2016

Antecedent Law and Ethics of Aid in Dying

Alan Meisel
University of Pittsburgh School of Law, meisel@pitt.edu

Recommended Citation

Alan Meisel, *Antecedent Law and Ethics of Aid in Dying*, 34 Quinnipiac Law Review 609 (2016).
Available at: https://scholarship.law.pitt.edu/fac_articles/514

Symposium

ANTECEDENT LAW AND ETHICS OF AID IN DYING

Alan Meisel[*]

ALAN MEISEL: Thank you very much Dean Brown, and thank you very much for the invitation to speak; it is my pleasure to be here this morning.

I am going to speak about the antecedent law and ethics that have developed in this country that have led us to the discussion that we are beginning to have, that we have really been having for a while, but has really begun to take-off in the last few years regarding physician aid in dying—physicians more actively aiding people in ending their lives—rather than what was going on for the prior forty or so years. That is where I want to start, because I think you need to know about the history before you can understand where we are today.

Admonitions to engage in advance care planning come from all sides; you'll hear them everywhere. We even have a National Healthcare Decisions Day in this country, every April.[1] I am pleased to say that the person who has organized and continues to run it is a former student of mine, Nathan Kottkamp, who received a J.D. and a Masters in Bioethics from the University of Pittsburgh.[2] Medicare will soon begin paying doctors to discuss advance care planning with patients.[3] So, we all get admonitions to do this kind of thing, but what is it and why is it important?

---

[*] Director, Center for Bioethics and Health Law, MSL Program, Health Law Certificate Program, University of Pittsburgh; Professor of Law and Psychiatry, University of Pittsburg School of Law. J.D., Yale Law School; B.A., Yale College.

[1] *See* NAT'L HEALTHCARE DECISIONS DAY, http://www.nhdd.org/#welcome (last visited Apr. 21, 2016) (noting that this year the National Healthcare Decisions Day is April 16).

[2] *About NHDD*, NAT'L HEALTHCARE DECISIONS DAY, http://www.nhdd.org/about/#about-us (last visited July 3, 2016).

[3] Revisions to Payment Policies Under the Physician Fee Schedule and Other Revisions to Part B for CY 2016, 80 Fed. Reg. 70886 (Nov. 16, 2015).

Advance care planning, basically, involves making decisions about what kind of health care we want, or do not want, when we're no longer able to make those decisions for ourselves. Although it is easy to state, it is not so easy, as I will explain, to put into practice.

Advance care planning is largely about decision-making for people who lack decision-making capacity.[4] Decision-making for people who have decision-making capacity is, conceptually, quite simple—informed consent.[5] We will be talking about informed consent in the program later today, but basically, the law of informed consent has developed for the last fifty or sixty years, and as far as the law is concerned it is pretty well established. Everyone knows what they are supposed to do; however, implementation is not always as perfect as the theory would have it. But certainly, that is how we are supposed to make decisions—doctors give patients relevant information, patients use the information to make decisions, and everything is fine from there on. It's not the reality, but that's the theory.

The question though is how does this theory apply to those individuals who lack decision-making capacity? On one extreme, we have people who are temporarily or permanently unconscious, and obviously incapable of engaging in any kind of discussion. At the other extreme, we have people who are not unconscious, but whose mental capabilities are seriously impaired by a variety of conditions—such as dementia, drug intoxication, and conditions such as uremic poisoning from kidney failure—which can interfere with their cognitive capacities.[6] They cannot engage in informed consent, so how are decisions to be made for them?

Traditionally, families made these kinds of decisions.[7] That was all well and good until we began to get into the modern realm of *end-of-life* decision-making, where it became clear that the decisions that families were often called upon to make could result in ending the patient's life.

---

[4] *Competence and Capacity: Decision-making Capacity Refers to the Ability to Make Decisions*, ADVANCE CARE PLANNING (last updated Feb. 29, 2016), http://advancecareplanning.org.au/advance-care-planning/for-professionals/competence-and-capacity ("A person is assumed to have decision-making capacity unless there is evidence to indicate it is in doubt.").

[5] *See, e.g.*, 38 C.F.R. § 17.32(b) (2015) ("In order to give informed consent, the patient must have decision-making capacity and be able to communicate decisions concerning health care.").

[6] *See, e.g.*, *Uremia – Symptoms, Causes, Treatments*, HEALTHGRADES, http://www.healthgrades.com/conditions/uremia (last visited Apr. 21, 2016) (noting that uremia can cause "confusion, loss of consciousness, . . . fatigue, [and] weakness").

[7] ARTHUR S. BURGER, WHEN LIFE ENDS: LEGAL OVERVIEWS, MEDICOLEGAL FORMS, AND HOSPITAL POLICIES 51 (1995).

