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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 Pittsburgh 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*, *Browning*, 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 legislation²⁴ 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

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*

going 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 decisions³⁰ 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 Lewin, *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 California⁵⁴ 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 horrors 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 debilitating 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.*

PALLIATIVE CARE AND END-OF-LIFE OPTIONS

Dr. Lynette Cederquist & Ellen Waldman***

DR. LYNETTE CEDERQUIST: Thank you. I want to thank everybody for inviting me to participate, and Professor Waldman for suggesting that there should be one physician in the room today. So I am very honored to serve that role today.

Professor Waldman suggested inviting me to address this topic in part because of my background in palliative care, hospice, and clinical ethics at the University of San Diego, but also because I was the physician plaintiff in the California lawsuit that sought to repeal the law that prohibits physician aid in dying. Our lawsuit was filed in parallel with the introduction of the aid-in-dying bill in California.¹ As a hospice physician and clinical ethicist over the last twenty years, I have had a great deal of experience with taking care of patients at the end of life, so I have had many opportunities to ponder what we should do, and what people want us to do as physicians. In California, after previously proposed physician aid-in-dying bills failed to pass, what finally brought this matter to the forefront was a case that became very public. It was even featured on the cover of People Magazine. The case of Brittany Maynard, a twenty-nine-year-old woman, newlywed, who was diagnosed with terminal brain cancer which failed treatments. Ms. Maynard then sought physician aid in dying.² She ultimately moved from California to Oregon to be able to access aid in dying.³ This became very pub-

* Director, Clinical Ethics Program, University of California, San Diego; Clinical Professor of Medicine, University of California, San Diego School of Medicine; M.D. Oral Roberts University School of Medicine. Completed internal medicine residency at the University of San Francisco affiliate program in Fresno, California.

** Professor of Law, Thomas Jefferson School of Law; LL.M., University of Virginia; J.D., New York University; B.A., Brown University.

¹ See 2015 Cal. Legis. Serv. 2d Ex. Sess. ch. 1 (West); Nick Cahill, *California Doctors Can't Yet Assist in Dying*, COURTHOUSE NEWS SERV. (Oct. 30, 2015), <http://www.courthousenews.com/2015/10/30/california-doctors-cant-yet-assist-in-dying.htm>.

² Nicole Weisensee Egan, *Terminally Ill 29-Year-Old Woman: Why I'm Choosing to Die on My Own Terms*, PEOPLE MAG. (Oct. 6, 2014), <http://www.people.com/article/Brittany-Maynard-death-with-dignity-compassion-choices>.

³ Bill Briggs, *Death With Dignity Advocate Brittany Maynard Dies in Oregon*, NBC

lic, and this propelled California to re-introduce legislation, which obviously did pass, and this also propelled the lawsuit that I was involved in.⁴ When I saw the case of Brittany Maynard, I believed that it should not have been necessary for her to move away from her home for her to access aid in dying. I felt that this was clearly wrong and that this was something that our state should legalize. I remember thinking at the time that if I had the opportunity to forward that cause, that I certainly would. Shortly thereafter I was contacted by the organization that really helped forward the legalization in California, to participate in the lawsuit.

Part of what cemented my decision to become involved, the part that I want to share with you today, is a story that puts a face on this issue. A couple weeks after I became involved in the lawsuit, a friend of mine from Los Angeles called me and said, "I have to share my story with you." He said,

Two years ago, I had a very close friend who had been undergoing treatment for brain cancer for six years. He went into remission and had a few good years, but then his tumor recurred. At that point, he tried treatment again but the treatment failed. This man was in his forties, and was still very vital. At the point in time when his physicians informed him that there was no further treatments to offer him, he asked them what to expect as the cancer progressed. His physician said, "Well, you have brain cancer, so that is not really that bad of a death; you won't be in pain. But, over the coming weeks and months you will lose your ability to walk, you will lose your ability to speak, you will lose control of your bowels and bladder, and you will be completely bed bound. But aside from that, it's not so bad." So, he thought that he was just not up for this. He had been under treatment for six years, he had a good quality of life, and he just was not willing to go through this at the end of his life.

He looked into moving to Oregon, but quickly discovered that he was not going to have enough time to move up there and establish residency. So, he called his friends and said, "I want your help. I want to plan my own death, and I do not want to wait until things take their course."

So, at this point my friend became involved in helping him. They contacted the Hemlock Society for assistance.⁵ This organization laid out the plan for them and gave them specific instructions on how to proceed with suicide at home. He had to go help his friend purchase helium tanks from party stores, get a turkey baster bag that he would secure over

NEWS (Nov. 2, 2014), <http://www.nbcnews.com/health/health-news/death-dignity-advocate-brittany-maynard-dies-oregon-n235091>.

⁴ Cahill, *supra* note 1.

⁵ The Hemlock Society later became End-of-Life Choices, which merged with another entity to form Compassion & Choices in 2005. See *Timeline*, COMPASSION & CHOICES, <https://www.compassionandchoices.org/who-we-are/timeline/> (last visited Mar. 6, 2016).

his head with an elastic band. They had to set all this up, and in doing so they were aware that they were committing a crime. This was horribly stressful for all of them.

In the end, they did assist him in doing this at home, and it was a very peaceful death with his family at his bedside. But, they were all traumatized by the feeling that they had committed a crime.

I want to share two things before I proceed on with my presentation. I want to read for you his reflection on this experience, and then I want to play a three-minute clip that his friend Jim made before his death, as a goodbye.

My friend wrote:

This is the story of Jim's death. I was glad to be able to help my friend in his life, and be able to avoid the suffering to come. But I will never be the same after that experience. I so vividly remember the absurdity of running around town to purchase the items on the list. He was so tired, and had such difficulty walking. But, they insisted that no one purchase these items for him, for the fear of legal repercussions. Instead of having a doctor help him die, I helped him walk into each of the stores, and count out the money to pay for the items on the list. I so remember the fear in his aunt's and mother's eyes that day. They were so afraid that Bill and I would be arrested for helping him and for signing the form. It is wrong that this time of grief was further complicated by the fear of the law.

So I am just going to play a little clip of his friend Jim.⁶ You can see that this is not a man who wanted to die. He was not a man who chose death out of depression. He obviously loved life.

I do want to touch on a little bit of what Professor Meisel also talked about. For many people—especially in the palliative care world where I come from—people are opposed to aid in dying because they believe that they can provide patients with a peaceful, comfortable death, without resorting to aid in dying. But as Professor Meisel pointed out, there are many sources of suffering that good palliative care cannot alleviate.⁷ Those are the predominant reasons that people seek aid in dying.⁸ In most cases, we can sufficiently control pain, but I would reinforce the reality that Professor Meisel commented on that we cannot sufficiently

⁶ To view the video, see PMOORE764, *Jim's Memorial Tribute in His Own Words*, YOUTUBE (Nov. 18, 2013), <https://www.youtube.com/watch?v=WDhbw8OW5Y4>.

⁷ Such factors include autonomy of decision-making and a lack of dignity. See Alan Meisel, Symposium, *Antecedent Law and Ethics of Aid in Dying*, 34 QUINNIPIAC L. REV. 609, 622–23 (2016); *Reasons for P.A.S., PHYSICIAN ASSISTED SUICIDE*, <http://physicianassistedsuic.weebly.com/reasons-for-pas.html> (last visited Mar. 6, 2016).

⁸ See *Reasons for P.A.S.*, *supra* note 7.

control pain in all cases. There are some cases of unrelieved physical suffering, no question about it, but again the majority of patients are seeking aid in dying out of more existential suffering—loss of meaning, loss of joy in life—as in the case that I just shared with you.

I always say that good palliative care and good hospice care is sufficient probably 90% of the time. But what about the 10% where it is not sufficient? I think aid in dying should always be a last resort for people, but it should be absolutely available.

Hospice-care providers always try to help people find meaning at the end-of-life, find meaning in their suffering, which I absolutely support. But at a certain point in time, suffering becomes meaningless, and we cannot ignore that fact. I believe it is not our role to decide whether a person's suffering is meaningful. We do our best to help our patients find meaning and closure at the end of their lives. That does not negate the option of allowing patients to choose when their life is done and their suffering has become meaningless and unbearable to them. I do not think that is our call to make.

People often point out the issue of uncertainty of prognosticating. This is of concern because, in order to access aid in dying, all legislation so far in the United States mandates that a person must have a prognosis of less than six months.⁹ Certainly, we are best at prognosticating in the setting of cancer. But even then, we are not that good at it. We are certainly a lot less able to prognosticate a survival of less than six months for other conditions such as end-stage lung disease, end-stage heart failure, or neurodegenerative disorders.¹⁰ These tend to be much more unpredictable courses. Dementia patients will not have access to aid in dying because of the decisional capacity requirement. As far as uncertainty in prognosticating, we contend with this all the time when deciding when to enroll people in hospice. So yes, we know we are not perfect at it. We live with uncertainty in medicine all the time. I do not think this is a valid argument for prohibiting aid in dying. We do the best we can with reasonable certainty.

As Professor Meisel reviewed, the courts have drawn this bright-

⁹ See, e.g., *FAQs*, DEATH WITH DIGNITY, <https://www.deathwithdignity.org/faqs/> (last visited Apr. 29, 2016) (noting that, to qualify for an aid-in-dying prescription a patient must be “diagnosed with a terminal illness that will lead to death within six months”).

¹⁰ See Irene J. Higginson & Massimo Costantini, *Accuracy of Prognosis Estimates by Four Palliative Care Teams: A Prospective Cohort Study*, 1 *BMC PALLIATIVE CARE* 1 (2002); John Henning Schumann, *The Worst Fortune Tellers*, *SLATE* (Aug. 8, 2010), http://www.slate.com/articles/health_and_science/medical_examiner/2010/08/the_worst_fortune_tellers.html.

line between passively allowing people to die versus actively ending peoples' lives.¹¹ There are many practices in palliative care that we offer which are legally and ethically permissible—limiting and withdrawing life-sustaining treatments, controlled sedation at the end-of-life, and allowing people to voluntarily stop eating and drinking. In reality, I believe that is an artificial bright-line, quite frankly. We all feel better saying, “Legally and ethically we allow this option, but we don’t allow this other option.” The line is particularly blurry when it comes to the practice of controlled sedation, when a person says, “I am suffering intolerably, just put me to sleep.” So we do allow the option of sedating them to the point of unconsciousness and keeping them sedated until they pass. Personally, I fail to see how that is really all that much different than physician aid in dying, or even euthanasia, even though we try to make a clear distinction.

Many people bring up the issue of whether aid in dying violates the Hippocratic Oath which admonishes physicians to “Do no harm.”¹² The argument against that is that, as physicians, we administer treatments all the time that sometimes have a great risk of harm to a person, with the intent of benefit. But, we go into it knowing that we may actually harm the person in the process of trying to help them. So if we were completely harm-adverse, we would never do surgery or administer highly toxic chemotherapy. There are many treatments we would never undertake because of potential harm, which would arguably violate the Hippocratic Oath. Concurrently, physicians render many aggressive life-prolonging treatments that only result in prolonged suffering, and fail to provide any meaningful benefit. I would argue that in those cases we are causing harm. If we are allowing a person a choice that reduces the burden of suffering at the end of life, how is that causing harm? I would say it is not.

With those points, I am going to turn it over to Professor Waldman, and then I will be back for further discussion.

ELLEN WALDMAN: I want to echo all of the earlier speakers thanks

¹¹ See *Cruzan v. Dir.*, Mo. Dep’t of Health, 497 U.S. 261, 270–97 (1990) (discussing the distinction and noting that “the majority of States in this country have laws imposing criminal penalties on one who assists another to commit suicide”).

¹² See *Hippocratic Oath*, BLACK’S LAW DICTIONARY (10th ed. 2014); but see Robert H. Schmerling, *First, Do No Harm – Harvard Health Blog*, HARV. HEALTH PUBL’N (Oct. 13, 2015), <http://www.health.harvard.edu/blog/first-do-no-harm-201510138421> (noting that “do no harm” is not part of the Hippocratic Oath, but instead derives from the translation “I will follow that system of regimen which, according to my ability and judgment, I consider for the benefit of my patients, and abstain from whatever is deleterious and mischievous”).

to the *Law Review*, the *Health Law Journal*, and all of the many professors and students who participated in bringing this event to fruition.

I am going to talk about the bill that was recently passed in California through the courageousness of our California legislators, and governor—a Jesuit, who publicly said,

In the end, I was left to reflect on what I would want in the face of my own death. I do not know what I would do if I were dying in prolonged and excruciating pain. I am certain, however, that it would be a comfort to be able to consider the options afforded by this bill. And I wouldn't deny that right to others.¹³

Then, Dr. Cederquist and I are going to talk a little bit about the dispute resolution work that ethics committees and ethics consultants do when conflict arises, with regard to treatments available at the end-of-life.

Professor Meisel gave you the information; I am going to give you the pictures. It is an interesting fact that many of our bioethics milestones are associated with appealing young women who found themselves at death's door, with a constricted set of choices, enduring a very visible purgatory—in newspapers, on TV, in the public eye—exposing the average citizen to the agonal dilemmas facing families and clinical staff that had previously been taking place behind closed hospital and nursing home doors.

The movement to bring aid in dying in California has been around for many years, but the campaign got a boost from Brittany Maynard, who moved from California to Oregon, as Dr. Cederquist mentioned, to avail herself of that state's very well-developed process for obtaining lethal prescriptions.¹⁴ Just a little bioethics quiz, can we identify all the young women on this screen—Karen Quinlan on the top left, Nancy Cruzan in the middle, Terry Schiavo on the top right, and Brittany Maynard bottom right.

The first thing that I want to say about our end-of-life option act is: notice the framing. This act is not entitled the “Physician-assisted Suicide Act,” it is not the “Aid-in-dying Act;” it is the “End-of-Life Option

¹³ Brakkton Booker, *California Signs Physician-Assisted-Suicide Bill Into Law*, NPR (Oct. 5, 2015), <http://www.npr.org/sections/thetwo-way/2015/10/05/446115171/california-governor-signs-physician-assisted-suicide-bill-into-law>.

¹⁴ *Brittany Maynard's Family, Compassion & Choices Partner With California Lawmakers on End-of-Life Option Bill*, COMPASSION & CHOICES (Jan. 21, 2015), <https://www.compassionandchoices.org/brittany-maynards-family-compassion-choices-partner-with-california-lawmakers-on-end-of-life-option-bill/>.

Act.”¹⁵ So, as in the case of abortion, the labels of pro-life and pro-choice were chosen with deliberation. One might say, this is the pro-choice law for those seeking autonomy—not autonomy in the decision of whether to bring into the world another life, but autonomy regarding the circumstances and path of one’s own passing. So this is framed as a law that expands choice, expands options, maximizes the freedom to choose at the end-of-life.

There is a lot packed into the single-spaced, twenty-six page document that is this new law, but I am just going to spotlight certain aspects about it. I want to talk briefly about the law’s carefully structured checks and balances—how it creates a pathway for patients who want assistance in ending their lives, but it is a pathway with many touches between patient and clinician. It is a pathway that is sufficiently long and arduous that patients who want to avail themselves of this option have to be pretty determined to get all the way through the process from beginning to end. And, I want to talk about what advocates are likely to point to as the strengths of the law, and what critics are likely to identify as its weaknesses.

The first point I want to make is that California made a very discrete choice not to move in the direction that Professor Meisel suggests might be a direction that some states go in.¹⁶ The patient, and only the patient, must be the requestor of aid in dying.¹⁷ It is not available through a healthcare proxy, it is not available through the request of a family member.¹⁸ It is the patient who must make the request. It is also not available to every patient. The patient must be at least eighteen, diagnosed with a terminal disease—defined as an incurable and irreversible disease that has been medically confirmed, and will, within reasonable medical judgment, result in death within six months.¹⁹ Also, the patient must be a California resident.²⁰ I think that was added because there was some concern about forum shopping. How does one establish residency? The patient can establish residency through one of the following proofs: (1) filing a California tax return for the most recent tax year, (2) owning property in California, (3) being registered to vote in California, or (4) possessing a California driver’s license.²¹ So, there

¹⁵ 2015 Cal. Legis. Serv. 2d Ex. Sess. ch. 1 (West).

¹⁶ Meisel, *supra* note 7, at 624.

¹⁷ CAL. HEALTH & SAFETY CODE § 443.2(c) (West 2016).

¹⁸ *Id.*

¹⁹ *Id.* § 443.1(q).

²⁰ *Id.* § 443.2(a)(1)–(3).

²¹ CAL. HEALTH & SAFETY CODE § 443.2(a)(3)(A)–(D).

must be some documented evidence of the patient's connection over time with the state. The patient must also have the capacity to make medical decisions, and capacity is defined, with a reference to our probate code, as having the ability to understand the nature and consequences of a healthcare decision, having an understanding of the benefits, risks, and alternatives inherent in their choices, and being able to communicate those choices either themselves or through a person that is familiar with their manner of communication.²² And again, the patient must be able to self-administer.²³ So if the patient's disease imposes a difficulty in actually being able to ingest the drug, that individual will not be able to benefit from this law.

The process has multiple aspects to it. The patient must make two oral requests at least fifteen days apart to the attending physician.²⁴ Those oral requests must be followed by a written request.²⁵ The written request must take a particular form, so there is suggested language in the statute.²⁶ If the patient is a non-English speaker, the form may be written in the patient's language, or written in English, accompanied by an interpreter's attestation.²⁷ California is a very diverse state; we have so many different ethnic groups, so the law is designed to ensure that everybody has access even if language poses somewhat of a barrier. There must be witnesses who attest to the patient's written request, and at least one of these witnesses must be unrelated to the patient.²⁸ One witness must also not be an employee or affiliated with the healthcare facility where the patient is receiving their care.²⁹ As these two provisions demonstrate, a lot of attention is paid to the possibility of conflicts of interest.

Much of the burden of carrying out this law falls on the attending physician.³⁰ The attending physician has twelve specific obligations.³¹ Before prescribing, the attending physician must determine that the patient has capacity, that the patient is in a terminal condition, that the request is being made voluntarily, and that the patient is a California resi-

²² *Id.* § 443.1(e).

²³ *Id.* § 443.2(a)(5).

²⁴ *Id.* § 443.3(a).

²⁵ CAL. HEALTH & SAFETY CODE § 443.3(a).

²⁶ *Id.* § 443.3(b).

²⁷ *Id.* § 443.11.

²⁸ *Id.* § 443.3(b)-(c).

²⁹ CAL. HEALTH & SAFETY CODE § 443.3(b)-(c).

³⁰ *See id.* § 443.5(a).

³¹ *Id.*

dent.³² The attending physician is also charged with explaining to the patient how the drug is to be ingested and safeguarded. So there are actual provisions that instruct the attending physician to talk to the patient about not taking the drug in a public place—like a park—and that the drug should be taken at home, preferably with someone else in attendance.³³

Additionally, the attending physician has to ensure that the patient is capable of informed consent.³⁴ If there is any indication of a mental health disorder—depression or some other condition that might be affecting the patient’s decision-making capacity—then the attending physician has the obligation to refer the patient to a mental health professional for review.³⁵ In addition, the attending physician must refer the patient to a consulting physician for medical confirmation of the diagnosis and the determination of capacity.³⁶ So the patient has multiple contacts with the attending physician, as well as a consulting physician, as well as a mental health specialist if there is an indication of some kind of mental health concern.

The attending physician must also ensure that the patient knows that she can rescind the request at any time.³⁷ Immediately before the written prescription is actually drafted, the physician has to perform another check on the patient’s capacity.³⁸ The physician has to fill out a particular checklist that is contained within the statute, and that checklist has to become part of the patient’s medical record.³⁹ After all of these steps are completed, the physician can either offer the drug directly, arrange for it to be made available through a pharmacy, or the statute actually says that physicians can use the “United Parcel Service, United States Postal Service, or Federal Express, or by messenger service.”⁴⁰ The legislators have specified certain logistical matters in the act itself.

The additional medical professionals and mental health professionals involved in this process also have carefully delineated obligations. If the patient is referred for a mental health evaluation, that physician must examine both the patient and the patient’s medical records, confirm the

³² See *id.* § 443.5(a)(1)(D).

³³ CAL. HEALTH & SAFETY CODE § 443.5(a)(5).

³⁴ *Id.* § 443.5(a)(2).

³⁵ *Id.* § 443.5(a)(1)(A)(i).

³⁶ *Id.* § 443.5(a)(1)(A)(ii).

³⁷ CAL. HEALTH & SAFETY CODE § 443.5(a)(6).

³⁸ *Id.* § 443.5(a)(8).

³⁹ *Id.* § 443.5(a)(11).

⁴⁰ *Id.* § 443.5(c).

patient's capacity, confirm that the patient is acting voluntarily and is not suffering from impaired judgment, and then write all of this up again in the patient's medical chart.⁴¹

The consulting physician who is called in to confirm the patient's diagnosis must also examine the patient, examine the patient's records, and—again—assess the patient's capacity to ensure that they are acting voluntarily and without coercion.⁴²

Interestingly, if the attending physician believes that the patient may be subject to some coercion or duress by a third party, the physician is directed to address the patient separately—that is, remove them from that third party—and question them as to the voluntariness of their decision.⁴³ We actually had a number of cases in our ethics committee (outside of the aid-in-dying context) where the physicians were quite worried about whether the patient was making decisions based on their own values or because they believed the decision was what the family member wanted. It is almost impossible, however, to get the patient alone in these cases, so this mandate—as Professor Meisel says—is easy to draft, but not so easy to implement.⁴⁴

The statute also lists a number of documentation requirements. The oral request has to be documented.⁴⁵ The written request has to be documented.⁴⁶ The attending physician's determinations regarding diagnosis, capacity, voluntariness, and informed consent have to be documented.⁴⁷ The consulting physician's determinations must be documented.⁴⁸ The mental health specialist's report must be documented.⁴⁹ The attending physician's offer to the patient to withdraw the request must be documented.⁵⁰ There is going to be a lot of paperwork associated with this process.

If all of the “t’s” are crossed and the “i’s” are dotted, for the clinical staff associated with this process, they are assured of civil, criminal, administrative, employment, and contractual immunity.⁵¹ There can be no civil litigation or disciplinary action brought against them—no referral

⁴¹ CAL. HEALTH & SAFETY CODE § 443.7.

⁴² *Id.* § 443.6.

⁴³ *Id.* § 443.5(a)(4).

⁴⁴ See Meisel, *supra* note 7, at 619.

⁴⁵ CAL. HEALTH & SAFETY CODE § 443.8(a).

⁴⁶ *Id.* § 443.8(b).

⁴⁷ *Id.* § 443.8(c).

⁴⁸ *Id.* § 443.8(d).

⁴⁹ CAL. HEALTH & SAFETY CODE § 443.8(e).

⁵⁰ *Id.* § 443.8(f).

⁵¹ See *id.* § 443.16.

to the medical complaint board, et cetera, et cetera.

Through a series of conscientious objector provisions in this statute, it is important to realize that the legislators here were trying to satisfy a large number of different interests. So there are provisions in the law that allow healthcare entities to opt-out, and not participate in any of this process.⁵² Those entities can prohibit their physicians from participating in this process, except when an individual physician, nurse, respiratory therapist, or anyone working within that healthcare entity wants to make a referral to physicians who will help patients receive aid-in-dying medication.⁵³ That behavior cannot be punished. So, these compromises ensure there is something for everyone in this bill.

The reporting requirements are also fairly extensive. California is following in the path of Oregon in maintaining records.⁵⁴ As has been stated, there is a lot of concern that these laws will be used to the disadvantage of traditionally marginalized individuals, so we are very interested in figuring out who is going to be asking for these prescriptions, for what reason, and who is actually using the drugs. So there will be extensive record keeping.

I think supporters of the bill will point to these very thick procedural requirements: the patients must request several times in several different forms to access these drugs; a lot of attention is paid to the patient's mental capacity and to the voluntariness of the request; the request must be informed and nobody is to be mistaken as to the effects of these drugs; there must be the involvement of not just the attending physician, but a second physician to confirm the diagnosis and patient capacity as well as the required involvement of the mental health specialist if there is any suspicion that the patient is suffering from mental illness.

I think advocates are going to appreciate that there is a provision in the statute that says that insurance companies cannot in the same communication deny requested medical care, and—at the same time—alert patients to the possibility of obtaining aid in dying.⁵⁵ This actually was a problem in Oregon, that insurance companies were saying, “Well, no,

⁵² *Id.* § 443.15(a).

⁵³ *See* CAL. HEALTH & SAFETY CODE § 443.15(h).

⁵⁴ *Id.* § 443.19(b); *see also* Editorial, *Jerry Brown Makes the Right Call in Signing California's Right-to-Die Bill*, WASH. POST (Oct. 9, 2015), https://www.washingtonpost.com/opinions/jerry-brown-makes-the-right-call-in-signing-californias-right-to-die-bill/2015/10/09/99aeb20-6c5d-11e5-b31c-d80d62b53e28_story.html (“The End of Life Option Act, modeled on a law implemented in Oregon in 1997, was signed by [California Governor Jerry] Brown on Monday. . . . [J]ust as in Oregon, it will be important that California require strict compliance, with good data collection and vigilant oversight.”).

⁵⁵ CAL. HEALTH & SAFETY CODE § 443.13(c).

we are not going to pay for this liver transplant; but, you should know that you can get a lethal dose of morphine through your local dispensary.”⁵⁶ Considering these scenarios, California thought that was an insensitive way to handle these issues, and they specifically prohibited insurance companies from including information about aid in dying in a medical-treatment-rejection letter.⁵⁷

What will critics emphasize? I think that anyone who thinks deeply about how our medical system is working in any of its different roles will point to the fragmentation of care, to the evaporation of long-term relationships between doctors and patients. I think there is going to be concern that, even though there are these forced medical contacts, the contact assumes that the doctors are going to be able to discern how well this patient is really functioning—how voluntary the request for the aid-in-dying treatment is. Some of these assessments—one would hope—would be made in the context of a longer-term relationship, but in our current environment, that is frequently not the case. I think that the critics are going to ask, “Will there be enough attention paid to possible alternatives in pain management, or is this going to become sort of an easy shortcut?” For those who believe that the new California law is too cumbersome, I think that there is going to be concern that this is really a difficult process, and that patients are going to need a fair amount of stamina to get all the way through it. So there may be criticism on that front. There is always going to be concern about elder abuse and about families who—maybe not explicitly, but implicitly—are sending messages that maybe this is a good route for a family member to take.

Already, we are seeing in California newspapers that this law is really just another effort at cost-containment and that, rather than spend money on our sick and impaired residents, we are just pushing for an easier and less expensive route.⁵⁸ So, there is going to be a lot of debate on that front.

I think at this point, we do want to talk about dispute resolution, but we would be happy to take some questions about the statute.

Questions

GREGORY J. PEPE: I wandered into a conversation with a Bioethicist at Yale Medical School and he is adamantly opposed to physician

⁵⁶ See Susan Donaldson James, *Death Drugs Cause Uprow in Oregon*, ABC NEWS (Aug. 6, 2008), <http://abcnews.go.com/Health/story?id=5517492&page=1>.

⁵⁷ CAL. HEALTH & SAFETY CODE § 443.13(c).

⁵⁸ See, e.g., Soumya Karlamangla, *Will California's End-of-Life Law Push Lethal Drugs Over Costlier Care*, L.A. TIMES (Oct. 18, 2015), <http://www.latimes.com/local/politics/la-me-end-of-life-medical-20151019-story.html>.

involvement in this process. His position is that we do not know what kind of long-term effect this is going to have on the physician-patient relationship. Will patients start to look at their doctors in a sort of jaundiced way as they get near the end of their lives—wondering whether or not there is a pre-disposition on your part, one way or another? How do you remove your own prejudices in this area? And then, why wouldn't society set up other kinds of systems to advise people on these kinds of decisions? Why is it being foisted upon physicians?

DR. LYNETTE CEDERQUIST: That is a great question. My perspective is that aid in dying is not something that should ever really be physician-initiated. Those of us who would be willing to participate would only do it at the request of a patient. We may advise patients of their choices at end-of-life, but we would not be saying, "Oh, I think you should avail yourself of aid in dying." That certainly may cause them to lose trust in the medical community. At the same time, I think being willing to be there and to participate when that is what my patient wants is what is important. For example, I have one patient now for whom I have cared for twenty years. She wanted to have a conversation with me about this but was very fearful of bringing it up because she really didn't know my perspective. She is 85 years old, and fearful of getting to the end of her life. She wondered what her options might be. We had very long and meaningful discussions, and she was very grateful that I was open to talking to her about it. She said that she felt like she had the right physician for her. So, there is great opportunity for physician involvement as long as it is not perceived as us pushing the treatment on people—which I think would be wrong—but rather availing ourselves. I think to be unwilling to go there with patients is just washing our hands of something that is difficult. I do not think that is right. This is my own perspective on physician involvement in the decision-making process.

AUDIENCE MEMBER: We often hear about botched death penalty executions, where the convicted party has a very painful death. So my question is, what is in place to ensure that these drugs will not have a similar effect on the patient wishing to die? As a follow-up, was there any consideration given to maybe having a doctor present when the drugs are administered in case anything does go wrong?

DR. LYNETTE CEDERQUIST: Our test of this question has been Oregon's experience for almost twenty years. The botched executions are protocols that were given intravenously, so they are completely different than what we use in aid in dying.⁵⁹ Those drugs can be botched because

⁵⁹ See Kimberly Leonard, *Drug Used in 'Death With Dignity' Is The Same Used in Exe-*

the IV infiltrates—what usually happens is that the drugs fail to actually get in the vein and that becomes very painful and unsuccessful. Whereas with aid in dying, the patient is given a prescription for oral medication to be taken in the patient's home. People have been able to successfully take it at home, fall asleep, go into a coma within a few minutes, and typically die within approximately twenty minutes in most cases.⁶⁰ It has been a much different experience than what we hear about with executions.

AUDIENCE MEMBER: Doctor, it is well established in ethics and in law that the informed consent process requires the physician to discuss all alternatives with the patient when advising regarding treatment decisions. Would you consider assisted suicide to be one of the alternatives that needs to be discussed at the physician's behest?

DR. LYNETTE CEDERQUIST: That is a good question. Actually in California, we have a law on the books that mandates physicians to outline treatment options at the end-of-life for patients that have a less than twelve month prognosis that was passed years ago before aid-in-dying legislation.⁶¹ It conflicts a little bit with the aid-in-dying law because it does not mandate physicians to inform their patients of this option. So there, and again, it is kind of the opt-out clause that we are not mandated to tell patients about this.

AUDIENCE MEMBER: I feel like the people who are taking advantage of the physician-assisted suicide laws in those states are portrayed in the media as people who love life and are not depressed. You mentioned before that they have to go through some sort of mental health diagnosis. If they are diagnosed with depression, what would be the next step with that?

DR. LYNETTE CEDERQUIST: Typically, we are worried about depression that is impairing their decisional capacity. We assess for this in hospice and palliative care all the time. Patients at the end-of-life are making treatment choices, and if we are concerned that their treatment choices are being made in the setting of depression, we will do a trial of treating the depression to see if their wishes change.⁶² I anticipate we

cutions, U.S. NEWS (Oct. 16, 2015), <http://www.usnews.com/news/articles/2015/10/16/drug-shortage-creates-hurdle-for-death-with-dignity-movement> (acknowledging the distinct methods of introducing pentobarbital into the human system in cases of lethal injection as opposed to oral ingestion in the context of physician aid in dying).

⁶⁰ *Id.*

⁶¹ CAL. HEALTH & SAFETY CODE § 442.5.

⁶² See Donald L. Rosenstein, *Depression and End-of-Life Care for Patients with Cancer*, 13 DIALOGUES CLINICAL NEUROSCIENCE 101, 103–05 (2013) (discussing the effects depres-

would do the same in the case of a patient requesting aid in dying.

AUDIENCE MEMBER: This is a follow up to this gentleman's question. The second part of his question related to taking the medication in a doctor's presence. Related to this gentleman's question—I was just looking at the statistics.⁶³ In 2010, Oregon stopped reporting certain information if the patient takes the aid-in-dying drugs outside the presence of a doctor.⁶⁴ Did California look at that in terms of the law, in terms of getting better statistics, in terms of whether there are adverse events? Can you follow up on that?

ELLEN WALDMAN: There is no requirement in the law that a doctor be present.⁶⁵ The doctor needs to discuss with the patient keeping the drug safe, taking the drug in a non-public area, and they advise the patient to discuss their plan to take the drug with family.⁶⁶ But, it is not a requirement. So, the law does not go so far as to require a physician's presence at the time of ingestion.

AUDIENCE MEMBER: [inaudible]

ELLEN WALDMAN: Well, I think that the expectation is that there will be family members present. Also, we are gathering data on who is requesting the medication.⁶⁷ We are not necessarily getting the best data on who is taking it, but it does give you a sense of who is expressing interest in this option and whether there are any patterns to be discerned there.

DR. LYNETTE CEDERQUIST: Also, again I can comment that in Ore-

sion have upon the decisional capacity of terminal cancer patients).

⁶³ See generally OR. PUB. HEALTH DIV., OREGON DEATH WITH DIGNITY ACT: 2015 DATA SUMMARY (Feb. 4, 2016) [hereinafter 2015 OREGON DEATH WITH DIGNITY REPORT], <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf>; see also OR. PUB. HEALTH DIV., OREGON'S DEATH WITH DIGNITY ACT—2014 (Feb. 2, 2015) [hereinafter 2014 OREGON DEATH WITH DIGNITY REPORT], <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year17.pdf>.

⁶⁴ OR. PUB. HEALTH DIV., OREGON DEATH WITH DIGNITY ACT—2013 (Jan. 22, 2014), <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year16.pdf> (“A procedure revision was made mid-year in 2010 to standardize reporting on the follow-up questionnaire. The new procedure accepts information about time of death and circumstances surrounding death only when the physician or another health care provider is present at the time of death.”).

⁶⁵ See OR. PUB. HEALTH DIV., FAQs ABOUT THE DEATH WITH DIGNITY ACT (last updated Feb. 18, 2015), <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/faqs.pdf> (“The law does not require the presence of a physician when a patient takes lethal medication.”).

⁶⁶ See CAL. HEALTH & SAFETY CODE § 443.5(a)(5).

⁶⁷ 2015 OREGON DEATH WITH DIGNITY REPORT, *supra* note 63; 2014 OREGON DEATH WITH DIGNITY REPORT, *supra* note 63.

gon, the overwhelming majority of patients who ultimately opt to get medication and take it are enrolled in hospice.⁶⁸ So, they are getting in-home hospice care and support, so often times there can be a hospice nurse present and available at the time that the patient takes it.

AUDIENCE MEMBER: Although there is a lot of paperwork that is involved, once the decision is made, is the dose just one administration?

DR. LYNETTE CEDERQUIST: Yes.⁶⁹

AUDIENCE MEMBER: Have there been any cases where the person has changed his or her mind in the middle of this procedure? What happens if somebody takes the pill and just has a eureka moment and decides, “I don’t want this to happen?” Has that ever been documented?

DR. LYNETTE CEDERQUIST: I am not aware of that happening. Many patients change their minds after filling the prescription and never take it.

ELLEN WALDMAN: We just have a few more moments. Both Dr. Cederquist and I sit on ethics committees and deal a little bit with the conflicts and efforts with conflict resolution that arise at the end-of-life.⁷⁰ So, I just wanted to spend a few minutes talking about that topic. The first thing to say is that resolving conflict at the end-of-life is that it is messy. People are not smiling and looking like they are having a super nice time. But most efforts in conflict resolution arise not in the context of what we are focusing on today—which is aid in dying—but in cases of disagreement where physicians believe the most appropriate course of action is to withdraw life-sustaining treatment and the family disagrees.⁷¹

So, just really briefly, forty years ago, when the New Jersey Supreme Court was hearing the *Quinlan* case,⁷² or twenty years ago, when

⁶⁸ 2014 OREGON DEATH WITH DIGNITY REPORT, *supra* note 63, at 2. (“Most . . . patients . . . (93.0%) were enrolled in hospice care either at the time the [aid in dying] prescription was written or at the time of death.”).

⁶⁹ Jennifer Fass & Andrea Fass, *Physician-Assisted Suicide: Ongoing Challenges For Pharmacist*, 68 AM. J. HEALTH-SYS. PHARMACY 846–47 (2011), <http://www.ajhp.org/content/68/9/846.full.pdf> (“The lethal dose prescribed is . . . to be consumed at one time.”).

⁷⁰ Dr. Cederquist chairs the Hillcrest Medical Center Hospital Ethics Committee in San Diego, California. Professor Waldman currently heads the International Mediation Institute’s Ethics Committee.

⁷¹ See Catherine M. Breen et al., *Conflict Associated with Decisions to Limit Life-Sustaining Treatment in Intensive Care Units*, 16 J. GEN. INTERNAL MED. 283, 285 (May 2001) (discussing the incidence and nature of interpersonal conflicts that arise when patients in the intensive care unit are considered for limitation of life-sustaining treatment).

⁷² *In re Quinlan*, 335 A.2d. 647, 647 (N.J. 1976) (“Father sought to be appointed guardian of person and property of his 21-year-old daughter who was in a persistent vegetative state

the United States Supreme Court was hearing the *Cruzan* case,⁷³ the more common disagreements at the end-of-life involved a hospital and physicians who were insisting on continuing treatment to a permanently unconscious or otherwise gravely ill individual and the family was seeking to have the treatment withdrawn.

Today, our more common disputes arise in a different configuration. Today, the positions are reversed. It is the physicians who are often times saying, "It is time to rethink the goals of care. We should not be continuing to provide nutrition and hydration, or continue to have this person hooked up to a breathing machine." And families say, "No, we want everything done. We want to continue with the feeding tubes, we want to continue with the respirator. We want the continuation of full medical support for our loved one." It is important to know that these "futility cases," as they are called, are almost never disputes between patients and doctors—the patient is almost never able to participate in a meaningful way.⁷⁴ These are disputes between the family and the medical team.

Sometimes, the disputes, as it was in the Schiavo case, are kind of inter-family, between different relations to the patient.⁷⁵ It is also important to note that when we use the term futility, we are not talking about a treatment that is physiologically useless. We are not talking about giving antibiotics when the patient is suffering from a virus. We are talking about treatments that have a physiological effect. They will keep the patient alive, sometimes indefinitely.

The issue is, is this a quality of life worth sustaining? We are not disputing over technical medical matters. These are value-laden disputes about what sort of life is worth perpetuating. Should we use our medical arsenal to sustain an existence that some claim is too impoverished to warrant the continued expenditure of medical resources?

This was the case of Hassan Rasouli, which ended up in front of the Canadian Supreme Court, and provided a pointed lesson on how these cases become litigation juggernauts.⁷⁶ Mr. Rasouli was an engineer in

and sought the express power of authorizing the discontinuance of all extraordinary procedures for sustaining daughter's vital processes.").

⁷³ *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 261 (1990) ("Hospital employees refused, without court approval, to honor the request of Cruzan's parents, co-petitioner's here, to terminate her artificial nutrition and hydration, since that would result in death.").

⁷⁴ James L. Bernat, *Medical Futility Definition, Determination, and Disputes in Critical Care*, 2 NEUROCRITICAL CARE 198 (2005), <http://www.ncbi.nlm.nih.gov/pubmed/16159066>.

⁷⁵ See generally Robert A. Burt, *Family Conflict and Family Privacy: The Constitutional Violation in Terri Schiavo's Death*, 22 CONST. COMMENT. 427 (2005).

⁷⁶ *Cuthbertson v. Rasouli*, [2013] 3 S.C.R. 341 (Can.).

Iran who immigrated to Canada.⁷⁷ Six months after he came to Canada, he was diagnosed with a benign brain tumor.⁷⁸ He had surgery. His wife is a doctor, by the way. Mr. Rasuli made it through the operation with no complications.⁷⁹ During the aftermath, however, he did not fare so well; he developed meningitis.⁸⁰ Within six weeks, the physicians came to the family and told them, “He is never going to wake up; you don’t really want him in this state for an extended period of time, do you?” The family’s response caught the physicians off guard; they said, “Well actually, we are Shia Muslims, and we do. According to our belief, only God can make these kinds of decisions. Doctors really, in our view, do not have any kind of moral authority.”⁸¹ The case quickly became hotly contested and went up through the court system.

How can mediation help? Just very briefly I want to draw explicitly from a wonderful article, written by Dean Brown, about the use of mediation in value disputes.⁸² In that article, she talks about what happens to people in conflict—and Dr. Cederquist and I have talked about this a lot—how we all engage in what psychologists have called the “fundamental-attribution error.”⁸³ When we look at the person we are in conflict with, we see their objectionable behavior as a function of their personality. They are acting because of some very malignant motivations or because of certain character defects they have.

On the other hand, when we look at our own behavior, we say, “Well, you know, that wasn’t my best day, but I was acting as a result of the very difficult situation that I found myself in.”

The imputation of negative motivations to the other while maintaining our own sense of the sort of righteousness of our position is a fundamental quality of conflict. If a mediator understands this dynamic, he or she can enter into these highly conflicted situations, and try to challenge that belief system. The mediator can suggest to the family, “Is it

⁷⁷ Nicholas Hune-Brown, *A Life Interrupted: Hassan Rasouli’s Journey from an Earache to a High-Stakes Battle Over End-of-Life Decisions*, TORONTO LIFE (Nov. 27, 2012), <http://torontolife.com/city/life/a-life-interrupted>.

⁷⁸ *Id.*

⁷⁹ *Id.*

⁸⁰ *Id.*

⁸¹ Hune-Brown, *supra* note 77.

⁸² Jennifer Gerarda Brown, *Deeply Contacting the Inner World of Another: Practicing Empathy in Values-Based Negotiation Role Plays*, 39 WASH. U. J.L. & POL’Y 189 (2012).

⁸³ *Id.* at 203; *see also* Mark Sherman, *Why Don’t We Give Each Other a Break*, PSYCHOL. TODAY (June 20, 2014), <https://www.psychologytoday.com/blog/real-men-dont-write-blogs/201406/why-we-dont-give-each-other-break> (“When we see someone doing something, we tend to think it relates to their *personality* rather than the *situation* the person might be in.” (emphasis original)).

possible that the doctors here are motivated by something other than cost control? Is it possible that they really are working with your husband's best interests in mind? Is it possible that they do care about you and your family?" At the same time, the mediator can plant the following seeds with the physicians, "I know you have labeled this family as difficult, irrational, and completely crazy, and that you now view them as hurdles to overcome as opposed to people to understand; but, is it possible that their belief system is something worth trying to understand? Is it worth trying to figure out what might be a viable solution from their perspective?"

AUDIENCE MEMBER: There is a lot we could talk about here, and you have a long day ahead of you. What I wanted to ask Dr. Cederquist while we are finally up here having our dialogue is what is the process that the Ethics Committee uses? And, in the two minutes that we have available, how would you explain that to the group?

DR. LYNETTE CEDERQUIST: We are often consulted when a conflict is already very well entrenched by the time they call us. It is a typical scenario—like Professor Waldman just described—in which the physicians feel it is time to withdraw life-sustaining treatments because they do not believe the patient is going to survive. The family has dug their heels in and still is insisting everything be done. They have come head to head, and now they call us. So we do participate as a mediator in that situation.⁸⁴

I always like to come into the situation and ask the question, why is this family demanding treatment that the physicians are clearly telling them is not useful? Why would someone ask for something in that situation? There are many reasons. Getting to the root of that question can be very helpful. Often times it may stem from their religious beliefs.⁸⁵ In other cases, they are acting out of profound grief and fear. They are not coming at this from any sort of reasoned, rational understanding that their loved one has no reasonable chance of survival—they are not thinking in those terms. They are thinking in emotive terms. So we need to understand that that is what is going on.

⁸⁴ See generally Nancy Neveloff Dubler, A "Principled Resolution": *The Fulcrum for Bioethics Mediation*, 74 LAW & CONTEMP. PROBS. 177 (2011) (discussing the core bioethical principals that support the creation of principled resolutions as fulcrums for resolving disagreements in the healthcare setting through mediation).

⁸⁵ See generally L.T. Niebrój, *The Influence of Religious Beliefs on Health Care: Between Medical Futility and Refusal of Treatment*, 57 J. PHYSIOLOGY & PHARMACOLOGY, Supp. 4, Sept. 2006, at 241 (discussing how people's religious beliefs play a role in their medical treatment decisions).

I try and help reframe the discussion. Often times, we will run the family meetings with the physician and the family both present, and sit down and discuss this. During these meetings, I like to start with pointing out the fact that we are all in this room for the same reason: we are all trying our best to help their loved one. The physicians are doing everything they can to help them. The family is doing everything they can as a family. We just need to try to find out how to do that together. So I try to realign them a little bit, instead of butting heads. I find that often times, the families will express gratitude to the physicians and say, "We know you have been doing everything you can. We understand that. We appreciate what you have done." So the meeting can soften the conflict a little bit.

I also like to try to get away from fighting about a specific treatment. People get very focused on asking, "Are we going to code this person or not?" They get very treatment focused; I try to pull away from that and say, "Let's talk about goals of care. What do you hope this would look like for your loved one? And, what do the physician's think that they can potentially accomplish? First, let's talk about that. Then we can talk about the treatments that can help us to achieve the goals we think we can accomplish." So, in two minutes or less, those are some of the kinds of things I try to get at in mediating such conflicts.

LEGISLATIVE PANEL:
AID-IN-DYING LEGISLATION IN CONNECTICUT

Tim Appleton, Rep. Stephen Harding,**
Rep. Kelly Luxenberg† & Nicole Stacy††*

JENNIFER HERBST: So, a continued good morning. I would like to add my welcome to the welcomes you have heard from Dean Jennifer Brown, my colleague Carrie Kaas, as well as the *Quinnipiac Health Law Journal* and the *Quinnipiac Law Review*. My name is Jennifer Herbst, I teach here at the Law School and the Medical School, and it is my pleasure this morning to moderate this panel on where the bill is, or where the bill has been, and sort of the current status of the aid-in-dying bill in Connecticut.

We have four panelists here who have been very involved with the conversations we have been hearing about. So the issues and the history, and where we have been from Professor Meisel, that brought us up to this point. And, then the details of the bill in California, and how California got through that from Professor Waldman and Dr. Cederquist.

Today, we have, from your left to your right, Tim Appleton, Representative Kelly Luxenberg, Representative Stephen Harding, and Nicole Stacy, here. I am going to have each one of them introduce themselves, because they know far better than I, what they would like you to know about them. In doing that I have asked them to give you a quick explanation of what initially drew them to conversations about end-of-life decision-making and what they have been doing up in Hartford to engage in these questions.

So, Tim, if you would like to start please.

TIM APPLETON: Thank you very much Jennifer for your kind introduction, and thank you Kelly, Stephen, and Nicole for agreeing to be on

* Tim Appleton is the Connecticut Campaign Manager for Compassion and Choices.

** Stephen Harding is a State Representative for the 107th General Assembly District, which includes Brookfield, Bethel, and Danbury, Connecticut.

† Kelly Luxenberg is a State Representative for the 12th General Assembly District, which includes part of Manchester, Connecticut.

†† Nicole Stacy is a Public Policy Assistant at the Family Institute of Connecticut.

the panel. My name is Tim Appleton; I am the Connecticut Campaign Manager and Regional Outreach and Campaign Manager for Compassion & Choices. Compassion & Choices is the largest and oldest non-profit organization in the country that works to expand care and choice at end-of-life.¹

I have been working on this legislation here in our state, as well as organizing on it, for the last three years, and similar to the California legislation the bill here in Connecticut would afford people that are terminally ill with less than six months to live an opportunity to seek out a prescription from their physician if such patients are mentally competent, that would hasten the end of their life.² I got involved in this work because of a dear friend of mine that was my same age, who was United States Special Forces Major, named Al. Al and I skied together quite often, as members of the National Ski Patrol.³ As he got older and more ill, his opportunity to beat me down the hill every other time became less and less. I was working at the state capital at the time this was happening. He became more and more sick from liver cancer, and we ended up, as anyone is able to do, contacting our legislator, and asked that a flag be flown and certified as flown on behalf of someone.⁴ We did that on behalf of my friend Al. The state capital police folded it beautifully in the triangle that everyone knows, and we presented it to him as he lay in tremendous pain, bloated with bile in his stomach because of his illness, unconscious, and unresponsive. We presented this flag to his son and his wife. I was very emotional, and at that time, I thought to myself, “We could do so much more for Al than just present a flag as a member of state government. We could offer Al a choice at the end of his life that might prevent the suffering that he was so very clearly undergoing at that time.” It was because of that moment in my life that I understood that this was something that I had to work on and specifically on Al’s

¹ See *About*, COMPASSION & CHOICES, <https://www.compassionandchoices.org/who-we-are/about/> (last visited Mar. 3, 2016); *Timeline*, COMPASSION & CHOICES, <https://www.compassionandchoices.org/who-we-are/timeline> (last visited Mar. 3, 2016) (explaining that the organization known as Compassion & Choices is the successor to the Hemlock Society, first formed in 1980, which merged with Compassion in Dying in 2005 to create Compassion & Choices).

² See An Act Concerning Aid in Dying for Terminally Ill Patients, H.R. 7015, 2015 Leg., Jan. Sess. (Conn. 2015); see also CAL. HEALTH & SAFETY CODE §§ 443.1 *et seq.* (West 2016).

³ See *National Ski Patrol Eastern Division Awards Program*, NAT’L SKI PATROL (Oct. 10, 2015), <http://www.nspeast.org/awards/archives/10-2015>.

⁴ For information regarding the flag request process, see *Flags on the Capital*, CONN. ST. CAP. POLICE, <https://www.cga.ct.gov/cop/cap-flags.asp> (last visited Apr. 16, 2016).

behalf. So I never talked to his family after that, but I just understand that the suffering that Al went through is something that could have been avoided and that we should work to correct. So, that is a very long answer to your very short question, I apologize.

JENNIFER HERBST: Well, thank you. We will have plenty of time for more discussion in a bit.

KELLY LUXENBERG: Thank you. Thanks Tim, thank you all for being here, and thank you for having me today. I am Kelly Luxenberg. I am a State Representative. I am serving in my first term, and I represent Manchester, Connecticut, which is about 10 miles east of Hartford.

I will tell you that I am really an unlikely poster child for the death with dignity legislation. If you had asked me four years ago where I was on this issue, I would have told you that I was against it. But, eighteen months to two years ago that really changed when the young woman, Brittany Maynard⁵ came on to the national scene and shared her own experience. This was a woman who had no interest in dying; she had every reason to live. She was young, she was beautiful, she had a beautiful family, a beautiful husband, and a beautiful outlook on life. But unfortunately, for her, she had terminal brain cancer that would end her life, and she wanted the choice to have that end be on her own terms.⁶ So the reason that this struck me was because she was my peer. We were about the same age. I had just had a baby, and I was looking at this young woman and thinking how courageous she is that she is going to take this control in her life.

