But What About Lloyd?
Thoughts and Reflections about
The Status of Medical Aid in Dying
December, 2024

Lloyd

I spend a lot of time thinking about end of life options. I suppose you could say that as an end of life doula, it's part of my job. But what I'm really thinking about is Lloyd. And I've been thinking about Lloyd every day for almost forty years.

Lloyd Ehrenberg was one of my closest college friends. A painter, graphic artist, windsurfer, parasailer, philosopher, ethicist, and one of the most amazing people I've ever known, Lloyd was not yet thirty when he was diagnosed with ALS.[1] Lloyd and I kept up a regular correspondence after college (those were the days of snail mail), and it took him several months to garner the courage to share the news of his diagnosis. He had already lost his job as the art director of a windsports magazine. The letter was the last he would write to me as he was rapidly losing his fine motor skills. Within a few months, I made the trip from Chicago to Oakland to see Lloyd for what would be the last time. Lloyd had given his caregiver the day off because he didn't want me to know that he needed a full-time caregiver. He stumbled about his basement flat with a walker until he fell. When I'd helped him up, he admitted he was now using a wheelchair.

With the wheelchair in my rental car, we drove to Redwoods Regional Park. After a long walk, we sat together, me on a bench and Lloyd in his chair, and talked for hours about all of Lloyd's dreams that would remain unfulfilled. We cried, mindful that Lloyd was already having trouble taking deep breaths. And we talked at length about Lloyd's fears about the progression of his illness. He had already lost the ability to paint, his bodily autonomy, and his physical dignity. As he lost breath support, he would lose the ability to communicate with distant friends—already he couldn't write letters. As his swallow reflex grew weaker, he would lose the ability to eat favorite foods. His friends, all his age, were all working. His family was in Southern California and he didn't want to be dependent on them. He was becoming more isolated, more dependent on strangers, afraid that the next day would be the one when he couldn't speak, or breath, or eat, without intervention. He dreaded the day when the only touch he would feel was the touch of strangers, and not the touch of a lover or friend. The irony of it all was that apart from the ALS, Lloyd was healthy and fit. He had a terminal illness, but not a terminal diagnosis. He would live at least another year, probably two or longer. But what would he be able to do if a day, or a week, or a month came when the psychic pain

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[1] Amyotrohic Lateral Sclerosis, known as ALS, is a neurodegenerative disease of the brain and spinal cord that causes progressive loss of muscle control. ALS may begin with muscle twitching or weakness in an extremity, but eventually it will affect control of the muscles needed to move, speak, eat, and breathe. There is no known cure and ALS is invariably fatal, although the course of the disease is highly variable. Some ALS patients develop frontotemporal dementia.
https://www.yalemedicine.org/conditions/amyotrophic-lateral-sclerosis
The average prognosis for ALS is 2 to 5 years after diagnosis, with about 10% of patients surviving 10 years and 5% living 20 years or longer. https://pmc.ncbi.nlm.nih.gov/articles/PMC3515205/

of being just a biologic spark inside a hollow shell of a person who couldn't communicate, who couldn't love or be loved the way he wanted to, who couldn't use color to express his emotions, just became too much to bear? I so wanted to be able to say that I would be there for him, but I couldn't. I wasn't even sure I knew what "being there for him" would mean.

I went back to Chicago. For some time, I heard from a group of Lloyd's friends who were crowdsourcing his living expenses so Lloyd wouldn't need to go back to his parents' home in Long Beach. Then I heard he'd gone back to Long Beach. After that, I heard nothing.

I tell this story because it is what plays in my head over and over and over when I think about the questions of law, ethics, and end of life options I'm writing about here.

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Pitting Man Against God

Pikuach nefesh, a core principle of *halakha,* is generally understood to mean that the preservation of human life overrides almost every other religious law or commandment of Judaism. This principle is undergirded by the idea that human life is holy and belongs to God. Ethical debates on medical aid in dying thus invite a contest between an individual's autonomy over their own body and whether human beings should face limitations in their interference with that which belongs to God. Put differently, are there circumstances in which God may afford the individual autonomy over their body even though the human has been created *b'tzelem Elohim.*

Many advances in medicine have made it possible to extend life by slowing or seemingly arresting the course of fatal illnesses. For example, many cancers that were once invariably terminal may now be treated through surgery, radiation, and chemotherapy to the point where the cancer is no longer present in the body at detectable levels: a state called remission. This does not mean that the patient is cancer-free, but there is no timetable for when the cancer will return and the patient may well die of another cause in the interim. Other advances in medicine have made it possible to keep a person alive, for example, with dialysis, or through the use of an artificial heart-lung machine while awaiting a potential donor for a transplant. Patients with primary or secondary corticosteroid insufficiency can be kept alive through replacement with artificial steroids. In each case, the means of sustaining life carries a cost for the patient: sometimes a patient is immuno-compromised as a result of treatment, other treatments are painful, time-consuming, and energy-sapping.