At that point, it became a little more complicated as to whether or not family members had the authority to make those decisions.[8]

Today it is pretty clear that family members do have that authority. This clarity emerged from a murky common law largely as a result of a long line of cases in state appellate courts, and to a far lesser extent the United States Supreme Court, beginning in 1975 and 1976 with the Karen Quinlan case in New Jersey.[9] *Quinlan* is the first *reported* end-of-life case,[10] and I emphasize the word *reported* because it is hard to believe that, as late as 1975, a scenario analogous to Karen Quinlan's had never occurred elsewhere. It is more likely that similar scenarios had occurred before 1975, but they did not result in litigation, or the litigation concluded at an early phase and thus was not reported. Newspaper articles and medical literature from the mid-twentieth century validate this assumption. As early as the 1950s–1960s books and journal articles--as a result of technological developments in medicines that made life extension feasible--began to discuss these issues.[11] A large array of medical achievements—CPR, antibiotics, ventilators, dialysis, a variety of other kinds of drugs that were developed—made it possible to prolong the lives of people who almost inevitably would previously have died, and therefore there were not really any decisions to be made, or very many decisions to be made, about how these patients were going to be treated.

The story of Karen Quinlan is one that is truly tragic. Quinlan was a

---

[8] COMPASSION & CHOICES, A BRIEF HISTORY OF THE AID-IN-DYING MOVEMENT AS WELL AS CURRENT EFFORTS FOR DECRIMINALIZATION 4–5 (noting that the *Quinlan* case was the first time that the New Jersey Supreme Court recognized that a patient, or family member, and not a paternalistic medical professional, was in the best position to make decisions as to the medical care and treatment that was appropriate).

[9] *See generally In re* Quinlan, 355 A.2d 647 (N.J. 1976); *see also How the "Right to Die" Came to America*, NAT'L CTR. LIFE & LIBERTY (2015), http://www.ncll.org/liberty-centers/Center-for-life-defense/cld-articles/57-how-the-right-to-die-came-to-america (discussing the *Quinlan*, *Cruzan*, *Browing*, and *Schiavo* cases that "paved the way for 'right to die' laws and the acceptance of euthanasia or mercy killing in America.").

[10] *In re Quinlan* was the very first reported U.S. court case to deal with the issue of end-of-life care. *See How the "Right to Die" Came to America*, *supra* note 9.

[11] In 1954, Joseph Fletcher published *Morals and Medicine*, predicting the coming controversy over the right to die. In 1958, Oxford law professor Glanville Williams published *The Sanctity of Life and the Criminal Law*, proposing that voluntary euthanasia be allowed for competent, terminally ill patients. In 1967, the first living will was written by attorney Louis Kutner and his arguments in favor of its utilization appear in the *Indiana Law Journal*. In 1969, Elisabeth Kubler-Ross published *On Death and Dying*, opening discussion of the once-taboo subject of death. *See Chronology of Assisted Dying*, DEATH WITH DIGNITY, https://www.deathwithdignity.org/assisteddyingchronology/ (last visited Apr. 26, 2016); *see also The Right-to-Die Debate and the Tenth Anniversary of Oregon's Death with Dignity Act*, PEW RES. CTR. (Oct. 9, 2007), http://www.pewforum.org/2007/10/09/the-right-to-die-debate-and-the-tenth-anniversary-of-oregons-death-with-dignity-act/.

twenty-one-year-old woman who became unconscious as a result of a drug and alcohol overdose.[12] She was taken to the hospital, she was resuscitated, and with ventilatory support she began to breathe, but she never regained consciousness.[13] After a period of time, her parents, having been advised by physicians that it was unlikely that she would ever recover consciousness, began to entertain the idea about terminating life support and allowing her to die. Her physicians strongly resisted this.[14] They did so probably for two reasons: (1) they were concerned about legal liability—criminal liability for criminal homicide of one sort or another if they allowed her to die,[15] and, (2) medical ethics—they were concerned that this was a violation of their oath to preserve life whenever possible.[16] Consequently, the doctors refused to terminate medical treatment and eventually her parents went to court. Her father was appointed guardian, and the New Jersey Supreme Court ultimately held that he had the authority to terminate life support if certain conditions were met.[17]

Quinlan was the first in a long line of cases between 1976, when the New Jersey Supreme Court issued its decision, and 1990, when the United States Supreme Court first heard a case of this sort—the *Cruzan* case.[18] So there was a period of roughly fifteen years in which there were about two dozen appellate cases around the country—obviously not one in every state—that had decided a case regarding this issue. There was a high degree of consistency in the reasoning and holdings of most of the cases, from which there began to emerge a consensus about how end-of-life decisions should be made.[19]

There were, of course, some differences about what the law ought

---

[12] *See* Robert D. McFadden, *Karen Ann Quinlan, 31 Dies; Focus of '76 Right to Die Case*, N.Y. TIMES (June 12, 1985), http://www.nytimes.com/1985/06/12/nyregion/karen-ann-quinlan-31-dies-focus-of-76-right-to-die-case.html?pagewanted=all.

[13] *See In re* Quinlan, 348 A.2d 801, 809 (N.J. Super. Ct. Ch. Div. 1975).

[14] *See id.* at 814.

[15] "The assumption has been that providing aid in dying would subject physicians to criminal exposure." Kathryn L. Tucker, *Aid in Dying: An End of Life-Option Governed by Best Practices*, 8 J. HEALTH & BIOMEDICAL L. 9, 10 n.5 (2012).

[16] SUE WALDMAN, THE RIGHT TO DIE: THE STRUGGLE OVER THE RIGHT TO DIE 29 (2001).

