Making Decisions at the End of Life: An Approach from Sacred Jewish Texts

RABBI RICHARD ADDRESS

It takes three things to attain a sense of signification Being:
God, a soul, and a moment.
And the three are always here.
Just to be is a blessing,
Just to live is holy.

THE EVOLUTION FROM JEWISH TEXTS

We are instructed in Jewish tradition to make choices for life. Human life remains the fundamental value within Judaism that serves as the foundation for our entire religious and ethical system. This is to be life that is in the "image and likeness of God," imbued by a sense of devotion to doing sacred acts (*mitzvot)* that affirm and support the power of our relationship to the mystery we call God.

In recent decades medical technology's progress has surpassed society's ability to absorb the impact and implications of an expanding possibility of choices. From new technologies at the beginning of life to the ability to extend the boundaries of life at its end, we are often presented with unique scenarios that challenge our relationship with God. A challenge is to establish a method of decision making, that while acknowledging the realities of medical technology, draws strength from the guidelines establish by Jewish tradition. These moments, as Heschel reminds us, are sacred moments when the power of God is present. However, as science and medical technology have progressed, the contexts for creating sacred moments of decision making have evolved in new and often dramatic ways. It is the purpose of this chapter to explore a model of decision making that focuses on the moments at the end of life. It is a model that is supported by the fundamental values of Jewish tradition while embracing the twin challenges of evolving medical technology and the belief in personal autonomy.

At the beginning of the twenty-first century, we find ourselves at the beginning of a great revolution, a revolution of longevity. The Jewish community is no different in this regard from the non-Jewish world. Indeed, demographic studies of the Jewish community contend that it is "graying" at a faster rate that non-Jewish communities, due in large part to longer life spans and the fact that Jewish birth rates for much of the non-Orthodox community barely reach two children per family. Theordore Roszak introduces the concept of this revolution by nothing that

> *Longevity is far more than a human interest item; it marks not only a massive change but a permanent one. . . . The largest growing sector of our population as of the early twenty-first century comprises those over eighty-five. By the middle of the twenty-first century, those who fail to reach that age, except by reason of accident, will fall into a new medical category: premature death. (Roszak 1998,10)*

We know that this is the longest-living, most health-conscious, mobile, and affluent older adult population ever. This reality is restructuring the way our society looks at work, retirement, leisure, sexuality, and political power.

Excerpt from: Kimble, Melvin A. and McFadden Susan H., eds. (2003) *Aging, Spirituality, and Religion – A Handbook Volume 2.* Minneapolis: Fortress Press.

The Jewish community reflects these new realities. These became obvious during a series of population studies of the Jewish community sponsored by local as well as North American Jewish communal agencies during 1990s. The majority of the current generation of Jewish older adults was born in North American and thus may have more in common with their grandchildren than their grandparents. Their "old country" may be the "old" neighborhoods of Philadelphia, Los Angeles, Baltimore, and Brooklyn – and not Eastern Europe. Like the non-Jewish population, this generation is more affluent, mobile, and educated than any in Jewish history.

What is also striking is that this longevity revolution is providing our society with a spiritual revolution as well. The gift of long life and life experience is being unwrapped in a desire to see how one's life and experience can make sense in a transcendent fashion. Pediatric responses are quickly cast aside. A life fully lived now demands a religious community that will provide adult responses to deeply spiritual questions.

As powerful as this revolution in longer life is, it faces a unique challenge as the cohort of the "baby boom" revolution joins their parents in a virtual aging explosion. As revolutionary as the current older adult generation is, their children, the "boomers," promise to expand the horizons and challenges of what it means to grow older. We can expect the spiritual search that marked much of the last decade to continue to expand. While the parents of the boomers may be seeking meaning at the end of their life, their children, once dubbed "a generation of seekers" (Roof, 1993), will push the exploration of spiritual meaning into new directions. One of the greatest challenges for contemporary synagogues is exactly how to respond to and anticipate the growing appetite for spiritual meaning that is so much a part of the baby boom generation.

