, *Our Town*, emphasized the idea that most of us are blind to the everyday wonders of the world. The theme of his play is simple: life is short; be certain to take time to smell the roses. He pointed out that death can come quickly and without warning. When the terms of our existence are considered in this manner, the seemingly trivial things do appear more important. One moment you are young and married and the next thing you know the white-haired lady by your side is seventy and has eaten 50,000 meals with you.

However, my family and I had to get about the business of dying. There was no getting around it or avoiding it. Loved ones will be the first to provide you, the dying patient, with the most comfort. I have listed some issues you need to keep in mind when you first learn of your prognosis:

1. One or two family members will make enormous personal sacrifices to help you. Of course, a spouse will almost always accept an inordinate amount of responsibility. Do not be surprised if a daughter, a brother-in-law, or a cousin from Memphis suddenly steps forward and offers assistance. Be grateful and accept their support graciously .

2. Some family members, but especially friends, will perceive you differently. Even before you manifest outward signs of serious illness, they will behave awkwardly around you. You might consider this a patronizing attitude. It is best to ignore this change and treat them the same as you have in the past. They will come around to their normal selves when they recover from the shock.

3. Happily accept all gifts from family and friends. It makes them feel better and you might receive something you like and appreciate.

4. Don't be afraid to ask for time alone like I did when I sat gazing out over the river. We all need time to be with ourselves. Some individuals, however, become inspired and driven to fill their every waking moment as if they are trying to cram a lifetime into a few weeks or months. The frenetic pace is enjoyable at times, but only within reason. Peace and quiet can be just as gratifying and require less energy. You must remember to maintain your health by balancing social and business commitments

5. Be your own counsel. None of us are 100% right—including our physician, our minister or other spiritual guide, our spouse, our family, our friends. It surprised me to discover that some people wanted to, in effect, “bully” me into making certain decisions once they learned I was terminally ill. This impulse may come from someone's own fear of dying. It is a response the patient must be alert to in order to diffuse the situation. A strong personality saying *do this* or *don't do that* can be hard to resist. What is important is to keep your own counsel. Consider alternatives. Ask others for advice. Make some telephone calls. Read some books.

6. Finally, slow down and ask your family and friends to slow down. There may not be *a lot of time*, but there is still a sufficient amount of it, in all but the most extreme cases, to think, plan, and prepare.

More than thirty years ago, Dr. Elizabeth Kübler-Ross wrote an enormously influential book in which she categorized the psychological changes terminally ill patients go through as they progress toward death. In *On Death and Dying*, Dr. Kübler-Ross delineates five stages: 1) Denial and Isolation, 2) Anger, 3) Bargaining, 4) Depression, and 5) Acceptance.

After the book's publication, this model helped family, friends, and caregivers better understand the mental states of terminally ill patients. Pediatric oncologists, ICU nurses, gerontologists, and other members of the medical community also gained important insights into the dying process. As a result, the hospice movement gained momentum and viability.

However, the “stages” theory has come under extensive criticism in the past decade. There have been an increasing number of claims that Dr. Kübler-Ross’s paradigm is too neat and all-inclusive. A notable example is Dr. Sherwin B. Nuland’s bestseller, *How We Die: Reflections on Life’s Final Chapter*. Some patients, he asserts, never progress beyond denial. He writes, “The clamor of [the patient’s] wish to live drowned out the pleadings of his wish to know.”

Nevertheless, patients and their families can benefit from Dr. Kübler-Ross’s discovery. There is value in having a “road map” for any trip and, as is usually the case, the final destination need not be arrived at by only one route.

The “trip” or “journey” metaphor for dying is as old as mankind. Greek mythology, for instance, depicted death as a dangerous voyage into the Hades underworld via the river Styx. The ancient Egyptians mummified the deceased and surrounded him with servants and material possessions, often including boats to aid him in his voyage to the afterlife. In Christianity, we speak of “going” to either heaven or hell. Wherever one believes he or she may end up, dying can be compared to a journey taken alone or in a crowd. It is similar to riding on a subway car during rush hour when, suddenly, everyone gets off except you.

One shocking irony about finding out you are terminally ill is that you may feel pretty healthy at the time. Although the initial diagnosis of renal cancer made me realize I was living on borrowed time, I can honestly say I was feeling as well as I have ever felt in my life when my physician told me I had metastasis of renal carcinoma. Unfortunately, as a critical care physician, I knew my good health would not last long and any treatment regimen I chose would be debilitating.

After the diagnosis, Rosemary and I traveled to a place that had been a favorite of ours in the past. The trip lasted only a week, but it was exhausting for us to get there and back. Yet, that vacation is now a special memory for us and we are grateful that we were able to go while there was still time.

Every terminally ill patient should make an attempt to do something personal and meaningful while he can. An around-the-world cruise may be out of the question. However, a visit to a favorite vacation spot, a childhood home, or, perhaps, to an old friend you have not seen in years may be feasible. These seem like such a natural and reasonable things to do. Yet, terminal patients suddenly have so many demands on themselves that such an excursion often never happens. A son or daughter who lives far away may want to come home for a couple of weeks. Or, you have treatment options, legal issues, or business demands to contend with first. Nevertheless, time away while one is still physically capable is tremendously valuable for peace of mind.

Business commitments are business commitments and require special consideration. I would like to define “business” very broadly here as any daily routine where there are continuing demands and expectations. I work as a physician and an academic administrator. In addition, I have numerous professional responsibilities, many of them related to my editorial roles on medical journals. Similarly, many terminally ill patients, young and old, create works of art, deliver newspapers, care for children, keep house, and participate in volunteer projects.

In all of these situations, there are two important factors that must be considered. First, there is the job itself that sooner or later must be done by someone else. A transition plan must be put in place. Secondly, employers and coworkers who only know you through work are usually not members of the private circle that consists of your physician, family, and friends. While they are no doubt sympathetic, their priorities may be dramatically different. You should not get upset because the position must be filled and the work completed by someone else.

The initial strategy the terminally ill patient must use in regard to work is honesty. There is no use covering up your condition for any longer than a few days at the most. Being honest is only fair to your employer, and there are practical issues to consider, such as the number of vacation and sick days you are entitled to, insurance benefits, and stock options.

I enjoy my work and find most of the tasks involved mentally gratifying. I would miss it if I suddenly retired or was forced to resign. As long as I am not impaired by either my illness or my choice of treatment, there is no reason why I should not continue pursuing my career interests.

Nevertheless, any occupation can become a difficult proposition for the person who suddenly has other important things on his or her mind. Seeking the advice of a trusted colleague or confidant at work may be a useful tactic. Use that person's judgment to determine your role and continuing viability in the organization. His or her advice may allow you to avoid any embarrassing confrontations.

It is important, however, for you to bring your career to a pleasant and satisfying conclusion. You may want to complete a special project or simply work until the end of the month. Whatever your goal, coming to closure at work is crucial for both yourself and your organization.

When my daughters were in college, the end of the academic year in the spring was always chaotic. Many parents know there are few events more hectic in life than moving their kids into or out of a dormitory room. Formal packing is seldom accomplished; there seems to be an endless number of laundry baskets of dirty clothes. Stereo speakers and tennis racquets are crammed into car trunks. There are frantic and tearful good-byes to both boyfriends and girlfriends.

Finding out the "bad news" from the "x-ray reports" is not quite the same scenario. However, there is a similar personal chaos and you suddenly feel that your life is like a car stuffed with loose ends and unpacked clothing. Like a college kid let loose for summer vacation, you may not know what is ahead but you know that the car is running and that you will soon be on your way.

The best advice is to take a deep breath, organize your thoughts, and put the car in gear.

CHAPTER TWO



“Cancer Pain”

Approximately 50-80% of patients in the advanced stages of cancer experience major pain; however, recent findings indicate that more than 40% of such patients receive inadequate relief. Pain affects people differently depending on such factors as age, gender, and personality type. The most common causes of pain are metastatic bone disease, nerve compression or infiltration, or obstruction of organs such as the intestines. All of the major treatment modalities may also contribute to your pain as well as any pre-existing conditions that are not directly associated with cancer. Through simple pharmacological prescriptions or nonpharmacological procedures, this pain can be managed 90% of the time for the eight million Americans who have cancer or a history of cancer.

However, the pain associated with cancer is often undertreated, and the majority of severely ill patients fear they will die in great agony. This undertreatment is largely the result of society's perception of addiction. Clinicians and patients often link drug use to drug abuse and erroneously believe cancer patients may turn into addicts. While drug use in our country is a serious and important issue, regulation of prescription medication has had an unfortunate impact on patients who are in severe pain.

When pain medication is prescribed and taken the right way, cancer patients do not become addicted. There is an impressive amount of data that confirm proper pain management as effective and non-addictive. Any patient who needs pain medications for a short time can easily discontinue them once the source of the pain is removed. Physicians can gradually reduce the dosage until the body has time to adjust to the change. Pain medication taken regularly for chronic pain can also be administered without fear of addiction.

If you are experiencing pain at any level, you should ask your physician for relief. You should not try to “tough it out.” Severe pain is easier to control when treatment begins while the pain is less severe. If one pain relief program doesn't seem to work, then ask your physician for another type of pain program. Patients react differently to different medications.

The National Cancer Institute and National Institutes of Health recommend that you ask the following questions when speaking with your physician about pain management:

What medications can you prescribe to relieve my pain?

How long should I take the medicine(s) and when?

Are there side effects?

Should I try alternative procedures to alleviate my pain?

Your physician will also have a better idea of how to treat the pain if you let him or her know where it hurts, how strong the pain feels, what makes the pain increase, what eases the pain, and how much your current medications help you. A variety of pain assessment tools have been developed, which include simple self-reports about pain intensity and specific descriptive information. Your physician

may also conduct a detailed history, a physical examination, a psychosocial assessment, and a diagnostic evaluation. It has also been suggested that a patient use a “pain diary” to record the characteristics of his or her pain and the effectiveness of treatment protocols. Effective pain management is commonly achieved by a “team approach” involving patients, their families, and health care providers.

Keep in mind that continual assessment of your pain is vital. A few people have side-effects, such as dizziness or feeling confused when they take pain medication. In this case, changing the dosage of your prescription or choosing an alternative medication can solve the problem. You may feel sleepy when you first take some pain medicines, but this response usually subsides within a few days. Persistent pain or development of pain in a new area may call for a modification in the diagnosis and/or treatment plan.

Elderly patients require special consideration. Like other individuals who experience cancer pain, they require aggressive drug therapy. However, aging patients are at an increased risk for drug reactions because they may have multiple chronic disease and sources of pain that are not directly associated with cancer. They may also have visual, hearing, motor, and cognitive impairment that may impede certain pain assessment instruments. Older patients are more likely to be sensitive to the analgesic effects of pain medication for a longer period of time. Consequently, physicians should use simpler pain management tools and maintain frequent direct contact with their elderly cancer patients.

Drug therapy is effective, low risk, often inexpensive, and usually works quickly. However, alternative methods can be used in addition to medication. The purpose of behavioral modification techniques is to alter a patient's perception by shifting his or her attention to something other than the pain. They are not to be considered a substitute to prescribed medication; rather, they are intended to help the patient relax. The goal of pain management is to provide pain relief as well as improve the patient's quality of life. You can work productively, spend time with your family, enjoy recreation, and function normally in society if you take an active role in your care.

