

To Die Well



Your Right to Comfort, Calm, and Choice
in the Last Days of Life

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Joseph Glenmullen, M.D.



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Against the complicated setting of modern medicine, life prolongation, and dying, I write this book for patients, families, and caregivers, in an effort to examine what contributes to a peaceful death and what does not. Specifically, the book is dedicated to those patients who did not have a peaceful death.

PREFACE



I've watched many families struggle with end of life. In this book I describe from my practice what has worked and not worked in the treatment of the dying patient, and I give the reader my observations as to what can ensure, as nearly as possible, a peaceful dying process.

Based on experiences from my practice and interactions with my colleagues, I address the turning points near the end of life when it is time to redefine the purposes of medical treatment. Is the goal to restore health, or is it time to change gears and instead concentrate on shepherding the patient as comfortably as possible through the dying process? Has life become so intolerable that dying is preferable to continued living? These are questions that need to be asked in a formal way with purposeful reasoning whenever a person is approaching the end of life. We shall see that a proper definition of the goals of treatment is critical to a peaceful dying.

This book also explores the ways in which patients and families can work with physicians to maintain control over the manner of dying. There are important questions to ask of physicians that are appropriate in a time when the former paternalistic approach by doctors is being replaced with shared decision-making in which patients' and families' wishes are paramount.

I've been able to write this book because of my own experience in the practice of medicine, in addition to work with organizations that promote the rights of the dying patient. I've written on end-of-life issues, and in the 1980s was the lead author of two articles, five years apart, in the *New England Journal of Medicine* on "The Physician's Responsibility Toward the Hopelessly Ill." Co-authored with several medical colleagues from around the country, one of these articles stated for the first time in a major medical publication that under certain circumstances it could be ethical to assist in the suicide of a dying patient who was suffering intolerably.¹ This belief, addressed in the chapters on hastened death, I still hold firmly.

The hastening of death in a terminal situation is different from what we usually consider suicide. Most of the time, we think of suicide as an inappropriate ending of life in a person who is psychiatrically depressed, whereas at the end of life the hastening of death in a situation of intolerable suffering should be regarded more appropriately as part of the whole spectrum of treatment. All of these actions are examined in detail in the chapters on hastened dying.

Many patients or families have graciously allowed me to include their stories in the book in the hope that their experiences might help others. All stories actually happened. Except for members of my own family, I have changed names and places and changed the story in minor ways to protect confidentiality.

Joseph Glenmullen, MD, helped me in the writing of this book through his discussions with me as to what should be in the book, his continuing critiques and suggestions during its writing, and his friendship.

Sidney H. Wanzer, MD
January 2000

TO DIE WELL

TURNING POINTS AT LIFE'S END



“What do you mean my mother has had a pacemaker installed to keep her alive?” I asked, aghast at the news. My ninety-two-year-old mother had severe Alzheimer’s disease and for years had been imprisoned in an undignified, meaningless existence.

“She developed a dangerous arrhythmia and would not have survived without it,” her physician responded.

“But her living will expressly said she didn’t want invasive medical procedures!”

At the other end of the phone, her physician was silent. Eventually, he repeated lamely, “She would not have survived without the procedure.”

“How could you have violated her wishes?!” I strained at the incomprehensible news. My mother’s living will, written long before she lost her mental faculties, made it clear she did not want her dying senselessly prolonged. Installing a pacemaker in this defenseless, ninety-two-year-old woman was nothing short of a massive medical assault. I was astounded. The news seemed unfathomable.

As soon as I was able, I flew from Boston to where my mother had been hospitalized. Nothing could undo the medical travesty that had been visited upon her, but I felt the need to see her, to question her doctor and the nursing home staff further, to do whatever I could to safeguard her wishes for the future. While I was the only physician in the family, my two older brothers shared my indignation over her medical treatment. Our father was spared the anguish over her mistreatment having died some fifteen years earlier.

All her life, my mother was a fiercely independent, intellectually vigorous woman used to making her own decisions. She was a large woman with a commanding presence—a career professional and mother in the 1930s and 1940s. She was a confident, handsome person whom I remember from my childhood days as being comfortably overweight. She had a wonderful sense of humor that balanced her natural tendency to assert her authority. In addition to raising three sons, she held various executive positions during a long and productive career. Ahead of her time, she was steadfast in her opinions, knew her own mind, and brooked no nonsense from anyone. She was proud of having shaken President Kennedy’s hand in the Rose Garden.

One of Mother’s more outspoken, well-known opinions was that she did not want her death prolonged if she became physically or mentally disabled and could no longer lead a meaningful, satisfying life. Many times over the years she proclaimed, “If I become senile, just take me out and shoot me.” In the 1970s, when living wills first came into use, Mother signed one, clearly indicating that she did not want her death prolonged by medical treatment if the quality of her life ever became so poor that there was no significant intellectual activity or reward. She entrusted the men in her life—my father, my two brothers, and me—with the responsibility for safeguarding this wish.

In 1985, when Mother was ninety years old, she fell getting out of bed and suffered a compression fracture of the spine. By then, she was forgetful and confused at times, a real change from all her previous years of direct and forceful action. After a month or so, it seemed clear to my brothers and me that she could no longer stay in the family home by herself. She and the three of us decided she

had to be admitted to a nursing home near one of my brothers.

