A Guide for the End of Life

A Review of
Beḥoref Hayamim/In the Winter of Life:
A Values-Based Jewish Guide for Decision Making at the End of Life.
edited by David Teutsch and Deborah Waxman
(Reconstructionist Rabbinical College Center for Jewish Ethics, 2002)

By Natan Fenner

The Center for Jewish Ethics at the RRC has produced a useful, thoughtful, accessible and topical guide for decision-making at the end of life. It provides conceptual frameworks, reasoning and guidance for making Jewishly informed, ethical decisions around end-of-life issues. The point of departure is a medically up-to-date, academically grounded and liberal Jewish perspective.

Beḥoref Hayamim contains a series of chapters drawing on each author's experience in the fields of medicine, medical ethics, congregational and Reconstructionist movement leadership, chaplaincy and Jewish healing. The chapters address decisions and concerns commonly faced in end-of-life care, including: advance directives, life support and resuscitation, information-sharing and communication between patient and caregivers, pain management, bedside advice for those offering emotional and spiritual support, assisted suicide and Jewish burial and mourning practices. Some authors reach conclusions or make arguments reminiscent of Reform responsa or Conservative interpretations/conclusions of *halakha*; however, the book is much more a guide and conversation-starter than a compendium of definitive pronouncements and formulae.

Values-Based Decision Making

The opening chapter, "Jewish Values and Decision Making," by David Teutsch, provides an orientation to and an explanation of values-based decision-making, and of the key Jewish values and terms that inform much of the discussion of end-of-life care in the succeeding chapters. One finds a clear resonance with the Reconstructionist approach to communal decision making in Teutsch's summary of the process of values-based decision making: determine facts, alternative actions and their outcomes, and relevant beliefs and values; examine relevant scientific and social-scientific approaches to understanding these; consider the historical and contemporary context, including the history and rationales of Jewish

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practice; look for norms that might exclude some actions; weigh the relevant attitudes, beliefs, and values; formulate decision alternatives; seek consensus . . . ; [and] make the decision (5-6).

Among the Jewish values and concepts identified in this chapter as relevant to the end-of-life conversation: *pikuaḥ nefesh* (saving a life); *eyt lamut* (there is a time to die—accepting death's inevitability); *kevod habriyot* (human dignity); *b'tselem elohim* (each human being's infinite worth derived from being created in the image of God); and *raḥmanut* (compassion/mercy). It also addresses terms more specific to and commonly used in Jewish bioethics discourse on end-of-life issues: *terefa* (a person certain not to recover from a terminal illness) and *goses* (in talmudic literature, one whose medical condition has so irreversibly deteriorated as to be expected to survive no more than three days). This introduction addresses both lay and professional readers, laying out a method for study and a foundation for a Jewish moral perspective on the questions raised by the other authors.

Advice for Caregivers

"Taking Control of Difficult Decisions," by William Kavesh, contains information and advice about advance directives that are helpful, particularly for individuals who are or may be designated as caregivers, proxies, surrogate decision-makers or as having healthcare power of attorney. In fact, this chapter provides useful questions and direction for individuals who are or should be considering or drawing up or revisiting their own advance directive, a category that arguably includes anyone over forty. Pages 22 to24 include a concise explanation of the content, approaches, common complications and strategies of advance directives. The chapter also brings a helpful discussion of some of the inducements and impediments — both from common experience and from those particular to the Jewish milieu — to completing advance directives.

In "End-of-Life Technologies," Kavesh explains some of the medical procedures most commonly addressed in advanced directives relating to life-support, together with rationales for using or declining them. Particular attention is given to cardio-pulmonary resuscitation (CPR), ventilators (artificial respirators) and feeding tubes.

In addition to outlining a medical perspective on these technologies, Kavesh makes frequent reference to *halakhic* and ethical sources (mostly from Conservative and Orthodox literature — the one citation of a Reform responsum in *Beḥoref Hayamim* occurs in a footnote to Chapter 9), and to generally held Jewish values.

