2010

Elder Law: Counseling Clients Who Are Terminally Ill

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Recommended Citation
Available at: http://open.mitchellhamline.edu/wmlr/vol37/iss1/11
ELDER LAW: COUNSELING CLIENTS WHO ARE TERMINALLY ILL

Kathryn Tucker†

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I. INTRODUCTION

As the older population continues to grow, it is becoming increasingly important for elder law attorneys to know the options available to elderly clients approaching death due to terminal illness, and consult with them about their plans and wishes for end-of-life care. Attorneys representing such clients on these matters will need to be prepared not only to assist in the preparation of documents that reflect the clients’ wishes, but also advise them on the range of available choices. This article offers suggestions on how elder law attorneys can maximize the chances that their clients’ health care preferences will be respected, actions to be taken if these wishes are not respected, possible limitations on care based on the conflicting views of an individual provider or health care institution, and how to plan strategically to ensure that such limitations do not undermine the clients’ wishes.

II. BACKGROUND

A. Statistics

The U.S. Census Bureau’s national population projection, released in 2008, forecasts that the population of those over sixty-five in the United States will increase significantly over the next four decades. In 2010, the projection estimates that the U.S. population over sixty-five will be 40.2 million, or approximately 13.0% of the total U.S. population. In 2050, it estimates that the same population will increase to 88.5 million. In other words, approximately 20.2% of the total U.S. population, or one out of every five Americans, will be sixty-five or older.

This drastic change is largely attributed to the aging of the baby boomers and medical innovation. Following World War II, between the years of 1946 and 1964, a large number of Americans were born, and they have collectively come to be known as the

2. Id.
3. Id.
4. Id.
“baby boom” generation. In 2011, the oldest of this generation will join the “sixty-five years and over” category of the U.S. Census Bureau, and thus begin the projected increase in the older population. Furthermore, with advances in medical technology prolonging life expectancy, this generation is anticipated to live longer than previous generations. The U.S. Census Bureau estimates that the life expectancy of 70.8 years in 1970 will increase to 79.5 years by 2020. Therefore, not only is the number of older Americans increasing, but so is the number of years they are expected to remain within that population.

With this increase in the older population comes an increase in the number of Americans who will become ill with a terminal illness. Aging is a risk factor for various terminal illnesses, including cancer and heart disease—the two leading causes of death for persons over sixty-five years of age. Seniors make up the majority of the terminally ill population. Because the likelihood of becoming terminally ill increases with age, it is important for elder law attorneys to know how to advise their clients about their options and rights as they approach death due to terminal illness.

6. Id.
B. The Cost of Failing to Plan and Inadequate Planning

Since the majority of the older population will face a terminal illness, it is likely that many seniors will seek advice to ensure that their wishes for end-of-life care will be respected. The legal system has developed a number of options to protect and maximize terminally ill clients’ control over the end-of-life decision-making process, including opportunities of which they may not be aware. Without proper planning, a terminally ill client may become subjected to unwanted, aggressive treatment, or, if incapacitated, rely completely on the discretion of an appointed guardian or surrogate who may not know the client’s wishes nor share the same values or beliefs as the client.

If seniors do not fully understand their end-of-life care options, and do not effectively communicate and document their desired plan for future health care treatment, the chance that their wishes will be known and respected is small. To maximize the chance that a client’s wishes will be known and respected, and to minimize the need for court proceedings, an elder law attorney plays an important role in assisting the client to understand their rights and options and communicate their wishes clearly.

III. Analysis

A. Pain Control

1. Palliative Care

As terminal illness advances, patients often come to the juncture where further curative treatment is not available or effective, and a transition to pain and symptom management, known as comfort care or palliative care, is appropriate. The focus of palliative care is to lessen the physical and emotional discomfort felt by dying patients, not to cure them of their ailments.


15. For a list of all fifty states’ and the District of Columbia’s guardianship statutes see 3 A. Kimberley Dayton et al., Advising the Elderly Client § 34:11, Table 1 (Kelley D. Cooper & Lori A. Checchi eds., 2010).