It really gave me pause and prompted me to think back on my own life. My father had Parkinson's disease, and unfortunately he passed away at his own hand when I was eleven years old. He ended up drowning himself; I think back to that time and about how difficult that was for me. Suicide itself has such a black mark on families, such a black mark on those who do it; it is like all the good in their life has been taken away. But, my dad had become so so sick. He was maxed out on all of the medications he could take. This was the mid-90s, and he had an experimental surgery called a pallidotomy⁷ at Yale-New Haven Hospital

⁵ See *About Brittany Maynard*, BRITTANY MAYNARD FUND, <http://thebrittanyfund.org/about/> (last visited Mar. 6, 2016).

⁶ See *id.*

⁷ The procedure involves destroying the overactive area of the brain that is causing the uncontrolled movements of Parkinson's disease. See *Pallidotomy (Posteroventral Pallidotomy) for Parkinson's Disease*, WEBMD (last updated Mar. 12, 2014), <http://www.webmd.com/parkinsons-disease/pallidotomy-posteroventral-pallidotomy-for-parkinsons-disease>.

that promised him everything. The doctors promised him the procedure would give him his life back,⁸ and the surgeon who did it decided that he was going to operate on both sides of his brain, which left my dad with the inability to swallow. He could not do the most basic of math problems, and he had previously been the executive vice president of a bank.

So looking back on this time, looking back on my mom, she acted as if my dad had merely slipped and fell. She did not want his life to have that black mark on it. So for the longest time, I convinced myself, “You know, he didn’t do it. It was an accident. He slipped, which isn’t uncommon for people with Parkinson’s.”⁹ My dad never learned how to swim.” But when I got into my twenties, and my brother and I started really talking about it, my brother’s position on the nature of my father’s death was, “You know, it gives me comfort to know that he was in control in those last moments. That he was not alone and cold and afraid as there was nothing he could do.” It was a thirteen foot drop. He was going to die; there was no other possible conclusion to his battle with the disease. To think about the juxtaposition of the undignified way in which he died and that it was also the last thing he was really in control of. Real choice.

As I came to the legislature that this issue came before, I really became an advocate for it. I testified and shared the personal story of what I went through. I wanted people in their last moments of life to be able to have that choice for themselves, and hope that it was a more dignified end for them than it was for my dad.

JENNIFER HERBST: Thank you Kelly. Stephen?

STEPHEN HARDING: Thank you so much for having me. I am Stephen Harding. I am a representative from the 107th District, which encompasses Brookfield, Bethel, and Danbury.

Just a little bit about myself. I am an attorney. I grew up in Connecticut, in the Danbury area. I went to law school in Manhattan. I came back up and have a small practice up here in the area as well as serving as a state legislator.¹⁰

On the aid-in-dying legislation, it is always something that you hear about—one of those sexy topics—that when I was running for election in the special election in February of last year, it was something that I was approached on a lot, on both sides of the issue. When I got up to

⁸ See *id.* (noting that after a pallidotomy procedure a patient with Parkinson’s disease should experience reduced tremors, muscle rigidity, and improved muscular movement).

⁹ See Peggy Gray & Kathleen Hildebrand, *Fall Risk Factors in Parkinson’s Disease*, 32 J. NEUROSCIENCE NURSING 222, 222 (Aug. 2000).

¹⁰ See *id.*

Hartford for one of my first public hearings, the primary topic of discussion was the aid-in-dying legislation. I walked into the room—where I am used to seeing just three or four people sitting there on their laptops, and all lobbyists that are paid to be there—and I see the room jam-packed. Moreover, the room was filled with people from all walks of life—black, white, young, old—and of all different opinions regarding the topic. This high level of public concern regarding aid-in-dying legislation really persuaded me to get involved in this particular topic and particular issue.

It is funny, because like every good politician, my mind has swayed. I have gone back and forth on a lot of things. I was raised with the strong Irish-Catholic guilt that absolutely this is wrong.¹¹ Then, as time went by, and I heard compelling testimony from Kelly Luxenberg at one of the public hearings,¹² and I said, “Well, you know maybe this is the right thing.” Then I started thinking about it, and what struck me the most, and what has hardened my position currently is that when I was hearing Kelly’s testimony, hearing others’ testimony, I started thinking about my grandmother, who, in my opinion, was the most selfless woman in the world. The part of this topic, in the context of my own grandmother that I was most scared of was this: would she do this for us? Would she go about and take a pill to end her life because she would not want to put the burden on the rest of the family? This fear is one that I likely share with all other families across the country. Even though it may not be the decision that our elder family members wanted, they may think it was the decision that the family wanted or would be in the best interest of the family.

So what I am nervous about and the reason why I am in the position I am in today is that I never want to make anyone feel guilty for being alive. And, I fear that, by this legislation, we may be doing that. I am open for a good discussion today, and maybe some people can discuss that particular issue and maybe change my mind again.

But, thank you for having me.

JENNIFER HERBST: Thank you Stephen. Nicole?

¹¹ See Daniela Altimari, *Catholic Church Poised for Pivotal Role In Aid-in-Dying Bill*, HARTFORD COURANT (Mar. 22, 2015), <http://www.courant.com/politics/hc-aid-in-dying-battle-ct-20150322-story.html> [hereinafter “*Catholic Church Poised for Pivotal Role*”] (noting that the Catholic Church’s position on aid-in-dying legislation represents a “dangerous devaluation of [human] life” and poses a severe threat to society’s moral underpinnings).

¹² See *Connecticut Residents Turn Out to Testify for Aid-in-Dying Law in Legislature*, COMPASSION & CHOICES (Mar. 18, 2015), <https://www.compassionandchoices.org/2015/03/19/connecticut-residents-turn-out-to-testify-for-aid-in-dying-law-in-legislature/>.

NICOLE STACY: Hi, I am Nicole Stacy. I am the Public Policy Assistant with the Family Institute of Connecticut.¹³ I do research. I have testified before the legislature. I started about three years ago, and I have always been—for many years—passionate about life issues. But, when I came to Connecticut I was unaware that I would be so involved in this area. I am actually a musician, and I envisioned myself getting a job with an orchestra, and hopefully doing that full-time.

Friends got me involved with the Family Institute of Connecticut. As it happened, my first year working there was, at least in recent memory, the same year as the first legislative attempt to pass this bill.¹⁴ So, I now have three years of experience working very intensely with this issue.

To be up-front, we do take a position against the proposed legislation. We understand that on both sides of the fence people have very intimate, personal, and sometimes painful experiences that are shaping their opinion. While we understand that, we do take the position that this is suicide, any distinction between assisted suicide and aid-in-dying, death with dignity, is an artificial and a semantic distinction. And, once you introduce the idea of suicide as a solution to human suffering, it is not an idea that you can easily contain no matter how many stringent safeguards you try to enact because people will look at that and say, “What about my suffering? Isn’t it real? Does it not matter?”¹⁵ We have looked at the nitty-gritty of each bill that has come before us, and we have identified a lot of issues with it, but that overall concern is what drives our position.

So, thanks.

JENNIFER HERBST: Thank you. Nicole, I was hoping that you might be able to start with all of the work that you have been doing, and, I will give everyone on the panel an opportunity to answer this: what surprised you during your work on these issues in Hartford? What has been the

¹³ See *The Team*, FAMILY INST. CONN., <http://www.ctfamily.org/parent/fic/the-team/> (last visited July 3, 2016). The FIC focuses on “[s]upporting marriage strengthening projects, research and educating people about religious freedom, parental rights, the unborn and threats to the family.” *About FIC*, FAMILY INST. CONN., <http://www.ctfamily.org/parent/fic/> (last visited Apr. 16, 2016).

¹⁴ The bill was brought before the Connecticut General Assembly for the first time in 2013. See *Past Attempts to Legalize Assisted Suicide in Connecticut*, PATIENTS RIGHTS COUNCIL, <http://www.patientsrightscouncil.org/site/connecticut/> (last visited Apr. 16, 2016).

¹⁵ See generally J. Pereira, *Legalizing Euthanasia or Assisted Suicide: The Illusion of Safeguards and Controls*, 18 CURRENT ONCOLOGY E38 (Apr. 2011) (noting that safeguards and controls are generally ignored leading to patients receiving aid-in-dying treatment who do not fit the required statutory definitions for a patient eligible for such treatment).

thing that you have not expected and why did it surprise you?

NICOLE STACY: What has surprised me? I would say that, you mentioned the incredible turnout, and I knew this was going to be a very hotly contested issue, but I did not expect us to be hearing testimony from very early in the morning until midnight. That has been a big surprise.

JENNIFER HERBST: Stephen?

STEPHEN HARDING: I'll supplement that point. What has surprised me is the amount of interest in this piece of legislation, as well as the amount of passion behind it on both sides. I would say that the most telling piece of testimony that I received in a public hearing, was a woman, and I wish I could remember her first name now, but a really courageous woman who was battling brain cancer, similar to the affliction that Brittany Maynard had out in Oregon. I was expecting her to come up and say, "Listen, I am suffering right now. I feel that I want to pass with dignity." But, she got up and said, "I want to live. I want life. I want to live every second, and you never know what is going to come after this. If I live a couple of months with the advancing technology, and the advancing medicine that we have today, you never quite know when that cure, when that great pill is going to come around the corner. And, I want to be here for it."¹⁶ She persuaded me to start looking at the selflessness issue, in regard to family members. And, she said, "I don't want to make anyone guilty for being alive. And, frankly, I know what burden that places upon my family, and what I am scared of is that someday, someone might be in my similar situation and take their life, even though they want to live. And, I certainly want to live every second."

It was one of the most passionate pieces of testimony I have ever seen up at the state capital. So I would say that was probably the most surprising part.

JENNIFER HERBST: Kelly?

KELLY LUXENBERG: Thank you. I was just told her name was Maggie. And, unfortunately she recently passed away. I would say to echo off of what Steve and Nicole said, it is so interesting to see first of all, the number of people who came out on both sides of the issue, but also that you could not pigeon-hole a supporter or opponent. Rather people are approaching this issue from all walks of life. So, on one hand, you have the disability community, who has this very vocal opposition

¹⁶ See Daniela Altimari, *Poignant Testimony As Aid-in-Dying Bill is Debated*, HARTFORD COURANT (Mar. 18, 2015), <http://www.courant.com/politics/hc-aid-in-dying-public-hearing-in-connecticut-legislature-20150318-story.html> (noting that Maggie Karner, a brain cancer patient, was an adamant opponent of the bill).

to the bill,¹⁷ but then you have the same people who are typically in that same advocacy group, who are for the bill.¹⁸ So there is never really that clear line and clear distinction of which group is for it, and which group is against it. Same thing with members of clergy—you have some against it, the Catholic Church being one of them,¹⁹ but then you have so many ministers who are coming forward and speaking in favor of this because of their experiences at peoples' bedsides at the end of their lives. So, I found that to be really interesting.

You know, I have only been a legislator for eleven months, so it is certainly the first time I experienced that kind of positioning with a piece of legislation.

JENNIFER HERBST: Tim?

TIM APPLETON: Thank you. And, to extend those remarks, the great diversity of thought and people in our State, to my way of thinking and the thinking of our supporters, points to the need for this legislation. We all come at this from different journeys in life, and to stand in judgment over the other, or to put one ahead of something else, is a question of fairness that maybe we could talk about.

One of the things that surprised me the most was that Quinnipiac did a poll in 2014 that found by a 2-to-1 margin that people are supportive of this legislation.²⁰ The following year, in spite of allies arrayed against this legislation that spent \$671,000 to defeat it, the polling numbers went up.²¹ When I go and speak to groups of people like this one, what surprises me when I start talking about this is that those polling numbers are accurate. Most of the people that I speak with, that come to

¹⁷ See, e.g., *Disability Rights Toolkit for Advocacy Against Legalization of Assisted Suicide*, NOT DEAD YET, <http://notdeadyet.org/disability-rights-toolkit-for-advocacy-against-legalization-of-assisted-suicide> (last visited Mar. 6, 2016) (the purpose of this website is to inform the general public of the detriments to aid-in-dying legislation, specifically to the community of people with disabilities, which the website authors viewed as discrimination against that community).

¹⁸ See *Aid in Dying and People with Disabilities*, COMPASSION & CHOICES, <https://www.compassionandchoices.org/what-you-can-do/get-involved/national-speakers-bureau/aid-in-dying-and-people-with-disabilities/> (last visited Mar. 6, 2016) (noting that among the actual community of people with disabilities, approximately 60–70% support aid-in-dying legislation).

¹⁹ See *Catholic Church Poised for Pivotal Role*, *supra* note 11.

²⁰ QUINNIPIAC UNIV. POLL, CONNECTICUT VOTERS BACK SUICIDE BILL ALMOST 2-1, QUINNIPIAC UNIVERSITY POLL FINDS; VOTERS CALL GOV. MALLOY'S TAX REFUND A GIMMICK (Mar. 6, 2014), http://www.quinnipiac.edu/images/polling/ct/ct03062014_g95hjs.pdf.

²¹ QUINNIPIAC UNIV. POLL, LOW DEM SUPPORT HURTS CONNECTICUT GOV MALLOY, QUINNIPIAC UNIVERSITY POLL FINDS; VOTERS SAY NO TO MORE CASINOS 4-1 (Mar. 11, 2015) http://www.quinnipiac.edu/images/polling/ct/ct03112015_C47tjgbf.pdf.

bipartisan events—like this one—that come to libraries, that come to forums all over the state are supportive of this legislation.²² What ends up happening at many of these events and forums is that as I am packing up and leaving, someone invariably comes to me, and will sit me down and talk about a very highly personal and emotional story about why they are supportive, and invariably it has to do with the terrible death of a loved one. That was something when I took this job, I did not expect, or plan for.

JENNIFER HERBST: So you may have already answered a bit of the question that I am going to have the panel respond to. You have all talked about the difficulty and the incredible lack of consistency across party lines and religious affiliations, that there is no general rule, and you cannot necessarily assume that you know where any one person stands on this, given any other understanding or knowledge about what they believe.²³ That can often make for very difficult political terrain. So in what you have been working with, what has been the most encouraging in the work that you have been doing?

TIM APPLETON: Well, for me, I can tell you, and Mr. Schwartz will also say the same thing, that when you get to levels of 2-to-1 support in any one poll, it crosses all of these different things that makes us different. Whether they are white, or black, Catholic, or Protestant, or Jewish—all of those different elements of diversity that makes Connecticut great—they are supportive of this legislation by a 2-to-1 margin.²⁴ You do not get to those numbers without that diversity of support. That is what is interesting about this to my way of thinking. And although there are very, very powerful voices arrayed against us, that have sometimes the loudest microphone, there is the great majority of the people in this state that are very supportive of this legislation.²⁵

JENNIFER HERBST: Kelly what has been most encouraging for you in your conversations about end-of-life decision-making?

KELLY LUXENBERG: I think the thing that has been the most en-

²² *See id.*

²³ *See* QUINNIPIAC UNIV. POLL, *supra* note 20 (“Public support for allowing assisted dying in Connecticut is a very personal issue, crossing partisan, gender[,] and age lines.”).

²⁴ *Id.* (noting that support for the legislation is found among Democrats, Republicans, and independent voters alike).

²⁵ A Quinnipiac University poll “found broad support among Connecticut voters” for the proposed Aid-in-Dying legislation. Daniela Altimari, *Q Poll Finds Broad Support for Aid-In-Dying Legislation*, HARTFORD COURANT (Mar. 11, 2015), <http://www.courant.com/politics/capitol-watch/hc-new-quinnipiac-university-poll-finds-majority-of-connecticut-voters-back-aidindying-bill-20150311-story.html>. For full poll results, see QUINNIPIAC UNIV. POLL, *supra* note 21.

couraging for me has been having the conversations with constituents about the issue and the level of respect of which they have shown me. I have, in the district that I represent, in Manchester, probably the most ardent woman in the disability community against this piece of legislation. She has come to the capital. She is very well spoken. She knew that coming into the issue when we first met that I was going to be speaking in favor of that. She invited me into her home, and I have a young daughter, she is almost two, and my daughter was there, and the woman is in a wheelchair, she does not have use of her hands, she really can only speak, and my daughter was climbing on her wheelchair, and just the graciousness that the woman showed me, knowing that we were on opposite sides of the issue and that this was an issue that was so personal for her, it is like Steve was saying that some people in the disability community are fearful that this would mean the end of their lives against their own wills.²⁶

So she was one who was just so gracious and I felt like we had a very meaningful conversation and it was something that even though we were definitely on totally different sides of it, that we really walked away with an understanding of each other. She reached out to me after I testified and I cried when I shared the story about my father because I had never been so candid about it, I had never said publicly that my father committed suicide, and she said to me that she wished she could come up and hug me, even though physically it was impossible. But then she also followed two people later and was testifying on the total opposite side of the issue. Because of the heart with which she shared, I have a real respect for her. And so to know that two people can be totally opposite but then walk away in such a friendly way with that mutual respect for each other, you do not often see that with such a polarizing issue.

JENNIFER HERBST: Stephen?

STEPHEN HARDING: So, Kelly has said it far more eloquently than I can, but essentially, the level of respect is a great point that she just made. I have been most fascinated by the fact that you have individuals on the farthest end of being in favor of this bill, and the farthest end of being against this bill, and there is a genuine level of respect for the opposing side. I think this is because they understand the passion, they understand the reasoning why the opposing side feels that way. For whatever reason, this legislation, this topic brings out the best in people, and

²⁶ See *Disability Rights Toolkit for Advocacy Against Legalization of Assisted Suicide*, *supra* note 17.

that has been the most surprising.

I will give an example of a constituent of mine. As I said, one of my first days up at the public hearing, I had met someone from Brookfield, who was actually for the bill. Even though I was asking questions that would hint that I was an opponent of it, he emailed me afterwards and said, “Thank you for the thoughtful questions. I really appreciate your candor on this topic. I look forward to speaking with you in the future.” He still emails me quite frequently, not only on this topic, but on others as well, always in a respectful manner that is very supportive.

So the respectfulness and the respectful public discourse is something that has astonished me the most with this topic.

NICOLE STACY: Yes, I also want to comment about the incredible diversity that I have seen working on this issue. We have an amazing coalition that includes people that we really have not worked with on very many, or any other, things before. You have people who consider themselves very conservative, very liberal. We had a wonderful lady who is disabled and is an activist—an out and proud lesbian. She came in with a guitar and sang a song. She said she had been arrested nineteen times protesting assisted suicide. I thought that was just fascinating. I have never met someone like that.

I think because we have this great coalition going, we have been able to accomplish so much more than our resources would suggest. I do kind of want to respond to the six hundred thousand dollars figure.²⁷ I can get into detail on that, but suffice it to say that the information on what groups have spent to lobby is all available through the State Ethics Office on their website.²⁸ We certainly have not spent that kind of money. The disability rights people do not have that kind of money and neither do we, but we have been able to accomplish a lot.

JENNIFER HERBST: So, next question. In terms of comparing or contrasting the Connecticut bill to the bills in California and Oregon, we heard from Professor Waldman, that the California bill includes mandatory reporting of certain aspects of the implementation.²⁹ We heard a question from a gentleman earlier today regarding data and the ability to collect data to determine, in the event that this bill goes through: what kind of information is necessary to collect, so that in one year, in five

²⁷ See *supra* text accompanying note 21.

²⁸ See *Lobbyist Filing System and Information*, OFF. ST. ETHICS (last modified Jan. 12, 2016), <http://www.ct.gov/ethics/cwp/view.asp?a=2309&q=428540ðicsNav=>.

²⁹ See CAL. HEALTH & SAFETY CODE § 443.19 (West 2015); OR. REV. STAT. ANN. § 127.865 (West 2015); H.R. 7015, 2015 Leg., Jan. Sess. (Conn. 2015).

years, or in ten years, we know that it is doing what it was intended to do, or that it is not doing what we want it to be doing? What information would you and your constituents and the people you work with like to see? What kind of information would they love to have to evaluate the benefits and potential risks of this legislation?

NICOLE STACY: Well, listening to just the little bit I heard earlier about the California bill, the reporting requirement is different. There did seem to be a lot about the California bill that is similar to what we have seen proposed in Connecticut.

I guess the best reference point that I have for reporting is Oregon. And to some extent, all of the bills that we have seen in the United States are based on Oregon's law in one way or another. Oregon does collect some information. It collects information about how many people made requests and receive prescriptions.³⁰ Moreover, the state collects data regarding the type of underlying illness, how old the patient was, what the patient's level of education was, whether the patient died at home, and whether there was a physician present at the time of the patient's death.³¹ But I would caution that the Oregon law is touted as a model of transparent reporting and there are serious gaps in that. In so many of these categories, you will see "unknown," where the information is just not known.³²

So there is a limit to how much information the state can gather. [Referencing Oregon reporting data,] "minutes between ingestion and death . . . number of patients with information unknown: 107."³³ That is out of 132, so the vast majority of those patients, we have no idea how long it took them to die.³⁴ So, I question whether reporting is really going to address the concerns that we have.

I do not know if I answered your question very well, but I tried.

JENNIFER HERBST: Stephen, what information, if you had your way, and you could reflect the concerns of your constituents, what information would they very much like to know about this type of legislation and the potential impact? Type of information you would potentially

³⁰ OR. PUB. HEALTH DIV., OREGON DEATH WITH DIGNITY ACT: 2015 DATA SUMMARY 1–3 (Feb. 4, 2016), <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf>.

³¹ *Id.* at 5–6.

³² *Id.* at 5–7.

³³ *See id.* "Data on time from ingestion to death is available for only 25 DWDA deaths during 2015. Among those 25 patients, time from ingestion until death ranged from five minutes to 34 hours. For the remaining two patients, the length of time between ingestion and death was unknown." OR. PUB. HEALTH DIV., *supra* note 30, at 4.

³⁴ The number of patients with information unknown is 107. *See id.*

like to put into the bill to collect so that in five or ten years we could actually assess the meaningful impact of this legislation.

STEPHEN HARDING: So, to Nicole's point, which is a good point, I think the time period between ingestion and death is something that is quite important, simply because I think people might have second thoughts. This is the most important decision a person is ever going to make in his or her life; it is literally life or death. And, so people waver, I waver all the time on certain tough decisions that I make, and the hard part is that I just cannot imagine the suffering when a person takes it and then perhaps has second thoughts after having taken it. So that would be really important to know.

With that said, I think one thing that is important to me is to have an understanding—through data compilation—of what the underlying disease or medical issue was that afflicted the patient.

I would think that something in regards to family being present or how many family members are alive is important to know. I think that is important to know as well because that goes back to the issue that I have been discussing where there might be pressures, not necessarily from the people in the family persuading them to do it, but pressures that the patient feels that he or she is a burden on the family. I think that would be important to know.

But, with that said, maybe it is the Republican in me, I do not know how important the reporting is because there is no going back after a patient undergoes the treatment. If there are one hundred people that have taken the treatment, and we have a certain report from one hundred people—one hundred people have passed. Whether or not the reporting determines that it is not a good thing, one hundred lives are lost in this certain manner. So, I do not know how effective the reporting would actually be.

JENNIFER HERBST: Kelly?

KELLY LUXENBERG: Thanks. I am glad that I have had a few minutes. I was originally just going to take the politician answer and answer another question, not the one that was asked. So when I was looking at the legislation, one of the things I found really helpful was all of the numbers that Oregon has kept track of. Of particular interest to me was all of the prescriptions that were given, versus the number that were administered. It was only about, I think it was a little over half, it was about 60% that actually administered the medication.³⁵ So, I think that

³⁵ See *id.* at 3 (“Of the 218 patients for whom prescriptions were written during 2015, 125 (57.3%) ingested the medication . . .”).

one of the things that I would really like to see Connecticut adopt along with this legislation is following those same kinds of procedures that Oregon has but knowing how patients feel throughout the process of acquiring and self-administering the aid-in-dying drugs. I do not know how you would measure it because it would be hard—like a pre- and post-test after you take the medication—that would not be possible. But really, I think it is important to look at whether having the prescription is what gives people comfort because then they know they have that control moving towards the end of their life. So we should be asking some of those questions to ascertain precisely why some people are choosing to acquire the drugs but not to take them. I would like to know if what they hoped to achieve has been met just by having the prescription available to them.

TIM APPLETON: It is a good question Jennifer, and in the interest of full disclosure, it was a question you asked out in the hallway before we got ready, and I have been thinking about it ever since.

JENNIFER HERBST: I tried to give you a heads up.

TIM APPLETON: In my moment of levity, one of the things that happens surrounding this issue is that it brings attorneys and physicians together, and we could do more of that. So I guess I would challenge the question a little bit and I would suggest that having listened to the opponents on this issue—in Maine testify, in Rhode Island testify, in Massachusetts testify, in New York state testify, and in Connecticut—that the one constant takeaway is that there is nothing that could make this bill better for the opponents of this legislation. To somehow suggest that if we mandated a reporting requirement, as they did in California and Oregon, that the opposition would suddenly relent, I am not so sure about that. There are, and Nicole has it at the other end of the table, you can go out to the Oregon Health Authority website and download the report, they have one every single year.³⁶ And, it all says essentially the same thing. That in eighteen years, there has only been 859 people that have self-administered this medication, in eighteen years.³⁷ One hundred thir-

³⁶ See generally *Death With Dignity Act Annual Reports*, OR. HEALTH AUTH., <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx> (last visited Mar. 5, 2016) (for a list of all available reports, beginning in 1999).

³⁷ See OR. PUB. HEALTH DIV., *supra* note 30, at 5. From 1998 to 2014, 859 patients died from ingesting Death With Dignity Act (DWDA) medications. In 2015, 132 patients died from ingesting DWDA medications. Since the passage of the DWDA, a total of 991 patients have died. *Id.*

ty-two administered the drug in 2015.³⁸ There is no rush to get this done. Not many patients are going to break down our doors to access this medication. This is a conversation that happens between a patient and a physician. Earlier during the previous segment, we talked about how this legislation and this law could somehow damage that relationship.³⁹ I would argue the opposite and suggest that it strengthens it. When a patient comes to a physician and asks for this medication, and the doctor has open ears and an open heart and engages in this conversation, that strengthens that relationship.

That is what we see in Oregon, and you do not need to take my word for it. There have been nine independent studies in peer-reviewed journals that say this.⁴⁰ Overall these studies say, as a result of this legislation, more and more physicians are seeking out more and more education, CME credits to help people with end-of-life choices. As a result, more and more terminally ill patients are entering, and remaining in, hospice until the time of their death.⁴¹ With that in mind, we understand that end-of-life care in states where this is legal, like Oregon, Washington State, Montana, Vermont, and now California, will provide better end-of-life care, will have better end-of-life care.

JENNIFER HERBST: So, now I would like to open it up to questions from the audience. We have a little bit of time for questions from folks in attendance. Feel free to direct it to a particular panelist, or the panel as a whole. Yes?

AUDIENCE MEMBER: I think that to the extent we can take out the emotionality of it, we all have wonderful anecdotes that make our point, whether it is on the Republican-Conservative side, or the Democratic-Liberal side. That is not the point for me. It is about choice. A lot of what you are saying makes me think of the abortion issue, which is still a very hot issue, even though I lived through the time when it seemed like it was resolved. What is so scary about people having the freedom of choice? If you do not want to get a prescription and have an end-of-life option, you do not have to engage in that.

³⁸ *Id.*

³⁹ Dr. Lynette Cedarquist & Ellen Waldman, Symposium, *Palliative Care and End-of-Life Options*, 34 QUINNIPIAC L. REV. 627, 639 (2016).

⁴⁰ See, e.g., M. Hall et al., *The Impact on Patient Trust of Legalising Physician Aid in Dying*, 30 J. MED. ETHICS 693 (2005).

⁴¹ See *FAQs*, DEATH WITH DIGNITY, <https://deathwithdignity.org/faqs/> (last visited Apr. 17, 2016); see also Lisa Schneckler, *Assisted-Suicide Debate Focuses Attention on Palliative, Hospice Care*, MODERN HEALTHCARE (May 16, 2015), <http://www.modernhealthcare.com/article/20150516/MAGAZINE/305169982>.

JENNIFER HERBST: Is that a question for a particular panelist, or is that question for the panel as a whole?

AUDIENCE MEMBER: Yes, I would like each panelist to answer what about an individual's freedom of choice is so scary, especially the two panelists who are opposed to aid-in-dying legislation, about giving people a choice?

JENNIFER HERBST: So, I think Stephen and Nicole that is directed at you.

STEPHEN HARDING: I am; I do not know whether Nicole is. I think that is a great point that you make. It is not necessarily about choice, but it is the influence of the choice, I think that is what I am nervous about. It is not necessarily the choice itself, but how you get to that choice. Does this legislation truly provide free choice or does it subject terminally ill patients to pernicious influence to opt for hastening death. I fear the latter is the ultimate outcome of aid-in-dying legislation, and that is what scares me.

AUDIENCE MEMBER: [Inaudible].

STEPHEN HARDING: I did not rephrase it. All I am saying is that it is a choice, and it is how you get to that choice. I think that is what is important to me. What is more important to you I think is, and understandably so and respectfully so, is the choice itself. What I look at, and maybe it is more pragmatic, is how you get to that choice itself.

And, what I am nervous about is that some people may be getting to that choice because of the wrong reasons, because it is not necessarily their choice, but they are influenced to have that choice.

AUDIENCE MEMBER: [Inaudible].

STEPHEN HARDING: If I insulted you, I apologize. I did not mean to insult anybody. But, I will tell you what is so scary—the idea of my grandmother, who was the most selfless woman in the world, killing herself because she feels that she is burdening her family. That is what is so scary.

NICOLE STACY: I certainly do not want to insult anyone's intelligence either, but I think we have to acknowledge that these choices are not made in a vacuum. There are a lot of factors that can influence a person, and I would argue that as opposed to increasing choice, this legislation could actually decrease choice for many people because it is a cost-conscious society that we are entering into. Hospital budgets are being cut. There is going to be pressure to conserve resources. Frankly speaking, this is always going to be the cheapest treatment, do you believe that an insurance company will necessarily do the right thing, or the cheap

thing?

We saw, and this reminds me of another difference with the California bill, it was good that the California bill states that you cannot deny somebody coverage for wanted treatment and offer them coverage for assisted suicide in the same notification.⁴²

In the long-run, I do not think it makes a lot of difference, but the California legislature did acknowledge that that was insensitive, because that happened to a couple of individuals.⁴³ That happened to a woman named Barbara Wagner. She wanted to be treated, her doctor wanted her to be treated, but she was denied by [the] Oregon State Health Plan, and they offered her medication for physician-assisted suicide in the same letter.⁴⁴ It also happened to an individual named Randy Stroup.⁴⁵ So there is the potential to reduce choice for people who do not have access to those resources.

To what Steve said, there are all sorts of pressures that can influence a person that are very subtle and they are not things that even the most careful legislation can address. Things like, somebody seeing their loved one collapse in a chair exhausted, and they know that is from caring from them. Those kinds of pressures you just cannot legislate for.

JENNIFER HERBST: So, I recognize that there is one question. There is room for one more question.

KELLY LUXENBERG: I am sorry, can I just say a couple of things about the question. I had an opportunity after I spoke about this, and like I said, this was not going—I was given the advice to have one signature issue of the legislative session—this was not it for me. Inadvertently, it ended up becoming one because I ended up on the front page of the

⁴² CAL. HEALTH & SAFETY CODE § 443.13(c) (West 2016) (“An insurance carrier shall not provide any information in communications made to an individual about the availability of an aid-in-dying drug absent a request by the individual or his or her attending physician at the behest of the individual. Any communication shall not include both the denial of treatment and information as to the availability of aid-in-dying drug coverage.”).

⁴³ Dan Springer, *Oregon Offers Terminal Patients Doctor-Assisted Suicide Instead of Medical Care*, FOX NEWS (July 28, 2008), <http://www.foxnews.com/story/2008/07/28/oregon-offers-terminal-patients-doctor-assisted-suicide-instead-medical-care.html>.

⁴⁴ Barbara Wagner is a “64-year-old Oregon woman, whose . . . last hope was a \$4,000-a-month drug that her doctor prescribed for her, but the insurance company refused to pay. What the Oregon Health Plan did agree to cover, however, were drugs for a physician-assisted death.” Susan Donaldson James, *Death Drugs Cause Uproar in Oregon*, ABC NEWS (Aug. 6, 2008), <http://abcnews.go.com/print?id=5517492>.

⁴⁵ Springer, *supra* note 43 (“Since the spread of his prostate cancer, 53-year-old Randy Stroup of Dexter, Ore., has been in a fight for his life. Uninsured and unable to pay for expensive chemotherapy, he applied to Oregon’s state-run health plan for help. [The plan] responded to Stroup’s request with a letter saying the state would not cover Stroup’s pricey treatment, but would pay for the cost of physician-assisted suicide.”).

Hartford Courant. My signature issue was to exempt baby diapers from sales tax.⁴⁶ So I was called down to speak to the woman's group down on the Shoreline—the Shoreline League of Democratic Woman Voters⁴⁷—and we got into talking about this issue. So here I am with this group of women, who were there when this question of choice, when the question of choice over body was really being fought for the generation in which they were in, and so I really posed the question to them: this is an issue, this is the same issue of choice. So I just wanted to thank you for putting that out there because every time I have sat here, it is not about forcing anyone to make a decision, but it is about giving them choice at the end of their life. So I certainly understand what Steve and Nicole are saying. I feel that, especially as Steve talks about his grandmother—the most selfless woman on the planet—I can fully, fully appreciate that, but for me, it does resonate to be like “my body, my choice.” So that is how I feel and thank you for the question.

AUDIENCE MEMBER: [Inaudible]. Are there some choices, which we do not have the right to make, and is it possible that in giving up the choice, or in making the choice so autonomously for death, that that is the least autonomous choice we can possibly make.

TIM APPLETON: I have heard on many occasions, opponents of this legislation say, “This is a solution without a problem.” This is not a solution without a problem. In Connecticut, there are nearly seven thousand people, according to the American Cancer Society statistics, that die of terminal cancer every single year.⁴⁸

I am not suggesting that all of them demand this choice. I am not suggesting that even half of them do. I am suggesting that I trust in them—those people, the people that are faced with terminal cancer every single year—that they can make decisions for themselves. I am fortunate enough to have a background that says, I would not cross the street to tell someone what to do unless they ask for my help. The people that I

⁴⁶ “Luxenburg is also working to repeal the tax on feminine hygiene products and put in a bill to repeal the tax on baby diapers. Baby diapers are considered clothing, meaning they can be taxed, while adult diapers aren't taxed because they are considered to be a medical expense.” Quoron Walker, *Kelly Luxenburg: New State Representative*, HARTFORD COURANT (Jan. 22, 2015), <http://touch.courant.com/#section/-1/article/p2p-82605681/>.

⁴⁷ The Shoreline League of Democratic Women is an organization that seeks to “unite Democratic women along the Connecticut shoreline” and focus “on issues important to women of all ages,” including the end of life choice. SHORELINE LEAGUE DEMOCRATIC WOMEN, <http://www.sldw.org/> (last visited Mar. 6, 2016).

⁴⁸ AM. CANCER SOC'Y, CANCER FACTS AND FIGURES 2015, at 6 (2015), <http://www.cancer.org/acs/groups/content/@editorial/documents/document/acspc-044552.pdf> (providing annual death rates resulting from cancer).

meet with, the supporters on this issue, and there are dozens in every single House District in this state, and hundreds in every single Senate District in this state. We should have faith in the choices that they make.

JENNIFER HERBST: So again, for everyone thank you very much to these panelists and the respect that they showed each other during this conversation. It is clear that this is difficult.

CATHOLIC DOCTRINE AND AID IN DYING

Janeanne Lubin-Szafranski & Gregory J. Pepe***

JANEANNE LUBIN-SZAFRANSKI: So, not only are we old, we are the last speakers of the day, so we will go quickly. I do want to make a few points before I begin, and to introduce myself to you. I have been a healthcare lawyer now for many years, and when it was not popular to be one, and certainly was not popular to be one as in-house counsel, which has always been my job, and it is actually quite amazing to see these young men and women now being fostered in the area that I have come to practice in and to believe so strongly in. With that I would like to extend my sincere thanks to the school for inviting me today. It has been a wonderful experience.

I also wanted to say that I am not here to teach you Catholic doctrine. When I started working in Catholic healthcare, almost thirty years ago, my mother was very excited because it was always her hope that either my brother would become a priest or I would become a sister, and she never realized either of those goals; but when I entered Catholic healthcare she felt a little bit exonerated, and certainly when I attended my final board meeting as President of St. Raphael's and the board members referred to me as "Sister Janeanne," we finally made it there for my mom.¹ Again, it is not my intention to teach you doctrine, but only really to stop and have a conversation about how the principles that anchor Catholic doctrine influence so many of the decisions that we who serve in Catholic healthcare make.

I also want to say that I am sure you will agree with some of the things I have to say and will disagree with many of the things I have to say. And, I must say that as a practicing Catholic now for over sixty years, I do that myself regularly. But I am certain, absolutely certain that the values upon which this discussion will be based, we share. These

* Sr. Vice President and General Counsel, St. Francis Care.

** Founding Principal, Neubert, Pepe & Monteith, P.C.

¹ *Saint Francis Names New General Counsel*, ST. FRANCIS HOSP. & MED. CTR. (Feb. 4, 2015), <http://www.saintfranciscare.com/News.aspx?id=10737419923>.

values are: dignity, respect, and an honest willingness to get up every morning and do the right thing by every human being we are called to serve. And, that is really what my life has been about professionally and personally.

Finally, I want you to know a little bit about the Catholic tradition, and then I would like to introduce you to the person probably who was most important in my life. The moral tradition of the Catholic Church is really quite simple—life is a gift, and it is a gift from a loving God.² It is a gift over which we have stewardship but not ownership. This moral tradition is certainly one of the major issues that we talk about in terms of autonomy—that we are stewards of our lives, but do not have absolute dominion over them. When applied in the context of today’s symposium, euthanasia, assisted suicide, or any word you would like to call it, is gravely wrong and causes moral distress.³

This concept is deeply rooted in the Fifth Commandment, which you do not get much more doctrinal than this: “Thou shalt not kill.”⁴ Moreover, you can see in Pope John Paul the Second’s proclamation, which is the root with respect to the law and the doctrine of the morality of life, that it is absolutely unacceptable for there to be the killing of a human being, whether it is done by your own hand or by the hand of another.⁵ My dad died very young from colon cancer. At the time that my dad died, it was a new experience for my family. I was a very young lawyer and I remembered being part of all those families—those of you who are practitioners know so well—who say, “You have to do everything, everything, everything.” And, I appreciate the paramedic’s earlier comment—we had no idea what “everything” meant. We did not have the ability to truly understand what “everything” meant. Because we were rooted in Catholic doctrine as a family, we truly did not even understand what that meant in terms of “everything Catholic.” So I really have spent a good deal of my life trying to figure out what “everything” would mean to most people. I have sat on ethics committees for more than 30 years, and I struggle every day. I am not an academic; what I am

² *Human Life and Dignity*, U.S. CONF. CATH. BISHOPS (2016), <http://www.usccb.org/issues-and-action/human-life-and-dignity/>.

³ *End Suffering, Not Life*, OSSERVATORE ROMANO (July 8, 2011), <http://www.osservatoreromano.va/en/news/end-suffering-not-life>.

⁴ *Exodus* 20:13 (King James).

⁵ Letter from John Paul II, Pope, to Bishops, Priests, Deacons, and Members of the Catholic Church, on the Value and Inviolability of Human Life 41–42 (Mar. 25, 1995) (available at http://w2.vatican.va/content/john-paul-ii/en/encyclicals/documents/hf_jp-ii_enc_25031995_evangelium-vitae.html).

is an everyday person who deals with these issues with doctors and nurses every single day of my life in Catholic healthcare. You would be surprised how very close we are to secular healthcare in terms of the issues and the challenges we face, always respecting the law with respect to the decisions that we make.⁶ This issue of assisted suicide may be one of the greatest challenges I have seen in my practice.

My dad used to always say to us, particularly after he was diagnosed, “Knowing you will die is one thing, but knowing that you are dying is quite another.” And, when you look at the two of those things in the context of making decisions, it is an extremely different experience both for the patients and for the caregivers. One of the movements that I am very involved in is called the Second Victim Movement, which some of you may have heard about.⁷ We often do not think about the “second victim” in making these decisions—the healthcare worker. Every day the doctors and the nurses who struggle with these decisions have their own moral imperatives and have their own reactions to the many things that happen to them as they are undergoing these life experiences with their patients.⁸ And, so I find these kinds of discussions really useful in terms of allowing me to go back to them and gain additional perspective. Again, it is very clear where the Catholic doctrine rests on this issue—human life is sacred, is inviolable in each and every stage of that life, and is an indivisible good.⁹

There have been many interesting discussions here today, and I would like to have a whole other set of symposia here about some of the issues we have raised—related to cost of care, value of care, and rationing care issues that are occurring out there. I do not mean to deviate from the theme here today, but I do want you to understand that whether we are willing to talk about it, it is happening as we practice—as we live today. All those things that we discussed earlier are happening in our healthcare environment today, and so it would behoove us to have that dialogue.

Certainly, moving back to our subject, the ethics of aid in dying and

⁶ See U.S. CONF. OF CATH. BISHOPS, ETHICAL AND RELIGIOUS DIRECTIVES FOR CATHOLIC HEALTH CARE SERVICES (Nov. 17, 2009), <http://www.usccb.org/issues-and-action/human-life-and-dignity/health-care/upload/Ethical-Religious-Directives-Catholic-Health-Care-Services-fifth-edition-2009.pdf>.

⁷ Albert W. Wu, *Medical Error: The Second Victim—The Doctor who Makes the Mistake Needs Help Too*, 320 BRIT. MED. J. 726, 726 (Mar. 18, 2000).

⁸ See, e.g., Susan D. Scott, *The Secondary Victim Phenomenon: A Harsh Reality of Health Care Professions*, PATIENT SAFETY NETWORK (May 2011), <https://psnet.ahrq.gov/perspectives/perspective/102#ref7>.

⁹ See *Human Life and Dignity*, *supra* note 2.

the ethics of euthanasia are pretty clear to the Catholic faith, and that is where I have my biggest struggle. Certainly, an act or an omission, which by itself causes death in order to halt suffering, is how the Church looks at the concept of euthanasia.¹⁰ Furthermore, the Church looks at there being value, real value, in terms of suffering.¹¹ This is where I struggle the most—standing by the bedsides of hundreds of people as they struggle and suffer—understanding and accepting the Church’s position with respect to the value of suffering. I can tell you that I can do it because it has been my faith base of so many years, and I have embraced the concept; but when you are standing by the bedside, whether it is of a loved one or a patient that you are working with, it brings a whole different dimension to that discussion. Often, we get involved in talking about ethical principles, in talking about ordinary versus extraordinary, or in talking about proportionate versus disproportionate care. One of the points that I certainly wanted to make is that Catholic theology believes that we must accept ordinary medical means of preserving life.¹² Ordinary means are those that would offer reasonable hope of benefit and not provide excessive burden on us, our family, or our community.¹³ This is part of the ethical and religious directives for Catholic healthcare.¹⁴ Understand that that is a substantial document that encompasses more than talking about end-of-life or talking about beginning-of-life. It encompasses the real faith-based values that we all hold. I have participated in dozens, if not hundreds of hearings with the Probate Court in Connecticut, with the Superior Court in Connecticut, with mediations, where we have tried to use mediation techniques with families to resolve these difficult issues. I have to say I am a big proponent of mediation. I think we should begin training ethics committees in mediation techniques, because to assume they have these skills is incorrect,¹⁵ and to assume they do not come at this with their personal biases and beliefs is equally incorrect. So I think we could go a long way towards training ethics com-

¹⁰ *What the Catholic Church Teaches About End of Life*, CAL. CATH. CONF., <http://www.catholic.org/sites/default/files/files/Catholic%20End%20of%20Life%20Teachings.pdf> (last visited Mar. 6, 2016).

¹¹ *See, e.g.*, Brian Pizzalato, *St. Paul Explains the Meaning of Suffering*, CATH. NEWS AGENCY, <http://www.catholicnewsagency.com/resources/sacraments/anoointing-of-the-sick/st-paul-explains-the-meaning-of-suffering/> (last visited Apr. 14, 2016).

¹² *See What the Catholic Church Teaches About End of Life*, *supra* note 10.

¹³ *Id.*

¹⁴ *See* ETHICAL AND RELIGIOUS DIRECTIVES FOR CATHOLIC HEALTH CARE SERVICES, *supra* note 6, at 21.

¹⁵ *See generally* Yvonne J. Craig, *Patient Decision-making: Medical Ethics and Mediation*, 22 J. MED. ETHICS, 164 (1996).

mittees in true mediation techniques.

We often start these end-of-life discussions by talking about what is extraordinary, and what is ordinary.¹⁶ The Catholic Church teaches that nutrition and hydration are, in fact, ordinary measures. Those are expected treatments, and they are not extraordinary. A ventilator, however, can be considered extraordinary.¹⁷ The reliance on a man-made machine to artificially operate as a human organ by continuously pressing to sustain a patient's life can be deemed extraordinary as well.¹⁸ Every day we make decisions, and I agree with the speakers who have come before me, probably nine out of ten of the end-of-life hearings that I am holding now in a Catholic hospital are due to medical futility. The doctors are coming to me and say, "No more, I can't do this to this human being anymore, and I have a family that is insisting that 'everything' continue to be done." And it is not the moral tradition of the Catholic Church, nor of the provider, to require futile medical care. We engage in horrendous discussions that occur at great cost to everyone involved. I have had credit cards thrown at me due to people believing that this is about cost. I have had people threaten the lives of me and my providers over the kinds of treatments that we are suggesting or not suggesting. I have had a hearing about a patient whose condition was so extreme as to cause necrosis—losing physical body parts in the bed—and we had to expose that reality to the family and to the judge during the hearing as a matter of necessity to compel agreement on comfort care measures, which is an extreme step, and the family still insisted to the judge that a miracle was theirs to have and that everything continue to be done. And the judge in New Haven, a man who I have a great deal of respect for, Judge John Keyes, made the most difficult decision, I think, of his career, to rule against the family and to rule in favor of futility, and to have the ventilator disconnected from this patient. I have been in the room of a patient who will beg me to ask the family to leave the room so they can whisper to me, "This is not what I want." So I have been in all of these situations, yet I still embrace a faith base, the Catholic faith base that I am here to represent today, that says that the sanctity of life does not prevent us from ending those extraordinary measures, but it brings a certain question to this equation about whether it is the right of anyone the right—not the choice, the right—of any human being to make that decision for

¹⁶ See ETHICAL AND RELIGIOUS DIRECTIVES FOR CATHOLIC HEALTH CARE SERVICES, *supra* note 6, at 21, 31.

¹⁷ *Id.* at 21, 29.

¹⁸ *Id.*

themselves actively as an ordinary choice?

We are always going to be talking a bit here about morals, ethics, stewardship, justice, and faith. And, with all of those things coming together, I had to ask myself, can we ever take emotion, can we ever take ethics, can we ever take principles out of this discussion? I do not believe we can. In thirty-five years of trying to do this work, I have never found the ability to remove any one of those things from the equation. It is when they clash and intersect that makes this work so interesting and fulfilling.

We are always weighing benefit versus burden.¹⁹ There is no question that this is one of those ethical principles, like autonomy, that always comes into the discussion. But what I find so interesting about this discussion is that we all have very different definitions about what is “burdensome,” and, similarly, very different definitions about what is “beneficial.”²⁰ And so, it is never an easy dialogue.

The United States Conference of Catholic Bishops, and as an aside I know that the Bishops in California are now about the business of bringing a petition to bear, to be sure, that the law that was just passed in California be stricken,²¹ are actively working by January 1st to obtain the necessary signatures, 366,000, on a petition to accomplish that goal.²² I had the great privilege of talking with several of them about why they felt this step was necessary. I asked why they would undertake to use the resources of the Church to do this. And their fundamental reason for doing this is, again, based on the belief that there is not an inherent right to this kind of autonomy,²³ and their belief that the autonomy question is almost an oxymoron. This is because to exercise the autonomy to kill oneself is in fact to remove all autonomy.²⁴ And so, the bishops said they feel on a very principled basis that it is necessary to chal-

¹⁹ See ETHICAL AND RELIGIOUS DIRECTIVES FOR CATHOLIC HEALTH CARE SERVICES, *supra* note 6, at 31 (noting that extraordinary and disproportionate means of preserving life are overly burdensome on the patient, the patient’s family, and the community and that a person does not have any obligation to undergo overly burdensome means because the cost of such means outweigh the benefits).

²⁰ See *id.*

²¹ *California Bishops Push for Referendum to Overturn Assisted Suicide Law*, LIFE SITE (Nov. 17, 2015), <https://www.lifesitenews.com/news/california-bishops-push-for-referendum-to-overturn-assisted-suicide-law>.

²² *Id.*

²³ See *id.* (“[Assisted suicide] removes all options, and all need for options, by ending a life before its natural time.”) The quotation by Catholic Archbishop Jose Gomez provides an indication that the view of the Church is that ending life before its natural time is inherently wrong, and thus one’s autonomy cannot extend so far as to make that choice.

²⁴ *Id.*

lence this law.²⁵ And, you know that we have had a struggle in Connecticut, I have worked with the legislature, I have spoken in opposition to the bills that have risen in Connecticut, and I think I will continue to do that because again, from my principle base, from that fundamental values base, I think it is important that we all understand what we are talking about here.²⁶ I do not like to talk about slippery slopes because I have slid down many of them, and I do not know, at the end of the day, at the end of any one of these hearings, that I will walk out of that room feeling any better than I did walking into the room, but I do know that I always feel true to those fundamental faith-based values.

Two things, I need you folks to be advocates to help us get ahead of this elephant. We live behind an enormous elephant, and it is messy and dirty behind there every day because we do not know what people really want, because we are not brave enough to have these conversations with them and because we do not engage in the proper discussions. And every Thanksgiving, which is coming up next week, I gather my extended family at my home—roughly forty of them—and I bake a giant birthday cake, and I put it on the table, and they laugh at me every year, and I say, “Are everybody’s advanced directives in order? Do I know what each and every one of you want? Has anybody changed their mind? Let’s talk about this, and then we will celebrate everyone who is alive here today.” And, my mother, who is 87 years old, and, you know probably the most likely candidate for us to be having to use any of her advance directives—but you never know—will say to me every year, “Oh yeah, everything is fine, everything is fine.” And then last year, she said to me, “I would like to change something,” and I said to her, “What would that be Mom?” She responded, “Well, I want your brother to be my decision maker for any end-of-life decisions.” And I said, “Mom, I’ve been your decision maker forever. What have I done?” She said to me, “I think that you will have a problem making those decisions that are necessary for me at the end of life. Your brother won’t.” And, I said, “Well, I am going to take that as a compliment.”

Finally, I worked for many years with the Sisters of Charities of St. Elizabeth of New Jersey,²⁷ Sister Anne Virginie Grimes,²⁸ who some of

²⁵ See *California Bishops Push for Referendum to Overturn Assisted Suicide Law*, *supra* note 21.

²⁶ See Jenn Bernstein, ‘Right to Die’ Bill Hearing Scheduled for Wednesday, FOX 61 (Mar. 16, 2015), <http://fox61.com/2015/03/16/right-to-die-bill-hearing-scheduled-for-wednesday/> (discussing the current debate over pending right to die legislation in Connecticut).