Feeding Tubes

The section on the "effectiveness of feeding tubes" is more accurately a depiction not of their utility and conditions for likely success, but rather of their ineffectivess and risks, and rationales for forgoing them. For readers not current with the medical literature and "best practices," it reads like a critical re-examination or reframing of an overused technology. In Kavesh's view, tube feeding shifts from a medical intervention that is widely used and seen as an aid to life to an "impediment to the departure of the soul from the body." (59-60)

Without including a rationale for when in a patient's life this reclassification of tube feeding becomes appropriate, the logic behind this view could be seen by some as unduly biased or overly broad in its application. The chapter could benefit from Kavesh's perspective on why or when, and for what kinds of underlying conditions, a feeding tube — still commonly offered or prescribed by physicians in many settings — might be an appropriate treatment option. This perspective would lend the reader a greater sense of balance or context for discerning how to respond, or what questions to ask or consider, when making such a decision. On the side of *refuat hanefesh* (healing of the spirit), Kavesh notes that it can be very reassuring for family members to try feeding their loved one orally after the removal of a feeding tube (61).

The Role of Relationships

"Forming New Relationships," by Paul Root Wolpe, examines the role and impact of relationships in *refuat hanefesh*. The quality and intensity of our primary familial, communal and professional caregiving relationships may significantly distress us, comfort us or otherwise shape our experience. The dying person and his or her familial and professional caregivers have different roles, obligations and challenges in this regard. Wolpe cites a number of midrashic sources containing vignettes on healing in the context of peer and caregiving relationships.

This chapter includes a sensitively written section on appropriate roles for caregivers in helping someone in their meaning-making efforts as they confront illness or death. As many professional caregivers who work with people in hospice or with terminal illness know, healing is possible — and the hope for healing can be a powerful motivator — even in the last days and hours of life. Wolpe enumerates some areas where dying persons and those supporting them might seek healing (*refuat hanefesh v'refuat haguf*), including study, prayer and communal and familial ritual.

Among his more *takhlis* (practical) suggestions, Wolpe highlights the importance of having or arranging companionship and emotional support when "bad news" (i.e., a grave or potentially shocking diagnosis) is to be delivered to someone, particularly if the physician or other bearer of such news is not prepared or in a position to remain with the receiver of the news and offer that support. Wolpe also explains that in the often chaotic and emotionally stressful setting of such conversations, designating a member of the personal or professional care team to record or remember important information can be invaluable, as details are easily forgotten, conflated or recalled out of context or out of proportion.

Acknowledging that some families prefer to keep significant medical (or ancillary) information hidden from a loved one whom they feel to be in a precarious condition, Wolpe advocates for truth-telling as a general rule. In a discussion that is essentially directed to physicians and family members of the affected person, Wolpe notes the tension placed on the entire caregiving system when it is asked to maintain a conspiracy of silence or outright deception. In his view, truth-telling may in fact support greater trust and hope (read also: healing) on the part of the patient.

Surrogate Decision-Makers and Pastoral Support

In the chapter "Families and Treatment Decisions," Wolpe articulates some of the challenges and stresses of caregiving and caregiver decision-making, including an all-too-common lack of clear guidance and support for those engaged in this sacred and potentially all-consuming endeavor. Wolpe delineates the roles that several of the primary constituents (family/loved ones, physician, rabbi) can play in support of good decision making about end-of-life care. It bears emphasizing (more than was done throughout the book) that when her/his decision-making capacity is acknowledged, the patient's voice is, in the normative medical and legal view, the first and last to determine preferences and treatment choices from among the given options. A surrogate decision-maker takes over, and a different level of responsibility devolves upon the family or significant others, only when the patient is not able to convey his/her wishes directly. Included in this section is a helpful clarification of the distinction between and appropriate places for substitute judgment and best-interest decision making.

Much of the discussion in this and other chapters focuses on the domain within which terminally ill or dying persons are no longer able to make or consent to medical decisions on their behalf. Wolpe notes some of the common ways that families run into conflicts over end-of-life treatment and care decisions. Sometimes these conflicts are inescapable, but Wolpe gives suggestions that may lend helpful perspective in some cases, both to smooth the decision-making process and to support s*helom bayit*, peace in the family.

Wolpe notes that "rabbis well-trained in hospital chaplaincy may be better able to serve the role of interpreter of complex medical ideas, but any rabbi can also serve in a pastoral role. . . . How the health-care team deals with the rabbi's role may depend on the physician's religion . . . as well as the type of hospital or facility" (74).