Following the spine fracture, Mother's ability to participate in medical decisions declined rapidly but she was initially involved in decision making to the extent possible; we kept her apprised of everything. We made sure that her wish not to prolong her death with aggressive medical treatment was prominently displayed in her medical record at the nursing home. Each time I went to visit her, I spoke with the head nurse, reminding her of the situation. We gave her doctor a copy of Mother's living will and discussed it with him on several occasions. There seemed to be no chance that her life would be inappropriately extended.

After Mother had been in the nursing home for some months, it was obvious she had Alzheimer's disease. Her memory became extremely poor, and she volunteered no opinions about anything (we knew then that she was really impaired!). Her responses to comments or questions were only a few words or less, and her usual strong appetite for books and newspapers had vanished. She simply sat in her chair and looked around the room—her commanding presence was gone. She had lost a lot of weight and had a stooped, hesitant posture. She didn't like to leave her room in the nursing home because she "felt sorry" for all the old people lined up in the hall, sitting in their wheelchairs, looking vacant. Little did she realize that she was just like them. When I visited, Mother barely recognized me. Several years earlier, she would have been aghast to have known what would become of her. The only saving grace was that now she did not realize what had happened.

What to talk about on these visits was always a problem. Conversation was principally monologue on my part. On one visit, I thought Mother might enjoy a game of gin rummy. For years she had loved card games, and she and I had played hundreds of games of gin.

"Would you like to play a game of gin?" I asked.

"Yes," she brightened up.

I dealt. Mother picked up her cards and did some arranging of them in her hand. She knew all the motions to go through—picking up, discarding, making the little noises she always made as the game went on. "Ah! . . . Ummm! . . . That's good . . . Oh, my." Pleased that I had thought of this form of communication, I thought the visit was going quite well. Then, Mother said with a bit of triumph that she always went with displaying one's winning hand, "I'll go down now!" She spread out her cards on the table, but there was nothing winning about them at all. No card matched another! All the arranging of cards in her hand, the picking up and discarding, and the murmurs of satisfaction—it all meant nothing. She was truly senile. Mother, as we had known her all our lives, was gone. We "played" another couple hands and quit. I left that visit quite depressed.

The call from her doctor announcing Mother's pacemaker came just weeks after that visit. The nursing aide had been taking Mother's routine pulse and temperature readings, and noted her pulse was only thirty-five, about half of what it normally was. She had suddenly developed a dangerous irregular heartbeat, an arrhythmia. The treatment for an arrhythmia is surgical implantation of an artificial pacemaker beneath the skin. If this is not done, the patient will usually die quickly—within hours or a few days—due to heart failure. Symptoms include profound weakness and shortness of breath. The latter can be treated successfully with morphine, but without the pacemaker, death in the immediate future is fairly certain.

In Mother's case, this would have been the desired end of her indignity. She could have been treated with morphine to relieve any distress, and the unwanted prolongation of her life could finally have come to an end. That was exactly the sort of release from her senile imprisonment that she, my brothers, and I wished for her.

Instead, her doctor transferred my mother to the local hospital where a pacemaker was surgical

implanted. We were easily reachable for discussing Mother's options, but he had proceeded quickly—without notifying or consulting any one of her three sons.

My mother lived an additional *five years* in a helpless, debilitated state lacking all dignity, total contrary to her written request. During those five years, she had no quality of life left. Mother never left her room, where she simply stared at the wall. She had no communication with her old friends. Indeed, she would not have been able to recognize them. For the last two years of her life, she needed assistance to go to the bathroom and for all her personal hygiene.

We fired her doctor and engaged the services of another physician who promised that nothing further would be done to prolong her life artificially. Ninety-two when the pacemaker was installed. Mother was ninety-seven at the time of her second and final death.

WHAT WENT WRONG

In my mother's case, she had anticipated a turning point in life well in advance, long before Alzheimer's disease had robbed her of her full mental capacities, and her living will was designed far ahead of time to make sure her wishes were carried out. (Now, advance directives, such as health care proxies, discussed later in the book, go even further to protect the rights of patients.) With her living will in place and the many discussions we had with Mother's doctor and nurses, I thought everything was all set. But we made a big mistake. We did not ask her doctor explicitly, Do you agree with this approach and will you promise to adhere to our mother's wishes? He had simply listened to us, and we had erroneously assumed that he agreed.

When my mother was assaulted with a pacemaker, she had not been living for some time; she had been dying. The aggressive medical treatment did not prolong her life; it prolonged her death. The pacemaker did not restore Mother to health, but instead artificially prolonged her dying for five years—an indignity she had expressly stated she did not want to endure.

MY MOTHER'S LEGACY

My brothers and I never got over the feeling of trespass against my mother, and the experience profoundly affected my actions toward end-of-life patients for the rest of my career in internal medicine. My mother's treatment was so outrageously wrong that it made me vow to try to change things for others. After that experience, I resolved that I would become an activist in promoting end-of-life rights and ensure that those rights were, as nearly as possible, honored. This book is an outgrowth of my experience helping patients and families make health care decisions at the end of life. Over the years, I worked hard to change some of the principles doctors have used in end-of-life care—away from the paternalistic approach and toward the empowerment of the patient's right to choose the type of care wanted at the end of life.