²⁷ The Sisters of Charities of St. Elizabeth of New Jersey is an organization “engaged in

you may have known and was a great lady. She taught me a great many things about being a good person; that really was her greatest goal as a mentor. She wanted the people that she worked with and the people who worked with her, at the end of the day, to be good people. And she would say every day, “Hundreds of thousands of dedicated doctors, nurses, administrators, social workers, and Catholic healthcare workers from all faiths and beliefs strive to fulfill the mission of caring for the sick, the vulnerable, the poor, people who entrust their lives and their deaths to us. It is never easy, it is always miraculous, and it is a sacred duty.” Sister Anne felt that this was a duty that we were called to, and whether we are lawyers, or doctors, or social workers, or paramedics, or professors, or whatever we might be, the work that we are about is truly a sacred duty. And for me, it has been a privilege to spend my life here in this space and certainly to mentor those who will be doing it after me.

So, I will ask Greg to come up and make some comments, and then maybe we can take some questions.

GREGORY J. PEPE: Thanks, Janeanne. I want to also comment that this is a wonderful thing for Quinnipiac Law School to have done. The one thing Janeanne did not tell you about the Catholic hospital tradition in the United States, or at least where she has been working, is that it is growing by leaps and bounds with the consolidation of the healthcare industry in the United States.²⁹ The network of hospitals that Janeanne works for, Trinity, is approximately ninety hospitals today nationwide.³⁰ The network is growing toward about 100,000 employees.³¹ Projections

education, health care, pastoral and social service ministries in 18 dioceses within the United States, El Salvador and Haiti.” The organization was founded in 1809 in Emmitsburg, MD and the New Jersey community was founded in 1859 by Mother Mary Xavier Meghan. *Who We Are*, SISTERS CHARITY ST. ELIZABETH, <http://www.scnj.org/index.php/who-we-are> (last visited Feb. 29, 2016).

²⁸ Sister Anne Virginie Grimes joined Sisters of Charity of St. Elizabeth in 1949, and became a member of the Hospital of St. Raphael’s Board of Trustees in 1967. Sister Anne served as president of St. Raphael’s Hospital from 1979 until 1986, and then as president of St. Raphael Healthcare system. Sister Anne also served as president of the St. Raphael Foundation and as vice chairwoman of the system’s board, stepping down in 2001. She was described as the “heart and soul of St. Raphael’s.” Jim Shelton, *Sister Anne Virginie Grimes, ‘Heart and Soul of St. Raphael’s,’ Passes Away at 84*, NEW HAVEN REG. (July 16, 2012), <http://www.nhregister.com/article/NH/20120716/NEWS/307169974>.

²⁹ One in six patients in the U.S. is cared for in a Catholic Hospital. *Facts & Statistics: Catholic Health Care in the United States*, CATH. HEALTH ASS’N U.S. (Jan. 2016), <http://www.chausa.org/about/about/facts-statistics>.

³⁰ St. Francis Hospital joined Trinity Health in 2015, which serves communities in twenty-one states with ninety hospitals and 124 continuing care locations. *About Us*, TRINITY HEALTH, <http://www.trinity-health.org/about-us> (last visited Feb. 29, 2016).

³¹ Trinity Health employs over 95,000 people, including more than 3,900 physicians. *Id.*

are that by the end of this decade, there could be as many as one hundred and fifty hospitals. And so, the directives of Catholic hospitals are going to be things that we have to pay attention to and that we are going to have to integrate into whatever kinds of planning we do. And they are very real. They reflect the belief systems of very many people.³² By and large, they are in line with what everybody believes. There are points at which their faith tradition departs from what some people would want to see happen. And so, the reality is that we are going to be dealing with these doctrines and we have to learn how to integrate them.

These are divisive issues in many places, and I thought it was very telling today that the one time when the temperature went up a little bit was when we had the legislators sitting down here in front of us all.³³ I think there is never more need to scream at somebody than when you think that they have the potential to make a law that is going to be binding on your behavior and your actions in the future. It was not at all that surprising because, actually by terms of stridency, that was pretty tame. The stuff that happens up in the capital, the things that happen in acts of civil disobedience, those things are not very tame. Of course what we have all seen is incidents where there are public demonstrations; there have been murders outside abortion clinics.³⁴ This is a debate about personal liberty versus control by the state. So these are issues that spark significant emotions on both sides. We saw a little bit of that today, and I suspect we are going to see some more of it, and I think it was very telling.

Earlier, we talked a little bit about the evolution of the legal construct, the legal thinking,³⁵ but it was really presented from the evolution of the judicial position on this, and what I really wanted to talk about is the evolution of the balance between personal liberty and the interests of the state to protect the populace because these cases also touch on that nerve. What I think a lot of commentators point to as the first case that

³² As of 2014, there were between 66.6 million and 79.7 million members of the Catholic population in the United States. *Frequently Requested Church Statistics*, CTR. FOR APPLIED RES. APOSTOLATE, <http://cara.georgetown.edu/index.html> (last visited Feb. 29, 2016).

³³ Symposium, *Legislative Panel: Aid-in-Dying Legislation in Connecticut*, 34 QUINNIPIAC L. REV. 647 (2016).

³⁴ Since 1993, there have been at least eleven people killed in attacks on abortion clinics in the U.S. Liam Stack, *A Brief History of Deadly Attacks on Abortion Providers*, N.Y. TIMES (Nov. 29, 2015), <http://www.nytimes.com/interactive/2015/11/29/us/30abortion-clinic-violence.html>.

³⁵ Alan Meisel, Symposium, *Antecedent Law and Ethics of Aid in Dying*, 34 QUINNIPIAC L. REV. 609 (2016).

touched off that kind of balancing act is *Roe v. Wade*.³⁶ Everybody knows that was the case where the Supreme Court decided that women are entitled, because they have a Constitutional right, to make a decision to have an abortion in the first trimester of their pregnancy.³⁷ What the Court found was this right to privacy, and I will read from the Court's decision, is embedded "in the concept of personal 'liberty' embodied in the Fourteenth Amendment's Due Process Clause; or in personal, marital, familial, and sexual privacy, said to be protected by the Bill of Rights or its penumbras"³⁸

Really, what I am most interested in in this area of the law is how it is that we balance that right to personal autonomy against the other issues that are involved in this decision. I think that the proponents of assisted suicide point out that people ought to have choice and that it really is a very personal decision.³⁹ Meanwhile, those who are opposed to it point to the fact that what we are doing is starting a course of action that could create a significant detriment to our society.⁴⁰ We talked a little bit about what impact this could have on the physician-patient relationship in the long-run? What does this do in terms of our thinking about people with terminal illness? Does it really push us down a slippery slope, despite Janeanne's unwillingness to go down there? Does it really sort of push us to a discussion about allocation of resources, and, using this tool—because that is what it is—to allocate healthcare among our population? Allocation of healthcare—or rationing—is something that we have been very resistant to do.⁴¹ It is interesting that the two legislators who were here have left the room, because you would not be able to engage them in anything that started with the word "rationing."⁴² Lawmak-

³⁶ 410 U.S. 113 (1973).

³⁷ *Id.* at 164.

³⁸ *Id.* at 129.

³⁹ See *The Right to Die*, ECONOMIST (June 27, 2015), <http://www.economist.com/news/leaders/21656182-doctors-should-be-allowed-to-help-suffering-and-terminally-ill-die-when-they-choose> (noting that some believe that "liberty and autonomy are sources of human dignity," and that "both add value to life").

⁴⁰ See *id.* (noting that some believe that right to die legislation is the "first step on a slippery slope where the vulnerable are threatened and where premature death becomes a cheap alternative to palliative care").

⁴¹ See Jonathan Oberlander, *Public Attitudes Toward Health Care Spending Aren't The Problem; Prices Are*, 28 HEALTH AFF. 1285 (2009) (noting Americans' reluctance to limit access to care as a cost-cutting measure).

⁴² There is some disagreement about the meaning of rationing. Policy analysts have two views: (1) macroallocation, which refers to decisions about distributing resources to institutions or types of services (i.e. how many open heart surgery beds there will be in a region); and (2) microallocation, which concerns how resources are distributed to individuals (i.e. decisions about who will receive open heart surgery). Most follow the microallocation definition

ers will run out of a room rather than discuss rationing. And, I understand that, but there is a part of this discussion that deals with costs.

So, if you look at *Roe v. Wade*, the principles of personal liberty as a Constitutional right sort of sets up, I think, a couple of the other cases that were mentioned, in particular the Karen Quinlan⁴³ case, because the court essentially said the same thing.⁴⁴ Keep in mind, the Karen Ann Quinlan case was decided only two years after *Roe v. Wade*, so it was still very much in the public consciousness—this whole concept that I have the right over my own decision-making about my own body, and the state does not have the right to tell me if I can or cannot have an abortion. In fact, the Karen Ann Quinlan case pushes that notion forward a little bit more—that notion that I (or my proxy) have the right to decide. I have the right to decide also, when I am going to die and the circumstances of how I am going to die.⁴⁵

As a digression, obviously people have committed suicide for millennia, so this is not a discussion about whether or not people have the right to commit suicide.⁴⁶ In the interest of disclosure, my wife's stepfather, who was a very healthy eighty-nine-year-old man but had seen his peer group confronted with dementia, have strokes, and lose autonomy, became almost obsessed by the fact that this could happen to him. He was a very dynamic, very smart guy, but he could not integrate the possibility of that happening to him into his day-to-day life; so he took his own life. And, of course, it was sort of the ultimate act of saying, "I don't care what the law says, I have the right to decide what I am going to do with my own body." But it makes you contemplate what it is that we are really talking about here, and, in some ways, what we are really talking about is the context in which that decision gets made and why we are involving doctors in that process. Basically, why would we put a doctor in the crosshairs of that, and that has as much to say about how

of rationing. Theodore R. Marmor & Jan Blustein, *Models of Rationing: Introduction to Rationing*, 140 U. PA. L. REV. 1539, 1539–40 (1992).

⁴³ Karen Quinlan was in a coma from 1975 until 1985, sparking national debate about the right to die. 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>.

⁴⁴ See *In re Quinlan*, 355 A.2d 647, 663 (N.J. 1976) (holding that under both the U.S. and New Jersey Constitutions there is a constitutional right to privacy which is "broad enough to encompass a patient's decision to decline medical treatment under certain circumstances").

⁴⁵ See *id.* at 661 (finding that Karen Quinlan had the right to choose to end life support and her father had standing to assert Karen's constitutional rights, as he was not merely an interloper, but rather was very involved with the case).

⁴⁶ In fact, there are several references to suicide in The Holy Bible. See 1 *Chronicles* 10:4–5 (King James); 1 *Samuel* 31:4–5 (King James); 1 *Kings* 16:18 (King James).

we perceive healthcare in this country, as well as the way doctors have generally been regarded in that process. The case of Karen Ann Quinlan, Nancy Cruzan,⁴⁷ and then ultimately Terri Schiavo,⁴⁸ I think, advanced the nation's thinking about this—about “my right, my personal liberty to make a decision about my end-of-life decisions.”

The thing that strikes me about the Terri Schiavo case, what I think is pretty remarkable, is that the Schiavo family went through, I think, fourteen different court proceedings, appeals, etc.⁴⁹ There was an intervention on the part of then Florida Governor Jeb Bush.⁵⁰ There were multiple pronouncements out of the White House by then President George W. Bush.⁵¹ Congress weighed in.⁵² And still, the public, I think, did not want politicians and lawmakers to get involved in this decision. I think if you read some of the commentary and some of the polling that came out, people thought that it was really Terri Schiavo's decision with her husband, and maybe in consultation with her family, about what should happen.⁵³ They did not want politicians messing with this. And,

⁴⁷ In *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990), the U.S. Supreme Court held that a state may require a clear and convincing evidentiary standard when guardians of an incompetent individual attempt to show the incapacitated individual's desire to discontinue extraordinary measures of life support. Nancy Cruzan died in December of 1990 after doctors removed her feeding tube pursuant to a court order issued after Cruzan's parents had produced clear and convincing evidence. See Tamar Lewin, *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/nancy-cruzan-dies-outlived-by-a-debate-over-the-right-to-die.html>.

⁴⁸ On February 25, 1990, Terri Schiavo suffered a cardiac arrest, fell into a persistent vegetative state, and began receiving food and hydration through a feeding tube. *In re Guardianship of Schiavo*, 780 So. 2d 176, 177 (Fla. Dist. Ct. App. 2001). Schiavo's feeding tube was removed on March 18, 2005 after a long court battle, and she died on March 31, 2005. *In re Guardianship of Schiavo*, 932 So. 2d 264, 264 (Fla. Dist. Ct. App. 2005).

⁴⁹ See Def.'s Opp. to Pls'. Mot. for Inj. at 1, *In re Guardianship of Schiavo*, No. 8:05-CV-530-T-27TBM (Fla. Dist. Ct. App. Mar. 21, 2005).

⁵⁰ Governor Bush's intervention was permitted by a state statute that was enacted in 2003, which gave the Governor the authority to issue a one-time stay to prevent the withholding of nutrition and hydration from Schiavo, citing several reasons. That law was challenged as unconstitutional by Terri Schiavo's husband Michael Schiavo. See *Bush v. Schiavo*, 885 So. 2d 321 (Fla. 2004), *cert. denied*, 543 U.S. 1121 (2005).

⁵¹ See, e.g., Press Release, The White House, President's Statement on Terri Schiavo (Mar. 17, 2005) (available at <http://www.georgewbush-whitehouse.archives.gov/news/releases/2005/03/20050317-7.html>).

⁵² See An Act for the Relief of the Parents of Theresa Marie Schiavo, Pub. L. No. 109-3, 119 Stat. 15 (2005); see also Carl Hulse & David D. Kirkpatrick, *Congress Passes and Bush Signs Legislation on Schiavo Case*, N.Y. TIMES (Mar. 21, 2005), <http://www.nytimes.gov/2005/03/21/politics/congress-passes-and-bush-signs-legislation-on-schiavo-case.html>.

⁵³ According to a Gallup poll conducted four days after the removal of Terri Schiavo's feeding tube, 56% of voters agreed with the decision to remove the feeding tube, while 31%

so part of that argues in favor of “well maybe this should not be the discussion that we have at the legislative level.”

On the other hand, in order to enable it, we really need legislative intervention because looking at this as lawyers, what we are really looking at are two exemptions that are important. First of all, there is an exemption from the law of homicide⁵⁴ because if you are going to prescribe something as a physician that allows somebody to take their life, and you know that is how they intend to use it, in the absence of an exemption, you could be prosecuted for homicide. In fact, in the Karen Quinlan and Nancy Cruzan cases that were mentioned, the parties involved had to go to court to get a court order because the doctors would not act, or even take the first step because they were afraid of being prosecuted under the homicide laws in their state.⁵⁵ And, the second thing is, as we found out during the George W. Bush administration, doctors are licensed to prescribe drugs, and as part of the licensure physicians are required to prescribe medication only for appropriate purposes.⁵⁶ The Attorney General under then President Bush was John Ashcroft, who was prompted by the Bush administration to issue an interpretative ruling that the prescribing of life-ending drugs was not in furtherance of a legitimate medical purpose.⁵⁷ The issuance of this interpretative ruling was primarily in response to Oregon enacting aid-in-dying legislation.⁵⁸ The logic behind Ashcroft’s interpretative ruling was that a physician needs a federal license to prescribe drugs⁵⁹—although it is in part and parcel with the state—and without the authority to prescribe drugs, a physician often cannot get medical staff privileges, cannot get insured, and cannot get licensed in the state. And so, Ashcroft

disagreed. David W. Moore, *Public Supports Removal of Feeding Tube for Terri Schiavo*, GALLUP (Mar. 22, 2005), <http://www.gallup.com/poll/15310/public-support-removal-feeding-tube-terri-schiavo.aspx>.

⁵⁴ See, e.g., OR. REV. STAT. § 127.885(1) (2015) (providing immunity from all civil, criminal, and professional liability to healthcare providers who participate in the Death with Dignity program in good faith).

⁵⁵ See *In re Quinlan*, 355 A.2d 647, 669–70 (1976). The county prosecutor maintained that criminal liability would attach to doctors who accelerated death of Quinlan pursuant to the exercise her right to privacy, but the court held that there would be no homicide in such circumstances, and even if there was a homicide, it was not unlawful. *Id.* See also *Cruzan v. Harmon*, 760 S.W.2d 408, 419 (Mo. 1988) (noting an interest of the Missouri Department of Health was to prevent homicide).

⁵⁶ 21 C.F.R. § 1306.03–.04 (2015).

⁵⁷ See *Dispensing of Controlled Substances to Assist Suicide*, 66 Fed. Reg. 56,607–08 (Nov. 9, 2001) (to be codified at 21 C.F.R. pt. 1306).

⁵⁸ *Id.*

⁵⁹ See 21 C.F.R. § 1306.03 (requiring licensure to prescribe controlled substances).

and the Bush administration thought this was a great way to squelch the Oregon law. The Supreme Court, however, refused to give the Attorney General of the United States veto power over the State of Oregon.⁶⁰ The states have traditionally had the right to regulate healthcare, and so the Supreme Court held that Ashcroft's ruling was an inappropriate exercise of the Attorney General's power, and the Court was not going to allow the Attorney General to veto essentially what the State of Oregon had decided.⁶¹

That summary brings us to where we are today. As I was listening to everybody speak here today, I realized that, in some ways, it is the medical community itself that is trying to foist this issue on us because there is not a day that goes by that you don't hear about some life-saving technique, a new drug, a new therapy, etc. I was involved in the creation of the first in-patient facility for people with AIDS in Connecticut, called Leeway⁶²—a really wonderful place. At the time that we conceived of this place, developed it, and finally built it, we had built a morgue because it was generally believed—and Janeanne was on the board there—that it was a one-way trip.⁶³ People did not survive AIDS at that time.⁶⁴ And really, AIDS today is just a chronic condition,⁶⁵ and that is in just a twenty year period. The biggest problem at Leeway now is finding a place to discharge people to because they still have AIDS, and many of them still have other issues, so we have had to build supportive housing.⁶⁶ But that is in a very, very small period of time. In twenty years, AIDS went from being a virtual death sentence to being a chronic condition that can be managed, such as chronic leukemia or other similar diseases. The healthcare industry keeps pushing us in this direction where

⁶⁰ *Gonzalez v. Oregon*, 546 U.S. 243, 269–70 (2006).

⁶¹ *Id.* at 274–75.

⁶² Leeway was founded in 1995 and is Connecticut's first and only nursing facility dedicated to caring for individuals with HIV/AIDS. *Home, LEEWAY*, <http://www.leeway.net/board> (last visited Mar. 6, 2016).

⁶³ See Jeremy A. Sitcoff, Note, *Death with Dignity: AIDS and a Call for Legislation Securing the Right to Assisted Suicide*, 29 J. MARSHALL L. REV. 677, 678 (1996) (noting that as of October 31, 1995, 311,381 people in the United States had died from AIDS); see also *id.* at 680 (classifying “person living with AIDS” as “terminally ill”).

⁶⁴ Between 1981 and 2000, there were 774,467 reported cases of AIDS in the United States, and 448,060 of those people had died. *HIV and AIDS: United States, 1981–2000*, 50 MORBIDITY & MORTALITY WKLY. 430, 430 (June 1, 2001).

⁶⁵ The definition of “chronic condition” varies widely. See Richard A. Goodman, MD, MPH, et al., *Defining and Measuring Chronic Conditions: Imperatives for Research, Policy, Program, and Practice*, 10 PREVENTING CHRONIC DISEASE, Apr. 25, 2013.

⁶⁶ Leeway has forty-one units of independent supportive housing. *LEEWAY*, *supra* note 62.

more and more of us are going to live longer and longer,⁶⁷ often requiring very significant healthcare services.

The interest of the healthcare business model is to keep pushing those boundaries. No one would argue that they ought to stop, or that the healthcare industry should stop innovating new treatments or proposing new initiatives to make us healthier. But, what often fails to happen is consideration of the cost that comes with pushing that boundary of mortality further down the road. When you keep mortality from the door, for a longer and longer period of time, what does that do to the quality of life, to the kind of life you want to live? Additionally, are there other parts of that dialogue that we are not having? I think that from my perspective, my father died some years ago of progressive heart failure, and about ten years before he died, he had a pacemaker⁶⁸ installed. At the time it was a device that the doctors said “is going to be something that will give you many more years, because if you have another heart attack you are going to die, and this will shock your heart back into a regular rhythm.”⁶⁹ I actually was with him on at least two or three occasions when that happened: we were at a restaurant one time and he slumped over, and then he popped back up; we were on the golf course one time, and he fell out of the golf cart, and then he got back in. It was like, “This is pretty amazing.” But in the last eighteen months of his life he said, “If I had known that this thing would have preserved my life so that I had to live like this now . . .” (“this” meaning heavy dependence on drugs to prevent his body from accumulating fluids; he was house-bound and could not do the things he liked to do); he said, “I would have never had it installed in the first place.” While I think this was a little disingenuous, it was where he got to because what he really meant, I think, was, “For eight years, this was a great device. But for the last few years, the fact that it keeps shocking me back into life at a time maybe when I would rather have it let me die is something that I would rather not have to deal with.”

So the technology—the ability of the medical community to have that kind of discussion with a patient—is something this country has to have a discussion about. And then, that discussion will naturally lead to the discussion of end-of-life planning.

⁶⁷ In 2015, the life expectancy in the United States was 78.8 years. *See Life Expectancy*, CTRS. DISEASE CONTROL & PREVENTION (last updated Jan. 20, 2016), <http://www.cdc.gov/nchs/fastats/life-expectancy.htm>.

⁶⁸ A pacemaker is a small device that uses electric stimulation to help control the heart-beat. *See What is a Pacemaker?*, AM. HEART ASS'N (2015), <http://goo.gl/XzIha2>.

⁶⁹ *See id.*

Before I conclude, I want to leave you with a couple of observations, and that is the third rail of this discussion—a rail that Janeanne touched on—the cost associated with aid in dying. I think that in the Managed Care course we have taught this concept of medical necessity. Medical necessity is a term of art that is in virtually every third-party-payor contract.⁷⁰ It means different things in different contracts, but basically, anybody who is involved in the managed care industry knows what medical necessity means, and your ability to obtain treatments, services, and products is determined by that third-party-payor's interpretation that such treatment is a medical necessity.⁷¹ Janeanne just reminded me that every day the baby boomers—those of us born post-World War II—every day, ten thousand of us turn age sixty-five.⁷² So, medical necessity is going to be a term that I think is going to come into play in one of two ways. One way we are already seeing, another way I think everybody is desperately trying to avoid. I will talk about the avoided way first. Let's assume that the Anthem and Cigna merger⁷³ and that the Aetna and Humana Healthcare merger⁷⁴ go through. That leaves this country with three major health insurers.⁷⁵ That means that people somewhere in three companies will start deciding what medical necessity means.⁷⁶ And then, that translates into the kind of healthcare we receive.⁷⁷ I wonder whether it will mean we get to keep our loved ones and our family members alive for longer in arrangements where there is no therapeutic benefit.⁷⁸ I wonder what it means if your religious conviction or your moral conviction inclines you to think that life should end naturally, and

⁷⁰ U.S. DEP'T OF HEALTH AND HUM. SERVS., SPECIAL REPORT, MEDICAL NECESSITY IN PRIVATE HEALTH PLANS: IMPLICATIONS FOR BEHAVIORAL HEALTH CARE 1 (2003).

⁷¹ *Id.* at 1, 3.

⁷² *Baby Boomers Retire*, PEW RES. CTR. (Dec. 29, 2010), <http://www.pewresearch.org/daily-number/baby-boomers-retire/>.

⁷³ *See Anthem and Cigna: Driving Health Care Innovation Together*, ANTHEM, <http://betterhealthcaretogether.com/> (last visited Apr. 15, 2016).

⁷⁴ *What This Means for Consumers*, AETNA HUMANA, <http://www.aetnaandhumana.com/what-this-means-for-you/for-consumers/> (last visited Apr. 12, 2016).

⁷⁵ Courtney Baird, Blog, *In the Nation's Interest: Top Healthcare Stories for 2016: Insurance Company Mergers*, COMM. ECON. DEV. (Feb. 16, 2016), <https://www.ced.org/blog/entry/top-healthcare-stories-for-2016-insurance-company-mergers>.

⁷⁶ *See id.* (discussing how the mergers may lead to a less competitive market, which has a negative impact on patients).

⁷⁷ *See id.* (discussing how the mergers may lead to a reduction in healthcare quality and insurance coverage).

⁷⁸ CAROL L. POWERS ET AL., HARVARD MED. SCH., CMTY. ETHICS COMM., MEDICAL FUTILITY: STRATEGIES FOR DISPUTE RESOLUTION WHEN EXPECTATIONS AND LIMITS OF TREATMENT COLLIDE 5–6 (2013).

you should not pull the plug on somebody, you should not remove their feeding tube or ventilator. I wonder whether, if there is no medical necessity to keep you alive in circumstances where the clinical consensus is that you will die within, say, 6 months, that the treatment you are receiving that is keeping you alive will not be covered anymore.⁷⁹ So if your conviction is to preserve life at all costs, fine, but you are going to pay for it.⁸⁰ There are lots and lots of similar decisions that already get made. For a long time, bone marrow transplants were things that people thought were routinely going to keep cancer patients alive, but insurance companies refused to pay for them because they were not proven to be effective and they were not determined to be medically necessary.⁸¹ By all accounts the final years when Terri Schiavo's case was in court, her care cost 1.5 million dollars.⁸² The first seven hundred and fifty thousand came from the settlement that her husband got in a medical malpractice case.⁸³ The rest of it we all paid for through government-sponsored third-party payment plans.⁸⁴ So those are considerations that if we look down the road on this right-to-die legislation, there may be others weighing in on this, and it would be an interesting topic with other players for a symposium for another day. The question on that day will be: what do we do about the cost if we do not honor the right-to-die? Can we afford not to have right-to-die legislation?

Like I said, the benefit is that I have the last word, so I am going to end it there. Thank you very much. Questions?

Questions

AUDIENCE MEMBER: I really welcome this as an end to this conversation because I certainly would not have agreed with you walking into the room, and I really appreciate the nuance of what you are saying and the difficulties that everyone in this field faces regardless of whether you are for or against this legislation, in being there when someone loses

⁷⁹ See generally *id.* (discussing the intersection between medical futility and moral and religious values).

⁸⁰ William M. Sage, *Managed Care's Crimea: Medical Necessity, Therapeutic Benefit, and the Goals of Administrative Process in Health Insurance*, 54 DUKE L.J. 597, 602 (2003).

⁸¹ See, e.g., *Medical Policy Search*, BLUECROSS BLUESHIELD MISS., <https://goo.gl/UxyUya> (recognizing that procedures to restore bone marrow function are used to treat cancer patients, yet the policy deems them not medically necessary).

⁸² Pamela H. Woldow, *A Legacy of Terri Schiavo: More Interest in Living Wills*, ACCT. TODAY (May 2, 2005), http://www.accountingtoday.com/ato_issues/2005_8/12808-1.html.

⁸³ Jonathan Weisman & Ceci Connolly, *Schiavo Case Puts Face on Rising Medical Costs*, WASH. POST (Mar. 23, 2005), <http://www.washingtonpost.com/wp-dyn/articles/A58069-2005Mar22.html>.

⁸⁴ *Id.*

their life, and you have to participate in that, you do not have a choice.

Well, I do not mean that, obviously I have no choice, and neither do you, but a doctor or a nurse or a healthcare professional or a lawyer or a company president, you have no choice but to participate in this event, and the difficulty of establishing where your moral feelings exist and coordinating that with someone else, they are enormous, and I really appreciate the opportunity to have this conversation today.

GREGORY J. PEPE: Thank you.

JANEANNE LUBIN-SZAFRANSKI: What is becoming an even more interesting dialogue is the conflict over medical necessity that Greg was speaking about now moving outside of the hands of payors and back into the hands of providers in a very negative way. Moreover, the way it is moving is in the form of bundled payments and risk competency; so what the payors are saying is, "We will give you one hundred thousand dollars to care for this patient with this disease profile. That is it. That is the money you get. Figure it out."⁸⁵ Now, you all make the decisions that are based on medical necessity, who gets what, when and how, or do you spend \$110,000, then that is on your dime.⁸⁶ Now, how many times can you afford to do that? If you spend \$90,000, in whose best interest is that, in terms of the decisions that are being made and the impact those decisions have on each party involved?⁸⁷

There are new legal risks arising in managed care, primarily moving the managed-care risks away from the payor and onto the providers.⁸⁸ Thus, the whole construct in delivering medical care, which at one time was seen as a much more pure and objective decision because somebody else in another place was making those medical necessity decisions, is changing as these kinds of decisions are becoming primary decisions for providers,⁸⁹ and that is raising a host of ethical issues. As Greg said, we should have another discussion that does not necessarily deal with end-of-life, but deals with every single aspect of life in healthcare.

GREGORY J. PEPE: Here is a statistic; I love statistics. End-stage re-

⁸⁵ Kurt Darr, *Physician-Assisted Suicide: Legal and Ethical Considerations*, 40 J. HEALTH L. 29, 58–59 (2007).

⁸⁶ *See id.* (discussing fixed sum payment schemes and denial of care).

⁸⁷ *Id.* (discussing the risk that patient interests will become less prominent).

⁸⁸ Troyen Brennan & Thomas Lee, *Risk-Shifting in Health Care and Its Implications: Part One*, HEALTH AFF. BLOG (Aug. 24, 2011), <http://healthaffairs.org/blog/2011/08/24/risk-shifting-in-health-care-and-its-implications-part-one/>.

⁸⁹ *See id.* (discussing the reasons behind the shift in risk and how it may change the roles of insurers, providers, and patients).

nal disease accounts for less than 1% of the Medicare population.⁹⁰ It accounts for about 7% of the Medicare budget.⁹¹ So there is obviously a population of a relatively small number of people who are gobbling a huge amount of the Medicare dollars. And, what has happened this year, just starting on July 1, 2015, a new concept kicked off that they promised will control costs and improve quality. It is called an Accountable Care Organization,⁹² which is, again, going to receive a bundled payment for end-stage renal disease treatment.⁹³ And, that bundled payment is going to be used by the participants in that structure to figure out how to treat these patients.⁹⁴

A couple of things that you would like to think about are, for example, who are the parties who are involved. Well the largest is the Davita Corporation, as well as nephrologists who deal with end-stage renal disease patients.⁹⁵ And if they know they are going to get \$100,000 a year for a discrete population, they have got to make that money stretch for a full year.⁹⁶ And what if that is not the right number? Maybe Davita Corporation can eat that money, but I can tell you that the nephrologists in Connecticut I work with cannot fund millions of dollars of deficit spending. We had this experience in the earlier days when there were actual withholds and big financial risk contracting with managed-care plans, and big Independent Physician Associations (“IPAs”) went bankrupt; they could no longer provide care, so the government had to step in as well as insurers had to step in.⁹⁷ So we had some experience with what

⁹⁰ *Chapter 11: Medicare Expenditures for Persons with ESRD*, U.S. RENAL DATA SYS. (2015), http://www.usrds.org/2015/view/v2_11.aspx.

⁹¹ *Id.*

⁹² Press Release, Ctr. for Medicare & Medicaid Serv., Accountable Care Organization (ACO) Investment Model (June 25, 2015), <https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2015-Fact-sheets-items/2015-06-25.html>.

⁹³ Press Release, Ctr. for Medicare & Medicaid Serv., CMS Launches New ACO Dialysis Model (Oct. 7, 2015), <https://www.cms.gov/Newsroom/MediaReleaseDatabase/Press-releases/2015-Press-releases-items/2015-10-07.html>.

⁹⁴ *Id.*

⁹⁵ *Id.*

⁹⁶ See Shailender Swaminathan et al., *Medicare’s Payment Strategy for End-Stage Renal Disease Now Embraces Bundled Payment and Pay-for-Performance to Cut Costs*, U.S. NAT’L LIBR. MED. NAT’L INST. HEALTH (Sept. 7, 2013), <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3766315/> (discussing the bundled payment structure).

⁹⁷ See James C. Robinson, *Physician Organization in California: Crisis and Opportunity*, 20 HEALTH AFF., no. 4, July-Aug. 2001, at 83–86 (describing how physician IPAs in California went bankrupt and were consumed by large entities due in part to low Medicare HMO payment rates).

happens when you try to transfer the risk of this cost to other entities, and it was not all good experience, because typically physician organizations are not good at assessing risk. That is why we have insurance companies: they know how to make those assessments.⁹⁸ And so for the insurance companies and the federal government to push that risk on to physician organizations seems, to me, like nobody wants to touch that electrified rail. Nobody wants to have the conversation about rationing, so let's just put it over on that person.⁹⁹

AUDIENCE MEMBER: Given that, I suppose that assisted suicide would be one of the most economical forms of "medical care," and then the next may be hospice. And, if hospice, given the managed care realm, saying you need to do with this amount of money to manage this disease process. Could hospice be preferable? Was it your step-father who had the implantable defibrillator who would say dying is an easier process, even if it is passive, than treatment?

JANEANNE LUBIN-SZAFRANSKI: Well I have to say that the first thing you need to do is decide what the definition of "cost" is. And, cost is far greater than just dollars when you are talking about healthcare.¹⁰⁰ But if you are only talking about dollars, although hospice care is something that I support one hundred percent, what people do not understand is that there is big difference between palliative care and hospice care.¹⁰¹ And you can provide a lot of patients with palliative care, without their classification as hospice patients.¹⁰² But, perhaps Greg's father-in-law would have been better served from a more palliative approach rather than approaching it from a hospice care or end-of-life perspective.

ALAN MEISEL: Question here for Janeanne Lubin-Szafranski, there is something I have never really understood, perhaps you can explain to

⁹⁸ See Alison Ritchie et al., *Shifting Reimbursement Models: The Risks and Rewards for Primary Care*, MED. ECON. (Apr. 8, 2014), <http://medicaleconomics.modernmedicine.com/medical-economics/content/tags/aca/shifting-reimbursement-models-risks-and-rewards-primary-care?page=full> (discussing the financial challenges for physicians in managing risk from Medicare's various reimbursement models, including bundled payments).

⁹⁹ Catherine Arnst, *Commentary: Getting Rational About Health-Care Rationing*, BLOOMBERG BUS. (Nov. 16, 2003), <http://www.bloomberg.com/bw/stories/2003-11-16/commentary-getting-rational-about-health-care-rationing>.

¹⁰⁰ Richard A. Armstrong, *The Human Cost of Federal Health Care Mandates*, DOCS 4 PATIENT CARE FOUND. (Oct. 8, 2015), <https://d4pcfoundation.org/the-human-cost-of-federal-health-care-mandates/>.

¹⁰¹ *Frequently Asked Questions about Hospice and Palliative Care*, AM. ACAD. HOSPICE & PALLIATIVE MED., <http://palliativedoctors.org/faq> (last visited June 12, 2016).

¹⁰² See *id.* (stating that while hospice care is always palliative care, not all palliative care is hospice care).

me. And that is, why should people who do not subscribe to your religious beliefs be bound by them?

JANEANNE LUBIN-SZAFRANSKI: It is a fair question and one that I have heard many, many times. I think that we have choices in terms of our faith base and the way that we deliver care. We in Catholic healthcare are a growing influence in terms of the health market,¹⁰³ but there are still secular choices that you can certainly make with respect to the delivery of care. When you agree to be cared for within the faith base that is our tradition, then I think that you are subjecting yourself in some sense to our values and to our base of tradition.¹⁰⁴

ALAN MEISEL: That is not what I am referring to. I am referring to law-making. Why should people who do not share your views about, for example, physician aid in dying, be bound by them because you oppose enacting the law that would permit it?

JANEANNE LUBIN-SZAFRANSKI: I think because of the moral imperative.¹⁰⁵

ALAN MEISEL: I do not understand what that means. Other people have moral imperatives that go the other way.

GREGORY J. PEPE: It gets back to this sort of balancing, does it not? Just as many people would argue that this country was founded on core religious principles that are morality-based principles as would argue that the country was founded on the right to self-determination.¹⁰⁶

ALAN MEISEL: I think the First Amendment says otherwise.

GREGORY J. PEPE: Well, the First Amendment is coming at it from a different perspective. But this debate always boils down to whether or not personal liberty trumps the core values that the country was built on.¹⁰⁷

¹⁰³ See *Facts & Statistics: Catholic Health Care in the United States*, *supra* note 29 (stating that one in six patients in the U.S. is cared for in a Catholic Hospital, generating \$109 billion in expenses).

¹⁰⁴ See *Canon Law*, CATH. HEALTH ASS'N U.S., <https://www.chausa.org/sponsorship/canon-law> (last visited June 12, 2016) (describing the religious canons that guide the Catholic Health Association, which differ from the principles adhered to by other-than-Catholic healthcare providers).

¹⁰⁵ See *Marriage & Respect for Life: Euthanasia and Assisted Suicide*, ROMAN CATH. DIOCESE PHX., http://www.diocesephoenix.org/euthanasia_and_assisted_suicide.php (last visited June 12, 2016).

¹⁰⁶ Bill Flax, Opinion, *Was America Founded as a Christian Nation?*, FORBES (Sept. 25, 2012), <http://www.forbes.com/sites/billflax/2012/09/25/was-america-founded-as-a-christian-nation/#59227954cd96>.

¹⁰⁷ See Steven K. Green, *Understanding the "Christian Nation" Myth*, 2010 CARDOZO L. REV. DE NOVO 245, 245–51 (2010) (contrasting the Founders' varying religious virtues with their unrelated ideological sources of inspiration for republicanism and constitutional rights).

ALAN MEISEL: But those who would seek to exercise their personal liberty by ending their lives are not requiring anyone else to do anything. Whereas those who seek . . .

GREGORY J. PEPE: Sure they are, sure they are.

ALAN MEISEL: No, they are not.

GREGORY J. PEPE: They are requiring that a physician prescribe drugs . . .¹⁰⁸

ALAN MEISEL: No, they are not requiring it. The physician has to cooperate. If every physician refuses to cooperate, then one cannot exercise his or her personal liberty in that regard. Whereas, what you are saying is that you have a particular position, which if enacted into law, which of course it is enacted into law now, prohibits other people from doing what they prefer to do.

GREGORY J. PEPE: Are you hoping that we are going to have an agreement here today?

No, it is the argument that comes up every single time these things come up in legislatures. And I was raised Catholic. I think that the position that the country's core founding values are religious-based values is just as valid as the position that our independent rights, our inalienable rights, are somehow personal and not subject to religion. You can disagree with me. That is okay; I respect that.

ELLEN WALDMAN: Dr. Cederquist and I wanted to bring this up, but we ran out of time. So, we will just sort of raise the point because we finally talked about costs, and I believe one of the comments was we do not want to get into the situation of rationing, but of course we ration every day and we ration on the basis of class. If you have lots of money, you can buy your way out of whatever restrictions insurance places on your access to care, and if you do not, then you are in the unenviable situation of either very poor care or none at all.¹⁰⁹ So, there is tremendous rationing that permeates our system.¹¹⁰ We just do not like to see it that way; it is kind of a framing issue.

JANEANNE LUBIN-SZAFRANSKI: I do not think that there is any question about that. And, I do think that there are many, many people in the healthcare industry who strive very hard to not make that so, and spend an awful lot of funds trying to bring some equity to that situa-

¹⁰⁸ *Opinion 2.211 – Physician-Assisted Suicide*, AM. MED. ASS'N (June 1994), <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2211.page?>

¹⁰⁹ Arnst, *supra* note 99.

¹¹⁰ *Id.*

tion,¹¹¹ but there is absolutely no question about it, we are making more and more critical rationing decisions. For example, the nursing home patient who we choose not to implant a new hip because the patient is not mobile so it is not cost effective to implant the hip. Is it the right or wrong thing to do? How do we apportion out our limited resources in terms of clinic time for the patients who do not have primary care physicians and the like? So you are absolutely right; it happens every day.

GREGORY J. PEPE: The other thing I would add is that I think this issue is going to get worse because the same kind of risk-shifting that is happening between payors and providers is also happening between payors and patients and insurance enrollees.¹¹² So there is going to come a day in the near future, when you cannot get a policy—or you cannot get an affordable policy—that does not have anything other than a \$5,000 or \$10,000 deductible. And, what does that mean to the person who makes \$30,000 a year, if their employer offers a \$10,000 deductible policy? You cannot afford that. So you go into the hospital, and you have a \$10,000 bill before your insurance kicks in. That is essentially going to be withholding care or withholding treatment from people who cannot afford it.¹¹³ And, you are going to have insurance, but that risk-shifting by the insurance industry to patients, I think, is the next foot to fall—or it is already falling. I just think, because a lot of employers are saying, “Well that is the only policy we can afford.”¹¹⁴ So we have just got to cross our fingers and hope that you do not get something that requires \$9,000 when we have a \$10,000 deductible.” I agree that is a horrible aspect of what is happening in our healthcare industry.

JANEANNE LUBIN-SZAFRANSKI and GREGORY J. PEPE: Thank you very much.

¹¹¹ See, e.g., *About PNHP*, PHYSICIANS NAT’L HEALTH PROGRAM, <http://www.pnhp.org/about/about-pnhp> (last visited July 3, 2016) (describing a non-profit organization of physicians that raises funds to advocate for universal healthcare).

¹¹² Ilfrad Islam, *Trouble Ahead for High Deductible Health Plans?*, HEALTH AFF. BLOG (Oct. 7, 2015), <http://healthaffairs.org/blog/2015/10/07/trouble-ahead-for-high-deductible-health-plans/>.

¹¹³ See *id.* (discussing how high deductible health plans result in the forgoing of treatment to patients in need).

¹¹⁴ See *id.* (discussing the extent to which high deductible health plans reduce healthcare costs for employers).

Essay

THE (IR)RATIONALITY OF (UN)INFORMED CONSENT

*Barbara A. Noah**

“Enough is as good as a feast.”¹

Imagine life as a long airplane flight. At birth, the plane gathers speed and lifts up into the air. In the early and middle years, if all goes well, it continues to gain altitude as we learn, grow, and establish some sort of career and family life. At some point, however, we achieve peak altitude and cruise at that height for a while. At some later point, the plane begins its descent and, eventually, approaches a landing strip. As the plane touches down and hurtles along the tarmac, its velocity decreases and it comes to a halt. The question many of us will face at the end of life is how long to spend in that final stage, decelerating on the landing strip. How much therapy and life-prolonging treatment is “enough” at the end of life?

Various public figures recently have generated interest in end-of-life matters. Brittany Maynard, a young woman with a brain tumor, spoke out about the lack of a medically-assisted-dying option in her home state of California—and moved to Oregon in order to obtain this assistance and avoid the inevitable and severe suffering associated with the end stages of her illness.² For every Brittany Maynard who faces

* Professor of Law, Western New England University School of Law. Thank you to the organizers of this symposium event for their excellent work and to René Reich-Graefe for his thoughtful comments. This essay is dedicated to the memory of my father, David Shepardson Pond. © Barbara A. Noah 2016.

¹ P.L. TRAVERS, *MARY POPPINS* (London, Harper Collins, 1934).

² See George F. Will, *Affirming a Right to Die with Dignity*, WASH. POST (Aug. 28,

death with pragmatism and dignity (while generating a good deal of public debate, admiration, and sympathy), there are the Larry Kings of this world who publicly rail against it.³ In a recent interview, the 81-year-old King described the various measures he takes to stave off aging and acknowledged that he finds his own death unimaginable.⁴ Ezekiel Emanuel has expressed yet another view—the desire to live a reasonably long life but to die before the usual disabilities of age overwhelm his functionality and ability to contribute to the world.⁵ These various approaches to dying illustrate vastly different abilities to confront mortality. Interestingly, it is the 29-year-old rather than the 81-year-old who is ready to accept death, even to descend early to the landing strip. In one respect, all three approaches promote the autonomous wishes of the individual in question—to avoid suffering by curtailing the dying process; to live as long as possible no matter what the physical or psychic cost, hoping for an ever-lengthening landing strip; to die at the “optimal” time, navigating the narrow gap between premature and “too late” death. And yet, these three approaches to mortality also share a common theme: the desire to exert control over that which ultimately cannot be controlled—a desire for control that is fundamentally at odds with the layers of uncertainty described in this essay.

The increased utilization of therapies and life-prolonging technologies at the end of life and its attendant ill effects on the experience of dying has received a great deal of attention in recent years.⁶ Several statis-

2015), https://www.washingtonpost.com/opinions/distinctions-in-end-of-life-decisions/2015/08/28/b34b8f6a-4ce7-11e5-902f-39e9219e574b_story.html.

³ See Mark Leibovich, *Larry King Is Preparing for the Final Cancellation*, N.Y. TIMES MAG. (Aug. 26, 2015), http://www.nytimes.com/2015/08/30/magazine/larry-king-is-preparing-for-the-final-cancellation.html?_r=0.

⁴ See *id.* (“I can’t get my head around one minute being there and another minute absent.”). King also would love to attend his own funeral, stating, “I would like the ceremony to begin, ‘Today we are honoring a 160-year-old man who was caught in bed by an irate husband’” *Id.*

⁵ See Ezekiel Emanuel, *Why I Hope to Die at 75*, ATLANTIC (Oct. 2014), <http://www.theatlantic.com/magazine/archive/2014/10/why-i-hope-to-die-at-75/379329/>.

Emanuel persuasively critiques the American desire for “immortality” but his personal vision of dying in his prime epitomizes a kind of vanity that is equally troubling. He writes,

[L]iving too long is also a loss. It renders many of us, if not disabled, then faltering and declining, a state that may not be worse than death but is nonetheless deprived. . . . *It transforms how people experience us, relate to us, and, most important, remember us. We are no longer remembered as vibrant and engaged but as feeble, ineffectual, even pathetic.*

Id. (emphasis added).

⁶ See, e.g., INST. OF MED., DYING IN AMERICA: IMPROVING QUALITY AND HONORING INDIVIDUAL PREFERENCES NEAR THE END OF LIFE (2014),

tics provide a snapshot of trends in end-of-life care: Only about one-third of patients in the United States die at home.⁷ We utilize significant amounts of hospital-based resources at the end of life,⁸ often with little or no measurable benefit to dying patients. Many patients in the U.S. receive interventions such as cardiopulmonary resuscitation, ventilator support, or ICU care even when they are very near to death.⁹ And these trends are not improving.¹⁰ This pattern of utilization of care at the end of life comes with serious costs to patients, families, and society. Imminently dying patients receive costly and invasive therapeutic care and life-prolonging treatment even when it is very likely that the benefits in terms of enhanced quality of life, increased survival time, or other measurable physical outcomes are limited or non-existent.¹¹ In fact, the default model is to provide life-sustaining care and often to continue therapeutic treatment, unless the patient goes through the emotionally and intellectually taxing effort of either a properly informed or a rather unin-

<http://iom.nationalacademies.org/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx> (roundly criticizing the care of the dying in the United States); see also ATUL GAWANDE, BEING MORTAL 259 (2014) (arguing that medicine should refocus its goals from extending life to “enabl[ing] well-being”).

⁷ See Joan M. Teno et al., *Change in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009*, 309 JAMA 470, 473 tbl.2 (2013) (concluding that, although only 24.6% of patients died in hospital in 2009 compared with 32.6% in 2000, percentages of deaths in long-term care facilities held steady at around 27% and deaths at home rose from 30.7% in 2000 to 33.5% in 2009). Estimates about deaths in hospitals vary. See, e.g., YAFU ZHAO & WILLIAM ENCINOSA, HEALTHCARE COST AND UTILIZATION PROJECT, THE COSTS OF END-OF-LIFE HOSPITALIZATIONS 1 (Apr. 2010), <http://www.ncbi.nlm.nih.gov/books/NBK53605/> (describing data from 2007 indicating that one-third of Americans died in hospital).

⁸ See Teno et al., *supra* note 7, at 473 tbl.2 (noting that, in 2009, 29.2% of patients who died had received care in an ICU in the previous thirty days).

⁹ See Amresh Hanchate et al., *Racial and Ethnic Differences in End-of-Life Costs: Why Do Minorities Cost More than Whites?*, 169 ARCHIVES INTERNAL MED. 493, 497–99 (Mar. 9, 2009) (surveying use of expensive end-of-life interventions among a large sample of Medicare beneficiaries and finding patterns of substantial expenditure on life-sustaining treatment in the final six months of life).

¹⁰ The most recent data indicate that, in 2009, 28.4% of patients received hospice care for only three days or fewer before dying, an increase from 22.2% nine years earlier. Moreover, 29.2% of Medicare beneficiaries remained in an ICU during the final month of life compared with 24.3% in the earlier period. See Teno et al., *supra* note 7, at 471–73. See also *id.* at 473 tbl.2 (finding that 11.5% of patients had been hospitalized three or more times in the three months before death, up from 10.3% in the previous studied period).

¹¹ In a very recent study that attempts to measure physicians’ perceptions of when they are delivering “futile” care to their patients, the data suggested that approximately 20% of patients in five critical care units studied were receiving futile or “probably futile” treatment. See Thanh N. Huynh et al., *The Frequency and Cost of Treatment Perceived to Be Futile in Critical Care*, 173 JAMA INTERNAL MED. 1887, 1889 & fig.1 (Sept. 9, 2013).

formed consent process and opts out.¹² At the same time, we underutilize hospice and palliative care.¹³

This is no small problem, and it is growing larger as the population ages. Choices about end-of-life care impact many individuals among the millions who die in the United States each year.¹⁴ Health care costs at the end of life are substantial.¹⁵ Numerous medical organizations and advocacy groups have begun to address the problem of overutilization of care at the end of life through improved training for health care providers and efforts to educate patients, families, and the public in general about the need for advance care planning.¹⁶ In the face of these pro-

¹² See Rachelle E. Bernacki & Susan D. Block, *Communication About Serious Illness Care Goals: A Review and Synthesis of Best Practices*, 174 JAMA INTERNAL MED. 1994, 1997 (Oct. 20, 2014) (explaining that “our health care system is oriented toward providing life-sustaining treatment, unless a patient actively chooses against it”).

¹³ See Teno et al., *supra* note 7, at 474 (noting that, although the use of hospice services has increased during the early 2000s, only 42.2% of Medicare beneficiaries with dementia and 59.5% of Medicare beneficiaries with cancer received hospice services at the time of death); Haiden A. Huskamp et al., *Discussions with Physicians About Hospice Among Patients with Metastatic Lung Cancer*, 169 ARCHIVES INTERNAL MED. 954, 955–56 (May 25, 2009) (finding that only half of patients with stage IV lung cancer had had any discussion with their physicians about hospice in the two months prior to death); Corita Grudzen & Deborah Grady, *Improving Care at the End of Life*, 171 ARCHIVES INTERNAL MED. 1202, 1202 (July 11, 2011) (discussing over-use of therapeutic interventions at the end of life and advocating that better quality care often requires emphasizing palliative measures and avoiding unavailing therapies that risk unnecessary suffering and iatrogenic harm).

¹⁴ See *Deaths: Final Data for 2013*, CTR. DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/nchs/fastats/deaths.htm> (last visited Mar. 2, 2016) (noting that 2,596,993 people died in 2013, equaling 821.5 deaths per 100,000 people).