Many of the moments that bring these generations together in their spiritual search are those involved with issues of decision making as life ends or is radically altered. The current longevity revolution can be seen as the foundation for this reality. Because of longer life, better health, great mobility, and access to health care, the denial of mortality is ever-present. In distinction to past generations, few people are given the gift to say goodbye to a loved one in person, to experience the sacredness of those moments, and, in their loved one's face and struggle, to see themselves. Roszak puts this in another format when he says that "never before have so many people entered their senior years by way of medical crisis, a contemporary rite of passage that brings them face to face with their own mortality. The cultural and political importance of that increasingly commonplace experience should not be overlooked. Death, if one survives its first call, is a great awakener of conscience and a call to serious reflection" (Roszak 1998,11).

Making decisions at the end of life, no matter what the context, produces moments of powerful spiritual potential. Hopefully, families will be afforded the opportunity to discuss their own feeling and wishes. Often, however, these moments arise suddenly and are filled with quiet fear and desperate loneliness. Yet, no matter how these situations arise, they are instances in which people seek the strength and guidance of their tradition to provide support and caring. Our textual tradition gives us the insight to construct a method of making sacred decisions at the end of life. Passages from Exodus provide us with interpretations that teach the importance of healing in light of illness (Exod. 15:26; 21:18,19). Leviticus 19 calls on us no to shirt our responsibilities to seek healing when we witness illness, and an interpretation by Maimonides of a text in Deuteronomy underscores that it is a *mitzvah* to try to restore lost health to someone who is ill (Deut. 22:2). The mood of these and other Rabbinic texts underscores

Excerpt from: Kimble, Melvin A. and McFadden Susan H., eds. (2003) *Aging, Spirituality, and Religion – A Handbook Volume 2.* Minneapolis: Fortress Press.

what can be called a fundamental ethic upon which decisions can be constructed. That ethic is *the dignity and sanctity of human life in dignity and sanctity.*

CONTEMPORARY "WILD CARDS"

This fundamental ethic or basic value 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 the family.

Autonomy presents the contemporary Jew with a great challenge. As products of our contemporary North American culture, we have been taught since childhood that individual rights are an inherent part of our society. The post-World War II generation raised this concept of personal autonomy to almost idolatrous levels. This stands in conflict with Jewish values. The individual, as *tzelem Elohim* (image of God), does not exist in a vacuum. By virtue of our being born, we exist in a fundamental relationship with God and are called to model that relationship with others in the world. The prayer book speaks to a theology that reminds the individual that the body and the soul spring from the mystery that is God. We are partners with God in this mind-body-soul dialectic. Traditional prayers acknowledge the miracles of daily life. They celebrate the ability of the body to function as a balanced network and recognize that, should something occur that would impede this network, our bodies would suffer and we would be unable to stand in life with God. Likewise, the tradition teaches that the soul that has been given to us by God will be taken at the time God chooses. This fundamental relationship between us and God is underscored in the prayer's final words, which remind us that we are to bless God, "in whose hands are the souls of all the living and the spirits of all the flesh." Judaism teaches that we are not free to do what we want when we want. Autonomy has limits and, in situations requiring extraordinary medical treatments at life's end, these limits can create profound spiritual tension.

The "wild card" of personal autonomy has an ally in the continually evolving arena of medical technology. The progress being made in the diagnosis and treatment of illness has further added to the vagueness of the absolutely application of the fundamental ethic by providing people with greater choices than in any time in history. In end-of-life situations this is especially true. The ability to prolong a life is measured against the same technology being able to delay the inevitability of death. Issues such as "quality of life" now occupy substantial amounts of dialogue. The lack of proper guidance, discussion, and preparation can lead to confusion, doubt, and guilt in the decision-making discussions. That is one reason why every major denomination in Judaism now affirms the need to discuss end-of-life situations in anticipation of need. The creation of a personal Advance Directive for Medical Care accompanied by a Durable Power of Attorney for Health Care has become a modern *mitzvah*. Medical technology has made these discussions a necessity.