In short, man has shifted the fulcrum between life and death such that it can no longer fairly be said that the time of one's death is in God's hands. This, and a raft of court cases in which patient's advocates have raised the argument for personal autonomy:

> I am my own;
> The time and means of my dying lie at the heart of my private life;
> I therefore retain the "right to die," and no one may take it from me.[2]

have prompted reappraisals by many major religions of their opinions on medically assisted death.

The Views of Other Major Religions

The **General Presbytery**, in August 2010, restated in no uncertain terms "humankind's dignity as God's sovereign creation," and reasserted "God's authority over life from conception to death." Rejecting all forms of medical aid in dying, the Presbytery continued:

> Physician-assisted suicide occurs when a physician provides a medical means for death, usually a prescription for a lethal amount of medication that the patient takes on his or her own.... Euphemistic expressions for physician-assisted suicide, such as assistance-in-dying, are specifically used to mask the true content of these actions and should be rejected. Further, *physician-assisted suicide must be distinguished from informed decisions by patients to refuse life-sustaining treatent in ways that compassionately respect individual autonomy.*[3]

Only the patient's right to refuse life-sustaining treatment is recognized.

A 2007 article offers an **Islamic** ethical perspective on the issue of medical aid in dying.[4] "According to Islamic teachings, life is a divine trust and can not be terminated by any form of active or passive voluntary intervention. . . . The moment of death, *ajal*, is under the control of Allah and the human has no say in this matter; the human can not and should not attempt to hasten or delay the *ajal*."[5] The Islamic Code of Medical Ethics, issued by the First International Conference on Islamic Medicine, held in Kuwait in 1981, does provide that "[i]f it is scientifically certain that life cannot be restored, then

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[2] Nigel M. de S. Cameron, "Autonomy and the 'Right to Die'" in *Dignity and Dying: A Christian Appraisal* (Grand Rapids, MI: Eerdmans Publishing, 1996) 23.

[3] *Sanctity of Human Life: Suicide, Physician-Assisted Suicide, and Euthanasia* (Adopted by the General Presbytery in session August 9-11, 2010) (emphasis added)

[4] Kiarash Aramesh and Heyhar Shadi, "Euthanasia: An Islamic Ethical Perspective," *Iran Journal of Allergy, Asthma, and Immunology,* 6 (Suppl. 5) (February 2007) 35-38.

[5] *Ibid.*

it is futile to diligently keep the patient in a vegetative state by heroic means or to preserve the patient by deep freezing or other artificial methods. *It is the process of life that the doctor aims to maintain and not the process of dying.*"[6] The Islamic Code for Medical and Health Ethics also recognizes and allows what has come to be known as the "double effect." That code specifically provides that it is not a mercy killing for a doctor to order the "intensified administration of a strong medication to stop a severe pain, although it is known that this medication might ultimately end the patient's life."[7]

The Church Council of the **Evangelical Lutheran Church in America** in November 1992 issued a "Message on End-of-Life-Decisions" that updated the social statement "Death and Dying" adopted in 1982 by the Lutheran Church in America. The questions presented in this message were "which decisions about dying are morally acceptable to concerned Christians and which ones go beyond morally acceptable limits?"[8] Among the convictions that orient the Lutheran Church are 1) that life is a gift from God, to be received with thanksgiving; 2) that the integrity of the life processes which God has created should be respected; 3) both birth and death are part of these life processes; 4) both living and dying should occur within a caring community; and 5) respect for each person mandates giving due recognition to each person's carefully considered preferences regarding treatment decisions.[9] The Lutheran Church distinguishes between "allowing death" and "taking life." Thus, "[w]hen medical judgment determines that artificially-administered nutrition and hydration will not contribute to an improvement in the patient's underlying condition, or prevent death from that condition, patients or their legal spokespersons may consider them unduly burdensome treatment. In these circumstances, it may be morally responsible to withhold or withdraw them and allow death to occur." Likewise, competent patients, as well as incompetent patients who have made their wishes known through advance directives, living wills, or in conversations with family or health care surrogates or proxies, may refuse treatment recommended by health care professionals where they do not believe that the benefits outweigh the risks and burdens. That the patient's judgment may disagree with the professionals does not free health care professionals from the obligation to give basic human care and comfort throughout the dying process which may follow.[10]

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[6] *Ibid.* (emphasis added)

[7] *Ibid.*

[8] "A Message on End-of-Life Decisions" issued by the Church Council of the Evangelical Lutheran Church in America upon the recommendation of the Division for Church in Society. Approved by the Board of the Division for the Church in Society and adopted by the ELCA Church Council on November 9, 1992. Published by the Department for Studies. Division for Church in Society. Evangelical Lutheran Church in America, 8765 W. Higgins Rd. Chicago, IL 6031-4190.