¹⁵ It is well documented that one-third of medical expenses for the last year of life are spent in the final month and that aggressive therapies and technologies in that final month account for nearly 80% of these costs. See Baohui Zhang et al., *Health Care Costs in the Last Week of Life: Associations with End-of-Life Conversations*, 169 ARCHIVES OF INTERNAL MED. 480, 480 (Mar. 9, 2009). Moreover, 30% of Medicare dollars spent pay for care for the 5% of Medicare beneficiaries who die each year. See Amber E. Barnato et al., *Trends in Inpatient Treatment Intensity Among Medicare Beneficiaries at the End of Life*, 39 HEALTH SERV. RES. 363, 364 (Apr. 2004).

¹⁶ For example, the American Society of Clinical Oncology has published a “best practices” model that recommends a series of conversations with patients with terminal cancer diagnoses, with various components to the ongoing discussion at sequential visits. See Thomas J. Smith et al., *American Society of Clinical Oncology Provisional Clinical Opinion: The Integration of Palliative Care into Standard Oncology Care*, 20 J. CLINICAL ONCOLOGY 880, 880 (2012) (“While a survival benefit from early involvement of palliative care has not yet been demonstrated in other oncology settings, substantial evidence demonstrates that palliative care—when combined with standard cancer care or as the main focus of care—leads to better patient and caregiver outcomes. These include improvement in symptoms, [quality of life], and patient satisfaction, with reduced caregiver burden. Earlier involvement of palliative care also leads to more appropriate referral to and use of hospice, and reduced use of futile intensive care.”); see also *Mission & Vision*, AM. ACAD. ON COMM. HEALTHCARE,

foundly troubling trends, many commentators (myself included) have provided detailed critiques of how we die and how we can communicate better about dying. No one seems to have acknowledged, however, that this is very likely an insurmountable problem that will only get worse as our population ages.

There are various ways to evaluate whether a dying individual is receiving “the right amount” of therapy or life-prolonging technology. In our health care system, the primary measure—based on both ethical principles and the law of informed consent—is to provide treatment that is subjectively consistent with the patient’s informed and autonomous wishes, values, and beliefs.¹⁷ One can also ask whether the treatment improves physical outcomes objectively by prolonging life or improving quality of life,¹⁸ or whether the cost of administering life-prolonging care at current levels is a wise expenditure of increasingly scarce health care dollars.¹⁹ By any of these measures, many dying patients are receiving “too much” therapy and life-prolonging care.²⁰

Many factors contribute to this situation, including a general cultur-

<http://www.aachonline.org/About-AACH/Mission-Vision> (last visited Mar. 2, 2016); ASS’N BEHAV. SCI. & MED. EDUC., <http://www.absame.org/dcms/about> (last visited Feb. 20, 2016) (providing information and resources for medical school and continuing medical education curricula).

¹⁷ *Schloendorff v. Soc’y of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914) (“Every human being of adult years and sound mind has a right to determine what shall be done with his own body . . .”).

¹⁸ Recent evidence suggests that the answer to this question frequently is “no.” More therapeutic and life-prolonging interventions at the end of life are associated with poorer outcomes. See Jennifer S. Temel et al., *Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer*, 363 NEW ENG. J. MED. 733, 736–38 (Aug. 19, 2010) (finding that patients recently diagnosed with lung cancer who began receiving palliative care immediately lived an average of three months longer than patients who received standard therapeutic treatment only); Matthijs Kox & Peter Pickkers, “*Less Is More*” in *Critically Ill Patients*, 173 JAMA INTERNAL MED. 1369 (June 10, 2013) (concluding, based on a meta-analysis of multiple clinical trials, that many common treatments for critically ill patients pose a high risk of iatrogenic harm compared with their potential benefit and ought to be used more cautiously).

¹⁹ On this measure, it also appears that we are not spending health care dollars wisely. A recent analysis of health care costs concludes that up to 35% of Medicare dollars at the end of life and up to 12% of Medicare dollars in total are being spent on clinically unsupported treatments and procedures. See David Cutler et al., *Physician Beliefs and Patient Preferences: A New Look at Regional Variations in Health Care Spending* (Nat’l Bureau of Econ. Research, Working Paper No. 19320, 2013), <http://www.nber.org/papers/w19320> (concluding that “cowboy doctors” were more likely to recommend intensive care beyond guidelines and that such doctors, rather than patient demand for care, were the primary driving force behind regional variations in the intensity of care provided to the dying).

²⁰ See Barbara A. Noah & Neal R. Feigenson, *Avoiding Overtreatment at the End of Life: Physician-Patient Communication and Truly Informed Consent*, 36 PACE L. REV. (forthcoming 2016) (manuscript at 3) (on file with author).

al denial of death, physicians' professional culture and fear of liability, physician avoidance of discussions about prognosis, and payment incentives that encourage overutilization of medical technologies.²¹ One particularly important cause, which is the focus of this essay, is the failure of physicians and patients to have timely, thorough, and honest conversations about care at the end of life. Here, one may posit that the better (though imperfectly) informed decisions resulting from these conversations can help reduce suffering and lead to care that more properly aligns with patients' well-considered values and preferences.²² Because the default model is to provide life-sustaining care unless the patient opts out, conversations about prognosis and goals of care provide an essential opportunity for patients to convey to their physicians their values and preferences about care at the end of life. In the absence of these detailed discussions, physicians in our health care culture assume that patients want, and consistently default towards, medical interventions even when they are actively dying.²³

The legal and ethical principle of informed consent creates a duty to inform patients of the risks and benefits of treatment and life-sustaining care (including likelihood of success measured by cure, palliation of symptoms, or extended life expectancy).²⁴ The remainder of this essay examines informed consent at the end of life in the context of the many uncertainties in which it necessarily operates, and attempts to explain some of the underlying reasons for its dysfunction. To be clear, informed consent to treatment and life-prolonging technologies, implemented with as much content and compassion as possible, remains the goal. But it is worth acknowledging the multiple, and often insurmountable, obstacles to making a "perfect" highest-utility decision in end-of-life care circumstances. We can only do our best to support making the "right" decision and, even then, we should do so with the knowledge that this decision

²¹ See *id.* (manuscript at 6–12) (describing and discussing the contextual factors that drive overutilization of care at the end of life).

²² In a recent paper, Neal Feigenson and I wrote about the implementation of informed consent law in end-of-life decision making and discussed various practices, including shared decision making and the use of informational videos, to improve patients' understanding of their choices. See *id.* (manuscript at 15–23).

²³ See Bernacki & Block, *supra* note 12, at 1995–97.

²⁴ See generally BARRY R. FURROW ET AL., HEALTH LAW § 3-11 (3d ed. 2015) (explaining that factors to be disclosed include diagnosis, nature and purpose of treatment, risks of treatment and, in some circumstances comparative data on the treating physician's skills, alternatives to the proposed treatment, prognosis with and without the treatment, and conflicts of interest); see also Noah & Feigenson, *supra* note 20 (manuscript at 22–27) (describing in detail the operation of informed consent law in the end-of-life context).

making will unavoidably remain subject to uncertainty and to our human limitations with regard to perfect rational choice.

Both physicians and patients frequently are reluctant to have these conversations, so the first challenge to making “good” choices at the end of life is to somehow ensure that these conversations *actually happen*. Patients generally rely on physicians to initiate conversations about end-of-life preferences,²⁵ and surveys indicate that the public wants physicians to discuss end-of-life issues.²⁶ Physicians, in general, are better positioned to initiate these conversations as repeat players with superior knowledge and no personal emotional implications beyond those that are part of their professional role. At the same time, our culture, which denies the reality of death and has little appetite for discussions about complex decisions at the end of life, presents a major obstacle to “good” decision making.²⁷ More generally, this culture of denial translates into a pervasive discomfort with the precarity of life and a concomitant desire to avoid thinking about mortality, at least until this becomes unavoidable. When these conversations *do* happen—even if we agree that “good” end-of-life decisions are decisions that reflect patients’ values and preferences after a series of discussions with physicians to explain the options and their potential benefits and adverse effects, and even if physicians and patients are willing to have these conversations together—barriers to good decision making remain.

Physicians and patients want to make the “best” choices about medical care for terminal illness but, given their bounded rationality, lack the omniscience needed to calculate all future possibilities without error. All human decision making, including medical decision making, occurs under conditions of irreducible uncertainty and resultant ambiguity. Philosophers Samuel Gorovitz and Alasdair MacIntyre offer an interesting and relevant theory of the nature of physician fallibility.²⁸ As they recount it, fallibility in medical decision making and treatment arises out of three distinct causes. The first is ignorance based on a limited under-

²⁵ See Karen Hancock et al., *The Truth-Telling in Discussing Prognosis in Advanced Life-Limiting Illnesses: A Systematic Review*, 21 *PALLIATIVE MED.* 514–15 (2007).

²⁶ See, e.g., *Kaiser Health Tracking Poll: September 2015*, KAISER FAM. FOUND. (Sept. 30, 2015), <http://kff.org/health-costs/poll-finding/kaiser-health-tracking-poll-september-2015/> (finding that 89% of those surveyed thought that doctors should discuss end-of-life care issues but that only 17% have actually had these discussions with a health care provider).

²⁷ See generally Barbara A. Noah, *In Denial: The Role of Law in Preparing for Death*, 21 *ELDER L.J.* 1 (2013) (discussing cultural, legal, and other reasons why patients and physicians avoid making end-of-life decisions).

²⁸ See Samuel Gorovitz & Alasdair MacIntyre, *Toward a Theory of Medical Fallibility*, 1 *J. MED. & PHIL.* 51 (1976).

standing of the medical issue—the physician has full access to information and collects it but cannot subjectively fully understand it.²⁹ The second is ineptitude based on the physician’s failure to access and follow available medical information—all of the information is available to arrive at a “correct” diagnosis and treatment plan but the physician, while capable of understanding the relevant information, fails to fully collect and process the information.³⁰ In either case, the physician either underperforms and fails to follow best practices or the physician suffers from and applies biases that interfere with a (boundedly) rational processing of the information. Both of these forms of fallibility can be overcome with better (i.e., more skilled, more careful, and more rational) effort.

By contrast, Gorovitz’s & MacIntyre’s third cause of fallibility is “necessary fallibility” in which that which must be understood scientifically in order to make the “best” decision simply cannot be known or predicted.³¹ In this scenario, no physician, no matter how skilled, careful, conscientious, and rational, can provide a solution or “best” recommendation because the solution is (at least, *ex ante*) unknowable due to the unpredictability of the multiple (objectively unknown and unknowable) variables involved in any patient’s prognosis or response to a particular treatment—in spite of the statistical averages or likelihoods that generally apply to the patient’s diagnosis. This type of necessary fallibility applies to every patient and every diagnosis and prognosis because every patient’s prognosis and future response to treatment remains subject to Knightian uncertainty.³² Not only is this uncertainty humanly unavoidable, but the degree of uncertainty and its impact on patient outcomes is, *ex ante*, unknowable. Accordingly, even a most skilled, careful, conscientious and rational physician’s judgment can be 100% wrong about a *particular* patient’s prognosis or response to treatment.

More specifically, let’s think for a moment about decisions with re-

²⁹ *Id.* at 65.

³⁰ *Id.* at 62–63.

³¹ *Id.* at 63. “[W]e have provided a theoretical account of why it is that knowledge about the individual patient is not merely essential, but is always and necessarily potentially inadequate to the extent that damaging error may result from conscientious, well-motivated clinical intervention by even the best-informed physicians.” Gorovitz & MacIntyre, *supra* note 28, at 65.

³² Knightian uncertainty refers to the idea that there are types of future contingent events and probabilities that are not capable of being quantified; hence, they are irreducible to quantifiable risks. See FRANK H. KNIGHT, *RISK, UNCERTAINTY, AND PROFIT* ch. 7 (1921). For a discussion of the application of Knightian uncertainty and its impact on every mode of rational decision making, see generally René Reich-Graefe, *Calculative Trust: Oxymoron or Tautology?*, 4 J. TRUST RESEARCH 66, 70–71 (2014).

spect to a cancer treatment using radiation that has a hypothetical 70% chance of success and a 30% chance of “no success” based on past application and experience. It is known that radiation kills cancer cells—this is an example of a knowable fact that is also actually known—a “known known.” It is also known that radiation will do damage to other parts of the body but not known what or how bad the damage might be in a particular person—this is an example of a “known unknown” contingent outcome. Based on the known knowns and known unknowns, a patient must make a decision about radiation treatment. The 70% chance of success only correlates with the known knowns and the known unknowns—and only as a statistical average for a homogenized group of past cancer patients. These statistical averages are still useful, however. As Lawrence Schneiderman has observed,

Most of us probably would agree that if a treatment has not worked in the last 100 cases, almost certainly it is not going to work if it is tried again. . . . The experience of 100 cases is attainable in many areas of medicine. This proposal is . . . one that seeks reasonable consensus where absolute certainty is impossible and therapeutic benefit is the goal.³³

But acknowledging this point is only the first step to accepting the full extent of uncertainty in making medical decisions.

The patient’s decision based on the statistical 70% chance of benefit described above, however, also entirely ignores the additional category of “unknown unknowns”—those contingent future variables impacting patient outcomes that are objectively unknowable at the time of decision making.³⁴ To make as rational a decision as possible, physicians and patients must acknowledge that unknown unknowns may always exist and may substantially impact the prognosis calculus and that they do not and rationally cannot know the extent of the unknown unknowns or how they might apply to the patient’s particular case. The 70-30 success ratio might have only a 10% application in the particular case due to un-

³³ See Lawrence J. Schneiderman, *Defining Medical Futility and Improving Quality of Care*, 8 *BIOETHICAL INQUIRY* 123, 125 (2011) (adding that “in the end, we all will have to accept some empirical notion of medical futility or else throw all commonsense to the wind”).

³⁴ Cf. KARL R. POPPER, *THE LOGIC OF SCIENTIFIC DISCOVERY* 280 (1961) (“The old scientific ideal of *episteme*—of absolute certain, demonstrable knowledge—has proved to be an idol. The demand for scientific objectivity makes it inevitable that every scientific statement must remain *tentative forever*. It may indeed be corroborated, but every corroboration is relative to other statements which, again, are tentative. Only in our subjective experiences of conviction, in our subjective faith, can we be ‘absolutely certain.’”), cited in Schneiderman, *supra* note 33, at 124 n.1.

known unknowns unique to the patient, i.e., that this patient, because of variables, is 90% likely not to fall into the 70-30 benefit-risk calculus that applies to the broader population of like patients. Notwithstanding this non-quantifiable-in-advance Knightian uncertainty (of known unknowns and unknown unknowns), patients who desire to live will form expectations³⁵ based on statistical averages, although these expectations may be irrational. Physicians, when they fail to acknowledge to themselves or disclose to patients this form of necessary fallibility, become complicit in patients' demanding and receiving potentially ineffective and harmful care.

In the specific context of medical decision making, the concept of clinical uncertainty is one form of necessary fallibility. Patients facing terminal illness frequently want their treating physicians to advise them as to the "best" treatment for their illness or condition. The problem is that, for multiple reasons, there is often no obvious "best" approach for any particular patient at any particular time. First, patients must understand that what is "best" depends at least to some extent on the patient's own goals of care. While one patient may be seeking maximal life extension no matter what the costs in terms of adverse effects, increased suffering, or medical dollars, another patient may prefer to focus on maintaining physical and intellectual functionality even at the cost of a potentially shorter lifespan. For this latter group of patients, the prospect of loss of meaningful ability to interact with the world might drive decisions to focus more on palliation of symptoms than on life prolongation. Second, clinical uncertainty means that the ability of physicians and patients to make rational calculations about the comparative desirability of various options within the context of the patient's subjective goals of care is always limited by the imperfections of predictive data on therapeutic response, adverse effects, and prognosis.³⁶

³⁵ See Niklas Luhman, *Familiarity, Confidence, Trust: Problems and Alternatives*, in TRUST: MAKING AND BREAKING COOPERATIVE RELATIONS 94, 97 (Diego Gambetta ed., 1988) ("You cannot live without forming expectations with respect to contingent events and you have to neglect . . . the possibility of disappointment . . . because it is a very rare possibility, but also because you do not know what else to do. The alternative is to live in a state of permanent uncertainty.").

³⁶ See generally JEROME GROOPMAN, *HOW DOCTORS THINK* (2007) (discussing clinical uncertainty in diagnosis and treatment recommendations); see also George A. Diamond, *Future Imperfect: The Limitations of Clinical Predictive Models and the Limits of Clinical Prediction*, 14 J. AM. C. CARDIOLOGISTS 12A (1989) (describing different ways in which statistical regressive models to predict clinical outcomes can go awry). Prognosis for meaningful recovery in many medical circumstances, such as for stroke patients, requires a discussion between physician and patient of complex variables such as the likelihood of regaining de-

It is, therefore, impossible to determine with any rational certainty a “best” or “optimal” treatment before the fact. Even after the fact, uncertainty will remain—who is to say that a different treatment might not have been better? Patients (and perhaps physicians) mistakenly view these sorts of decisions like forks in the road at which one can take a “right turn” or a “wrong turn” when they are in fact more like a river delta into which multiple rivers flow but all of which end up in the sea. Choosing the best treatment is very different from a financial investment in which one attempts to buy the “best” stock. With stock investing, one can look at past data and make a bet. If the initial money invested creates a return, one can assess retrospectively whether the chosen stock gave the best return on investment by comparing how the money would have performed if invested in a different stock. With humans and medical treatment, by contrast, one can never look back and assess with any certainty whether a different choice would have been “better”—because humans can only make the investment once and with no ability to compare alternative outcomes. Moreover, as soon as a treatment decision has been made and implemented, biases will often kick in in order to shore up confidence in the decision. At some point, patients have to make a decision and begin (or forgo) treatment, and they naturally crave reassurance that they are doing the “best” thing. These decisions are perhaps “informed” to the extent that physicians provide information about likelihood of success, but the concept of “informed” is greatly limited by the fallibility factors described above.

Necessary fallibility encompasses the idea that a patient’s ability to make truly informed decisions about end-of-life care is limited by the patient’s (and physician’s) own abilities to process complex information rationally.³⁷ In addition, both physicians and patients also regularly em-

degrees of physical function and this, too, is difficult to predict as a scientific matter because there are so many variables. A meta-analysis of data from multiple studies on the recovery of stroke patients who were receiving mechanical ventilation found that prognosis was generally poor, with 58% of these patients dying within 30 days, but that a minority of patients survived without severe disability. See Robert G. Holloway et al., *Prognosis and Decision Making in Severe Stroke*, 294 JAMA 725, 725–27 & tbl.1 (Aug. 15, 2005). The authors of this study caution that physicians can be unrealistically optimistic or pessimistic in various circumstances and argue that physicians should think carefully about how they convey prognostic evidence. See *id.* at 729 & tbl.3 (offering the example of explaining to a patient a surgical intervention as giving a person “a 50% better chance of an improved outcome” versus that same intervention increasing the person’s chance “of an improved outcome from 5% to 7.5%” (internal quotation marks omitted)).

³⁷ See Herbert A. Simon, *A Behavioral Model of Rational Choice*, 69 Q.J. ECON. 99 (Feb. 1955) (describing the limitations of humans to process information due to limited access to data and limitations of intellectual calculative abilities as bounded rationality).

ploy biases and heuristic shortcuts that will further interfere with boundedly rational informed decision making. Optimism bias constitutes one example of this sort of limitation in the context of decisions about treatment and life-prolonging technologies for those with life-threatening illness. Patients tend to think they will be among the fortunate one percent who greatly outlive the statistical prognosis for their disease or who respond unusually well to an otherwise non-curative therapy.³⁸ Patients also frequently discount the likely non-curative value of certain invasive treatments, either because this information is not included in the informed consent conversations or, as is relevant here, because they have accidentally or deliberately failed to understand that it is impossible to predict with any accuracy the effects of the treatment in a particular case.³⁹ With the plane already decelerating on the landing strip, these patients wonder whether and how it can take off again. Physicians also tend to be unduly optimistic, overestimating the remaining life expectancies of seriously ill patients and conveying prognoses in overly optimistic terms.⁴⁰

The fear of death and denial of mortality constitute the flipside and ultimate driver of unreasonable optimism and make confronting these ineluctably imperfect choices, reasoning through them in the context of personal beliefs and goals of care, and then making an informed but rationally never perfect choice very difficult. Truly informed consent re-

³⁸ See Lynn A. Jansen et al., *Unrealistic Optimism in Early-Phase Oncology Trials*, 33 IRB: ETHICS & HUMAN RES. 1 (2011) (finding that, although participants in an early phase trial understood that the treatment would not cure their cancer, a majority of those surveyed nevertheless exhibited an optimism bias in believing that the experimental drug would control their disease and that they would experience only benefits from the drug and no side effects).

³⁹ With respect to chemotherapy for metastatic cancer, one study found that 69% of patients with lung cancer and 81% of patients with colorectal cancer mistakenly believed that the chemotherapy they were receiving was likely to cure their disease. See Jane C. Weeks et al., *Patients' Expectations About Effects of Chemotherapy for Advanced Cancer*, 367 NEW ENG. J. MED. 1616, 1619–20 (Oct. 25, 2012) (noting, however, that “[p]aradoxically, patients who reported higher scores for physician communication were also at higher risk for inaccurate expectations” regarding the curative potential of chemotherapy).

⁴⁰ See Nicholas A. Christakis & Elizabeth B. Lamont, *Extent and Determinants of Error in Doctors' Prognoses in Terminally Ill Patients*, 320 BRIT. MED. J. 469, 470–71 (Feb. 19, 2000) (finding that, in predicting patients' remaining life expectancies, physicians were correct only 20% of the time and were over-optimistic 63% of the time and concluding that a closer doctor-patient relationship was associated with over-optimistic predictions); Elizabeth B. Lamont & Nicholas A. Christakis, *Prognostic Disclosure to Patients with Cancer Near the End of Life*, 134 ANN. INT. MED. 1096, 1099 (2001) (finding that, in communicating expected survival times to patients with terminal cancer, physicians were frank with patients only 37% of the time, provided deliberately inaccurate survival estimates 40.3% of the time and preferred to offer no estimate for 22.7% of the patients studied).

quires both courage and an understanding of the limits of knowledge, knowability, and rationality. So in every case, the ethical value of autonomy is to some extent a construct that assumes patients have endless time to process endless amounts of perfect and complete information to make a perfectly rational end-of-life decision. This is simply not the case.

If a physician is completely honest, he or she must recognize and accept that necessary fallibility is impossible to overcome. In general, the word “fallibility” implies incompetence or failure, but in the context of necessary fallibility, the use of the word is inapt and actually harmful. There is nothing morally wrong with necessary fallibility, and physicians should not let this sort of uncertainty inhibit them from either disclosing the limits of knowledge to patients or from acknowledging to themselves that this sort of limit is okay and indeed inevitable.⁴¹ Both statistically and rationally it is clear that, in predicting the future, doctors can and will get it wrong without *being* wrong. Physicians are mortals with bounded rationality like the rest of us. In this sense, the whole idea of “best” treatment does not apply (either objectively with respect to medical data or subjectively with respect to a particular patient). Perhaps, it is some underlying sense of this unavoidable “fallibility” that leads physicians and patients to want to do “everything” (and thus unwittingly reinforce their optimism biases). Nevertheless, physicians must do the best they can. For these reasons, they have an ethical obligation to take the lead in initiating discussions about treatment choices and the use of life-prolonging technologies.

And so, the title of this essay attempts to capture the idea that informed consent has its limits, but also that avoiding the effort to achieve truly informed consent is an irrational choice because it risks serious negative outcomes for patients. The cultural tendency to avoid thinking too much about mortality, even when one is terminally ill, together with

⁴¹ Cf. Gorovitz & MacIntyre, *supra* note 31 at 64–65 (discussing, in the context of claims about medical malpractice, the point that injury is no proof of a physician’s culpability). The authors write,

If physicians were to act as if they recognized this point, they might become far less reluctant to acknowledge, systematize, and learn from injury. But that would require a widespread willingness on the part of patients also to acknowledge the point, and thereby to lower their expectations about what physicians can accomplish

Id. at 65. I suggest here that the same analysis applies to physician recommendations with respect to end-of-life interventions. Acknowledging fallibility would be a good thing for both physicians and patients if both can understand that this sort of fallibility does not also imply culpability.

physician avoidance of truthful and thorough conversation about the risks, benefits, and alternatives to treatment and life-sustaining therapy, means that many dying patients will make an irrational choice to remain un(der)informed. When physicians take the path of least resistance and let this un(der)informed state continue, they do their patients no favors.⁴²

We all need to form some expectations about the future in order to function in the present,⁴³ but the trick is not to get too attached to these expectations (whether it is flight path, time at cruising altitude, landing strip length or similar aspects of the future). Those people who acknowledge on a daily basis the uncertainty of the future and the precarity of life are probably going to be more readily able to accept the idea of terminal illness and to make treatment decisions that are both well-informed (as to known knowns, known unknowns, and the unknowable impact of unknown unknowns) and consistent with their individual values and goals of care. And accepting uncertainty—about prognosis or efficacy of treatments—will be easier for patients whose physicians also acknowledge and discuss the uncertainty that is inherent and unavoidable in virtually all complex medical care decisions. Physicians themselves, by the very nature of their work, live with clinical uncertainty and life's precarity every day and sharing this reality with their patients is more likely to bring patients and physicians together in a collaborative decision-making team than to destroy hope or leave patients feeling abandoned. It also can optimize the rationality of patients' informed consent and thus their confidence in having made a proper choice under the most challenging of circumstances.

⁴² Of course, these sorts of conversations are necessarily emotionally challenging, and more so if the patient exhibits reluctance. See Elisa J. Gordon & Christopher K. Daugherty, *'Hitting You Over the Head': Oncologists' Disclosure of Prognosis to Advanced Cancer Patients*, 17 *BIOETHICS* 142 (2003) (describing the results of a small focus group discussion with physicians in which many expressed reluctance to convey statistical details about prognosis because they felt that the information would seem too abrupt and would interfere with patients' hope). But without some information about what is knowable about the patient's prognosis, patients are more likely to consent to treatment that provides no benefit while simultaneously exposing them to serious adverse effects.

⁴³ See Luhman, *supra* note 35.

Article

AID IN DYING: THE AVAILABILITY OF IDEAL MEDICATIONS FOR USE IN “RIGHT TO DIE” JURISDICTIONS IN THE UNITED STATES

*Taimie Bryant**

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On October 5, 2015, California joined three other states with aid-in-dying or so-called “right to die” or “death with dignity” statutes, which

* Professor of Law, University of California at Los Angeles, School of Law. I gratefully acknowledge the assistance of George Eighmey, President of Death with Dignity National Center; Silvan Luley and Ludwig A. Minelli of DIGNITAS; Robb Miller, former Executive Director, current Board Member, and contributor to the drafting of Washington’s Death with Dignity Act, and Dr. Robert W. Wood, Volunteer Medical Advisor, both of End of Life Washington (formerly Compassion & Choices of Washington) who readily, generously, and patiently shared their extraordinary knowledge and thoughtful perspectives on the subject of this Article. I would also like to thank my UCLA Law School colleague, Allison Hoffman, for thoughtful comments on the manuscript and Ofer Lion, Esq., an expert on all aspects of nonprofit organization and tax law, for very informative discussions about technicalities of charitable foundation program-related investments. My thanks also to Scott Dewey, an historian and UCLA Law Library research librarian who applied his remarkable research skills to find materials necessary for a full exploration of the topic, to Ian Deibert who served as my research assistant when I first started exploring the legal parameters for nonprofit foundation support of for-profit businesses, and to Lynn McClelland, a UCLA Law Library research librarian whose specialties are medical, health, and nonprofit law.

authorize doctors to lawfully prescribe lethal dose medications and pharmacists to lawfully fill those prescriptions under certain specified conditions.¹ All of these statutes are similar, having been modeled after the original Oregon statute enacted by petition in 1997. Among other provisions, they require that a patient have received a terminal diagnosis² with a prognosis of no more than 6 months to live,³ that the patient is competent to make a voluntary, informed decision regarding use of the lethal dose prescription⁴ and is also made aware of other standard medical options,⁵ and that the patient has met the waiting period,⁶ residency,⁷ and written request requirements.⁸ All existing aid-in-dying statutes also require information collection, but information about usage of the California and Vermont statutes is not yet available.⁹ Washington and Oregon's records reveal low usage of the statutes.¹⁰ Moreover, not all pa-

¹ California's End of Life Option Act, CAL. HEALTH & SAFETY CODE §§ 443–443.22, was approved by the Governor on October 5, 2015. See 2015 Cal. Legis. Serv. 2d Ex. Sess. ch. 1 (West), https://leginfo.ca.gov/faces/billTextClient.xhtml?bill_id=201520162AB15; Ben Adler, *California Governor Signs Hard-Fought, End-Of-Life Legislation*, CAL. PUB. RADIO (Oct. 5, 2015), <http://www.capradio.org/articles/2015/10/05/jerry-brown-signs-end-of-life-bill/>. The other three states are Oregon, Oregon Death with Dignity Act, OR. REV. STAT. §§ 127.800–.897 (2015), https://www.oregonlegislature.gov/bills_laws/ors/ors127.html, Washington, Washington Death with Dignity Act, WASH. REV. CODE §§ 70.245.010–.904 (Supp. 2015), <http://app.leg.wa.gov/rcw/default.aspx?cite=70.245>, and Vermont, Patient Choice at End of Life Act, VT. STAT. ANN. tit. 18, §§ 5281–5293 (2015), <http://legislature.vermont.gov/statutes/fullchapter/18/113>.

² CAL. HEALTH & SAFETY CODE § 443.2 (West 2016); OR. REV. STAT. § 127.805; WASH. REV. CODE § 70.245.020; VT. STAT. ANN. tit. 18, § 5283(a) (West 2016).

³ CAL. HEALTH & SAFETY CODE § 443.1(q); OR. REV. STAT. § 127.800 (12); WASH. REV. CODE § 70.245.010(13); VT. STAT. ANN. tit. 18, § 5281(10).

⁴ CAL. HEALTH & SAFETY CODE §§ 443.1(e) & (i), 443.5(a)(2) & (a)(8), 443.6(c), 443.7(b), 443.8(c)–(d), 443.10, 443.11; OR. REV. STAT. § 127.830; WASH. REV. CODE § 70.245.070; VT. STAT. ANN. tit. 18, §§ 5282–5823.

⁵ CAL. HEALTH & SAFETY CODE §§ 443.5(a)(2)(E), 443.11; OR. REV. STAT. §§ 127.800(7)(e), 127.815(c)(E), 127.897; WASH. REV. CODE §§ 70.245.010(7)(e), 70.245.040(1)(c)(v), 70.245.220; VT. STAT. ANN. tit. 18, §§ 5282, 5283(a)(6)(C)–(E).

⁶ CAL. HEALTH & SAFETY CODE § 443.3(a); OR. REV. STAT. § 127.850; WASH. REV. CODE § 70.245.110; VT. STAT. ANN. tit. 18, § 5283(a)(2), (a)(12).

⁷ CAL. HEALTH & SAFETY CODE §§ 443.1(o), 443.2(a)(3); OR. REV. STAT. § 127.860; WASH. REV. CODE § 70.245.130; VT. STAT. ANN. tit. 18, § 5283(a)(5)(E).

⁸ CAL. HEALTH & SAFETY CODE § 443.3(a)–(d); OR. REV. STAT. §§ 127.805 & 127.810; WASH. REV. CODE §§ 70.245.020–.030; VT. STAT. ANN. tit. 18, § 5283(a)(4).

⁹ CAL. HEALTH & SAFETY CODE §§ 443.5, 443.6, 443.8, 443.9, 443.19 (information collection has not yet begun because the statute has only recently taken effect); OR. REV. STAT. § 127.865; WASH. REV. CODE §§ 70.245.120, 70.245.150; VT. STAT. ANN. tit. 18, § 5293 (records are not available for public reporting or access until 2018).

¹⁰ Oregon's mandatory annual reports, spanning the years from 1998 to 2014, may be found at the Oregon Health Authority's website,

tients who fill lethal dose prescriptions take the medication.¹¹ Despite low usage rates in these states, no indication of abuse of the statutes, and considerable popular support for such laws,¹² aid-in-dying statutes remain difficult to enact in the United States.¹³

This Article examines a particular aspect of aid-in-dying statutes that affects patient utilization of aid-in-dying statutes and, potentially, the feasibility of enacting such statutes in states that do not already have them: the statutory requirement of “self-administration” or “ingestion” of the lethal dose medication by the patient and the limited availability of ideal medications for hastening death.¹⁴ In Part II, I explore reasons

<https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx>. Washington State’s reports for the years from 2009–2014 are posted at the Washington State Department of Health’s website, <http://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct/DeathwithDignityData>. Oregon’s 2014 report notes that since 1998, a total of 1,327 terminal patients received a lethal dose prescription, of which 859 (64.7%) used the medication. OR. PUB. HEALTH DIV., OREGON’S DEATH WITH DIGNITY ACT—2014, at 2 (2015), <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year17.pdf>.

¹¹ See, e.g., OR. PUB. HEALTH DIV., *supra* note 10. For additional support, see also the Oregon and Washington websites mentioned in note 10.

¹² See, e.g., *Strong Public Support for Right to Die: More Americans Discussing—and Planning—End-of-Life Treatment*, PEW RES. CTR. (Jan. 5, 2006), <http://www.people-press.org/2006/01/05/strong-public-support-for-right-to-die/>; Dennis Thompson, *Most Americans Agree With Right-to-Die Movement: 74 Percent Now Believe Terminally Ill Should Have Choice to End Their Lives*, HEALTHDAY (Dec. 5, 2014), <http://consumer.healthday.com/mental-health-information-25/behavior-health-news-56/most-americans-agree-with-right-to-die-movement-694268.html>.

¹³ In early 2015, 26 additional states were considering aid-in-dying laws, but as of Feb. 16, 2016, only California has joined Oregon, Washington, and Vermont by enacting one. See *Death-With-Dignity Boom: 26 States Now Considering Laws*, COMPASSION & CHOICES (Feb. 3, 2015, 8:47 PM), <https://www.compassionandchoices.org/2015/02/03/death-with-dignity-boom-25-states-now-considering-laws/>. Michael Ollove, *More States Consider ‘Death With Dignity’ Laws*, PEW CHARITABLE TRUSTS-STATELINE (Mar. 9, 2015), <http://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2015/3/09/more-states-consider-death-with-dignity-laws>.

¹⁴ See CAL. HEALTH & SAFETY CODE §§ 443.1(i)(4) & (p), 443.4(a), 443.5(a)(2)(B)–(C) & (a)(5)(A)–(B) & (E), 443.9(b), 443.11(c); OR. REV. STAT. § 127.875; WASH. REV. CODE §§ 70.245.010(12), 70.245.170. Vermont’s statute does not use the term “ingest” in any permutation and instead refers to the lethal medication being “self-administered.” See VT. STAT. ANN. tit. 18, §§ 5282, 5283(a)(1)–(2) & (4), 5284. Washington’s statute also uses the term “self-administer” more frequently but also defines it explicitly to mean “ingesting.” WASH. REV. CODE § 70.245.010(12). California’s statute alternates the terms but similarly defines “self-administer” to mean a person’s “affirmative, conscious, and physical act of administering and ingesting” a lethal drug. CAL. HEALTH & SAFETY CODE § 443.1(p). Oregon’s statute does not use the term “self-administer” and only includes “ingesting” in its section regarding insurance or annuity policies. OR. REV. STAT. § 127.875.

for decreasing access to those medications and, in Part III, limitations associated with different sourcing possibilities. I conclude that it may well be necessary to use less-than-ideal medications until the Food and Drug Administration (“FDA”) recognizes the need for and legitimacy of FDA-approved drugs specifically for the purpose of hastening death and pharmaceutical companies have sufficient incentives to produce and sell them at reasonable cost to consumers. Until relevant laws, FDA drug approval procedures, and pharmaceutical corporate incentives align with strong public support for aid-in-dying statutes, the lack of ideal medications will work a hardship on individuals seeking to use the statutes, particularly those with fewer financial resources. Moreover, since the statutes provide that individuals may use lethal dose medication without medical assistance, lack of a consistently available supply of ideal drugs for implementing such a statute could negatively impact the willingness of some legislators to support a proposed aid-in-dying statute.

I. INTRODUCTION

In states with aid-in-dying laws, physicians may lawfully write lethal dose prescriptions for drugs to be ingested or self-administered by the patient. There is no statutory definition of “self-administration” or “ingestion,” and there has been no judicial interpretation of those terms. They have been understood to mean self-administration of the lethal dose by the individual in the same way that the individual autonomously consumes nutrition and hydration.¹⁵ The individual must bring the medication into his or her system, with the full understanding that doing so will result in death.

This requirement may provide privacy to the individual using the statute, evince an individual’s strong and continuing commitment to hasten death, allay concerns about a slippery slope into euthanasia, and dis-

¹⁵ Interview with Robb Miller and Dr. Robert W. Wood, End of Life Washington, in Seattle, Wash. (May 29, 2015); Telephone interview with George Eighmey, President, Death with Dignity National Center (Jan. 25, 2016). Conventional dictionary definitions associate “ingestion” very strongly with eating, drinking, or otherwise taking a substance into the body by the mouth. *See, e.g., Ingest*, MERRIAM-WEBSTER DICTIONARY, <http://www.merriam-webster.com/dictionary/ingest> (last visited Mar. 5, 2016); *Ingest*, FREEDICTIONARY, <http://www.thefreedictionary.com/ingestion> (last visited Mar. 5, 2016); *Ingestion*, CAMBRIDGE DICTIONARY, <http://dictionary.cambridge.org/us/dictionary/english/ingestion> (last visited Mar. 5, 2016). The term has also been used in a more general way, however, as taking something into the body (or into a jet engine), not necessarily through the alimentary tract, which perhaps remains closer to the Latin root meaning to put, pour, or throw into. *See Ingest*, DICTIONARY.COM, <http://dictionary.reference.com/browse/ingestion> (last visited Mar. 5, 2016).

tance—while not discouraging—medical service providers of all types from involvement in a person's intentional death.¹⁶ Thus, the rigor asso-

¹⁶ Telephone interview with George Eighmey, *supra* note 15.

In 2015 in Oregon, no health care provider was present at death in 79.2% of instances of use. OR. PUB. HEALTH DIV., OREGON DEATH WITH DIGNITY ACT: 2015 DATA SUMMARY 6 (2016), <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf>. In Washington, the extent of health-care-provider presence is less clear because the Executive Summary for 2014 does not report the data in separate categories of “present at ingestion” and “present at death,” as Oregon’s report does. In 2014 in Washington, some kind of health care provider was present for some part of the process in 68% of instances of use, although in only 6% was the health care provider a physician. WASH. STATE DEP’T OF HEALTH, 2014 DEATH WITH DIGNITY ACT REPORT EXECUTIVE SUMMARY 9 (2015), <http://www.doh.wa.gov/portals/1/Documents/Pubs/422-109-DeathWithDignityAct2014.pdf>.

The purpose of aid-in-dying laws is to protect physicians and pharmacists from legal liability such that lethal dose prescriptions can be written and filled by individuals qualified under the statute to receive physician assistance with hastening their deaths. That does not mean that all physicians would be in favor of such a law or assist an individual, of course. Physicians differ with regard to willingness to participate in any aspect of the intentional death of another. For instance, participation in death penalty executions raises many of the same ethical issues. Some believe that assisting in the intentional taking of human life conflicts with their training and moral orientation toward medicine and fellow human beings, while others believe that participation in death penalty executions is a moral obligation arising from the need for medical assistance when medical procedures are performed. Frank Romanelli et al., *Issues Surrounding Lethal Injection as a Means of Capital Punishment*, 28 PHARMACOTHERAPY 1429, 1433–34 (2008).

As for the specific context of aid in dying, there are also varying views, which are complicated by many factors, including lack of clear conceptual distinction between withdrawal of life support, “physician-assisted suicide,” and euthanasia. Several studies in the 1990s reveal a variety of physician perspectives. *See, e.g.,* Jerald Bachman et al., *Attitudes of Michigan Physicians and the Public Toward Legalizing Physician-Assisted Suicide and Voluntary Euthanasia*, 334 NEW ENG. J. MED. 303, 306 (Feb. 1, 1996), <http://www.nejm.org/doi/full/10.1056/NEJM199602013340506>; Jonathan S. Cohen et al., *Attitudes Toward Assisted Suicide and Euthanasia Among Physicians in Washington State*, 331 NEW ENG. J. MED. 89, 90 (July 14 1994), <http://www.nejm.org/doi/pdf/10.1056/NEJM199407143310206>; Diane E. Meier et al., *A National Survey of Physician-Assisted Suicide and Euthanasia in the United States*, 338 NEW ENG. J. MED. 1193, 1199 (Apr. 23, 1998), <http://www.nejm.org/doi/full/10.1056/NEJM199804233381706>.

The Catholic Church has also played a role in this aspect of aid-in-dying statutes. The Catholic Church opposes aid-in-dying statutes. *See* U.S. CONF. OF CATH. BISHOPS, ETHICAL AND RELIGIOUS DIRECTIVES FOR CATHOLIC HEALTH CARE SERVICES 32 (5th ed. 2009) (Part Five, Directive 60, forbidding euthanasia and assisted suicide), <http://www.usccb.org/issues-and-action/human-life-and-dignity/health-care/upload/Ethical-Religious-Directives-Catholic-Health-Care-Services-fifth-edition-2009.pdf>. The Church owns or controls many health care facilities, and aid-in-dying statutes have exceptions that allow health care facilities (Vermont) or healthcare providers (California, Oregon, Washington) to prohibit use of the statutes under specified circumstances. Thus, even if a physician is willing to assist a patient seeking to use such a statute, the physician may be employed by a Catholic medical facility where use of the law is prohibited. *See* CAL. HEALTH & SAFETY CODE § 443.15(a); OR. REV. STAT. §

ciated with the “self-administration” or “ingestion” requirement may play an important gatekeeping function. Yet, it also creates challenges for patients and for the concept of a relatively quick and painless hastened death when the most appropriate drugs are scarce or prohibitively expensive.

The ideal drug for implementation of an aid-in-dying statute would be easily tolerated by the gastrointestinal tract, have no undesirable side effects such as tremors or sweating, induce unconsciousness relatively quickly, and result in death shortly thereafter.¹⁷ These standards are important for those attending the death as much as for the individual who is dying. Aid-in-dying statutes generally encourage individuals to inform their family members,¹⁸ and it is not uncommon for family members or friends to attend an individual’s death.¹⁹ Easily tolerated drugs that induce unconsciousness relatively quickly and result in death within an hour provide ease for the patient and for family members or friends attending the patient’s death. Other important criteria are affordability, so that the statute can be used by anyone regardless of financial or insurance status, and shelf-life longevity, since there is no legally required time period within which individuals must use the prescription.

Until recently, drugs meeting these criteria have been readily available.²⁰ Sodium pentobarbital powder and secobarbital have been rela-

127.885(4) & (5)(a); WASH. REV. CODE § 70.245.190(2)(a); VT. STAT. ANN. tit. 18, § 5286 (providing exceptions to the aid-in-dying law such that patients may not use the law if healthcare facility or provider prohibits its use); see also *Facts & Statistics: Catholic Health Care in the United States*, CATH. HEALTH ASS’N U.S. (updated Jan. 2016), <https://www.chausa.org/about/about/facts-statistics> (“Comprised of more than 600 hospitals and 1,400 long-term care and other health facilities in all 50 states, the Catholic health ministry is the largest group of nonprofit healthcare providers in the nation. Every day, one in six patients in the U.S. is cared for in a Catholic hospital.”).

¹⁷ Interview with Robb Miller & Dr. Robert W. Wood, *supra* note 15; E-mail from Silvan Luley, DIGNITAS, to author (Feb. 15, 2016, 09:20 am PST) (on file with author).

¹⁸ CAL. HEALTH & SAFETY CODE §§ 443.5(a)(5)(C) & 443.11(a) & (c); OR. REV. STAT. §§ 127.835 & 127.897; WASH. REV. CODE §§ 70.245.080 & 70.245.220.

¹⁹ It is difficult to know how many individuals have family members present with them at the time of death because of the way in which data about the circumstances are reported. Washington’s Report for 2014, however, states that 88% of individuals seeking to make use of Washington’s Death with Dignity Act informed family members, and 92% died in their or a friend’s or family member’s home. WASH. STATE DEP’T OF HEALTH, *supra* note 16, at 8–9. Oregon’s reported percentages for 2014 are 90.5% and 89.5%, respectively. OR. PUB. HEALTH DIV., *supra* note 16, at 5.

²⁰ See Kimberly Leonard, *Drug Used in ‘Death with Dignity’ Is the Same Used in Executions*, U.S. NEWS & WORLD REP. (Oct. 16, 2015), <http://www.usnews.com/news/articles/2015/10/16/drug-shortage-creates-hurdle-for-death-with-dignity-movement>.

tively affordable even at the high dose required to induce death.²¹ Lethal doses of these barbiturates are easy to ingest as long as the stomach is prepared with an anti-emetic, and the patient usually falls asleep, followed by loss of consciousness within about ten minutes of ingestion.²² Death typically follows within about an hour.²³

For reasons explored in Part II of this Article, barbiturates are no longer readily available in the United States. Supplies of shelf-stable sodium pentobarbital powder and pills are decreasing in availability, and the pricing of the second best alternative, secobarbital, is resulting in decreased access as well. As will be discussed in Part II, barbiturate prescriptions and production fell when benzodiazepines became doctors' and pharmaceutical companies' sedatives of choice. The decline also coincided with the federal government's decision to move drugs containing barbituric acid to Schedule II under the Controlled Substances Act, which indicates greater risk of abuse and makes prescribing barbiturates more burdensome. Manufacturer and physician preferences for apparently safer drugs and for avoiding risks of litigation resulting from the use of highly lethal drugs appear to be important drivers of this decline, but there has also been substantial and successful opposition to potential and actual use of barbiturates for death penalty purposes.

Given these background factors, it is perhaps not surprising that the price for a lethal dose of liquid sodium pentobarbital is \$15,000–\$25,000.²⁴ The price for a lethal dose of secobarbital, another barbitu-

²¹ In this Article “affordable” refers to drugs that most people can afford and which would be reasonable for nonprofit organizations to subsidize for individuals who cannot afford to purchase on their own or who do not have insurance coverage for the drugs. *See id.*

²² E-mail from Dr. Robert W. Wood, End of Life Washington, to author (Apr. 11, 2015, 4:03 pm PST) (on file with author). *See also* WASH. STATE DEP'T. OF HEALTH, *supra* note 16, at 9 (loss of consciousness occurs within one to ten minutes of ingestion); OR. PUB. HEALTH DIV., *supra* note 16, at 7 (loss of consciousness occurs within two to fifteen minutes).

²³ E-mail from Dr. Robert W. Wood, End of Life Washington, to author (Feb. 5, 2016, 1:00 pm PST) (on file with author). *See also* WASH. STATE DEP'T HEALTH, *supra* note 16, at 9 (death typically occurs within one to ninety minutes); OR. PUB. HEALTH DIV., *supra* note 16, at 7 (death typically occurs within eleven minutes to one hour). A similar pattern has been observed at DIGNITAS, which has assisted people in hastening death since 1998. As described by DIGNITAS, “after drinking [sodium pentobarbital], the patient gets drowsy and falls unconscious within 2–5 minutes. This is followed by slipping deeper into a coma. The person breathes like a deep-asleep person. About 20–30 minutes after drinking, the breathing becomes shallower, slower and finally, on average about 40 minutes after drinking, breathing stops and death occurs.” E-mail from Silvan Luley, DIGNITAS, to author (Feb. 16, 2016, 10:21 am PST) (on file with author).

²⁴ Leonard, *supra* note 20; *FAQs: How Much Does the Medication Cost?*, DEATH WITH DIGNITY, <https://www.deathwithdignity.org/faqs/> (last visited Mar. 5, 2016). The price varies by pharmacy.

rate, has risen to \$3,000–\$5,000.²⁵ Clearly, these are not prices easily within everyone's reach. Although current reports from Washington and Oregon reveal that most individuals who used those states' aid-in-dying statutes were covered by insurance, there is no information as to whether their insurance covered the cost of medication for purposes of hastening death.²⁶ The Oregon Health Plan, the Medicaid program for Oregon State, covers secobarbital for this use, but few people insured by the Oregon Health Plan use their insurance coverage for aid-in-dying purposes.²⁷ Some insurance companies offer policies that will cover some of the costs of secobarbital, but it is not clear how many do, what the extent of coverage is, or the likelihood of continued coverage of an ideal medication if a less expensive workable drug combination is available.²⁸

Nonprofit organizations dedicated to helping people who are seeking to use aid-in-dying statutes have worked with doctors and pharmacists to come up with a viable, affordable combination of available drugs.²⁹ The new combination, which was reported in Oregon's Public Health Report on usage of its aid-in-dying statute for the first time in 2015, is phenobarbital, chloral hydrate, and morphine sulfate.³⁰ This

²⁵ Leonard, *supra* note 20; *FAQs*, *supra* note 24.

²⁶ WASH. STATE DEP'T OF HEALTH, *supra* note 16, at 5; OR. PUB. HEALTH DIV., *supra* note 16, at 5.

²⁷ See THE TASK FORCE TO IMPROVE THE CARE OF TERMINALLY-ILL OREGONIANS, THE OREGON DEATH WITH DIGNITY ACT: A GUIDEBOOK FOR HEALTH CARE PROFESSIONALS 18, 86 (2008), <https://www.ohsu.edu/xd/education/continuing-education/center-for-ethics/ethics-outreach/upload/Oregon-Death-with-Dignity-Act-Guidebook.pdf> ("The Oregon Health Plan (OHP) may be an option for low-income patients. OHP covers 'comfort care,' including hospice, in-home health services, pain management, and costs associated with the Oregon Death with Dignity Act."). George Eighmey, President of Death with Dignity National Center, reports that Oregon's experience has been that, so far, few individuals covered by OHP have made use of Oregon's Death with Dignity Act. Telephone interview with George Eighmey, *supra* note 15.

²⁸ According to George Eighmey, President of Death with Dignity National Center, some patients have health insurance policies that cover this, but it depends on the company and the policy, and it is not clear how many companies provide coverage or the extent of coverage when they do. Telephone interview with George Eighmey, *supra* note 15.

²⁹ Leonard, *supra* note 20; *FAQs*, *supra* note 24.

Doctors and pharmacists in Washington state developed the new drug combination now in use after having been alerted to the problem by End of Life Washington, which assists patients in using Washington's aid-in-dying statute. End of Life Washington has coordinated efforts to provide an alternative, including providing feedback about how the combination is working and ways in which it might be helpful for those doctors and pharmacists to adjust the formula. Interview with Robb Miller & Dr. Robert W. Wood, *supra* note 15. These efforts are also supported by Death with Dignity National, which shares the same interests as End of Life Washington in seeking patient access to appropriate, lower-cost medication. Telephone interview with George Eighmey, *supra* note 15.

