

End-of-Life Decisions: A Discussion Guide

By:
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A. Overview

Unprecedented advances in medicine and pharmacology are modern blessings. They also create new and ever-more perplexing challenges. The blessings allow us to live longer and longer, but prolonged life often brings physical, mental, and psychological disabilities that surpass the present limits of science. The new circumstances particularly affect demographic groups like the "sandwich generation" as it struggles to make life-and-death decisions about a parent who lingers on life-sustaining systems while at the same time tending to a family and raising children. An aged spouse is also especially vulnerable when called upon to make decisions about a suffering lifetime partner. Quality-of-life decisions that define life in terms of physical and/or mental competence and self-sufficiency complicate the equation, and sometimes pit family members against one another in the legitimate quest to determine if and when to "pull the plug." It is not easy to act on the anguishing decision even when all family members agree on what to do: guilt and remorse complicate the impact of seeing a loved one suffer and interfere with the proper unfolding of the mourning process.

But suppose manipulating the plug is not even an option. Perhaps the choice is, rather, whether to expedite death by administering drugs or by withholding nutrients. Both acting and not acting are partners to guilt, fear, shame, inadequacy. Can lose-lose ever become win-win? What do win and lose mean in the context of concern for the welfare of the caregiver and the dignity and self-esteem of the loved one who depends on you—literally—for life and death? We learn: "There is a time for being born and a time for dying" (*Ecclesiastes*3:2). But how do we know when the dying time has come? Are we free to determine time and method?

Judaism has much to teach us about living and dying (and, indeed, about all ultimate questions). However, there are no unequivocal answers for these daunting questions. Moreover, some Jewish positions contradict others. Besides, new science poses new moral questions regarding, for example, premature birth/neonatal care, brain function, dementia, cardiac resuscitation, oncology, and a host of other conditions that necessitate judgment calls about whether or not to intervene, for life or for death. Bio-ethicists, religious leaders, politicians, doctors, jurists—and most of us—will, sooner or later, confront the myriad questions arising from the simple fact that we are living longer than at any time in history. (NOTE: Increasing longevity does not characterize many parts of the world where living conditions and the unavailability of modern medicine preclude long life. Nor is living longer evident among some population segments in many advanced countries.)

It is tempting to look on the 2005 Terri Schiavo case as a framework for this *Reform Judaism* "Focus" section because the tragedy mobilized opinions and caused many who had not thitherto struggled with the question to think about it. Yet a similar surge of public interest surfaced in 1975 when Karen Ann Quinlan's parents requested the hospital to disconnect their brain-dead young daughter from a respirator. Hospital officials refused, but lost their case in the New Jersey Supreme Court. Quinlan survived in a vegetative state for nine years, breathing on her own, fed through a tube. These are two highly visible examples of modern disputes. The pathos plays itself out much more frequently away from public glare.

Deciding whether a loved one should continue to linger or should be helped to die has far-reaching consequences apart from what the decision means for the person we love. The emotional drain on those who must make the decision is profound, especially when family members disagree on a course of action. When this happens, the bitter dispute can permanently scar the family constellation. Further, family members who challenge the patient's wishes, even when that patient is competent to make his or her own life-or-death decisions either in person or in a living will, face additional emotions of guilt and betrayal.

"End-of-Life Decisions" explores these and related questions in the seven selections that comprise this *Reform Judaism* "Focus" section. This guide summarizes each in turn and provides discussion suggestions framed as three "Big Ideas":

- 1. It is very difficult to decide whether to hold on to life or let the loved one go.*
- 2. Empowering the dying person to make final decisions acknowledges the patient's rights, helps us remember that the loved one is central in the drama, and provides us with a measure of consolation.*
- 3. Jewish sources provide guidance, not absolutes, regarding end-of-life decisions.*

B. Summaries.

1. "Introduction."

This brief piece emphasizes:

- a. the deeply personal nature of end-of-life circumstances and decision making;
- b. the practical value and consolation found in the guidance provided by Jewish tradition;
- c. the importance of seeking a measure of comfort when facing the loss of a loved one.

2. "The Last Dance." by Rabbi Jonathan Kendall.

Rabbi Kendall suggests that the early and superstitious practice of changing the name of a dying person to thwart death is somewhat akin to drawing on modern medical technology for the same purpose. Then, as now, people face the dreaded what-to-do question at the bedside of a loved one. Then, as now, people placed in such positions frequently resent it. Resentment creates anger and ultimately guilt on top of the other emotions inevitable at such times. We respond to such circumstances according to our relationship not only to the patient but also to other members of the family. Death does not always unite families; sometimes it exacerbates their apartness.