[17] *See In re* Quinlan, 355 A.2d 647, 672 (N.J. 1976) ("If [a] consultative body agrees that there is no reasonable possibility of Karen's ever emerging from her present comatose condition to a cognitive, sapient state, the present life-support system may be withdrawn and said action shall be without any civil or criminal liability therefor on the part of any participant, whether guardian, physician, hospital or others.").

[18] Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261 (1990).

[19] *See* Alan Meisel, *Physician-Assisted Suicide: A Roadmap for State Courts*, 24 FORDHAM URBAN L.J. 817, 821–25 (1997).

to be. There was also a concern in every state that did not have an authoritative judicial decision about what the law was in those states. Nonetheless, medical practitioners in those states began to adhere to the consensus developing in other states.

These cases began to highlight the important issues in end-of-life decision-making that began to become accepted since that time. The first important issue is who has the authority to make decisions about forgoing or continuing treatment when patients are unable to do so for themselves?

Second, what standards are these decision-makers supposed to use? Can they make any decision they want? Or are there to be some guidelines, prescribed by law, for this decision-making process?

Third, what role are the courts supposed to play in end-of-life decision-making? Now, up until this point, 1990 or so, there had sometimes been resistance to allowing family members to make decisions to forgo life-sustaining treatment for their relative. The resistance commonly resulted in litigation that went to the highest court in those states. Those state appellate court decisions were pretty much consistent, hence the development of this consensus. But did that mean that resort had to be had to the judicial process every time there was an issue of end-of-life decision-making?

So let me say something about these various points in the consensus. The first one, who decides? The patient decides if the patient has the capacity to decide, but that is not really what we are talking about today. We are talking about situations in which the patient does not have the capacity to decide. The patient might have appointed someone beforehand, referred to as a proxy—*i.e.*, a patient-appointed surrogate—to make decisions for him or her should decision-making capacity later be lost.[20] But what we found, of course, is that most people had not done this kind of thing, and although there has been a tremendous emphasis on advance care planning in the last twenty-five years or so, still many, many people—the vast majority of Americans—have not appointed someone to act on their behalf if they are no longer able to make medical decisions.[21]

---

[20] A patient may appoint a proxy through a durable power of attorney for health care. *See End of Life: Helping with Comfort and Care*, NAT'L INST. ON AGING (last updated Jan. 20, 2015), http://nia.nih.gov/health/publication/end-life-helping-comfort-and-care/planning-end-life-care-decisions.

[21] Of the more than 7,900 respondents to a survey conducted as part of a study published in the January 2014 edition of *The American Journal of Preventative Medicine*, only 26.3% had an advance directive. *New Study on Advance Directives: Lack of Awareness Continues to*

During this period of time, especially post-*Cruzan*, state legislatures filled the breach by enacting legislation empowering family members to make decisions in the absence of a patient-appointed surrogate, and most states now have surrogate (sometimes referred to as family) decision-making statutes.[22] These statutes tend to follow what was the common practice before there was any legislation, which is to say that spouses have primary authority to make decisions. If there was no spouse, or the spouse was incapable of making decisions, then adult children of a patient, siblings, parents of adult children, and clearly, parents of minor children, had the authority to do so. Under these statutes, after this list of relatives is exhausted states tend to vary somewhat on who has the authority to make these decisions, but generally speaking, close family members do.[23]

Moreover, in the few states that have no legislation[24] today "the family," whatever that means, has the authority to make these decisions by virtue of common law.[25] This was the practice and the courts essentially recognized the medical tradition of consulting with family members to make these kinds of decisions. So today, the issue of "who decides?" is not quite the vexing one that it was in 1975–76 in the *Quinlan* case, or even as it might have been as recently as fifteen or twenty years ago.

By what standards should these decisions be made? This issue has been a bit more contentious. As I said before, for competent patients, informed consent is the mechanism for decision-making, and there are standards in law for what information needs to be disclosed.

For patients lacking decision-making capacity, the courts have

---

be a Barrier for Americans in Making Medical Wishes Known, NAT'L HOSPICE & PALLIATIVE CARE ORG. (Dec. 16, 2013), http://www.nhpco.org/press-room/press-releases/new-study-advance-directives.

[22] *See* ABA COMM'N ON LAW & AGING, DEFAULT SURROGATE CONSENT STATUTES (2014), http://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.authcheckdam.pdf (describing surrogate statutes adopted in every state).

[23] For example, in the District of Columbia, the order is (1) Spouse or domestic partner, (2) Adult child, (3) Parent, (4) Adult Sibling, (5) Religious superior, if in religious order, or a diocesan priest, (6) Close friend, and (7) Nearest living relative. D.C. CODE ANN. § 21-2210 (West 2016). Whereas in Delaware, the order is (1) An individual orally designated as surrogate, (2) Spouse, unless petition for divorce, (3) Adult child, (4) Parent, (5) Adult sibling, (6) Adult grandchild, (7) Adult niece or nephew, (8) Adult aunt or uncle, and (9) Close friend. DEL. CODE ANN. tit. 16, § 2507 (West 2016).

[24] For a list of states having surrogate decision-making statutes, see ALAN MEISEL ET AL., THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING § 8.10 (Supp. 2016).

