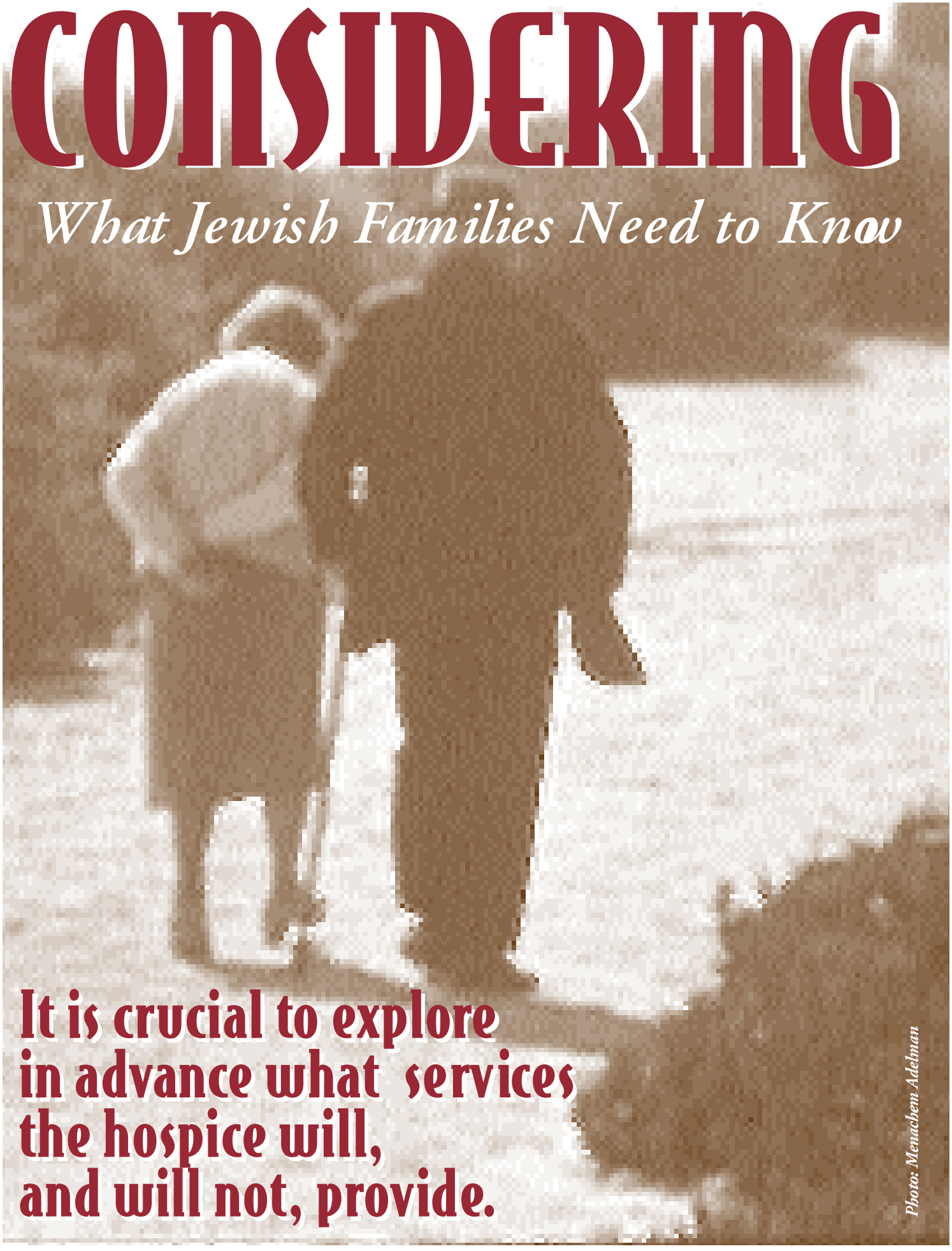
CONSIDERING

What Jewish Families Need to Know



It is crucial to explore in advance what services the hospice will, and will not, provide.

