

Marquette Elder's Advisor

Volume 1 Issue 4 Spring

Article 5

When a Person Wants to Die: Legal Considerations

Charles F. McKhann Yale University School of Medicine

Follow this and additional works at: http://scholarship.law.marquette.edu/elders



Part of the <u>Elder Law Commons</u>

Repository Citation

McKhann, Charles F. (2000) "When a Person Wants to Die: Legal Considerations," Marquette Elder's Advisor: Vol. 1: Iss. 4, Article 5. Available at: http://scholarship.law.marquette.edu/elders/vol1/iss4/5

This Featured Article is brought to you for free and open access by the Journals at Marquette Law Scholarly Commons. It has been accepted for inclusion in Marquette Elder's Advisor by an authorized administrator of Marquette Law Scholarly Commons. For more information, please contact megan.obrien@marquette.edu.

When a Person Wants to Die: Legal Considerations

With the legalization of physicianassisted suicide in Oregon, individuals
in other states have begun to closely
examine their own legislative restrictions and their personal options to
determine end-of-life decisions.

Examined below are the medical reasons why people may want to die, the
legal background and current status of
existing laws, the various options open
to the terminally ill person (voluntary
dehydration, suicide, assisted dying,
euthanasia, and the double effect), and
the role of the legal counselor.

By Charles F. McKhann, M.D.

he thought that a person who is seriously ill may need to turn to an attorney for advice on how to end his or her life is hard to imagine. However, that day may be approaching as the complexities associated with illness and death implicate legal issues. The legalization of physician-assisted suicide in Oregon has encouraged individuals in many other states to closely examine their own legislative restrictions and their personal options, both legal and otherwise. This article will discuss the medical reasons why people may want to die, the legal background and the current status of existing laws, the various options open to the person who is terminally ill, and the role of the attorney in counseling such a person.1 While information about mechanics and methodology for ending life would probably come from a physician, an attorney is a reasonable source for information about minimizing the legal risk for family, friends, physicians, and other caregivers.

Why Would a Person Want to Die?

Someone who is seriously ill and has a short life expectancy may wish to terminate his or her life for a variety of reasons. Foremost among them is to avoid unnecessary pain and other forms of suffering, including common events such as nausea, vomiting, inability to swallow or talk, incontinence, extreme fatigue, and a sense of suffocation. Closely associated with these actual symptoms is the fear of such symptoms. Cancer patients usually experience severe pain before adequate pain control can be instituted. Because more medication may be needed later, large doses of morphine are not used to control low levels of pain. Instead, medication is increased as needed and not usually before the patient experiences the more severe pain. Hence,

Charles F. McKhann, M.D., is a professor in the Department of Surgery at Yale University School of Medicine, New Haven, Connecticut.

the fear is founded on experience and reality. Another reason a person may wish to die is to maintain desired levels of dignity and quality of existence, preferring to end life before these two goals are obliterated by disease. Finally, and perhaps most important, is the desire of many to exercise their autonomy and to be in control of the circumstances of their dying. This desire often comes to the fore in response to the significant loss of control imposed by the disease and its treatment.

In an era of managed care, which is all too often mismanaged, with many millions of people uninsured, it is uncomfortable to think that severely ill people would wish to shorten their lives for financial or altruistic reasons. However, the complexities of our health care system are such that this is indeed a fact and likely to remain so for years to come. The burden of prolonged terminal illness can wipe out the savings of a family. For some families, the financial burdens may extend one or two generations beyond the person who is dying, taking with them college educations and financial security.

History of Suicide

In ancient Greece and Rome, suicide was an honorable and accepted way to end life in the face of significant suffering. Physicians were expected to provide hemlock and other drugs to make this possible. Although suicide was always against the teachings of Judaism, early Christianity tolerated it because the promise of eternal life in heaven was made so attractive that many sought martyrdom to obtain this goal. This attitude was finally brought to an end in the fifth century A.D. by St. Augustine, who taught that suicide was the deliberate killing of oneself and therefore prohibited under the commandment "Thou shall not kill." This prohibition was absolute and remains so today in the teaching of the modern Catholic Church. The church, however, was joined by the state in the late middle ages. Kings could see no reason why the church should confiscate property following a suicide while they. the rulers, needed the money just as badly. By making suicide against the law, the crown could acquire the property, and did so until modern times.

The twentieth century saw the medicalization of suicide. Suicidal thoughts or attempts were considered signs of mental illness and to be treated if at all possible. In the 1960s, various states abolished

their laws against suicide, not because they thought that suicide was truly justifiable, but because making the suicide attempt a criminal act gave the wrong message to patients who needed treatment if they survived. In full bloom, the medicalization of suicide presumes that people who wish to end their lives prematurely are by definition mentally disturbed, irrational, and not responsible for their actions.