THE FIRST LIVING WILLS

The first activist involvement I had was about forty years ago when I worked with the Massachusetts Committee for the Living Will. In retrospect, it is amazing to see how much opposition there was to the concept of the simple living will in the 1960s and 1970s, something we now regard as a routine matter. The living will stated only what one's preferences were in a document that was to be used as an aid in medical decision making when the patient was no longer able to participate. Yet, the living will was the focus of vigorous opposition by the Catholic Church. I vividly recall testifying before the judicial committee of the Massachusetts legislature on behalf of a law that would recognize the right of the patient to make such statements, at the time tangling with a monsignor of the Church who stated that "it is noble to suffer." However, society's regard for the principles of a living will was slowly and surely changing, and people began to talk about it more and more.

THE MEDICAL PROXY

In 1983, a new concept for protection of end-of-life rights was first enacted into law in California when the durable power of attorney for health care was approved—the medical proxy law. This permitted patients to delegate to an agent the power to speak on their behalf, if they were unable to do so, with the same authority that patients would have had if able to speak for themselves. This was a big advance in protecting autonomy at the end of life, and it was quickly followed in the next decade by similar laws in other states. The living will and the medical proxy are both discussed in more detail in [Chapter 12](#) on legal matters and medical planning.

DOCTORS SPEAK OUT

In 1989, a group of twelve leaders of American medicine wrote an article in the *New England Journal of Medicine* that outlined the responsibilities of the physician toward the hopelessly ill patient. I do not consider myself to be "a leader of American medicine," but I did organize the production of that article (along with the sponsorship of the Society for the Right to Die). Ten of the twelve authors felt that it could be ethical for a physician to assist in the suicide of a terminal patient who was suffering intolerably, under certain circumstances.¹ This was the first time that, in a major medical journal in this country, such a statement had been made, and it brought about a great deal of attention and discussion.

At the time of its publication, I was on a one-week visit to my boyhood home to say goodbye to my brother who was dying of lung cancer. The storm of media attention that the article generated resulting from that one sentence in the rather lengthy article, astounded me. For most of the first several days after the publication of the article, I was dealing with calls from newspapers, radio stations, and TV from all parts of this country and abroad—all in the same house in which my brother was dying at that very same time. Those calls persisted in a slowly tapering fashion for a year. They brought home to me how strongly people want ethical and moral approval for the option of ending life when suffering is intolerable. I found myself dealing at the same time with both the abstract principle of autonomy at the end of life and the realities of my brother who at that very time was dying a difficult death.

Similar articles that followed have given moral and ethical backing to physicians who have had discussions with patients about options for an earlier death. Timothy Quill stands out as a physician who courageously detailed and publicized his efforts to aid a suffering patient in 1991 and his own father in 2004 in articles in the *New England Journal of Medicine*.²

A RECENT CATALYST FOR THE PUBLIC'S ATTENTION

In 2005, the Schiavo case drew national attention to the tragedies that can occur at the end of life when planning is either not done or is not carried out in practice. The most troublesome problem in the Schiavo case was that no documentation—neither a living will nor a health care proxy—existed to substantiate that Terri Schiavo, a patient living in a persistent vegetative state, would not have wanted her life prolonged. In the absence of such documentation, Terri Schiavo's husband, Michael Schiavo, ended up in a legal battle with her parents, Mary and Bob Schindler, who wanted to continue life support. Eventually, support was withdrawn, and she was allowed to die. But, by the time the conflict erupted in 2005 in the national media, Terry Schiavo had already lived in a vegetative state, with no hope for recovery, for fifteen years!

Proper attention to two turning points in decision making near the end of life can help prevent the problems my mother and Terry Schiavo had. These turning points must be recognized if serious difficulties are to be avoided. That is the crux of this book.

WHAT ARE THE TWO TURNING POINTS AT THE END OF LIFE?

The first medical turning point near the end of a person's life is the time when the patient turns away from aggressive treatment aimed at restoring health and opts instead for comfort measures to ease the dying process. A second turning point may occur in a very few patients who are suffering intolerably in spite of all comfort measures that are properly administered, such that the patient wishes to hasten dying and thereby shorten the period of suffering. Critically important for this second turning point—that most patients do not need to face, but sometimes do—is the availability of legal options for relief discussed later in this chapter and in [Chapter 8](#) and [9](#).

THE FIRST TURNING POINT: OPTING FOR COMFORT CARE ONLY

During most of our lives, medical treatment is aimed at curing illness and restoring health. With our doctors, we push ahead vigorously to try to achieve a cure or improvement. The basic premise is that recovery to a satisfying, meaningful life is possible, and the efforts of patients and caregivers reflect this goal. Treatment may be rigorous, sometimes painful, and with many side effects, but they are

justifiable and are usually accepted, when restoration of health is the eventual goal.

~~With all that our doctors can do now to restore health and prolong life, most of the time we are~~ debt to modern medicine. However, when cure or significant improvement is no longer possible in person near the end of life, the goal of therapy should change to that of providing comfort care alone—not prolonging the dying process. This turning point is critical to recognize because, if it is not recognized, inappropriate extension of life occurs.