Too often individuals find themselves in situations where their wishes for treatment have not been made known. They exist in a coma, at the end of a prolonged siege of dementia or in a vegetative state. With no discussion beforehand, physician and family members are left with few answers to difficult questions. The challenge is how to have these discussions in light of the widely held cultural belief in personal autonomy. This is where significant conflict may occur. How can we understand the wishes of an individual in light of the guidelines of Jewish tradition? How can we balance the belief that "this is my

Excerpt from: Kimble, Melvin A. and McFadden Susan H., eds. (2003) *Aging, Spirituality, and Religion – A Handbook Volume 2.* Minneapolis: Fortress Press.

life" against the Jewish tradition's belief that life is a gift from God and that the end of that life is in God's domain? This tension may be understood by looking at the mood of Jewish tradition, which reminds us that while the amount of life this is granted to us may be out of our control, what we do with that life – its quality or meaning – rests squarely within our hands.

This introduces us to the possibility of a third wild card, one that is emerging with increasing regularity and one that needs to be part of the discussion of how we apply Judaism's fundamental ethic to a particular life situation. This third factor is the desire for spiritual significance, the search for one's own meaning and purpose. This new dynamic is a result of the longevity revolution. As we age we renew our sense of search for how our life can be lived so as to achieve meaning. The Jewish tradition stressed this point. Life is to be lived, even to the last moments. In each moment there is opportunity to find and provide meaning. More and more we give credence to the theme of Sherwin Nulan's book *How We Die* in that we choose how we die influenced by the ways in which we chose to live. As each life is unique, so too is each individual's death. "Every one of death's diverse appearances is as distinct as that singular face we each show the world during the days of our life. Every man will yield up the ghost in a manner that the heavens have never known before: every woman will go her final way in her own way" (Nuland 1994, 3).

GUIDELINES AND BOUNDARIES

In each person's life there is always the possibility of meaning, even as that life winds down. The works of Abraham Joshua Heschel reinforce our continuing need to search for the mystery of our own meaning within our existence. A theme of Heschel's writings is that we human beings are constantly in search of meaning, and this search is cemented in a partnership with God. "To the biblical mind man is not only a creature who is constantly in search of himself but also a creature God is constantly in search of. Man is a creature in search of meaning because there is a meaning in search of him, because there is God's beseeching question, 'Where art though?'" (Heschel 1959, 238-39).

Judaism reminds us that even at the end of life there can be meaning and the opportunity for *mitzvot.* This gives even greater importance to the need for families to discuss the issue of how to approach, treat, and manage the decisions that arise as life ends. In spite of the belief in personal autonomy, there still exists the desire for life to have meaning, a desire made all the more urgent in light of the choices brought about by medical technology. The fundamental value of life's dignity and sanctity and the preservation of that life in dignity and sanctity still remain our foundation. Yet, given the wild cards, how can we begin to apply this ethic? Is it absolute in every situation?

No, and this the gift of Jewish thought in the area of decision making at the end of life depends on the context of the case before us for the application of the fundamental value. Each individual case is best judged on its own, based on the particular situation. Decisions regarding a person's quality of life are best left to that individual or to a duly appointed surrogate if the individual becomes unable to make his or her wishes known. Again we see the importance of creating opportunities for these discussions to take place, discussions that will lead to the creation of necessary Advance Directives for Medical Care.

The importance of examining the context of a particular situation is reinforced by the specific legal guidelines that may impact when and how decisions are made. These guidelines are based on specific categories drawn from Jewish textual tradition. It is safe to assert that, with the dignity and sanctity of human life as our fundamental value, it is not permitted to actively end a human life. It is safe to assert

Excerpt from: Kimble, Melvin A. and McFadden Susan H., eds. (2003) *Aging, Spirituality, and Religion – A Handbook Volume 2.* Minneapolis: Fortress Press.

that everything should be done to return a person to wholeness and life. Jewish tradition emphasizes this value when it reminds us that to save a human life (*p'kuch nefesh*), we are permitted to abrogate almost every Jewish law. Yet there does exist a boundary, drawn from Jewish legal tradition, beyond which different approaches to treatment apply. Up until that boundary is reached, the mood of Judaism is to mandate that everything must be done in order to save a human life. Once, however, that boundary is crossed, a different mood exists. That boundary is called *goses*, and it refers to a patient who is moribund and whose death is imminent. Here the wild card of technology comes into play for, while tradition defined imminent as within three days, current technological prowess has rendered that definition moot. It is possible to prolong a moribund life via technology. The question then asserts itself as to whether you are prolonging a life or delaying the death.