[9] *Ibid.*

[10] *Ibid.*

The Lutheran Church recognizes that healthcare professionals have a responsibility to relieve suffering and that this may include the aggressive management of pain, even when it results in an earlier death, sometimes called "double effect." This is not considered a deliberate action of a physician to take the life of a patient. Deliberate destruction of life created in the image of God is contrary to the Christian conscience of the Lutheran Church.[11]

The 70th General Convention of **The Episcopal Church** entered a resolution of principles and guidelines with regard to "the forgoing of life-sustaining treatment in the light of our understanding of the sacredness of human life."[12] The Episcopal view is that:

> It is morally wrong and unacceptable to take a human life in order to relieve the suffering caused by incurable illness. This would include the intentional shortening of another person's life by the use of a lethal dose of medication . . . *However, there is no moral obligation to prolong the act of dying by extraordinary means and at all costs if such dying person is ill and has no reasonable expectation of recovery.*[13]

The Episcopal Church takes the further step of expressing its "deep conviction" that any proposed legislation on the part of national or state government regarding right to die issues must "take special care to see that the individual's rights are respected and that the responsibility of individuals to reach informed decisions in this matter is acknowledged and honored."[14] Thus, the church encourages its members to execute during good health and competence advance written directives, living wills, declarations concerning medical treatment and durable powers of attorney setting forth medical declarations that make clear a person's wishes "concerning the continuation or withholding or removing of life-sustaining systems," noting that the execution of such advance written directives constitute "loving and moral acts."[15]

In **Buddhism**, there is no central authority competent to pronounce on matters of doctrine or ethics. There are fundamental moral values and principles accepted by virtually all schools of Buddhism. These values and principles, as reflected in scriptural

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[11] *Ibid.* The Church goes on to "recognize that responsible health care professionals struggle to choose the lesser evil in ambiguous borderline situations—for example, when pain becomes so unmanageable that life is indistinguishable from torture." *Ibid.*

[12] Episcopal Archives Research Report 1991-AO93 "Establish Principles With Regard to the Prolongation of Life," 70th General Convention, *Journal of the General Convention of the Episcopal Church, Phoenix, 1991* (New York: General Convention, 1992) 383.

[13] *Ibid.* (emphasis added)

[14] *Ibid.*

[15] *Ibid.*

teachings, custom, tradition, and the opinion of distinguished teachers provide guidance for the individual conscience.[16] A life in any one existence begins at conception and ends at death: in the interval between these events, the individual is entitled to full moral respect. Death is generally considered to have occurred when the body is bereft of three things: vitality (*ayu*), heat (*usma*), and sentiency (*vinnana*). Opinion among Buddhists is divided as to whether these ancient criteria correlate with the modern standard of brain death.[17] The Buddhist prohibition on taking of life would seem to extend to both the assistance of suicide, including providing medical aid in dying, and euthanasia. Compassion, however, is also an important Buddhist moral value and there appears to be "increasing awareness of how a commitment to the alleviation of suffering can create conflict with the principle of the inviolability of life."[18] Buddhism appears to make a moral distinction

> Between the person who rejects medical care with the express purpose of ending his life, and the person who resigns himself to the inevitability of death after treatment has failed and the medical resources have been exhausted. The moral distinction is that the first patient seeks death or "makes death his aim: to use Buddhaghosa's phrase, whereas the second simply accepts the inevitability and proximity of death and rejects further treatment or nourishment as pointless." The first patient wishes to die; the second wishes to live. However, the second patient is resigned to the fact that he is beyond medical help.[19]

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[16] Damien Keown, "End of life: The Buddhist View," *Lancet* (2005) 366:952-55.

[17] *Ibid.*

[18] *Ibid.*

[19] *Ibid.*

Moral Logic and Mortal Responsibilities

Danish philosopher Soren Kierkegaard observed that "dying well is the highest wisdom of life."[20] The moral logic of the right to die comprises three principles: first, that every individual has a fundamental interest in bodily integrity; second,that every individual has a fundamental right to be free from invasive medical interventions that are likely to be futile in prolonging or restoring a quality of life; and third, that every individual is entitled to self-determination about decisions to end life according to their values.[21] The first wave of laws to recognize these interests authorized patients to execute advance directives requesting treatment or the discontinuation of treatment. The scope of the right to die under advance directives was primarily a negative right: the right to refuse or withdraw burdensome medical interventions.[22] This "negative" right to die could not legitimize a patient's claim to physician-prescribed medication to end life, which reflects "the moral logic of a 'positive' right to assistance in carrying out one's desired actions."[23]