[25] *Id.* §3.11 nn.82 & 83.

promulgated three different standards. The predominant one is the "substituted judgment standard," which essentially instructs the surrogate—the person who is making the decision for the patient—to consider what the patient would have wanted under these circumstances. This standard places the surrogate in the patient's shoes and requires the surrogate to make that decision based on his or her knowledge of the patient's goals, values, interests, and any relevant information the patient would take into account if he or she were to make the decision.[26] That seems reasonable, because if competent patients can make decisions for whatever reasons *they* want, the emphasis on *they*, their own personal interests, values, goals, etc., then shouldn't we be trying to replicate that for patients who lack decision-making capacity? Everyone is pretty much in agreement that this framework will best promote individual autonomy.

A small minority of courts has been more stringent and determined that there must be clear and convincing evidence of the patient's wishes: merely attempting to replicate what the patient would have wanted—substituted judgment—is not good enough.[27] Under this standard, the patient must have actually made and articulated a decision about the matter in question before losing decision-making capacity. That is the stance that the New York and the Missouri courts took about thirty years ago,[28] but that has softened quite a bit, and most decision-making in those states—in fact, if not in law—adheres to the substituted judgment standard.

Then there are situations in which we have absolutely no idea what the patient would have wanted, and some courts and some legislatures have admonished us that, in those circumstances, we should attempt to do what is in the patient's best interests.[29] Like so much of what I am go-

---

[26] "The court should also take into account the patient's past decisions regarding medical treatment, and attempt to ascertain from what is known about the patient's value system, goals, and desires what the patient would decide if competent." *In re* A.C., 573 A.2d 1235, 1251 (D.C. 1990).

[27] *See, e.g.*, Cruzan *ex rel.* Cruzan v. Harmon, 760 S.W.2d 408 (Mo. 1988); *In re* Westchester Cty. Med. Ctr., 531 N.E.2d 607 (N.Y. 1988).

[28] In *In re Storar*, the New York Court of Appeals held that "no one, not even a concerned family member, can refuse life-sustaining treatment for another person without clear and convincing evidence of the patient's own wishes. . . . New York and Missouri are the only two states that condition the withdrawal or withholding of life-sustaining treatment on clear and convincing evidence of the patient's wishes." N.Y. DEP'T OF HEALTH, WHEN DEATH IS SOUGHT 52–53 (1994).

[29] "New York's healthcare proxy law permits adults to grant an agent the authority to make some or all treatment decisions, including decisions about life-sustaining measures. Under the law, the agent must decide in accord with the patient's wishes, if they are reasonably known, or, if they are not reasonably known, *in accord with a judgment about the patient's*

ing to say today, that is much easier said than done.

The final issue concerns the role of the courts in end-of-life decision-making. The courts have clearly stated that they do not want to routinely be involved in these kinds of cases. They strongly, and almost unanimously, believe that these are the kinds of decisions that ought to be made in the clinical setting, between patients with decision-making capacity and healthcare professionals, or between healthcare professionals and the surrogates for patients who no longer have decision-making capacity. The courts, however, are always open in the cases of intractable conflict among those involved in the decision-making process, or where there may be a conflict of interest between the surrogate and the patient. In those instances, of course, the courts are available to hear these kinds of cases, but ordinarily, it is not necessary. (The sole exception is Massachusetts, where the Supreme Judicial Court continually held throughout the 1970s and 1980s that only courts were the proper forum for making end-of-life decisions[30] but that position appears to have gone by the wayside in practice.[31]) That is pretty well established because it's clear that there are far fewer decisions coming out of state courts today than there were twenty-five or thirty years ago. Maybe two or three decisions per year now, as opposed to ten or fifteen decisions per year when the law was far more uncertain on these issues.

The central issue, however, in end-of-life decision-making for patients lacking decision-making capacity, is how are we supposed to know their wishes? Well, some people have told us. When I say "told us," I mean literally, through conversations, which might be referred to as an oral directive, although that sounds kind of formal. Sometimes people would say something like, "no heroics, at the end of life when I am dying, no heroics, let me die peacefully." Others might say something more specific, such as, "I never want to be on . . . ," then fill in the blank, whatever it is: ventilator, dialysis, feeding tube, or a combination of those kinds of things. Sometimes these discussions would be quite informal.[32] They might be in reaction to one of the important cases, because the important cases always made the news. The Karen Quinlan

---

best interest." *See id.* at 51 (emphasis added).

[30] *See* Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417 (Mass. 1977).

[31] MEISEL ET AL., *supra* note 24, § 3.21.

[32] *See A.C.*, 573 A.2d at 1251 ("[T]o determine the subjective desires of the patient, the court must consider the totality of the evidence, focusing particularly on written or oral directions concerning treatment to family, friends, and health-care professionals.").

and Nancy Cruzan cases had national media attention.[33] There used to be something called news magazines, and there was something called newspapers as well, some of you may remember those. These cases made the front page of those publications, and people talked about these issues all the time.[34] Then, there were more localized cases that made the local headlines, and people talked about those as well. You might go visit someone in a hospital or in a long-term care facility, who was seriously ill, or increasingly becoming demented, losing their decision-making capacity as well, and the visitor might say, "Boy, at the end of my life, I don't want to be in that kind of situation. Don't do that to me." Often they would say it to children, or spouses, people who they knew might someday be in a position to make those kinds of decisions.