The *goses* is a person whose flame of life is flickering out and, while we may not be permitted to actively snuff out that flame, we are enjoined to do everything in our power to make sure that the flame flickers out in dignity and sanctity. For the *goses* all aggressive medical treatment options have been exhausted. An individual may be hooked up to many machines; debilitating therapies may have been tried; and in the worst-case scenarios, the patient may even be unconscious. The arsenal of medical treatment has been exhausted. Are we still commanded to pursue aggressive treatment in such cases? Judaism says no. When the end of life is clear, when the journey has been completed, when the flame is flickering out, we are under no obligation to prolong suffering or pain, because that only reduces the value of dignity and sanctity. Ongoing communication between a family, a patient, a health-care provider, and a rabbi is fundamentally important in determining when a person crosses this boundary. There are no set rules. There is no set standard. Each individual case stands on its own.

Jewish tradition's position that there are times when it is permissible to allow the flame of life to flicker out is based on classic Jewish texts. Jewish life draws its vitality from the evolving analyses of texts, analyses that allow current issues to be viewed through a historic lens of faith and relationships. The text that informs much of this discussion centers on the death of the beloved Judah Ha-Nasi.

Rabbi Judah was in the last stages of life. His students gathered outside his house in Jerusalem and prayed that he might live. Judah's maidservant, seeing that these prayers were actually hindering the natural process of Judah's death from taking place, ran to the top of the house and threw down a large pottery jar. The crashing of the jar on the ground caused the prayers of the students to stop and at that instant, Rabbi Judah's soul departed (Babylonian Talmud, *Kettubot* 104a). Rabbi Judah, in other words, was definitely *goses.* Given those facts, it was permissible to seek relief and allow the flame of life to flicker out in dignity and sanctity. This story also opens us to a discussion of the role of prayer in the healing and caring process. Many scholars understand that in certain contests it is permissible to pray that an individual be granted release from the pain and suffering associated with the final moments of life. Given the realities of medical care that presently exist, we need to be reminded that dignity, sanctity, and comfort are basic Jewish values that need to be a part of the decision-making process as the final moments of life unveil themselves.

Too often as life ebbs families are called upon to make a decision as to a loved one's care. The textural tradition of Judaism reminds us that while we are not permitted to actively end a life, when the category of *goses* is operative it is permissible to remove what may be impediments to the natural, dignified means of dying. Rabbi Judah's story has echoes in other tests as well. Rabbi Chananya ben Teradyon, as he was being martyred, allowed the removal of water-soaked tufts of wool that would have delayed the impact of the fires that were consuming him (Babylonian Talmud, *Avodah Zanah* 18a). The classic Jewish

Excerpt from: Kimble, Melvin A. and McFadden Susan H., eds. (2003) *Aging, Spirituality, and Religion – A Handbook Volume 2.* Minneapolis: Fortress Press.

law code of the sixteenth century, the *Shulchan Aruch*, continues this discussion when it permits the removal of that which may impede the final process of death. Contemporary commentators interpret the imagery of loud pounding sounds such as the chopping of wood (*Yoreh Deah* 339.1) to permit the removal of extraordinary machinery or treatments when life's final stage is reached.

Keep in mind that Judaism is clear on its insistence that no one may actively end a life. The *goses* is considered a living person. Yet, many people are faced with agonizing decisions regarding end-of-life treatment that go beyond simply removing so-called impediments. Can we find guidance in situations where someone is dealing with great pain and suffering? Here as well we see possibilities of action. Pain and suffering are not values that bring dignity to a person or enhance a person's sanctity. In cases such as this, the category of *goses* is critical. In such a situation is it permissible to increase types of medication in order to relieve excruciating pain and suffering of a dying person, then the answer is yes. If it is our intent to end a life, to "put this person out of his or her misery," then the answer is a resounding no. A discussion drawn from Reform Jewish sources on the issue of relieving pain in the final hours of a person's life concludes that:

> We may take definite action to relieve pain, even if it is of some risk to the *chayei-sha-a* the last hours. In fact, it is possible to reason as follows: It is true that the medicine to relieve his pain may weaken his heart, but does not the great pain itself weaken his heart? And: May it not be that relieving the pain may strengthen him more than the medicine might weaken him? At all events, it is a matter of judgment, and in general we may say that in order to relieve his pain, we may incur some risk as to his final hours. (Jacob 1983, 256-57)

A discussion from the Orthodox point of view affirms the basic mood of Judaism regarding these "quality of life" issues in the contexts of decision making at the end of life. "Judaism is concerned about the quality of life, about the mitigation of pain and the cure of illness whenever possible. If no cure or remission can be achieved, nature may be allowed to take its course. To prolong life is a mitzvah, to prolong dying is not" (Tendler and Rosner 1993). These situations of decision making reinforce the need for families to have the necessary conversations among themselves so that decisions can be made with knowledge of an individual's wishes. During many of the discussions, the concern for an individual's quality of life is often raised. Here again, the concept of seeking to understand the context of an individual and a situation is helpful. Quality of life is by definition a subjective issue. Decisions regarding a person's quality of life are best left to that individual or to a duly appointed surrogate if the individual is incompetent. The completion of appropriate documents in connection with honest family discussion can be seen as a modern-day *mitzvah*.

The emphasis on examining the context of an individual's medical situation in light of treatment decisions points to a way of looking at these considerations in a nonlinear manner. The wild cards that impact our current society have allowed us the opportunity to see the end of life as a gradual unfolding of stages. Elliot Dorff has been instrumental in helping to develop the point of view. Responding to the impact of medical technology, and the need for people to seek more control over their treatment options, Dorff has reintroduced a classic Jewish term into the discussions of decisions at the end of life. Building on the work of David Sinclair, Dorff writes of the concept of *terefah,* which he defines as someone who has been diagnosed with an irreversible, terminal illness. This is a person for whom it would be permissible not to treat in an aggressive manner. The person who has become *terefah* is really no longer a healthy person and evolves into the status of *goses* in the last days hours, and moments of life. Dorff echoes other scholars when he reminds us that in these final stages of life we are mandated

Excerpt from: Kimble, Melvin A. and McFadden Susan H., eds. (2003) *Aging, Spirituality, and Religion – A Handbook Volume 2.* Minneapolis: Fortress Press.

not to prolong death. Rather, the intent of our actions needs to be, by appropriate palliative and comfort care, to sanctify and dignify life (Dorff 1998).

This category represents a new stage in the process of dying. Manuy individuals now function in this category. They may be in this stage for a long time, given the reality of medical technology. In this category greater leeway is available for decision making that may in fact prolong life. Indeed, it is in this stage that often someone will opt for more aggressive treatments or say to their physician and family, "Enough." Again, the valu of open and honest discussion and the evaluation of the particular context in which the individual finds himself or herself is of crucial importance. Few of these decisions are arrived at without great anxiety, fear, and doubt. These are profoundly spiritual moments in which, as Heschel reminds us, the relationship between man and God is present.

The fundamental value of Judaism, viewed against the context of a particular case, allows us to make informed Jewish choices. Choice, a basic component of Jewish thought, is the final aspect of this decision-making construct. In Deuteronomy we are reminded that we are given choices all the time in our life. They are choices between life and death, good and evil, the blessing and the curse. We are called upon to "choose life" (Deuteronomy 30), so that those who follow us will be blessed. Often it is difficult to see how the decisions that people must make regarding end-of-life situations can be seen as a blessing. The texts, as mentioned above, often remind us that there is no blessing in pain and suffering and that there actually may be times when prayers are said so that a person can be released from the final stages of life. Examining the context against the values of Jewish tradition can give us secure guidelines for making Jewish choices. The discussion with family, caregivers, and clergy of these values in light of a particular context is the pathway for coming to a sense of wholeness in what is a difficult stage in a family's life.