Cognitive-behavioral methods give the patient a sense of control and help him or her develop coping skills to manage the pain. However, alternative pain management techniques are more likely to succeed if they are introduced early in the course of the illness. Family members can assist you by obtaining the proper information and encouraging you to try several different strategies. Simple relaxation techniques can be used during episodes of brief pain or anxiety. Focusing your attention on something other than the pain, including counting, praying, listening to music, talking to a friend, or repeating statements such as “I can cope,” can help you replace negative thoughts with more positive images or activities.

I want to encourage you to remain as active as possible while you still have the strength and energy to do so. I am not talking about intense exercise or difficult aerobic activity. Generalized weakness and aches and pains associated with cancer and its treatment can be improved by physical interventions other than medication. Low-impact exercise will help mobilize stiff joints and restore

coordination and balance. For example, ambulatory patients can simply walk around the block with help of a friend or loved one. This activity will get you out of the house and strengthen your muscles. Physical therapists and caregivers can help the functionally limited patient with range-of-motion exercises to restore muscle strength. Other physical interventions include acupuncture, massage and vibration therapy, and immobilization (e.g. using braces to help maintain correct body alignment).

The patient also needs to distinguish physical pain from mental anguish. Psychological problems, which are also addressed in Chapter Six, are often experienced by a cancer patient as his or her disease progresses. The relationship between poor pain management, depression, and suicidal thoughts should not be ignored. Anxiety, fear, and depression are common reactions and can be relieved by psychotropic medication and therapy. Also, patients often feel more self-assured by participating in support groups. You can ask your physician, nurse, religious guide, or other health care professional for information about services available in your area. Your “team,” which includes family members, friends, and health care providers, may also want to participate in these sessions to discuss your needs and treatment.

In a small number of cases, the above mentioned behavioral, physical, and drug treatments do not alleviate pain and invasive therapies need to be used. Your physician will recommend various procedures that can be used in addition to pain medication and nonpharmacological methods. For example, radiation therapy is aimed directly at the cause of the pain to reduce primary and metastatic tumors, and surgery to remove a tumor has the potential to reduce pain or relieve tumor compression. These methods decrease the tumor mass and are conducted for palliative purposes only. For chronic, intense cancer pain, a neurosurgeon can apply a local anesthetic or neurolytic agent, such as a nerve block, that will provide local relief for a longer period of time. However, these methods should be considered only after drug and cognitive therapy are no longer effective. The risks and benefits of neurosurgical interventions should be discussed thoroughly with your physician and family.

In summary, effective and reliable pain management is something you should not be afraid to seek from your physician. The earlier you express your needs the easier it will be to control pain in its early stages. You can be confident that the proper use of drug therapy will help you enjoy daily activities, sleep easier, and experience a better quality of life.

CHAPTER THREE



“Critical Caring”

This chapter deals with the extremely complex relationship between the terminally ill patient and the medical community. On a personal level, dying is a simple and private matter. Unfortunately, this is not the case with contemporary America's medical community, which involves hospitals, ambulances, and hospices; primary care physicians and specialists; and diagnostic imaging centers and home health care organizations. In addition, there are insurance companies, which consist of everything from government programs such as Medicaid and Medicare to private Health Maintenance Organizations (HMOs). The terminally ill patient must navigate his or her way through this medical maze as well as possible. I assure you it will not be easy.

A friend of mine told me the story of a fifty-year-old wife and mother who was dying of breast cancer. Her highly educated, university-employed family decided to provide her with home health care and cautiously prepared for her death. They made it possible for friends to visit and say good-bye, which created a very peaceful situation. Everything was under control until the university's insurance company refused to pay an ambulance bill. It was not a lot of money, but the "unfairness" and "unsympathetic attitude" of the insurance company almost sent the family, including the patient, over the edge. The family did not return to an even keel until my friend advised them to simply return the bill to the university insurance office for reprocessing and to forget about it for six months.

Terminally ill patients and their families have too much to worry about to allow medical industry bureaucracy to interfere with the dying process. Yet, the medical establishment is absolutely necessary and can be a great help to everyone. It can also create unnecessary confusion and problems.

For example, a research study published in the *Journal of the American Medical Association* and widely reported in the popular press concluded that physicians and other health professionals are often ignorant of the wishes and directions of dying patients and their families. Fewer than half the physicians knew their patients did not want to be resuscitated. Do-not-resuscitate orders were written 46% of the time just two days prior to death instead of being well-planned in advance.

The study further noted that most physicians and caregivers do not communicate well with patients or their families about death. Doctors attempt futile and agonizing heroic survival efforts for terminally ill patients who would be better served by being made comfortable. Many physicians find themselves in conflict with their oath if they do not save the sick, even when such efforts are useless, expensive, and ultimately detrimental. The patient needs to sort out his or her desires and make them known and noted.

Medical students and residents who are faced with learning massive amounts of scientific and medical knowledge, which will double and triple before they even

go into practice, find it difficult and irrelevant from their point of view to take contemplative classes on ministering to the terminally ill or studying the ethics of dying. Sometimes these course are not even offered or, at best, sporadically taught in academic medical centers. In addition, pupils pick up the subliminal message from physicians, nurses, and other health professionals that it is easier to hide behind complicated high tech machinery or complex pharmacological compounds to keep patients alive instead of engaging in a straight-forward discussion on death and dying.

Of course, patients and their families often share the blame for not realistically confronting their own situation. Who would not want everything possible done to save a parent, spouse, or child? Plus, few people have the sophisticated medical knowledge needed to understand the complexity and effectiveness of what is currently being done or plans for future treatment.

In a sense, what both the medical profession and the patient need is someone to step in and make the right rational decision. In Shakespeare's play, *The Tempest*, the magician Prospero plays this role. At play's end, he sorts out all of the conflicts between the victims of the shipwreck and the island inhabitants. Unfortunately, not many Prosperos walk the hallways of today's hospitals.

Therefore, health care professionals, families, and terminally ill patients must struggle with many difficult medical decisions. Dr. Patrick Francis Sheehy in his book, *On Dying With Dignity*, describes the best outcome:

If the patient has been fortunate enough to have a physician who can be completely honest with him, the patient will begin to see he has a second option. This is to exercise the right to quit frantically seeking a miracle or cure and face the fact of his death.

Below are eight questions the dying individual and his or her family should ask the medical professionals. The questions deal with crucial topics that need to be proposed and resolved, but it is not required that they be delivered in any particular order.

1. What is my disease?

Patients are obligated to find out as much as possible about their own disease. You can do research at libraries or browse bookstores for information that will provide a basic overview of the terminology and progression of your disorder. There are also national organizations, lay experts, and local support groups that provide brochures, video tapes, and/or counseling in order to further understanding of terminal illness. Ignorance is not bliss in this regard and the more a patient and his or her family knows, the better able everyone will be to cope with what is happening.

2. Whom do I trust?

Search for a single individual you can trust to consolidate information and offer advice. This does not mean you should disregard all other health professionals and ignore reasonable directions and guidance. To avoid confusion, however, you need to focus on one person as the final arbitrator. He or she will

normally be the physician specialist in charge of the case or, possibly, a family practitioner who shares a close relationship with you. After you have made your decision, be certain to inform the individual you choose.

3. Should I seek a second opinion?

A corollary to point two above is to seek a second opinion. It will provide increased peace of mind and erase any doubt your physician has made an egregious error. More importantly, a second opinion also offers a slightly different perspective that may improve your understanding of your illness. Do not be embarrassed or afraid you will make your physician angry when you tell him or her you would like to speak with someone else. Second opinions are perfectly acceptable and not frowned upon by the medical community. In fact, your insurance company may insist on one. The original diagnosis is usually confirmed and patients are therefore more amenable to following prescribed treatment plans.

4. Why would I go into the hospital?

Below, I have listed four basic explanations for why a terminally ill patient is admitted to a medical institution. Keep in mind that not all of them may apply to you. In addition you may be hospitalized for more than one reason on different occasions.

1. Confirmation of the initial diagnosis and an analysis of where the patient stands in the disease process.
2. Treatment that requires hospitalization such as an operation.
3. A severe exacerbation or a progression in the disease that needs stabilization or special attention.
4. The final degenerative process of the disease that cannot be effectively handled at home or even in a hospice setting.

5. What are the hospital rules about terminally ill patients?

Few members of the general public know to ask this question; however, hospitals and medical centers have written regulations and procedures that outline in detail how the hospital will deal with terminally ill patients. These are not treatment rules in terms of medical prescriptions or “how to” do surgery. Instead, these protocols, as they are often called, deal with how to handle such unofficial acronyms as NEM (no extraordinary measures) or NRA (no resuscitation agreement). Not only are hospitals obligated, but they are also willing to share this information with you and your family.

One point you need to remember is that hospitals--except in extreme cases--do not label a patient as “TERMINALLY ILL.” There is no sign above the hospital bed and the words are not written in bold across the patient’s chart. A hospital is not a hospice, which is an organization that deals solely with people who are in the final stages of dying. (See Chapter Six for a more detailed discussion of hospices). A hospital, on the other hand, is a collection of individuals dedicated to saving and preserving life. This is why problems and misunderstandings concerning resuscitation orders and ICU stays may develop between the terminally ill patient and health care professionals. I have often observed families who are so overcome with grief and despair they assume everyone they come in

contact with from the orderly to the night nurse to the dietitian—and, of course, every physician who may stop by the patient's room—knows their loved one's entire history and current status. This is seldom true. Therefore, when appropriate, family members or patients themselves, should inform the staff about their particular situation. As a result, everyone involved can avoid awkward moments or intense arguments and the patient will be able to rest in a more comfortable atmosphere.

6. What resources are available from the medical community?

When hospitals as we know them today were first organized after the Civil War in the late nineteenth century, many were created as “doctors’ hospitals.” A group of physicians often joined together and converted an old mansion in order to shelter patients who were severely ill and could not be treated at home. Incidentally, home care was the preferred method of treatment throughout the history of early medicine. It was generally accepted that the doctor was the “outsider” who made house calls to the sick and frail.

During the social evolution of medical care in the twentieth century, these roles were reversed. The patient now, in effect, visits the doctor's house. Hospitals have subsequently become one of the most democratic and socially conscious institutions in the country. The poorest man in a city might very well share a room with the richest and they both, regardless of their ability to pay, receive identical care. Physicians treat all classes of individuals from a variety of social, demographic, and economic backgrounds. Over the years, hospitals have responded to this increase in demand by providing services that are not directly related to medical care. For example, health institutions commonly offer psychological, financial, and religious counseling, and physician referrals.

It is important for a terminally ill patient and his or her family to know what their particular medical institution offers in terms of special services, even if they are able to rely on their own private resources. A visit to a hospital financial counselor to inquire about insurance benefits and payment plans is a wise move. In the rush to admit a patient, information is sometimes left out or incorrectly recorded. A fifteen minute meeting may avoid later stress and anger over incorrect bills. A conversation with a social services coordinator may provide you with previously unknown information, such as government entitlement programs, home health care services, and area hospice locations.

7. What should we do if it seems like nothing is being done or, on the other hand, things are being done that we know nothing about and have no control over?

There is no question that hospitals can be the source of confusion and agitation during these trying times. You may feel very calm and seemingly in complete control when all of a sudden a group of individuals sweeps in and rushes you away because Dr. So and So (Who? I didn't catch the name!) has ordered a MRI right away. Unfortunately, these types of events are inevitably going to happen. Again, it is always important to go to the individual whom you have identified as your primary contact. Have him or her paged in the hospital or called

at home if the situation is truly upsetting. It is this person's obligation and responsibility to help. Most of the time he or she will know exactly what is happening and will be able to reassure you. If not, that person will be happy to investigate the situation as soon as possible.