Bad Deaths

While it seems irreverent to think of any deaths as being good deaths, there are some illnesses that are often associated with prolonged and severe terminal suffering. These include cancer, AIDS, two neurological diseases associated with severe muscular weakness (multiple sclerosis and amyotrophic lateral sclerosis, or Lou Gehrig's disease), and pulmonary failure. Added to this list must be the most common and in many respects the most feared of all afflictions of the aged, Alzheimer's disease.

Years ago, we feared being snuffed out by disease too early in life. Now, in far greater numbers, we fear prolonged dying with extreme suffering or even lingering deaths that may include years of being incapacitated and in nursing homes. Public interest in assisted dying is centered on our fears of these two possibilities, fears that are reinforced by the experience of family and friends and by visits to hospitals, hospices, and nursing homes. Today, we are beginning to realize that it is possible to have longer and more fruitful lives and still be spared the needless distress of a bad death.

Rational Suicide

We are gradually recognizing that people who want to die are not all necessarily depressed and irrational; rather, some have valid reasons that are easily understood by objective and rational people. People wishing to terminate their lives understand their diseases and where they are in the course of their illnesses; the alternatives to an earlier death such as further treatment, comfort care, and/or hospice; the impact that an earlier death will have on their family and friends; and the compatibility of the decision with their other personal values and beliefs. They may have considered their decision over a significant period of time and discussed it with objective listeners such as physicians, attorneys, and family members.

Although an individual may not be competent in all spheres, he or she may be perfectly competent to make medical decisions. For example, a sane person may not be able to balance his or her checkbook or even know today's date. In the medical sense, competence is a decision-specific process. Absolute orientation to time and place is not required to understand the risks and consequences of dangerous but potentially life-saving surgery. It should be understood and accepted that the desire of seriously ill patients to shorten the duration of their suffering is by itself no reason to consider them incompetent to make a medical decision.

Closely associated with competence is the question of depression in people who wish to end their lives and suffering early. Clinical depression, which often leads people to suicide, is usually quite distinct from the sadness and "reactive" depression that is experienced and expressed by people with fatal illnesses.2 Superficially, the two emotional states are similar in that insomnia, fatigue, loss of energy, poor appetite, weight loss, and feelings of hopelessness are common to both. The distinction between clinical and reactive depression is that the person who has clinical depression usually has a history of previous depressive episodes, even attempts at suicide, and often has required treatment. Such people are usually withdrawn and have poor relationships with others. They express feelings of worthlessness, guilt, shame, and low selfesteem. Their depression is often complete, extending to every aspect of life, so that there is no pleasure or enjoyment to be experienced or anticipated. The death wishes may be truly self-destructive and even violent, motivated by anger and the desire for revenge against other people or the world at large. When clinical depression comes on for the first time after a major loss, such as a death, loss of a job, or loss of a partner, it is usually self-limited, with complete and permanent recovery. Bipolar depression is episodic, and therefore self-limited; but the patient knows that it will recur.

In contrast, reactive depression to a terminal illness is built around the illness itself. Blame is centered on the disease, not on self, family, or the outside world. The grim, long-term outlook augments the stress of the illness and the treatment. Rapport with the family is usually good and continuous, and the patients are often very concerned about the effect that their deaths will have on loved ones. They may even see death as a form of altruism to

avoid being a burden on their families or communities. Instead of having guilt or regrets about their past life, people with reactive depression are more apt to express pride in their accomplishments and see themselves as good people beset by a bad disease. They usually continue to enjoy what they can in life, looking forward to significant holidays and enjoying the company of family and special friends. They may even have some limited goals such as arranging their affairs properly. A sense of humor is often retained and even used to raise the spirits of others. Dying patients usually consider their diseases to be a violation of what was previously a normal life. They would prefer to live if they could do so in comfort but would prefer death to their current condition. Most physicians and psychiatrists do not have any trouble distinguishing between these two forms of depression.

Legal Background and Court Decisions

The advancing tide of autonomy and personal rights has brought us to the point where our courts and public opinion are ambivalent about legalization of assisted dying. Public polls for many years have indicated that 65 percent of our population believe that more permissive laws should be passed. However, most attempts to pass such laws have failed. Because the issue is emotionally and politically hot, legislatures avoid it whenever possible. Furthermore, appellate courts in our federal system are split on the constitutionality of the right to assisted dying. Individuals, legislators, and courts consider assisted dying a private and personal issue between the patient and physician that should not be under legal control at all. To better understand the current issue it is important to review the legal steps that have taken place over the last 50 years that have brought us to our present position and will almost certainly carry us into the future.