16. For a list of state surrogate consent statutes see id. § 33:43.

Sometimes medication used for palliation also has the “double effect” of hastening death. However, as the U.S. Supreme Court recognized in *Vacco v. Quill*, if the physician intends to lessen the patient’s pain and distress, not bring about her death, the patient has the right to as much medication as necessary to achieve relief, even if the time of death is advanced.\(^\text{18}\) In *Washington v. Glucksberg*, Justices O’Connor and Breyer wrote concurring opinions reflecting the view that palliative care, including the intervention known as palliative sedation, serves as an alternative for aid in dying.\(^\text{19}\)

### 2. Hospice Care

Palliative care is always a part of hospice care.\(^\text{20}\) According to the National Hospice and Palliative Care Organization (NHPCC), the focus of a hospice is “the belief that each of us has the right to die pain-free and with dignity, and that our loved ones will receive the necessary support to allow us to do so.”\(^\text{21}\) Hospice care is concerned with providing patients and their families with physical and emotional comfort at the end of life.\(^\text{22}\) Hospice care often includes medical treatment used to reduce symptoms, grief counseling, and social services.\(^\text{23}\) Doctors, nurses, clergy, social workers, and volunteers\(^\text{24}\) work together to provide such

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19. 521 U.S. 702, 736–37 (1997) (O’Connor, J., concurring) (stating that there is no need to determine “whether a mentally competent person who is experiencing great suffering has a constitutionally cognizable interest in controlling the circumstances of his or her imminent death,” because “the parties and amici agree that in these States [New York and Washington] a patient who is suffering from a terminal illness and who is experiencing great pain has no legal barriers to obtaining medication, from qualified physicians, to alleviate that suffering, even to the point of causing unconsciousness and hastening death.”); *Id.* at 792 (Breyer, J., concurring) (“Were the legal circumstances different—for example, were state law to prevent the provision of palliative care, including the administration of drugs as needed to avoid pain at the end of life—then the law’s impact upon serious and otherwise unavoidable physical pain (accompanying death) would be more directly at issue.”).


24. *Id.*
personalized care in every U.S. state. Depending on the patient’s preferences and the availability of resources, hospice care can take place at the patient’s home, freestanding hospice centers, hospitals, nursing homes, and other long-term care facilities. It is also covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.

Hospice care can help dying patients to conclude their lives with peace and dignity, and the number of Americans who take advantage of these services has been increasing. In 2008, the number of patients receiving hospice care reached 1.45 million Americans, 83.2% of which were sixty-five years of age or older. Although these numbers suggest that hospice care is a popular choice among seniors nearing the end of life, it remains an underused resource. In the same year, only 38.5% of deaths in the United States were under the care of a hospice program, and the median length of service was a mere 21.3 days, even though hospice care is available to anyone who has a life expectancy of six months or less. To promote awareness of this end-of-life option and provide an opportunity for a less painful and more peaceful death, hospice care should be among the various options that elder law attorneys discuss with their terminally ill clients.

3. Failure to Adequately Treat Pain

Although physicians can relieve pain in nearly ninety percent of dying patients, many seniors suffer from pain without adequate relief. According to the National Pain Foundation, 47–80% of

25. Id.
27. Id.
29. Id.
30. Id. at 6.
31. Id. at 4.
32. Id. at 5.
older adults in community settings do not receive treatment for pain, nor do 16–27% of older adults living in institutionalized settings. Another study found that eighty-four percent of older patients with dementia who suffer from pain do not receive any pain treatment at all. When a terminally ill client does not receive appropriate pain control, the law provides her with several avenues through which she can seek accountability and/or recovery. In situations where pain care was inadequate, clients (or their survivors) may file complaints with the state medical and/or nursing board, or with a regulatory agency. In addition, the client or her survivors may want to consider tort litigation and seek recovery of damages and/or injunctive relief.

Bergman v. Eden Medical Center was a landmark case establishing the duty of a physician to provide adequate pain and symptom management to a terminally ill patient. Bill Bergman was an eighty-five-year-old man dying of lung cancer and suffering from excruciating pain when he was admitted to a California hospital. He remained in the hospital for five days, during which time he received ineffective treatment for his pain and continued to suffer. He was discharged with his pain at a level of ten on a ten-point scale. When the hospice nurse visiting Mr. Bergman at his home after his discharge from the hospital attempted to contact the physician who provided care to the patient in the hospital, the physician refused to take the call. The nurse then obtained strong pain medication from another physician; Bill Bergman finally achieved some relief and died the next day. For six days, he

36. Id.
38. Id.
40. Doctor Tagged with $1.5M Verdict in Landmark Elder Abuse Case, supra note 39.
41. Id.
42. Id.
43. Id.
44. Id.
endured excruciating pain without adequate relief. Since California’s medical negligence laws do not allow for the recovery of pain and suffering damages after the death of the patient, counsel for the survivors brought a claim under the state’s civil elder abuse statute. That statute permits the recovery of pain and suffering damages even after the patient’s death, although it requires showing more than mere negligence, but proof of recklessness. Notwithstanding this heavy burden on the plaintiffs, the jury returned a verdict of $1.5 million in damages for Bill’s pain and suffering. In states that allow the recovery of pain and suffering damages in medical negligence claims following the patient’s death, plaintiffs can obtain recovery more easily by showing negligence.