8. How will my family and I pay for the hospital?

Monetary issues will be discussed in more detail in the next chapter. However, I will briefly discuss in this section the fiscal relationship between the terminally ill patient and the medical community. First, you should be aware that financial professionals in the health care field are experts in explaining complex billing procedures and private insurance or Medicaid/Medicare requirements. The labyrinth of hospital accounting departments can be more easily navigated with their assistance. If you are careful to correct errors and update pertinent information in a timely fashion, you and your family will be able to avoid any future hassles. Patients with even the best of insurance policies will most likely owe money on the remainder of their hospital balance. If the amount is significant, you may want to inquire about payment plans.

Often, *several different* physicians and medical organizations will send you a bill for their services. A hospital does not appear to be like a shopping mall where you stop in at different stores and expect to pay each time you buy something. However, it actually operates financially in a similar manner. For example, your family doctor, specialist, and radiologist may bill you separately. You may receive a request for payment from the hospital emergency room and/or the ambulance that carried you there. In addition, the television in your room and your medication will most likely appear as an additional cost on the invoice. This is because hospitals commonly contract these services and they are billed separately.

Above all else, it is important for you and your family not to panic. Hospitals and physicians usually do not want to be overly aggressive and often will not turn over outstanding bills to collection agencies until considerable time has passed. Check all bills thoroughly, ask questions when you do not understand something, and keep in touch with the appropriate financial professionals.

These eight questions will not answer all the problems a terminally ill patient and his or her family will encounter at the hospital. They also will not resolve any interpersonal conflicts with your primary caregiver.

However, America also offers the best medical care available in the world today. The most riveting book ever written about cancer, Alexander Solzhenitsyn's novel *Cancer Ward*, portrays a terminally ill individual in a Soviet hospital at mid-twentieth century. We have improved vastly over those primitive conditions. Yet, a patient and his or her family, who are understandably in severe distress, may not be able to appreciate a modern medical institution's efficiency, courtesy and helpfulness. That is perfectly understandable. Nevertheless, almost uniformly across America, hospitals are available to help terminally ill patients and their families. Interacting with medical organizations and health care professionals wisely will bring comfort and relief for those afflicted.

CHAPTER FOUR



“An Early Frost”

A terminally ill person does not need convincing that a will is a good idea. However, writing or updating a will may be one of the first psychological crises faced by you and your family. A patient in the early stages of the disease naturally holds out some hope for recovery, particularly if he or she is able to function normally and is relatively pain free. The family, as well, will be optimistic. As a result, considering the idea of devising a will may cause you to become discouraged and deeply depressed. It is as though everyone has suddenly given up or accepted your prognosis before the illness has naturally defined itself. It is understandable to put off decisions that in and of themselves feel “accepting” or in “anticipation” of death.

Monetary decisions, in general, deeply affect the terminally ill. Finances connote a cold and calculating image, which is often devoid of any emotion and can devastatingly reduce a long and complex life to a single column of black numbers on white paper. One hundred fifty years ago in Victorian England, Charles Dickens symbolized the vacuousness of financial affairs in his description of an inheritance lawsuit in the opening pages of *Bleak House*. “Jarndyce vs. Jarndyce” had existed so long in the courts that all the original participants, including the attorneys, had long since passed away as the case proceeded through the system. In other words, finances often take on their own bleak life and have a numbing effect on the human spirit.

Financial questions can also create great stress if the terminally ill person is the primary provider for his or her family. First, how will your spouse and/or children survive? Even if you own a substantial insurance policy, what are the long-term financial implications for the family? How far into debt will the illness drive them before the patient dies?

Perhaps the terminally ill person is also the family money manager. This personal job will have to be transferred in a similar manner to your work position, as I described earlier. The process can be tedious and time-consuming and, no doubt, will lead to discussions about past practices and future procedures. Your spouse, parents, or children may be unpleasantly surprised by the family’s pecuniary condition. The problems can range from total financial upheaval to not being able to find such items as past tax records, which can help determine the fiscal status of the family. Total communication with all parties involved in your estate is important. For example, what good is an insurance policy if other members of the family know nothing about it?

Deciding who will inherit your belongings is often at the heart of family disputes both prior to and long after your death. No family can be perfect or plan for every foreseeable crisis. You might think your estate is settled and your wishes recognized; however, one of your survivors may change his or her mind about what to keep from your past. For instance, it may be mutually decided that your daughter inherits the antique writing desk while your son will receive the beat-up

car you drove to work. No problem—until your daughter concludes, suddenly, that she wants the car instead. You may be beyond caring, but this unplanned dispute over the car can be a major inconvenience for the living.

Careful financial and estate planning can solve problems and arrange limited resources for maximum benefits. It can mean the difference between a loving resolution for the person who is ill and a prolonged grieving process confused with financial bitterness for the family. It is crucial that one must start early, seek help when appropriate, and make certain everyone who has a stake in what happens is informed. Not telling your nephew Charlie that he is the Executor of your estate until the day before you die is not prudent management.

It is beyond the scope of this book to provide a complete guide to the financial implications of dying. Individual circumstances will dictate what type of decisions need to be made and your viable options. However, what follows is a general guideline that may serve as a checklist.

The Will

A will is a statement concerning what should be done with your possessions and financial assets after you die. It need not be complicated or even drawn up by an attorney. However, it is usually advisable to involve one. If you feel you cannot afford a lawyer, lookup the number of your local legal aid society in the phonebook and call them. Depending on your income and personal assets, you may be able to have a will prepared for free or at minimal cost. Individuals with multiple investments or a complex family structure, such as a spouse from a previous marriage or multiple children, will require professional legal assistance.

It is crucial you complete the will before you become critically ill. Putting it off may lead to questions later concerning your mental status at the time of its preparation. Objections could surface retrospectively as soon as you begin medical treatment, especially if it involves potent drugs such as pain medication or chemotherapy.

A side benefit, and not an insubstantial one, is that the terminally ill patient will discover his or her assets and/or possessions in the process of gathering information for the will itself. One may uncover forgotten resources, such as insurance policies and designated beneficiaries. Organizing and accumulating the family's financial affairs will hopefully improve the patient's self-confidence as he or she faces the cost of medical treatment.

Power of Attorney

One mistake families and patients make is waiting to authorize a power of attorney. Keep in mind this decision should be made while you are in complete control of your mental faculties. If the designation of power of attorney is stalled until it becomes absolutely necessary, the legality of the transfer of authority could, in fact, become questionable.

The duties of the person who has been given power of attorney range from writing checks, authorizing bill payments, and overseeing estate expenditures from your trust to serving as the contact person for nursing services and other medical organizations. He or she will assume total responsibility for the financial

decision making after you have become impaired or incapacitated. Be open with friends and family members when considering your options. One can designate a spouse, a child, or a trusted friend to oversee these matters.

Terminally ill patients must contemplate, therefore, not only how they want their assets dispersed but also who will be the one to execute their financial goals. This person needs to be competent in addition to being able to work well with both you and your family. If you designate someone in whom you and your family have trust and confidence, you will also provide a great amount of relief for everyone involved.

Insurance

Everyone has insurance—even people who do not think they do. For example, spouses and children are entitled to survivor benefits from the government if the deceased paid Social Security taxes. Social Security payments may prove to be substantial over time, particularly for children. One should also consider alternative insurance sources. Veterans and current members of the armed forces, for example, are sometimes allowed compensation for funeral or burial costs. The Veterans Administration will also provide counseling, vocational rehabilitation, and a monthly stipend to veterans whose illness can be traced to their time in the military. As mentioned earlier, consulting your employment health policies may reveal accumulated benefits from a previous job.

Obviously, a terminally ill person is not a good insurance risk. You will most likely find it difficult to increase the monetary value of your policy. However, your insurance agent or representative should be able to advise you on your alternatives and expedite the necessary paperwork. An often overlooked aspect is what to do with the money when it arrives after your death. This is an appropriate concern for a terminally ill person who is worried about a spouse's standard of living or a child's college education. Enlisting the aid of a financial advisor and drawing up a plan to deal with not only the insurance money, but also savings and other liquid money assets is a wise move.

As your health insurance policy is considered an asset, you should investigate its terms and level of coverage. What rules and requirements does it dictate in regard to hospital stays, special or experimental treatments, diagnostic measures, and long term and/or at-home based care? Policies may make provisions for nursing services or other alternative health care services. Full knowledge of the restrictions of your health insurance coverage will allow you to avoid unpaid medical bills and disappointment. You may also discover something you did not know before, such as the availability of certain assistance programs like Medicare and Medicaid.

Donations and Memorials

A person need not be rich to establish some type of remembrance in his or her name. A financial legacy is a way of telling an institution or an organization it had special meaning for you. The two most common beneficiaries are religious organizations and educational institutions. If you are unable to afford a monetary contribution, it may be possible to plant a tree on your favorite golf course or

install a bench in a local park. In fact, anything is possible as long as people are informed ahead of time concerning your wishes.

Organizations, believe it or not, are sometimes wary of gifts, especially those that appear unannounced. Questions are always asked up front. Is the gift free and clear or are there unresolved state and tax implications? Does the gift have unreasonable or unacceptable conditions attached: one's oil portrait displayed at the church entryway or a scholarship limited to distributions to persons born during the first week of August? And, finally, will the gift cover the cost of what the person wants to do?

Again, a common theme throughout this chapter applies here: plan ahead. Setup a meeting early on with the organization or, at least, make a phone call. Most will have guidelines they will happily share with you. Also, inquire about their policy for memorial fund contributions from friends and family. If you adhere to their procedures, they will be more likely to follow your wishes.

Taxes

The old saying is there are two certainties in life—death and taxes. It may come as a surprise that someone is required to file an income tax return in your name on April 15th of the following year after your death. This return includes all applicable taxes. Forms can be dealt with routinely if there is a person designated to handle this responsibility. In addition, there may be tax implications involved in your will. You should discuss any questions with an income tax accountant or consultant.

Work Benefits

Individuals who learn they are terminally ill while they are still employed may face complex financial issues. There is the possibility you will be terminated, demoted, or reassigned to a different department. A confidential meeting with your human resources representative or personnel office may help to diffuse the situation. It is important to know whether your organization or firm provides the pertinent insurance, spousal benefits, and payment of accrued sick leave and/or vacation time. The American with Disabilities Act, passed by Congress in 1992, may protect your interests in this matter.

Responsible Dying

Finding out you are terminally ill is, without a doubt, something serious and intimate. At this point, you may be inclined to avoid or ignore impending financial issues; however, you must balance the seriousness of the illness with its implications. In turn, your friends and family may react in a similar manner. The biggest danger the terminally ill person faces is to be silent, to do nothing. You must find the courage to break the silence. Openly discuss practical matters, funeral arrangements, and personal concerns with your family. Helping them face these difficult issues now will help them handle the grieving process better after you are gone.

One caveat occurs to me here. A person must, despite responsible preparation for death, accept the condition that he or she cannot arrange

everything. In addition, the patient needs to recognize that family members will be presented with unexpected complications and intense sadness no matter how much planning is done in advance. Their lives will naturally change as they grow older and, in turn, so will their needs. Allowing for their independence is a necessary part of responsible dying.