Background Cases: Autonomy and Personal Rights

The modern era of legal recognition of autonomy and personal rights with respect to health matters began in 1965 with the U.S. Supreme Court's decision in *Griswold v. State of Connecticut.*³ The Supreme Court concluded that states could not prohibit the use of contraceptives by married adults.⁴ Prior to this decision, many states had laws against the sale of contraceptive devices under any circumstances. Shortly after this case was decided,

the right to purchase and use contraceptives was extended to unmarried people.

In Roe v. Wade, the U.S. Supreme Court significantly extended privacy rights, concluding that women's right to privacy and autonomy included the right to have an abortion under almost any circumstances. The Court's decision has been under unrelenting attack over the years, even within the Supreme Court itself. Several states have succeeded in limiting women's rights to abortion, but at the present time it seems unlikely that the original decision will be completely reversed.

Background Cases: Refusing and Withdrawing **Treatment**

Although the issue of abortion near the beginning of life continues in the public eye, the extension of personal rights and autonomy to the end of life is on its own legal journey. In 1975, Karen Ann Quinlan collapsed with respiratory failure at a party following an unfortunate combination of alcohol and drugs. Her condition developed into a persistent vegetative state requiring a respirator and nourishment through a tube in her stomach. Her parents requested that the respirator be removed to allow her to die but the physician, hospital, and trial judge refused. However, the New Jersey Supreme Court cited the right to privacy and stated that "the State's interest contra weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims. Ultimately there comes a point at which the individual's rights overcome the State's interest."7 Quinlan was taken off of the respirator but surprisingly resumed spontaneous respiration and survived until 1985. The principle of privacy, however, was established, as was the right of the family to speak for the patient.

In Cruzan v. Harmon,8 the Missouri Supreme Court was confronted with the family's right to discontinue treatment. Following a car accident in 1983, Nancy Cruzan remained in a persistent vegetative state, dependent on tube feedings, although not dependent on mechanical respiration. The primary issue before the court included whether the individual has the personal right to refuse treatment. The second issue was whether the family's decision-making rights were as influential as the individual's rights. The Missouri Supreme Court held that the state's interest outweighed that of the parents who would not be allowed to decide for an incompetent child without clear evidence of what the child herself would have preferred.9

The U.S. Supreme Court upheld the Missouri court's decision and in addition asserted that the competent conscious individual has an absolute right to refuse treatment.10 Cruzan was allowed to die when friends testified that she had talked to them about not wanting to live with artificial support. Although two states, Missouri and New York, require strong evidence of the individual's personal feelings on the subject, following the Cruzan decision, major steps were taken in every state to encourage people to examine their own wishes and prepare advance directives.

In addition to the Supreme Court's decision in Cruzan, several state supreme courts advanced the rights of patients or their surrogates to refuse medical treatment and life support. In In re Conroy,11 the New Jersey Supreme Court held that a family could request termination of artificial feeding through a nasal gastric tube when the patient was incompetent. Additionally, in Bouvia, 12 California Supreme Court held that a competent patient had a right to refuse tube feedings, regardless of her motives. In Bouvia, although the plaintiff knew that she would die, the court felt that the decision was neither medical nor legal but personal. Although Bouvia was granted the right to discontinue treatment, she elected to continue treatment and remain alive.

It is interesting to note that many of these and other formative cases involved patients who were incompetent or unconscious, thus leaving the responsibility to decide with the families. The courts seemed reluctant to deal with the wishes of the fully competent patient who, with appropriate reason, wished to die. This situation still pertains today with respect to physician-assisted dving.

Federal Courts and the Supreme Court

In the previously discussed cases, the primary issue was whether the right to discontinue medical treatment was a constitutionally protected right. In contrast, in Compassion in Dying¹³ the issue before the court was whether a person who is terminally ill has a constitutionally protected liberty interest in hastening his or her death. The plaintiffs included four physicians, three patients, and an organization called Compassion in Dying. The three patients were terminally ill, competent adult patients who wished to hasten their deaths with the aid of their physicians. However, the physicians were deterred from providing assistance because a Washington statute made it a felony to knowingly aid another person in committing suicide. On appeal, the U.S. Court of Appeals held that the statute prohibiting "physicians from prescribing life ending medications for use by terminally ill, competent adults who wished to hasten their own deaths, violates the Due Process Clause of the Fourteenth Amendment." Furthermore, the court stated that "not only is that state's interest in preventing such individuals from hastening their deaths of comparatively little weight, but its insistence on frustrating their wishes seems cruel indeed." ¹⁵

Similarly, in Quill v. Koppell,¹⁶ two New York statutes penalizing physician-assisted suicide were challenged for violating the Equal Protection Clause of the Fourteenth Amendment. The plaintiffs were physicians who asserted that the penalties within the statute prohibited them from complying with the requests of their terminally ill, mentally competent patients for help in hastening their deaths. On appeal, the court of appeals held that "physicians who are willing to do so may prescribe drugs to be self-administered by mentally competent patients who seek to end their lives during the final stages of a terminal illness."¹⁷