In fact, professional chaplains, whose ranks include many rabbis and cantors, have special training not only to serve in an interpretive role among patient, family members and the health-care team, but also in helping people address other issues that may impinge significantly on both decision making and spiritual care/well-being, i.e. suffering, theological questions and religious and cultural perspectives on illness and death. Professional chaplains often enjoy a degree of standing and collegial rapport within a health-care institution that allows them to support or advocate effectively for religious, values-based decisions. Hence, when a hospital or other facility has a professional chaplain on staff or available through a community chaplain program, that individual should be considered as a potential resource to the dying person and the caregivers, which may or, as is often the case, may not include a congregational rabbi.

Coping with Suffering

Issues of pain and suffering, their personal and theological impact, and modes of coping and decision making related to these issues are addressed in the chapter "Pain and Suffering" by Sheila Segal. This chapter includes anecdotes that lay out in concrete terms different modes of companionship, *bikur ḥolim* (visiting the sick), *gemilut ḥasadim* (acts of kindness), and prayer on behalf of the person facing terminal illness or imminent death, with the particular focus on addressing, relieving or forbearing physical and emotional pain.

Noting the blurred boundary in contemporary experience between the traditional categories or stages of *goses* and *terefa*, Segal considers a "person to be at the 'end of life' if he or she is suffering from a disease or condition for which there is no cure and no reasonable hope of improvement" (87). Segal then delineates, for the person at the end of life who is also in pain, ethical guidelines surrounding the "duty to relieve pain:" "any intervention that prolongs the dying process... [or] causes or prolongs pain may be rejected or discontinued; there are situations in which acceptance of death is in the best interest of the individual; . . . pain must be treated as aggressively as necessary" (88).

The scenarios articulating and honoring the pain experienced by care-givers, and acknowledging the impact of intense or sustained pain and suffering on decision making, may make for helpful, affirming reading for individuals in that position.

Given the room for decision-making autonomy and permissiveness granted in this and other chapters of *Beḥoref Hayamim*, Segal also includes an important caveat that each individual experiences pain, and may find comfort, in unique ways. Therefore, we must always hearken and be sensitive not only to the broader field of options and to our own stance with regard to end-of-life care, but to the particular per-son before us, with his/her inclinations and experience, in his/her particular condition and moment.

Spiritual Accompaniment

"End-of-Life Care," by Myriam Klotz, concentrates on the opportunities and demands inherent in spiritually accompanying the dying person. This chapter provides guidance for the simple yet sometimes quite challenging act of being with someone who is dying. Encouraging approaches to prayer and to shared silence are offered in support of meaningful and spiritually supportive visits. Klotz also provides a succinct guide for conducting a personalized healing service, which can be a resource for the professional officiant or for those inclined to convene such a service without the guidance of a clergy member.

The intended audience for this chapter seems to be professional caregivers (medical or spiritual) with interest—but perhaps without extensive training—in what Klotz refers to as *hitlavut ruhanit*/spiritual accompaniment, or in working with patients who are not so versed in prayer or in articulating their own spiritual needs.

In describing some of the profound personal, spiritual and relational transformations that can take place when someone is dying, Klotz notes that caregivers can encourage healing and spiritual development during this process. While honoring the transformative potential of being present for and with someone at the end of life, there is perhaps an unintended sense not only of opportunity, but also of expectation or responsibility for fostering some kind of healing or growth that the caregiving reader might assume. Such a sense of responsibility would for many seem unduly heavy and — given that not all deaths appear graceful — unreasonable.

Healing Rituals

Klotz's presentation of healing services or healing rituals pictures the identified recipient at the center of a circle of caring. For some people nearing the end of their lives who may not have the interest or energy to participate in this kind of choreography, the offer to pray on their behalf, or the knowledge that they are remembered during moments of communal prayer, such as a congregational *mi shebeirakh* prayer for healing, may be comforting. The ill or dying person need not be present to derive a sense of spiritual support from others' attentions; and a community or a group of caregivers may also find strength and comfort in linking together in this way. Furthermore, the team-like bonds of connection and support that are established or deepened among friends, family and a caring community may come to serve as an important, affirming bridge when that same group of people is mourning together after the death.