Friends and family will take their cues from the person who is ill. Their loss will be handled in a more positive manner if you do not assume they inherently know your wishes. Since everyone tends to have unique personalities, loved ones may interpret your thoughts and actions differently. In addition, they will be required to continue their own personal and business lives while they try to comfort you. They will be facing a world of financial realities at a time when they are also experiencing emotional vulnerability. If the person who is dying reaches out to them and states his or her intentions, the confusion will be minimal and the distress manageable. In this way, the ill and dying extend a loving gift to those who will survive them.

Putting one's personal and financial affairs in order leads to increased peace of mind for the person who is dying. The worries about how the family will survive and how they will manage through the illness itself, can hopefully be resolved. It restores one's sense of control over significant matters and will benefit family members for a long time.

The Checklist

In summary, I have listed below a series of recommendations, or a checklist, for organizing one's financial affairs. These suggestions are in no way meant to be all-inclusive. Nor do they pertain only to the terminally ill. It is prudent for anyone to make arrangements for the care of his family after death.

The Will. Consult with an attorney. Discuss information in the will with involved members of the family.

Power of Attorney. Prepare in advance for the transfer of financial decision-making authority to someone who is qualified to act on your behalf in case you become incapable of handling those matters yourself. Again, it would be wise to speak with an attorney.

Insurance. Investigate available benefit packages and study your options. Make an appointment to talk with your insurance agent or representative. Also, fully consider the terms of your policy and explore other possible sources of health insurance coverage. You may be eligible for Medicare, Medicaid, and/or Veterans Administration services for the sick and disabled.

Donations and Memorials. If you want to establish a memorial or donate money to a particular organization or religious group, discuss your wishes with the persons in charge and closely follow their guidelines.

Taxes. Be advised that there will be tax schedules and payments due after you are deceased. You may wish to consult a tax accountant or consultant.

Work Benefits. Examine work-related benefits.

CHAPTER FIVE



“Afraid! Of whom am I afraid?
Not Death—for who is He?”

The cold and calculating reality of dealing with personal finances is in sharp contrast to the warmth and peace achieved by coming to terms with a spiritual presence. The rules and regulations one must follow in order to adhere to legal and/or business obligations give way to a growing sense of personal understanding with God.

As the terminally ill person approaches dying, understanding God may be easy or very difficult. There are numerous facts that come into play; many of which may have been suppressed or repressed for years. Whereas, financial matters tend to focus on where you are in the world at this precise moment, spiritual considerations tend to encompass your entire existence. It is common in conversation with the terminally ill to have them reflect on how religion has affected their lives. Individuals will remember their parent's religious attitude along with their own significant childhood moments, such as baptisms, bar mitzvahs, first communions, weddings, or funerals. Some may recall spiritual revelations, epiphanies, or personal miracles.

One of the first great works of English literature, *Pilgrim's Progress*, by the late seventeenth-century writer John Bunyan, recounted the metaphorical trek of a man in search of spiritual guidance and fulfillment. Pilgrimages are a common theme in almost all religions. Jesus, Mohammed, and Buddha, for example, spent a significant part of their earthly existence searching for a greater understanding of the human condition or closeness with a higher being. Jesus spent forty days and forty nights in the desert, Mohammed traveled to Mecca, and Buddha wandered the land as an ascetic. Mankind's own spiritual quests have translated into epic proportions, such as Moses' parting of the Red Sea, the medieval Crusades to the Holy Land, or Joseph Smith's and Brigham Young's trip across the United States to establish Mormonism in Utah.

A terminally ill person usually does not have the stamina to participate in a long pilgrimage. Nevertheless, you can visit a childhood church, temple, or mosque. In addition, you can visit holy shrines or other significant monuments in your chosen religion that are closer to home. In this way, the dying patient is able to make his or her own symbolic spiritual trek.

You may be able to identify easily the religious guideposts of your life, but the journey may be arduous. There is no guarantee you will find what you are looking for. Still, you have no choice but to reconcile yourself with God or your chosen religion in some manner. To that end, allow me to suggest a few tips for the spiritual traveler.

Quality of Life

Facing the possibility of premature death often forces us to take a look at where we have been and where we are currently in our lives. Some people come to the conclusion they have not accomplished enough, loved enough, or contributed enough to the world. Others feel fulfilled and satisfied with what they have done and view death as a natural progression. Nevertheless, it is important to consider the “quality of life” you wish to pursue now.

Making this determination often requires an introspective look at what is important to you, what makes you feel complete. Is there something you always wanted to do but never tried? Is there an individual you had a disagreement with in the past and you now want to make amends? What activity brings you true joy and satisfaction? In my case, it is important for me to continue my professional work, write about my experience with cancer, and spend time with my family.

How you choose to live the rest of your life is a private and personal matter. It is something, however, that should not be disregarded. A positive state of mind can influence your body’s reaction to treatment and can make a difference. It will also allow you to experience a more enjoyable quality of life.

A Religious Guide

It is important to speak to someone who is a representative of your religious persuasion, whether it is a minister, priest, rabbi, or other cleric. This person may not be well-known to you or you may have known him or her for many years. Any member of your religious community can serve this role, it does not have to be “the leader” of your particular place of worship. In any case, the topic of dying in a spiritual sense will most likely be new for you.

Your religious guide is in charge of meeting your “spiritual needs.” The term “spiritual needs” is commonly overused and has an almost commercial ring to it. The terminally ill person, in this instance, does not need a guide to settle practical issues such as donations or funeral arrangements. Your religious guide will be able to do much more for you.

First of all, he or she can put your impending death in a broader religious context and neutralize some of your anger and isolation. Religious phrases and passages that you did not listen to very closely before will be interpreted by your guide with new meaning. You may suddenly see that theology provides great comfort in its breadth and understanding of personal tragedy. There is consolation in the fact that so many have gone before you and thought long and hard about the consequences of death. If you pause and reflect on their teachings, you realize they have paved the way.

Secondly, a religious guide offers personal solace and compassion. An experienced grief counselor is adept at answering questions and putting some of your fears to rest. True, you receive sympathy from friends, family, and, occasionally, your physician. Yet, the understanding provided by your spiritual guide is special and unique.

Thirdly, your guide discusses in detail your religion's view of the afterlife. This topic is particularly difficult—especially in contemporary secular society. Nevertheless, it is now an issue that interests us deeply and weighs heavily on our minds. You may feel embarrassed about asking your spouse or physician about the “afterlife.” Your religious guide can address this question freely and in an uncomplicated manner.

Finally, a religious guide restores, renews, and invigorates your faith. He or she can define “faith” or “belief” and show how it spiritually drives and propels our spiritual pilgrimage. Facing death, naturally, severely tests one's convictions. You may ask yourself, “Why would God do this to me?” The preservation, or in some cases restoration, of one's faith allows you to overcome this question and understand that God has not singled you out but that you are progressing through the natural process of life.

Family Member

The possibility should not be overlooked that someone in your family is meaningful to you in a spiritual and religious way. Often, this role is assumed by a spouse. Many couples often read their holy book or pray together each night. However, it is just as likely that a surviving parent, a son or daughter, or even a distant relative responds spiritually to your needs and can be your religious guide. Since religion is such a private and personal consideration, this individual may not step forward and volunteer his or her assistance. You must openly communicate this prospect because that person may be waiting for some indication from you. Anyone can help you enormously, if you simply ask.

Prayer

As a physician who has spent the majority of his life as a scientist, I was very interested in an article in the *Wall Street Journal* that was published about two months after I was diagnosed with metastasis of renal cancer. The headline read “The Healing Power of Prayer is Tested by Science.” Writing on the power of prayer as a form of “remote healing,” the journalist reviewed research projects at a number of universities, including the University of California at San Francisco, Temple University, and the University of New Mexico. Their hypothesis, stated here in general terms, is that the body emits an energy that can be affected in invisible ways by positive energy from another source—a kind of interactive energy exchange.

Deeply religious people will surely applaud this recognition of what they have for centuries called the “power of prayer.” Praying is a fundamental activity in most religions; the very cornerstone of faith and hope. For some of us, it is something we see in every aspect of our daily lives. We teach little children to pray at meals and at bedtime. Students promise God they will study more in the future if they pass an important exam today. Sports fans pray their favorite team will win the “big game.” We hope we get what we want for Christmas. But, of course, prayer is so much more important.

Prayer is important because it is a personal and private communication between oneself and a greater being. It is also the acceptance of the unknown in terms of trust and hope. The English poet John Dryden wrote long ago: "Death in itself is nothing; but fear/To be we know not what; we know not where." The act of prayer allows us to bridge that gap between the present and the unknown future without fear. It allows us comfort in knowing that this world of pain and suffering, for the healthy and the ill, will dissipate after death into peace and understanding.

In the Intensive Care Units where I worked for several years, I often observed family members and friends praying for a critically ill or injured patient. In the context of the hospital setting, the act seemed a useless gesture compared to the jumble of high tech machinery surrounding the patient. Yet, I also saw that prayer brought solace and peace not only to the person praying but somehow, indescribably, to the patient as well.

Church and Cemetery

As it becomes more difficult to travel anywhere except to medical appointments and treatments, it may be worthwhile for as long as possible to attend your church, synagogue, or other place of worship on a regular basis. Looking forward to church and its fellowship is extremely rewarding. It is also comforting to know that your friends and family have your interests at heart. For someone who has not been a church member for most of his or her life, it can also be a potent experience.

In the same vein, visiting the cemetery where you will be buried, if burial is the choice that you have made for your remains after you die, is not the morbid experience you may think it is at first. Again, returning to a theme that I have reiterated throughout the book, it is better to be comfortable with the atmosphere and trappings of death than to treat them with fear and needless horror. Most cemeteries are located in naturalistic and peaceful settings, and visiting your final resting place will ease your mind and even provide you with some sense of the afterlife.

Private Meditation

It is important to note that the terminally ill patient may not accept God or belong to any organized religion. Yet, it is my experience that most people believe in *something*. A person may believe, for example, in the healing power of nature and its cycle. He or she may find peace in the fact that death is a natural process and a return to the greater whole. Others may believe in meditation, which is the power to think through a situation and arrive at a suitable resolution. Whatever one's beliefs are, it is important to find a way to come to terms with the idea of death.

*“Afraid! Of whom am I afraid?
Not Death—for who is He?”*

These lines from a poem by Emily Dickinson speak to the core of what religious belief can do to remedy one’s normal fear of the unknown. Faith overcomes death and turns it into just another phase in the natural transition of life. The recognition of death as a transition stage to a higher understanding is common among most religions.

Yet, if religion allows us to look forward, it also allows us to look back. Dr. Patrick Francis Sheehy in his book on *Dying With Dignity* writes in his conclusion: “For the dying patient, religion is important when it makes life dignified and worthwhile.” Religion allows us to reflect on our good deeds, our selfless acts, and the best moments of our existence. It is part of our personal history and our broader community. It also permits reconciliation and forgiveness for the mistakes we may have made. Finally, if we let it, religion will bring us comfort at the most trying time of our life.

CHAPTER SIX



“Please Come Here and Help Me”

The words “Please come here and help me” are uttered by Ivan Ilych Golovin near the end of his life in Leo Tolstoy’s short novel *The Death of Ivan Ilych*. This profound work of literature is one of the greatest explorations of life and death ever written. The main character is an ordinary man living in late nineteenth-century Russia. He has a family, is educated, and serves as a judge. He also suffers from an incurable disease. Tolstoy describes his physical and psychological journey as torturous and painful; however, it is a path that all of us who are terminally ill must take. Ivan consistently denies he needs any assistance and, by doing so, believes he is resisting his disease. He eventually comes to understand that his family and friends are there to comfort him. Only then can he say the words, “Please come here and help me.”