The U.S. Supreme Court heard Quill and Compassion in Dying on appeal in Washington v. Glucksberg. 18 The Court overturned the appellate court decisions, voting unanimously that the statutes in New York and Washington did not violate the Constitution.19 Several statements softened the Court's seemingly total rejection of assisted dying. Justice Rehnquist noted that "throughout the nation, Americans are engaged in ernest and profound debate about the morality, legality, and practicality of physician assisted suicide. Our holding permits this debate to continue, as it should in a Democratic society."20 Justice Souter stated that the court should "stay its hand to allow reasonable legislative consideration," acknowledging that "legislative institutional competence is the better one to deal with that claim at this time."21 Justice O'Connor emphasized the use of the double effect, that no restriction should be placed on the medications that patients receive from qualified physicians to alleviate their suffering, even if it causes unconsciousness and hastens death. "The challenging task of crafting appropriate procedures for safeguarding . . . liberty interest is entrusted to the

'laboratory' of the States."22 Justice Breyer would substitute "the right to die with dignity" for "the right to commit suicide with another's assistance."23 At the core of new laws "would lay personal control over the manner of death, professional medical assistance, and the avoidance of unnecessary and severe physical suffering combined."24 Justice Stevens noted that there is "significant tension between the traditional view of the physician's role and the actual practice in a growing number of cases. . . . I would not foreclose the possibility that an individual plaintiff seeking to hasten her death or a doctor whose assistance was sought, could prevail in a more particularized challenge." Future cases will determine whether such a challenge may succeed."25

The somewhat hedged opinions of the Supreme Court, reversing very strong opinions of two lower courts, reflect the ambivalence of the public and our court system concerning assisted dying and the obviously conservative outlook of our current Supreme Court. Many see these decisions as leaving the door ajar for the states and for individuals and their physicians to consider and act on their own attitudes toward assisted dying.

The Laboratory of the States

There have been many instances where state legislatures have delayed or avoided addressing controversial issues. Abortion and assisted dying are clearly such issues. A few states have the option of addressing issues through public initiatives or referendums to bypass their legislatures through a more representative approach to lawmaking when needed. Three states, California, Washington, and Oregon, attempted to pass laws permitting physician-assisted dying. These initiatives were defeated in California and Washington by narrow margins of 52 to 48, but passed in Oregon with 60 percent of the population voting in favor of assisted dying.

Oregon is the only state to carry such a law in its books at the present time, but several others are examining the issue closely, with Maine planning for a public initiative in November of 2000. The Oregon law requires that the patient have a terminal illness, with a life expectancy of less than six months. In addition, the statute requires that the patient must be suffering and must understand the nature of the decision, the prognosis, and the available alternatives, including comfort care and hospice. The patient must make the request on at least

two occasions, two weeks apart. One request must be in writing and witnessed. The patient must be competent and informed. Two physicians must talk with the patient and examine him or her, affirming that the request is autonomous and that the patient is competent and appropriately informed. Either physician may request psychiatric review.

In 1998, 23 people in Oregon were given prescriptions for lethal drugs.²⁶ Fifteen used the drug to end their lives, six died without taking any drugs, and two were still alive at the end of the year. There was no record that any of these individuals suffered from major depression or was in any way pushed or abused by others.

The Patient's Options

With this medical and legal background, we can now look at what are today's options for the competent, conscious patient who is suffering significantly and wants to die sooner rather than later. We have already seen that the right to refuse or discontinue treatment extends to all forms of artificial support systems, including artificial feeding. The natural extension of this is to refuse normal, oral ingestion of food and drink.

Voluntary Dehydration

Although dehydration and starvation contribute to the deaths of many terminal patients, including those in hospice, the possibility of using dehydration to deliberately shorten life is rarely considered. This may be because the image of adding thirst to other end-of-life problems is not acceptable. It is well recognized, however, that the terminal patient does not appreciate thirst in the same way as does a healthy person and the symptoms are quite easily controlled. Death from dehydration, in which no fluids are ingested, is associated with a form of autosedation and somnolence and usually takes seven to 10 days. This situation is not the same as starvation, where fluids are provided and the dying process can require many weeks.