Rabbi Kendall reminds us that Judaism teaches neither to hasten death nor prolong its coming, a position that reflects the conflicting goals of holding on and letting go. Our relationship to the patient--including the conscious and unconscious memories we carry of that relationship--profoundly influences the decision, especially when "natural" outcomes may not be certain.

Reminiscing on his father's death, Rabbi Kendall concludes that it is not us, but the loved one, who is the central character in the drama.

3. "Together in the Dark." by Dr. Rachel Naomi Remen.

Remen explores the complex emotions that are deeply rooted in the relationship each player in the drama has had with the dying person. Decision-making conflicts ensue because each family member's relationship with the patient is unique and prompts different perspectives on what's best for the loved one – although the unacknowledged question frequently is: What's best for me? Remen believes that the resolution of the paradox lies in accepting two premises: the dying person has the right to decide whether his or her life is worth keeping; the dying person's decision is valid for him or her even when we disagree with it. Such action empowers and dignifies the patient in the last moments of living— and that should be the family's goal.

The author observes that the death experience, while it mobilizes pain and a sense of loss, is also a time for quiet reflection on things that really matter. Mourners can find comfort in this final gift from a loved one that enables them to discern new insights about others as well as themselves.

Remen suggests that a written living will may not always suffice to assure that the dying person's wishes are clear; ideally, a taped message should augment the will. This is becoming more and more important because medical science continues to push our understanding of life itself to new frontiers. The resulting need to make end-of-life decisions becomes ever more insistent and terrifying; it leaves us "...struggling in the dark" in uncharted areas.

4. "Stumbling on the Edge of Life." by Rabbi Edythe Held Mencher.

Jewish tradition commands us to choose life (*Deuteronomy 30:19*), says Rabbi Mencher, but at the same time our culture imbues us with the idea that "quality of life" also counts. The conflict occasions one of the most difficult end-of-life dilemmas imaginable, leaving it to each person to define "quality" and to determine whether it should be a valid factor in decision-making. Deciding becomes increasingly difficult as science improves life-sustaining techniques that are neutral on the question of life's quality.

Rabbi Mencher reminds us that the absence of a living will places a heavy burden on a family. In one of her case studies, as in the Quinlan case (see above), removal of life-sustaining equipment was opposed by the doctor despite the wishes of the family. The doctor ultimately conceded removal of all help except the feeding tube. Rabbi Mencher analyzes these developments in the light of the Jewish teaching which says that death should not be impeded or hastened.

Making a life-or-death decision is fraught with difficulty. Competing opinions, outside pressures, and emotional turmoil can delay a conclusion. Rushing the process can lead to later regret. Yet, as Rabbi Mencher shows, regret also accompanies a decision delayed. Thus, we cannot escape the responsibility to act. Deciding to let go provides an opportunity to say good bye, a significant aspect of the grieving process.

5. "A Jewish Guide to the Moral Maze of Hi-Tech Medicine." by Rabbi Mark Washofsky.

Rabbi Washofsky demonstrates that while there is much in Jewish teaching to guide life-and-death decision-making, each situation demands its own analysis and requires careful consideration in applying Jewish law. However, all cases have this in common: The cornerstone of the law rejects killing a patient, no matter how noble the motivation, and, at the same time, prohibits interfering with an imminent death.

These fundamental stances, and other laws relating to a *goses* (dying person), are derived from the Talmud and couched in the language of its times, starting about two thousand years ago. Talmudic positions, in turn, are based on even older Torah teachings. It falls to us to determine whether the intent of ancient metaphor and simile extends to the ability of modern science to delay death even when it cannot heal. Is withholding treatment that prolongs life but does not heal the cause of impending death the same as killing?

The author reviews a 1994 Central Conference of American Rabbis statement that reinterprets the imperative to save life to include a commandment to practice medicine in order to heal. This principle of "therapeutic effectiveness" demands that a medical procedure promote healing rather than merely delay death. The principle, Rabbi Washofsky says, enables us to base moral judgments on Jewish teaching, even though no two cases are the same and the principle has to apply on a case-by-case basis. He notes that the recent Schiavo case illustrates how hard it may be to apply the principle with respect to nutrition and hydration in any given instance.

Rabbi Washofsky urges us to understand that a prayerfully arrived at hard-to-make choice about life and death is neither good nor bad. It is simply the best judgment a patient or family can make guided by Jewish sources.

6. "Time." By Rabbi Terry Bookman.

This brief adaptation from Rabbi Bookman's latest volume reminds us that two ways of viewing time govern reality: linear and cyclical. The first conception takes us from a starting point to an ending, from birth, through life, to the finality of death. The second views the universe and our own existence as a closed system with no discontinuities--no past, present, or future.