However, more formal mechanisms developed—living wills being the first and probably the best known to the general public—to enable a person to state in writing what his or her wishes are regarding end-of-life care.[35] A person could expressly state, "I never want to have this," or, "I would like to have this. I want everything possible done." In fact, as more and more public discussions of these things took place, and the discussions tended to be towards *limiting* treatment, some people began to worry that treatment would be limited when they did not want it to be. They felt that if they did not make their wishes *for* treatment clear, they might be abandoned and medical care that might be possible would not be tried.

Another formal mechanism for planning end-of-life care is the healthcare power of attorney—a document by which people can appoint an agent, sometimes referred to as a surrogate or proxy—to make deci-

---

[33] *See, e.g.*, Tamar Lewen, *Nancy Cruzan Dies, Outlived by a Debate Over the Right to Die*, N.Y. TIMES (Dec. 27, 1990), http://www.nytimes.com/1990/12/27/us/nancy-cruzan-dies-outlived-by-a-debate-over-the-right-to-die.html ("Miss Cruzan's case became the centerpiece of a bitter debate about how and when families can decide to withdraw nourishment or medical treatment to bring about the death of an incapacitated loved one."); McFadden, *supra* note 12 ("Karen Ann Quinlan, who slipped into a coma 10 years ago and became the center of a national debate on the definition of life and the right to die, died yesterday at a nursing home in Morris Plains, N.J.").

[34] *See, e.g.*, Andrew H. Malcolm, *Judge Allows Feeding-Tube Removal*, N.Y. TIMES, Dec. 15, 1990, at 10; *see also 2d Missouri Father Blocked From Letting Comatose Daughter Die*, N.Y. TIMES, Dec. 31, 1990, at 8; Joseph F. Sullivan, *Girl-In-Coma Case Will Start Today: Jersey Court to Hear Plea by Parents to Withdraw Life-Sustaining Device*, N.Y. TIMES, Sept. 22, 1975, at 37.

[35] "A living will is your written expression of how you want to be treated in certain medical circumstances." *Living Wills, Health Care Proxies, & Advance Health Care Directives*, AM. BAR ASS'N, http://www.americanbar.org/groups/real_property_trust_estate/resources/estate_planning/living_wills_health_care_proxies_advance_health_care_directives.html (last visited May 13, 2016).

sions for them when they can no longer do so themselves.[36]

Then, we could combine the two together and have a directive that says, "I hereby appoint so-and-so to make decisions for me when I am no longer able to make my own. These are the kinds of things I want that person to take into account in making decisions." Again, they could be general kinds of instructions, or they could be more specific kinds of instructions.

More recently, we have developed what is called "POLST," physician's orders for life-sustaining treatment (or, in some states, called "MOLST," medical orders for life-sustaining treatment), by which these kinds of wishes are negotiated or discussed between the physician and the patient, or the physician and the patient's proxy.[37] The decisions are then entered into orders in a medical chart, which is thought to give more force to the patient's choices because they are more readily available and because doctors are accustomed to writing orders that are then carried out either by resident physicians, nurses, or other appropriate healthcare professionals, depending on the nature of the orders.

There are problems, however, with all of these advance care-planning techniques. One of the problems is that the directives often contemplate discrete treatments. "I do not want to ever be on a feeding tube." "I do not ever want to have CPR, or dialysis," or something like that. The problem is that in many instances of end-of-life decision-making, what is involved is not a single, discrete treatment, but rather a treatment process—a course of events. It is exceedingly difficult—I am being generous—it is practically impossible to foresee in advance just what treatments are going to be needed and in what order. Yes, for example, it is true that in the case of chronic obstructive pulmonary disease there are going to be certain kinds of decisions that probably need to be made, but there are often unanticipated decisions that need to be made as well. It is the unanticipated decisions that are very difficult to plan in advance. These are just some of the decisions that will have to be made: What about the place of treatment? Or the place of death? Where is one going to be treated? Long-term care, rehabilitation, acute care facility, home, residential hospice, in-patient hospice? A variety of decisions of that sort have to be made. They often have implications about the kind of care one is going to receive, as well as the quality of care, but certain types of care are not administered in certain places. Then there are pay-

---

[36] *See id.*

[37] *What Is POLST*, POLST, http://www.polst.org/about-the-national-polst-paradigm/what-is-polst/ (last visited May 13, 2016).

ment issues that arise as well. Who is going to pay for these kinds of things? What does Medicare pay for—it is usually Medicare that is the payer because end-of-life decisions most often involve people who are on Medicare.[38] Will private insurance pay for these kinds of things? If so, or if not, how will that affect decision-making? It is impossible to know these kinds of things in advance.

What about patients who linger for a long period of time? It is very difficult to foresee what is going to happen. What kind of course of events is going to occur? What kinds of treatment decisions may need to be made at various points?