Only in the last half-century has this decision to change goals become necessary. In the pre-antibiotic era, desperately ill patients frequently succumbed to untreatable pneumonia, and many of the life-prolonging procedures we now consider routine simply did not exist. The situation then was far simpler with regard to decisions about pushing on with treatment. One did everything one could until the end when death mercifully supervened due to natural causes. Now, we have incredible technologies with which life can be medically improved and prolonged. This is progress, but when medical technology is not reined in appropriately, life can be prolonged beyond the point of positive return. The price paid emotionally and physically—and the quality of life—may not be worthwhile, and many of us in this situation might feel we were better off if nature were simply allowed to take its course.

The purpose of medical care at this first turning point should become that of easing the patient through the dying process as painlessly and comfortably as possible. This does not imply less care, but simply redirecting care toward reducing pain and distress, and allowing the patient peaceful last days. This turning point should be defined *before* treatment is begun that might unintentionally prolong life.

Another story illustrates the problem. This story along with that of my mother sets the stage for the rest of the book, which explains the ways patients can avoid these unfortunate situations and stay in control at the end of life.

RICHARD: A LONG DYING

Joseph Glenmullen had a haunting experience with the wrong kind of end-of-life care while working in the emergency department of a community hospital during his training. Like most community hospitals, it drew patients from the practices of nearby physicians and nursing homes. His story follows.

Especially on Friday afternoons and evenings, when the staffs of the local nursing homes would be reduced for the weekend, the ambulances would roll up to the emergency department doors one after another with elderly patients brought for more aggressive treatment than was available at the nursing homes. One of the most common scenarios was that of patients being brought in for aggressive treatment of pneumonia with intravenous antibiotics. These elderly patients typically had severe dementia, often Alzheimer's disease. They had few cognitive abilities left: few memories and little or no idea of who they were or what was happening to them. In the hospital, they would be poked and prodded with intravenous needles. Often, they had to be restrained in the bed because they would not cooperate, their wrists and ankles bound to the bedposts. Their scanty clothing, a thin hospital johnny was constantly twisting off them as they writhed in bed, exposing their naked vulnerability. When I was on call, I would be awakened all night long, paged by the nurses to restart IVs these elderly patients had torn out in their efforts to wrestle free of their restraints. As I would restick them

with their IVs, all I could think was, pneumonia would be these patients' best friend, a release from their living deaths. Instead, they were subject to a relentless medical juggernaut.

One patient in particular, Richard, has always stuck out in my mind. He was wheeled into the emergency department having fallen out of bed at the nursing home and broken his hip. He had severe Alzheimer's-type dementia; his mind was completely gone; one could not communicate with him in any meaningful way. His arms were gaunt and outstretched, tied to the corners of the hospital stretcher, and his legs were bent at the knees by contractions of what remained of his wasted muscles. Richard looked crucified on the hospital gurney.

Richard's life had been devoid of any quality for years. I assumed he was coming to the hospital for control of his pain from the hip fracture. Imagine my surprise to discover he was being admitted for a total hip replacement! "Why put someone in his condition through such a traumatic surgery?" I asked one of the senior doctors in the emergency ward. "We don't have time to ask those questions," was the reply from the senior doctor as he looked forlornly at the rows of patients on stretchers lined up waiting to be seen. Then he added, with painful resignation, "His hip replacement will be practice for an orthopedic surgery resident."

Looking at Richard, I knew I did not want to live out the last years of my life warehoused in a nursing home, with my brain wasted away, my carcass kept alive by merciless medical treatment, waiting to be used for "practice" in medical training. Nor did I want that to happen to anyone in my family, to anyone I love.

When I heard Richard's story, the phrase "warehoused in a nursing home" jumped out at me. Harsh as it sounds, that's exactly what happened to my mother in the five years she lived after getting a pacemaker. Even before Richard was medically assaulted with a new hip, with his severe Alzheimer's dementia, he had no quality of life left. His was a failed turning point for many reasons: the lack of preplanning, the lack of an advance directive such as a medical proxy, the lack of involvement of family members who could have changed the course of his treatment, and, most of all, the lack of any recognition of the need for a turning point.

In Richard's case, as in my mother's, the doctors became too narrowly focused on treating the diagnosis instead of the patient. Richard was treated as a "hip fracture," and my mother was seen as a case of "arrhythmia," rather than the whole human beings they were. In both instances, nature was not allowed to take its course. Instead, aggressive medical treatment intervened to prolong their dying. This is also what happened to Terri Schiavo, who languished in a nursing home for fifteen years before the conflict between her husband and her parents came to a head in 2005.

THE SECOND TURNING POINT: A HASTENED DEATH

In rare instances after the first medical turning point toward comfort care only has been reached, even meticulously rendered, maximum comfort care is not enough to control a dying patient's suffering. Under these circumstances, a hastened death is an option some of us might wish to exercise, and it may be the most humane approach. This is done only when death is clearly imminent, anticipated suffering is intolerable to the patient, and all comfort measures have failed.

Due to advanced medical technology, the majority of us will have to take the first turning point some time in our lives— abandoning aggressive medical treatment in favor of comfort care only. B

very few of us will ever reach the second medical turning point of hastening death because modern medicine is so sophisticated in controlling pain or distress. There are few failures to provide reasonable comfort. Still, everyone should be prepared in advance to consider this second turning point should it become necessary. Even in the rare instances in which pain or distress cannot be adequately controlled, some patients will still not want to hasten death. That is their right. Likewise, it should be the right of those who do wish to hasten death to do so, in these rare circumstances.