Cyclical time, embedded in many religions and emphasized by Judaism, mirrors the natural world. In cyclical time, death is no more the end than birth is the beginning. Both are stages in a seamless progression of events. Those we love do not simply disappear; they continue in ways we do not comprehend, ways that continue to link us to them. In this we find both solace and attachment to a wider realm of being.

Linear time teaches that all things end. Cyclical time teaches that we are one with what was, what is, and what is to be.

For more on the Jewish view of time see Leo Baeck. *The Essence of Judaism*. (New York: Schocken, 1948.) pp. 226-7; Abraham J. Heschel. *The Earth is the Lord's & The Sabbath*. (New York: Meridian, 1963) – Part II, pp. 8-9; Franz Rosenzweig. *The Star of Redemption*. (New York: Holt et al, 1970). –pp. 292-3

7. "Reform Resources."

Lists some of the many Reform resources that are accessible through the URJ Press and other Unionfor Reform Judaism departments.

C. "Big Ideas" to Explore.

1. It is very difficult to decide whether to hold on to life or let the loved one go.

Jewish tradition teaches us to preserve life and, if necessary, to violate even the Sabbath to do so (*Yoma*84a,b). Judaism also teaches that to save one life is to save the entire world (*Sanhedrin* 4:5). Further, God intends us to live by the commandments, not die by them (*Leviticus* 18:5).

On the other hand, Jewish tradition insists that we must imitate God in practicing compassion and mercy because we are created in God's image.

Such contradictory positions pose a dilemma because we can choose only one of two conflicting values of equal merit. No resolution of a dilemma entirely satisfies; we are subject to remorse and guilt whichever path we take, wondering if we made the right decision and in a timely manner.

Questions for Discussion

1. Life or mercy? Which value takes priority? Why?
2. Schiavo's husband chose mercy; her parents chose life. Quinlan's parents chose mercy; her doctor chose life. Leonia's children chose mercy; her doctor chose life (see Mencher article). How would you have decided the dilemma in each circumstance? Explain.
3. Is the choice for mercy a choice for euthanasia? If not, explain. If yes, is it a permissible choice anyway? Review Rabbi Washofsky's article *after* discussing.
4. Consider this excerpt:

...a fundamental ethic upon which decisions can be constructed: *the dignity and sanctity of human life and the preservation of that human life in dignity and sanctity*.

This fundamental ethic...in Judaism, serves as the foundation for a methodology of decision making. The difficulty in the application of this value to all cases is manifest by the presence in our culture of two "wild cards": autonomy and technology. These two realities flow as twin currents through the social fabric of our world. They impact the fundamental value by introducing shades of gray, reminding us that decisions at the end of life are often not between what is good or bad, but variations of those themes, reflected against the wishes of the individual and a family. Address, *loc. cit.*, pp. 37-8.

Define *dignity* and *sanctity*. Why do these comprise a "fundamental Jewish ethic?" How does this ethic affect life-and-death decisions?

5. We have the technical know-how to prolong the life of a dying person for a long time. Does that mean we should do so? Explain

2. Empowering the dying person to make final decisions acknowledges the patient's rights and helps us remember that the loved one is central in the drama.

Because it is difficult to set aside our own needs, especially in crisis moments, we can never be sure whether the decision to end or sustain a life is influenced by what we think is best for us. Remen's corrective is to place the wishes of the dying person above all else. Rabbi Kendall tells us that the patient, not the family, is the primary subject.

We can cope better with the profound emotions of an end-of-life situation by clarifying our responsibility. While a living will, power-of-attorney for health care, or taped message by the patient removes some of the burden from family, it is frequently necessary to be the patient's advocate to assure that medical personnel honor those wishes.

Questions for Discussion

1. How might an aware patient be empowered even in the absence of a living will? Grollman *loc. cit.* suggests a "decalogue."

THOU SHALT NOT: Be Afraid to Touch. Hesitate to Smile and Laugh.

Be Uncomfortable with Silence. Offer Untrue Statements. Believe

You Need to Have All the Answers and Solve All the Problems.

THOU SHALT: Accept the Feelings of the Sick Person. Share Time

Together. Offer to Help. Locate Other Supports. Respect the Privacy

And Integrity of the Sick Person. – pp, 163-5.

Which "commandments" empower the patient the most? Which empower the least? Explain. What would you add to the lists?