Klotz also mentions the *Vidui*/deathbed confessional prayer and who might recite it as the end of life draws near [118]. For those who are encouraged to make use of this prayer or explore this liturgy further (there are a number of versions revolving around the central themes Klotz outlined), texts of and explanations for the prayer can be found in various rabbi's manuals, and in some daily prayerbooks (including various Orthodox versions and the Reform movement's *Gates of the House*); and online in English (translation by Amy Eilberg at *www.myjewishlearning.com/lifecycle/Death/Dying/Text_of_Viddui*) and in Hebrew (a scanned version can be found at *www.irakaufman.com/atneed/*), among other sites. The Web site of the National Center for Jewish Healing (*www.ncjh.org*) is another source for readings, study texts and prayers for those facing grave illness and death.

Hospice Care

"A Time to Die: Reflections on Care for the Dying" by Amy Eilberg describes what hospice is, and how a hospice approach is consonant with both Jewish tradition and a holistic world view. The chapter enumerates commonly expressed needs of dying people, including the need to feel heard and to grieve. Eilberg advocates for a recognition of the preciousness of our finite lives informed by a clear awareness of our mortality, the cultivation of which can have profound and positive effects on our consciousness.

This chapter includes material that would be helpful both to lay people and health-care professionals who have mixed feelings about hospice or who labor under the conception that hospice, with its inherent acknowledgement of and concession to death's inevitability, goes against values Judaism holds dear. Eilberg addresses directly Jewish concerns about and perceived obstacles to hospice care. She balances a historical orientation for "life at all cost" and "death as enemy" with an equally grounded Jewish concern for choosing treatment that addresses the ill person's most important concerns, and offers the greatest hope for relieving one's most deeply felt pain and fears. Eilberg highlights the traditional Jewish teachings around the meaning of *refuah sheleymah* (complete healing of body and spirit), death as a part of life, *eyt lamut* (there is [a time to be born and] a time to die), and death as a motivator for focusing our efforts for good while we are alive.[1]

Acceptable Actions at the End Of Life

Wolpe's chapter on "Ending Life" explores the issues of hastening death, including suicide and assisted suicide, and the nuances of active and passive euthanasia — which are among the more wrenching questions that are increasingly confronting ethicists and lay people alike when considering the condition and the desires of people suffering with debilitating, terminal illness and intractable pain.

Wolpe refers to talmudic passages describing the deaths of Rabbi Yehuda HaNasi and Rabbi Hanina ben Teradion, and commentaries on the suicide of King Saul. In Wolpe's understanding, these passages show not encouragement but certainly some latitude for understanding and acceptance — *bediavad*/after the fact — of actions that hastened death in circumstances that were dire, torturous to the point where there was a risk of desecration of the Divine, and offering no possibility of physical recovery or escape. Regardless of the path chosen by individuals confronting such dire and intractable suffering when death is already imminent, Wolpe argues that "decisions made within the spirit of human caring and Jewish ethics that have the medical and spiritual welfare of the dying patient firmly as the top priority are all touched ultimately by the presence of God" (147).

Goses or *Terefa*?

Wolpe notes that "the model of *goses*

suggests that we can remove impediments (including, in the view of the majority of scholars quoted in this volume, respirators and feeding tubes that keep the *goses* from dying naturally), but not actively cause the death of another" (139). He then notes that "some scholars suggest that modern dying fits more into the category of the *terefa*, one who is clearly and severely terminally ill" (and is expected to die within a year)(139).

While both considerations emphasize the "underlying intention . . . to maintain the dignity of the dying, and not to unduly hasten their deaths" (139), the ramifications of this change in classification are significant, as Wolpe deduces in the latter case the permissability not only of removing life supports but also of administering pain medications even in a way that may shorten life.

This section would have benefited from greater detail and more reference to sources in the ethical literature that spell out the criteria for determining when to use the *terefa* framework rather than that of the *goses*; the logical steps that proceed from the terefa designation; and the import Wolpe derives from the statement that "one who kills the *terefa* is exempt from (earthly) punishment" (139).

Mourning Practices

"Death and Mourning" by Richard Hirsh appears, with only minor changes, as it was published previously by the Reconstructionist Rabbinical Association as *The Journey of Mourning: A Reconstructionist Guide*. It provides sensitive and comprehensive guidance for undertaking the decisions and the *mitzvot* associated with *avelut*/mourning, *k'vod hamet*/honoring the deceased and *niḥum avelim*/comforting mourners.