This second turning point will be discussed in much more detail in chapters toward the end of this book. We shall see that hastening death because of intolerable distress can take several forms, some of them absolutely legal and noncontroversial and some involving the patient's directly taking his or her life, which can be much more complicated legally. As of this writing, in the United States, the latter is clearly legal only in Oregon, where such a death is usually referred to as "physician-assisted suicide."

I prefer the term *physician aid-in-dying* or *hastened dying* because hastening of death in a terminal situation is different from what we normally consider to be suicide, which is most commonly thought of as the act of a person prematurely and inappropriately ending his or her life. By contrast, physician aid-in-dying can be seen as medical treatment, part of the spectrum of options for people suffering from the end of life.

Later chapters will discuss methods of hastening death used by patients in recent years, including methods that are legal and ethical, and also methods that are still evolving in their acceptance by public opinion and our legal system, such as barbiturates (in states other than Oregon) and the growing use of inhaling helium as ways of hastening death for terminally ill patients.

THE IMPORTANCE OF RECOGNIZING LIFE'S TURNING POINTS

Planning for and taking life's turning points represent some of the biggest decisions you will make in your life. This is true whether you are making the decision for yourself or helping a parent, spouse, or other loved one to make the decision. For this reason, turning-point decisions need to be formal discussions among the patient, family, doctors, nurses, and anyone else who will play a key role in supporting the patient once the decisions are made. Later chapters of this book offer the key issues and questions that need to be addressed to ensure that all aspects of the decisions are considered. These include looking carefully at the patient's diagnosis, prognosis, second opinions, treatment choices, and quality of life—in addition to the various options that can help ensure a peaceful death.

The key to staying in control of one's medical fate is educating yourself about the options, deciding in advance what course you want treatment to take, clearly communicating this to a medical team, making sure they agree to follow stated wishes (or finding others that do), and legal empowerment of family members to act on your behalf if and when you are no longer able to act because of physical or cognitive disability.

This topic has become politically charged. The Schiavo case demonstrated how the "pro-life" constituency in this country has organized itself against the right to stay in control of the end of life. This has become one of the most hotly contested issues in the national political arena, and has led many people to reflect on their own choices and values. Against this turbulent background, *To Die Well* is intended to provide you and your family with the information you need about the last days of your life.

RIGHTS OF THE DYING PATIENT



In order to plan for the best care at the end of life, it is vital to understand your rights as a patient. These are numerous, which most people do not realize. The majority of these rights, which ensure comfort and dignity and allow patients to remain in control at life's turning points, are protected by court decisions that have become established case law, based on constitutional rights and common law. As a result, the rights enumerated in this chapter are legally and ethically not controversial. Every patient and family member should be aware of them.

WHAT ARE YOUR RIGHTS?

Absolute or near-absolute rights, protected by our courts:

- *If you are no longer able to participate in medical decision making, you have the right to have your medical proxy (agent) speak for you with the same authority that you yourself would have if you were still able to make decisions.* This presumes that you have made in writing such a delegation of authority, a subject covered in the chapter on legal matters and medical planning. The appointment of an agent ahead of time is essential if your wishes about end-of-life care are to be carried out.
- *You have the right to have pain and suffering relieved with sufficient medication and vigorous pain management.* This is not codified in law in many states, but it is almost universally agreed upon by organizations that promulgate national medical standards of practice (e.g., Joint Commission on Accreditation of Healthcare Organizations). At life's first turning point, comfort care becomes the focus of treatment rather than restoring health. Even though relieving pain and suffering with large doses of medication can run the risk of an earlier death, pain relief is a priority at this stage in life, and adequate pain relief is essential to ensuring your comfort and dignity. This right is placed under the "absolute or near-absolute" category, although I recognize that it is sometimes not respected. Some doctors are still excessively wary about using enough medication to relieve symptoms, and patients or their agents may occasionally need to insist that this is standard medical practice and must be observed. You should ask your doctor, nursing home, hospital, or hospice what their policies are regarding pain management, since such policies may have a huge effect on your future comfort.
- *You have the right to refuse all unwanted treatment.* This is true even if refusal might bring about death more quickly. The refusal by you or your legally appointed agent of any undesired treatment or procedure is an absolute right. No one can carry out any medical

action that affects you without your consent, no matter what it is. The only exception to this might be in the instance of someone administering emergency care to you if you are suddenly not able to speak in your behalf and the attending person does not know your circumstances, or a very special and infrequent circumstance of some sort that has required the intervention of a probate court.

- *You have the right to refuse any unwanted treatment that has already begun.* This can be more difficult psychologically than refusing a treatment before it has been started, but ethically and legally there is no difference between discontinuing an already established treatment and not having begun it in the first place.
- *You have the right to refuse all nutrition and hydration.* This is also an almost absolute right, and it can be of great importance if a dying person wishes to shorten the period of terminal suffering. Refusing all liquids leads to dehydration and an earlier death. This is discussed at length in the chapter on hastened death.
- *You have the right to refuse cardiopulmonary resuscitation (CPR).* CPR is known as a “heroic measure” in medicine. Most people want heroic measures only when restoring health is the goal of treatment. Insuring this requires special do-not-resuscitate orders in accordance with state public health department regulations regarding emergency care, discussed later in the book.
- *You have the right to change doctors.* Doctors vary in their willingness to discuss end-of-life options, and they vary in their comfort level with patients who want to maintain control. Change doctors if you are not entirely satisfied with this critical member of your health care team. You are a customer who is purchasing a product (health care), and you have every right to choose who provides that care. Sometimes, due to local circumstances, HMO restrictions, or geography, this freedom of choice may not be easy to bring about, but if there is a choice available, you can make it. I have found that patients are often embarrassed to bring up the subject of changing doctors, but they should not be. This involves emotions and personal considerations, but the patient as a consumer has the right to make the decision.