B. Preparing for Legal Incapacity

1. Advance Directives

Should a client become incapacitated without having documented her wishes regarding future health care, her medical preferences are unclear. Consequently, she risks undergoing treatments that conflict with her own beliefs and desires in addition to surrendering decision-making authority to someone who may not know her wishes, or share her beliefs. Advance directives such as living wills, health care powers of attorney, do not resuscitate orders, and Physician Orders for Life Sustaining Treatment (POLST) are all documents that clients can use to help ensure that their health care preferences are honored in the event of incapacity. They allow a client to specify, in advance, the type of care that she does and does not want, as well as designate a surrogate who she trusts to make health care decisions not otherwise specified. Since the number of legally incapacitated seniors is large and only 2% to 15% of Americans have advance

45. Id.
46. Id.; see CAL. WELF. & INST. CODE § 15610–15610.65 (West 2010).
47. See CAL. WELF. & INST. CODE § 15610–15610.65 (West 2010).
49. Pain Management, supra note 37, at 19.
directives, it is an essential task of the elder law attorney to inform their clients about these documents and assist in their preparation if the client so desires.

One type of advance directive is the living will. A living will is a written document that specifies the circumstances in which a client would and would not want various sorts of life prolonging treatment. It does not designate an agent for decision-making, and usually requires that the client/patient be in a prerequisite condition of terminal illness or in a permanent vegetative state before it becomes effective.

A second type of advance directive is a durable power of attorney for health care (DPOAHC), also known as a health care proxy. By this directive, the client designates an agent to make health care decisions for her in the event that she becomes incapacitated. A DPOAHC does not require the principal to delineate her preferred medical treatments for all conditions as the directive confers a certain scope of authority to an agent who uses discretion as health care issues arise, including when new medical technologies emerge. State statutes govern the DPOAHC in every state, all of which require that the client become incapacitated before the agent has decision-making authority. A DPOAHC gives the agent a wide range of authority, including the ability to order the removal of life-sustaining treatment whether or not the patient is terminally ill or in a vegetative state. However, it is important to note that the scope of the agent’s authority may be limited in the context of mental health treatment. For example, agents in the majority of states do not have the authority to commit the principal to a locked mental facility, force her to take psychotropic medication, or subject her to electroconvulsive therapy. Some states have enacted statutes that permit the creation of mental

51. 3 DAYTON ET AL., supra note 15, § 33:14.
52. Id.
53. Id. § 33:15.
54. Id.
55. For a list of state health care power of attorney statutes, see id. § 33:41.
56. Id.
57. Id.
58. Id. § 33:18.
59. For a list of state special mental health advance directives statutes, see id. § 33:42.
health advance directives so that a client may choose the type of treatment she wishes to accept if she suffers from a mental illness while incapacitated.  

A DPOAHC also gives the agent access to the principal’s medical records and other health care related documentation. This authority is in tension with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) which strives to protect the confidentiality of patient’s medical records and related information. Although HIPAA allows access to medical and related information when the person seeking access is permitted by state law to make health care decisions for a principal, directives should include a “HIPAA clause” that explicitly gives the agent access to the principal’s information. Doing so will prevent confusion and secure the agent’s access to the information necessary to make an informed decision on behalf of the principal.

If a terminally ill client does not execute a DPOAHC and becomes incapacitated, a surrogate may gain the authority to make decisions regarding the client’s health care, regardless of whether he knows the client’s wishes or shares the client’s values and beliefs which inform end-of-life decision making. Therefore, the implementation of a DPOAHC is particularly important for a terminally ill client who is “unbefriended,” who has no close relatives, or who is part of a non-legally sanctioned relationship, such as same-sex partners or unmarried heterosexual couples. Choosing an agent that knows and respects the client’s health care wishes will help to ensure that the treatments the client does and does not undergo while incapacitated reflect her own medical preferences. An elder law attorney should strongly encourage open communication between the chosen agent and the client so that the agent does not compromise the client’s beliefs.