This chapter deals with dying patients and medical treatment in the latter stages of their disease. There is a crucial point that all dying individuals must understand as they move toward death: in most cases, their involvement with physicians, nurses, and medical institutions, such as hospitals or hospices, will continue to increase and become a dominant aspect of their lives.

The patient may very well be at peace with dying and have every intention of being surrounded by family and friends when it is time. He or she may have signed do-not-resuscitate orders or requested not to be placed on life support. However, divorcing yourself completely from the medical establishment in our contemporary society is not necessarily in your best interest.

The thrust of this book is to make the process of dying a systematic, understandable, and natural process. Nevertheless, it would be wrong to deny that there are moments—and even extended periods of time—of psychological rage, family dysfunction, and general chaos. These times can seldom be avoided although their impact can be lessened through the efforts I discussed earlier on these pages, such as planning, communication, and faith. The final days in the hospital can often be the most chaotic just at the point when peace may be what is needed.

Why is this so?

It all goes back to Ivan Ilych’s simple request, “Please come here and help me.” The body as it progresses through the disease process does not give up. Bolstered yet battered by drugs and other interventions such as radiation treatments or surgical procedures, the body is at war. And that war is devastating to the patient. There is pain, often severe, and psychological disorientation. Medical assistance is invariably needed to try and maintain the status quo.

Unfortunately, in the medical community, death is often considered the unnatural enemy. Writing in the *Journal of the American Medical Association*, Dr. Jack D. McCue states:

Dying, which was once viewed as natural and expected, has become medicalized into an unwelcome part of medical care. It has been distorted from a natural event of great social and cultural significance into the end point of untreatable or inadequately treated disease or injury. Worse,

death has become medicine's enemy—a reminder of our limitations of medical diagnosis and management.

Without question, this attitude is partially a product of modern technology. Modern science seemingly provides us with a chance to cure anything and everything. It is no wonder then that the person dying becomes a medical pariah, a bearer of death whose terminal disease defies the “technologic” of modern medicine.

Nevertheless, as a critical care physician, I believe the medical community as a whole has improved its attitude toward the terminally ill patient—if not toward death itself. Physicians who might blame the patient for certain disorders such as AIDS or lung cancer, which result from smoking, have come to understand that “terminal” is a human reality. They are not the moral begetters and determiners of who can justifiably have a terminal condition. Our role as medical practitioners is simply to administer to the suffering.

Many physicians have lost the sense that a terminally ill patient reflects their inability to “save” everyone, and perhaps, have also lost the consequent notion that a terminally ill patient must in some way carry the “blame” for his or her illness. A terminal diagnosis always hits hard and the victim, as well as those who care for him or her, is caught in an overwhelming sense of loss, fear, anger, and frustration with the common core of mortal human existence.

I also believe there has been an increased public awareness of diseases in general. Society has become better educated and more informed in general due to the increased role of the media and television in our lives. Drs. John W. Carnes and H. James Brownlee, Jr., writing in the January, 1996, *Medical Clinics of North America* note:

...many laypersons in the United States are now more sophisticated about health issues and treatment options. Although the word cancer [for example] continues to carry a significant emotional charge, a growing segment of the population now realizes that death comes in a variety of forms, many of which are treatable, if not curable in some cases.

Years ago, the word “disease” was unspeakable in our culture. We didn't discuss it. We whispered its name to each other as though it was a naughty word. Today, we are more accepting of the fact that disease as an entity is not a selector. Its impact is present solidly across the board. The absence of secretiveness has allowed caregivers, counselors, and families to step forward and work better with the sick. It is no longer the sole responsibility of the physician to provide support to dying patients, it is now everyone's concern.

A final factor that has improved the medical community's attitude toward the terminally ill is the opportunity, through modern treatment techniques, to make them more comfortable physically. We are much more sophisticated about dealing with the health problems of the terminally ill. Two generations ago, a patient was not told his or her disease was terminal. It was thought that an “ordinary” person could not handle the distressing news. Now, however, health care professionals know that a fully informed patient is much more receptive to treatment options. I do not think it is a coincidence that honesty has been accompanied with increasingly better medical practice.

In summary, the sensitization of the health care field, the increased knowledge of the average person, and the ever-improving treatment of serious diseases have all come together to create a better atmosphere and understanding between the medical community and the terminally ill patient. Although the situation is not perfect and never will be perfect—death will remain the physician's primary enemy—the recent advances in medicine and in quality of care need to be recognized.

The remainder of this chapter will focus on the medical aspects of the terminally ill's final days or weeks.

Psychological Concerns

In a sense, this entire book is meant to be about the psychological issues of learning you are terminally ill. We all use euphemisms to talk about mental problems. For example, this book describes how “to get your house in order” or “to find peace of mind.” It is also designed to help your family and friends come to an understanding of what you are facing emotionally. However, your mental state cannot be minimized by clichés. There exists a great amount of pressure on all involved, including health care professionals, and depression, anxiety, or denial can interfere with the effectiveness of your treatment.

Up front, all participants—meaning the patient, family members, friends, and health care professionals—must be aware that the disease itself or the treatment protocol can cause a psychological reaction. In this case, I am not speaking of being depressed because you are told you have cancer. Terminal diseases and the medical weapons used to combat them, namely drugs, are known to have a very serious impact on the body. Psychotic reactions can manifest themselves in delusions, uncontrollable depression, hysteria, excessive anger, or any other of a multitude of symptoms. Your behavior will be difficult to predict, although most physicians, nurses, and medical social workers are trained to know what to expect in these situations. It is possible that you will not suffer from any mental abnormalities. However, it is rare that a terminally ill patient progresses through his or her disease without experiencing some psychological reaction due to medication or treatment plans.

It is naturally very distressing if a patient suddenly turns on a spouse with excessive anger, which may even evidence itself with physical or verbal abuse. In addition, the dying individual may attempt to hurt himself or herself. My best advice as a physician who has seen patients react in such a manner is to discuss drug or chemotherapy treatment thoroughly beforehand with your health professionals. Nurses particularly have insight into the tell-tale signs that may precede psychotic episodes.

The fortunate news is that in the vast majority of cases these episodes pass rather quickly. Often, treatments can be adjusted, modified, or discontinued and the problem will fade. Otherwise, scheduling a consultation with a psychologist or psychiatrist may prove helpful to both the patient and family members. For some individuals, a drug may be prescribed to specifically counter the psychological reaction.

The advice in the above paragraph also applies to finding a solution to psychological problems that patients naturally face when they learn they have a

terminal illness. Often, their personal difficulties emerge as relatively minor understandable changes in behavior and progress into severe and complex psychiatric issues. A short list includes stress, worry, depression, anger, and fear. Here are some more points to consider:

1. Obviously, almost everyone—the sick and non-sick—experiences these problems to some extent throughout life. Yet, the terminally ill are vulnerable to having them escalate into more serious psychological episodes. What are the warning signs to alert family and friends? The terminally ill patient may initiate unplanned and/or impulsive actions, such as withdrawing all of his or her money from a bank account or disappearing for a weekend—before becoming incapacitated. He may withdraw from social interaction or appear not to enjoy some formerly favorite activities. Appetite suppression, suicidal thoughts, moodiness, agitation, and sleeplessness are also common signs of depression and/or anxiety.

2. Terminally ill patients may become abusive to themselves or to family members. Drinking excessively or taking addictive drugs can contribute to a violent situation at home.

3. Excessive stubbornness or rebelliousness may also prove to be warning signs. This is particularly noticeable in relation to health care professionals who can become “the enemy” to the terminally ill patient for no apparent reason.

It is up to family members to seek counsel from caregivers when they notice these signals. In some cases, religious figures are also able to provide support and advice. Sometimes old friends or distant relatives who have been involved in a similar situation can be of assistance.

The Grieving Process for Friends and Family

I briefly want to address the subject of grief and how it will affect your family members after your death. Urge them to openly discuss their own anger and frustrations with friends, counselors, and social service workers. They, too, will progress through Dr. Kübler-Ross’s five stages of mourning (denial, anger, bargaining, depression, and acceptance) in some form and will need support. They should seek an outlet for their sadness instead of internalizing it. This can be accomplished in many ways:

1. Family members can vent their emotions in a creative manner by painting, writing in a journal, composing a poem, or singing Gospel hymns. The French Impressionist, Claude Monet, was broken hearted by the death of his first wife. In an 1879 letter to a friend, he wrote, “I am devastated, and have no idea where to turn or how to organize my life with two children. I am much to be pitied, for I am very pitiable.” Although Monet was never fully able to express his grief, he commemorated his first wife’s death by painting “Camille on Her Deathbed.”
2. The actor Gene Wilder recently opened a cancer support facility in memory of his late wife Gilda Radner, who died of ovarian cancer in the early 1980’s. The original “Gilda’s Club,” located in New York City, is designed to provide a home-like setting for terminally ill patients and their families to come together and help one another. In this vein, survivors should consider participating in local support groups with

- friends and family members in a relaxed, comfortable environment.
3. A visit to the library or bookstore will reveal an enormous amount of literature on death and dying. One can read some of the great works of literature I describe in Chapter Nine or find a contemporary self-help book (see Additional Readings for a list of recommended publications).
 4. Grief counseling with a health care professional is also an alternative. As mentioned earlier, he or she can prescribe medication to minimize the effects of depression and/or anxiety and can institute a treatment plan. The mourner can also seek advice from a religious guide or meditate in order to find peace of mind.
 5. The most important form of advice to those who have lost a loved one is simply: *do not be afraid to cry*. No one should be embarrassed or self-conscious about doing so. It is a perfectly natural reaction to personal tragedy.

It should be noted that mourning is a *slow process*. It may take years or a lifetime to recover from the loss. While coworkers and business associates may expect your survivors to return to “normal” in a matter of months, it is not that easy. In addition, the pain associated with your death may reemerge during important life events for them, such as weddings, graduations, award ceremonies, and child birth.

Euthanasia, Suicide, and Assisted Suicide

Although never officially sanctioned by church, state, or the medical profession, taking one’s own life to avoid pain and suffering is often considered by the terminally ill patient. The widely publicized assisted suicides performed by Dr. Jack Kevorkian have created several ethical questions over the legality of such activities. In addition, there are societies and organizations that advocate what they call a “peaceful death.”

As a physician, I am pledged to honor the integrity of human life and will never advocate any form of suicide as an “easy way out.” Besides being morally opposed to it, I realize that there are too many factors that exist for the terminally ill patient that preclude resorting to such tragic measures. For example, have all treatment protocols run their course? Is the patient psychologically stable? How will suicide impact the family and its finances?

The only positive effect that the assisted suicide debate has had on the medical community is a renewed focus on making the terminal patient comfortable in the very final stages of death. Suicide advocates are correct in emphasizing that patients who have absolutely no medical hope should not be put through useless and painful treatment procedures. When everything reasonable has been done and the disease course has not been significantly altered, physicians must inform the patient, if he or she is conscious, and the family so appropriate action can be taken.

Home Care

The medical condition of a terminally ill person continually fluctuates. There will be some good days—days so good, in fact, hope will surface that he or she has had a remission or taken a small step to recovery. Unfortunately, except in a very small percentage of patients, such good days are only a blip on a chart that

is inexorably getting worse. This downward movement has a tendency to pick up speed as the disease progresses. First, the patient's normal life style is interrupted when he or she first receives a diagnosis of terminal illness. It is as if someone applied the emergency brake and everything comes to an abrupt stop. Next, a patient may need to leave his or her job, have daily medical treatments, or limit physically and mentally taxing activities. Still, for a time after the initial diagnosis, a terminal patient can carry on some semblance of normalcy.