As Justice Neil Gorsch argued prior to his appointment to the Supreme Court, construing the right to die as a positive right contains an inexorable moral logic that would inevitably permit not only legalized medical assistance in dying, but also legalized physician-administered euthanasia. Thus, those jurisdictions that now permit medical aid in dying, continue to prohibit physician-administered euthanasia not as a matter of logic, but as a prudential matter and because of the opposition of the American Medical Association.[24] The AMA Code of Medical Ethics Opinion E-5.7 expresses the perspective

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[20] Kierkegaard S. At a Graveside. In: Hong HV Hong EV, editors. Three Discourses on Imagined Occasions, Princeton (NJ) Princeton University Press: 1993:69-106, *as quoted in* Courtney S. Campbell, "Mortal Responsibilities: Bioethics and Medical-Assisted Dying," *Yale Journal of Biology and Medicine* 92 (2019) 733-739. *See also* Shmuly Yanklowitz, *45 Great Philosophers and What They Mean for Judaism.* Resource Publications (Eugene, OR)2024. 126-130 (each individual is 'free and self-determining")

[21] Courtney S.Campbell, "Mortal Responsibilities: Bioethics and Medical-Assisted Dying," *Yale Journal of Biology and Medicine* 92 (2019) 733-39.

[22] *Ibid.* With respect to the right to refuse or withdraw burdensome medical interventions, *compare* Rabbi Irving Greenberg, *The Triumph of Life: A Narrative Theology of Judaism*, The Jewish Publication Society: Philadelphia 2024, 24, (the law of *tza'ar ba'alei hayim* (not to cause pain to living beings)

[23] *Ibid.*

[24] *Ibid.,* House Action:Recommendations Adopted in Lieu of Resolutions 15-A-16 and 14-A-17 by the Council on Ethical and Judicial Affairs of the American Medical Association. June 2019 ("The council recognized that supporters and opponents share a fundamental commitment to values of care, compassion, respect, and dignity, but diverge in drawing different moral conclusions from those underlying values in equally good faith. The council further recognized that medicine must learn from experience of physician-assisted suicide, and must ensure that, where the practice is legal, safeguards are improved."

of those who oppose physician assisted suicide: "Physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose societal risks."

The Current State of the Law

Over the past twenty years, consensus has been growing over what constitutes fair and ethical medical aid in dying. That consensus is reflected in the laws now in effect in 11 U.S. jurisdictions, and currently under consideration in others. In particular, the "End-of-Life Options for Terminally Ill Patients Act," introduced January 13, 2025, in the 104th General Assembly of the State of Illinois as Senate Bill SB0009:

> Authorizes a qualified patient with a terminal disease to request that a physician prescribe aid-in-dying medication that will allow the patient to end the patient's life in a peaceful manner. Contains provisions concerning the procedures and forms to be used to request aid-in-dying medication; the responsibilities of attending and consulting physicians; the referral of patients for determinations of mental capacity; the residency of qualified patients; the safe disposal of unused medications; the obligations of health care entities the immunities granted for actions taken in good faith reliance upon the Act; the reporting requirements of physicians; the effect of the Act on the construction of wills, contracts, and statutes; the effect of the Act on insurance policies and annuities; the procedures for the completion of death certificates; the liabilities and penalties provided by the Act; the construction of the Act; the definitions of terms used in the Act; and other matters.[25]

The turning point for the widespread acceptance of medical aid in dying in the United States seems to have been a matter of semantics. Ecclesiastes 3:1-2a reminds us that we are mortal beings, and that "[t]here is a time for everything and a season for every activity under heaven: there is a time to be born and a time to die." "Physician-assisted dying," which seems to give the physician an active role in bringing about death, sounded too much like active euthanasia or, at best, assisted suicide, for people to feel comfortable that it was (1) an exercise of the patient's voluntary will; and (2) not a

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[25] Substantially similar legislation is pending before the House of Commons as the "Terminally Ill Adults (End of Life) Bill [As Amended in Public Bill Committee]: A Bill to Allow adults who are terminally ill, subject to safeguard and protections, to request and be provided with assistance to end their own life; and for connected purposes." Ordered, by the House of Commons, to be Printed, 26 March 2025. Published by the Authority of the House of Commons.

suicide. Medical aid in dying, in contrast, is seen not as helping an individual who wishes to die, but rather as helping an individual who wishes to live, but has nonetheless accepted the inevitability of their death, from a disease which cannot be reversed, to avoid prolonged suffering. And, indeed, medical aid in dying, in each of the 11 U.S. jurisdictions where it is permitted, requires:

- At least two requests, one of which *must be in writing signed by the patient,* and witnessed by at least two persons, neither of whom will inherit from the patient*;*
- Separated in time, generally by at least two weeks although the time may be shortened in extraordinary circumstances;
- Examination by two physicians who concur that the patient is suffering from a terminal illness and it is probable that without further treatment the patient will die within six months;
- A declaration of mental competence by the physicians;
- Examination by a psychiatrist where mental competence is in question;
- That the patient be able to self-administer the lethal medication, which usually must be mixed and ingested by the patient without assistance by any third person; and
- That the request for medical aid in dying cannot be made in the form of an advance directive, nor can it be made by a health care proxy or any other agent acting on the patient's behalf.