60. Id. § 33:18.
61. Id. § 33:15.
63. Id. § 164.502(g).
64. 3 DAYTON ET AL., supra note 15, § 33:19.
65. For a list of state surrogate consent statutes, see id. § 33:43.
66. See id. § 33:20.
67. Id.
68. Id. § 1:14.
Also important are do not resuscitate (DNR) orders, and a recent iteration which has been adopted by many states and localities, the Physician’s Order for Life Sustaining Treatment (POLST). These orders are written by the client’s physician, based on the client/patient’s instructions regarding preferences for care, and provide medical orders regarding care. To prevent emergency responders from resuscitating clients against their will, many states have enacted statutes to protect the wishes of the client. These statutes usually call for, among other requirements, proper identification, certification as terminally ill, and the use of a particular form. A terminally ill client may also want to consider wearing medical identification jewelry to further alert providers that she has a DNR or POLST. Since seventy-five percent of emergency responders check for this form of identification, investing in this option would be an effective means of increasing the chance that a client’s wishes will be known and respected.

It is critical for an elder law attorney to discuss all relevant options with the client, set out in detail the client’s health care preferences, and regularly update the directives as changes occur in the client’s medical condition or in medical technology. The attorney should refer to the state statutory forms when drafting an advance directive, as these forms will be more likely to be recognized by the medical community. Furthermore, to avoid irreconcilable conflicts, an attorney may explicitly state which instruction should prevail in the event of a conflict or consolidate all advance directives into a single document as is suggested by the Uniform Health Care Decision Act (UHCDA).

69. POLST, Physician Orders for Life-Sustaining Treatment Paradigm, http://www.ohsu.edu/polst (last visited Oct. 7, 2010). POLST are sometimes called by other similar names, such as Medical Orders for Life Sustaining Treatment (MOLST).
70. 3 DAYTON ET AL., supra note 15, § 33:16.
71. For a listing of state Emergency Medical Services DNR statutes, see id. § 33:44.
72. Id.
74. For a compilation of state statutory forms, see 3 DAYTON ET AL., supra note 545, §§ 33:45–114.
75. Id. § 33:15. For the full text of the Uniform Health Care Decisions Act, see http://www.law.upenn.edu/bll/archives/ulc/fnact99/1990s/uhcda93.htm.
Whatever type of advance directive a client chooses to execute, she must make sure that family and caregivers know of its existence and make it available to those who require it. Failure to do so may result in confusion as well as the implementation or delay of certain medical treatments in a manner that does not conform to the client’s wishes. To promote accessibility of the directive and communication between the client, her family, the appointed agent, and physician, an elder law attorney can offer to send all relevant documents to the appropriate parties. The client should also retain the directive in such a way that it is well protected and readily available. This may be done by providing copies of the directive to all relevant persons or by utilizing a service that will both store and provide the document as needed. In case of unexpected incapacitation, some attorneys also supply their clients with laminated wallet cards that indicate the existence of an advance directive as well as provide the necessary contact information of their health care agents. If the advance directive is only stored in a location that a third party cannot access in a timely fashion, such as a safety deposit box, the client’s wishes may remain unknown, thus increasing the likelihood that she will become subjected to medical treatment that conflicts with her health care preferences.

2. Health Care Providers’ and Institutions’ Unwillingness and Failure to Comply

The Uniform Health Care Decisions Act (UHCSA), drafted to bring uniformity to advance health care directives among the states and adopted by Colorado, Idaho, Maine, Maryland, Nevada, New Mexico, U.S. Virgin Islands, Virginia, and Wisconsin,

79. Storing Your Advance Directives, supra note 77.
delineates the obligations of a health care provider and institution when it is unwilling to comply with the client’s or agent’s instructions. The health care provider’s or institution’s unwillingness to comply with these instructions is justified if the requested treatment or refusal of treatment conflicts with the provider’s conscience or an institutional policy that was timely communicated to the client or agent. They may also refuse to comply with the instructions if the client or agent requests ineffective medical treatment or treatment that contradicts the provider’s or institution’s generally accepted health care standards. Once the health care provider or institution declines to comply with the instructions, it must promptly inform the client or agent, assist, if needed, in transferring the client to another provider or institution that will adhere to her wishes, and continue providing care until the transfer occurs. To prevent these conflicts and delays in treatment, an elder law attorney should, if possible, direct her client to a health care provider or institution that will respect the treatment requests set forth in her advance directive.