³⁰ OR. PUB. HEALTH DIV., *supra* note 16, at 6.

combination costs about \$450–500 per lethal dose but has not yet been used for as long as sodium pentobarbital and secobarbital.³¹ Initial reports suggest that the formula effectively hastens death but that there are some difficulties with its use.³² As in the lethal injection death penalty context, single drug protocols appear to work more smoothly than multi-drug combinations to secure an easier death. Thus, it is important to understand why access to ideal medications has decreased and to explore ways to restore access for aid-in-dying purposes.³³

II. A BRIEF HISTORY OF BARBITURATE PRESCRIPTION AND USAGE IN THE UNITED STATES

Barbituric acid, first synthesized in 1864, is the chemical foundation for the class of drugs known as barbiturates.³⁴ Barbiturates depress

³¹ Leonard, *supra* note 20; *FAQs*, *supra* note 24.

³² Interview with Robb Miller & Dr. Robert W. Wood, *supra* note 15. The new combination “tastes worse, burns the mouth, and may take longer to work.” Jonel Aleccia, *Aid-in-Dying Advocates Develop Option to Pricy Drug*, SEATTLE TIMES SUNDAY (Apr. 3, 2016) (quoting Dr. Bob Wood of End of Life Washington), <http://www.pressreader.com/usa/the-seattle-times-sunday/20160403/281509340330179>.

That there are difficulties with use stands to reason, considering the fact that drug combinations instead of single drug protocols have also posed challenges in the death penalty context. *See, e.g.*, Jerry A. Coyne, *The Three-Drug Death Penalty Cocktail Is a Mess*, NEW REPUBLIC (May 4, 2014), <http://www.newrepublic.com/article/117641/three-drug-cocktail-death-penalty-used-oklahoma-mess>; Ed Pilkington, *British Drug Company Acts to Stop Its Products Being Used in US Executions*, GUARDIAN (May 15, 2013), <http://www.theguardian.com/world/2013/may/15/death-penalty-drugs-us-uk>.

Also, according to Robb Miller, former Executive Director and current Board Member of End of Life Washington, “the chloral hydrate mixture can only be created by compounding pharmacies, a fraction of the pharmacies in operation, thereby reducing access to life-ending meds because a significant number of those compounding pharmacies will opt out of participating/filling prescriptions for life-ending meds. So ‘a fraction of a fraction.’” E-mail from Robb Miller, former Executive Director and current Board Member of End of Life Washington, to author (Mar. 24, 2016, 12:49 pm PST) (on file with the author).

³³ *See, e.g.*, Coyne, *supra* note 32. On February 18, 2016, Travis Hittson was executed with intravenous administration of the single drug, sodium pentobarbital. Hittson’s execution apparently proceeded smoothly with death occurring within about 10 minutes of administration of the drug. Associated Press, *Former Navy Crewman Travis Hittson Executed in Georgia for Killing Fellow Sailor*, AL.COM (Feb. 17, 2016), http://www.al.com/news/index.ssf/2016/02/former_navy_crewman_travis_hit.html. This is unlike reported executions in which drug combinations were used. *See* Coyne, *supra* note 32; Pilkington, *supra* note 32.

³⁴ ERNEST HARTMANN, *THE SLEEPING PILL* 13 (1978); ANDREA TONE, *THE AGE OF ANXIETY: A HISTORY OF AMERICA’S TURBULENT AFFAIR WITH TRANQUILIZERS* 21 (2009); NAT’L INST. MENTAL HEALTH PUB. INFO. BRANCH, *THE UP AND DOWN DRUGS: AMPHETAMINES AND BARBITURATES* 3 (1969); Francisco López-Muñoz et al., *The History of*

the central nervous and respiratory systems.³⁵ They can reduce blood pressure, disrupt normal heart rate, and cause circulatory collapse.³⁶ The mechanism of death in acute barbiturate toxicity is usually severe respiratory system depression after the individual has lost consciousness.³⁷ A barbiturate is classified as long-acting, intermediate-acting, short-acting, and ultra-short acting, depending on how long it takes for the barbiturate to reach peak blood levels and how long the effects of the barbiturate last.³⁸ All barbiturates share the characteristic that the upper therapeutic range for the drug is relatively close to fatal toxicity, with shorter-acting barbiturates reaching peak blood levels the most quickly.³⁹ They are

Barbiturates a Century after Their Clinical Introduction, 1 NEUROPSYCHIATRIC DISEASE & TREATMENT 329, 329 (2005).

³⁵ HARTMANN, *supra* note 34, at 13, 15.

³⁶ *Id.* at 15; Charles O. Jackson, *Before the Drug Culture Barbiturate/Amphetamine Abuse in American Society*, 11 CLIO MEDICA ACTA ACADEMIA INTERNATIONALIS HISTORIAE MEDICINAE 47, 50 (1976).

³⁷ HARTMANN, *supra* note 34, at 145.

³⁸ DAVID E. SMITH & DONALD R. WESSON, NAT'L INST. ON DRUG ABUSE, DEP'T OF HEALTH, EDUC. & WELFARE, DIAGNOSIS AND TREATMENT OF ADVERSE REACTIONS TO SEDATIVE-HYPNOTICS 5-6 (1974). Dr. R.S. Fisher described these different classifications by reference to their lethal toxicity, finding that shorter acting barbiturates were associated with death at lower blood levels than blood levels of longer acting barbiturates. Russell S. Fisher, *Notes from the Medical Examiner: Barbiturate Toxicity*, 240 NEW ENG. J. MED. 395, 395 (1949). In 1956, biochemistry research focused on acute barbiturate poisoning confirmed the relationship between the classification of barbiturates along a spectrum of long-acting to short-acting and the rate of physiological clearing: "Blood-levels of the long-acting drugs were higher, and the rates of fall slower, than those of the short-acting ones. . . . Patients who had taken short-acting barbiturates usually recovered more rapidly." P.M.G. Broughton et al., *Acute Barbiturate Poisoning*, 267 LANCET 180, 181 (Jan. 28, 1956). In 1970, Drs. Gillett and Warburton explored the question of barbiturate lethal toxicity in the context of necropsy. Their findings are consonant with those of Fisher and Broughton, Higgins, and O'Brien. Roger Gillett & Frank G. Warburton, *Barbiturate Blood Levels Found at Necropsy in Proven Cases of Acute Barbiturate Poisoning*, 23 J. CLINICAL PATHOLOGY 435 (1970). Francisco López-Muñoz and his coauthors describe differing uses of barbiturates related to their being longer or shorter acting. López-Muñoz et al., *supra* note 34, at 338. *See also* Dimitri A. Cozaniotis, *One Hundred Years of Barbiturates and Their Saint*, 97 J. ROYAL SOC'Y MED. 594, 596 (Dec. 2004).

³⁹ HARTMANN, *supra* note 34, at 13 (stating that after barbituric acid derivatives were introduced, they "quickly took over the entire world market for hypnotics and sedatives.").

Most hypnotic drugs have been lethal drugs. They usually possess a low therapeutic index because they are non-specific CNS depressants and respiratory depressants. A dose not too much larger than the therapeutic dose can often result in coma and death. For instance, the usual effective dose of secobarbital, the most widely used hypnotic barbiturate, is 100 mg; insomniacs quite often take 200 or 300 mg or even more at night. Lethal doses are difficult to estimate exactly because of wide variations between individuals; however, a fair estimate would be to say that 800 mg can produce coma, and 2000 to 3000 mg are likely to produce death in a normal adult. Children, adults having especially low body weight, adults with various illnesses,

dangerous also because the therapeutic dose is highly variable by individual and by an individual's changing physical circumstances and other pharmacologic circumstances; what is therapeutic for a person at a particular time can be deadly for another or for the same person under different physical circumstances such as loss of weight or illness.⁴⁰ Yet, despite risks of abuse and accidental death, Edward Shorter, a social historian of medicine, contends that "for patients for whom [barbiturates and amphetamines] were legitimately prescribed, they worked in ways that later generations of drugs have not been able to replicate: Depressed and insomniac patients got well and stayed well for years on them without becoming dependent."⁴¹

Sodium pentobarbital and secobarbital are short-acting barbiturates ideally suited for aid-in-dying statutory purposes because it is feasible to consume as a single dose the quantity necessary to rapidly produce sleep, followed by a fatal effect that occurs easily and relatively quickly after ingestion.⁴² Despite decades of extensive use, short-acting barbiturates are now in extremely short supply in the United States.⁴³ Various explanations have been offered to account for the shortage of these barbiturates, but the primary reason appears rooted in history—their replacement by drugs reputed to have more biologically targeted efficacy and higher patient safety profiles.⁴⁴ Opposition to the death penalty has also had an adverse impact on the current availability of these drugs.⁴⁵ In this Part, I trace some of the relevant history of drug development, marketing, use, and legal regulation leading to the difficulty of obtaining these ideal drugs for aid-in-dying purposes.

and adults taking other depressant medication can be in danger from considerably lower doses. Thus, for these drugs, a dangerous dose is not very many times the usual therapeutic dose.

Id. at 144.

⁴⁰ *Id.*; TONE, *supra* note 34, at 24.

⁴¹ EDWARD SHORTER, BEFORE PROZAC: THE TROUBLED HISTORY OF MOOD DISORDERS IN PSYCHIATRY 33 (2009).

⁴² Fisher, *supra* note 38, at 395.

⁴³ Toine Pieters & Stephen Snelders, *From King Kong Pills to Mother's Little Helpers—Career Cycles of Two Families of Psychotropic Drugs: The Barbiturates and Benzodiazepines*, 24 CANADIAN BULL. MED. HIST. 93, 101 (2007).

⁴⁴ SHORTER, *supra* note 41, at 33; TONE, *supra* note 34, at 161; Pieters & Snelders, *supra* note 43, at 102–03; Diane K. Wysowski & Carlene Baum, *Outpatient Use of Prescription Sedative-Hypnotic Drugs in the United States, 1970 Through 1989*, 151 ARCHIVES INTERNAL MED. 1779, 1782–83 (Sept. 1991).

⁴⁵ See generally Kevin Sack, *Shortage of Widely Used Anesthetics Is Delaying Executions in Some States*, N.Y. TIMES (Sept. 29, 2010), <http://www.nytimes.com/2010/09/30/us/30drug.html>.

A. *Physician Receptivity, Strong Consumer Utilization, and High Production Levels*

Barbituric acid became available in medicinal form for the first time in 1903 under the brand name Veronal, ushering in an era of pharmaceutical psychotropic drug development and accelerating a worldwide shift in the direction of believing that ingesting physician-prescribed pharmaceutical products could make the experience of life easier.⁴⁶ It was rapidly and enthusiastically adopted by prescribing doctors and the public, even as the scientific and medical literatures from the very first year of its introduction reported safety problems, such as ease of overdose and addiction, troubling side effects, and allergic reactions.⁴⁷ Additional hazards, such as drug interaction problems⁴⁸ and geriatric hypersensitivity,⁴⁹ emerged as experience with barbiturates increased.

Barbiturates' initial popularity in medical circles in the early 1900s was due in part to comparison with previous dangerous and less helpful drugs,⁵⁰ promotion by pharmaceutical companies,⁵¹ consumer interest in using Veronal and its successor drugs,⁵² and barbiturates' utility in a variety of contexts.⁵³ They were not suitable for use in patients with schizophrenia,⁵⁴ but they were broadly applied in many other contexts such as depression, anxiety, insomnia, epilepsy, chronic alcoholism, obstetrics, ulcers, and hyperthyroidism,⁵⁵ and as an antidote for cocaine intoxica-

⁴⁶ Jackson, *supra* note 36, at 47, 55.

⁴⁷ Pieters & Snelders, *supra* note 43, at 97–98.

⁴⁸ According to current drug information provided at the UpToDate patient drug information website, pentobarbital (a short-acting barbiturate) can produce the following adverse effects: “abnormal thinking, agitations, anxiety, ataxia, [central nervous system] excitation, confusion, depression, dizziness, drowsiness, fever, hallucinations, headache, hyperkinesia, insomnia, nervousness, nightmares, psychiatric disturbances, somnolence.” *Pentobarbital: Drug Information*, UPTODATE, <http://www.uptodate.com/contents/pentobarbital-drug-information> (last visited Apr. 10, 2016). The website further warns: “Withdrawal: Anticonvulsants should not be discontinued abruptly because of the possibility of increasing seizure frequency”; and that pentobarbital can reduce the serum concentration of beta-blockers, which are used for anxiety relief, and may diminish the effect of contraceptives, leading to contraceptive failure. *Id.*

⁴⁹ For instance, pentobarbital is not recommended for use in the elderly and should be used with caution in patients who are debilitated. *Id.*

⁵⁰ López-Muñoz et al., *supra* note 34, at 330.

⁵¹ Pieters & Snelders, *supra* note 43, at 96–97.

⁵² SHORTER, *supra* note 41, at 19–20.

⁵³ TONE, *supra* note 34, at 22; Pieters & Snelders, *supra* note 43, at 96.

⁵⁴ Pieters & Snelders, *supra* note 43, at 96.

⁵⁵ TONE, *supra* note 34, at 22; Pieters & Snelders, *supra* note 43, at 96.

tion.⁵⁶ Doses at the upper end of the therapeutic range could be used as an anesthetic for minor surgeries.⁵⁷ As time went on, pharmaceutical companies combined barbituric acid with other chemicals to further extend the breadth of medical applications of barbituric acid.⁵⁸ Production levels increased dramatically, resulting in easy consumer access with or without prescriptions.⁵⁹

Veronal, the drug that started it all in 1903,⁶⁰ was introduced during the “golden age” of patent medicines, when pharmaceutical companies began zealously promoting their patented products.⁶¹ Merck and Bayer, which produced Veronal, “created special scientific information departments to promote the new scientifically-tested drugs directly to doctors and pharmacists through articles, leaflets, advertisements and the distribution of free samples.”⁶² Clinical psychiatrists also published rave reviews of Veronal, praising its range of applications and superiority to previous drugs.⁶³ Physicians began prescribing Veronal apparently because it was promoted by pharmaceutical companies as safer and more effective than previous drugs and because patients requested it.⁶⁴

The public warmed immediately to Veronal. Within one year, it was considered a fashionable drug worthy of its much higher price than any of its predecessor drugs, which were relegated to use among the institutionalized poor.⁶⁵ Perhaps one reason that barbiturates became so widely used in the United States is that the Harrison Narcotics Tax Act of 1914⁶⁶ restricted access to opiates,⁶⁷ but other reasons, such as the promotion of barbiturate use as socially acceptable—even fashionable—and high-volume production of barbiturates, were important, too.

The worldwide success of Veronal and its equivalent drug, Medinal, produced by Schering Labs,⁶⁸ was a clear economic signal to develop additional drugs based on barbituric acid. Pharmaceutical manufac-

⁵⁶ Cozanitis, *supra* note 38, at 596.

⁵⁷ López-Muñoz et al., *supra* note 34, at 330, 337.

⁵⁸ SHORTER, *supra* note 41, at 21.

⁵⁹ López-Muñoz et al., *supra* note 34, at 338–39.

⁶⁰ The same chemical marketed as Medinal by Schering Labs does not appear to have become quite as widely known. SHORTER, *supra* note 41, at 19.

⁶¹ Pieters & Snelders, *supra* note 43, at 96.

⁶² *Id.* at 96–97.

⁶³ *Id.* at 96.

⁶⁴ TONE, *supra* note 34, at 21–22.

⁶⁵ Pieters & Snelders, *supra* note 43, at 97.

⁶⁶ Pub. L. No. 63-223, 38 Stat. 785 (1914).

⁶⁷ Pieters & Snelders, *supra* note 43, at 97.

⁶⁸ SHORTER, *supra* note 41, at 19.

turers responded in the 1920s and 30s with the “second generation” development of thousands of barbiturate derivatives.⁶⁹ Ultimately, far fewer of those barbiturates were regularly prescribed.⁷⁰

Although these second generation drugs were marketed as shorter acting and, therefore, safer,⁷¹ not all of the second generation barbiturates turned out to be significantly safer. Among the second generation of supposedly safer barbiturates were sodium pentobarbital⁷² and secobarbital⁷³—both short-acting barbiturates ideal for aid-in-dying purposes precisely *because* it is easy to cause death quickly and painlessly with a manageable single dose.⁷⁴ Second generation barbiturates posed significant risks of death from the drug itself or from accidents associated with impairments due to barbiturate use,⁷⁵ and these barbiturates also shared with first generation barbiturates highly variable therapeutic ranges.⁷⁶

There appears to be little difference between first and second generation barbiturates in terms of actual safety; they all pose significant safety risks. Even so, barbiturates remained extremely popular drugs among the general public from the time they were introduced,⁷⁷ long past patent protection expiration,⁷⁸ and even after safer benzodiazepines, such as Valium, became physicians’ preferred prescriptions in the 1960s and 1970s to address anxiety and insomnia and to provide mild sedation.⁷⁹ One author tracing the history of sleeping pills has written that “it is likely that phenobarbital and secobarbital . . . have been used in larger quantities than any other sleeping medication in human history.”⁸⁰

Teenagers’ use of barbiturates was common and worrisome,⁸¹ yet

⁶⁹ “By 1950 more than 2,000 barbiturates had been synthesized, some 50 different barbiturates were on the market and about a dozen were in common use.” Pieters & Snelders, *supra* note 43, at 99; *see also* López-Muñoz et al., *supra* note 34, at 330, 333.

⁷⁰ López-Muñoz et al., *supra* note 34, at 330.

⁷¹ Pieters & Snelders, *supra* note 43, at 98–99.

⁷² Sodium pentobarbital was first sold in 1930. *See* López-Muñoz et al., *supra* note 34, at 333.

⁷³ Secobarbital was first synthesized in 1929 and was first marketed as secobarbital sodium in 1934. *See* López-Muñoz et al., *supra* note 34, at 333.

⁷⁴ Lisa M. Krieger, *Barbiturates Common as Soothing Drugs, but Also Well-Known Killers*, S.F. GATE (Mar. 28, 1997), <http://www.sfgate.com/news/article/Barbiturates-common-as-soothing-drugs-but-also-3127647.php>.

⁷⁵ HARTMANN, *supra* note 34, at 146.

⁷⁶ TONE, *supra* note 34, at 24.

⁷⁷ Pieters & Snelders, *supra* note 43, at 97.

⁷⁸ Edward C. Mansley et al., *The Utilization of Medicines beyond Patent Expiration*, 11 F. HEALTH ECON. & POL’Y, no. 2, 2008, at 5.

⁷⁹ Pieters & Snelders, *supra* note 43, at 102–04.

⁸⁰ HARTMANN, *supra* note 34, at 13.

⁸¹ Jackson, *supra* note 36, at 48 (“Most ominous in the early pattern of misuse was the

the drugs were also widely used by adults going about their daily lives in socially responsible ways.⁸² It was considered appropriate and understandable for people to take the edge off the strain they felt. Demand resulted in so much legal and illegal production that barbiturates could be obtained more cheaply than marijuana or opiates.⁸³ Certainly, the first barbiturates, such as Veronal, were cheaper than psychoanalysis, the fashionable so-called “talking cure.”⁸⁴

Production levels of barbiturates were high from the very beginning.⁸⁵ Greatest production volume increases seem to have begun in the 1930s, continued through the 1940s and 1950s when wartime and post-war uses of barbiturates soared, and waned slowly thereafter as benzodiazepines, such as Valium, became more popular and more commonly prescribed.⁸⁶ By 1936, it is estimated that 70 tons (140,000 pounds) of barbiturates were sold, an increase of 400% from 1933.⁸⁷ During the period of 1941–1947, annual barbiturate production in America increased tremendously from 531,000 pounds in 1941 to 900,000 pounds in 1947.⁸⁸ Annual production declined slightly after that high point, seem-

appearance in the 1930's of abuse among youths and young adults. In the last years of that decade there were numerous reports of teenagers employing barbiturates for intoxicating purposes. The federal Food and Drug Administration also accumulated records of ‘an unbelievably large number of traffic accidents’ which that organization attributed to youthful barbiturate misuse.” (footnote omitted); In 1972, two doctors published an article in which they claimed that the dominant choice of psychoactive drugs had shifted in the direction of heroin and barbiturates and that initial experimentation, “episodic intoxication” with drugs, and intravenous barbiturate use was occurring among younger people. Donald R. Wesson & David E. Smith, *The Downer Hearings: A Current Perspective on the Politics of Barbiturates in America*, 5 J. PSYCHEDELIC DRUGS 45, 46–47 (1972).

⁸² Jackson, *supra* note 36, at 55.

⁸³ TONE, *supra* note 34, at 26.

⁸⁴ In her book, *The Age of Anxiety*, Andrea Tone writes that “the real issue that faced those struggling with debilitating worries, insomnia, and phobias was the cost and limited availability of professional [psychoanalytic] treatment.” *Id.* at 20. Medication substituted for the “talking cure.” Tone writes,

In the early 1930s, low-income clinics in Berlin, Vienna, and London admitted those who seriously needed analysis but could not pay for treatment. There was no equivalent in the United States; across the board, American psychoanalysts charged between \$10 and \$50 an hour in the 1930s. Together with certain ingrained biases against the profession, time and money kept most anxious patients out of analysts’ offices. The talking cure was either culturally foreign or priced beyond reach, a privilege of the affluent rather than the birthright of all.

Id. Tone calls barbiturates “a poor man’s alternative to psychoanalysis.” *Id.* at 22.

⁸⁵ See TONE, *supra* note 34, at 23.

⁸⁶ López-Muñoz et al., *supra* note 34, at 338 (“It was during the 1930s and 1940s that barbiturates attained their greatest popularity and were most widely used . . .”).

⁸⁷ *Id.*

⁸⁸ Jackson, *supra* note 36, at 50.

ingly due to decreased exportation to other countries,⁸⁹ but use in the United States remained strong.⁹⁰ In 1957, annual barbiturate production was estimated at 864,000 pounds,⁹¹ “enough to provide ten million adults with a sleeping tablet every night of the year.”⁹² Barbiturate consumption remained strong even after the introduction of Valium in 1963.⁹³ Unfortunately, usage was heavy not only *despite* its reputation for killing people but *because* of it. Barbiturate poisoning was a preferred suicide method and was second only to carbon monoxide gas.⁹⁴

Producers made it easy for consumers to have access to barbiturates, and consumers received mixed messages about the hazards of barbiturates. For example, there were reports of celebrities’ dangerous misuse of barbiturates from the time that Veronal was in use to the late 1990s.⁹⁵ Yet medical opinion consistently differed as to safety assessments of barbiturates.⁹⁶ In addition to mixed signals about the safety of barbiturates, reasons for high levels of barbiturate consumption de-

⁸⁹ *Id.*

⁹⁰ López-Muñoz et al. state that the peak of barbiturate use was during the 1950s. López-Muñoz et al., *supra* note 34, at 340.

⁹¹ Joseph F. Sadusk, Jr., *Size and Extent of the Problem*, 196 JAMA 707, 708 (1966).

⁹² Jackson, *supra* note 36, at 53.

⁹³ Cozantitis, *supra* note 38, at 596.

⁹⁴ *Id.*; Jackson, *supra* note 36, at 53.

⁹⁵ Celebrity use and misuse was reported in the press from the beginning. For instance, Marcel Proust reportedly took an entire box of Veronal in combination with allobarbitol and opium and lived to write about how awful the experience was. SHORTER, *supra* note 41, at 21. According to Shorter, Veronal was so associated with suicide that Bayer thought about asking playwright Arthur Schnitzler not to have his protagonists commit suicide with it. *Id.* at 21–22. In addition to news about misuse of barbiturates, there was also a popular book published in 1922 called *The Black Candle*, which described barbiturates as risky as opiates. Pieters & Snelders, *supra* note 43, at 98.

Similarly, over the course of the history of barbiturate use in the United States, barbiturates have been implicated in the deaths of several celebrities, including Marilyn Monroe, Judy Garland, and Elvis Presley, among others. *See, e.g.*, TONE, *supra* note 34, at 161.

Barbiturates mixed with alcohol are what caused rock star Jimi Hendrix to pass out, choke and die. They also claimed the lives of actress Marilyn Monroe, radical guru Abbie Hoffman, American Conservatory Theater founder William Ball and Jeanine Deckers, the ‘Singing Nun,’ who killed herself with 150 pills and a shot of cognac. Karen Ann Quinlan, the New Jersey teen whose years in limbo between life and death launched the right-to-die movement, suffered major brain damage after mixing alcohol and barbiturates at a party.

Krieger, *supra* note 74. Edward Shorter reports that statistically, barbiturates did have a higher suicide rate than other drugs used for similar purposes, although statistical analysis of suicide is difficult. And yet, the use of barbiturates for suicide may not be considered high relative to how many people were taking it for a variety of purposes and due to the relative ease of obtaining it. SHORTER, *supra* note 41, at 22.

⁹⁶ SHORTER, *supra* note 41, at 22–23; Jackson, *supra* note 36, at 48–50.

scribed in more detail below include society-wide familiarity with the drug, its utilization in concert with amphetamines to manage sleep without sacrificing alertness the next day, wartime government's encouragement of barbiturate use among military personnel, the prevalence of pharmaceutical combinations of barbiturates and other chemicals to address a wide range of health problems, and the public's ease of access to barbiturates even without a medical prescription. Consumption remained high until negative reports and opinions about barbiturates finally reached a crescendo in the 1960s, which coincided with pharmaceutical companies' introduction and marketing of benzodiazepines.⁹⁷

Sixty years of barbiturate use occurred between 1903 when Veronal entered the marketplace and 1963 when Valium, a wildly successful benzodiazepine, was introduced.⁹⁸ During those sixty years, consumers in all parts of society had become familiar with barbiturates and tailored their use to their specific needs.⁹⁹ For instance, some opiate drug abusers were using barbiturates to tide themselves over when opiates were not readily available,¹⁰⁰ while "upstanding citizens" were using it to get "a good night's sleep." Perhaps consumers placed barbiturates into the category of the "devil you know;" they had considerable familiarity with the drug through individual use and knowledge of others' use. Particularly after amphetamines (stimulants) were introduced in 1932,¹⁰¹ some consumers learned to become "Ping-Pong" users.¹⁰² They were the housewife or businessman who used barbiturates to fall asleep and amphetamines to address the next morning's barbiturate hangover.¹⁰³ Barbiturate/amphetamine combinations were also used to create euphoria or well-being not experienced when only one of the drugs was used.¹⁰⁴

This relationship between barbiturates and amphetamines was also useful in World War II military situations.¹⁰⁵ The military provided am-

⁹⁷ SHORTER, *supra* note 41, at 22–23. Pieters and Snelders suggest that medical opinion began to coalesce around a negative view of barbiturates at about this time: "Whereas in 1956 there was still divided opinion among medical experts as to the addictive, habit-forming and abuse potentialities of barbiturates, a decade later there was worldwide consensus about their status as drugs of dependence and abuse." Pieters & Snelders, *supra* note 43, at 101.

⁹⁸ SHORTER, *supra* note 41, at 19, 98.

⁹⁹ TONE, *supra* note 34, at 25.

¹⁰⁰ *Id.* at 26.

¹⁰¹ Jackson, *supra* note 36, at 47.

¹⁰² *Id.* at 55.

¹⁰³ *Id.*

¹⁰⁴ Pieters & Snelders, *supra* note 43, at 100. Edward Shorter reports that other barbiturate combinations with other drugs were also frequently used. SHORTER, *supra* note 41, at 31–33.

¹⁰⁵ Jackson, *supra* note 36, at 49.

phetamines to facilitate endurance,¹⁰⁶ and barbiturates were provided for a number of purposes, such as relief of combat fatigue, treatment of traumatic memories, and to provide relief from pain while dying.¹⁰⁷ Many Americans learned of the utility of barbiturates from accounts of its use in military contexts,¹⁰⁸ and many military personnel were barbiturate/amphetamine-experienced and continued to use those drugs as they re-entered civilian life.¹⁰⁹

The foregoing has focused on the relationship between barbiturate and amphetamine use as a partial explanation for the extensive use of barbiturates, but that combination was not the only one in use. Historian Edward Shorter contends that pharmaceutical preparations of barbiturate combinations with other drugs were the reason that “barbiturates worked their way by 1950 into almost every corner of American therapeutics.”¹¹⁰ Examples he gives are of pharmaceutical companies’ combinations of phenobarbital plus other chemicals for irritable bowel syndrome and pediatric elixirs.¹¹¹

Finally, ease of access was a very large factor in the initial development of the market and its continuity even after prescriptions were required and even after doctors had turned primarily to other drugs.¹¹² One aspect of access to barbiturates was the volume of production discussed above.¹¹³ Another was an active non-medical market in barbiturates; an estimated 50% of all barbiturates produced were available through non-medical channels after diversion from the manufacturer.¹¹⁴ In addition,

¹⁰⁶ *Id.*

¹⁰⁷ TONE, *supra* note 36, at 23; Jackson, *supra* note 36, at 50.

¹⁰⁸ TONE, *supra* note 36, at 23–24.

¹⁰⁹ See Jackson, *supra* note 36, at 49–50; Pieters & Snelders, *supra* note 43, at 99–100.

¹¹⁰ SHORTER, *supra* note 41, at 21.

¹¹¹ *Id.* at 21.

¹¹² Jackson, *supra* note 36, at 50.

¹¹³ *Id.*

¹¹⁴ *Id.* Sadusk describes several different types of diversion that existed in 1966. Sadusk, *supra* note 91, at 707–08.

At the hearings [of the Senate Subcommittee to Investigate Juvenile Delinquency, with a focus on barbiturate abuse], ex-addicts and many professionals testified that most barbiturates used by addicts are manufactured in this country by legitimate drug companies. The “pills” then reach the black market by being diverted in bulk quantities to Mexico, where they are repackaged and smuggled back into the United States.

Other sources by which barbiturates may reach the black market are from robberies of drug warehouses, physicians’ offices, and private homes. Some black market barbiturates come through careless, misinformed, or unethical prescribing by physicians or through unethical dispensing by pharmacists.

Wesson & Smith, *supra* note 81, at 47.

barbiturates were manufactured from diverted shipments of chemicals that were originally intended for industrial applications.¹¹⁵ Veronal might have been a drug of affluence initially, but barbiturate production increased to the point that pricing fell to easily affordable levels and remained low for decades.¹¹⁶

B. Regulation

Three years after the introduction of Veronal, the Federal Food and Drugs Act of 1906¹¹⁷ was enacted. Unlike chemicals in its predecessor drugs, the chemical foundation of Veronal, barbituric acid, escaped identification as a dangerous chemical requiring label warnings¹¹⁸ and was not added to the list of dangerous drugs until 1951.¹¹⁹ The fact that chemicals in Veronal's predecessors were included in that list while the active chemical in Veronal (barbituric acid) was not, suggests that Veronal was viewed by regulators as well as doctors as comparatively safe, at least in 1906.

Beginning in 1926, access to barbiturates was increasingly regulated for safety reasons in countries outside the United States,¹²⁰ but until the 1940s, in most of the United States, people could obtain barbiturates "over-the-counter" without consulting a physician to advise them about barbiturates' uses and risks.¹²¹ Public officials had reason to believe that barbiturates posed significant health and safety risks,¹²² but they were

¹¹⁵ Sadusk, *supra* note 91, at 707.

¹¹⁶ TONE, *supra* note 34, at 26 ("Increased production and competition caused a rapid and dramatic price drop putting barbiturates within the reach of even the less affluent. By the 1940s, barbiturates cost about fifteen cents per capsule and by 1950, about a dollar a dozen.").

¹¹⁷ Pub. L. No. 59-384, 34 Stat. 768 (1906) (repealed 1938).

¹¹⁸ *See id.* § 8, 34 Stat. at 770 (The chemicals deemed dangerous at that time were "alcohol, morphine, opium, cocaine, heroin, alpha or beta eucaine, chloroform, cannabis indica, chloral hydrate, acetanilide, or any derivative or preparation of any such substances contained therein.").

¹¹⁹ *See* Charles Wesley Dunn, *The New Prescription Drug Law*, 6 FOOD DRUG COSM. L.J. 951, 961 (1951).

¹²⁰ Pieters & Snelders, *supra* note 43, at 98.

¹²¹ Thomas R. Blair, *Barbiturates*, in CULTURAL SOCIOLOGY OF MENTAL ILLNESS: AN A-TO-Z GUIDE 76 (Andrew Scull ed. 2014) ("In 1950, a single dose of a barbiturate cost about 10 cents, and, in many states, could be obtained without a prescription."); *see also*, Jackson, *supra* note 36, at 48 ("Legislative efforts to combat abuse of both drugs quickened in the 1940's, though the controls developed were never adequate. By 1945 thirty-five states and possessions had passed legislation restricting the sale of barbiturates or amphetamines or both." (footnote omitted)).

¹²² Cozanitis, *supra* note 38, at 596.

From 1928 to 1937, of just over one million hospital admissions from ten centres,

relatively slow to address those risks, perhaps because drug regulation was not yet highly developed as a concept or priority and medical opinion on the safety of barbiturates was mixed.¹²³

State and local governmental regulation of access to barbiturates preceded federal regulation in the United States.¹²⁴ In 1922, New York City became the first municipal government to require a prescription for barbiturates, but pharmacists outside of New York City could dispense barbiturates without prescription until 1939.¹²⁵ In 1929, California became the first state to enact a law to regulate distribution and sale of barbiturates, yet barbiturates could still be easily obtained in nearby states.¹²⁶ Non-medically-prescribed-drug access proliferated through diversion of the manufactured drug and through interstate commerce, such as the sales of barbiturate tablets at truck stops.¹²⁷ More and more states placed restrictions on barbiturate access such that by 1945 thirty-five states had made barbiturates prescription-only drugs.¹²⁸

Even as different states and municipalities enacted prescription-only dispensing requirements, barbiturates continued to be available without prescription due to legal loopholes¹²⁹ and an active black market.¹³⁰ Based on safety concerns, production levels perceived as exces-

143,000 were in consequence of barbiturate intoxication; the corresponding figure from 1940 to 1945 was 200,000. New York City hospitals were reporting that one death every 36 hours was related to barbiturate misuse or abuse. The number of suicides involving barbiturates was second only to that resulting from carbon monoxide poisoning. Warnings were sounded by medical and pharmaceutical associations but they fell on deaf ears. . . . The American legislative process for barbiturate control was posing difficulties.

Id.

¹²³ See, e.g., SHORTER, *supra* note 41, at 22–23.

¹²⁴ TONE, *supra* note 34, at 22.

¹²⁵ *Id.*

¹²⁶ López-Muñoz et al., *supra* note 34, at 338.

¹²⁷ TONE, *supra* note 34, at 26.

¹²⁸ Jackson, *supra* note 36, at 48.

¹²⁹ *Id.* at 51 (“While most states had dangerous-drug laws restricting barbiturates and amphetamines to prescription sales, by the end of the 40’s at least, few had any restriction on refills.”); *id.* at 53 (“The nature of the distribution system [of barbiturates] remained the same as in the 1940’s except that bootleg operations increased through the decade while non-prescription sales declined. In part, this was the consequence of a weakness in the 1951 Durham-Humphrey Amendment, which made it easier to prosecute offenders in retail outlets than those involved in the larger bootleg traffic.”); *id.* at 54 (“While most state statutes covered sale of barbiturates and amphetamines many laws did not apply to mere possession. As late as 1960 Detroit police, for lack of such a law, were forced to release two truck drivers found to possess 5,000 amphetamine tablets.”).

¹³⁰ Cozantitis, *supra* note 38, at 596; Charles Grutzner, *Grave Peril Seen In Sleeping Pills: Medical Studies Show Effect of Excessive Use Is Worse Than That of Narcotics*, N.Y. TIMES,

sive, extent of interstate trafficking, and predicted likelihood that chronic users of barbiturates would become drug addicts, the United States put federal restrictions in place in 1951.¹³¹ The law designated barbiturates as prescription-only drugs, required labeling to that effect, provided that pharmacists' refilling prescriptions on an unauthorized basis was tantamount to selling illegal drugs,¹³² and criminalized possession without a prescription.¹³³

The imposition of increased regulation did little to slow consumption. In 1953, the Food and Drug Administration's Associate Commissioner John L. Harvey said, "The illegal sale of barbiturates is probably our number one regulatory problem in the drug field, with the illegal sale of amphetamines as runner-up."¹³⁴ In 1961, the FDA was concerned enough to devote 75 person-years to illegal prescription drug sales, most

Dec. 16, 1951, at 1; Jackson, *supra* note 36, at 48 ("In parallel fashion illicit abuse of [barbiturates and amphetamines] increased roughly in proportion to the volume of so-called legitimate use, though that growth would continue even when medical need began to level off."); *id.* at 50 ("A 1951 estimate was that half the sleeping capsules produced in the country were diverted into illicit ends. . . . A second means of distribution was through irresponsible druggists who knowingly sold these and other drugs illegally without prescriptions."). Jackson also describes physicians who prescribed drugs without regard to risks and pharmacists who filled the prescriptions, relying on the legality of doing so because the prescription was written by a physician. *Id.* at 51; *see also* TONE, *supra* note 34, at 22 (reporting the case of a pharmacist who filled a prescription for 6 Veronal capsules ninety-six times without the physician's awareness).

¹³¹ Grutzner, *supra* note 130, at 54; Dunn, *supra* note 119, at 960–61.

¹³² Durham-Humphrey Amendment, Pub. L. No. 82-215, 65 Stat. 648 (1951). The new law was not wholly new; it was an amendment to Section 503(b) of the Food, Drug, and Cosmetic Act of 1938, which was criticized by pharmacists as "disturbing the traditional physician-pharmacist-patient relationship." John P. Swann, *FDA and the Practice of Pharmacy: Prescription Drug Regulation Before the Durham-Humphrey Amendment of 1951*, 36 PHARMACY HIST. 55, 55 (1994) (internal quotation marks omitted). According to Swann, an historian for the FDA, "from the FDA's standpoint, there were more than a few instances in which pharmacists destroyed lives and families, exceeding the bounds of ethics and law by refilling, sometimes incessantly, prescriptions for potent and dangerous drugs such as barbiturates, amphetamines, and sulfa drugs." *Id.*

There were also amendments to other Sections. Barbituric acid was added to the list of habit-forming drugs in Section 502(b) to which the strictest labeling, manufacturing, and dispensing rules applied. The law and its implications are described at length by Charles Wesley Dunn in an address delivered at the Midyear Meeting of the American Pharmaceutical Manufacturers' Association on November 26, 1951. The law was enacted in October of 1951 and took effect in April of 1952. *See* Dunn, *supra* note 119, at 951–69. In that same month, the *New York Times* published a front page story describing the law and reporting a medical doctor as saying that "addiction to sleeping pills is far more dangerous to the patient and to society than is heroin addiction." Grutzner, *supra* note 130, at 54.

¹³³ Grutzner, *supra* note 130, at 54.

¹³⁴ Jackson, *supra* note 36, at 53.

of it to barbiturates and amphetamines,¹³⁵ and in 1965, Dr. Sadusk of the FDA spoke to the General Scientific Assembly at the American Medical Association meetings about continuing severe problems in curtailing illicit traffic in barbiturates.¹³⁶

In 1965, Congress enacted the Drug Abuse Control Amendments Act.¹³⁷ The law was designed to control illegal distribution of several drugs, including barbiturates, and a Bureau of Drug Abuse Control was the primary vehicle for enforcement.¹³⁸ It lasted for only two years before its functions were transferred to the Bureau of Narcotics and Dangerous Drugs within the Department of Justice.¹³⁹ Then, in 1972, barbiturates were placed on Schedule II under the Controlled Substances Act, which is the designation for drugs highly susceptible of abuse, such as narcotics and methamphetamine.¹⁴⁰ Writing and filling prescriptions for these “Schedule II” drugs is more burdensome for physicians and difficult to justify when they could easily prescribe other, reputedly safer, drugs.¹⁴¹

Historian Edward Shorter contends that “[t]his was essentially the end of the barbiturates in the North American world for any purpose save prescribing phenobarbital for epilepsy.”¹⁴² Increased legal regulation by itself, however, does not fully explain why sodium pentobarbital and secobarbital are so scarce. The history of barbiturates contains conflicting perspectives on the drugs’ continued utility when newer drugs were developed and exacerbated already divided medical opinions about the drugs’ risks of tolerance, addiction, and abuse.¹⁴³ Indeed, from some points of view, barbiturates are simply the victims of cycles of enthusiasm for new drugs followed by disillusionment borne of experiences revealing deficiencies in the drugs and adoption of newer drugs not neces-

¹³⁵ *Id.* at 54.

¹³⁶ Sadusk, *supra* note 91, at 707–09.

¹³⁷ Pub. L. No. 89-74, 79 Stat. 226 (1965).

¹³⁸ Swann, *supra* note 132, at 66.

¹³⁹ *Id.* at 66–67.

¹⁴⁰ SHORTER, *supra* note 41, at 23–24.

¹⁴¹ *See, e.g.*, 21 U.S.C. § 829 (2012) (providing differing prescription requirements for Schedule II, III, IV, and V substances); JOSEPH T. RANNAZZISI & MARK W. CAVERLY, U.S. DEP’T OF JUSTICE, DRUG ENF’T ADMIN., OFFICE OF DIVERSION CONTROL, PRACTITIONER’S MANUAL § 5 (2006), http://www.deadiversion.usdoj.gov/pubs/manuals/pract/pract_manual012508.pdf; *Questions & Answers: Issuance of Multiple Prescriptions for Schedule II Controlled Substances*, U.S. DEP’T JUST., http://www.deadiversion.usdoj.gov/faq/mult_rx_faq.htm (last visited Feb. 9, 2016).

¹⁴² SHORTER, *supra* note 41, at 24.

¹⁴³ *See, e.g.*, Jackson, *supra* note 36, at 54.

sarily better than the drugs they replaced.¹⁴⁴

C. *From the Past into the Present*

How did American society go from huge demand and supplies of barbiturates to the current situation of insufficient supplies for aid-in-dying statutory purposes? In 1966, there were 10 manufacturers of basic barbiturates in the United States,¹⁴⁵ but now in the United States there are no manufacturers of sodium pentobarbital powder approved for use in humans or of secobarbital, the two ideal barbiturates for patient utilization of aid-in-dying statutes. The last company in the United States to produce secobarbital (under the trade name Seconal) was Marathon Pharmacy, which sold its legal interests in the drug to the Canadian manufacturer Valeant in 2015.¹⁴⁶ Secobarbital (Seconal) is still available in the United States but at a price of \$3,000 to \$5,000 for a lethal dose.¹⁴⁷ Like secobarbital, sodium pentobarbital is still available but only at an extremely high price and only in liquid form, which, depending on the circumstances, may not have the desired shelf-life of the powder form.¹⁴⁸ Other barbiturates, such as phenobarbital, still exist but are longer-acting and, therefore, slower to take effect and to reach peak blood levels necessary for death to occur promptly as a result of a reasonably sized dose.¹⁴⁹

¹⁴⁴ Pieters and Snelders deploy German psychiatrist Max Seige's observation that psychoactive drugs have "career" cycles to consider the enthusiastic adoption of barbiturates, the emergence of concerns about side effects and safety risks, and the development of benzodiazepines. The latter, too, give rise to concerns about side effects and are ripe for replacement. Pieters & Snelders, *supra* note 43, at 95–99. Edward Shorter takes this view even further, arguing that we have misread the record on actual risk and, in so doing, have lost efficacious drugs, such as short-acting barbiturates, in favor of drugs that do not perform as well. SHORTER, *supra* note 41, at 24, 33.

¹⁴⁵ Sadusk, *supra* note 91, at 707.

¹⁴⁶ *Marathon Pharmaceuticals, LLC Divests Non-Strategic Products to Focus Exclusively on Rare Disease Treatments*, MARATHON PHARMACEUTICALS (Feb. 10, 2015) [hereinafter *Marathon Pharmaceuticals*], <http://marathonpharma.com/news/2015/02/marathon-pharmaceuticals-llc-divests-non-strategic-products-focus-exclusively-rare-disease-treatments/>.

¹⁴⁷ See Leonard, *supra* note 20; *FAQs*, *supra* note 24.

¹⁴⁸ *FAQs*, *supra* note 24 (regarding the current price of liquid sodium pentobarbital). The longer stable shelf-life of powdered sodium pentobarbital is preferable because an individual can lawfully obtain the lethal dose long before s/he may decide to actually use it.

¹⁴⁹ See sources cited *supra* note 38. Relative lethality of barbiturates is reported by Smith and Wesson, *supra* note 38, at 9. They identify phenobarbital as a long-acting barbiturate and secobarbital and pentobarbital as short-acting barbiturates. This classification system of ultra-short to long-acting refers to length of time to reach peak blood levels. *Id.* at 5. See also Fisher, *supra* note 38, at 395.

The short answer to the decline in barbiturate availability is that Americans have moved on to reliance on other drugs that they believe—accurately or not—are safer and serve the same purposes.¹⁵⁰ Americans ask for, and doctors prescribe drugs more specifically designed to alleviate depression or anxiety¹⁵¹ instead of prescribing barbiturates, which were once broadly prescribed for various conditions.¹⁵² The barbiturate/amphetamine relationship has also been replaced. One no longer need use a relatively non-specific drug such as barbiturates for sleep when more specific non-barbiturate drugs, such as Ambien and Lunesta, became available.¹⁵³ The military has also moved on from barbiturate/amphetamine use to newer classes of drugs, such as antidepressant drugs.¹⁵⁴ Finally, it stands to reason that doctors are no longer trained in medical school to prescribe barbiturates for the purposes for which they were prescribed most frequently prior to 1963 and that pharmaceutical companies now promote newer classes of drugs. Medical science has moved on, leaving drugs such as sodium pentobarbital in place primarily, if not exclusively, for situations for which no other drug is as effective, such as certain types of epilepsy that require in-hospital intravenous administration.¹⁵⁵

It is tempting, but impossible, to ascribe initial loss of sodium pentobarbital and secobarbital availability in the United States to the efforts

¹⁵⁰ For instance, non-barbiturate, benzodiazepine antidepressant drugs were increasingly prescribed for insomnia instead of barbiturates. Wysowski & Baum, *supra* note 44, at 1781–82. They report that barbiturates continued to be the drug of choice for suicide even after antidepressant drugs were more frequently prescribed, noting that psychiatrists were less likely than other medical specialists to prescribe barbiturates. *Id.* at 1782–83. Only after availability of highly lethal barbiturates became quite limited did antidepressants become utilized more frequently for suicide.

¹⁵¹ See, e.g., *What Drugs Are Used to Treat Depression?*, WEBMD, <http://www.webmd.com/mental-health/medications-treat-mental-disorders> (last visited Feb. 8, 2016).

¹⁵² SHORTER, *supra* note 41, at 20, 151; López-Muñoz et al., *supra* note 35, at 341 (“The barbiturates introduced clinically one century ago were the first pharmacological agents to have demonstrated—in an historical period that was therapeutically inhospitable—a real efficacy in different neuropsychiatric disorders.”).

¹⁵³ Martha Rosenberg, *Why Ambien and Other Sleeping Aids Are Very Dangerous and May Need to Be Off the Market*, ALTERNET (Sept. 10, 2014), <http://www.alternet.org/drugs/why-ambien-and-other-sleeping-aids-are-very-dangerous-and-may-need-be-market>.

¹⁵⁴ See, e.g., Mark Thompson, *America’s Medicated Army*, TIME (June 5, 2008), <http://content.time.com/time/magazine/article/0,9171,1812055,00.html>.

¹⁵⁵ See, e.g., Frank W. Drislane, *Convulsive Status Epilepticus in Adults: Treatment and Prognosis*, UPTODATE (last updated Feb. 22, 2016), <http://www.uptodate.com/contents/convulsive-status-epilepticus-in-adults-treatment-and-prognosis>.

of death penalty opponents who applied pressure on manufacturers in Europe and the United States to stop the manufacture and sale of drugs ideal for death penalty execution purposes.¹⁵⁶ Lethal injection began in the United States only in 1982,¹⁵⁷ after production and sales of all types of barbiturates had already declined significantly. Moreover, until 2009 a different barbiturate, sodium thiopental (“thiopental”), was used in most state execution protocols.¹⁵⁸

Even though death penalty opposition did not have much to do with the initial decrease in availability of sodium pentobarbital in the United States, it has surely had an adverse impact on the ability to obtain it for aid-in-dying purposes from European companies now that it is no longer made in the United States. When death penalty opponents applied sufficient pressure to reduce thiopental production, states began using sodium pentobarbital in 2010.¹⁵⁹ Accordingly, death penalty opponents have applied similar pressure on manufacturers and distributors to prevent the use of sodium pentobarbital for death penalty executions.¹⁶⁰ Sodium pentobarbital is still available at a reasonable price in Europe, where there are few concerns about diversion for death penalty uses.¹⁶¹ European manufacturers could limit sales in the United States to aid-in-dying purposes, but, so far, only extremely expensive sterile injectable liquid sodium pentobarbital is available.¹⁶² In the next Part, I consider alternative means of addressing the gap in availability of ideal drugs for this purpose of using aid-in-dying statutes.

III. SOURCING POSSIBILITIES

Sodium pentobarbital is not currently widely available for human use in the United States, but it is widely available for veterinary uses, such as euthanizing animals.¹⁶³ Veterinary sodium pentobarbital cannot

¹⁵⁶ Pilkington, *supra* note 32. The concept was approved in 1977; Texas, in 1982, was the first state to use the drug protocol approved for use in executions: the Chapman Protocol. Romanelli et al., *supra* note 16, at 1430.

¹⁵⁷ Romanelli et al., *supra* note 16, at 1430.

¹⁵⁸ *State by State Lethal Injection*, DEATH PENALTY INFO. CTR., <http://www.deathpenaltyinfo.org/state-lethal-injection> (last visited Apr. 12, 2016).

¹⁵⁹ *Id.*; see also Coyne, *supra* note 32; Pilkington, *supra* note 32.

¹⁶⁰ See *infra* notes 186–189 and accompanying text.

¹⁶¹ The only European country with the death penalty is Belarus. See *The Death Penalty in Belarus*, DEATH PENALTY WORLDWIDE (Sept. 20, 2013), <http://www.deathpenaltyworldwide.org/country-search-post.cfm?country=Belarus>.

¹⁶² Leonard, *supra* note 20; *FAQs*, *supra* note 24.

¹⁶³ As in humans, it is used in-hospital to treat a severe type of epileptic seizures. *Pentobarbital (Nembutal Sodium)*, PETEDUCATION.COM,

be used in humans, even if the purpose is to hasten death, because federal law prohibits prescribing any veterinary drug for use in a human.¹⁶⁴ If this rule were exclusively an FDA rule, it might have been possible to petition for an exemption for its usage in aid-in-dying contexts. The odds of success would have been quite low, however, since the FDA would be unlikely to make such an exception, especially for controversial use in hastening death. As it is, the rule is a congressionally enacted statute. Therefore, any change, including an exception carved out for aid-in-dying purposes, would require statutory enactment or amendment by Congress. While theoretically possible, given the controversial nature of autonomy in end-of-life decisions and two U.S. Supreme Court opinions finding no federal constitutional right to physician-assisted death,¹⁶⁵ it is unlikely that Congress would approve such an exception at this time. Since use of veterinary sodium pentobarbital in humans is prohibited, this Part explores other sourcing options: encouraging former and current manufacturers of sodium pentobarbital and/or secobarbital to continue production at affordable pricing for aid-in-dying purposes, relying on compounding pharmacies to import the raw materials for production, and importing the manufactured drugs.