2. *Newsweek* (July 25, 2005. Anne Underwood, "A Dream Before Dying," pp. 50-51) discusses the book, *Dreaming Beyond Death*, by Rev. Patricia Bulkley and Kelly Bulkley, which suggests that many people have extraordinary dreams in their final days and weeks. These dreams can help the dying grapple with their fears, find the deeper meaning in their lives, even mend fences with relatives. Yet all too often caregivers dismiss them as delusional or unworthy of attention...It's a loss on both sides...Talking about end-of-life dreams can give family members a way to broach the uncomfortable topic of death...For the dying, discussing such a dream can provide a simple way to articulate complex emotions...to the extent the dying person finds comfort in any such dream, so do surviving relatives. How might you encourage a dying person to share dreams or other thoughts with relatives? How might such an exchange achieve Remen's goal of quiet reflection and empowerment?

3. Why is *bikkur cholim* – visiting the sick – a cardinal *mitzvah*?

4. Read the following from Nuland, *loc. cit.*

...terrible solitude is the subject of Tolstoy's story "The Death of Ivan Ilyitch." ... the terrible solitude of a death made lonely

by withholding the truth, "this solitude through which he [Ivan Ilyitch] was passing, as he lay with his face turned to the back of the divan, a solitude amid a populous city, and amid his numerous circle of friends and family...Ivan could share his terrible knowledge with no one," and he had to live thus on the edge of destruction--alone, without anyone to understand and pity him.

The origin of his wife's attempted deception seems to have been her own determination not to deal with the emotional consequences this truth would precipitate.

There is another element, too, that these days often conspires to isolate the mortally ill. I can think of no better word for it than *futility*. Pursuing treatment against great odds may seem like a heroic act to some, but too commonly it is a form of unwilling disservice to patients; it blurs the borders of candor and reveals a fundamental schism between the best interests of patients and their families on the one hand and of physicians on the other. –pp. 245-6.

- a. Is it ever advisable not to tell a dying person how sick he or she is, or that a prognosis is not good? Explain.
- b. How may vigorous pursuit of treatment be a disservice to patients?

3. Jewish sources provide guidance, not absolutes, regarding end-of-life decisions.

Jewish opinions vary on a host of end-of-life issues because Jewish teaching frequently provides contrary principles, some of which are found in the "Focus" articles, including:

- "There is a time to for being born and a time for dying." *Ecclesiastes* 3:2
- "The dying person is like a living person in all respects." *Semachot* 1:1
- An action that hastens death is forbidden: "one who touches him has blood," but it is permitted to remove an obstacle to the death of a dying person. *Yoreh De'ah* 339:1
- It is obligatory to practice *pikuach nefesh* – saving life. *Leviticus* 18:5
- The ultimate goal of a medical procedure is to heal (*refu'ah bedukah*), not sustain life. CCAR, 1994
- "I have put before you life and death...choose life." *Deuteronomy* 30:19

Other teachings include:

- "He should pay for the loss of his time and assuredly cause him to be healed." *Exodus* 21:19
- "One should not cry out that his soul should return since he cannot live thereby but a few days." *Sefer Hasidim*, par, 234
- A dying person should not be left alone, so that he or she will not feel abandoned. *Yoreh De'ah* 339:4
- "The Torah has granted the doctor the privilege of healing." *Kitzur Shulchan Aruch* 192:3
- "One who is seriously ill may use for his cure any article that is forbidden, as the compliance of no law must be insisted upon in a case of saving a life in danger" [except, in other rulings, where you must give up life to avoid idolatry, immorality, and murder –ADBJ]. *Kitzur Shulchan Aruch* 192:7
- "After the soul has departed, they should put a light feather under his nose, and if it does not move, ever so slightly, it is certain that the person is dead." *Kitzur Shulchan Aruch* 194:5

Questions for Discussion

a. Find the contradictions.

b. Suggest how to resolve the dilemmas when making end-of-life decisions. Explain your reasoning in each instance. NOTE: You may have to paraphrase some statements to reflect modern understandings and techniques.

D. Resources.

Richard F. Address, ed. *A Time To Prepare: Revised Edition* (New York: URJ Press, 2002).

Earl A. Grollman. *Caring and Coping When Your Loved One Is Seriously Ill* (Boston: Beacon Press, 1995).

Isaac Klein. *A Time To Be Born, A Time To Die* (New York: United Synagogue of America, 1976).

Elisabeth Kubler-Ross. *Death: The Final Stage of Growth* (New Jersey: Prentice-Hall, 1975).

Elisabeth Kubler-Ross. *Living With Death and Dying* (New York: Macmillan, 1981).

Sherwin B. Nuland. *How We Die. Reflection's on Life's final Chapter.* (New York: Knopf, 1994).

Jack Riemer. *Jewish Reflections on Death* (New York: JPS/Schocken, 1974).

O. Ruth Russell. *Freedom to Die: Moral and Legal Aspects of Euthanasia* (New York: Human Sciences Press, 1975).

Jack D. Spiro. *A Time To Mourn: Judaism and the Psychology of Bereavement* (New York: Bloch, 1967).

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