Even when a client executes a valid advance directive, it is readily available to all necessary persons, and the client is in a facility that willingly provides such treatment, certain issues may still hinder the effective implementation of the client’s wishes. The most prevalent of these issues arises when a client’s directive is not in accord with her family’s wishes. For example, a physician may refrain from terminating life prolonging treatment in the absence of a court order in fear of a negligence or wrongful death suit even though an advance directive explicitly calls for the cessation. Living will and health care power of attorney statutes immunize health care providers and agents from liability so long as they act in good faith. However, if the health care provider refuses to honor the instructions given by an agent, it may be held liable for any

83. UNIF. HEALTH CARE DECISIONS ACT § 7(d)–(g) (1993).
84. Id. § 7(e).
85. Id. § 7(f).
86. Id. § 7(g)(1)–(3).
88. Id.
89. 3 DAYTON ET AL., supra note 15, § 33:15.
damages that resulted from its failure to comply. When a physician knowingly or negligently provides treatment that conflicts with an advance directive, the patient or her family can file a lawsuit “under constitutional theories of privacy and self-determination, or as actions for medical malpractice, informed consent and/or battery.” Elder law attorneys should counsel their clients in a manner that prevents the costly, time consuming, and emotionally trying litigation process. As discussed above, proper communication among the involved parties in addition to proper documentation is the best strategy an attorney can employ to ensure that her client’s wishes are respected.

C. Aid in Dying

In seeking a peaceful death when confronted by a dying process the patient finds unbearable, clients may want to choose aid in dying. This refers to when a mentally competent, terminally ill patient requests a prescription for medication that the patient can self administer to bring about a peaceful death. Whether or not aid in dying is an end-of-life option available to a terminally ill client depends on the state in which the client resides. If the client resides in Oregon, Washington, or Montana, she can obtain this treatment. Both Oregon and Washington make this option legal by statutory enactments. Montana respects this choice based on a decision of the Montana Supreme Court. It is less clear whether aid in dying is available in other states. It may be that this intervention will become increasingly available by enactment of

90. Id.
91. Martin, supra note 87. See also Klavan v. Chester Crozer Med. Ctr., 60 F. Supp. 2d 436, 440 (E.D. Pa. 1999) (physicians left Klavan in a vegetative state after providing treatment that was not prohibited in his advance directive); Anderson v. St. Francis-St. George Hosp., Inc., 671 N.E.2d 225, 229 (Ohio 1996) (not wrongful life; negligence and battery); Estate of Leach v. Shapiro, 469 N.E.2d 1047, 1054 (Ohio Ct. App. 1984) (not wrongful life; if life-sustaining treatment was used without surrogate’s consent, could receive compensation for both medical expenses and mental and emotional suffering stemming from unnecessary and interfering treatment).
laws, or court decisions, which make it affirmatively legal. It is also possible that the intervention will begin to be governed by standard of care, which is how most medical practice is governed.⁹⁵ A client choosing aid in dying can consume the medication prescribed to bring about a peaceful death, fall deeply asleep, and soon thereafter die peacefully.⁹⁶ The option of aid in dying allows clients to die on their own terms, with loved ones present and in familiar surroundings, rather than forcing them to endure a dying process which they find unbearable. If a terminally ill client resides in a state in which aid in dying is available, it offers another option to consider in planning for end-of-life care.

IV. CONCLUSION

Numerous options are available to a terminally ill client as she plans for end-of-life care, and it is the obligation of her attorney to navigate her through the law, informing her of these options, ensuring the implementation of her health care preferences, and taking appropriate action if her preferences are not honored. Since these issues are particularly prevalent in the older population, elder law attorneys must remain knowledgeable of the perpetually changing laws surrounding end-of-life options. The Elder Law Bar should advocate to protect and expand the rights of the terminally ill. Such bar associations should adopt policy supportive of empowering their clients with autonomy in end-of-life decision making. Far too many terminally ill seniors are subjected to unwanted medical treatments, or find themselves trapped in a dying process which they find unbearable. Elderly clients should be empowered to choose health care that conforms to their own beliefs and preferences so that they may conclude their lives with dignity.

⁹⁶. Aid in Dying, supra note 13, at 35.