As discussed in the previous Part, corporate decisions to produce barbiturates have been intertwined with the history of barbiturate prescriptions and death penalty opposition. Pharmaceutical companies encouraged doctors to prescribe barbiturates when first developed, but the interests of pharmaceutical companies, physicians, and dispensing pharmacies aligned in the direction of reduced manufacture and prescription once the apparently much safer benzodiazepines were developed, the extent of abuse and lethality of barbiturates was extensively documented, and it became burdensome to prescribe barbiturates even for those patients for whom they might be ideal because of heightened regulatory requirements. These changes occurred before the use of barbiturates in lethal injection death penalty protocols, but death penalty opposition is definitely a factor in current availability. Oppositional advocacy has affected corporate willingness to manufacture ideal short-acting

<http://www.peteducation.com/article.cfm?c=26+1303&aid=1455> (last visited Apr. 12, 2016). It is also used for euthanasia of animals. It is listed as on-label for dogs but is widely used on other animals as well. *Euthasol (pentobarbital sodium and phenytoin sodium) Solution*, VIRBAC, <http://www.virbacvet.com/products/detail/euthasol-solution> (last visited Feb. 8, 2016); *Euthanasia Guidelines*, U. MINN. - RES. ANIMAL RESOURCES, <https://www.ahc.umn.edu/rar/euthanasia.html> (last visited Feb. 8, 2016).

¹⁶⁴ 21 U.S.C. § 353(f)(1)(A) (2012).

¹⁶⁵ *Vacco v. Quill*, 521 U.S. 793 (1997); *Washington v. Glucksberg*, 521 U.S. 702 (1997).

barbiturates and increased the likelihood that importation for aid-in-dying purposes would not succeed.

Barbiturates are a part of the three-drug Chapman Protocol that has been used for execution by lethal injection since 1982.¹⁶⁶ As recently as 2009, however, most state protocols made use of the ultra-short acting barbiturate, thiopental, to induce unconsciousness.¹⁶⁷ The shift to pentobarbital for this purpose began to occur only when American manufacturers stopped manufacturing thiopental, apparently due to pressure from anti-death penalty advocates,¹⁶⁸ and importation of thiopental had also been successfully challenged.¹⁶⁹ Both of these have implications for current sourcing of short-acting barbiturates for aid-in-dying purposes.

State departments of corrections' attempts to import thiopental manufactured in Austria were successfully thwarted by a lawsuit against the FDA for failure to prevent importation of a drug not approved or reviewed for safety and efficacy¹⁷⁰ and imported from a manufacturer not registered with the FDA for the importation of the drug.¹⁷¹ Specifically in this case, the Court found that the FDA had never approved the safety and efficacy of thiopental, even when it was produced in the United States, and that importing an unapproved, highly dangerous drug from an unregistered company in a foreign country could not be justified by deference to law enforcement entities and the particular purpose for which those entities had ordered the thiopental.¹⁷² The FDA had argued that the uses intended by the states' departments of corrections fell outside the FDA's "public health role,"¹⁷³ presumably because the drug would be used by those law enforcement entities to lawfully kill people. The Court of Appeals for the District of Columbia affirmed these holdings, stating that the FDA may not use law enforcement entities' judgment or the specific intended use to justify failure to fulfill its non-discretionary mandate to keep unapproved drugs and drugs from unregistered sources from entering the United States.¹⁷⁴

For two reasons, this case of unlawful importation of an unapproved drug for death penalty purposes portends difficulty with import-

¹⁶⁶ Romanelli et al., *supra* note 16, at 1430.

¹⁶⁷ *Id.*

¹⁶⁸ Coyne, *supra* note 32; Pilkington, *supra* note 32.

¹⁶⁹ *Beatty v. FDA*, 853 F. Supp. 2d 30 (D.D.C. 2012).

¹⁷⁰ *Id.* at 36–43.

¹⁷¹ *Id.* at 34–35.

¹⁷² *Id.*

¹⁷³ *Beatty*, 853 F. Supp. 2d at 35.

¹⁷⁴ *Cook v. FDA*, 733 F.3d 1, 12 (D.C. Cir. 2013).

ing *or* manufacturing comparatively highly lethal (short-acting) barbiturates¹⁷⁵ for the purpose of assisting individuals in hastening death. One is that, like the intended use of thiopental for death penalty executions, sodium pentobarbital is an unapproved drug for the purpose of patient utilization of aid-in-dying statutes. That sodium pentobarbital was previously approved for some medical uses does not alter the fact that production of sodium pentobarbital for a new use would have to be approved through a new drug application procedure. Also, as emphasized in the *Beatty* decision, the FDA has a non-discretionary mandate to protect human health and safety, which does not yet appear to include approving drugs designed to hasten human death.¹⁷⁶

Although it might at first appear that approving medications ideal for hastening human death would conflict with the FDA's mission, it is possible to understand approval of such medications as falling squarely within the FDA's mission of protecting human health and safety. In the context of lawfully using aid-in-dying laws, it is a matter of safety as well as patient comfort that medications most appropriate for ending life quickly and easily be lawfully prescribable and readily available. A related way in which the FDA's mission can be interpreted to include approval of these drugs rests on an understanding of aid-in-dying laws as reducing the prevalence of individuals' attempts to commit suicide under circumstances that would be covered by aid-in-dying statutes.¹⁷⁷ Approving the best drugs for the purpose of patient utilization of aid-in-dying laws enhances the efficacy of statutes designed for that public purpose.

The FDA allows the manufacture, marketing, sale, and importation of drugs only if they have been proven safe and effective for the intended uses for which they will be prescribed.¹⁷⁸ If a manufacturer wants to expand the list of intended uses to include, say, hastening death, the manufacturer would have to submit a "new drug" application to the FDA. That is a requirement because the "newness" of a drug arises from "newness of use of such drug in diagnosing, curing, mitigating, treating,

¹⁷⁵ By "highly lethal" I mean short-acting barbiturates that reach peak blood levels quickly and whose lethal dose is relatively close to the top of the therapeutic range.

¹⁷⁶ *Beatty*, 853 F. Supp. 2d at 43.

¹⁷⁷ Ludwig A. Minelli, *Suicide Prevention Must Be Complemented by Suicide-Attempt-Prevention*, WORLD FED'N RIGHT-TO-DIE SOCIETIES 2012 CONGRESS, June 15, 2012, <http://www.dignitas.ch/images/stories/pdf/diginpublic/referat-wf-kongress-suizidversuche-e-15062012.pdf>.

¹⁷⁸ 21 U.S.C. §§ 321(p)(1) & 355 (2012); *see also, e.g.*, *United States v. 118/100 Tablet Bottles*, 662 F. Supp. 511 (W.D. La. 1987).

or preventing a disease, or to affect a structure of function of the body, even though such drug is not a new drug when used in another disease or to affect another structure or function of the body.”¹⁷⁹ A new drug application requires applicants to submit “full reports of investigations which have been made to show whether or not such drug is safe for use and whether such drug is effective in use.”¹⁸⁰

A new drug application to include the “intended use” of hastening death could be submitted with the position that this new drug would effectively “affect a structure or function of the body” for the purpose intended, or, arguably, “treat” or “mitigate” a condition affecting the function of the body. However, the FDA has not yet approved any drug whose purpose is to kill human beings, and it is difficult to imagine testing protocols, including human trials, that would meet the FDA’s current ethical and legal standards.¹⁸¹ If the FDA’s position in *Beatty* was that death penalty purposes were far removed from its public health role,¹⁸² it is questionable whether aid-in-dying purposes would fare much better, despite interpretive room in the FDA’s mission to protect and advance public health by “helping to speed innovations that make medicines more effective, safer, and more affordable[.]”¹⁸³

Once the FDA has approved a drug, its approved intended uses are “labeled uses,” and drug labels come with instructions and warnings regarding a drug’s labeled uses.¹⁸⁴ Physicians have legal latitude to prescribe drugs for off-label uses.¹⁸⁵ Manufacturers, however, do not have comparable latitude.¹⁸⁶ There would be considerable risk if manufactur-

¹⁷⁹ 21 C.F.R. § 310.3(h)(4) (2015).

¹⁸⁰ 21 U.S.C. § 355(b)(1).

¹⁸¹ Guidance provided by the FDA regarding safety reporting requirements for those seeking FDA drug approvals does not provide for submission of the type of data that could be obtained from public records of use of aid-in-dying statutes or logs of volunteers who assist those who hasten death in accordance with aid-in-dying statutes. See, e.g., U.S. DEP’T HEALTH & HUMAN SERVS., FDA, CTR. FOR DRUG EVALUATION & RES., GUIDANCE FOR INDUSTRY AND INVESTIGATORS: SAFETY REPORTING REQUIREMENTS FOR INDS AND BA/BE STUDIES (Dec. 2012), <http://www.fda.gov/downloads/Drugs/. . /Guidances/UCM227351.pdf>.

¹⁸² *Beatty v. FDA*, 853 F. Supp. 2d 30, 35 (D.D.C. 2012).

¹⁸³ *Statement of FDA Mission*, FDA, <http://www.fda.gov/downloads/aboutfda/reportsmanualsforms/reports/budgetreports/ucm298331.pdf> (last visited Feb. 17, 2016).

¹⁸⁴ See, e.g., James M. Beck & Elizabeth D. Azari, *FDA, Off-Label Use, and Informed Consent: Debunking Myths and Misconceptions*, 53 FOOD & DRUG L.J. 71, 76 (1998).

¹⁸⁵ See *id.* at 76–80.

¹⁸⁶ Federal law prohibits manufacturers from putting “misbranded” drugs into interstate commerce. 21 U.S.C. § 331(a) (2012). A drug is “misbranded” if its label does not provide adequate directions for consumer use. *Id.* § 352(f)(1). The FDA defines “adequate directions for use” as “directions under which the layman can use a drug safely and for the purposes for which it is intended.” 21 C.F.R. § 201.5 (2015). A drug prescribed for a use that is “off-label”

ers manufactured and marketed drugs *exclusively* for off-label uses because, by definition, those uses have not received FDA approval and would be unapproved “new drugs.”¹⁸⁷ As long as physicians are prescribing for on-label uses, the drug can be lawfully manufactured for both on-label and off-label uses, although there are limitations on manufacturer promotion of off-label uses.¹⁸⁸ If on-label use prescriptions completely disappear, however, manufacture *exclusively* for off-label use may well be deemed illegal under current statutes and regulations,¹⁸⁹ and it could easily become illegal even if it is not clearly illegal by interpretation of current statutes and regulations.¹⁹⁰

It is tempting to characterize aid-in-dying use of pentobarbital or secobarbital as an on-label use because barbiturates have already been approved for sedation, and hastening death with barbiturates could be

would not come with adequate “directions under which the layman can use [the] drug safely and for the purposes for which it is intended” because the intended uses were not approved.

¹⁸⁷ 21 U.S.C. §§ 321(p)(1), 355.

¹⁸⁸ What constitutes “promotion” of an off-label drug is in legal flux. On May 7, 2015, Amarin Pharma filed suit challenging the FDA’s refusal to allow Amarin to market its fish oil-derived drug for a use additional to the use approved by the FDA (an “off-label” use). *Amarin Pharma, Inc. v. FDA*, 119 F. Supp. 3d 196, 212–15 (S.D.N.Y. 2015). After a preliminary injunction protecting Amarin’s right to provide truthful and non-misleading information about the drug at issue in the lawsuit, Amarin and the FDA reached a settlement that includes both Amarin’s right to provide truthful and non-misleading information about the specific drug and a review procedure so that Amarin and the FDA can avoid or resolve disputes about what constitutes truthful and non-misleading information. Proposed Stipulation and Order of Settlement, *Amarin Pharma, Inc. v. FDA*, No. 15-3588 (S.D.N.Y. Mar. 8, 2016), ECF No. 84, <https://www.healthlawpolicymatters.com/wp-content/uploads/sites/8/2016/03/amarin-1.pdf>. This lawsuit follows a 2014 decision in which the Second Circuit held that a sales representative could not be convicted of conspiracy to put a misbranded drug into interstate commerce simply because the representative described off-label uses. *United States v. Caronia*, 703 F.3d 149 (2d Cir. 2012). Since *Caronia* was decided, there has been speculation about the extent to which the legal definition of “promotion” has shifted. *See, e.g.*, Kellie Combs & Albert Cacozza, *Drug Promotion in the Post-Caronia World*, UPDATE (Mar./Apr. 2013), <https://www.ropesgray.com/newsroom/alerts/2013/03/Drug-Promotion-in-the-Post-Caronia-World.aspx>; Thomas Sullivan, *U.S. v. Caronia, One Year Later: FDA’s Position on Off-Label Promotion Remains the Same, but Changes Are Looming*, POL’Y & MED. (Feb. 20, 2014), <http://www.policymed.com/2014/02/us-v-caronia-one-year-later-fdas-position-on-off-label-promotion-remains-the-same-but-changes-are-looming.html>.

¹⁸⁹ *See supra* note 186.

¹⁹⁰ *Caronia*, 703 F.3d at 168 (“[W]here off-label drug use is exceptionally concerning the government could prohibit the off-label use altogether.” (citing *United States v. Bader*, 678 F.3d 858, at 873–75 & n.10 (10th Cir. 2012) (proscribing off-label use of human growth hormone))). One legal analysis suggested alternative FDA responses to *Caronia*, such as putting in place “new restrictions or penalties that would prevent doctors from prescribing certain classes of products off-label” and that the FDA could “curb off-label prescribing, refusing to approve a drug unless the manufacturer agreed to seek certification from every prescribing physician that the drug will be used on-label.” Combs & Cacozza, *supra* note 188.

considered a form of terminal sedation. However, the approved intended uses of barbiturate prescriptions have never included hastening human death, and barbiturates have not been certified through FDA procedures as “safe” for that purpose. Barbiturate ingestion resulting in death is considered “overdosing” or “abuse;” barbiturate sedation is supposed to be temporary, not permanent. As long as short-acting barbiturate prescriptions are being written for on-label uses, such barbiturates can be lawfully produced even if prescriptions for these barbiturates are also written for off-label uses, such as hastening death in an aid-in-dying context. Thus, an important key to continued access to short-acting barbiturates for aid-in-dying purposes is that they are still being prescribed for on-label uses.

If short-acting barbiturates continued to be used by that subset of patients for whom such barbiturates are, even now, the most effective treatment,¹⁹¹ there might well be sufficient on-label use to stave off concerns about barbiturate manufacture devolving into the illegal production of off-label drugs. Under such circumstances, access to barbiturates for aid-in-dying use would not be at risk as long as manufacturers decided to produce them at all, although price considerations would not be addressed simply by assurance that production would continue. As discussed in Part II, however, barbiturate prescriptions have been declining for several decades now. Barbiturate prescriptions declined in proportion to increasing prescriptions for benzodiazepines, and other newer drugs have since replaced benzodiazepines.¹⁹² Pentobarbital was available in oral form for insomnia as recently as the early 2000s, but even by that time “the use of barbiturates [was] circumscribed to quite specific therapeutic applications.”¹⁹³ Currently, pentobarbital is available in the United States only in injectable form; it is labeled only for sedation and certain manifestations of severe epilepsy.¹⁹⁴ The latter is a condition requiring hospital inpatient intravenous administration.¹⁹⁵ It is also used off-label to induce barbiturate coma in patients with severe brain trauma, but this practice is somewhat controversial as it does not appear to improve clinical outcomes.¹⁹⁶

¹⁹¹ SHORTER, *supra* note 41, at 33.

¹⁹² *Id.* at 122–25.

¹⁹³ López-Muñoz et al., *supra* note 34, at 340.

¹⁹⁴ *Pentobarbital: Drug Information*, *supra* note 48.

¹⁹⁵ Drislane, *supra* note 155.

¹⁹⁶ *Pentobarbital: Drug Information*, *supra* note 48; Edward R. Smith & Sepideh Amin-Hanjani, *Evaluation and Management of Elevated Intracranial Pressure in Adults*, UPTODATE (last updated July 10, 2013), <http://www.uptodate.com/contents/evaluation-and->

Even if the challenges of off-label use are addressed, access could still be negatively affected by pricing. The current market for aid-in-dying purposes is quite small; few individuals use aid-in-dying statutes in the states where they exist, and few states currently have such statutes. The combination of liability exposure associated with making a drug so easily abused, few prescriptions written now that there are apparently safer medications, and prescription regulatory hurdles results in a market so small that a manufacturer such as Akorn can justifiably claim that sodium pentobarbital is a boutique drug whose high price of \$15,000 to \$25,000 is legitimate under current marketing and production circumstances.¹⁹⁷ Such pricing places sodium pentobarbital out of reach for the great majority of people seeking to use aid-in-dying statutes, and secobarbital pricing appears headed in the same direction.

Generic production seems unlikely. A generic equivalent was manufactured when the patent for pentobarbital expired in the 1930s,¹⁹⁸ but there is no generic manufacture in the United States now. Even with the relatively modest expense associated with a generic drug application (currently the fee alone is \$76,060 and a manufacturer would have to incur the expense of proving bioequivalence¹⁹⁹), it is difficult to imagine that a drug manufacturer would have sufficient incentive to engage in production of such a lethal drug with so few on-label medical applications. In light of safer alternatives and pentobarbital's high potential for abuse, it is even possible that the FDA would not approve an oral formulation now, as there is no need for the drug for its previous oral uses (anxiety and insomnia).

Some European pharmaceutical companies still manufacture sodium pentobarbital powder, which is available in Europe at reasonable cost for a variety of purposes, including assisted dying under circumstances similar to what is allowed under American aid-in-dying statutes.²⁰⁰ Due to continuing use of the death penalty in some states, how-

management-of-elevated-intracranial-pressure-in-adults; López-Muñoz et al., *supra* note 34, at 341.

¹⁹⁷ See, e.g., S. LOCHLANN JAIN, *MALIGNANT: HOW CANCER BECOMES US* 10 (2013) (“[T]he rise of a few ‘boutique’ drugs, in which extremely expensive drugs are profitable at the cost of excluding many from access.”).

¹⁹⁸ Mansley et al., *supra* note 78, at 5; see also Pieters & Snelders, *supra* note 43, at 98–99.

¹⁹⁹ *Abbreviated New Drug Application (ANDA) and Prior Approval Supplement (PAS) Fees*, FDA, <http://www.fda.gov/ForIndustry/UserFees/GenericDrugUserFees/ucm319568.htm> (last visited Feb. 22, 2016); see generally SHASHANK UPADHYE, *GENERIC PHARMACEUTICAL PATENT AND FDA LAW* §§ 7:10–7:54 (2014).

²⁰⁰ E-mail from Silvan Luley, Dir. DIGNITAS, to author (Mar. 19, 2015, 08:06 am PDT)

ever, no European company sells powder-based sodium pentobarbital in the United States. Death penalty opponents secured from those companies a pledge that their products would not be sold for death penalty purposes,²⁰¹ and an easy way to honor the pledge is to eliminate sales to the United States.

Lundbeck, a Danish company that subscribes to the pledge,²⁰² licensed its right to sell sterile injectable sodium pentobarbital (trade name Nembutal) in the United States to Akorn, which manufactures other sterile injectable pharmaceuticals at its manufacturing locations in New Jersey and Illinois.²⁰³ This form of sodium pentobarbital is not the most desirable for aid-in-dying purposes because of its price. The price, at \$15,000–\$25,000 per lethal dose,²⁰⁴ is a significant deterrent to its usage in aid-in-dying contexts. Moreover, the shelf-stable powder form of the drug is most appropriate for aid-in-dying purposes because there is no legal requirement that individuals use filled prescriptions within a set period of time, but it appears that Lundbeck retains the right to distribute the sodium pentobarbital powder it manufactures. So far, it appears that Lundbeck has declined to sell the encapsulated powder form in the United States either directly or through a licensing agreement, perhaps due to risk that the drug would be used for death penalty executions. Lundbeck, like other European companies that manufacture sodium pentobarbital, signed the pact forbidding sales of pharmaceuticals for such purposes.²⁰⁵ The pact is narrowly drawn such that those companies *could* sell sodium pentobarbital powder for aid-in-dying purposes,²⁰⁶ but those companies might well want to avoid further problems with death penalty opponents or problems from new opponents—those against aid-in-dying statutes.

Unlike sodium pentobarbital, secobarbital was produced in the United States until quite recently. Marathon Pharmacy sold its rights to

(on file with author).

²⁰¹ See, e.g., *Sign the Pharmaceutical Hippocratic Oath*, REPRIEVE (Mar. 26, 2012), http://reprise.webfactual.com/publiceducation/2012_03_26_pharma_hippocratic_oath/; *Ethical Statements from Pharmaceutical Firms*, REPRIEVE (May 29, 2014), http://reprise.webfactual.com/publiceducation/2012_03_26_ethical_statements/.

²⁰² *Pharma Firm Lundbeck Wins Ethical Award for Stopping Use of Drugs in Executions*, REPRIEVE (Mar. 29, 2012) [hereinafter *Lundbeck*], http://www.reprise.org.uk/press/2012_03_29_lundbeck_ethical_award/.

²⁰³ Press Release, Akorn, Inc., Akorn Acquires Three Hospital-Based Injectables from Lundbeck (Dec. 22, 2011) (available at http://www.akorn.com/dynamic/news_45.pdf).

²⁰⁴ *FAQs*, *supra* note 24, at 5.

²⁰⁵ *Lundbeck*, *supra* note 202.

²⁰⁶ See, e.g., *id.* (noting that “now only legitimate medical users of the drug are permitted to purchase pentobarbital in the U.S.”).

Seconal to Valeant, a Canadian pharmacy, in 2015.²⁰⁷ Prior to its sale, Marathon supplied Seconal to pharmacies filling aid-in-dying prescriptions.²⁰⁸ At the time of the sale to Valeant, the price of a lethal dose of Seconal was approximately \$1,800.²⁰⁹ Shortly after the sale to Valeant, the price increased dramatically and was at around \$3,500 per lethal dose at the end of January 2016.²¹⁰ Seconal has now reached the price at which it makes sense to develop lower cost drug combinations, which will enable utilization of aid-in-dying statutes by people of all income levels. Such development is underway, and the use of alternative drugs has begun appearing in state reports.²¹¹ The development process requires working with several drugs and addressing challenges not experienced when using a single drug, sodium pentobarbital or secobarbital.²¹² Using either of those drugs is superior, at least at this point in utilization of aid-in-dying statutes.

Since mandatory record-keeping began in Oregon (1998) and Washington (2008), secobarbital has been used consistently for aid-in-dying purposes, except for a short period between 2012 and 2013 when pentobarbital was used predominantly.²¹³ Pentobarbital is considered

²⁰⁷ *Marathon Pharmaceuticals*, *supra* note 146.

²⁰⁸ Betsy Q. Cliff, *Oregon's Death With Dignity Act: Individuals Who Want to Use State Law May Find A Tough Road*, BULLETIN (DEC. 18, 2008), <http://www.bendbulletin.com/csp/mediapool/sites/BendBulletin/News/story.csp?cid=1546154&sid=497&fid=151>.

²⁰⁹ Interview with Robb Miller & Dr. Robert W. Wood, *supra* note 15.

²¹⁰ *Id.* Pricing varies by pharmacy. Death with Dignity, a national nonprofit dedicated to the enactment and implementation of aid-in-dying statutes, states that the cost varies between \$3,000 and \$5,000. See Leonard, *supra* note 20; *FAQs*, *supra* note 24.

²¹¹ See OR. PUB. HEALTH DIV., *supra* note 16, at 6.

²¹² The current protocol consists of three drugs, including chloral hydrate. *Id.* Chloral hydrate is a very old drug, which has been in use since 1869 as a minor sedative, apparently without major side effects. SHORTER, *supra* note 41, at 18–19. Slight gastric irritation may be a problem. HARTMANN, *supra* note 34, at 12. Use of chloral hydrate in combination with other drugs results in a lethal effect but use of drug combinations is less ideal than a single drug, such as sodium pentobarbital and secobarbital. See Coyne, *supra* note 32.

Greater problems with drug combinations as compared to fewer problems from the use of single drugs have been noted in the death penalty context. *New Republic* author Jerry Coyne notes several problems with the three-drug “cocktail” preferred until recently by state departments of correction and that since 2010, more death-penalty states have had smoother executions when using single drug protocols. Coyne, *supra* note 32. It is, however, exactly those drugs that are now so difficult to obtain in the United States for either purpose.

²¹³ See OR. PUB. HEALTH DIV., OREGON'S DEATH WITH DIGNITY ACT—2013 REPORT 5 (2014), <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year16.pdf>; OR. PUB. HEALTH DIV., OREGON'S DEATH WITH DIGNITY ACT—2012 REPORT 5 (2013), <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year15.pdf>; WASH. STATE DEP'T OF HEALTH, 2013 DEATH WITH

preferable to secobarbital primarily because of the labor involved in emptying the contents of 100 capsules of Seconal, the only currently available form of secobarbital.²¹⁴ It is also preferable because pentobarbital dissolves more easily in liquid, which makes it easier to prepare and to swallow.²¹⁵ During the period of time of predominant pentobarbital use, pentobarbital powder was available through compounding pharmacies, which lawfully obtained supplies from abroad because it was no longer produced in the United States.²¹⁶ That window of opportunity closed when restrictive legislation was enacted in 2013 making it illegal to import any drug that is not on a “bulk drug list.”²¹⁷ The bulk drug list has not yet been released. Moreover, pentobarbital powder is not currently on the draft list, and it appears that it has not been proposed for inclusion.²¹⁸ Even if pentobarbital powder is proposed for inclusion, it seems unlikely that it would be placed on the list. No health organization has identified it as an “essential” drug,²¹⁹ safer drugs exist for the purposes for which pentobarbital would be prescribed, and pentobarbital in sterile solution is still readily available for very limited, specific uses for which only pentobarbital is appropriate.²²⁰

Clearly, companies have few incentives to produce short-acting barbiturates, which are highly lethal and unnecessary for normal medical purposes now that safer drugs for the same purposes exist. Secobarbital

DIGNITY ACT REPORT 8 (2014), <http://www.doh.wa.gov/portals/1/Documents/Pubs/422-109-DeathWithDignityAct2013.pdf>.

²¹⁴ Interview with Robb Miller & Dr. Robert W. Wood, *supra* note 15.

²¹⁵ *Id.*

²¹⁶ See, e.g., *Compounding Pharmacies and Lethal Injection*, DEATH PENALTY INFO. CTR., <http://www.deathpenaltyinfo.org/compounding-pharmacies> (last visited Feb. 3, 2016). Secobarbital could be lawfully imported because it was already approved by the FDA for efficacy and safety when used as a sedative. Secobarbital, like pentobarbital, has never been approved for the purpose of killing people.

²¹⁷ Drug Quality and Security Act, Pub. L. 113-54, 127 Stat. 587 (2013); see also Sabrina Tavernise, *Bill on Drug Compounding Clears Congress a Year After a Meningitis Outbreak*, N.Y. TIMES (Nov. 18, 2013), <http://www.nytimes.com/2013/11/19/us/bill-on-regulating-drug-compounding-clears-senate.html>.

²¹⁸ See U.S. FOOD & DRUG ADMIN., U.S. DEP'T OF HEALTH & HUMAN SERVS., BULK DRUG SUBSTANCES NOMINATED FOR USE IN COMPOUNDING UNDER SECTION 503A OF THE FEDERAL FOOD, DRUG, AND COSMETIC ACT, <http://www.fda.gov/downloads/drugs/guidancecomplianceregulatoryinformation/pharmacycompounding/ucm467373.pdf> (last visited Feb. 3, 2016).

²¹⁹ See *Essential Medicines*, WORLD HEALTH ORG., http://www.who.int/topics/essential_medicines/en/ (last visited Feb. 3, 2016); see also WORLD HEALTH ORG., WHO MODEL LIST OF ESSENTIAL MEDICINES, 19TH LIST (Apr. 2015), http://www.who.int/selection_medicines/committees/expert/20/EML_2015_FINAL_amended_AUG2015.pdf?ua=1.

²²⁰ See *Pentobarbital: Drug Information*, *supra* note 48.

is still available but may go the way of pentobarbital. Compounding pharmacies can no longer import the materials necessary to produce short-acting barbiturates for aid-in-dying purposes, either.

If the problem of corporate incentives to start or resume production of short-acting barbiturates is simply the economics of producing a drug with a very small (and decreasing) market and not primarily due to uncertainties associated with risks of litigation arising from production of a highly lethal medication, one possible way forward lies in the legal ability of charitable not-for-profit foundations to provide interest-free loans or grant monies to for-profit entities for the purpose of furthering their charitable missions.²²¹ U.S. tax law also allows foundations to make a Program-Related Investment (“PRI”) if doing so furthers the foundation’s charitable mission.²²² Unlike a grant, a PRI is an investment that is intended to generate a return to the foundation. The *purpose* of the investment may not be to generate a financial return, however; the purpose must be to further the charitable mission of the foundation. Upon receiving the return, the foundation must reinvest the financial return as another PRI or qualifying distribution of another type.²²³

Because PRIs can be used to develop new products or expand services, a PRI could be used to create or invest in an existing business to manufacture sodium pentobarbital powder. Appropriate PRIs are attractive to private foundations because they count towards the 5% annual distribution requirement,²²⁴ are considered a charitable use asset while the investment is outstanding, and are exempt from excess business holdings penalty taxes (because the investment supports the foundation’s mission).²²⁵ PRIs are not disfavored by the U.S. Treasury Department or

²²¹ See, e.g., Kelsey Sheehy, 8 *Nonprofit Microfinance Lenders in the U.S.*, NERDWALLET.COM (Sept. 17, 2015), <http://www.nerdwallet.com/blog/banking/top-nonprofit-microfinance-organizations-that-lend-in-us/>; Rachel Kaufman, 10 *Top Microfinance Companies*, CNN MONEY (July 15, 2011), http://money.cnn.com/galleries/2011/smallbusiness/1107/gallery.top_microfinance_companies/.

²²² See 26 U.S.C. § 4944(c) (2012); see also Ofer Lion & Douglas M. Mancino, *Program-Related Investments and Private Foundations — New Guidance Reflects the Modern World*, MISSION INVESTORS EXCHANGE (Apr. 2012), <https://www.hunton.com/files/News/04f9ec38-f7ab-42a2-b33a-62a1177c7e86/Presentation/NewsAttachment/2f9ee986-2a44-4657-b006-62f8c325b073/programrelatedinvestmentsprivatefoundations.pdf>.

²²³ Lion & Mancino, *supra* note 222; Ellie Winninghoff, *The Untapped Power of PRIs*, PRIVATE WEALTH MAG. (Nov. 14, 2012), <http://www.fa-mag.com/news/the-untapped-power-of-pris-12577.html>.

²²⁴ See 26 U.S.C. § 4942; 26 C.F.R. § 53.4942(a)-2 (2014).

²²⁵ Nicole Motter, *Why Program-Related Investments Are Not Risky Business*, FORBES (Feb. 21, 2013), <http://www.forbes.com/sites/ashoka/2013/02/21/why-program-related-investments-are-not-risky-business/#2467a631f8ea>; see also Allison L. Evans & Christine M.

the Internal Revenue Service.²²⁶ A PRI or grant could be used to incentivize pentobarbital production by an existing American or foreign pharmaceutical company.

Nonprofit foundations can and do play an important role in assisting for-profit enterprises when doing so furthers those foundations' charitable missions. Foundation involvement in the history of making a highly controversial non-surgical oral abortion drug available in the United States is one such example. Mifepristone was originally developed in 1988 by the French company Roussel-Uclaf, which wanted to avoid sales in the United States and other countries where abortion was still controversial.²²⁷ Under pressure to make the drug available in the United States but wanting to avoid any direct involvement, Roussel-Uclaf eventually donated the rights to make and distribute mifepristone in the United States to the Population Council, a nonprofit foundation dedicated to promoting reproductive health.²²⁸

The Population Council had difficulty finding a manufacturer and distributor because anti-abortion advocates promised business disruptions, such as boycotts and picketing, and there had already been violence associated with anti-abortion advocacy.²²⁹ After many legal and financial setbacks, the Population Council licensed its rights in mifepristone to a women's health pharmaceutical company (Danco Laboratories,

Petrovits, *Recycling Charitable Dollars: IRS Gives Green Light to More Program-Related Investments*, J. ACCT. (July 31, 2013), <http://www.journalofaccountancy.com/issues/2013/aug/20137610.html>.

²²⁶ See, e.g., Evans & Petrovits, *supra* note 225; LUCIA BENABENTOS ET AL., STRATEGIES TO MAXIMIZE YOUR PHILANTHROPIC CAPITAL: A GUIDE TO PROGRAM RELATED INVESTMENTS 32 (April 2012), <https://www.missioninvestors.org/system/files/tools/ximize-your-philanthropic-capital-a-guide-to-program-related-investments-lucia-benabentos-justin-storms-carlos-teuscher-and-jon-van-loo-linklaters-llp.pdf> (noting various IRS rulings allowing flexibility in structuring of PRIs); *Program-Related Investments*, IRS (last updated Mar. 31, 2015), <https://www.irs.gov/Charities-&-Non-Profits/Private-Foundations/Program-Related-Investments>.

²²⁷ Michelle La Mothe et al., *A 20-Year Journey: The History of the Abortion Pill (or How Hewlett-Packard Funded RU-486)*, FREE REPUBLIC (Feb. 9, 2006), <http://www.freerepublic.com/focus/f-news/1575246/posts> (transcript of a live radio broadcast originally recorded on Nov. 9, 2000).

²²⁸ *Id.*

²²⁹ See, e.g., Marlene Cimons, *Boycott Called for Products from Firms Tied to RU 486*, L.A. TIMES (June 2, 1994), http://articles.latimes.com/1994-06-02/news/mn-65104_1_specific-products; Rachel Zimmerman, *Abortion-Pill Venture Keeps To Shadows Awaiting Approval*, WALL STREET J. (Sept. 5, 2000), reposted as *Abortion Pill Nears a Federal Decision*, ST. PETERSBURG TIMES ONLINE (Sept. 7, 2000), http://www.sptimes.com/News/090700/news_pf/Worldandnation/Abortion_pill_nears_a.shtml (noting violence and murders perpetrated by anti-abortionists).

LLC), which was newly incorporated in the Cayman Islands and whose only product would be Mifeprex, based on mifepristone.²³⁰ Danco Laboratories was specifically set up in ways designed to maintain secrecy and insulation from disruption and violence.²³¹ With Mifeprex as its only product and significant reliance on nonprofit sector support,²³² Danco would be relatively immune from economic boycotts.

The Population Council petitioned the FDA to approve Mifeprex as a new drug.²³³ Over fierce opposition by anti-abortion advocates, in 2000, the FDA finally approved Mifeprex, with limitations on the prescribing doctor and the circumstances under which the drug could be marketed and procured by women.²³⁴ Even with the required FDA approvals, finding a manufacturer of mifepristone, the active ingredient in Mifeprex, was as fraught with difficulty as was setting up Danco Laboratories as the manufacturer and distributor of Mifeprex.²³⁵ Finally, a manufacturer in China (the Hua Lian Pharmaceutical Company) received FDA approval and was given the contract to produce mifepristone.²³⁶ Danco Laboratories manufactured Mifeprex from mifepristone and then distributed the drug to doctors in accordance with FDA requirements.²³⁷

As a *Washington Post* article points out, Danco is legally incorporated as a for-profit entity, but its officers and investors have been primarily interested in the social value of making Mifeprex available to American women.²³⁸ Several nonprofit foundations were involved in

²³⁰ See Robert O'Harrow, Jr., *Drug's U.S. Marketer Remains Elusive; Fearing Abortion Foes, Danco Keeps Location, Phone Number Secret*, WASH. POST (Oct. 12, 2000), <https://www.washingtonpost.com/archive/politics/2000/10/12/drugs-us-marketer-remains-elusive/8b7b732b-0f23-4c96-9051-714cd3d9f6f8/>.

²³¹ *Id.*

²³² *Id.*; La Mothe et al, *supra* note 227; Melody Petersen, *Abortion Pill Distributor Energized by New Mission*, N.Y. TIMES (Sept. 30, 2000), <http://www.nytimes.com/2000/09/30/us/abortion-pill-distributor-energized-by-new-mission.html>.

²³³ *RU-486 Application Confirmed*, WASH. POST (Apr. 2, 1996), <https://www.washingtonpost.com/archive/politics/1996/04/02/ru-486-application-confirmed/c421280d-f5e1-44ae-9ec0-5e294a8fbca5/>.

²³⁴ Marc Kaufman, *FDA Approves Abortion Pill; Family Planning Groups Hail 'Milestone'*, WASH. POST, Sept. 29, 2000, at A1.

²³⁵ See, e.g., Zimmerman, *supra* note 229; Petersen, *supra* note 232.

²³⁶ Philip P. Pan, *Chinese to Make RU-486 for U.S.*, WASH. POST (Oct. 12, 2000), <https://www.washingtonpost.com/archive/politics/2000/10/12/chinese-to-make-ru-486-for-us/97e37b0f-a6fd-41f5-8ce3-d2af86adea63/>; Charles Hutzler, *RU-486 Manufacturer Disclosed*, ABC NEWS (Oct. 12, 2000), <http://abcnews.go.com/Health/story?id=117901>.

²³⁷ O'Harrow, *supra* note 230.

²³⁸ *Id.*

getting the drug to market. The Buffet Foundation “made at least \$2 million in interest-free loans to the Population Council. . . . [which] was in turn used to conduct clinical trials on [mifepristone].”²³⁹ The David and Lucile Packard Foundation loaned Danco and the Population Council \$10 million to support their efforts to receive FDA approvals,²⁴⁰ while George Soros’ Open Society Foundation indirectly supported the project with grants to allied non-profit organizations seeking to make mifepristone more widely available.²⁴¹ According to ABC News, the Rockefeller Foundation assisted the Hua Lian Pharmaceutical Company in procuring the production contract.²⁴² Since the general tax rule is that nonprofits may not use their charitable assets for the benefit of for-profit businesses,²⁴³ Danco had to have been considered only an incidental beneficiary of a plan that would further these nonprofit foundations’ charitable missions.

If, analogously, a nonprofit foundation sought to further its mission by supporting corporate production of sodium pentobarbital or secobarbital to increase and stabilize availability of the drug for use in aid-in-dying contexts, the challenge would not be the legality of using charitable assets for that purpose. The challenge would be receiving FDA approval to manufacture or import a drug whose intended purpose is killing people, even in contexts in which it is lawful to prescribe and to use it for that purpose. As long as sales for on-label purposes would also be possible, approval should be less of a problem, but certainly if on-label prescriptions disappear, it would be difficult at this point to obtain FDA approval.²⁴⁴

²³⁹ *Id.*

²⁴⁰ *Id.*; Zimmerman, *supra* note 229.

²⁴¹ Zimmerman, *supra* note 229; Petersen, *supra* note 232.

²⁴² Hutzler, *supra* note 236.

²⁴³ See 26 U.S.C. § 4945(d) (2012); see also BETSY BUCHALTER ADLER ET AL., THE RULES OF THE ROAD: A GUIDE TO THE LAW OF CHARITIES IN THE UNITED STATES ch. 4, at 8–9 (2012) (ebook), [http://www.adlercolvin.com/pdf/private_foundations/Rules_of_the_Road_\(00078886\).pdf](http://www.adlercolvin.com/pdf/private_foundations/Rules_of_the_Road_(00078886).pdf); *How to Lose Your 501(c)(3) Tax Exempt Status (Without Really Trying)*, NONPROFIT RISK MGMT. CTR., http://www.nonprofitrisk.org/library/articles/How_to_Lose_Your_Tax_Exempt_Status.shtml (last visited Jan. 28, 2016) (addressing private benefit/inurement and unrelated business income grounds for revocation of tax exempt status, among others).

²⁴⁴ FDA approval might be possible if there is a credible prediction that prescriptions for on-label use will increase or if the FDA interprets its mission to include approving drugs whose purpose is to most safely enable use of existing lawful procedures, such as hastening human death in jurisdictions with aid-in-dying laws.

IV. CONCLUSION

Aid-in-dying statutes exist in four states, with the possibility of more states enacting such statutes in the foreseeable future. Crafted with political mindfulness and awareness of Oregon's successfully enacted and implemented statute, these statutes require individuals seeking to hasten death to "self-administer" or "ingest" a lethal dose of medication lawfully prescribed for that purpose. This is understood to mean ingestion by the same means by which the individual autonomously takes in nutrition and hydration.²⁴⁵ The requirement of autonomous ingestion is said to provide privacy and also evinces voluntary decision-making on the part of the individual taking the medication.²⁴⁶ The requirement also distances others from participating directly in hastening that person's death. No medically trained person is needed to insert an intravenous line, for instance. Yet, the availability of appropriate medications for ingestion is a challenge because the most appropriate medications are, of course, quickly lethal, and production for on-label uses has been declining steadily for many years. Although there may be a subset of patients for whom barbiturates are the most effective drugs for their conditions, short-acting barbiturates have been replaced almost entirely by other drugs that do not share these barbiturates' painless and quickly lethal properties. This has exacerbated the problem of off-label uses eclipsing on-label uses such that it could become illegal to manufacture them.

The need to address appropriate drug availability is great in states where aid-in-dying statutes already exist and is important as more and more states consider adopting aid-in-dying statutes. Sodium pentobarbital liquid is not an option for reasons of price, sodium pentobarbital powder is not available at all, and Seconal (secobarbital) appears to be moving in the same direction of low affordability/availability. Valeant, which purchased the right from Marathon Pharmacy to produce Seconal, was recently accused of raising prices to extraordinary levels soon after acquisition of low-cost drugs, in order to capture huge profits.²⁴⁷ Even if

²⁴⁵ A difficulty with limiting the interpretation of "ingestion" to "oral ingestion" is that there are individuals who meet all of the requirements for utilizing the statute except that they have lost the ability to swallow. For those individuals the use of devices to enable the introduction of lethal dose medication into their bodies would be important. Intravenous or via PEG (percutaneous endoscopic gastrostomy) introduction of lethal dose medication is not necessarily preferable in individuals for whom swallowing is still possible. *See* Interview with Silvan Luley, DIGNITAS, in Chicago, Ill. (Sept. 19, 2014).

²⁴⁶ Telephone interview with George Eighmey, *supra* note 15.

²⁴⁷ Matthew Perrone & Tom Murphy, *Drugmakers Planned Big Price Hikes to Pad Profits*, *Congress Finds*, ASSOCIATED PRESS,

price were not an issue, importation exclusively for an off-label use could be legally problematic. Alternatives in the form of protocols relying on multiple readily available drugs are being developed, but the general consensus is that single drug protocols are preferable. This means that people who would seek to use an aid-in-dying statute have decreasing access to the ideal drugs for that purpose, which jeopardizes their right to make use of aid-in-dying statutes.

To some extent, this is just another example of the inequities of drug availability among American consumers. So far, no pharmaceutical company has offered a needs-based charitable reduction in the price of a lethal dose of a barbiturate or to manufacture or distribute the drug at a reduced price if prescribed for an aid-in-dying purpose.²⁴⁸ Foundation support has subsidized the cost of secobarbital on a financial need basis, but that support cannot keep up with price increases for secobarbital and is now available only for the drug combination currently used in Washington and Oregon.²⁴⁹ Similarly, private health insurers may decide to cover only the cost of less-than-ideal drug combinations, if they cover any cost of aid-in-dying medications at all.

The financial challenges of sodium pentobarbital and secobarbital availability could, perhaps, be addressed, but there is still the problem of decreasing on-label use to the point that it could become illegal to manufacture either of these drugs for the off-label use of hastening human death. That would be a problem that foundation support of individuals or to incentivize companies to produce secobarbital or pentobarbital could not solve.

From the standpoint of utilizing aid-in-dying statutes, it would be ideal for the FDA to approve short-acting barbiturates for use as single drugs in aid-in-dying contexts; hastening death where lawful to do so would become an approved on-label use. At present, the FDA does not seem likely to interpret its mission and drug approval protocols to permit approval of drugs whose purpose is intentional shortening of human life. Indeed, seeking exceptions to or altering the interpretation of the FDA's public health mission to include pathways to approval of drugs for use in

<http://ireader.olivesoftware.com/Olive/iReader/SeattleTimes/SharedArticle.aspx?document=S TCD%5C2016%5C02%5C03&article=Ar00403> (last visited Feb. 9, 2016). Valeant may profit also because of increased prescriptions now that the Supreme Court of Canada has held that laws prohibiting physician aid in dying are unconstitutional. *Carter v. Canada*, [2015] 1 S.C.R. 331 (Can.), <http://www.canlii.org/en/ca/scc/doc/2015/2015scc5/2015scc5.html>.

²⁴⁸ Interview with Robb Miller & Dr. Robert W. Wood, *supra* note 15; telephone interview with George Eighmey, *supra* note 15.

²⁴⁹ Interview with Robb Miller & Dr. Robert W. Wood, *supra* note 15.

the aid-in-dying context seems currently as unpromising as pursuing Congressional amendment of statutes that veterinary sodium pentobarbital be prescribable for use to lawfully hasten human death. The concept of hastening death is controversial, and two U.S. Supreme Court opinions deny the existence of a constitutionally protected right to physician-assisted hastening of death.²⁵⁰

The conundrum is this: although popular support for aid-in-dying statutes is strong,²⁵¹ full societal acceptance of lawfully enacted aid-in-dying statutes would include the legal abilities to prescribe and to use the best medications for the purpose, and yet in order to get to that point of legal acceptability it is important to be using those drugs now. The drugs currently most suitable for this purpose are not readily available at an affordable price in the United States. Access to ideal drugs for hastening death in aid-in-dying jurisdictions is a matter of the patient's financial wherewithal and drug manufacturers' willingness and legal ability to produce the medications. Accordingly, much is currently resting on new, less expensive multi-drug protocols using readily available drugs. The multi-drug protocol now in use does effectively hasten death, but it can cause burning in the mouth and can take longer for the individual to die. Unfortunately, due to escalating pricing of Seconal, there may be increasing reliance on less-than-ideal drugs until the FDA understands its mission to include providing approval mechanisms for on-label usage of ideal medications for hastening death in aid-in-dying jurisdictions and pharmaceutical companies have sufficient incentives to produce those medications at reasonable price to consumers.

²⁵⁰ *Vacco v. Quill*, 521 U.S. 793 (1997); *Washington v. Glucksberg*, 521 U.S. 702 (1997).

²⁵¹ See, e.g., *Strong Public Support for Right to Die*, *supra* note 12; Thompson, *supra* note 12.

Excerpt

IS LEGALIZING EUTHANASIA AN EVOLUTION OR REVOLUTION IN SOCIETAL VALUES?

KILLING AS KINDNESS: THE PROBLEM OF DEALING WITH SUFFERING
AND DEATH IN A SECULAR SOCIETY

*Margaret Somerville**

I. INTRODUCTION

In my book “*Bird on an Ethics Wire: Battles about Values in the Culture Wars*” I explore the concept of human dignity and what respect for it requires and show that it is a contentious topic in both ethics and law. Recently, courts have been equating suffering to the loss of dignity and vice versa. They define dignity as requiring that persons have control over what happens to them and, consequently, also equate a loss of autonomy and self-determination with the loss of dignity. This approach is consistent with American physician Eric Cassel’s definition of suffering as having a sense of one’s own disintegration and being unable to prevent that, a sense of a loss of control over what happens to one.¹ Often, claims with regard to what respect for a person’s dignity and autonomy requires are framed as respect for a right to choice. In short, allowing “choice” regarding what happens to oneself is put forward as the remedy for a loss of dignity and an appropriate means to relieve suffering.

* Professor Faculty of Law and Faculty of Medicine, Founding Director, Centre for Medicine, Ethics and Law Samuel Gale Chair in Law, McGill University. This article was originally published as a chapter in MARGARET SOMERVILLE, *BIRD ON AN ETHICS WIRE: BATTLES ABOUT VALUES IN THE CULTURE WARS* (McGill-Queen’s University Press 2015). Reprinted with permission.

¹Eric Cassel, *The Nature of Suffering and the Goals of Medicine*, 326 NEW ENG. J. MED. 1140, 1140–41 (1992).

At present, physician-assisted suicide and euthanasia are the most prominent and contentious issues in relation to which maintaining a person's dignity, relieving suffering, and the proper approach of the law in dealing with suffering are relevant considerations. The law already seeks to uphold or restore dignity by giving terminally-ill, suffering persons who want to die control over the treatments they receive. Requirements for informed consent—which from the perspective of giving control over her treatment to the patient can be characterized as a “suffering reduction mechanism”²- and rights to refuse life-prolonging treatment are examples. However, pro-euthanasia advocates argue that the necessary and only sufficient control of suffering is to be able to choose death.

Pro-euthanasia advocates see euthanasia principally as a way to relieve people's suffering. They view suffering as the greatest evil and the relief of it as trumping almost all other values— respect for individual autonomy is the major exception. One of the challenges in responding to this argument in the euthanasia debate is that it's not easy to give meaning to suffering other than through religion, which was the way many people dealt with suffering in the past. But today, many people are not religious. When suffering cannot be given any worth or meaning and a person does not believe that there is anything inherently wrong in inflicting death on a suffering person, at least one who requests and gives informed consent to it—that is, they believe this is not unethical—it is very difficult to convince them that legalizing euthanasia is a bad idea.

Considering how we should respond to suffering, especially as a society, also raises the philosophical claim that it is not the job or proper role of medicine or the law to relieve all suffering and that in trying to do so physicians and law-makers are unjustifiably crossing boundaries that should be respected.³ And that leads to the question: How, then, does and should the law deal with suffering? First, let's look at how some law students view it.

II. HOW SUFFERING IS PERCEIVED

I used to teach a course, “Ethics, Law, Science and Society,” to up-

² Margaret Somerville, *Human Rights and Medicine: The Relief of Suffering*, in INTERNATIONAL HUMAN RIGHTS LAW: THEORY AND PRACTICE 505–522 (Irwin Cotler & F. Pearl Eliadis eds., The Canadian Human Rights Foundation, 1992), and DEATH TALK: THE CASE AGAINST EUTHANASIA AND PHYSICIAN-ASSISTED SUICIDE 205–217 (2d ed., McGill-Queen's University Press 2001).

³ See, Daniel Callahan, *When Self-Determination Runs Amok*, 22 HASTINGS CTR. REPORT, no. 2, Mar.-Apr. 1992, at 52.

per year and graduate law students at McGill University and one of the topics we discussed was euthanasia. I've researched euthanasia, physician-assisted suicide, the ethics and law of palliative care and pain relief treatment, decision-making at the end of life, and related topics, for nearly three decades and published a 433-page book, *Death Talk: The Case against Euthanasia and Physician-Assisted Suicide*.⁴ Yet, I came away from the class feeling that I had completely failed to communicate to most of my students what the problems with legalizing euthanasia were—that I was hitting a steel wall. This was not due to any ill-will on their part; rather, they seemed not to see euthanasia as raising major problems—at least any beyond preventing its abuse—a reaction I found very worrying.⁵

So, I emailed my students explaining I felt “that I had not done a good job in presenting the euthanasia debate . . . [and] decided to see if I could work out why not by writing about it.” I attached an early draft of my article setting out my thoughts in that regard and asked for comments; I received several, very thoughtful replies.