Agreed-upon rights, but not necessarily backed by specific law in every state:

- *You have the right to have valid advance directives considered.* Advance directives are formal, written decisions made prospectively about your end-of-life care, directions that indicate your wishes in advance. Living wills, medical proxy designations, and do-not-resuscitate (DNR) orders are examples that are all discussed in the chapter on legal matters and medical planning. The degree to which they are binding is discussed in that chapter. Living wills, simple statements of your wishes, may or may not be binding. Other forms of advance directives have more legal force. The situation can vary from state to state and situation to situation, although the basic principles are generally recognized.
- *You have the right to be fully informed of all treatment options available to you for end-of-life care.* Ask your doctor about all the options, especially palliative treatment. He or she should inform you of the risks and benefits of each option (whether palliative or curative in aim) as well as the probabilities of treatment success. This is part of “informed consent,” which is now the subject of many regulations by governmental agencies and

standard-setting groups (e.g., Joint Commission on Accreditation of Healthcare Organizations), plus case law. The doctor has an obligation to inform the patient fully about his or her illness and treatment options and procedures. Not informing the patient fully is substandard medicine.

- *You have the right to know the ways in which undesired lengthening of life can be avoided in situations of suffering at the end of life.* This is discussed in detail in the chapter on hastening death. In a way, it falls under the right to informed consent, noted previously, but you will find few laws or regulations that specifically address undesired prolongation of life. Rather, it is what a conscientious doctor would discuss with the patient. Your doctor should raise this issue, and, if he or she does not, ask about it yourself. If suffering is intolerable despite all efforts directed at relief, you can inquire about legal options for hastening death and not prolonging the dying process. Your doctor—due to personally held beliefs—may not agree to assist in legal ways of hastening death, but you certainly have the right to ask. Organizations, such as *Compassion and Choices* and *Final Exit Network* (both discussed later in the book), can discuss legal options on this subject if your doctor will not. Very few patients actually ever need aid-in-dying, but every patient should think through this critical question in advance.

HOW CAN YOU ENSURE YOUR RIGHTS ARE HONORED?

Although the previously mentioned rights are well established and generally not controversial, they are often disregarded, most often because patients and families do not realize what their rights are. Even doctors sometimes need to be reminded and educated about these rights of the dying patient.

There are ways in which people can ensure their rights are respected and their wishes for end-of-life care are met.

- Knowing your rights is basic and most important. You need to be prepared to stand up for them—insist on them.
- Discuss your rights with family and caregivers. Talk about potential problems.
- Always remember that you alone are ultimately in charge of what is done and not done as long as you are competent. This is a very basic concept that confuses many people.
- Make your wishes clear so that you do not leave decisions to others who may make choices for you that you would not want. Indicate your wishes ahead of time with advance directives. This helps you stay in charge when you are no longer competent. If you become unable to make medical decisions, your appointed agent (proxy), speaking on your behalf, can protect your interests. This person needs clear prior instruction by you and needs to act vigorously in your behalf. (Living wills, medical proxy designations, and DNR orders are discussed in [Chapter 12](#) on planning ahead with advance directives.)
- Define goals and stay focused on the goal of treatment—one of the most important ways of ensuring rights are met. Is restoring health the goal? Or, have you reached the turning point where comfort care becomes the goal? If definition of goals is done as a formal

exercise, the protection of rights and care of the patient are made much easier.

- ~~Keep treatment in the simplest setting possible (i.e., home, hospice facility, nursing home, and hospital, in order of increasing complexity). The simpler the setting, the more easily rights can be ensured. This dictum tends to be true as long as proper and sufficient palliative care can be rendered in the simpler setting. Sometimes, it might not be possible to get the needed degree of palliative expertise in the simpler setting, and, in this case, one might give up some degree of control in the more complicated setting as the price to be paid for the expertise. In the next chapter on comfort care, we shall see how increasing complexity of treatment increases the difficulty of protecting rights. Most of the time, rights are most easily protected at home when home care is workable and feasible. Avoid transfer to the hospital unless it is clearly necessary for the control of symptoms.~~
- Ask for a referral for hospice care. The hospice movement has matured greatly in the last twenty years, and expert advice on and assistance with end-of-life problems is now available from hospice units in almost all communities. This does not replace one's usual health care team, but supplements it. Hospice is used to working closely with other health-care providers, and they can provide invaluable help.

THE OFFICE VISIT: AN OLDER PERSON CONFUSED ABOUT RIGHTS

Alice was a charming woman in her mid-seventies, extremely devoted to her husband George, who had suffered a very bad stroke the previous year. This was evident from the way she spoke of him—lovingly and gently. Her son Wilbur accompanied her to my office, and I was instantly won over by them. The patient himself, too disabled to come with his family, must have been a wonderful man. He had to have been, to have such a wife and son.