Eventually, though, they must decide on long term care options. The terminally ill person and his or her family usually have three choices: to seek hospitalization, to establish formal home care, or to seek respite in a hospice setting. Hospitals, as mentioned earlier, are generally reserved for specific treatments, such as surgery, or for crisis situations. Home care is often the first choice because it buys more time for the patient to be surrounded by a familiar environment, family, and friends.

Dr. Betty Davies and her co-authors in their excellent book *Fading Away: The Experience of Transition in Families with Terminal Illness* list four factors that determine home care success for the terminally ill patient. These factors are:

1. ***Able and Available Caregiver.*** Successful home care can only happen with full-time devotion to the patient by one or more family members and friends. This is around the clock duty. It is stressful and difficult work that will often be done in social isolation for the caregiver.
2. ***Comprehensive and Reliable Home Care Resources.*** The caregiver must have access to and know how to use or administer all medical equipment, medicine, and personal hygiene materials needed by the patient. A visiting nurse service should be engaged at least once a week or be on call to help with emergencies. Family and friends who are not directly involved must relieve the caregiver on a regular basis so he or she can pursue an independent life. In addition, they should recognize the caregiver's limitations. For example, a mother caring for a terminally ill child cannot be expected to cook meals, run errands, and shop for a husband and other children.
3. ***Patient's Physical Condition.*** The patient's condition cannot become too complex or overwhelming for the caregiver. There is a limit to what a lay person can do to maintain intricate medical machinery or consistently enhance the diet of a patient rapidly losing weight.
4. ***Suitable Physical Environment of the Home.*** Some residences or apartments are just not physically suited for home care. Houses with multiple stairs or bathrooms that are only on the second floor present obstacles that eventually cannot be overcome. Similarly, if a house or apartment is too small and/or the family is too large, extended home care may not be a reasonable alternative.

In summary, almost all terminally ill patients will receive some degree of home health care. Many times, families are so devoted to the idea of the patient staying at home that they manage to care for the patient to the very end. While this is a noble effort on their part, the decision to provide lengthy home care cannot be entered into lightly. Not everyone can be expected to live up to this high

standard. A family member should not feel guilty because he or she is unable to quit working in order to help a sick parent, child, spouse, or sibling. In fact, a job may be essential in order to pay mounting medical bills. The fact remains, however, that successful home care often dominates the home life of family members.

Hospices

The modern hospice movement began in the 1960's in England through the efforts of a British physician, Dame Cicely Saunders. According to authors Maggie Callahan and Patricia Kelley in their book *Final Gifts*:

Dr. Saunders proposed a new way of caring for such [terminally ill] patients—a hospice like those of the Middle Ages, but organized as a peaceful place...[which] combined loving, compassionate care with sophisticated medical intervention that emphasized palliative care (relief of symptoms) rather than curative care (treatments or procedures intended to stop or reverse an illness or condition).

Today, the American *hospice* commonly concentrates on care for patients in the final stages of cancer. A few other diseases, most notably those associated with the heart, are also treated at hospices. Two other well-publicized terminal illnesses, Alzheimer's disease and AIDS, tend to have their own hospice-like settings but do not generally use the same terminology. Since the course of Alzheimer's tends to take a longer period of time, individuals are usually admitted to an institution similar to a nursing home for the elderly. AIDS, which is a blood born disease, requires a separate setting in order to cater to its patients' specific needs.

In all cases, hospices work on the principle of providing comfortable maintenance care in a pleasant setting for a person in the final stages of his or her terminal disease. Hospices are always "family friendly" and, indeed, depend on families to be present as much as possible for support. In addition, patients will meet, possibly for the first time, others who are going through the same personal tragedy. This sense of community is calming and relaxing for anyone who needs to be understood by another human being.

Most medium to large cities offer a variety of hospice services and locations. If you live in a small town or rural community, an effort should be made to find one close to home. Although the terminal patient may never stay in a hospice, for one reason or another, friends and family should investigate their options and arrange for your admittance in the early stages of the disease process. It provides a safety net when home care is no longer feasible and hospitalization is not possible.

It should be understood, however, that a hospice serves as a final destination. When a patient enters one, he or she understands that it is a necessary and concluding act. Sometimes, the amount of drugs taken to ward off pain is so great that he or she is only dimly aware of what is happening.

The emergence of the hospice movement over the past thirty years has proved to be a great advancement in the care for the terminally ill. Hospices permit peace, dignity and repose at a time when those qualities are vitally needed. They are the last place where the patient can say, "Please come here and help me."

CHAPTER SEVEN



“Caregiving: Advice for Your Family Members”

Nancy L. Mace and Peter V. Rabins address the needs of family caregivers in their book, *The 36-Hour Day*. Although the book is primarily intended to give guidance to those caring for someone with a dementing illness, such as Alzheimer's, the authors outline general principles that can also be used by dying individuals and their families. The major point of the book is this: the person or persons responsible for your care require special attention and advice. Most people are inexperienced at knowing how to act or behave when someone they love is dying of a terminal illness.

There are some important issues you need to keep in mind when family members assume the responsibility of your care. First, loved ones will react to your prognosis in a variety of ways. Some may express their emotions intensely while others may not exhibit any outward signs of distress. Facing the reality of losing a loved one can also lead to mixed feelings of love and anger directed at the person who is sick. Doctors or other health care professionals may also become the target for their anger. They may even feel betrayed by God.

Secondly, as a result of your illness, your family members will be saddled with new responsibilities that may cause some stress in their lives. The future is now uncertain and the threat of separation often leads to a feeling of chaos. Although you are the one with the terminal illness, its effects touch the lives of everyone around you. Your family members may feel trapped by accompanying you to frequent medical appointments or providing full-time assistance at home. Your children, siblings, or spouse may be required to assume new roles in the family that make them feel inexperienced or uncomfortable, such as balancing the checkbook or washing the laundry. It may be difficult to drop everything at a moment's notice when you need them or to make plans that depend on the status of your health. Balancing their already busy schedules with your care can lead to exhaustion and fatigue.

Lastly, medication or the illness itself sometimes causes the sick to say or do negative things. Consequently, caregivers often feel abused and succumb to complex emotions, such as depression, hopelessness, embarrassment, guilt, intense sadness, and isolation. They may use alcohol, sleeping pills, tranquilizers, or other drugs to relieve the stress. However, taking these types of drugs may lead to even more fatigue, greater depression, and physical illness.

I do not want to make it sound as if your care were a *burden* for your family members. You will find that your spouse, children, siblings, or distant relatives will step forward to provide an inordinate amount of assistance. They want to help you. However, we all have limitations that can result in some natural, but unpleasant, human emotions. There is no *right* way to react to the impending death of a loved one, but there are steps your family members can take to lessen the grief for themselves.

Since their help is extremely important to you, make sure they know it.

Acknowledge their efforts and let them know you love them. They appreciate it if they are asked how they are and how they feel they are managing. If you think a family member is experiencing too much stress, advise him or her to seek help from a social worker or clergy member. Talking with other individuals outside of the family who have experienced a similar situation can also be empowering. Family members should consider exercising, visiting a friend, taking a vacation, walking, or simply relaxing with a pet if they feel they need a break. During these difficult times, laughter and happiness may seem out of place; however, we all know that a simple smile can instantly improve someone's spirits.

Caregivers should focus on one thing at a time, one day at a time. Your family should make it a goal to be informed, to exchange information with everyone involved in your care, and to support medical research. If someone in the family is required to learn new skills in order to effectively manage your state of affairs, advise him or her to seek guidance from experts, to purchase a book, or to ask other friends for their ideas. Again, let them know they are not expected to suddenly become a whiz at financial decision making or managing the housework. Remind them to compromise and to delegate responsibility to other family members.

When more than one family member decides to play an active role in your care, it is imperative that everyone involved meet and exchange ideas. Family members who are unfamiliar with the day to day responsibility of your care may be too critical or unsympathetic toward the primary caregiver. Social stereotypes regarding which family member should be in charge of what may be employed in making decisions instead of truly analyzing the best course of action. On the other hand, family members who take care of the daily operations need to remember that distant relatives care just as much. When everyone makes the commitment to listen to each other, compromise is the most reliable method to solve family crises.

The approach to caring for a terminally ill individual at home requires patience, flexibility, and sufficient resources. As mentioned in earlier chapters, some homes may not be conducive to providing quality care and certain accommodations need to be made. As you become weaker, tasks such as walking around the house, climbing stairs, or washing and dressing yourself will become increasingly difficult. Several aids and adaptations can be introduced in your home in order to make it safer, such as handrails on the stairs or by the toilet. A walking stick or a wheelchair will give you the confidence to leave your house and take in some fresh air. A low chair, bed, or toilet may be difficult for you to negotiate as your energy level decreases. Bed blocks and chair and toilet raisers can often fix this problem and can be found at pharmacies or medical supply stores.

As a terminally ill patient's condition deteriorates, he or she will be spending more time in bed. You may want to make a suggestion that your bed be moved to the family room so you can continue to take part in the lives of everyone around you and feel less isolated. However, this may not be an option if privacy is a concern for you. You may not want to reveal to family and friends some of the unpleasant physical aspects of being severely ill, such as catheters, sores, and iv's, as you start to lose some of your independence.

Caregivers often feel uneasy about maintaining a loved one's personal hygiene. They may want to consult a nurse or other health care professional about ways in which to protect your privacy and to make you feel comfortable. There are also certain adaptations that can be made in the bathroom in order to make it safer. Handrails and "shower seats" are commonly used and can be easy to install. Patients in the advanced stages of cancer also experience a decrease in appetite. Consequently, caregivers often become overly attentive of the dying patient's diet. However, strong smelling meals, fatty foods, and large portions may not be the answer. Instead, caregivers may want to consider smaller portions at regular intervals and prescribed food supplements.

The dying patient's needs may rapidly change as his or her disease progresses. Caregivers constantly need to assess and anticipate your needs before they become a problem. When caregivers feel like things are getting "out of control," a nurse or other health care professionals can provide advice, information, and support. Many medical centers now have palliative support teams who serve as an important asset for many caregivers and terminally ill patients. Nurses and occupational therapists and physical therapists often visit patients' homes.

Many family members are frightened by how they will react when a loved one dies at home. However, there is usually some indication that death is near and caregivers can prepare for it by following the guidelines I outlined in earlier chapters. It will also help if a physician explains to them the changes in levels of consciousness and breathing prior to death. They may request that family members and/or a religious guide be present during this time. They may also want to keep your physician's telephone number or pager by the telephone if they feel like they are going to panic. Once death has occurred, it is important that a doctor certify the death and sign the appropriate paperwork.

Your caregivers will be able to provide quality and loving assistance if they balance your physical and emotional needs with their own. They can feel that they are playing a positive role if they make a commitment to stay informed, to continually assess your needs, and to monitor their own health. It would be wrong to look solely at the needs of the patient and to neglect those of the family. Each family is unique and will respond to the challenge of providing home care differently. At the same time, relatives should not feel guilty if they find that a hospice is more suitable for your needs. It is important to listen to your loved ones, to explore any fears they may have about your illness, and to identify the options available to them.