One student explained that she thought I was giving far too much weight to concerns about how legalizing euthanasia would harm the community and our shared values, especially that of respect for life, and too little to individuals' rights to autonomy and self-determination, and to euthanasia as a way to relieve people's suffering.

She emphasized that individuals' rights have been given priority in contemporary society, and they should also prevail in relation to death. Moreover, legalizing euthanasia was consistent with other changes in society, such as respect for women and access to abortion, she said.

I had suggested in my article that, among other causes of the move to legalize euthanasia, the vast exposure to death that we are subjected to in both current-affairs and entertainment programs might have overwhelmed our sensitivity to the awesomeness of death and, likewise, of inflicting it. But one of my students responded, “If anything, I think many of our reactions come not from an overexposure to death, but from an aversion to suffering, and an unwillingness or hesitancy to prolong pain.”

The *Carter* case shows a judge at the trial level,⁶ Justice Lynn

⁴ DEATH TALK, *supra* note 2.

⁵ This story about my students first appeared as part of an opinion article. See Margaret Somerville, *The Case against Euthanasia*, OTTAWA CITIZEN (June 27, 2008), <http://www.canada.com/ottawacitizen/news/story.html?id=de02045d-51b1-4f4b-aa1a-157f3f79651b>.

⁶ *Carter v. Canada* (Attorney General), 2012 BCSC 886.

Smith of the British Columbia Supreme Court, articulating, in great detail, both the same approach as the students took and the reasoning on which they based their approach. She ruled that prohibiting physician-assisted suicide is unconstitutional, because it is necessary medical treatment for the relief of the suffering of people with disabilities who are unable to commit suicide without assistance. The British Columbia Court of Appeal overruled Justice Smith's judgment on the grounds that it was contrary to the then binding precedent of the Supreme Court of Canada's ruling in the *Rodriguez* case,⁷ in which a narrow majority held that the Canadian *Criminal Code's* prohibition of assisted suicide was constitutionally valid.⁸ The plaintiffs in the *Carter* case appealed to the Supreme Court of Canada, which in effect overruled its previous precedent in the *Rodriguez* case without expressly doing so and allowed the appeal, relying on and strongly endorsing Justice Smith's findings of both law and fact.⁹

III. THE *CARTER* CASE¹⁰

At 355 pages containing 137,000 plus words, the trial court judgment of Justice Smith in the *Carter* case¹¹ in the Supreme Court of British Columbia, is rightly described as a tome. But it is one with groundbreaking impact for Canadian society, because it has been upheld on appeal by the Supreme Court of Canada. Leaving aside abortion, it constituted the crossing of the thousands-of-years old, line-in-the-sand which established that we must not intentionally kill another innocent human being (the only exceptions being where that is the only way to save human life, as in justified self-defence) or help them to kill themselves.

In striking down the prohibition of assisted suicide in section 241(b) of the Canadian *Criminal Code*¹² as unconstitutional, Justice Smith took the first step in legalizing physician-assisted suicide in Canada and, where the person is incapable of committing suicide because of physical disability, euthanasia. One of the plaintiffs, Gloria Taylor, a

⁷ *Rodriguez v. British Columbia (Attorney General)*, [1993] 3 S.C.R. 519.

⁸ *Carter v. Canada (Attorney General)* 2013 BCCA 435.

⁹ *Carter v. Canada (Attorney General)*, 2015 SCC 5.

¹⁰ The analysis of the trial level judgment of the *Carter* case was first published in RONALD M. GREEN & NATHAN J. PALPANT, *SUFFERING AND BIOETHICS: EXPLORING INTERACTIONS BETWEEN PAIN, SUFFERING, AND THE LAW* 201–227 (Oxford University Press 2014). I am grateful for the kind permission of the editors and publisher to use the content of that chapter as a basis for this text.

¹¹ *Carter v. Canada (Attorney General)*, 2012 BCSC 886.

¹² Canada Criminal Code, R.S.C. 1985, c C-46 (as amended).

woman suffering from ALS (Lou Gehrig's disease) wanted to have a physician assist her in committing suicide at a time and a place of her choosing. Justice Smith legitimized and granted Ms. Taylor's wish. Ms. Taylor subsequently died of natural causes. Because, the Supreme Court of Canada relied so heavily on this first instance judgment in reaching its conclusion that an absolute prohibition on "physician assisted dying" was in breach of the *Canadian Charter of Rights and Freedoms*¹³ - without meaning any disrespect, one could say the Supreme Court hid behind the skirts of the trial judge, especially with regard to questions of fact - it merits close analysis.

Read as a whole, Justice Smith's judgment gives a strong impression that she is far from neutral about physician-assisted suicide and euthanasia, but, rather, favors these interventions in certain circumstances. In particular, the judgment seems to give undue weight to the evidence of witnesses in favor of legalizing physician-assisted suicide, while massively devaluing that of those who oppose it. But the Supreme Court of Canada found the contrary: "The trial judge's findings were based on an exhaustive review of the extensive record before her".[3]¹⁴ However, with the exception of an affidavit from a Belgian academic on the abuses of euthanasia in his country, the Supreme Court at its hearing refused to allow the admission of evidence which would have corrected this imbalance in Justice Smith's assessment of the evidence.[109] Moreover, the trial judge's emphasis on the relief of suffering—the words "suffer" and "suffering" appear 212 times in her judgment—gives rise to what appear to be philosophical and social biases being imposed by her upon the wealth of evidence submitted by both parties.

Thus, one can question Justice Smith's conclusions that physician-assisted suicide is not inherently unethical; that the availability of legalized physician-assisted suicide is necessary "medical treatment" for some people; and the very lengthy legal justification she constructs to allow her to implement her rulings to these effects. That justification was largely based on a selective application of *Canadian Charter of Rights and Freedoms*¹⁵ jurisprudence and was established by distinguishing the

¹³ Canadian Charter of Rights and Freedoms, Part I of the Constitution Act, 1982, *being* Schedule B to the Canada Act, 1982, c 11 (U.K.).

¹⁴ Numbers in square brackets referencing a court's holding refer to paragraphs in the Supreme Court of Canada's judgment, those in round brackets to paragraphs in the trial court's judgment in the *Carter* case.

¹⁵ Canadian Charter of Rights and Freedoms, Part I of the Constitution Act, *supra* note 13.

precedent set by the Supreme Court of Canada in the *Rodriguez* case,¹⁶ which had found the prohibition of assisted suicide to be constitutional in a fact situation very similar to Ms. Taylor's.

A majority of the Court of Appeal of British Columbia overruled Justice Smith by holding that the *Rodriguez* precedent applied. But the Supreme Court of Canada reinstated Justice Smith's finding that she was not bound by *Rodriguez* on two bases: that since that case the law had changed and there were new facts. With regard to the change in the law, after agreeing with Justice Smith that the *Criminal Code*'s absolute prohibition of assisted suicide breached all sec 7 Charter rights – rights to life, liberty and security of the person – the Supreme Court ruled that she was also correct that the test for compliance “with the principles of fundamental justice” that sec 7 allows to render such breaches constitutional had changed. It now required that to be constitutionally valid legislation must not be overbroad, that is, not breach the rights of people who do not fall within the legislature's object in enacting the legislation:

[*Rodriguez*] did not apply the principle of overbreadth as it is currently understood, but instead asked whether the prohibition [of assisted suicide] was “arbitrary or unfair in that it is unrelated to the state's interest in protecting the vulnerable, and that it lacks a foundation in the legal tradition and societal beliefs which are said to be represented by the prohibition” (*Rodriguez*, at p. 595). By contrast, the law on overbreadth, now explicitly recognized as a principle of fundamental justice, asks whether the law interferes with some conduct that has no connection to the law's objectives (*Bedford*, at para. 101). This different question may lead to a different answer. [46]

And, with regard to the change in the facts:

The matrix of legislative and social facts in this case also differed from the evidence before the Court in *Rodriguez*. The majority in *Rodriguez* relied on evidence of ... the widespread acceptance of a moral or ethical distinction between passive and active euthanasia. [47]

The Supreme Court ruled that distinction was no longer accepted.

I will now examine, in more detail, some of the issues raised in the *Carter* judgment and how the Supreme Court endorsed the way in which they were dealt with by Justice Smith.

¹⁶ *Rodriguez v. British Columbia (Attorney General)*, [1993] 3 S.C.R. 519.

A. *The Primary Goal of Prohibiting Physician-Assisted Suicide*

Central to both the trial court's and Supreme Court's judgments, is whether protecting vulnerable people is the only purpose of the prohibition on physician-assisted suicide. Justice Smith rejects the Attorney General of Canada's argument that the purposes are more extensive, including upholding respect for human life and the integrity of the medical profession, and "preventing negative messages about the value of human life, particularly the value of the lives of individuals with disabilities." (1187). Likewise, the Supreme Court of Canada rejects the Attorney General of Canada's argument

that the object of the prohibition [of assisted suicide] should also be defined more broadly as simply "the preservation of life". [75] . . . Section 241 (b) is not directed at preserving life, or even at preventing suicide — attempted suicide is no longer a crime. . . . The direct target of the measure is the narrow goal of preventing vulnerable persons from being induced to commit suicide at a time of weakness. [78]

The Supreme Court also held that rights to refuse life-support treatment, including artificial hydration and nutrition, show that there is no overriding goal of "the preservation of life". [66] That is correct, but this goal or object should have been argued as maintaining "respect for life", including at the societal level, and emphasis should have been placed on the argument that there is a difference-in-kind, not just a difference-in-degree, between justifiably *allowing someone to die* of natural causes and *killing them* with a lethal injection or helping them to kill themselves. Both the trial judge and the Supreme Court expressly rejected this distinction.

If the prohibition of assisted suicide were meant to uphold "respect for human life," in general, at the societal level, then, in all probability, it would not, in stark contrast to these rulings, be found to be unconstitutional on the grounds on which both courts relied, which focused very strongly on individuals' rights. Justice Smith ruled, and the Supreme Court agreed, that the prohibition was overbroad because of its harmful impact on people with disabilities, such as Ms. Taylor, who want to commit suicide but need assistance to do so, in that it was absolute, with no exceptions for people such as Ms. Taylor. Consequently, the prohibition impaired her *Charter* rights to "life, liberty and security of the person"¹⁷ more than was necessary for the state to achieve its legitimate

¹⁷ Canadian Charter of Rights and Freedoms, Part I of the Constitution Act, *supra* note

goal of protecting vulnerable people. In other words, limiting the goal of the prohibition on assisted suicide to the protection of “vulnerable people” is essential to the reasoning that the prohibition is unconstitutional, because it is overbroad.

This raises the issue of whether Parliament should include in any legislation it passes to implement the Supreme Court’s decision, as the court invited it to do, a provision that the object of the legislation is also to uphold respect for human life at both the individual and societal levels. I would strongly recommend that it do so, as even if completely banning physician-assisted suicide is not possible without using the Charter’s section 33 “notwithstanding clause”, this would enable Parliament to severely restrict access to assisted suicide and euthanasia.

In light of the object identified for the prohibition of assisted suicide, it is not surprising that Justice Smith’s conclusions, and those of the Supreme Court, do not give substantial weight to institutional or societal protections or needs, but are focused principally at the individual level and giving individuals’ claims priority, which in Ms. Taylor’s case was her claim of a right to access assisted suicide for the relief of suffering. In other words, they accept an individual’s suffering, as the principal justification for euthanasia and that its presence means an individual’s request for “assisted death” trumps other claims and considerations. Here’s how the Supreme Court opens up its judgment:

It is a crime in Canada to assist another person in ending her own life. As a result, people who are grievously and irremediably ill cannot seek a physician’s assistance in dying and may be *condemned to a life of severe and intolerable suffering*. A person facing this prospect has two options: she can take her own life prematurely, often by violent or dangerous means, or she can suffer until she dies from natural causes. *The choice is cruel*. [1] (Emphasis added)

The last four words tell us what their decision will be. And the Supreme Court turns to the stories of individuals’ suffering and difficult deaths to support this outcome:

The stories in the affidavits vary in their details: some witnesses described the progression of degenerative illnesses like motor neuron diseases or Huntington’s disease, while others described the agony of treatment and the fear of a gruesome death from advanced-stage cancer. Yet running through the evidence of all the witnesses is a constant theme — that they suffer from the knowledge that they lack the ability to bring a peaceful end to their lives at a time and in a manner of their own choosing. [14]

We must listen to and take into account such stories, but they are not all that we need to hear and to take into account.

There is also a paradox here in that the focus on individual persons' suffering and, hence, vulnerability, a focus which is meant to protect vulnerable people, is being used to place them at risk from assisted suicide by legitimizing it. The same reversal of an initial protective goal has occurred with the concept of quality of life. Initially "quality of life" was developed as a concept intended to protect and promote life through the argument that everyone had a right to the resources, especially healthcare resources, needed to maintain an acceptable "quality of life." Now the concept is often used to achieve the exact opposite outcome, namely, that a person's "quality of life" is so poor that they are better off dead or, at the least, don't merit the expenditure of resources needed to keep them alive.

Having decided that the ban on assisted suicide is intended primarily to protect vulnerable persons, Justice Smith then concludes, and the Supreme Court agrees, that an absolute ban on it is not necessary to implement that goal and, moreover, that an absolute ban infringes Ms. Taylor's *Charter* rights as a disabled, suffering person, and, by extension, those of other and similarly situated "vulnerable persons":

In this case, I have found that the infringement [of the *Charter*] arises from the preclusion of physically disabled persons who are grievously ill and *experiencing intractable suffering* from ending their lives. Thus, it is the *absolute nature* of the prohibition against assisted suicide that requires justification, not the prohibition overall. In other words, the real question is whether the defendants have demonstrated justification for criminalizing the rendering of assistance in suicide to persons such as Gloria Taylor. [Emphasis added] (1171)

In reaching this conclusion, Justice Smith takes into account Ms. Taylor's own views that she does not need protection from assisted suicide as helping to establish that she does not. In other words, the judge gives priority to the value of individual autonomy in relation to a decision to commit suicide to avoid suffering. She rules that a safeguarded exception should be allowed and sets out the conditions for such an exception. Justice Smith envisions that the cases in which physician-assisted suicide or euthanasia is acceptable will be rare. But it is important to note that the method she sets out in her exception is broad and without the safeguards that might assure its application only in very restricted cases. Exactly the same observations are true of the Supreme Court's ruling in this regard.

Because it is so unusual, and especially because it was adopted by

the Supreme Court, I wish to note here the way in which Justice Smith interprets the right to life enshrined in section 7 of the *Canadian Charter of Rights and Freedoms*:

[The prohibition on assisted suicide in section 241(b) of the Criminal Code] infringes Ms. Taylor's right to life. (13) . . . [T]he legislation affects her right to life because it may shorten her life. Ms. Taylor's reduced lifespan would occur if she concludes that she needs to take her own life while she is still physically able to do so, at an earlier date than she would find necessary if she could be assisted. (17)

To say the least, this is a novel way to construct a breach of Ms. Taylor's *Charter* right to life. In effect, this reasoning converts the right to life to a right to death by physician-assisted suicide or euthanasia. The Supreme Court endorsed this approach as follows:

. . . [W]e do not agree that the existential formulation of the right to life *requires* an absolute prohibition on assistance in dying, or that individuals cannot "waive" their right to life. This would create a "duty to live", rather than a "right to life", and would call into question the legality of any consent to the withdrawal or refusal of lifesaving or life-sustaining treatment. The sanctity of life is one of our most fundamental societal values. Section 7 is rooted in a profound respect for the value of human life. But s.7 also encompasses life, liberty and security of the person during the passage to death. It is for this reason that the sanctity of life "is no longer seen to require that all human life be preserved at all costs" (*Rodriguez*, at p. 595, per Sopinka J.). And it is for this reason that the law has come to recognize that, in certain circumstances, an individual's choice about the end of her life is entitled to respect. [63]

It merits noting the lengthy reasoning the Supreme Court uses here to reach its conclusion that "an individual's choice about the end of her life is entitled to respect": it has eight separate steps. But as mentioned previously, while it's correct "that all human life [need not] be preserved at all costs", that does not mean that it may be intentionally taken. Not preserving human life and taking it are not commensurable and are not the same ethically or legally. Provided it can be justified in any given circumstances, not preserving life can be ethical and legal; intentionally taking life has never been such, except when it is the only reasonable way to save innocent human life, as in self defence.

With respect to who are the suffering persons who may have access to physician-assisted suicide, in speaking about palliative care services in British Columbia, Justice Smith refers to "the end-of-life population" (692). She does not define this term which in the Royal Society of Cana-

da Expert Panel Report on *End of Life Decision Making* encompasses a continuum beginning with a serious diagnosis or injury.¹⁸ This expansion of a term that traditionally is used for those in the last days or weeks of life to all with chronic conditions resulting from illness and injury presages precisely the dangerous expansion along a “slippery slope” from the “limited” exception the judge proposes. Likewise, the Supreme Court did not require a person to be terminally ill to have access to “physician assisted death”.

There is something chilling about Justice Smith’s construction of an “end-of-life population” that is not present when we speak of “dying people,” “vulnerable people,” “terminally ill people” or, even, “the terminally ill”. First, we do not know to whom it refers. But, if, as seems plausible, Justice Smith has accepted the approach of The Royal Society Expert Panel report, to which the Supreme Court also refers with approval [7], it may encompass all individuals with a serious diagnosis or injury that might be fatal in the course of time. And, of course, it is notoriously difficult to predict with any certainty the timing of death in relation to even obviously terminal illnesses for which no clinical treatment is possible.¹⁹

Just as troubling is the dropping of the word people or person. It is dehumanizing, depersonalizing and allows easier dis-identification from the person or people concerned. “The end-of-life population” is a term that marks off the people labeled as such from the general population. They become “them”, in contrast to the “rest of us.” It brings to mind Susan Sontag’s metaphor of the two “kingdoms,” the *kingdom of the well* and the *kingdom of the sick*, but, if physician-assisted suicide or euthanasia were legalized, with even more alienating and frightening connotations:

Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.²⁰

Justice Smith’s depersonalized and undefined generalization of an “end-of-life population” also brings to mind the dystopic world imag-

¹⁸ ROYAL SOC’Y OF CAN., EXPERT PANEL: END-OF-LIFE DECISION MAKING (2011).

¹⁹ Tom Koch, *End of Life, Year after Year after Year*, 181 CAN. MED. ASS’N J. 868 (2009).

²⁰ SUSAN SONTAG, *ILLNESS AS METAPHOR AND AIDS AND ITS METAPHORS* 3 (New York Anchor Books/Doubleplay 1978).

ined by P.D. James in her novel *The Children of Men* in which elderly persons' duty to die is enacted through a form of mass suicide called the Quietus (quiet us).²¹ And this disposal of the fragile through a "duty to die" was famously argued as policy by Colorado Governor Richard Lamm in the 1980s²² as well as by, in a modified form, ethicist and Hastings Center Fellow Daniel Callahan in the 1990s.²³

The point, yet again, is that despite the promise of very restricted relaxation of the current legal prohibitions protecting persons, implicit in Justice Smith's decision is the invitation to expansion of physician-assisted death to many people not dying, but diagnosed with a serious illness or disabled or, simply, suffering. The same is probably even truer with respect to the Supreme Court's ruling:

Section 241 (b) and s. 14 of the *Criminal Code* unjustifiably infringe s. 7 of the *Charter* and are of no force or effect to the extent that they prohibit physician-assisted death for a competent adult person who (1) clearly consents to the termination of life and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition.
[147]

The Supreme Court explicitly requires that informed consent to "physician-assisted death" (physician-assisted suicide and euthanasia) be obtained. But that is not possible unless all reasonable alternatives to the proposed "treatment" are offered.²⁴ This means that fully adequate palliative care must be available before a patient's consent to "physician-assisted death" would be valid. We know, however, that only 16 to 30 percent of Canadians who need palliative care have access to it, which is appalling. We also know that many patients who ask for euthanasia change their minds when given good palliative care.²⁵ And, because the Canadian Medical Association was proposed as one of the main advisers to the government about the steps it should now take in response to the *Carter* judgment, it's immensely worrying that in their factum as an in-

²¹ P.D. JAMES, *THE CHILDREN OF MEN* 68–79 (Knopf Canada 1992).

²² See T. KOCH, *THIEVES OF VIRTUE: WHEN BIOETHICS STOLE MEDICINE* (MIT Press 1990).

²³ DANIEL CALLAHAN, *SETTING LIMITS: MEDICAL GOALS IN AN AGING SOCIETY* (Simon & Schuster 1987).

²⁴ *Reibl v. Hughes*, [1980] 2 S.C.R. 880; *Hopp v. Lepp*, [1980] 2 S.C.R.192.

²⁵ Keith G. Wilson et al., *Desire for Euthanasia or Physician-Assisted Suicide in Palliative Cancer Care*, 26 *HEALTH PSYCHOLOGY* 314 (2007); see also Harvey Max Chochinov et al., *Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life*, 23 *J. CLINICAL ONCOLOGY* 5520 (2005).

tervener in the Supreme Court of Canada appeal, they expressly said that the non-availability of palliative care should not be a reason to refuse “physician-assisted death”.

B. Suicide Is Not a Crime

Justice Smith focuses on the Canadian Parliament’s repeal of the suicide and attempted suicide offences in 1972 and accepts, as she is bound to do by the precedent established by the Supreme Court of Canada in the *Rodriguez* case²⁶ that this was not done to give a personal choice to die priority. She states:

As to the objective underlying Parliament’s repeal . . . the majority [in *Rodriguez*] held that the objective was not to recognize a consensus that the autonomy interest of those who might wish to kill themselves is paramount to the state interest in protecting the lives of citizens; rather, it was to recognize that attempted suicide did not mandate a legal remedy. (926)

In the same vein, the Supreme Court notes that we can see that

Section 241 (b) [prohibiting assisted suicide] is not directed at preserving life, or even at preventing suicide — [because] attempted suicide is no longer a crime. [78]

With respect, I would explain the matter differently: the crimes of suicide and attempted suicide were abolished to try to save the lives of suicidal people. It was hoped that if they were not threatened with the possibility of being charged with a criminal offence in seeking medical help to treat suicidal ideation, they and their families would be more likely to seek such assistance.

In coming to her conclusions about the acceptability of legally permitted assisted suicide, throughout the judgment Justice Smith relies heavily on the fact that it is not a crime to commit or attempt to commit suicide, and asks, why then is it a crime to assist it? She opines:

[T]he law does not prohibit suicide (15). . . . The plaintiffs . . . argue that there is no ethical distinction between the laws that permit suicide and those that prohibit physician-assisted suicide. (176) . . . What is the difference between suicide and assisted suicide that justifies making the one lawful and the other a crime, that justifies allowing some this choice, while denying it to others? (1010)

²⁶ *Rodriguez v. British Columbia (Attorney General)*, [1993] 3 S.C.R. 519.

The answer is, as explained above, that decriminalizing suicide and attempted suicide is intended to protect life; decriminalizing assisted suicide does the opposite. We try to prevent suicide and, importantly, there is no right to commit suicide. If there were such a right, we would have a duty not to treat people who attempt suicide, in order to try to save their lives, and to let them die.

The difference between suicide and physician-assisted suicide is fundamental. Suicide is a solitary act we may try to prevent but which is carried out by the individual, usually in despair. Physician-assisted suicide is a social act in which medical personnel licensed and compensated by the state in Canada are involved in the termination of the life of a person with the approval of the state. It asks not that we attempt to preserve life, the normal role of medicine and the state, but that we accept and act communally upon a person's judgment that his or her life is unworthy of continuance.²⁷ It is to see the infliction of death as an ethical, appropriate and justified response to suffering. This is exactly the message that those trying to prevent suicide want to negate totally.

Assisted suicide thus involves a separate ethical enquiry that distinguishes it from suicide, an enquiry which is not undertaken in either the trial or Supreme Court judgments: this is the ethics of society's and a physician's complicity in helping a person to kill themselves. Legalized physician-assisted suicide involves both these forms of complicity: society is complicit in legalizing the procedure and a physician, licensed by society and, in Canada, compensated by it, is complicit in carrying it out.

For this reason the value of respect for life, especially at the societal level of respect for human life in general, is differently impacted by assisted suicide, as compared with suicide. The former contravenes this value, and particularly at the societal level, in a way that the latter does not.

Justice Smith relied on the dissenting judgment of Chief Justice Lamer of the Supreme Court of Canada in the *Rodriguez* case to find that

... s. 241(b) of the *Criminal Code* creates an inequality by preventing persons physically unable to end their lives from having the option to choose suicide, while other members of the public have that option. He [Chief Justice Lamer] found that the inequality is imposed because of a physical disability, a personal characteristic among the grounds of discrimination listed in s. 15(1) [of the Canadian Charter]. He concluded, at 549-50, that the inequality constitutes a burden or disadvantage since it limits the ability of persons who are subject to

²⁷ I am indebted to Canadian bioethicist, Dr. Tom Koch, for this formulation of the issue.

the inequality to take and act upon fundamental decisions regarding their lives and persons; for them, “the principle of self-determination has been limited”. Differing from the majority, he found that the infringement of s. 15 was not justified under s. 1 [of the Charter]. (1014)

But Justice Smith fails to mention that in order to rule to this effect the Chief Justice recognized a *right* to choose to commit suicide. The way in which the Chief Justice’s ruling is summarized in the head note to the *Rodriguez* case throws a different light on the passage from his judgment upon which Justice Smith relies:

This inequality—the *deprivation of the right to choose suicide*—may be characterized as a burden or disadvantage, since it limits the ability of those who are subject to this inequality to take and act upon fundamental decisions regarding their lives and persons. (Emphasis added)²⁸

Does such a right mean that we would have correlative obligations not to prevent people making that choice? Certainly, hospital emergency rooms and healthcare professionals faced with a patient who has attempted suicide do not, at present, act on that basis. And psychiatrists who fail to take reasonable care that their patients do not commit suicide, including by failing to order their involuntary hospitalization in order to prevent them committing suicide, can be liable for medical malpractice (negligence), unprofessional conduct (they lose their medical licenses), and, even, criminal negligence, in extreme cases.

The Supreme Court avoided addressing the issue of discrimination. In responding to the question, “Does the Prohibition on Assisted Suicide Violate Section 15 of the *Charter*?” prohibiting discrimination, it ruled:

Having concluded that the prohibition [of assisted suicide] violates s. 7, it is unnecessary to consider this question. [93]

C. Weighting the Evidence Disproportionately

Consistent with focusing on the risks and harms to individuals, the vast majority of the evidence to which Justice Smith gives credibility is empirical. Correlatively, she dismisses or gives short shrift to evidence she labels as non-empirical, which includes evidence of risks and harms to existential realities such as important shared societal values. In fact, the word “empirical” appears with great frequency in the judgment—28

²⁸ *Rodriguez v. British Columbia (Attorney General)*, [1993] 3 S.C.R. 519.

times in all. (It is paired with the words studies, research, evidence, knowledge, data, foundation, work, proof, and precision.) Suffering can be empirically established, although the evidence that demonstrates it is to a large extent subjective. In the *Carter* case it was introduced in evidence by witnesses who described either their own circumstances of illness and disability, and explained why they wanted the option of physician-assisted suicide to be available, or those of loved ones, who had also wanted that option. The Supreme Court emphasizes this evidence, focusing on individual cases and the suffering they manifest, starting with Gloria Taylor's situation [12] and continuing by referring to witnesses' descriptions of horrible diseases and suffering, the agony of treatment and the fear of a gruesome death. [14] As mentioned previously, at the very beginning of its judgment, the Supreme Court summarizes how it sees the situation of these people:

A person facing this prospect has two options: she can take her own life prematurely, often by violent or dangerous means, or she can suffer until she dies from natural causes. The choice is cruel. [1]

In contrast to the weight she gives to the plaintiffs' evidence, Justice Smith dismisses or gives little weight to most of the defendants' expert witnesses' testimony on the grounds that it's not empirically based. (See, for example, such references by the judge to the evidence of Dr Jose Pereira, Baroness Ilora Finlay, and Dr. Herbert Hendin (664)) The problem here is that many of the risks and harms of legalized physician-assisted suicide and euthanasia, at levels other than the individual one, are metaphysical risks and harms (to values, beliefs, attitudes, norms and so on) not physical risks and harms, the former of which are not necessarily assessable through empirical research, especially those that will occur in the future. The strong emphasis on empirical evidence, to the exclusion of other valid and accepted research methodologies, means that what can't be measured or counted is treated as unimportant or ignored.

In summary, almost all of Justice Smith's analysis, in particular of the risks and benefits of physician-assisted suicide, is at the level of the individual suffering patient, who wants physician-assisted suicide. By focusing her analysis at this level and treating empirical evidence as the only relevant or credible evidence, Justice Smith, in effect, uses an exclusionary mechanism to eliminate the evidence of the defendant governments' experts against legalizing physician-assisted suicide. In doing so, she weighs the balance heavily in favor of the relief of suffering as

the overriding value and a strong justification for physician-assisted suicide and euthanasia.

After refusing to allow the Attorney General to bring further evidence to clarify the problems with Justice Smith's rulings on the evidence, the Supreme Court examined these rulings in relation to Justice Smith's finding that sec 1 of the Charter's requirement of "minimal impairment" of Charter rights for the impairment to be constitutional was not fulfilled, and concluded as follows:

This question [whether an absolute prohibition of assisted suicide is required] lies at the heart of this case and was the focus of much of the evidence at trial. In assessing minimal impairment, the trial judge heard evidence from scientists, medical practitioners, and others who were familiar with end-of-life decision-making in Canada and abroad. She also heard extensive evidence from each of the jurisdictions where physician-assisted dying is legal or regulated. In the trial judge's view, an absolute prohibition would have been necessary if the evidence showed that physicians were unable to reliably assess competence, voluntariness, and non-ambivalence in patients; that physicians fail to understand or apply the informed consent requirement for medical treatment; or if the evidence from permissive jurisdictions showed abuse of patients, carelessness, callousness, or a slippery slope, leading to the casual termination of life (paras. 1365-66). [104]

...

As to the risk to vulnerable populations (such as the elderly and disabled), the trial judge found that there was no evidence from permissive jurisdictions that people with disabilities are at heightened risk of accessing physician-assisted dying (paras. 852 and 1242). [107]

...

The evidence, she concluded, did not support the contention that a blanket prohibition was necessary in order to substantially meet the government's objectives [of protection of vulnerable people]. We agree. A theoretical or speculative fear cannot justify an absolute prohibition. [119]

...

We find no error in the trial judge's analysis of minimal impairment [of section 7 rights, required under section 1 of the Charter for the impairing law to be constitutionally valid]. We therefore conclude that the absolute prohibition [on assisted suicide/physician assisted death] is not minimally impairing. [121]

D. Underlying Assumptions and Principles

Both Justice Smith and the Supreme Court of Canada make assumptions that assisted suicide (and euthanasia) is not inherently wrong and, moreover, that access to such an intervention is morally required in certain circumstances, in particular, to relieve suffering. In all probability, they are doing the same as we find in the Royal Society Expert Panel

Report²⁹ and the Quebec National Assembly one,³⁰ both of which were admitted in evidence at trial against the defendants' objections, and both of which were referred to by the Supreme Court. [7] This is simply to assume, without justifying doing so, that individual autonomy is the value that always takes priority. Like both those reports, Justice Smith's entire judgment, and that of the Supreme Court, is also consistent with the adoption of a philosophical base of moral relativism and an approach of utilitarianism, which favor seeing relief of suffering as an overriding justification for physician-assisted suicide and euthanasia.

In addressing the question of whether the principle of preservation of life has exceptions, Justice Smith, first, finds that it does, and then accepts the evidence of one of the plaintiffs' expert witnesses, Canadian philosopher Professor Wayne Sumner, to the effect that death is not a loss or bad, if there is no benefit in a continuing life, in other words, that a poor quality of life and suffering can justify such an exception. Here's her reasoning which includes a passage from Professor Sumner's evidence:

With respect to the first question [Does a physician have an overriding duty to support the inviolability of life and refrain from intentionally causing death, or can it be ethical, in an individual case, for a physician to assist a competent and informed patient who requests hastened death?], I think that the real difference of opinion is not about the value of human life; no-one questions that the preservation of human life has a very high value in our society. Rather, the difference of opinion is about whether the preservation of human life is an absolute value, subject to no exceptions. (350)

Professor Sumner explores this point:

Normally we assume that death is one of the worst fates that can befall us, which is why in both ethics and law the causing of death is taken to be such a serious matter. But what makes death such a bad thing in the normal case is what it takes away from us—the continuation of a life worth living. The disvalue of death is therefore a direct function of the value of the life thereby lost. This is the *deprivation account* of the badness of death: death is bad for us by virtue of depriving us of the goods of continued life. On this account showing that death would be bad for a person requires a comparison between two possible futures for that person: the one in which he dies and the one in which he lives on. If the goods of further life would outweigh the evils then it would be better for the person to continue living, and death would therefore be a harm to

²⁹ ROYAL SOC'Y OF CAN., *supra* note 18.

³⁰ SELECT COMM. OF THE ASSEMBLÉE NATIONALE OF QUÉBEC, REPORT ON DYING WITH DIGNITY (2012).

him since it would deprive him of this good future. [Emphasis in original.]
(351)

On the other hand, if the “evils” of continued life outweigh its goods, death is not a harm as nothing good is lost. This is a quality of life argument couched in different terms, those of non-deprivation. The person’s quality of life is seen as being so poor that they are not deprived of any benefit - indeed, they are benefited - by their life being taken.

Although Justice Smith speaks of this approach applying “in an individual case”, this same reasoning could readily be applied to babies with disabilities, people with dementia, and so on. Justifying the taking of or not maintaining the lives of such people on the basis of their poor quality of life and the suffering continued life involves is usually supported on the grounds they are “individual cases,” and the cumulative effect of the decisions taken in those cases is ignored. But the cumulative effect is to wipe out the people with a specified characteristic as a group. For instance, in North America around 85 percent of Down syndrome babies are now aborted. And, in 2011, two bioethicists caused an international furor when they published a paper in a highly respected journal proposing “post birth abortion”: parents who have a Down syndrome child, whom they would have aborted if they’d known of its condition, should be allowed to have it killed after birth (legalized infanticide).³¹ In this respect, it is relevant to point out that the Groningen protocol in the Netherlands allows the parents of severely disabled newborn babies to request that they be euthanized.³²

It merits noting in the context of exploring the cumulative effect of legalizing physician-assisted suicide and euthanasia that both the Royal Society panel’s report³³ and the Quebec National Assembly Select Committee report³⁴ raise the issue of whether euthanasia should be available for mentally incompetent people, for instance, those with Alzheimer’s disease. Neither report comes out against that being allowed, but, rather, they leave the question open stating that this is an issue to be examined further at a later date. However, if physician-assisted suicide is medical treatment meant to relieve suffering, as supporters of it argue it is, then it would be discriminatory to offer it to mentally competent peo-

³¹ Alberto Giubilini & Francesca Minerva, *After-Birth Abortion: Why Should the Baby Live?*, 39 J. MED. ETHICS 261 (2013).

³² Eduard Verhagen & Pieter J.J. Sauer, *The Groningen Protocol—Euthanasia in Severely Ill Newborns*, 352 NEW ENG. J. MED. 959, 996 (2005).

³³ ROYAL SOC’Y OF CAN., *supra*, note 18.

³⁴ SELECT COMM. OF THE ASSEMBLÉE NATIONALE OF QUÉBEC, *supra* note 30.

ple and not to incompetent ones.

E. The “No Difference” Argument

The essence of the “no difference” line of pro-euthanasia argument, which was accepted by Justice Smith and the Supreme Court and is central to their judgments, is that we already accept and practice interventions, such as withdrawal of life-support treatment or the provision of necessary pain management that results in death or could shorten life, respectively, and there is no ethical or moral difference between these, on the one hand, and physician-assisted suicide and euthanasia,³⁵ on the other, and there ought to be no legal difference. The argument is that the latter are of the same kind as the former and legalizing them is just a further incremental step along a path that we have already taken and regard as ethically and legally acceptable. Justice Smith puts it this way:

That spectrum [of acceptable interventions at the end-of-life] already encompasses decisions where the likely consequence of the decision will be the death of the patient. (1240)

I call this strategy “legalizing euthanasia through confusion.”³⁶ It depends on a misleading and, I would argue, false analogy. The issue in the “euthanasia debate” is not *if* we die—we will all die eventually - but the ethics and law of *how* we die. People who oppose physician-assisted suicide and euthanasia believe these are unethical ways to die and can be validly distinguished from the other ways in which life may be shortened and, consequently, the former should remain prohibited. The difference can be summarized as that between allowing a person to die a natural death and killing the person.

The essential ethically and legally relevant differences between the two kinds of interventions do not include that between an act and an omission, on which pro-euthanasia advocates, such as Canadian law professor, Jocelyn Downie, allege anti-euthanasia proponents rely.³⁷ Like the *acts* of physician-assisted suicide or euthanasia, an *omission*, for example, withdrawal of life-support treatment that results in a person’s

³⁵ In this section, in using the word euthanasia, I intend it to include physician-assisted suicide.

³⁶ Margaret Somerville, *Euthanasia by Confusion*, 20 U.N.S.W. L.J. 550 (1997); see also DEATH TALK, *supra* note 2, at 119–43.

³⁷ JOCELYN DOWNIE, *DYING JUSTICE: A CASE FOR DECRIMINALIZING EUTHANASIA AND ASSISTED SUICIDE IN CANADA* (Univ. of Toronto Press 2004).

death, can be (but, unlike physician-assisted suicide or euthanasia, is not necessarily) ethically, morally and legally culpable. The relevant differences between these two kinds of interventions lie in the primary intention with which they are undertaken and in causation of death.

The distinction between pain relief treatment and euthanasia hinges on the physician's primary intention in giving the treatment, the patient's need for the treatment given and the appropriateness of the choice of the treatment, for instance, an injection of potassium chloride which kills a patient is not a pain relief treatment.

Pain relief treatment given with a primary intention to relieve pain and reasonably necessary to achieve that outcome is not euthanasia, even if it did shorten the patient's life (which is a very rare occurrence for correctly titrated treatment). Any intervention, including the use of pain relief drugs, carried out with a primary intention of causing the patient's death and resulting in that outcome, is euthanasia.

Acting with a primary intention to kill is a world apart from acting with a primary intention to relieve pain. And this is not a novel or exceptional approach. The law recognizes the relevance of such distinctions in intention daily. If we accidentally hit and kill a pedestrian with our car, it is not murder; if we deliberately run him down with our car intending to kill him, it is. It's the same act, but different intentions make the difference.

People in pain are among the most vulnerable persons, so the issue of adequate pain management has special application in relation to them. As Albert Schweitzer said, "Pain is a more terrible Lord of mankind than death itself." A person in pain can want to die by any means, rather than have to go on living in pain. Consequently, we have serious ethical obligations—and I would argue legal obligations—to offer everyone fully adequate pain management.

An adverse consequence of equating pain management to euthanasia is that it can make people who reject euthanasia reject adequate pain management for ethical or religious reasons, or because of fear that if they consent to it, they will be euthanized. Experience in the Netherlands shows that the latter is not an unjustified fear: It's been alleged that Dutch physicians have interpreted patients' consent to pain management as consent to euthanasia.³⁸

The *primary intention* is also different in withdrawing life-support treatment, on the one hand, and physician-assisted suicide and euthana-

³⁸ Lauren Vogel, *Line Between Acts and Omissions Blurred, Euthanasia Critics Argue*, 184 CAN. MED. ASS'N J. E19–E20 (2012).

sia, on the other. In withdrawing life-support treatment, the primary intention is to respect the patient's right to refuse all treatment or to remove medically futile treatment or that where the burden of the treatment for the patient outweighs any benefits. In physician-assisted suicide or euthanasia the *primary intention* is to help the patient to kill himself or to kill him, respectively. The former intention is ethically and legally acceptable; the latter intentions are not.

Patients have a right to refuse treatment, even if that means they will die. Such a refusal is an exercise of their right to autonomy and self-determination, but the content of that right in such situations is a right not to be touched without their consent including by treatment—a right to inviolability—not a right to die.

Pro-euthanasia advocates use recognition of the right to refuse treatment even when it results in death, to argue that, likewise, patients should be allowed to exercise their right to autonomy and self-determination to choose death through lethal injection. As explained above, they say that there is no morally or ethically significant difference between these situations, and there ought to be no legal difference.

They found their argument by wrongly characterizing the right to refuse treatment as a “right to die”, and then generalize that right to include euthanasia and physician-assisted suicide. But the right to refuse treatment is not a “right to die” and does not establish any such right, although death results from respecting the patient's right to inviolability. The right to refuse treatment can be validly characterized as a “right to be *allowed* to die”, which is quite different from a right to be killed that proponents want legalized euthanasia to establish.

This particular pro-euthanasia line of argument is just one more example of promoting euthanasia through deliberate confusion between interventions, such as acting on valid refusals of treatment, that are not euthanasia and those that are.

This brings us to the issue of causation, which also differentiates refusals of treatment that result in death from euthanasia.

In refusals of treatment that result in death, the person dies from her underlying disease—a natural death. The withdrawal of treatment is the occasion on which death occurs, but not its cause. If the person had no fatal illness, she would not die. And, moreover, sometimes patients, who refuse treatment and are expected to die, do not die. In contrast in euthanasia, death is certain and the cause of death is the lethal injection. Without that, the person would not die at that time from that cause.

The fact that the patient dies in both refusing treatment that results

in death and in euthanasia is one of the causes of the confusion between the two situations. If we focus just on that outcome of death, we miss what the real point of distinction between the two situations is.

Here's how Justice Smith articulated the plaintiffs' expert witnesses' "no difference" arguments, which she endorsed (see, for example, at 335, 339, 349) and which the Supreme Court, not only, accepted, but also, used as a central rationale for finessing (*quaere* overriding) its previous decision in the *Rodriguez* case that the absolute prohibition of assisted suicide and euthanasia in the Canadian Criminal Code were constitutionally valid:

[T]he plaintiffs argue that the current line drawn between permissible and impermissible end-of-life care is based upon distinctions that in reality have no practical ethical or moral force. They also argue that there is no ethical distinction between the laws that permit suicide and those that prohibit physician-assisted suicide." (176) . . . One of the main arguments for the proposition that physician-assisted death can be an ethical practice is that physician-assisted death is ethically indistinguishable from conventionally ethical end-of-life practices such as withholding or withdrawing treatment or administering palliative sedation." (186) . . . However, as set out in my review of the evidence with respect to safeguards, in the opinion of a number of respected ethicists and practitioners, physician-assisted death *in an individual case* is not ethically distinguishable from currently legal and ethically accepted end-of-life practices. (Emphasis added) (1369)

The Supreme Court described Justice Smith's formulation of this "no difference" argument as follows:

The trial judge began by reviewing the current state of the law and practice in Canada regarding end-of-life care. She found that current unregulated end-of-life practices in Canada — such as the administration of palliative sedation and the withholding or withdrawal of lifesaving or life-sustaining medical treatment — can have the effect of hastening death and that *there is a strong societal consensus that these practices are ethically acceptable* (para. 357). After considering the evidence of physicians and ethicists, she found that the "preponderance of the evidence from ethicists is that there is no ethical distinction between physician-assisted death and other end-of-life practices whose outcome is highly likely to be death" (para. 335). Finally, she found that there are qualified Canadian physicians who would find it ethical to assist a patient in dying if that act were not prohibited by law (para. 319). (Emphasis added) [23]

It's interesting to speculate why Justice Smith, yet again,³⁹ limited

³⁹ See *Carter v. Canada (Attorney General)*, 2012 BCSC 886.

her statement to “an individual case.” Read in relation to the judgment as a whole it is probably because she requires justification for physician-assisted suicide in each case and that would require that the person were “grievously ill” (1271), that is, suffering. But it could also be taken to mean such interventions are not able to be justified as a group or on the whole, because of their cumulative impact on important shared values, in particular respect for life, or at institutional and societal levels, issues which Justice Smith does not consider in any depth or at all. Or it could be that the judge wants to avoid setting a precedent that people with a certain disability are automatically identified by that disability as having a claim—or even a right—with respect to having access to physician-assisted suicide or euthanasia.

The Supreme Court adopts a “no difference” approach and expands on Justice Smith’s reasoning in analysing what respect for the sec 7 Charter rights to “liberty and security of the person” require, making these rights protective of a very broad scope for the exercise and dominance of individual autonomy and, concurrently, more easily breached by any restriction on a person’s “choice”:

We agree with the trial judge. An individual’s response to a grievous and irremediable medical condition is a matter critical to their dignity and autonomy. The law allows people in this situation to request palliative sedation, refuse artificial nutrition and hydration, or request the removal of life-sustaining medical equipment, but denies them the right to request a physician’s assistance in dying. This interferes with their ability to make decisions concerning their bodily integrity and medical care and thus trenches on liberty. And, by leaving people like Ms. Taylor to endure intolerable suffering, it impinges on their security of the person. [66]

This broad interpretation of sec 7 rights combined with a very narrow interpretation of the valid object of prohibiting assisted suicide allowed the Supreme Court to find, respectively, breaches of all sec 7 rights and a lack of justification for those breaches.

The Supreme Court also added that requiring respect for “the principles of fundamental justice” if breaches of sec 7 rights are to be constitutionally valid, is connected with respecting people’s dignity:

In *Re B.C. Motor Vehicle Act*, [1985] 2 S.C.R. 486 (the “*Motor Vehicle Reference*”), Lamer J. (as he then was) explained that the principles of fundamental justice are derived from the essential elements of our system of justice, which is itself founded on a belief in the dignity and worth of every human son. To deprive a person of constitutional rights arbitrarily or in a way that is overbroad or grossly disproportionate diminishes that worth and dignity. [81]

In considering the impact on physicians, patients and palliative care of legalizing physician-assisted suicide, Justice Smith recognizes there will be both positive and negative effects, but concludes the positive ones will outweigh the negative.(1270-1285):

For physicians who see no ethical distinction between assisted death for grievously ill patients and certain current legal end-of-life practices, the law draws an arbitrary line and promotes a kind of hypocrisy. Removing it would permit physicians a more open relationship with their patients and support intellectual honesty in the ethical debate. Indeed, evidence from other jurisdictions suggests that physicians are able to provide better overall end-of-life treatment to patients at the end of their lives once the topic of assisted death is openly put on the table. (1271)

As mentioned previously, Justice Smith considered in her judgment the personal stories of people who recount serious suffering because physician-assisted suicide or euthanasia was not available. Personal stories of those who oppose these interventions, while submitted, apparently were not a factor in her deliberations.

Yet, in contrast to the rulings cited above, Justice Smith notes that the Supreme Court of Canada recognized, in the *Rodriguez* case, that there is a valid distinction between refusing life-support treatment and euthanasia:

Rodriguez also summarized and clarified the law regarding the common law right of patients to refuse consent to life-sustaining medical treatment, and to demand that such treatment be withdrawn or discontinued. As I have earlier described, the majority [of the Supreme Court] accepted that there is a valid distinction between the role of physicians in those situations and the role of physicians in assisted suicide or euthanasia, based on the intention of the physician. (929)

Clearly the Supreme Court is no longer of this view.

In the context of considering the “no difference” line of reasoning, it merits noting that a common thread among all end-of-life interventions, and their goal, is the avoidance or relief of suffering. The pro-euthanasia argument is that such relief is the overriding priority and an end that justifies any necessary means of achieving it, including assisted suicide and euthanasia. While people who are anti-euthanasia are also anti-suffering, they strongly disagree that outcome should be realized through the infliction of death.

F. *Dismissing Slippery Slopes*

Justice Smith's rulings regarding the practical and logical slippery slopes in jurisdictions which had legalized "physician assisted death" are of major importance, because they were accepted by the Supreme Court which, as noted previously, refused Canada's request to bring evidence to show they were factually wrong.

In assessing the practical slippery slope—the risks of abuse if an absolute ban on physician-assisted suicide is not maintained and it's permitted under certain conditions— Justice Smith considers "life ending acts without explicit request" (LAWER) and the presence of mental illness in people wanting physician-assisted suicide. She extensively reviews "medically assisted dying" legislation in Oregon, and The Netherlands and Belgium and notes that prohibiting physician-assisted suicide and euthanasia doesn't prevent them from being carried out (see, for example, (523)). And, she again, conflates pain relief and withdrawal of treatment, on the one hand, with euthanasia, on the other. (525)

The judge's reassuring conclusions about the effectiveness of safeguards in the jurisdictions she examines are, however, far from universally shared and evidence for the existence of both practical slippery slopes and logical slippery slopes—the expansion of justifications for physician-assisted suicide and euthanasia—is very convincing. In fact, her findings in this regard were expressly rejected by the High Court of Ireland in *Fleming vs. Ireland and others*,⁴⁰ after the court extensively reviewed the evidence on which Justice Smith relied. Here's how their finding is summarized:

In that case [the *Carter* case at trial level], the Canadian court reviewed the available evidence from other jurisdictions with liberalised legislation and concluded that there was no evidence of abuse. This Court also reviewed the same evidence and has drawn exactly the opposite conclusions. The medical literature documents specific examples of abuse which, even if exceptional, are nonetheless deeply disturbing. Moreover, contrary to the views of the Canadian court, there is evidence from this literature that certain groups (such as disabled neonates and disabled or demented elderly persons) are vulnerable to abuse. Above all, the fact that the number of LAWER ("life-ending acts without explicit request") cases remains strikingly high in jurisdictions which have liberalised their law on assisted suicide (Switzerland, Netherlands and Belgium)—ranging from 0.4% to over 1% of all deaths in these jurisdictions according to the latest figures—without any obvious official response speaks for itself as to the risks involved.

⁴⁰ *Fleming v. Ireland & Ors*, [2013] IEHC 2.

Yet the Supreme Court of Canada held:

The trial judge then turned to the evidence from the regimes that permit physician-assisted dying. She reviewed the safeguards in place in each jurisdiction and considered the effectiveness of each regulatory regime. In each system, she found general compliance with regulations, although she noted some room for improvement. [25]

The trial judge made no palpable and overriding error in concluding, on the basis of evidence from scientists, medical practitioners and others who are familiar with end-of-life decision-making in Canada and abroad, that a permissive regime with properly designed and administered safeguards was capable of protecting vulnerable people from abuse and error. [Headnote]

A chilling example of the logical slippery slope is the euthanizing, in December 2012, of 45 year old twins in Belgium. Deaf since childhood, Marc and Eddy Verbessem were facing the additional disability of blindness. Accepting that they were irremediably suffering, their physician euthanized them.⁴¹

Justice Smith rules that the nature of the risks of “medically assisted death” is no different from other end-of-life decisions. In other words, she again adopts the “no difference” approach, outlined above, to reject the dangers of physician-assisted suicide opening up slippery slopes by accepting the plaintiffs’ suggestion,

that the very same risks exist with respect to current end-of-life practices [as with physician-assisted suicide]. A patient who chooses to withdraw from life-sustaining treatment may present exactly the same challenges to caregivers, who need to know if the patient is truly giving informed consent, is not suffering from untreated depression, or is acting under some kind of duress or coercion. (1237)

Justice Smith does not look at the slippery slope in the Netherlands constituted by the expansion of justifications for euthanasia and she does not mention the major increase in the use of terminal/palliative sedation (the patient is sedated until they die) in Belgium.⁴² This can be euthanasia (terminal sedation) where it is used to continuously sedate a patient until they die from lack of food and fluids, but is not in circumstances

⁴¹ Howard Koplowitz, *Deaf Twins Euthanized: Belgian Brothers Marc And Eddy Verbessem Wanted to Die Because They Were Going Blind*, IBT (Jan. 16, 2013), <http://www.ibtimes.com/deaf-twins-euthanized-belgian-brothers-marc-eddy-verbessem-wanted-die-because-they-were-going-blind>.