Alice had been referred by a psychiatrist colleague of mine who had called to ask if I would speak with them about their options for George at the end of his life. Following the stroke, George had been unable to speak. Communication was reduced to questionably meaningful nods of the head. He choked on food and water and was fed via a gastrostomy tube into his stomach. He had had repeated aspiration pneumonia, which precipitated hospital admissions and antibiotics. He had been in several fine institutions, starting with a famous tertiary center where he was on a respirator, ending with his present nursing home. Whenever George had a threatening fever or respiratory difficulty, he would be rushed back to either an emergency room or a hospital ward for aggressive treatment. He remained totally, completely, and hopelessly disabled.

Alice was confused as to what she should do. She had a properly executed medical proxy that gave her complete authority to speak on her husband's behalf, but she did not really understand that she had that power, and, if she had known, she did not know what to do with it. She was distressed at George's predicament and felt desperately that *something* needed to be done—but was not sure what that could be.

We talked for an hour, and I gave her my thoughts. At the end, as Alice and her son left, both expressed profound appreciation for what I had told them and said that no one in all their multitude of medical contacts had ever spoken to them about my suggestions. They left with new resolve to address

George's predicament in a different way—and they seemed relieved and somewhat encouraged.

What had I told them? I discussed what to me were simple concepts and plans of action, not profound or controversial. They were the rights listed previously, all commonsense statements that simply needed to be clarified and understood by the wife and son. I told them not to feel guilt for a firm decision to render comfort care only. George was slowly dying from his stroke, and they were not killing him by saying no to further aggressive intervention. I emphasized that there was no difference ethically or legally, between a treatment discontinued and a treatment never started in the first place. I urged them to identify the medical person in charge (it needed to be one doctor). Above all else, I pointed out how important it was to work with that person to define the goals of treatment, which were no longer to restore health but rather to provide comfort measures only to ease the dying process.

The rights that exist for patients at the end of life are powerful rights, but they are of no avail if not understood and championed.

THE FIRST TURNING POINT: FROM ACTIVE TREATMENT TO COMFORT CARE



WITHDRAWING UNWANTED TREATMENT, THE FIRST STEP

The first turning point, as we saw in [Chapter 1](#), is that time in a dying patient's illness when there is no reasonable expectation of a cure or of restoring health. Efforts now turn solely to providing the care that will keep the patient as comfortable and peaceful as possible through the dying process.

Stopping aggressive treatment aimed at curing the illness is the essential first step of comfort care. This decision can be difficult even when the patient and family realize the turning point has come and agree that comfort care only is the correct approach.

This was illustrated to me by Marie, a woman in her fifties who had cancer of the esophagus. She was a housewife who had raised a family of several children in a suburban town outside Boston and also held a part-time job in one of the retail stores near her home in order to help meet family expenses. Marie was a very hard worker who loved her family and life. Unfortunately, she had been a heavy smoker, and cancer developed in her esophagus—one of many areas where cancers can arise as a result of smoking. Marie had an initial surgery to remove what portions of the cancer could be removed, and then she received radiation. (This was many years ago, and there was no chemotherapy at that time that was thought to be helpful or advisable for that particular growth.)

Marie's cancer recurred and began to block her ability to swallow. She regurgitated food and fluids, which she could not get past the obstruction in her upper esophagus. A small feeding tube was surgically placed through the abdominal wall into Marie's stomach. Through this tube, she received liquid nourishment for a number of weeks during which time she swallowed nothing by mouth—thereby avoiding the obstruction. However, Marie continued to waste away due to the advancing cancer, and she became profoundly weak. Her body chemistry was abnormal. She began to speak very little and to sleep fitfully much of the time. Medications were necessary to control general distress and anxiety, and morphine seemed to work best.

In one of the last real conversations she had, Marie told me and the family, "I want to die, and I want the tube feedings to stop." She said this at just about the time I would have said the same myself were I in her position. Until then, she could interact with her family and friends to some extent, but now she could do so only with great effort. She had no enjoyment of any part of the day and was bedridden. Marie wanted to be freed from her ordeal and did not want further treatment other than comfort measures. This seemed to me and to Marie totally rational and appropriate, but it was difficult for the family to accept. However, after considerable discussion with the family, and with their approval, I removed the feeding tube, and from then on Marie had no more fluid administered to her.

any route other than the tiny amount needed for intravenous administration of morphine. She quickly became dehydrated, which was not a distress to her in her somnolent condition. The continuous use of fairly large doses of morphine prevented her being aware of any distress. She died several days later quietly and peacefully.

Marie's tube feeding had become an unwanted treatment and an obstacle to a peaceful and natural death, and at her request it had been withdrawn. That alone sufficed to hasten the end of her suffering. Withdrawing treatment in this situation was accepted by the patient, family, and her caregivers—not happily or easily, but realistically and eventually without reservations.

The stopping of unwanted treatment stands out clearly as the first thing to do when the goal of treatment switches to comfort care only. There is absolutely no legal or ethical problem with this, although it is amazing how many people feel that it is somehow improper to stop a treatment that has already been started. That belief is wrong. There is no difference legally or ethically between stopping any sort of treatment and never having started it in the first place. This includes chemotherapy, surgery, radiation, hormone treatments, or other aggressive measures, plus such simple measures as intravenous fluids or liquid nutrition given through a feeding tube into the stomach.