This chapter is a thoughtful, useful, liberal Jewish substitute for, or complement to, such classic, encyclopedic and more (Conservative/Orthodox) legally framed works as Rabbi Maurice Lamm's *The Jewish Way in Death and Mourning* and Rabbi Alfred J. Kolatch's *The Jewish Mourner's Book of Why*. Among the topics addressed are a Reconstructionist approach (using a historically informed, humanistic/naturalistic lens) to questions about life after death. It is well suited for lay readers (mourners, individuals or communities preparing or wishing to offer comfort and support) seeking step-by-step guidance and explanation regarding the important elements and arrangements for funerals, *shiva* and related topics. It may also serve as a resource of helpful perspectives for clergy working with liberal Jews and addressing questions that arise in the contemporary context, such as non-Jews mourning for Jews and vice-versa.

The chapter also provides practical guidance and thoughtful suggestions from a Reconstructionist perspective regarding infant death, the confluence of *shiva* and Jewish holidays, increasingly common liberal practices and concerns around cremation, and the recitation of Kaddish by other than first-degree mourners or in the absence of a *minyan*.[2]

A Need to Speak

In the section addressing the comforting of mourners during the first year following their loss, the point is made that "widows and widowers often report that…they experienced the loss of friendship with couples who may not have known how to adjust" (170). Indeed, in my experience working with bereaved individuals and with grief support groups, many mourners express a need to speak occasionally or repeatedly of their loved ones or of their feelings in the months after their loss, as part of their healing process. While counseling can be helpful, particularly, as Hirsh notes, when there is a long-term lack of adjustment to the loss, friends or relations with the patience to do so should indicate their interest, willingness and availability to listen.

I had a minor quibble with the statement that Reconstructionist Judaism "no longer affirm[s] many of the traditional ideas about life beyond death" (172). While I agree that the movement does not endorse many of these views, I am among many Reconstructionist rabbis who, in practice, frequently explore, work with and at least indirectly affirm individual mourners' sometimes traditional, other-worldly, and even admittedly irrational views about life after death.[3]

To Hirsh's advocacy for the traditional practice of having only mourners (rather than the entire congregation) recite *Kaddish Yetom* (the Mourner's Kaddish) (175), I would add that communal support is expressed, in part, through the collective responses (*amen, yehei sh'mei rabbah, brikh hu*) that are part of the recitation.

Traditional and Progressive Perspectives

One element I found lacking in the book was guidance for liberal Jews who are caring and making decisions for loved ones who are more traditionally or halakhically observant. As a chaplain who encounters a wide range of Jewish practice and knowledge, I feel that this helpful collection would have been strengthened by the inclusion of advice or additional bibliographic resources for this constituency.

Beḥoref Hayamim is a very readable, useful, and current volume that provides good resource material for a realm of decision making and care that is increasingly common and increasingly important in many of our lives. The book contains helpful anecdotes, a familiar Reconstructionist lens and citations for many of the rabbinic sources that inform discussions of Jewish end-of-life-care ethics, without trying to arrive at or present a particular halakhic stance for its liberal readers. The chapters would make excellent stand-alone study texts in adult or continuing professional education settings, as well as for individuals or families wanting to clarify their values or formulate advance directives in a Jewishly informed way. The book is recommended reading for congregational clergy, and other lay and professional caregivers who seek a liberal Jewish perspective on end-of-life issues.

1. Another polemic addressing Jewish concerns about "giving up" and shifting into a palliative mode is found in the concise volume by Rabbi Daniel S. Brenner, et al., *Embracing Life and Facing Death: A Jewish Guide to Palliative Care* (CLAL, 2002). This guide also outlines some of the primary tasks — as understood by longtime proponents of the hospice movement and Jewish spiritual care providers—associated with, for example, responding to a diagnosis, formulating advance directives and an ethical will, living with illness, addressing suffering, seeking forgiveness and making peace in one's relationships and reciting the vidui/deathbed prayer.

2. Regarding the customary graveside recitation, *HaMakom yinaḥem*/"May God comfort you along with all the mourners of Zion and Jerusalem," while many have understood this phrase as embodying messianic hopes, as Hirsh notes (160), another widely recognized meaning given to these words has to do with the recognition and comfort of being part of and somehow connected to a larger community of mourners across the continents and the generations.

3. Hirsh does note that irrespective of what a movement's ideology or theology may suggest, "individual Jews will choose what they believe about life beyond death — regardless of their denominational affiliation. In such a highly personal area of spiritual conviction, that is entirely appropriate" (160).