My feeling is that advance care planning is illusory. Yes, we can try to do it. We probably should. Despite my extreme skepticism, I myself do have a healthcare power of attorney with instructions. But I do not have any illusions that it is necessarily going to be followed and, indeed, maybe I won't want it to be. That is the other problem: I do not know what is going to happen at some point. I think, one has to just trust other people to make the right decisions for you. You attempt to designate who those people are, but even then it is very difficult to know who would carry out your wishes. Is someone who loves you, who is very close to you, who wants to do the best thing for you, the best person to do it? That person is also self-interested, because that person may want to keep you alive longer than you want to be kept alive, which may entail some suffering along the way that you would prefer to forgo. On the other hand, it may turn out that the people you thought were your loved ones love the idea of not dissipating your estate with the costs of medical care more than they love you. So there are all kinds of components that are just impossible to figure out in advance.

I talked before about the end-of-life consensus, and I want to come back to that again and to the issues that are really the theme of today's conference—more actively aiding dying. The courts, in creating or developing this consensus, have drawn a very clear line between what they were accepting, acknowledging, pronouncing to be legal, and that which they were not. That bright line that they drew was between passively hastening death and actively hastening death.[39]

Here's what the courts, in effect said: Passively hastening death is okay as long as we do it by the appropriate standards.[40] Actively has-

---

[38] *See 10 FAQs: Medicare's Role in End-of-Life Care*, HENRY J. KAISER FAMILY FOUND. (Nov. 5, 2015), http://kff.org/medicare/fact-sheet/10-faqs-medicares-role-in-end-of-life-care/.

[39] Meisel, *supra* note 19, at 823.

[40] *Id.* at 822.

tening death is never okay. That's off the table. We are not talking about that. That is criminal homicide.[41] We will not allow it. It is impermissible for a physician to provide a patient with the means to end his or her life whether indirectly by providing the patient with a prescription to obtain lethal drugs or directly by actively administering those drugs through an injection or an infusion. We will not allow that.

Now, why did the courts do this? Well, they didn't say. But, I think that it is pretty clear that, first of all, many judges had moral objections to this, as did legislators when bills later came before legislatures to legalize actively hastening death. It was a break with a long-standing legal tradition. Also, I think, more pragmatically, they feared that if they allowed actively hastening death, there would be public outcry, and that would undermine passively hastening death—that is, allowing patients to die from forgoing treatment. So, they said, we are going to take one little step at a time. Yes, it is okay to terminate life support for Karen Quinlan who is permanently unconscious.[42] But if she does not die, we cannot actively intervene to end her life. Of course, some of you who know the case will recall that she did not die when her ventilator was removed in 1976; she lived another ten years, unconscious the whole time.[43] She eventually died of an untreated infection.[44] But, nobody ever intervened to say, "Let's give her a lethal injection and put an end to this."

So the courts approved passively hastening death—what we now call forgoing life-sustaining treatment, termination of life support, etc. But they condemned actively hastening death—euthanasia, physician-assisted suicide, suicide itself—whether brought about by a healthcare professional, a physician, a nurse, or a lay person. Criminal. Not permissible.

What was the rationale for this? Well, they put forth a few different rationales. One for allowing passively hastening death was that, in such cases, there was no criminal liability because of a lack of causation.[45] The patient's death was not caused by human beings, but rather, by letting nature take its course; it was caused by the underlying condition. Another rationale is intent, that is, the intent of the people involved, whether physician, or the surrogate decision-maker, was to relieve suf-

---

[41] *Id.* at 825.

[42] *In re* Quinlan, 355 A.2d 647, 672 (N.J. 1976).

[43] McFadden, *supra* note 12.

[44] *Id.*

[45] Meisel, *supra* note 19, at 839.

fering, not to end life.[46] Whereas, in actively hastening death, the patient is committing suicide, or a third person is assisting suicide, and the intent is specifically to end life.[47] Therefore, this bright line was drawn between the two.[48]

That distinction, however, has begun to break down. It has begun to break down, I think, in part because it is very hard to uphold. When we allow patients to die, we may say that we are intending to relieve suffering, as we are, but we also know with substantial certainty that the patient will die. In the eyes of the law, that constitutes intent.[49] So, even when allowing a patient to die there is an intent to end the patient's life.

Beginning in the 1990s, there has been a trend towards legalization of actively hastening death—by "lethal prescription," but not by "lethal injection." A very slow trend, obviously. Oregon began the trend by passing the first legislation in 1994.[50] Washington,[51] Montana,[52] Vermont,[53] and California[54] followed later, mostly by popular decision—either the legislature or voter initiative. In one instance—Montana—legalization was brought about by judicial decision. And, there is a case brewing in New Mexico now before the New Mexico Supreme Court.[55] We do not know how that is going to come out. The lower court in New Mexico had allowed for physician aid in dying actively.[56]

The United States Supreme Court considered this issue in 1997 in two cases and held that there was no federal constitutional right to physician aid in dying.[57] But, it also held that states were not prohibited by the Constitution from enacting statutes that would legalize it or by doing so by judicial decision. The Court also acknowledged that aggressive

---

[46] *Id.* at 832–33.

[47] *Id.* at 832.