Photo: Menachem Adelman

HOSPICE CARE

Hospice programs provide comfort and pain management to terminally ill patients who are no longer seeking curative treatments. Though the concept is accepted by the broader community, Orthodox Jews often ask if hospice care is compatible with* halachah *and Torah* hashkafah. *We owe it to ourselves and our loved ones to explore every option before making decisions that may strongly affect the final stages of life.

By Moshe Borowski, ACSW

The shock of learning of a terminal prognosis can understandably cause much confusion and upheaval for patients and families. It is common to see reactions of denial and disbelief, coupled with the resolute hope for cure. Such feelings may account in part for the various misconceptions which people often have surrounding hospice care.

Common Hospice Myths

Hospice is a place to send people when they are close to dying.

While hospice care is reserved for patients who are near the end of life, hospice actually represents a philosophy of caring rather than an actual physical structure. Hospice services are primarily provided *at home*, where patients can remain in the comforting company of friends and loved ones.

Some hospices offer *short-term* inpatient crisis care (usually located in a local hospital or nursing home) with the goal of having patients return home once the medical issues become managed. Under certain circumstances, some nursing home residents may be eligible for hospice services.

Hospices basically prescribe pain relievers, which any physician can do

Certainly, any licensed physician is capable of prescribing pain medications; however, many studies have noted the apparent reluctance of some practitioners to pursue aggressive pain management.[1] In addition to controlling pain, hospice care is also quite comprehensive and holistic, attending to the physical, emotional and spiritual needs of patients. Services are provided by an interdisciplinary team of health care professionals, which may include: physicians, nurses, clergy, social workers, therapists (occupational, physical and speech), nutritionists, home health aides and trained volunteers. Patients are viewed within the context of family and friends, whose needs are addressed as well.

Hospice care is restricted to elderly patients suffering from end-stage cancer

As we know all too well, "death knows no bounds." Although the majority of hospice patients are elderly, hospices are sensitive to younger adults as well. Some hospices are geared to serving children and adolescents – organizations such as Chai Lifeline or local *bikur cholim* societies may be helpful in identifying appropriate programs for youth.

While approximately 80% of hospice patients are afflicted by some type of end-stage cancer, there are numerous illnesses (for example, ALS, chronic heart failure, liver and kidney diseases) which may be considered terminal depending on their stage of progression. Based on federal regulations, there are some basic criteria for admission to a hospice program:

- A physician must certify that the patient has a prognosis of six months or less if the illness were to take its "natural course"
- The patient cannot be receiving any life-prolonging treatments
- The patient and family agree to the patient receiving palliative care.

Major Jewish Concerns

Hospice care has often been perceived as medically incompatible with *halachah*. In addition, many people are concerned that hospice programs encourage patients and families to give up hope, a concept antithetical to Jewish thought. What are some common concerns about the hospice approach, and are there implications for Jewish patients?

(Please note: the author's views do not necessarily represent the philosophies of the general hospice movement or the practices of any particular hospice programs. The following discussion is not meant to be a decisive analysis of either the medical or halachic aspects of hospice care. It is

advisable to speak with the actual hospice being considered, as well as a *rav* or *posek* versed in issues of medical *halachah, before* admitting a patient for hospice care.)

What are the possible side effects of heavy reliance on morphine and other analgesics to treat pain?

As with many medications, pain relievers, known in the medical profession as opioids, may have possible side effects, including temporary dulling of the senses, constipation, addiction, and at its most extreme, hastening of death. The hospice movement often cites numerous studies to minimize such concerns.[2] Clearly, physical reactions differ from patient to patient, and also depend on the particular illness being treated.

Patients often feel uplifted... after their admission to a hospice program.

A defining point of hospice care is that a patient's medical needs and medication regimens are closely monitored; the medical staff can adjust doses, or change medications, in the event that the pain relievers in use create unwanted side effects. Also, hospices anticipate a patient's pain needs, as opposed to the classic medical model of addressing pain that has already surfaced.