The combination of voluntary dehydration and sedation provides a route to ending life early that is legally and morally acceptable. The patient has a right to refuse to take food or fluids and the physician can provide appropriate analgesia and sedation to control the symptoms of the underlying disease as well as the thirst. Controversy exists around the difference between terminal dehydration, which is initiated by the patient and supported by

the physician, and terminal sedation, in which the physician first provides heavy sedation so the patient cannot eat or drink. The interface between these two allows the physician and patient some latitude to negotiate how much sedation to provide and when. Legally, it is preferable if the patient initiates the process by refusing food and drink a few hours before any sedation is instituted. From then on the physician is treating the patient's symptoms, ensuring that death is free of suffering, which he or she is justified to do. The law does not look upon the refusal of fluids by a dying patient as suicide, and therefore providing relief of symptoms is not assisting suicide.

Suicide v. Assisted Dying

Suicide through the use of firearms or other violent methods is entirely too common today, particularly among elderly men. It does represent a potential method for the terminally ill person who has the strength and the equipment to carry out the act. On the other hand, it imposes violence on the person who is really seeking peace. It is a lonely act that cannot be discussed with anyone else. It is also an antisocial act that still carries a heavy stigma in our society. Finally, suicide is intensely painful for the family who retains a horrible image of personal violence and tremendous guilt over not recognizing the problem or attempting to solve it. It is frequently seen as an ultimate act of rejection. Suicide with drugs has the advantage of being painless and nonviolent. Appropriate drugs can be difficult for most people to obtain, although they are readily accessible on many urban street corners. Once on hand, the drugs must be successfully hidden lest some family member find them and thwart the plan. Secrecy and exclusion are necessary elements in most suicides.

The patient with a terminal disease who wishes to end his or her suffering has little in common with a young person who is distressed over a terminated love affair. In contrast to the term "suicide," assisted dying is a more appropriate term for the terminally ill person. Here a physician, preferably one who knows the patient and his or her disease, provides a prescription for a lethal drug that the patient can take if and when he or she so desires. Many patients take solace in having on hand the means to end their own lives, although they never actually do so. The physician is in a position to evaluate the patient's disease and his or

22 Elder's Advisor

her understanding of the prognosis and to encourage the patient to discuss his or her plans with appropriate members of the family. The physician should not have to insist that the family be involved, but in states where assisted dying is against the law this involvement may be essential to protect the physician from subsequent legal action brought on by some member of the family.

Assisted dying has been legalized in Oregon, but in all other states it is still against the law. However, there are many physicians who are known to help appropriate patients die, and many more say that they would do so if it were legal. Patients can confront their physicians directly with their problems and their needs. The physician in turn may or may not agree to help. A patient who is insistent on dying may avoid such direct confrontation by asking for sleeping pills, usually of the barbiturate family, to ensure proper sleep. By requesting drugs that suppress respirations, patients would be allowed to end their own lives when and if they chose to. The physician may recognize this approach but comply with the request regardless of the patient's intent. Some physicians have been known to suggest such an approach when they themselves are uncomfortable with the more direct request. The final act is an autonomous one, clearly in the hands of the patient, with the physician being removed from the event once he or she has provided the prescription.

Euthanasia

In voluntary active euthanasia, the physician directly administers a lethal drug to the patient, usually intravenously. Although this method is legal and is the favored method of assisted dying in Holland, it is neither legal nor being seriously contemplated in the United States at the present time. An advantage of this method includes the certainty that the intervention will not fail. Unlike prescribing medication, this method transfers the responsibility for ending a patient's life to the physician rather than requiring that the patient take the final step. From the physician's point of view, euthanasia is a far more active step than writing a prescription that may or may not be used. The drugs used to end life through euthanasia usually include a barbiturate to produce a deep sleep followed by a muscle relaxant to stop respiration. The immediate effect and responsibility for the act makes most physicians reject this approach. Physicians opposed to this approach have at their disposal a backdoor to euthanasia that is open and frequently used.

The Double Effect

Many drugs have side effects that must be accepted if one wishes to obtain the primary effect. Chief among these is morphine, the drug most commonly used to control severe pain. Morphine's major side effect is suppression of respiration. Although the concept of the double effect had its origins in the Catholic Church to rationalize killing in selfdefense and in war, it is commonly applied to medical situations and is the morally and medically acceptable umbrella under which physicians often help people to die. The requirements are that the drug must be given primarily for its good effect, namely to relieve pain. Death should not be the intended result of giving the drug but may be foreseen and accepted as a possible consequence. The benefit of pain relief should outweigh the risks of earlier death. However, the intent can be nebulous and subjective and even adjusted to meet circumstances. The patient may see death as preferable to continued suffering, and death may be his or her primary, not secondary, goal. From the physician's point of view, large doses of narcotics are often needed and the question is how far can the physician go in providing such relief before his or her intent is questioned and the bounds of the double effect exceeded. In reality, many patients are allowed to die through the double effect of narcotic drugs such as morphine. The double effect is usually exercised in the hospital or hospice where appropriate drugs can be given continuously. The doses may be increased independently by the physician or may be requested by the patient or family: "I don't want to suffer (we do not want to see him suffer) at all, no matter what."