[48] *Id.*

[49] *See* RESTATEMENT (THIRD) OF TORTS: LIAB. FOR PHYSICAL HARM § 1 (AM. LAW INST., 2010); MODEL PENAL CODE §§ 2.02(2)(a), 210.2(1)(a) (AM. LAW INST. 2016) (setting forth that acting "knowingly"—that is, "he is aware that it is practically certain that his conduct will cause such a result"—is sufficient *mens rea* to satisfy an element of the crime of murder).

[50] Meisel, *supra* note 19, at 855.

[51] Washington Death with Dignity Act, Initiative 1000, 2009 Wash. Legis. Serv. ch. 1 (West).

[52] Baxter v. State, 224 P.3d 1211 (Mont. 2009).

[53] Patient Choice at End of Life Act, 2013 Vermont Laws no. 39 (West).

[54] End of Life Option Act, 2015 Cal. Legis. Serv. 2d Ex. Sess. ch. 1 (West).

[55] *See* Morris v. Brandenburg, 356 P.3d 564 (N.M. App.), *cert. granted*, No. 35,478 (N.M. Aug. 31, 2015).

[56] *Id.* at 570.

[57] Vacco v. Quill, 521 U.S. 793 (1997); Washington v. Glucksberg, 521 U.S. 702 (1997).

palliative care was permissible.[58] And, aggressive palliative care involves administering medications to patients that have the potential for ending their lives, though that is not the avowed intent of doing so. The avowed intent is to provide pain relief to patients, but with knowledge that the pain relief may result in the patient's death.[59] And, the Court issued a new invitation to re-litigate this question if adequate palliative care turned out to be unavailable.[60]

What are the lessons of the legalization of physician aid in dying in the states where it has occurred? We have almost twenty years' experience in Oregon, and there are no documented reports of abuse. Is there abuse? There may well be, but, certainly not very much. At least none has been documented. The parade of horribles has not materialized. It was predicted that minorities, women, the poor, and other vulnerable groups would be pressured into ending their lives, but there does not seem to be any evidence that this kind of thing has occurred.

There are, however, limitations—strong limitations—on the use of physician aid in dying in each state in which it is legal, Oregon being the model. First of all, physician aid in dying is limited to people with decision-making capacity.[61] So, if you have lost decision-making capacity, you can no longer avail yourself of actively ending your life. Second, people have to self-administer the medication.[62] Some people who still have decision-making capacity may have lost the ability to administer the medication to themselves—that is, taking a large number of pills, usually barbiturates. Furthermore, the people who are subject to the law must be terminally ill to avail themselves of the law.[63] Although terminal illness is a bit of a flexible concept, there are plenty of people with chronic debilitative illnesses, not considered to be terminally ill, not likely to die within six months, for whom the statute is unavailable and would like to be able to avail themselves of it.[64]

There are also limitations on hospice and palliative care. They do not address the loss of autonomy. Ninety-one percent of the people in Oregon who have obtained a prescription to end their lives have done so

---

[58] *Vacco*, 521 U.S. at 802.

[59] *Id.*

[60] *Glucksberg*, 521 U.S. at 792 (Breyer, J., concurring).

[61] OR. REV. STAT. ANN. § 127.830 (West 2015).

[62] *See id.* § 127.875 (referring to the "patient's act of ingesting medication to end his or her life").

[63] *Id.* § 127.805.

[64] *See id.* § 127.800.

because they fear loss of autonomy.[65] Eighty-seven percent who requested a prescription wanted it because of the decreased ability to participate in the activities that make life enjoyable.[66] And, 71% received a prescription because of loss of dignity.[67] These are the three main reasons that people want a prescription. Palliative care and hospice care do not and cannot always address the issues that impel people to seek a prescription to end their lives.

Furthermore, another limitation is that not all physical pain is fully treatable. Some palliative-care physicians will take issue with that. But sometimes, in order to adequately treat pain, one must make the patient unconscious and, even then, there is sometimes breakthrough pain—and you can tell the patients are in a great deal of pain—despite the fact that they are unconscious. Also, hospice and palliative care can be quite burdensome to families as well as to the patients, and patients may not wish that for their families. Hospice can be burdensome to a family because most hospice care occurs at home. That means that the family is the primary caretaker 24/7, has to administer medications, has to be there to witness the patient's death, and sometimes the dying process can take quite a long time.

What does the future hold in this regard? Well, one thing would be a geographical expansion of physician aid in dying. We are beginning to see that. But, as I said before, it is very slow. The first statute was enacted in 1994.[68] Here, it is more than twenty years later, and still only five states out of fifty—10%—have accepted physician aid in dying. There have been a large number of states where bills have been introduced, but, most of these bills do not really stand much of a chance of getting out of committee.[69]

The expansion of the groups covered by physician aid in dying would be another way to expand it. For example, should patients who lack decision-making capacity be permitted to issue an advance directive

---

[65] OR. PUB. HEALTH DIV., OREGON'S DEATH WITH DIGNITY ACT—2014, at 2 (2015), http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year17.pdf.

[66] *Id.*

[67] *Id.*

[68] Meisel, *supra* note 19, at 855.