Further provisions are made for instances where one health care provider is unwilling to prescribe the necessary lethal agent and must refer the patient to a second provider, and also, where necessary, for transfer of the patient to a facility where the lethal medication may be ingested.

The Jewish Views on Medical Aid in Dying: Then and Now

At one time all three major branches of Judaism (Orthodox, Conservative, and Reform) rejected medical aid in dying as contrary to Jewish ethics. A central tenet of Jewish law and tradition is the sanctity of all human life. Jewish law derives from Torah, Talmud, and its commentators. This creates a particular challenge in the arena of medical *halakha*, where many of today's most pressing issues were not imaginable 100 years ago, let alone a millenia or longer ago.[26] When it comes to a decision to end one's own life, a patient's autonomy must yield because their body belongs not to them, but to

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[26] Rabbi Dov Linzer, "Medicine and Society: Treatment of Terminally Ill Patients According to Jewish Law," **Virtual Mentor**, *American Medical Association Journal of Ethics,* Vol. 15, No. 12 (Dec. 2013) 1081-1087.

God.[27] In addition to the duty to protect life, however, Judaism recognizes a duty to alleviate suffering. Thus, even Orthodox Judaism recognizes that it is not appropriate to intervene to extend life where suffering is great; instead, natural death should be allowed to take its course.[28] The duty to protect life is not tantamount to a duty to prolong suffering.

In 2022, the Central Conference of American Rabbis issued Responsa 5783.1 "Medical Aid in Dying." There, the *Sh'eilah* was twofold: whether a Jew may opt for physician-assisted death in jurisdictions where civil law allows it, and whether a Jewish medical practitioner may assist a patient in dying? In reconsidering their 1994 Responsa rejecting medical aid in dying, the CCAR Responsa Committee argued that they were "in accord with the life affirming *and* realistic perspective of our tradition in responding to that small number of patents for whom physician-assisted dying is the only treatment available for what clinicians refer to as 'total pain.'"[29] They relied on the following words of R. Joseph Dov Soloveitchik: "Law that lacks *tzedakah*, that does not draw from the wellsprings of feelings and tenderness of heartfelt ways of pleasantness and inner kindliness, that is confined by its boundaries and does not break through its border to go beyond what the law requires—such law is absolute wickedness."[30]

In short, the Responsa Committee found new medical evidence as grounds for change in the law. This evidence was the concept of "total pain," a condition first identified in 1967 by Dame Cicely Saunders, the founder of the modern hospice movement. Saunders coined the term "total pain" to describe the multifactorial nature of the pain experienced by palliative care patients: pain that originated in the physical, psychological, social, and spiritual domains. Saunders was the first to point out that unless all dimensions of total pain were addressed, optimal pain relief was not possible, and that as total pain increased, the patient experiences a spiralling loss of control over their life. This, in turn, leads to further pain and, ultimately, to despair.[31]

The Responsa Committee recognized, as a corollary to the concept of total pain, "that there is a difference between *biological existence* and *living*."[32] The expression of

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[27] Where even a small amount of risk is involved, a patient is permitted to forgo potentially life-saving treatment; likewise, the patient may forgo treatment that will cause the patient distress. *Ibid.*

[28] The source for this rule is the Talmudic story of Rabbi Jude the Patriarch, who was dying in great pain. While his students prayed for his life to be extended, his maid dropped a vessel from a balcony above, distracting the students from their prayers, so that his soul could pass and his suffering end. Nedarim 40a. *Babylonian Talmud*. Jerusalem: Vagshal Publishing Ltd. 1993.

[29] CCAR Responsa 5783.1 "Medical Assistance in Dying"

[30] Joseph Dov Soloveitchik, *Halakhic Morality: Essays on Ethics and Masorah,* ed. Joel B. Wolowelsky and Reuven Ziegler (New Milford, CT: Magid Books, 2017) 135

[31] CCAR Responsa 5783.1 *citing* Cicely Saunders, *The Management of Terminal Illness* (London: Hospital Medicine Publications, 1967)

[32] CCAR Responsa 5783.1

this difference invites us to ask, what is the human life that is at the core of *pikuach nefesh*? Mere biological existence, in this analysis, is not what has been created *b'tzelem Elohim*, or every living organism, from a single-celled amoeba to a whale would be considered to have been created in God's image. It is "living" that distinguishes humans from other biological matter, and it is the *living human* at the core of *pikuach nefesh*. Where total pain reduces a person's humanity to mere biological existence, the *nefesh* has already been extinguished.