Attorney's Role²⁷

The attorney's responsibility to dying patients is to understand exactly what patients want and why and to advise them accordingly. The attorney must know what the patient's options are, recognizing that the options may be governed and even limited by where the patient is domiciled at the time. The three usual places are in a nursing home or hospital or at home. We will look at the most common issues and options in each of these locations.

In the Nursing Home

The competent patient who is in a nursing home may wish to write an advance directive or to ensure the acceptance of one that was written in the past. Such instruction usually involves withholding treatment in terminal disease when the patient may no longer be competent. Some nursing homes accept "Do Not Resuscitate" orders written in the hospital while others require new orders.

For the patient who is already incompetent, the family or a surrogate may request legal help to force the nursing home to obey an existing advance directive. The most common issue is the treatment of a demented patient (usually with Alzheimer's disease) for an acute infection. Pneumonia, characterized as the "old man's friend," was the usual cause of death of many elderly nursing home residents. However, nursing homes are now quick to transfer patients who have acute infections to the emergency room of a nearby hospital where antibiotic treatment is almost always instituted. The patient may return to the nursing home in a few days, weakened but alive, to face gradual decline until another infection comes along months or even years later. The result is a missed opportunity to let nature take its course and end the life of a person who never wanted to live under such circumstances. In anticipation of this possibility, many patients admitted to nursing homes write very specific advance directives, refusing treatment in the face of any life-threatening emergencies. The families may agree with this choice and the attorney may be called in for support against the wishes of the nursing home. The attorney may be asked to discuss the advance directive when the patient is first admitted to the nursing home to be sure that the instructions are clear, or the attorney may be contacted when the emergency arises if the nursing home appears reluctant to adhere to the directive.

The patient who is conscious but not competent, such as an Alzheimer's patient, but who has no advance directive, as is too often the case, must depend on the nursing home's willingness to allow the family to act as a surrogate. This is much more problematical and open to negotiation. Nursing homes may be more conservative than most hospitals, and understandably do not want to have their residents die when there is the slightest possibility of legal liability. Strict regulations in most states require evidence of the patient's wishes. Surrogate and/or family members and their attorneys must be

unanimous in insisting that the patient's wishes be obeyed. In the absence of responsible family, the attorney may be the surrogate decision maker by having power of attorney for a patient, having been previously appointed by the patient or the court.

Patients or families may also contact an attorney to insist that the patient be maintained in comfort and free of pain, regardless of any side effects of the medication. Again, nursing homes may be reluctant to give adequate doses of narcotics even for patients with evidence of severe suffering. The family or attorney must emphasize that the nursing home is allowed to administer medication without fear of liability. If the nursing home refuses to comply with the physician's orders, the issue should be taken beyond the administration of the nursing home.

In the Hospital

The acute care hospital usually admits patients who are sicker than nursing home patients. The common medical issue that occasionally has legal implications is to insist that the medical staff of the institution not prolong the life of a patient beyond what he or she wants. Unfortunately, transferring a patient to a hospital often means a change in the responsible personnel. A more aggressive team of physicians and nurses may replace a long-time physician who knows the patient well, including what he or she has wanted in the past and would want in the future.

The problem is the conscious and unconscious confidence of physicians in applying their technical knowledge and skill to seriously ill patients. Modern medicine exists in a state of optimism that can be hard to deflect. The result is that patients are often given inflated hopes of the possibility that treatment will be successful, in an atmosphere where everything that can be done should be done, unless someone says no. Patient, family, and attorney are all in a position to say no. Recognizing futility can be as hard for some physicians as it is for many families. The converse of this is also true, namely getting families to recognize obvious medical futility, as seen by the physicians. Although concerted efforts may be made to encourage the family to consent to the removal of life-support systems, the family has the legal right to refuse.

The hospitalized patient is in the best place to receive sufficient doses of narcotics to trade on the double effect. This usually comes about as the result of a private conversation between patient and physician, occasionally involving the family. The patient's attorney is unlikely to be brought into it for fear that too much discussion will attract attention. Increasing the doses of narcotics for a patient who is already receiving large doses is a subtle judgment call that rarely arouses any curiosity, particularly when the patient is obviously dying.

It should be noted that most hospitals have policies that allow caregivers to refuse to participate in activities that they personally consider to be morally wrong (e.g., abortion). Hence a nurse may refuse to administer a narcotic dose that she believes is excessive. However, there are many nurses who are compassionate and familiar with the dying and will place the patient's needs and wishes ahead of other considerations.

The patient may ask outright for psychological oblivion, even if it may mean shortening life. The attorney probably serves his or her client's interests best by also not looking too closely into what is happening, assuming that an earlier death really is in the client's best interest.