CHAPTER EIGHT



“So Sweet a Place”

Dr. Thomas Attig, an expert in death, dying, and the grieving process, has written:

Those who suffer losses are affected in all dimensions of their lives. Grief is at once, physical, emotional-psychological, intellectual-spiritual, and social. This pervasive impact can shake the foundations of self-understanding and orientation in the world and pose significant challenges to personal integrity and to the perceived meaningfulness of continued living.

At the very end of life, there is often a shift in emotion from the terminally ill patient to his or her family. For most of the dying process, the focus is on the patient. Family members and friends must try and be the steadfast rock to which the patient may attach an ever tenuous anchor. But, I have often observed how the roles are suddenly reversed. The patient, now at peace with dying, becomes the anchor to which the tired and frazzled caregivers affix a last line.

Dr. Attig is correct that grief becomes an all-encompassing emotion and there is only so much a terminally ill person can be expected to do to convince inconsolable family members and friends that everything is fine. Nevertheless, one of the patient's last acts can be to convey a sense of love and appreciation to those around him or her. This is important because it provides the patient with a last meaningful act. After weeks and months of being examined, medicated, and cared for like a baby, the patient can still perform an act that no one else can do for him or her. The patient can say "Thank you" and "I love you" and "I will be okay" and "Please remember me but get on with your own life." These words effectively take family and friends "off the hook." It helps to alleviate the sense that there was something more that could be done or they somehow failed the patient.

The final stage of death is a mixture of peace and lingering fear, hope and final despair, technology and no technology. Patients find it hard to believe that family members will be able to continue without them, yet also want to guarantee their survival in any way possible. Days stretch out endlessly, yet it also seems like there is no time left.

The following is a discussion of end-of-life issues that need to be addressed; however, many of them should not necessarily be taken care of at the last minute.

The Funeral

Funerals fall into the same category as wills, which were discussed in an earlier chapter. A funeral must be planned and arranged for just like a will. Outside advice must be sought. All sorts of decisions of varying importance must be made. Yet for all the business involved in this process, the need to go through it

is another depressing “FINAL” signpost on death’s road. In other words, when you start planning your funeral, a big chunk of hope is broken off.

However, a person can be buoyed and comforted by knowing that a funeral is a way of making a final statement. Pre-planning with a funeral home can save money, time, and much uncomfortableness for you and your family at the time of physical death. Also, you can decide on how you want the funeral prepared and carried out. The unique jazz funerals on Bourbon Street in New Orleans are an American tradition that exemplifies the celebration of someone’s life. The same can be said of an Irish wake. On the other hand, you may wish for a very formal religious ceremony; a high funeral mass, for example, in the Catholic Church. Many people are choosing a memorial service instead of a tradition funeral. Whatever one’s history or religion, a funeral proclaims his or her life, accomplishments, personality, and beliefs.

Funerals in the United States usually cost several thousand dollars or more depending on your chosen details. Cremation or even a modest service at a funeral home with a casket and cemetery plot amounts to a considerable amount of money. It is important to remember this is money well spent to assure peace of mind for both the terminally ill patient and his or her grieving family.

One thing to count on is that you will not be alone when it comes time to plan the funeral and/or church service. The funeral director and your religious guide, whether he or she is a priest, rabbi, minister, or family member, has been through the ceremony before and can offer valuable advice and suggestions. However, one cannot forget that unlike the religious guide, the funeral director is a businessperson who will make more money depending on what services you choose.

The selection of a funeral director is critical. The funeral home industry has greatly reformed itself since the 1960’s when there was a series of books, articles, and films that uncovered corrupt practices in the industry. Still, “buyer beware.” If the family does not have an established funeral home from past deaths, the best advice is to ask friends for a recommendation.

A short list of funeral/religious service suggestions for the patient’s family includes:

1. Check out all expenses and make sure they are in writing. This includes everything, such as the funeral home, limousine, caterer, place of worship, and other miscellaneous services. For example, many people do not realize they need to pay for certain items associated with their place of worship. For example, reserving extra chairs or scheduling a gathering after the service may be an additional cost.
2. Inform the funeral organizers of special requests, such as your favorite music or personal readings, well in advance.
3. Notify pall bearers if needed.
4. Make certain special friends or distant relatives are notified of the patient’s death. Not everyone sees obituaries (see below) or hears the news.
5. Out-of town family and friends require special attention. Even though it may not be appropriate, the fact remains that a bereaved family is often suddenly burdened with people expecting to stay at their house.

6. Make sure you find out what else is going on at the place of worship, funeral home, or even in the city on the day of the service. A funeral scheduled with no time cushion right before or after a wedding may cause some embarrassment. Or, trying to maneuver a funeral procession around a St. Patrick's Day parade may also be frustrating.
7. Cemetery selection may or may not be a critical issue for a family. Often, there is already a designated plot or only one graveyard in the town and no need for any discussion. Otherwise, choosing a cemetery is something the terminally ill person can and should participate in well ahead of time. Similar to the selection of a funeral director, purchasing a plot is a business arrangement that should be treated as unemotionally as possible. Be alert to hidden costs, such as yearly upkeep fees. Your friends or religious guide can help with this decision. Again, do this early. It is not something that should be decided on at the last minute.

The Body

Although a somewhat morbid topic for most people, as a physician I feel an obligation to briefly discuss what happens to the body after death. Although many terminally ill patients' bodies are too racked with disease to qualify for organ transplantation, there are circumstances when it is possible. In this case, depending on the recommendation of the attending physician, I would urge everyone to participate in organ donation. It is an opportunity to make a last meaningful contribution to society. Along similar lines, a person may be interested in donating his or her body to a medical school to further education.

Throughout the history of mankind, the two most common practices for disposing of bodies have been cremation or in-ground burial. In David Carroll's *Living with Dying: A Loving Guide for Family and Friends*, an exceptional book on death and dying done in a comprehensive questions and answer format, the author compares the pros and cons for both of these options. He notes the purity and psychological finality of cremation, but acknowledges that some people find it too violent an action to inflict on their loved one's body. A cremation, nevertheless, is considerably less expensive than a burial. On the other hand, in-ground burial is more traditional and a cemetery provides a place of mourning for family and friends. However, a decaying body is not a pleasant image and cemeteries are not necessarily permanent. It is not unheard of for cemeteries to be in the way of roadway construction projects or fall victim to natural disasters such as floods, tornadoes, and earthquakes.

Again, whatever choices are made, the terminally ill patient and his or her family should discuss their options openly and frankly so the appropriate arrangements can be finalized in a timely manner.

Official Business

When a person dies, the subsequent official or legal matters generally fall into two categories: those that are urgent and those that can wait.

Activities that can be dealt with at a later time involve the reading of the will and the allotment of insurance money. These are anticipated events and can be

executed in the weeks or even months following the death. In fact, unless there is some particular pressing reason, it is best to wait and allow the survivors to recover and regain their composure.

However, there is some business that needs to be done immediately and cannot be put off. An official death certificate, which is signed by the attending physician, and other paperwork needs to be completed by a designated family member. At some point, someone, often the funeral director, will ask how many death certificates the family needs for their records. These usually cost only a couple of dollars each. It may seem like an odd and unexpected question; however, original death certificates are required by many different financial, government, and legal organizations, and it is best to order a sufficient number. For example, insurance companies, investment firms, and banks all need *original* certificates. Copies will not be accepted. It is time consuming and difficult to “reorder” more, so surviving family members should be certain to order enough.

When the terminally ill person is ready, he or she should consider composing an obituary. Most of us have read one and are familiar with its contents. An obituary serves a variety of purposes, but its primary aim is to announce the location and time of the funeral. In addition to listing information concerning memorials or donations on behalf of the deceased, it is a brief tribute to a person’s work history, military record, hobbies, interests, volunteer activities, and survivors. It is also a historical document that acts as a permanent record of a person’s life and, for a number of reasons, may be researched fifty or a hundred years from now. Lastly, business associates, debtors, creditors, and colleagues, are notified officially of your death.

The obituary needs to be mailed or delivered immediately after the death to all local newspapers, and maybe hometown dailies. People are usually surprised to learn that they generally charge per inch of copy and extra for pictures to print obituaries. However, they will publish a simple death notice for free. Also, copies of the obituary or death notice should be sent to distant relatives and organizations that have an interest. School alumni organizations and veteran groups are two examples.

Your survivors should know that airlines often give discounts to individuals who are traveling because of a death in the family. They often require an obituary and/or a death certificate as proof.

If you share a safe-deposit box with someone else, or own one outright, be sure to examine its contents or close the account when you are still able to do so. A good time would be when you are organizing your financial and/or legal affairs. Otherwise, the safe-deposit box is sealed until the death notice is processed and eventually can only be opened in the presence of a bank official. As a result, family members cannot access critical papers without a great deal of hassle. An alternative is to add a “joint owner” to your account. He or she will be able to deal with the contents of the box after your death.

A final point to be made under “Official Business”: in this day of mass mailings, a terminally ill person will continue to receive mail for years after his or her death. This mail can become emotionally upsetting, as well as just plain

annoying, for your survivors. One option your family has is to return the items and request that your name be removed from the mailing list. Unfortunately, this proposition is expensive and involves an inordinate amount of time. It is a little like commanding the ocean waves to stop beating on the shore. Companies are obliged by law to delete names when ordered to do so, but your family can never reach everyone. As long as a name is out there on just one list, it will be duplicated and used over and over again. It is probably best to ignore the problem and deal with it in the best way possible.

Closure

You may want to make a special effort to tell your relatives and caretakers that you love them if you have not done so before. Your family and friends may find it helpful to write to you. It would certainly be appropriate for anyone you have had problems with in the past to write you now to reconcile your differences, so you may achieve some type of closure. This is your last chance not only to thank those people who have gone above and beyond your expectations but also to reconcile past arguments.

An Elegy

An elegy is a poem or song composed as a lament for someone who is dead. Elegies have fallen out of favor in modern times and I think that is too bad. Why? Because it allows the writer and his or her audience to offer a final good-bye to a loved one. It also provides a moment to pause and think about what the deceased meant to him or her.

In his own introduction to one of the great elegies in English literature, “Adonis,” the romantic poet Percy Bysshe Shelley, concludes by talking about the final resting place of the poem’s subject. Shelley calls it “...so sweet a place.” At the time of death, it is what I wish for myself and for everyone else—that we will find comfort and peace in “...so sweet a place.”

CHAPTER NINE



“The Last Chapter— Life after Death”

How do I contemplate my life after death?

In the end, one is left with the eerie thought of death's aftermath. Obviously, the world will continue with little or no change except for those who loved me. Mercifully, the memory of my dying and the pain associated with it will fade. Hopefully, they will remember the good times and my love for them.

Then, I am left to ponder what happens to me. Obviously, I do not know the answer. I can only hope and pray that what I have read of the visions of Great Writers is true. I know one thing: it will not be painful. I have a "power of attorney" and my wife Rosemary knows what to do. I have followed my own suggestions as outlined in earlier chapters. When the end comes, I will be sedated and given pain relief if any is needed. In this way, actual death is taken care of.

But, what happens to me after that? Again, I don't know. However, I have faith in God and eternal life. During my youth and middle-age, I was always "too busy" for God. I used the image and reputation of the evangelist as an excuse for my attitude. How could so many of them beg and steal money from the poor? How could God permit such an injustice? I now realize that God is not responsible for this injustice, man is.

I pray for forgiveness for the wrongs I have done in my life and hope to be forgiven. Because God is love.