The Responsa relates a story from the midrash of a woman who was tired of living.

> It happened that an extremely elderly woman came before R. Yose ben Chalafta, and said to him, "Rabbi, I am too old, and my life is distasteful to me. I can taste neither food nor drink, and I would like to depart from this world." He said to her, "What accounts for your long life?" She said, "I am accustomed, even if there is something very dear to me, to set it aside and go early to the synagogue each day." He said, "Refrain from going to the synagogue for three consecutive days." She did so, and on the third day she fell ill and died.[33]

The Responsa continues:

> R. Yose apparently finds nothing strange about this woman's attitude; accordingly, he makes absolutely no effort to dissuade her. He acknowledges and validates her sense that because she is incapable of doing the things that make life an act of living, she is merely existing, and he actively tells her how to bring an end to her existence.

In short, life here is no longer a divine gift; it has become a form of torture and the woman is experiencing total pain. The decision to die gives the elderly woman agency over an otherwise uncontrollable situation.[34]

Thus, as to the question whether a Jew may opt for a physician-assisted death where the civil law allows it:

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[33] *Yalkut Shimoni* II, §943.

[34] CCAR Responsa 5783.1

> We are now facing the reality that palliative care does not address every individual sufferer's experience of *total pain*. If we accept that we are obligated to heed the patient when their experience of their own illness leads them to reject treatment, we believe that we are also obligated to heed them when their experience of their own illness is that their pain is so complete—such an overwhelming and intolerable combination of physical, psychological, social, and spiritual pain—that even palliative care no longer provides adequate therapeutic effectiveness and they can no longer bear to live in such pain.[35]

The Responsa Committee went further, noting that there are circumstances where a physician-assisted death can be a justifiable decision in accord with Jewish law and tradition even for someone with a chronic but not inherently fatal condition.[36]

> The reality of modern medicine is that some individuals are afflicted with severe physical illnesses or injuries that leave them alive *and* conscious, but in such limited circumstances that life is more of a curse than a blessing to them. For us to tell such an individual that their only option is to change their mental attitude so that they can experience joy in life and gratitude to God for keeping them alive, seems a cruelty beyond measure. Therefore, while we hope that a person even in a seriously compromised condition would find a way to value living, we conclude with sadness that this is not always possible, and that, for some few individuals, the model of the anonymous old woman and of R. Chanina must remain an option.[37]

Consistent with their ruling on providing medical aid in dying to a patient who is able to self-administer the lethal agent, the CCAR Responsa Committee went on to say that it would be in accord with Jewish law and tradition for a Jewish physician to provide an assisted death to an individual in total pain for someone with a terminal diagnosis for whom death is not imminent or for someone suffering total pain as the result of a chronic, but not inherently fatal condition. The Committee went on to specify certain safeguards that it would want to see to ensure that individuals are not coerced or encouraged into opting for assisted dying under circumstances, such as financial

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[35] CCAR 5783.1

[36] Medically-assisted death, while not currently available for those with non-terminal conditions in any U.S. jurisdiction, may be available for those with non-terminal conditions under limited circumstances in Canada.

[37] CCAR 5783.1

limitations, that should have no bearing on such a decision. Likewise, the Committee expressed concern that the decision be that of the patient, and the patient alone, and, further, that the decision not be made out of depression, fear, or panic. In that regard, the Committee favors the use of advance directives to ensure that decisions are made by patients while they are competent.[38]

Although the CCAR Responsa has been read as free medical aid in dying in those U.S. jurisdictions where it is currently legal, a close reading reveals that the Responsa is narrower:

> We agree *in principle* that in an era in which medical technology can prolong life to a point that a person's existence becomes torture to them, when *r'fuat haguf* is no longer possible, we can, at least, support the choices of those individuals for whom death is *r'fuat hanefesh*. We are not convinced that *in practice* any jurisdiction currently meets these conditions, but we set them forth nonetheless.
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> 1. A Jew suffering from a terminal illness whose death is not imminent may, where it is legal, avail themselves of physician-assisted dying under the following circumstances:
>   a. The patient has full and unlimited access to all effective medical care necessary for enabling them to live a meaningful life so far as they are able.
>   b. The patient and their legal heirs have made formal attestation that financial considerations have played no role in this decision.
>   c. The patient has undergone careful screening by a trained committee of professionals to ensure that the motivation is not untreated depression.
> 2. A Jew suffering from a debilitating chronic illness that is not inherently fatal may choose to avail themselves of physician-assisted dying as a last resort, if living with the degree of suffering they must endure is intolerable, subject to the criteria stipulated above.
> 3. A Jew suffering from mental illness (but not a terminal illness or chronic and debilitating illness other than mental illness) may