The decision to withdraw treatment may be difficult psychologically, as well as emotionally. Because it is human nature to worry about stopping a treatment that one has previously had enough faith in to begin. However, if the first turning point has been taken in a formal way through discussions among patient, family, and doctors who agree that it is highly improbable health can be restored, and if the goals have been redefined, this option of stopping a previously initiated treatment should not present a problem psychologically.

WHAT IS IDEAL COMFORT CARE?

In the last decade, palliative (comfort) care has become a specialized form of care in that there is now a defined body of knowledge about what works best. It is something physicians and other caregivers have had to learn. When this knowledge and these skills are put to use, terminal patients in the great majority of instances *can* be kept comfortable.

Optimal comfort care means that the physician will exert meticulous care, attention to the smallest details, close and frequent follow-up, extreme compassion, and the best pain management (the latter addressed in the next chapter in more detail). Comfort care means paying attention to a myriad of problems that can lead to distress or unease, whether physical or psychological in origin.¹ Because this is now the caregivers' principal obligation, all the emotional energy invested in seeking a cure can be directed to the patient's immediate well-being in an all-inclusive approach—ideally with frequent visits from the physician and other support personnel. Although much of comfort care is common sense, specialized skills may be necessary, and the doctor or patient should not hesitate to ask for whatever consultations are necessary, especially in the area of pain control.

Comfort care does not imply less attention from the doctor. There is an unfortunate tendency on the part of some physicians for this to happen, since, after the first turning point, the more dramatic and appealing attempt to cure the disease is put aside. When this is done, a few physicians are let down when the patient and family decide to abandon attempts to cure, and may tend to “let the nurse or hospice take care of it.” Comfort care cannot be regarded as simply something to be done in the

absence of more worthy goals.

~~In my own practice, I was able to give this care personally, whether in the office, hospital, or home—and the location and frequency of visits with the dying patient were my choice. These days you may find it difficult to get the personalized attention from your physician that you desire. There are a number of factors causing this to be true: the highly specialized nature of much of our medical care now, insurance considerations, and the great pressures on physicians to see more patients per day. A lot of work goes into work against having your doctor attend you as frequently as you would like, especially at home. Most doctors do not make house calls and the physician consequently delegates more of the care at the end of life to either the nurse or hospice worker. That is a reality I accept but not one with which I agree. Strong advocacy for your needs may solve this to some extent but, most likely, not completely.~~

To ensure meticulous comfort care, you should consider engaging the services of the hospice movement, which can be extremely important in translating the change in goals into reality. Almost all dying patients can benefit by the involvement of hospice experts. To get the full benefit of the hospice approach, they should be consulted early, as soon as the turning point has been reached and goals have changed. Hospice is discussed in more detail later in this chapter.

UNDERSTANDING WHAT SYMPTOMS ARE PART OF THE DYING PROCESS

Patients and families need to understand that some happenings are part of the dying process so that the patient who is receiving comfort care is not pushed to fight fruitlessly against symptoms that need to be accepted. Avoiding food, not taking in much fluid, subsequent dehydration, extreme lethargy, sleeping a lot, and the inability to get out of bed are all prime examples of symptoms that naturally occur in the dying process and should not be fought by family, caregivers, or the patient.

I have frequently seen families of dying patients struggle vainly to get the patient to eat more or to “you can keep your strength up” or to urge the patient that he must get out of bed because “you will lose your strength.” These are useless exhortations for the dying patient and serve only to make the situation more stressful. Acceptance of these symptoms as a normal happening will allow a more peaceful death.

This does not mean that all symptoms that go along with the dying process should simply be accepted—far from it. Many things can happen that can successfully be treated and relieved, while not prolonging dying. For example, breathlessness can be due to a variety of causes, and the symptom is usually treatable. If the underlying cause is not remediable, the symptom itself can be dealt with by morphine, an excellent agent for suppressing the feelings of shortness of breath. Anxiety and panic feelings are often present, and these are clearly responsive to anti-anxiety medications that are quite specific for these particular symptoms. And, as we see in the next chapter, pain is definitely in the category of treatable symptoms.

Drs. R. Sean Morrison and Diane Meier at Mount Sinai School of Medicine in New York City recently wrote an excellent summary of symptom control at the end of life, referring to nausea, constipation, depression, anxiety, shortness of breath, and pain—all being symptoms that mandate the attention of the physician and other caregivers.² The bottom line is to accept the first category of symptoms in the dying patient (lethargy, weakness, no appetite, weight loss, and others), as noted previously, but to aggressively address the remediable forms of distress, as described by Morrison and Meier. Discuss with your doctor which is which.

THE LITTLE THINGS ARE ALSO IMPORTANT WHEN ONE IS DYING

Sometimes even the smallest details can be an upsetting problem for the patient, as I experienced recently.

My oldest brother, Bob, died with prostate cancer at age eighty-five in North Carolina only a few weeks before I wrote this chapter. He had this disease for about ten years and was originally treated with radiation. Several years ago, the cancer recurred, and his physicians started him on hormone therapy. Surgery for increasing bladder outlet obstruction by the cancer growth was not a feasible option because of the previous radiation in the area, and some months before his death, he required the insertion of a permanent catheter into the bladder to allow proper urine flow. He began to lose weight

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