Pain relievers can help alleviate some of the physical and emotional agitation that often accompanies the final stages of a terminal illness, and at times may even increase alertness and assist patients experiencing respiratory distress. Though opioids can, in fact, also depress respiratory functions, patients usually become tolerant to these effects; generally speaking, dosages are increased gradually and incrementally

Potential Jewish concerns:

Decreasing a patient's pain and increasing his/her alertness, certainly is improving one's quality of life. Judaism's opposition to hastening death, via opioids or any other methods, is starkly clear. As Dr. Abraham S. Abraham, medical director of Shaare Zedek Jerusalem Medical Center, is careful to note, "It is taken for granted that a patient in pain should be treated with any, and as much, pain relieving medication as necessary. *Under no circumstances,* however, may such medication be administered to *shorten* life."[3] Rav Moshe Feinstein *zt"l* explicitly stated, "To shorten a life, even one of agony or suffering, is forbidden… albeit if the action was taken for compassionate reasons, even at the patient's behest."[4] Medical literature cites instances in which a "double effect" occurs: the opioids provide the intended effect of controlling pain, along with the potentially adverse and undesired secondary outcome of depressing respiration to the degree that the dying process is hastened.[5] Yet when provided by experts in the field, pain management should hopefully not hasten death, but rather enhance, and at times lengthen, a patient's life span.

What level of care is provided? As mentioned, only patients who are not seeking curative treatments are eligible for hospice services, which are designed to provide palliative care to help ease suffering.

It is well documented that many secondary issues, both medical (dehydration and infections, for example) and emotional (anxiety and depression) can stem from a patient's terminal illness. Individual hospices may reserve the right to determine which treatments they consider curative in nature, as opposed to purely palliative. For some patients, hospice interventions are the most aggressive and comprehensive care they have received in some time. Patients often feel uplifted, medically and emotionally, soon after their admission to a hospice program.

Potential Jewish concerns There is discussion among *poskim* as to what degree of curative treatments a patient may be halachically obligated to pursue *before* turning to a hospice program.[6] Assuming that hospice care is in order, it is important to know that various secondary medical issues may arise, including (but not limited to) the need for intravenous (IV) hydration, antibiotic therapies or blood transfusions. Since every hospice has its own approach to care, it is crucial to explore *in advance* what services the hospice will, and will not, provide.[7] It is also highly advisable to confer with a rabbi about halachically mandated interventions *before* admitting patients to a hospice program.

Do patients need to be aware of their diagnosis and/or prognosis?

Literature within the fields of medicine and bioethics is replete with debates regarding the pros and cons of fully disclosing a patient's diagnosis and prognosis. Hospices generally favor the approach that open discussion is ultimately best for patients and families. However, it is not uncommon for families to request that patients not be apprised of their situations. This may stem from a variety of issues, such as:

Protecting a loved one from anticipated psychological pain Opposition to disclosure may be endemic to the human condition: people, regardless of race, color or religion, often choose to withhold information in hopes of protecting their loved ones from the psychological pain (and possible resulting physical reactions) of knowing that they are dying.

Denial. Many families and patients are in denial of what their physicians have informed them, or about what they are physically and emotionally experiencing. The word "denial" often conjures negative connotations, but it can at times serve as a very effective

coping tool.[8] (Practically speaking, it may prove difficult to determine the point at which denial ceases to be in an individual patient's best interests.)

Potential Jewish concerns:

Jewish families are often insistent that the patient not be informed of a terminal prognosis, and sometimes the diagnosis as well. There may be various factors that contribute to this decision, including:

Cultural taboos against discussing death and dying Within the Soviet émigré population, for example, topics of serious illness and dying are often avoided at all costs.[9] Holocaust survivors may also have issues around these topics related to the horrifying experiences they underwent during World War II.[10]

Religious objections Generally speaking, *halachah* discourages informing an individual of anything that may impair his or her physical and/or emotional well-being.[11] (Some medical literature goes so far as to describe efforts to enhance a patient's understanding of his dire condition as an "assault of truth."[12]) However, *halachah* does stress the importance of a person having the opportunity to "set one's affairs in order."[13] Weighing these factors is literally a question of *dinei nefashot* [decisions regarding life and death] and therefore requires appropriate consultation.