⁴² Johan Bilsen et al., *Medical End-of-Life Practices under the Euthanasia Law in Belgium*, 361 NEW ENG. J. MED. 1119, 1121 (2009).

where it is the only reasonable way to relieve serious pain and suffering (palliative sedation). In other words, whether sedation is terminal or palliative depends on all the circumstances, including the patient's medical situation, the medication used and its dosage, and the alternative treatments available.

We can ask why terminal sedation is being favored over "classic" euthanasia methods (lethal injections) that have been used up to the present, for instance, in the Netherlands. Might palliative sedation make the patient's death seem more like a natural death? Might it reflect a moral intuition there's something wrong in intentionally killing another human being and the killing is less obvious when a lethal injection is avoided? Or might it just be that administrative requirements, such as the requirement to report cases of euthanasia, are inapplicable to terminal sedation?

G. *Prioritizing Autonomy and Choice*

At its simplest, the euthanasia debate can be seen as a clash between the value of "respect for life" and the value of respect for individual autonomy, usually backed up by a "relief of suffering" argument, and disagreement as to which should take priority. People who oppose euthanasia give priority to respect for life and point out that pain and suffering can be relieved without killing the person who suffers, including, where warranted, by palliative sedation.

In contrast, the value of "choice" or individual autonomy and self-determination is central to the pro-euthanasia argument and because it gives the person a sense of control is seen, in itself, as reducing suffering. Here are some examples of how that argument is expressed by Justice Smith in her judgment:

No-one should be deprived of liberty, or *forced to suffer*, without adequate cause. Failing to respect an autonomous choice to die risks paternalism. [Emphasis added] (315)

For people with liberal values, paternalism is always a major harm. Then Justice Smith rules:

In my opinion, the law [prohibiting assisted suicide] creates a distinction that is discriminatory. It perpetuates and worsens a disadvantage experienced by persons with disabilities. *The dignity of choice* should be afforded to Canadians equally, but the law as it stands does not do so with respect to this ultimately personal and fundamental choice [to die]. [Emphasis added] (1161)

But, even assuming that there is a legally relevant distinction, in view of the fact that no one has a right to commit suicide and, where possible, people who attempt it will be prevented from doing so, one can query whether the law creates a discriminatory distinction. The Supreme Court takes a complementary but different approach; it identifies a lack of access to “physician assisted death” – a lack of that choice - as a cause of suffering saying, as cited previously:

Yet running through the evidence of all the witnesses is a constant theme — that they suffer from the knowledge that they lack the ability to bring a peaceful end to their lives at a time and in a manner of their own choosing.[14]

I also note here Justice Smith’s use of the phrase “the dignity of choice”, which I have not encountered before. As I’ve discussed elsewhere, dignity is a complex and controversial topic in bioethics; and choice is a neutral concept in the sense that some choices will enhance human dignity, others will harm it, and it’s *what* we choose that makes a choice ethical or unethical, not just the presence of choice, itself.

H. Justifying Physician-Assisted Suicide and Euthanasia through Relief of Suffering

As noted already, respect for individual autonomy and choice is one of the primary values for supporters of legalizing euthanasia, the other is the relief of suffering. Justice Smith links these values to each other and also gives priority to the relief of an individual’s suffering over risks of harm to other individuals from the precedent set by the means used to relieve that suffering. She states:

[M]y review of all the evidence shows that the ethical and practical arguments in favour of making physician-assisted death available to the limited category of patients described [include that]. . . . It is unethical to refuse to relieve the suffering of a patient who requests and requires such relief, simply in order to protect other hypothetical patients from hypothetical harm. (315(l)). . . It must not be overlooked that what is at stake for someone in Gloria Taylor’s situation is not merely autonomy, nor is it simply autonomy with respect to physical integrity. It is the *autonomy to relieve herself of suffering*. [Emphasis added] (1156)

The Attorney General of Canada argued that

the Court must address whether the autonomy interests and suffering of some individuals are outweighed by the public benefits of promoting the value of

every life, preserving life, protecting the vulnerable, preventing abuses, maintaining the physician-patient relationship and promoting palliative care. (1247)

But the judge rejects arguments that harm to society can outweigh individuals' rights to autonomy, although she requires the presence of suffering for those rights to extend to physician-assisted suicide and euthanasia. In doing so, the judge limits the scope of a person's autonomy to choose death, by requiring the presence of suffering. In other words, the presence of suffering is functioning as a limiting device on the exercise of a legal right to autonomy with respect to self-willed death and the assistance of a physician in implementing that goal.

The Supreme Court addressed the Attorney General's arguments that allowing the permissive regulatory regime [-"physician assisted death"-] accepted by the trial judge "accepts too much risk", and that its effectiveness [to prevent abuse of physician-assisted death] is "speculative" (R.F., at para. 154) [118], and, therefore, the prohibition of assisted suicide was justified under sec 1 of the Charter. The Supreme Court responded that "[t]he burden of establishing minimal impairment [under sec 1] is on the government." It continued:

The trial judge found that Canada had not discharged this burden. The evidence, she concluded, did not support the contention that a blanket prohibition was necessary in order to substantially meet the government's objectives. We agree. A theoretical or speculative fear cannot justify an absolute prohibition. As Deschamps J. stated in *Chaoulli*, at para. 68, the claimant "d[oes] not have the burden of disproving every fear or every threat", nor can the government meet its burden simply by asserting an adverse impact on the public. Justification under s. 1 is a process of demonstration, not intuition or automatic deference to the government's assertion of risk (*RJR-MacDonald*, at para. 128). [119]

Justice Smith also sees the presence of suffering at the end of life as differentiating suicide in that context from it in other contexts, and as a justification for the former: "[The Attorney General of] Canada mistakenly presumes that Canadians do not see a difference between assisted death in response to intolerable suffering at the end of life, and suicide arising out of mental illness or transitory sadness." (1262) The judge does not consider that many suicidal people also experience what they perceive as "intolerable suffering" and the likely impact of the message that this passage gives that suicide is an appropriate response to suffering, at least in some circumstances. The Supreme Court does not address the issue of the impact of legalizing "physician assisted death" on legit-

imating suicide, in general.

Suffering is a very difficult reality to deal with in post-modern secular democracies, such as Canada. Traditionally we have accommodated suffering in our lives, by finding meaning in it, but we largely did that through traditional religion. In secular societies, it is much more difficult for many people to find such meaning. Yet it can be found, as many stories of deep suffering and bravery that move us profoundly attest.

I. Accepting Physician-Assisted Suicide and Euthanasia as Medical Treatment

Justice Smith appears to accept the argument that legalizing euthanasia could enhance palliative care. (See, for example, 584, 585, and 721) and the Supreme Court notes this finding.[26 and 107] This goes some way, at the least, towards treating euthanasia as, as some have termed it, “the last act of good palliative care.” It’s also consistent with the “no difference among them” approach to a spectrum of end-of-life medical interventions that include euthanasia and physician-assisted suicide, discussed above. But my colleague, Donald Boudreau, a specialist physician, and I adamantly reject that euthanasia can ever be medical treatment, as it is fundamentally incompatible with the healing role of physicians.⁴³ It merits noting that as a result of Quebec palliative care physicians protesting the inclusion of “medical aid in dying” in the definition of palliative care, the definition in article 3(3) of *An Act respecting end-of-life care* was amended, although not to their satisfaction. It now reads: “end-of-life care” means palliative care provided to persons at the end of their lives, including terminal palliative sedation, and medical aid in dying.”

Apart from other considerations, whether euthanasia is medical treatment matters in Canada for jurisdictional reasons. Governance of medical treatment is a provincial, not a federal, jurisdiction, which is one reason why the report, “Dying with Dignity,” of the Quebec National Assembly Select Committee,⁴⁴ and the Quebec College of Physicians and Surgeons both argue that it is medical treatment. The Supreme Court has recognized it as such ruling:

⁴³ Donald Boudreau & Margaret A. Somerville, *Euthanasia Is Not Medical Treatment*, 106 BRIT. MED. BULL. (2013), <http://bmb.oxfordjournals.org/content/early/2013/03/26/bmb.ltd010.full>.

⁴⁴ SELECT COMM. OF THE ASSEMBLÉE NATIONALE OF QUÉBEC, *supra* note 30.

Health is an area of concurrent jurisdiction; both Parliament and the provinces may validly legislate on the topic: *RJR-MacDonald Inc. v. Canada (Attorney General)*, [1995] 3 S.C.R. 199, at para. 32; *Schneider v. The Queen*, [1982] 2 S.C.R. 112, at p. 142. This suggests that aspects of physician-assisted dying may be the subject of valid legislation by both levels of government, depending on the circumstances and focus of the legislation. We are not satisfied on the record before us that the provincial power over health excludes the power of the federal Parliament to legislate on physician-assisted dying. [53]

This ruling means the Quebec Government has the right to pass laws to regulate these “treatments” and physicians to administer them to patients.

But, if, as we are told, society wants physician-assisted suicide and euthanasia legalized, should physicians or some other professionals carry them out? In other words, should we clearly separate those interventions from medical treatment?

It’s a controversial suggestion, but I propose that the “medical cloak” – the “white coat” – must be taken off legalized physician-assisted suicide and euthanasia, that is, physicians should not be the ones to carry them out.

One reason, among many, to take the medical cloak off physician-assisted suicide and euthanasia is that it causes people to fear physicians, accepting pain relief treatment, and hospice and palliative medicine and care.

As well, placing a medical cloak on physician-assisted suicide and euthanasia, yet again, causes confusion. It makes these interventions seem safe, ethical and humane, because those are the characteristics we associate automatically with medical care, when, in fact, we all need to question the ethical acceptability of legalizing physician-assisted suicide and euthanasia and physicians being authorized to carry them out.

One suggestion for alternative practitioners, that has shocked even people who are euthanasia advocates, is to consider having specially trained lawyers, which is not my original idea.⁴⁵ The justification put forward for this choice is that lawyers understand how to interpret properly and to strictly apply laws and, for pro-euthanasia advocates, ensuring that in order to prevent abuse is their major concern, not euthanasia itself.

Justice Smith turns to the British Columbia Prosecutorial policy on assisted suicide for definitional assistance with respect to whether physi-

⁴⁵ See R.M. Sade & M.F. Marshall, *Legistrotanatory: A New Specialty for Assisting in Death*, 39 PERSP. BIOLOGY & MED. 547 (1996).

cian-assisted suicide is medical treatment:

In the policy, “palliative care” is defined as “a qualified medical practitioner, or a person acting under the general supervision of a qualified medical practitioner, administering medication or other treatment to a terminally ill patient with the intention of relieving pain or suffering, even though this may hasten death”. The policy states that that conduct, “when provided or administered according to accepted ethical medical standards, is not subject to criminal prosecution.” (303)

In other words, the policy can be expansively interpreted as placing physician-assisted suicide and euthanasia in same category as other end-of-life treatment interventions that “may hasten death”. This “no difference” reasoning, which I have discussed already, is central to both the trial judge’s and the Supreme Court’s decisions.

Justice Smith was deeply impressed with the evidence given by American philosopher and bioethicist, Professor Margaret Battin, an expert witness for the plaintiffs, who is a prominent advocate of legalizing physician-assisted suicide and euthanasia. She extensively reviewed and endorsed Battin’s views about

the core principles central to the [assisted suicide and euthanasia] debate: liberty (also referred to as freedom, self-determination or autonomy) and mercy (compassion, or the right to be free from pain and suffering) . . . [and] a third core value for physicians, non-abandonment. (239)

The judge also extensively reviews research by Battin and her colleagues on euthanasia in the Netherlands and the American state of Oregon and endorses their findings that abuses are within acceptable limits.⁴⁶ She approvingly quotes Battin to the following effect:

Those who oppose physician aid in dying must show that the principles of liberty and *freedom from suffering* that are basic to an open, liberal and democratic society should be overridden. (Emphasis added) (241)

In short, a reversal of the burden of proof is justified on the basis of respecting liberty and implementing freedom from suffering.

⁴⁶ As already noted, the High Court of Ireland came to the opposite conclusion after reviewing the evidence on which Justice Smith relied.

J. Balancing Autonomy and the Common Good

I would like, here, to summarize how I see the Supreme Court of Canada's judgment in regard to the central issue in the *Carter* case, striking the balance between upholding individual autonomy and protecting the common good.

By adopting a very expansive interpretation of the sec 7 Charter rights – the rights to life, liberty and security of the person - with respect to the scope of their protection of individuals' rights to autonomy, the Supreme Court was able to find that they were all violated. In stark contrast, the Court adopted a very narrow interpretation of what was required to protect the common good, in fact, in effect it eliminated this consideration as a valid objective of the prohibition of assisted suicide. The combination of this expansive approach and this narrow approach allowed the Court to rule, first, that all the sec 7 rights were breached by an absolute prohibition of assisted suicide and, second, that these breaches could not be justified under the "saving provisions" of the Charter and, therefore, the absolute prohibition was unconstitutional.

The Court was able to reach this conclusion through three main steps in its reasoning, all of which, in my respectful opinion, raise problems. To summarize: First, as examined already, at the heart of the *Carter* judgment are the "no difference" arguments, which are in error when based on false analogies and failures to distinguish between differences of degree and differences of kind, indeed expressly rejecting such distinctions, as the Court did in ruling there was "no difference" between withdrawing life support treatment to allow a person to die a natural death and inflicting death (helping a person to kill herself or, even, killing her). Second, the Court focused on the requirements for upholding the value of "preservation of life", as the relevant value in determining whether an absolute prohibition on assisted suicide was justified. In ruling that it was not justified, the Court relied heavily on its finding, which is correct, that the value of "preservation of life" is not absolute, citing, once again, the acceptance of the withdrawal of life support treatment as legal and ethical as showing this. The problem, in my opinion and as I have explained previously, is that this is not the correct value against which to test whether an absolute prohibition on assisted suicide is justified. Rather, the value of "respect for life" and what is required to uphold this value is the relevant one, and, I propose, that does require an absolute ban. And, third, the Court accepted several other "no difference" arguments, including that there is no difference between suicide

and assisted suicide, therefore, if suicide is not a crime assisting suicide should not be a crime.

K. *Values Related to Human Life*

Finally, in analyzing the *Carter* case, I wish to briefly note the large number of values related to human life that Justice Smith identifies in her judgment, some of which are also to be found in the Supreme Court judgment, and which inform her decision.

Concepts of a *right to life*, *respect for life*, the *preservation of life*, the *inviolability of life*, the *protection of life*, the *sanctity of life*, and *quality of life* are all referred to by Justice Smith. They are all related – not least by their connecting thread of dealing with life - and some are used interchangeably. There can be, however, differences among them, which, despite sometimes being nuanced, are important to understand for two reasons: such understanding can lead to different conclusions about ethics than would otherwise be the case; and it can provide insights that would be otherwise unavailable.

I want to note here the legal rule of statutory interpretation against redundancy, namely, that when a different word or term is used in the same statute, it is meant to refer to something different from a synonymous word or term used in the same statute. Although that rule does not apply to the *Carter* judgments because they are not legislation, the wide variety of words and terms used in them to describe the same realities raises questions in this regard, which are relevant to how the judgments should be interpreted in some instances.

1. “Right to Life”

As discussed previously, both Justice Smith and the Supreme Court ruled that the prohibition of assisted suicide affected Ms Taylor’s right to life because it may shorten her life. “Ms. Taylor’s reduced lifespan would occur if she concludes that she needs to take her own life while she is still physically able to do so, at an earlier date than she would find necessary if she could be assisted.” (17) This reasoning converts the right to life to a right to death by physician-assisted suicide or euthanasia.

2. “Respect for Life”

Justice Smith links “*respect for life*” with “*protection of life*”,

which I discuss shortly, and interprets it through that latter lens, which radically alters how the requirements of the former are defined. She writes:

Canada says that the preservation of human life is a fundamental value in Canadian society and that respect for life transcends individual, religious and diverse cultural values. Canada does not assert a state interest in the absolute protection of all human life. It says, however, that respect for this fundamental value is reflected in the state's interest in not condoning the taking of human life, and embodied in the criminal law. (168). . .

For the purposes of both its s. 7 and s. 1 [Charter] analyses, the majority [in *Rodriguez*] held that the objective of s. 241(b) is the protection of the vulnerable who might be induced in moments of weakness to commit suicide. It held that objective to be grounded in the state interest in protecting life, and in the state policy that human life should not be depreciated by allowing life to be taken. (926)

Limiting the purpose of prohibiting assisted suicide to the protection of vulnerable people means that if, in a given case, they don't require this protection (as the judge rules Ms. Taylor does not) abandoning it does not contravene respect for life. This creates a large unprotected population, in Justice Smith's vague phrase the "end of life population", for whom the protections promised to the population at large will not hold. They are excluded by judicial fiat.

Compare this with the reverse order of analysis, which starts from respect for life: Respect for life requires protection of vulnerable people as members of the human community – indeed, it requires protection of all human lives - and failure to provide that protection contravenes respect for life. As this comparison shows, starting points of analyses and basic presumptions are not neutral with respect either to decisions which are based on them or to outcomes.⁴⁷

As well, Justice Smith looks at respect for life only at the level of the individual person or, at most, primarily through that lens. She does not consider what might be required if we are to maintain respect for human life, in general, and at institutional and societal levels. Those analyses could result in different conclusions as to what is required.

But focusing the analysis, in particular of the risks, harms and benefits of physician-assisted suicide, at the level of the individual patient is inevitable when the analysis is directed through a *Charter* lens, as is true

⁴⁷ Margaret Somerville, *Law Marching with Medicine but in the Rear and Limping a Little: Ethics as "First Aid" for Law*, in *ETHIK UND RECHT—DIE ETHISIERUNG DES RECHTS [ETHICS AND LAW—THE ETHICALIZATION OF LAW]* 62 (Silja Voneky et al. eds., 2013).

in the *Carter* case. The *Charter's* main purpose is to protect individuals from wrongful exercises of state power that unjustifiably interfere with their rights. Any competing claims of society and avoiding harm to institutions or society are taken into account mainly at a secondary justificatory analytic stage under section 1 of the *Charter*. As can be seen in the *Carter* case, these latter claims can be downplayed by the judiciary. The *Carter* judgment, at both the trial court and Supreme Court levels, contains little in-depth consideration of the impact on societal values and on the institutions of law and medicine of legalizing physician-assisted suicide. It merits noting that the same failure to give sufficient weight to societal claims and needs, and unwillingness to uphold those claims, is manifested in Parliament's enormous reluctance to use the *Charter's* "notwithstanding clause", which allows Parliament to validate legislation that the courts have found to be unconstitutional.⁴⁸

The *Charter* makes available so many tests for assessing whether legislation is in compliance with its provisions that it can be used by a court to "analyze to death" any legislation. (See an example of such analysis by Justice Smith at (1358)) This can have wide implications, including that individuals can use the *Charter*, in effect, to overrule democracy. For instance, the April 2010 vote in Parliament of 228 "against" 59 "for" a private member's bill that would have legalized physician-assisted suicide and euthanasia, which is noted by Justice Smith (112), is, in practice if not in theory, overruled by the *Carter* judgment. Yet it's hard, especially for politicians, to criticize court rulings based on the *Charter*, without running the risk of being labeled in a stigmatizing way.

3. "Preservation of Life"

As has been discussed earlier in this article, "*preservation of life*" is another term used in the *Carter* judgment. It can be distinguished from "respect for life". The former is not always required, ethically or legally, the latter is. Not preserving life by justifiably allowing a person to die a natural death does not contravene the requirements of respect for life. For instance, in certain circumstances, withdrawing life support treatment when a competent patient gives an informed refusal of such treatment, either at the time or through "advance directives", is not only, justified, it is ethically and legally required.

⁴⁸ Canadian Charter of Rights and Freedoms, Part I of the Constitution Act, *supra* note 13, § 33.

In addressing the question of whether the principle of preservation of life has exceptions, Justice Smith, first, finds that it does, a finding endorsed by the Supreme Court, and then, as discussed previously, accepts the evidence of one of the plaintiffs' expert witnesses, Professor Wayne Sumner, to the effect that death is not a loss or bad, if there is no benefit in a continuing life, in other words, that a poor quality of life can justify such an exception.

4. "Inviolability of Life"

Justice Smith uses the term "*inviolability of life*" [350]. This is not a concept in common use, at least in Canada, and it seems that she employs it to mean a belief, which she does not share, that life must never be intentionally taken. The right to inviolability is, however frequently spoken of in the context of medical ethics and law and encompasses the right not to be touched without one's consent, a right that protects a person's physical and mental integrity. It is a negative content right (a right against unconsented to interference) not a positive content right (a right to something).

The doctrine of informed consent, which the judge explores at length, is linked to inviolability. One's right to inviolability is not breached by interventions to which consent has been given. And consent protects one's rights to autonomy and self-determination. But just because one consents to an intervention does not mean that it is ethical or legal as, for instance, the Criminal Code of Canada provides: "No person is entitled to consent to have death inflicted on him, and such consent does not affect the criminal responsibility of any person by whom death may be inflicted on the person by whom consent is given".⁴⁹ As a result of the *Carter* case this provision will no longer apply to "physician-assisted death" carried out in accordance with the requirements specified by the Supreme Court. [147]

5. "Protection of Life"

Justice Smith also refers to "*protection of life*" as a valid goal, for instance, in this passage:

To reiterate, the purpose of the prohibition against assisted suicide is the protection of vulnerable persons from being induced to commit suicide at times of

⁴⁹ Canada Criminal Code, R.S.C. 1985, c C-46, §14 (as amended).

weakness, a purpose grounded in the respect for and the desire to protect human life. (1362)

One question this raises is the difference, if any, between protection of life and respect for life. Intentionally taking human life can be justified when that is the only reasonably possible way to save human life, as in justified self-defence or “just war”. These actions involve taking the life of an aggressor in order to protect the lives of the persons placed in serious danger by the aggressor. But the judge is not speaking of such a situation here. She speaks of protecting the lives of vulnerable people, not taking life to protect life, and of respect for and protection of life in general. Her interpretation of the “right to life” could, however, help in interpreting what she contemplates by protection of life: she views the right to life as requiring that physician-assisted suicide be allowed in certain circumstances, because when people with disabilities know that they can have assistance to commit suicide, they will wait longer to do so. Might the judge also see this as protecting life for the same (misguided) reason?

6. “Sanctity of Life”

Although many people use the terms “*sanctity of life*” and “respect for life” interchangeably, they can be distinguished, in some regards. The former tends to be used by people whose values are primarily based on religious beliefs and who can have even more stringent requirements with regard to what is required to respect human life, than those who are anti-euthanasia and use the term “respect for life” to describe the basis for their opposition.

Because the concept of “*sanctity of life*” is often associated with religion, that association is commonly used to dismiss claims based on it. In contrast, the existence of a “societal consensus” is often argued in support of a claim for legalizing euthanasia. The following passage from the trial judgment is one example that manifests both approaches:

[T]he plaintiffs say that if the purpose of the law is to uphold a particular religious conception of morality [sanctity of life] (about which there is not a consensus in Canadian society), it is an invalid purpose. They suggest that there is a societal consensus supportive of their claim (177) . . . [to legalize physician-assisted suicide, namely] that the current line drawn between permissible and impermissible end-of-life care is based upon distinctions that in reality have no practical ethical or moral force. (176).

As to a societal consensus, alone, ethically validating a claim, we should keep in mind that just because a majority supports a certain position does not mean that stance is ethical: democracy is only as ethical as the people who vote. And it is interesting to contemplate that the etymology of the word religion is *re ligare* to bind and re-bind together through shared belief, that is societal consensus.

In assessing the relevance of “the principle of sanctity of life”, which Justice Smith finds was “espoused in the *Rodriguez* decision” (300), she takes into account the British Columbia Prosecutorial Policy for the crime of assisted suicide. This sets out the conditions for initiating such prosecutions, which has the effect of limiting such prosecutions, overall. She rules the policy is relevant for three reasons:

First, the policy may shed some light on social consensus about the ethics of assisted suicide or euthanasia. Second, the British Columbia policy incorporates by reference accepted medical ethical standards. Finally, the plaintiffs suggest that the prosecution policy marks a significant change since *Rodriguez*. The plaintiffs characterize the B.C. policy as “remarkable” because, they say, it appears to allow for the exercise of discretion not to prosecute a person who has violated the assisted suicide provision and thus to contradict the principle of sanctity of life espoused in the *Rodriguez* decision. (300)

It’s important to point out that, as the BC Prosecutorial policy accurately states, that recognizing “society’s interest in protecting the sanctity of human life . . . does not require life to be preserved at all costs.” (307) In other words, “the prohibition of euthanasia does not imply a commitment to vitalism, namely the doctrine that life should be prolonged at all costs.”⁵⁰ But not adhering to a value of preserving life no matter the cost is not the same as intentionally inflicting death.

In referring to “sanctity of life” Justice Smith writes that the plaintiffs argue there is “no societal consensus supporting a principle of the absolute sanctity of human life but that there is a societal consensus supporting the principle of a person’s autonomy over his or her own body” (167). She accepts this argument and finds that personal choice (autonomy) trumps sanctity of life. In doing so, as pointed out previously, she echoes the assumption on which the reports of both the Royal Society Expert Panel⁵¹ and the Quebec National Assembly Select Committee⁵²

⁵⁰ Farzaneh Zahedi et al., *End of Life Ethical Issues and Islamic Views*, 6 IRANIAN J. ALLERGY ASTHMA & IMMUNOLOGY, supp. 5, Feb. 2007, at 5, 9.

⁵¹ ROYAL SOC’Y OF CAN., *supra* note 18.

⁵² SELECT COMM. OF THE ASSEMBLÉE NATIONALE OF QUÉBEC, *supra* note 30.

are based.

The Report of the Select Committee of the National Assembly of Quebec on “Dying with Dignity” is especially interesting with respect to the concept of sanctity of life. Like Justice Smith, the committee starts from and takes throughout its report a purely utilitarian approach and it adopts, as the overriding value, respect for individuals’ rights to autonomy and self-determination, justifying this stance on the basis, among other examples, of the decline in adherence to religion. The committee writes that “La valeur du caractère sacré de la vie a subi une transformation notable” (“The value of the sanctity of life has undergone a significant transformation” Translation: MS) relative to other values, which means that now it doesn’t necessarily take priority.

As mentioned above, pro-euthanasia advocates often argue that seeing life as “sacred” is a religious value and, because of that, it should not be taken into account in the public square. The Quebec committee report endorses this view: “Rappelons cependant que dans un État laïque comme le nôtre, les croyances de certains ne sauraient servir de base à l’élaboration d’une législation applicable à tous. » (“However, note that in a secular state like ours, the beliefs of some cannot be the basis for the development of legislation applicable to all.” Translation: MS)

Although the world’s major religions uphold the principle of sanctity of life/respect for life, it is not simply a religious precept. (I prefer to use the term “respect for life”, rather than “sanctity of life”, to avoid religious connotations and associations.) What German philosopher Jurgen Habermas calls “the ethics of the [human] species”⁵³ and I call “human ethics”,⁵⁴ which must guide secular societies such as Canada, also embrace this principle. Whatever one’s views regarding the value of sanctity of life/respect for life, it’s a foundational value of all societies in which reasonable people would want to live, as the *Canadian Charter of Rights and Freedoms* recognizes in enshrining it. As is true of the Quebec committee report, the Royal Society report and the *Carter* judgment, pro-euthanasia advocates dismiss the harm to the value of respect for life, especially respect for human life, in general, at the societal level, that legalizing euthanasia would necessarily entail.

Justice Smith concludes that

[t]he sanctity of life is a principle that is not absolute in our society (it is sub-

⁵³ JURGEN HABERMAS, *THE FUTURE OF HUMAN NATURE* (Polity Press 2003).

⁵⁴ MARGARET SOMERVILLE, *THE ETHICAL IMAGINATION: JOURNEYS OF THE HUMAN SPIRIT* (House of Anasi Press 2006).

ject to exceptions such as self-defence) and, while it is central to the value system of a number of religions, that does not settle its place in a secular society. (315)

As observed already, the exception of self-defence that the judge mentions does, indeed, inform the scope of what the value of respect for life requires. The only justification for intentionally taking human life in self-defence is when that is the only reasonably available way to save human life. (The same requirement that human life may only be justifiably taken to save human life is true for “just war”; traditionally abortion, which was only justified, when necessary to save the mother’s life; and capital punishment which was justified as preventing the condemned person from killing again.⁵⁵) Physician-assisted suicide and euthanasia do not fulfill that requirement.

And the Supreme Court of Canada opines on the sanctity of life as follows:

The sanctity of life is one of our most fundamental societal values. Section 7 is rooted in a profound respect for the value of human life. But s. 7 also encompasses life, liberty and security of the person during the passage to death. It is for this reason that the sanctity of life “is no longer seen to require that all human life be preserved at all costs” (*Rodriguez*, at p. 595, per Sopinka J.). And it is for this reason that the law has come to recognize that, in certain circumstances, an individual’s choice about the end of her life is entitled to respect.[63]

In this passage the Supreme Court commingles respect for human life, the value of human life, sanctity of human life, and the preservation of human life; it gives priority to individual autonomy in relation to all of these concepts; and it espouses a moral relativist philosophy in deciding “that, in certain circumstances, an individual’s choice about the end of her life is entitled to respect”.

7. “Quality of Life”

I have already mentioned the concept of “*quality of life*”, which is often spoken of as in opposition to “sanctity of life”. One difference between these two concepts is that “quality of life” is based in moral relativism and utilitarianism – it all depends on the circumstances whether life is worth living and, if not, physician-assisted suicide and euthanasia

⁵⁵ DEATH TALK, *supra* note 2.

are ethical – and “sanctity of life/respect for life” is principle based, a belief that all human life has dignity and must not be taken, because it’s inherently wrong to do so.

As discussed previously, paradoxically, initially “quality of life” was developed as a concept intended to support and promote life through the argument that everyone had a right to the resources, especially healthcare resources, needed to maintain an acceptable “quality of life”. Now the concept is used to achieve the exact opposite outcome, namely, that a person’s “quality of life” is so poor that they are better off dead or, at the least, don’t merit the expenditure of resources to keep them alive.

Although assessment of quality of life is often treated as an objective exercise, we know there is a great deal of subjectivity and discretion involved. Research has shown that healthcare professionals assessed patients’ quality of life as lower than the patients themselves assessed it.⁵⁶ Factors such as dis-valuation – we grade a negative event, such as going blind, as much worse when we have not experienced it, than when we do – and decision making about hypothetical traumas are not the same as the decisions we make when faced with those traumas in real life.

In conclusion of this section on “Values related to human life”, both ethics and the law operate on the basis of a presumption in favor of life. This does not mean that life must be preserved at all costs, but it does mean that if our acts or omissions will have an effect of shortening life or not sustaining it we must be able to justify what we do. In short, the default position in both law and ethics is a presumption in favor of life. Justice Smith’s judgment does not reflect that position and her interpretations of many of the concepts I have discussed show the same approach. It’s an open question whether the same can be said of the Supreme Court’s judgment, but it’s relevant in answering that question to recall that the Supreme Court strongly endorses Justice Smith’s reasoning and findings.

IV. LOOKING BEYOND THE INTENSE INDIVIDUALISM OF THE *CARTER* CASE

There is a radical difference between valuing only what we want in relation to our own life or also valuing the lives of generations to follow and deciding what we owe to them, and acting accordingly. Legalizing physician-assisted suicide or euthanasia in order to allow personal preferences concerning death to prevail, as Justice Smith and the Supreme

⁵⁶ Julia Addington-Hall, *Who Should Measure Quality of Life?*, 322 *BMJ* 1417 (2001).

Court do in the *Carter* case, is an example of the former. Rejecting physician-assisted suicide or euthanasia, because of the harm we believe it would do to individuals, our shared values, societal institutions, society, and future generations, is an example of the latter. Before we would legalize assisted suicide or euthanasia, we need to ask ourselves, "If we do that, how might our great-great grandchildren die?" and answer honestly.

Physicians and nurses must be sensitive to patients' pain and suffering and meet it with great compassion, but that must be done without intentionally inflicting death. Suffering reduction and death infliction must never be equated.

Physicians' and nurses' absolute rejection of intentionally inflicting death is necessary to maintaining people's and society's trust in both their own physicians and the profession of medicine as a whole. This is true, in part, because physicians and nurses have opportunities to kill that are not open to other people.

Physicians and nurses need to continue to have a clear line that powerfully manifests to them, their patients, and society that they do not inflict death. Both their patients and the public need to know with absolute certainty—and be able to trust—that is the case. Anything that blurs that line, damages that trust, or makes physicians or nurses less sensitive to primary obligations to protect and respect life is unacceptable. Legalizing physician-assisted suicide or euthanasia would do all of these.

Moreover, it is a very important part of the art of medicine to sense and respect the mystery of life and death, to hold this mystery in trust, and to hand it on to future generations—including future generations of physicians. We must consider deeply whether legalizing physician-assisted suicide or euthanasia would threaten this art, this trust, and this legacy. I believe it would.

The "euthanasia debate" is a momentous one. It involves our individual and collective past (the ethical, legal, and cultural norms that have been handed down to us as members of families, groups and societies); the present (whether we will change those norms); and the future (the impact that this would have on those who come after us). We need a much broader analysis and a great deal more thought, before we would follow down the path that Justice Smith and the Supreme Court of Canada map out in the *Carter* case.

The central issue in the *Carter* case is not just what compassion for Ms. Taylor and people in the same situation as she is, might lead people, who do not have ethical or moral problems with physician-assisted sui-

cide or euthanasia - who, it appears, include Justice Smith and the nine judges of the Supreme Court - to recommend. The central issue is whether we will abandon some of the most important foundational values of our Canadian society. If we are going to do that at the least we should explicitly recognize that is what we are doing. At both the trial stage and in the Supreme Court, the *Carter* judgments are, with respect, a total failure in that regard.

V. CONCLUSION

In this article I have explored the interaction of ethics, law and pain and suffering by focusing on the issues of physician-assisted suicide and euthanasia. I have taken this approach because I believe that what our societies decide about legalizing these interventions will be the defining event for each of them of the first half of the 21st Century.

In making those decisions, we need to keep in mind an old saying in human rights: "Nowhere are human rights more threatened than when we act purporting to do only good." This warns us that the good that we hope to realize can blind us to the harms and risks also unavoidably involved in doing that good. When the good we seek is the relief of serious suffering, our moral intuition that it is wrong to intentionally kill another human being can be overwhelmed. Such intuitions are important guides in making good ethical decisions.⁵⁷ And while we ignore our feelings at our ethical peril,⁵⁸ our emotional reactions to an individual person's suffering need to become "examined emotions", if we are to avoid the danger of their misleading us ethically.⁵⁹

By arguing against physician-assisted suicide and euthanasia, I am proposing that there are and should be ethical and legal limits to our freedom to alleviate suffering and that these interventions are not legitimate means of doing so. Just as the axiom "freedom in fetters" tells us that we must restrict freedom to some extent, to protect and maintain the conditions that make freedom possible, so we must restrict what we do to relieve suffering to ensure that we protect and maintain the shared values that are necessary if we are not to risk creating a society in which no reasonable person would want to live.

These limits mean that within bioethics and biolaw we must posi-

⁵⁷ SOMERVILLE, *supra* note 54, at 28–31, 62–72.

⁵⁸ Leonie Welberg, *The Moral Brain*, 8 NATURE REV. NEUROSCIENCE 326 (May 2007), <http://www.nature.com/nrn/journal/v8/n5/full/nrn2141.html>.

⁵⁹ SOMERVILLE, *supra* note 54, at 28–31, 53–93.

tion our moral and legal obligations to relieve suffering, such that they are consistent with upholding respect for human life, both at the level of the individual person and human life, in general, at the societal level. Fortunately, we have new tools to relieve suffering that will help us to achieve that balance. Often, the unprecedented powers of the new medicine and science face us with additional serious ethical difficulties. In relation to relieving pain and suffering, the opposite is true. Research is providing us with means never before possible to help those who need our help to relieve their pain and suffering.

For millennia, our kinds of societies have prohibited euthanasia and assisted suicide, why then now, when there is nothing new about the circumstances in which these interventions are called for and there is so much more we can do to relieve suffering, do we think intentionally inflicting death is a good response to suffering? A wise answer to that question requires much thought.⁶⁰ What would be the long-term impact of death by euthanasia becoming the norm? How would that affect the way in which we view and treat people who are old, vulnerable and disabled? We must address these and many other questions before changing the law to allow the intentional infliction of death.

I hope that my analysis of the *Carter* case in this article will convince you that we cannot overemphasize the gravity of the situation we now face as a result of the Supreme Court of Canada's decision in that case.

This decision does not represent an evolution in the foundational values that bind us together as a society, but a revolution, a radical departure from upholding the value of respect for life. This value implements the belief and practice that we must not intentionally kill another human being. To allow that constitutes radical change, not only, for individual Canadians, but also, to the institutions of both law and medicine, because the law is changed to allow killing and physicians are authorized to carry it out. In a secular society, such as Canada, law and medicine carry the value of respect for life for the society as a whole. Their capacity to do that in Canada is seriously damaged by this decision, which is primarily focused on what individuals want, that is on individual autonomy and self-determination.

Making euthanasia and assisted suicide part of medical practice is not, as pro-euthanasia advocates claim, and the trial judge and Supreme court agreed, a small incremental change consistent with interventions

⁶⁰ Margaret Somerville, *Legalizing Euthanasia: Why Now?*, in *DEATH TALK*, *supra* note 2, at 105–118.

that we accept as ethical and legal, such as honouring patients' refusals of life-support treatment that allow them to die. Allowing physicians to inflict death on their patients is different-in-kind, not just different-in-degree, from other interventions we accept as ethical and legal. Moreover, legalizing euthanasia represents a seismic shift in our fundamental societal values, not just another step on a path we've already taken.

And for 2,400 years, consistent with the Hippocratic Oath, euthanasia has never been characterized as a medical treatment. It should not be now. Indeed, if it is legalized, it should be kept out of medicine.

Just as we now realize our actions could destroy our physical ecosystem and we must hold it on trust for future generations, we must also hold our metaphysical ecosystem—the collection of values, principles, beliefs, attitudes, shared stories, and so on that bind us together as a society—likewise, on trust for them. In this regard, there is no more important value than respect for life. That requires that we always react to pain and suffering with deep compassion and assistance to relieve it, but that we kill the pain and suffering, not the person with the pain and suffering.⁶¹

We must also consider the values that we should hold on trust for future generations if they are to inherit a world in which reasonable people would want to live. We must ask ourselves how our great-great-grandchildren will die if we legalize euthanasia. I believe that history will see what we decide about “physician inflicted death” as having been the defining ethical-legal-societal event of the 21st Century, which means it is a momentous decision.

VI. EPILOGUE

The Supreme Court of Canada handed down its judgment in *Carter* on 6th February 2015 and gave Parliament twelve months to pass legislation implementing its rulings. The Conservative Government under Prime Minister Stephen Harper set up a committee of three eminent people to consult Canadians and make recommendations to Parliament (it was chaired by Dr. Harvey Max Chochinov a highly respected psychiatrist who specializes in psychiatric care of terminally ill people). In October 2015 the Conservative government lost the Federal election and the Liberal party under Justin Trudeau's leadership was elected. Pro-euthanasia advocates had complained that two of the three members of the Chochinov committee had given evidence in the trial court in *Carter*

⁶¹ DEATH TALK, *supra* note 2, at 218–232.

as witnesses for Canada arguing against legalizing euthanasia, with the implication that they would be biased against euthanasia. The new Liberal government instructed the Chochinov committee not to make recommendations as mandated in its original instructions, but only to report on what it had found from hearing witnesses and visiting jurisdictions in which euthanasia or physician-assisted suicide is practised. It then established a joint committee of the House of Commons and the Senate of the Parliament of Canada, comprised of sixteen members, a strong majority of whom were known to favor legalizing physician-assisted suicide and euthanasia, with instructions to consult Canadians and report to Parliament. The Government obtained from the Supreme Court a four month extension of the deadline to enact legislation to June 6th 2016. The committee's report was tabled in Parliament on 25th February 2016. It was extremely liberal in its recommendations regarding who should be able to have access to euthanasia and on what conditions. Parliament now has a Bill before it which is more restrictive than the report recommended. It remains to be seen what the enacted legislation will be. Below is a description of the submission I made to the Parliamentary committee and my experience in appearing before it as an invited witness on the last day of its hearings, 4th February, 2016.

A. Submission to the Special Joint Committee on Physician-Assisted Dying of the Parliament of Canada, 4th February, 2016

I was invited to appear before the 'Special Joint Committee on Physician-assisted Dying' of Parliament and provided with written instructions setting out the matters the committee wished me to address. These did not include the question of whether or not Canada should legalize euthanasia and physician-assisted suicide. Therefore, I want to put on the record that I believe euthanasia and physician-assisted suicide (what the Supreme Court of Canada calls physician-assisted death/dying) are inherently wrong and should remain criminally prohibited.

It seems, however, to be a foregone conclusion that Parliament will legalize euthanasia (a word I use to refer to both euthanasia and physician-assisted suicide), so the issue is how to limit the harms and risks of that.

Consequently, in order to do the least damage possible to important shared societal values, especially respect for human life, and to vulnerable Canadians of legalizing euthanasia, I am willing to provide some recommendations for limiting its harms and risks."

1. “*Carter* as a Floor not a Ceiling”

I had a strong impression the committee was strongly pro-euthanasia. A telling phrase, used by a co-chair and repeated by others, characterized the Supreme Court of Canada’s decision in *Carter* as “a floor not a ceiling”. In short, this embodies an approach that Parliament can make euthanasia more available than *Carter* requires, but not less available. What would that mean?

The committee’s questions showed what they might have been contemplating, which has been borne out by their subsequent report.

Should euthanasia be available for children? May an incompetent person (for instance, one with Alzheimer’s disease or other dementia) be euthanized if they have left advance directives consenting to it? May a surrogate decision-maker consent to euthanasia? Should it be available to mentally ill people without physical illness?

People who believe legalizing euthanasia is a terrible mistake often warn of the risks and harms of the slippery slopes it entails: the “practical slippery slope” – abuses of euthanasia, once it is seen as legally acceptable – and the “logical slippery slope” – the people eligible for it and the circumstances in which it may be provided inevitably expand. Powerful examples of both these slopes have evolved in the Netherlands in the last 40 years and Belgium in the last 14 years. But Canada needn’t wait that long if, as I feared, I was correct about what the committee might recommend and Parliament might accept. We’ll start at the bottom of these slopes.

So I addressed the question, “What would a more restrictive approach complying with the *Carter* ruling look like? Here is the testimony I gave:

2. Autonomy v. Respect for Life

The Supreme Court recognized that the values of respect for individual autonomy and “sanctity of life”, especially protection of vulnerable people, were competing claims and both had to be taken into consideration.

“On the one hand,” the Court wrote, “stands the autonomy and dignity of a competent adult who seeks death as a response to a grievous and irremediable medical condition. On the other stands the sanctity of life and the need to protect the vulnerable.”⁶²

⁶² *Carter v. Canada (Attorney General)*, 2015 SCC 5, para. 2.

In the past in many societies, including Canada, religion was the main institution used to uphold the value of respect for life at a societal level. Respect for life is a preferable term to “sanctity of life”, because respect for life is not just a religious value. It is a foundational value in every society in which reasonable people would want to live.

And it must be upheld at two levels: that of every individual person’s life and in society in general.

In 21st century secular Western democracies, such as Canada, medicine and law are the main institutions carrying the value of respect for life for society as a whole. Their capacity to do so will be damaged by euthanasia. It’s in every Canadian’s interests to make that damage as small as possible.

So, to turn to the question the committee asked me to address, what “framework of a federal response on physician-assisted dying . . . [would] respect the constitution, the Charter of Rights and Freedoms, and the priorities of Canadians?” I would add, “and do the least harm to the value of respect for life and to healthcare professions and institutions, and create the fewest risks for vulnerable people, both in the present and the future.”

The following proposals are made with that extended question in mind.

3. Physician-Assisted Death is an Exception

As the Court made clear in *Carter*, access to physician-assisted death (euthanasia) on certain conditions is an exception to the criminal prohibitions of culpable homicide and assisted suicide, and other than that very limited exception those crimes remain in force.

To avoid the future “normalization” of euthanasia, as has occurred in the Netherlands and Belgium, and which would have very serious consequences for future generations of Canadians, the legislation to govern euthanasia must make it clear that euthanasia is such an exception, should only be used as a last resort, and rarely.

If Canada had the same percentage of deaths by euthanasia as the Netherlands and Belgium currently have (conservatively, about 3.6 percent), we would have between 9,000 and 10,000 euthanasia deaths each year.

To help achieve the necessary clarity, I suggest the legislation be entitled *An Act to amend the Criminal Code to allow for an exception to conviction for culpable homicide and assisted suicide*.

This means those not complying with the law allowing euthanasia

could be criminally liable and also that the person seeking euthanasia must show they fulfil the conditions for having access, that is, they have the burden of proof.

That would be consistent with what both the trial court judge and the Supreme Court proposed the law should establish: “a stringently limited, carefully monitored *system of exceptions*”⁶³ and “a carefully-designed system imposing *stringent limits* that are scrupulously monitored and enforced,”⁶⁴ respectively.

In short, euthanasia must be treated as an exceptional intervention, very carefully safeguarded and rarely used.

In further support of this approach, I note that between 1991 and 2010 Parliament rejected motions or bills promoting assisted suicide or euthanasia on no less than twelve occasions, so legalizing euthanasia is an unprecedented change of mind and direction on Parliament’s part.

4. Specific Considerations

The committee asked me to address three specific categories of considerations:

1. Eligibility criteria (e.g. age, capacity, condition, addressing vulnerability);
2. Processes and procedures (e.g. mechanics of a request, oversight, privacy considerations);
3. Roles and regulation of healthcare practitioners (e.g. who should do what, rights of conscience, discipline and penalties)

I will do so very briefly and far from comprehensively.

a. Eligibility:

The first requirement is that the person requesting euthanasia has been offered high quality palliative care, including fully adequate pain management. Apart from other reasons, this is legally required in order to obtain an informed consent to euthanasia.⁶⁵

The person must be mentally competent and provide informed consent up to and including the point at which euthanasia is administered. (Informed consent is a process, not an event.) This requirement acts as a

⁶³ Carter v. Canada (Attorney General), 2012 BCSC 886, para. 16 (emphasis added).

⁶⁴ Carter v. Canada (Attorney General), 2015 SCC 5, para. 105 (emphasis added).

⁶⁵ See Reibl v. Hughes, [1980] 2 S.C.R. 880 (Can.); Hopp v. Lepp, [1980] 2 S.C.R.192.

protection for vulnerable incompetent people (for example those with dementias, such as Alzheimer's disease) and means that advance directives cannot be used for euthanasia and consent to it from surrogate decision-makers is not allowed.

Euthanasia should be restricted to people who are terminally ill (a life expectancy of less than four weeks) from a physical illness, disease or disability and experiencing extreme physical suffering.

Euthanasia should not be allowed for children unable to consent for themselves. Whether it should be available for "mature minors" is a separate question.

b. Processes and Procedures:

Two physicians, one of whom is a specialist in the type of disease from which the person suffers, must each confirm in writing that the person fulfils the conditions for access to euthanasia and that they have been offered all reasonable alternative interventions, including high quality palliative care and pain management.

A psychiatric consultation to rule out conditions such as depression, or coercion, undue influence of others, or duress is required, at the least where there is any possibility of these factors affecting the request for euthanasia or consent to it or any doubts about the person's mental competency.

A Superior Court judge should certify that all legal requirements for access to euthanasia are fulfilled.⁶⁶

Euthanasia must not be administered earlier than 15 days after it is requested.

A national research and review body should be established to collect records of all cases of euthanasia, investigate cases where there might have been non-compliance with the law, and report, at least annually, in a way that does not breach individuals' privacy, but informs Parliament, provincial legislatures, courts, professional licensing and disciplinary bodies, medical institutions, the public, and so on. This body should also be able to make recommendations for changes in law, regulations or practice when these are needed to prevent abuse of euthanasia or to protect vulnerable people.

⁶⁶ Chief Justice McLachlan imposed this safeguard requirement in her dissent in *Rodriguez*, as did five Judges of the Supreme Court in granting Parliament a four-month extension to draft legislation in response to the *Carter* judgment. See *Rodriguez v. British Columbia (Attorney General)*, [1993] 3 S.C.R. 519.

c. Roles and Regulation of Healthcare Practitioners:

For nearly 2,500 years, physicians and the profession of medicine have recognized that assisted suicide and euthanasia are not medical treatment and this position should be maintained and these interventions should be kept out of medicine.⁶⁷

Consequently, a new profession should be established to carry out euthanasia. The practitioners should not be healthcare professionals or, if so, only ones who have permanently retired from practice. Practitioners should be specially trained, licensed and have travel money provided to give people across Canada equal access to euthanasia.

If this approach is not adopted, two publicly available lists of physicians and institutions should be established, those who will provide euthanasia and those who will not. This is a reasonable compromise between Canadians who agree with euthanasia and those who oppose or fear it. The Supreme Court emphasized that the Charter right to “security of the person” includes freedom from fear about what could happen to us when we are dying, which often seems to be forgotten or ignored with respect to this right of those fearful of euthanasia.

This approach will also solve most freedom of conscience issues. Healthcare professionals must not be forced to provide or refer for euthanasia when they have ethical or conscience objections to doing so. It must be kept in mind that respect for physicians’ freedom of conscience is not only necessary to respect them, it is also required to protect patients and can be the last such protection against doing them serious harm or other serious wrongdoing.

Members of Parliament must be intensely aware in deciding who will have access to euthanasia and on what conditions that they are not just legislating for presently living Canadians, but also for future ones, their great-great-grandchildren and beyond, with respect to how they will die and the extent to which respect for life will be upheld in future Canadian societies.

Whether or not we agree with physician-assisted death, legalizing physician-assisted suicide and euthanasia is a seismic shift in our most fundamental values as individuals and foundational values as a society.

I believe future generations will look back on the legalization of assisted suicide and euthanasia as the most important social-ethical-legal values decision of the 21st century and the decisions that Parliament will make about the legislation and regulations to govern those interventions

⁶⁷ See Boudreau & Somerville, *supra* note 43.

are an integral part of that decision.

Respectfully submitted,

*Margaret Somerville,
McGill Centre for Medicine, Ethics and Law,
Montreal*