[69] *See, e.g.*, Daniela Altimari, *Aid-in-Dying Bill Fails To Get A Vote By Legislative Committee*, HARTFORD COURANT (Apr. 8, 2015), http://www.courant.com/politics/hc-aid-in-dying-bill-0409-20150408-story.html; Ovetta Wiggins, *Effort to Legalize Assisted Suicide Fails – Again – in Maryland*, WASH. POST (Mar. 3, 2016), https://www.washingtonpost.com/local/md-politics/effort-to-legalize-assisted-suicide-in-maryland-fails/2016/03/03/fe92ea74-e14b-11e5-846c-10191d1fc4ec_story.html.

for physician aid in dying, authorizing a doctor to prescribe the medication for the patient to take if the patient is still able to, even though the patient lacks decision-making capacity? Physician aid in dying for patients who cannot self-administer the medication is another important, neglected matter, but in this case, we are no longer talking about patient self-administered dying; we are talking about active euthanasia, where the doctor or someone else is the person who administers the lethal substance. Just as a bright line had been drawn between actively and passively hastening death, another exists between patient-administered dying and physician-administered dying.

Finally, there is physician aid in dying by surrogate decision-makers in the absence of a healthcare power of attorney or a living will authorizing physician aid in dying to be actively administered. In other words, could a surrogate say, using the substituted judgment standard, that the patient would have wanted to end his or her life and thereby authorize the active ending of the patient's life? That, of course, leads us to a discussion of the slippery slope of nonvoluntary, or even involuntary, euthanasia and the breach of yet another bright line—the one involving voluntariness. In other words, could we just begin to end patient's lives without their knowledge or permission because it is convenient for us—whether for society at large, or for the individuals involved—rather than because it is what the patient wants? And, that of course, is the concern—the bottom of the slippery slope—that, I think, impedes a lot of the progress at the top of the slope. Some people are, as a matter of principle, morally opposed to actively ending patients' lives regardless of whether or not the patient consents. Others are concerned on pragmatic grounds. While they do not object in principal, they are concerned in practice that we will wind up in a situation that would be seriously objectionable if not potentially horrific because of our inability either to draw lines or, once drawn, to prevent them from eroding.

Well, that is a brief tour of end-of-life decision-making in the United States, from the early days, 1976—the *Quinlan* case—up to the present time. From the acceptance of allowing patients to die who were terminally ill and who no longer wished to be kept alive, to a situation of more actively assisting patients to end their lives. That, I guess, will be the subject of the rest of the program today, and I look forward to hearing about that from the rest of you. Thank you very much.

Questions

[Question Inaudible]

ALAN MEISEL: The question was about termination of nutrition and hydration, especially medically supplied nutrition and hydration—feeding tubes. There was a great deal of consternation when this issue first arose in the early 1980s about whether this was starving people to death, thereby actively ending their lives. I think that, certainly in law, the dominant position is—and the Supreme Court has pretty much accepted this position in the *Cruzan* case, in dictum—that we are talking about medically supplied nutrition and hydration, medical treatment just like any other, and it can be foregone on the same basis as any other medical treatment.[70] So, if a surrogate had the authority, through an advance directive to terminate antibiotics, or dialysis, then that individual would also have authority with respect to medically supplied nutrition and hydration.

Justice O'Connor, in the *Cruzan* case, said in a concurring opinion that we do not even have to classify this as a medical treatment.[71] It is an infringement upon liberty if there is no consent to it—medically supplied nutrition or hydration.[72] Hence, the patient has the authority to discontinue it or a surrogate does, if that would have been the patient's wish.[73]

Today, there is still strong political opposition to physician aid in dying. Bills sometimes get introduced by a legislator who is either very much in favor of this or trying to please constituents. But most legislators do not want to have to vote on these kinds of issues. It is kind of amazing, I think, that the California legislature approved a bill of this sort earlier this year. I thought that most legislators were too chicken to want to face these kinds of votes and that it was not going to happen for a long time, and that if other states were to legalize it, it would either be by judicial decision or by voter initiative. And, it has been implemented primarily by voter initiative, because I do not think judges are particularly happy—especially in states where judges are elected—to go on record either, as approving this because of fear of political fallout. This is somewhat counter-intuitive because there is not a great deal of opposition in the country anymore. I have not seen public opinion polls recently on this, but the older public opinion polls, roughly 75% of people polled, and if that is representative sample of Americans, approved of actively hastening death in one form or another,[74] usually in the form of physician aid in dying—providing a prescription.[75]

---

[70] Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261, 279 (1990).

[71] *Id.* at 288 (O'Connor. J, concurring).

[72] *Id.*

[73] *Id.* at 289.

[74] Meisel, *supra* note 19, at 818.

[75] *Id.* at 818 n.6.

Frustratingly, despite the fact that polling suggests significant support for physician aid in dying, when it comes time to vote on a ballot initiative, opponents of the initiative tend to prevail. For example, in Massachusetts, some polling showed two-to-one support for the 2012 initiative,[76] but the initiative was ultimately defeated 51% to 48%.[77] What happens is that those who very strongly oppose this pull out all the stops and put a lot of pressure on public opinion through advertising, and have prevailed in Maine, Massachusetts, and Michigan, where voter initiatives have been defeated.

---

[76] *Massachusetts "Death With Dignity" Initiative, Question 2 (2012)*, BALLOTPEDIA, https://goo.gl/4c7Yli (last visited June 18, 2016).

[77] *Id.*