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[38] The CCAR Committee encourages congregational rabbis to promote death literacy among their congregants. As an end-of-life doula, one of my roles is to work with rabbis to educate congregations about end of life options and the importance of executing and regularly reviewing and updating advance end-of-life care directives.

not avail themself of physician-assisted dying, since we cannot properly evaluate their state of mind.

4. A Jewish physician who recognizes that a suffering individual has a terminal or incurable condition that has placed them in a state of what palliative medicine refers to as "total pain" may respond to the sufferer's desire to end their suffering by administering or making available drugs that will terminate the individual's life, subject to the stipulations above.[39]

In 2020, Rabbi Elliot Dorff wrote a rabbinic ruling on behalf of the Committee on Jewish Law and Standards of the Rabbinical Assembly that provides guidance in matters of *halakha* for the Conservative Movement.[40] In many respects, that ruling is substantially similar to that of the Reform Movement. Rabbi Dorff, however, focuses his analysis on the laws in effect in California[41] and Canada in order to give guidance to Jews living in those jurisdictions. Rabbi Dorff first acknowledges that "'A terminally ill patient suffering terrible pains who *actively kills himself* is not considered as one who knowingly committed *suicide*, and none of the rites relating to burial and mourning are withheld from him.'"[42] Dorff continues by approvingly discussing the doctrine of "double effect:"

> In the isolated case where pain is unbearable, whether as a result of a recently contracted disease (e.g., bone cancer) or a prolonged condition or degeneration, expression of compassion is just not enough; one must do what one needs to do to enable the patient to stop suffering. . . . We need to assure that the patient has been provided as much pain medication as necessary, even at the cost of losing consciousness, . . . but sometimes doctors know full well that . . . the amount necessary to quell the pain will simultaneously kill the patient. . . .[43]

Dorff concludes "it is critical that rabbis make clear that, legally as well as medically, aid in dying is not a suicide but rather a compassionate effort to alleviate pain caused by the underlying disease that is taking the person's life."[44] Rabbis should offer

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[39] CCAR 5783.1

[40] Elliot N. Dorff, "Assisted Suicide/Aid in Dying Reconsidered: 'God's Compassion Embraces All God's Creations' (Psalms 145:9)," YD 345.1997c, https://www.rabbinicalassembly.org/sites/default/files/assets/public/halakhah/teshuvot/199112000/dorff_suicide.pdf

[41] Callifornia's law is substantially similar to that of every other U.S. jurisdiction permitting medical aid in dying.

[42] Dorff, "Assisted Suicide," *quoting* Avraham Steinberg, M.D., *Encyclopedia of Jewish Medical Ethics,* Fred Rosner, M.D., trans. (Jerusalem and Nanuet, NY: Feldheim, 2003) 3:1056-57 (italics in the original)

[43] Dorff, "Assisted Suicide," at 35.

[44] Dorff, "Assisted Suicide," at 36.

empathy and support to patients, family members, and doctors in situations where family members are witnessing a patient in such great uncontrollable pain that the patient reaches the point of asking for aid in dying. Kindness in such cases, says Dorff, is not enough. "The patient has a Jewish legal right to gain aid in dying and the doctor has legal permission in Jewish as well civil law to provide it."[45]

Dorff stops short of permitting medical personnel to administer lethal drugs to a patient in uncontrollable pain. As a matter of publi

policy, he interprets Jewish law to allow physicians to provide aid in dying to patients in uncontrollable pain who can administer drugs to themselves, but ban active euthanasia. At the same time, he would "stand aside without judgment of either the patient or the physician in cases of people in uncontrollable pain seeking aid to end their own lives and who need a physician to administer it in jurisdictions that allow that.[46]

Where Does That Leave Lloyd?

None of the U.S. jurisdictions where medical aid in dying is legal allow an individual to express a preference for medical aid in dying in any form of advance directive or by proxy. One can write an advance directive that says:

> in the event that as a result of catastrophic injury or illness I suffer total pain and lack the ability or the competence or both to express my contemporaneous wishes, I would like it to be known that in the event I reach a point where my condition is either terminal or there is no prospect for a meaningful recovery, and I am unable to communicate verbally or in writing, unable to breathe on my own, unable to eat or drink, and/or suffering from extreme physical, psychic, social, and spiritual pain, I request medical aid in dying. Further, in the event that I am unable to self-administer medical aid in dying, I ask that it be administered to me by a medical professional

But there is no jurisdiction that will recognize and give effect to such an advance directive. Nor can someone with ALS wait until they have been diagnosed and then prepare an advance directive, or rely on a health care proxy to make the request for them. Under every U.S. law that permits medical aid in dying, the request must be made and repeated orally, by the patient themself, and memorialized in writing, and the request must be made when the person has a prognosis of six or fewer months to live.