There is also another opportunity to see in these stages a way to sanctify and dignify the life that has been given to us. There is a Jewish tradition, based on the stories at the end of Jacob's life in the book of Genesis, of the "ethical will." This is a practice that urges one generation to leave behind a document in "which is the bequeathed a spiritual, moral, and ethicl legacy. In essence this is another way in which we transmit the fundamental values of life's dignity and sanctity and fulfill our responsibility to pass on those values to the people wo remain after our death,. A personal ethical will is a gift that a apparent gives his or her child. It is a testimony about living, a prescription based upon one's own experiences in living a righteous life. It should be compiled with the same detailed thought and planning that we devote to creating documents that instruct about the distribution of our property and assets as well as our wishes regarding medical treatment.

The choices we make, individually or as a family, in preparation for life's final stages speak volumes about who we are as human beings. Jewish tradition has evolved guidelines and approaches, based on sacred texts that can inform and support our discussions in these most difficult times. The decision-making model of value, context, and choice springs from a belief that in facing the ultimate aloneness and alienation of death, we can strive to embrace these final stages of life with a sense of the sacred. It is in the contexts of these final stages that the mystery of God so often present, as are our souls and the preciousness of the moment.

Excerpt from: Kimble, Melvin A. and McFadden Susan H., eds. (2003) *Aging, Spirituality, and Religion – A Handbook Volume 2.* Minneapolis: Fortress Press.

BIBLIOGRAPHY

Address, R. (2000) “Making Sacred Choices at the End of Life.” In Life Lights (pamphlet series). Woodstock, VT: Jewish Lights.

Dorff, E. (1998). Matters of Life and Death: A Jewish Approach to Modern Medical Ethics. Philadelphia, PA: Jewish Publication Society.

Heschel, A. J. (1959) Between Man and God. New York, NY: Free Press.

Gordon, H. (1998). *When It Hurts Too Much to Live: Questions and Answers about Jewish Tradition and the Issues of Assisted Death.* New York, NY: Union of American Hebrew Congregations, Department of Jewish Family Concerns.

Jacob, W., ed. (1983). *American Reform Responsa*: Collected Responsa of the Central Conference of American Rabbis, 1889-1983. New York, NY: The Conference.

Jacob, W., and M. Zemer, eds. (1994), *Death and Euthanasia in Jewish Law*. Pittsburgh, PA: Freeholf Institute for Progressive Halakha/Rodef Shalom.

Kogan, B. (1991). *A Time to Be Born and a Time to Die*. Hawthorne, NY: *DeGruyter*.

Nuland, S. (1994). HJow We Die: *Reflections on Life’s Final Chapter*. New York, NY: Knopf.

Ochs, C., (1994), Song of the Self-Biblical Spirituality and Human Holiness. Valley Forge, PA: Trinity Press International.

Roof, W. C. (1999), Spiritual Marketplace: Baby Boomers and the Remaking of American Religion. Princeton, NJ: Princeton University Press.

------- (1993). *A Generation of Seekers.* New York, NY: Harper Collins.

Rosner, F. (1991). *Modern Medicine and Jewish Ethics*. 2nd ed. Hoboken, NJ: K’tav and New York Yeshiva University Press.

Roszak, T. (1998). *America the Wise: The Longevity Revolution and the True Wealth of Nations*. New York, NY: Houghton Mifflin.

Sinclair, D. (1989). *Tradition and the Biological Revolution.* Edinburgh: Edinburg University Press.

Tendler, M. and Rosner, F. (1993) “Quality and Sanctity of Life in the Talmud and Midrash.” Tradition 1/28:22-27.

Union of American Hebrew Congregations (1996). “The Role of Pain and Suffering in Decision Making.” New York, NY: UAHC Bio-ethics Study Guide VIII.

Excerpt from: Kimble, Melvin A. and McFadden Susan H., eds. (2003) *Aging, Spirituality, and Religion – A Handbook Volume 2.* Minneapolis: Fortress Press.

------- (1994). *A Time to Prepare: A Practical Guide for Individuals and Families in Determining One's Wishes for Extraordinary Medical Treatment and Financial Arrangements.* New York, NY: UAHC Press.

------- (1991). "The Living Will: Advance Medical Directives." New York, NY: UAHC Bio-ethics Study Guide IV.

Excerpt from: Kimble, Melvin A. and McFadden Susan H., eds. (2003) *Aging, Spirituality, and Religion – A Handbook Volume 2.* Minneapolis: Fortress Press.