Since I am saved, I come back to my original question. What will happen to me after death? I still have no answer. What have the great writers and true visionaries of the world conveyed?

I have looked and this is what I have learned.

In *The Divine Comedy*, Dante and Virgil visit paradise. There, the feeling of love is portrayed through the image of light. This interpretation is pretty vague.

In Goethe's *Faust*, Faust is forgiven by God after a terrible life and is welcomed by a mystical being who leads him back to grace. What does this mean?

Hemingway, in *For Whom the Bell Tolls*, expresses the concept that death does not denote defeat. Again, no answer.

Hemingway re-examines this issue in one of his final books, *The Old Man and the Sea*. The Cuban fisherman, Santiago, struggles with the forces of death and emerges victorious. Although exhausted and beaten, he proclaims, "A man can be destroyed but not defeated." The book can be interpreted as Christian allegory: Santiago is the Christ figure who, through his epic battle with the sea, teaches the boy about faith and perseverance.

In *The Tempest*, Shakespeare philosophizes that life is much like the illusion of a stage play. Prospero shows mercy toward those who have harmed him. Again, no answer.

The description of the character Beth in Louisa May Alcott's *Little Women* is one of literature's few accounts of the death experience:

Seldom except in books do the dying utter memorable words, see visions, or depart with beatified countenance, and those who have sped many parting souls know that to most the end comes as naturally and simply as sleep. As Beth had hoped, the "tide went out easily," and in the dark hour before the dawn, on the bosom where she had drawn her first breath, she quietly drew her last, with no farewell but one loving look, one little sigh.

With tears and prayers and tender hands, mother and sisters made her ready for the long sleep that pain would never mar again, seeing with grateful eyes the beautiful serenity that soon replaced the pathetic patience that had wrung their hearts so long, and feeling with reverent joy that to their darling, death was a benignant angel, not a phantom full of dread.

While this passage brings me closer, I am still not satisfied.

In my favorite work of literature, *Our Town* by Thornton Wilder, the playwright creates a contemporary drama about ordinary people in the small town of Grover's Corners, New Hampshire. The themes of Acts I, II, III are birth, marriage, and death respectively. Act I depicts the childhood of the main characters and in Act II we see them marry. Emily dies prematurely during childbirth in Act III and returns afterwards to observe her family. In desperation, she states: "They don't—understand—do they?"

Wilder's theme is that life ends quickly and often without warning. Since our time here is short, we need to take the time to smell the roses. People are often blind to the everyday wonders of life. The stage manager, who serves as the play's narrator, tells the audience near the conclusion that they are residents of this little star, "the earth," and are struggling to reach their potential. Although this concept is touching, it still does not provide an answer.

In *Walden*, Henry David Thoreau shows us how to seek serenity and fulfillment. He goes to Walden Pond to search for his own soul. There, he is able to live freely and uncommitted. He leaves the woods after he achieves unity with nature and its creations. He states that "the mass of men lead lives of quiet desperation." His book is a gift to mankind. However, it still does not contain the answer.

In viewing the classics, I am struck by their beauty; however, I am also struck by the fact that they largely have life as their subject—not life after death.

One ends by going to the Bible. In it, the faithful are promised eternal life. I do not need to know more. My search is complete. I have the answer.

Last Words

He Never Told Me He Loved Me

A death that is anticipated gives family and friends time to prepare for and begin the mourning process. In contrast to someone who loses a loved one in a violent or sudden accident, they are given the opportunity to accept the reality of your prognosis and face their imminent sorrow. Open communication between all parties involved can help reconcile feelings of intense sadness, hopelessness, fear, anger, guilt, abandonment or resentment. Furthermore, reflection and contemplation can help alleviate stress and anxiety over unfinished issues. It permits everyone to experience increased peace of mind knowing that their sentiments were articulated and their needs fully recognized.

However, survivors may feel uncomfortable or embarrassed about such an intimate and private conversation. They may not understand their emotions or know how to adequately formulate their thoughts. This final chapter is designed to provide a format in which messages can be conveyed to you in a nonthreatening manner. It opens the door for such a dialogue and can, at the very least, assuage the fears of those who are close to you. On the other hand, there will be some people who are at ease with the topic of dying and will not have any trouble expressing themselves to you. In either case, ask friends and family to write a letter or a simple statement so you can enjoy their thoughts, musings, praises, and/or reflections while you are still living. They can use this opportunity to celebrate your life, remember your personal and business achievements, and record your family history.

Here are some questions family and friends may want to consider when writing their letter or personal statement:

1. What are you going to miss the most about him or her?
2. What is your fondest memory?
3. What achievements or contributions would you like to commemorate?
4. In what way has he or she contributed to your life?
5. Is there something you always wanted to tell him or her but never had the chance?
6. What words of strength and happiness can you offer him or her?

These sample questions are meant “to help get the ball moving” and only a suggestion. It should be emphasized that there are no “right” or “wrong” answers and anyone can write whatever makes him or her feel comfortable. You may want to consider purchasing a “journal” so your father, mother, children, siblings, other family members, and friends and coworkers can write freely and on more than one

occasion. Accept and enjoy what your loved ones have written and communicated to you. Believe that their praises are genuine and that you have been an indelible presence in their lives. It is refreshing to learn how other people view you—maybe you never realized the impact you have had on their lives. Hopefully, you will come to the same realization that I have—life has been good to me.

My father was a very quiet man. Personal discussion was difficult for him. For example, he never told me that he loved me or was proud of me. Consequently, I never told him that I loved him and was proud of him. I never let him know my profound respect for his achievements. He died suddenly of a heart attack when I was in my third year of medical school. I've always regretted that he died possibly without knowing of my love. I have tried to correct that by telling my family hundreds of times that I love them and am proud of them. But, it is too late to tell my father.

The terminally-ill, like me, should make sure such a discussion with their loved ones takes place before it is too late. If such a discussion is difficult, one can always write his feelings on a card, in a journal, or in a letter. It is also the time when the terminally-ill should try to mend any “broken fences” both within the family and elsewhere. Sometimes the original argument can scarcely be remembered, but families remain distant for years. It is time to forgive as well as to ask to be forgiven. Remember the simple phrase, “let bygones be bygones.”

As emphasized by Dr. Henri J. M. Nouwen, you should forgive your parents for not being able to give you unconditional love; brothers and sisters for not giving the support you may have needed; your spouse for any losses, including the loss of intimacy with time; and friends or relatives for not being there when you expected them. Additionally, forgive yourself for many of life's transgressions. Only then can healing begin.

Your death may then bring those left behind closer together. Conflict, anger, misunderstanding, or resentment in addition to grief is even more painful, but can be avoided by your constructive actions. Remember to leave love to those left behind instead of sadness and grief. In *The Four Loves*, C.S. Lewis writes:

If you want to make sure of keeping your heart intact, you must give your heart to no one, not even to an animal. Wrap it carefully with hobbies and little luxuries; avoid all entanglements; lock it up safe in the casket of your selfishness. But in that casket—safe, dark, motionless, airless—it will change. It will not be broken—it will become unbreakable, impenetrable, irredeemable. The only place outside of Heaven where you can be perfectly safe from the dangers of love is Hell.

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A classic intellectual examination of illness and dying which focuses on the symbolic meanings of tuberculosis and cancer.

KIDNEY CANCER ASSOCIATION SERVICES

We Have Kidney Cancer

is a 56-page booklet describing the diagnosis and treatment of kidney cancer. It also covers other issues important to patients and families.

Kidney Cancer News

is a quarterly newsletter containing news of importance to patients, families, physicians, and public policy makers.

Pamphlets

are published for patients and physicians. Four of the most popular are *Access to Cancer Drugs World Wide*, *13 Steps to World Class Cancer Care*, *Emotional vs. Rational*, and *Managing Cancer Pain*

Support Group Meetings

are held by the Association several times per year in various cities so kidney cancer patients can meet other patients and learn how successful patients have dealt with their disease. Some emotional support, and a lot of practical advice to help patients and families.

A National Convention

brings patients and families together with the leading physicians and scientists in the field of kidney cancer. Held once per year, it is a unique medical conference which covers the newest therapies for treating kidney cancer and important issues such as patient rights. It is the ultimate support group meeting with patients from across the country.

kidneycancerassociation.org

Visit the KCA on the world wide web at www.kidneycancerassociation.org. E-mail us at office@kidneycancerassociation.org

If you do not have access to the web, your public library can provide you with access.

Physician Referrals

are routinely provided to patients, particularly those who are located in remote areas or who have complicated or unusual medical problems. The Association's Medical Advisory Board is also available to consult with physicians.

Public Policy and Advocacy Programs

are conducted by the Association to get new drugs through the FDA, increase research on kidney cancer, and reform laws and government regulations which influence the quality of patient care. Copies of KCA public policy papers, including testimony before Congressional committees and government agencies, such as the Food and Drug Administration, are available upon request.

Research Programs

are funded and encouraged by the Association. The Association can also put patients in touch with scientists working on specific projects in the field of kidney cancer.

Question & Answer Assistance

is routinely provided to patients who call the Association.

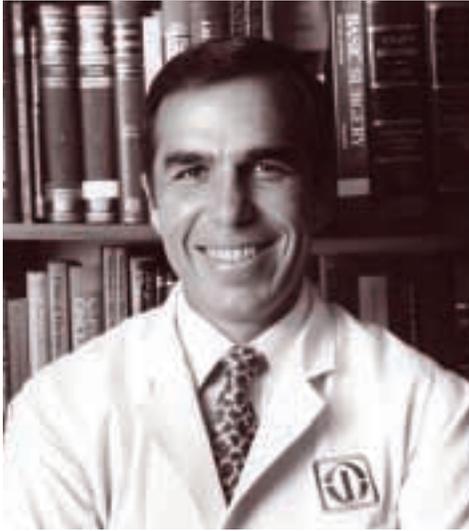
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Patients and healthcare professionals are encouraged to join the Kidney Cancer Association and to participate in its programs.

Membership is free and open to patients, family members, health professionals, and the general public. However, only contributing members have voting rights and direct the Association's work. Working together, we can change the world and improve the lives of all patients. You matter. You can make a difference.

About the Author



Dr. Roger C. Bone served as the Distinguished Professor of Medicine at Rush University-Rush Medical College in Chicago, Illinois. Dr. Bone was the President and Chief Executive Officer of the Medical College of Ohio between 1993 and 1996 and was previously the Dean of Rush Medical College and Vice President of Medical Affairs for Rush-Presbyterian-St. Luke's Medical Center.

Dr. Bone completed his undergraduate education at Hendrix College and accepted the Hendrix College Distinguished Alumni Award. He received his medical education at the University of Arkansas for Medical Sciences and underwent his residency training at the University of Texas Southwestern Medical School, where he was also a Pulmonary Fellow. Since his days as a medical student, Dr. Bone was actively involved in clinical and research activities and received many honors and awards for his efforts, including the 1997 Distinguished Investigator Award from the Society of Critical Care Medicine and an Honorary Doctor of Philosophy degree from the University of Arkansas for Medical Sciences. Dr. Bone published more than 1,000 articles and edited more than 56 books. He also served on the editorial boards of numerous journals and was a guest lecturer at over one hundred medical schools around the world.

In 1994, Dr. Bone received the American Cancer Society Courage Award. Rush Medical College and Rush University established the Roger C. Bone President's Endowed Chair, and committed all of the interest earned from that Chair to fund the Institute for the Study and Education of the Dying Patient. Dr. Bone succumbed to kidney cancer in 1997.

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