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[45] *Ibid.*

[46] Dorff, "Assisted Suicide," at 41-42

For patients like Lloyd, provision must be made for specifying medical aid in dying in an advance directive or by health care proxy. When I visited Lloyd, he knew that he would need medical aid in dying: that a day would come when he was overwhelmed by the realization that he had been reduced to a biological existence without a *nefesh*, and he knew that by the time that day arrived he would be unable to ask for help. Instead, he was asking me, months or years ahead of time to make sure this help would happen for him—something I couldn't do, but could have done if it was permitted by a health care proxy.

Lloyd also knew that when the day came that he was ready to die, he would not be able to self-administer a lethal dose of medication. Someone else would have to do it. There is currently no law in the U.S. which permits a physician or other medical professional to actually administer medical aid in dying to a patient. Lloyd knew this. He was looking at me, and asking whether administering a lethal dose of medication to him was something I would be able and willing to do. But even for Lloyd, even for someone I loved, no matter how ethical and morally correct I thought such a course would be, I couldn't agree to break a criminal law.

ALS patients are not the only population who find themselves unfairly excluded by the parameters of today's medical aid in dying laws. In an effort to avoid a "slippery slope," state legislatures have drawn narrow boundaries around who may seek medical aid in dying. By disallowing requests for medical aid in dying by advance directive or health care proxy, they have excluded persons who suffer catastrophic brain injuries including hemorrhagic strokes that leave them paralyzed, blind, unable to communicate, and without any reasonable chance of meaningful recovery. By disallowing physicians to administer medical aid in dying, legislatures may force some patients, for example, those with Parkinson's, to opt for an earlier death than they otherwise might, while they are stilll able to self-administer the drugs.

Conclusion

The medical aid in dying scheme hypothesized in the Reform Responsa would have treated an ALS patient like Lloyd with the same level of dignity and respect afforded other patients with terminal diagnoses. Unlike present U.S. laws, it would have allowed him to exercise agency over his own decline by preparing a detailed advance care directive that would make provision for a medically assisted death at the point in his disease process when he believed his life would become unbearably painful. In the alternative, it would have allowed him to request medical aid in dying through a health care proxy who knew his wishes. At that point, the scheme hypothesized in the Reform

Responsa would also have allowed a Jewish doctor to administer a lethal agent to Lloyd to provide him a gentle death.

In hypothesizing a medical aid in dying scheme different from the laws currently in effect in many U.S. jurisdictions, the Responsa Committee heeded the warning that "Law that lacks *tzedakah*, that does not draw from the wellsprings of feelings and tenderness of heartfelt ways of pleasantness and inner kindliness, that is confined by its boundaries and does not break through its border to go beyond what the law requires—such law is absolute wickedness."[47]

- Medical aid in dying was not legal in California when Lloyd died. Today, it is. But today's law, which would not afford Lloyd a better death than the one he suffered, is not ethical because it does not offer the same benefit to ALS patients that it affords to other patients with terminal diagnoses. Medical aid in dying schemes must be changed to allow patients to request medical aid in dying in advance directives and living wills or by proxy, and to allow medical personnel to administer lethal drugs to patients who are unable because of their condition to self-administer them.

> [T]he Talmud recognizes that in every generation, there are certain human beings prepared to stand up in the face of any power, even God, to champion life, demand justice, and appeal for compassion. These special souls are said to display "chutzpah even in the face of heaven—*chutzpah afilu kelapei shemaya"* [BT *Sanhedrin* 105a]. Chutzpah, in this definition describes a rare quality of moral courage. This chutzpah is at the heart of Judaism.[48]

For the medical aid in dying laws to be fair, state legislatures must exhibit *chutzpah afilu kelapei shemaya* and amend existing laws to enable ALS patients to elect medical aid in dying as an end of life option.

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[47] Joseph Dov Soloveitchik, *Halakhic Morality: Essays on Ethics and Masorah,* ed. Joel B. Wolowelsky and Reuven Ziegler (New Milford, CT: Magid Books, 2017) 135

[48] Geoffrey D. Claussen, *Modern Musar: Contested Virtues in Jewish Thought*. Jewish Publication Society Philadelphia: 2022 *quoting* Edward Feinstein, *The Chutzpah Imperative* (2015) 122-123