Following discharge from the hospital, terminal patients may feel strongly about living their final days at home, in familiar surroundings with easy access to family and friends. If the family is willing and able to provide the nursing care, this is an ideal situation. Visiting nurses and home hospice programs can supplement and support the efforts of the family in many ways.

Nursing homes are often unable to provide significant medical needs, especially intravenous feeding. Hospice, on the other hand, is renowned for its experience and skill in caring for the dying, particularly in the areas of pain and symptom control. It too is reluctant to provide intravenous fluids or feedings, preferring that patients and families accept the restrictions imposed by the terminal disease. The concept of a terminal disease and the finality associated in the public mind with admission to hospice makes some people reluctant to consider transfer until they are nearly dead, or to avoid it altogether by remaining at home. Occasionally attorneys may be involved in such end-of-life decisions.

Complicated interactions between patient and family and among different members of a family are common in the hospital. The legal hierarchy is the competent patient, the spouse, adult children (not necessarily in any order), parents, and siblings. Last-minute decisions in stressful circumstances may create significant hostility in a family. The primary responsibility is to respect the wishes of the patient, if they are known.

Much comment has been made about the potentially abusive family member who may have an underlying motive to see the patient die in hopes of benefiting from the estate. Far more common is the almost equally, but more understandably, abusive family member who hears the patient say "enough" but admonishes the physicians not to listen. "I don't want to be left alone," said by a spouse, can create severe guilt in a patient who wants to end his or her suffering. Under such circumstances, hospital physicians often feel justified in assuming a more active, interventional role. For instance, the wife of an unconscious and dying patient of mine ended the dissension within her family by stating "we have to stop thinking of ourselves and think of him. He certainly would not have wanted this."

Every effort should be made to reach a consensus within a family and between the family and the medical staff. One approach is to accept a compromise such as "OK, let's try the ventilator for one week and if there is no improvement then we will discuss whether to discontinue it." Do-not-resuscitate orders can be taken to court, but our courts are predisposed to "life" under most circumstances and therefore reluctant to let a person die. It is far better to settle the question out of court. Many hospitals' medical ethics committees represent another source of help. These committees can give advice and be very supportive; however, they carry no legal authority.

At Home

Any discussion of the circumstances surrounding the end of life that takes place at the patient's home (or in the attorney's office) is apt to involve long-range planning with a wide spectrum of options. The most frequent and obvious topics include the development of an advance directive or living will and the documented appointment of a surrogate. Patients who acknowledge and understand their illness can obtain information from their physician concerning the possible and probable events that may occur toward the end of life. In addition to the usual generalities included in a living will, the attorney can be quite specific about

the management of particular events that may be confronted

The living will provides the surrogate with an autonomously produced document. Usually the nearest of kin, either a spouse or a responsible child, is named as a surrogate. Where there is known or expected dissension within the family, the attorney can help by encouraging the client to make his or her desires clear to all concerned in the presence of the attorney and well documented so that future difficulties can be avoided.

The period following the execution of a living will and prior to a terminal illness may provide an ideal time for their clients to disclose their long-range wishes, objectives, and plans. A person who has experienced the loss of a loved one to a terminal illness may want to ensure that "this won't happen to me." Clients may reveal that they and their physician have mutually agreed on the course of action in the event of a terminal illness and that they have "reached an understanding."

An increasingly common concern among healthy adults is the possibility of developing Alzheimer's disease. Thirty percent of all people over the age of 80 have some form of dementia, and the number of people living long lives is increasing rapidly.29 At the present time there is no or medically acceptable legally way that Alzheimer's patients can have their life ended, regardless of how much planning and arranging they did when they were well. Their living will would have to be binding they are no longer competent to consent to anything, or do anything to end their own life, a life that may remain suspended in a mental vacuum for years.

Regardless of what a client wants, or what an attorney suspects that the client may want, it is important to be sure that that client's ideas are autonomous and voluntary. To ensure that this is the case, the following questions should be answered: Is the client rational and competent to make medical decisions? Is the client's understanding of the disease and prognosis accurate, and the planning, so far as he or she reveals it, appropriate to the circumstances? Is there any evidence of coercion by members of the client's family, or does he or she have their support?

Financial concerns about medical expenses are a fact of life in our society, with its uneven and very limited health care system. A patient may be concerned about the financial impact of the illness on his or her family. Thus, it is important for the attorney to consider the implications of these concerns. Life insurance and some forms of trusts carry a waiting period of two or three years before the death benefits are paid. Therefore, attempts to make special provisions toward the end of life may not succeed. Similarly, late changes in wills or trusts may or may not be appropriate.

Finally, it should be noted that in states where assisted dying is not legal, a patient is unlikely to discuss a planned suicide. It is almost axiomatic that the rational patient would never discuss such plans with an attorney. The exception to this may be the patient who has a long-standing professional or personal relationship with an attorney and turns to him or her as a friend as well as an advisor. Here, friendship and his or her own moral compass must guide the attorney. If the patient is competent and terminally ill, I would hope that the attorney would not feel it was necessary to interfere. A reasonably broad discussion of all of the possibilities could avoid the problem of giving direct advice. Such a conversation would be relatively safe for the attorney since it would be very unlikely to go beyond the room. If the family was already involved, or likely to become involved, they should be encouraged to participate in the discussion.

Patients may hint at what they want to do by going beyond the usual discussion of setting their affairs straight and trying to make sure that their family understands the financial issues that will follow their death. If there is any indication, direct or indirect, that a client is seeking to shorten his or her life, the attorney should be sure that the client understands the need to reduce or eliminate the legal risk to the family. If the client plans to take a lethal dose of medication and the family is aware and involved, they may wish to be present. It is important that they do not do anything that can later be construed as providing physical help. In fact, there is minimal risk incurred from simply being present. Two organizations, the Hemlock Society³⁰ and Compassion in Dying,³¹ provide trained volunteers who will sit with the patient and the family throughout the dying process. It is equally important that members of the family do not attempt to thwart the patient's wishes at the very end.

In states that forbid assisted dying, it is in the physician's best interest for the death to appear to be from the disease itself or as the result of normal treatment. This may mean delaying any assistance

until the patient is a few days or weeks from dying from the disease so that death is not too early or unexpected. The physician may prefer to provide multiple prescriptions during an extended time period to allow the patient to accumulate the medication. Finally, treatment of pain and suffering with a continuous drip of morphine can be carried out at home and the dose can be increased as needed, accepting the double effect that may occur. For instance, AIDS patients in California frequently request a morphine drip with the understanding between patient and physician that the medication will be used to end the suffering.

With most states having laws against assisted dying, the patient who wishes to obtain such help is in a difficult position. However, it is a fact that many physicians are willing to help their patients die, particularly patients who they know well and for whom they have cared a long time. The patient will not know where his or her own physician stands on this issue without asking. If it is important to the patient, he or she should raise the issue while there is still time to transfer to another physician. Although there is no obligation to do so, I see no reason why an attorney should not suggest that a client discuss assisted dying with his or her own physician. The help that is wanted may be available.

Endnotes

- 1. See Charles F. McKhann, M.D., A TIME TO DIE (1999).
- 2. G. M. Burnell, Psychiatric Assessment of the Suicidal Terminally Ill, 54 HAWAII MED. J. 510 (1995); interview with Dr. James Ciarcia, Associate Clinical Professor of Psychiatry, Yale University (August 1999).
- 3. See 381 U.S. 479 (1965).
- 4. See id. at 485.
- 5. See 410 U.S. 113 (1973).
- 6. See In the Matter of Karen Quinlan, 348 A.2d 801 (1975), rev'd, 355 A.2d 647 (1976).
- 7. See 355 A.2d 647 at 662.
- 8. See 760 S.W.2d 408 (1988).

- 9. See id. at 426.
- 10. See 497 U.S. 261 (1990).
- 11. See In re Conroy, 486 A.2d 1209 (N.J. 1985).
- 12. See 179 Cal. App. 3d 1127 (1986).
- 13. See 850 F. Supp. (W.D. Wash. 1994).
- 14. 179 F.3d 790, 793 (9th Cir. 1986).
- 15. Id.
- 16. See 870 F. Supp. 78 (S.D.N.Y. 1994).
- 17. 80 F.3d 716 (1996).
- 18. See 521 U.S. 702 (1997).
- 19. See id.
- 20. Id. at 735.
- 21. Id. at 788.
- 22. Id. at 736.
- 23. Id. at 790.
- 24. 521 U.S. 702, 790 (1997).
- 25. Id. at 739.
- 26. See A. E. Chin, Legalized Physician Assisted Suicide in Oregon: The First Year's Experience, 340 New Eng. J. Med. 577, 583 (1999).
- 27. Interview with Stuart Werner, attorney of the legal affairs office of Yale New Haven Hospital (Sept. 1999).
- 28. I am indebted to Fred Flatow, M.D., Medical Director of Connecticut Hospice, for information about the traditions and practices of the hospice.
- 29. Interview with Guy M. McKhann, M.D., Professor of Neurology, Director, Mind-Brain Institute at Johns Hopkins University, Baltimore, MD (Sept. 1999).
- 30. The Hemlock Society USA, P.O. Box 101810, Denver, CO 80250-1810.
- 31. Compassion in Dying Federation of America, 6312 SW Capitol Highway, Suite 415, Portland, OR 97201.