Experience shows that in many cases, a physician will explain the prognosis to the family, which chooses not to inform the patient to avoid depressing or frightening him. The patient, on the other hand, often senses that the illness is serious, and is therefore careful not to verbalize this feeling, so as not to unduly burden the family. It is very common for patients and relatives to opt for this route of mutual silence without any formal discussion on the issue.

Regardless of the family's rationale for withholding information from the patient, it is important that hospice staff work together with the family to meet their personal, cultural or religious wishes. This issue should be discussed with the hospice administration *before* the patient enters the program, and staff members may need to be briefly reminded during initial family visits.

Reciting *Vidui* is an issue that arises near the end of life. [Often referred to as the "deathbed confessional" (*Vidui shchiv mei'ah* as discussed in *Yoreh Dèah* 338:2), this verbal acknowledgement of one's transgressions is integral to the process of *teshuvah* a person should undergo before death.] Explaining the need for *Vidui* without startling or depressing the patient, and at what point to introduce this concept, are difficult issues that confront families, rabbis and chaplains.[14]

What advance directives are required?

Hospices often encourage the signing of a Do Not Resuscitate (DNR) order, however, there is no federally mandated prerequisite to do so. It is vital that patients and families realize that medical treatment may hinge on what directives have, or have not, been given. It is common to find people who feel uncomfortable signing a DNR on either moral or religious grounds.

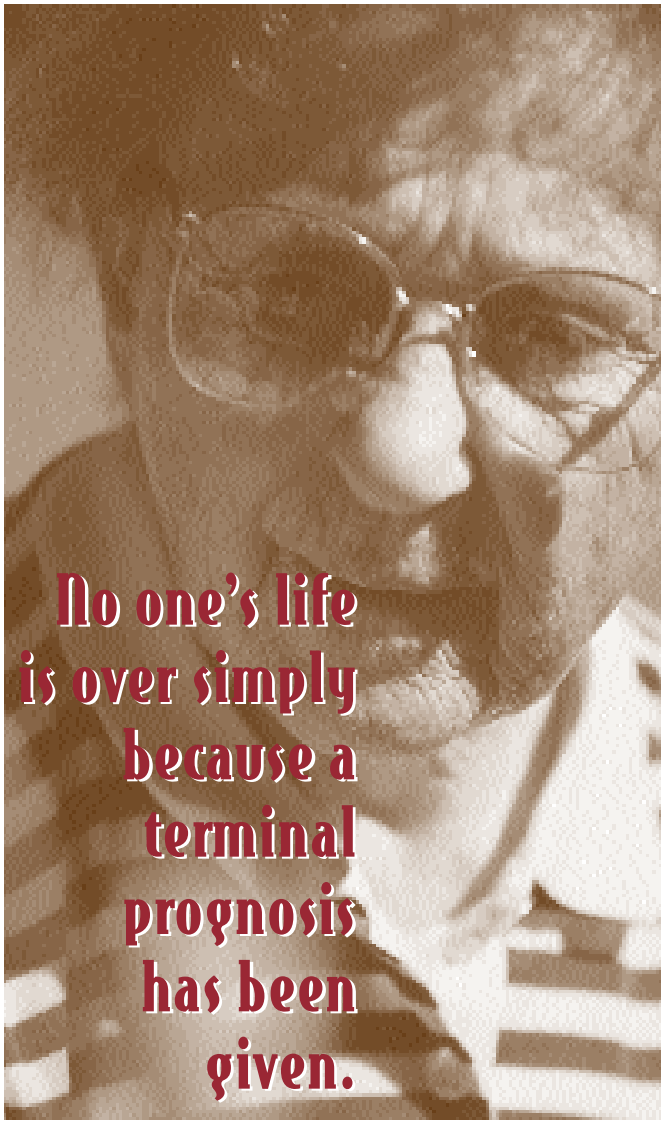
Potential Jewish concerns

DNRs are the source of much debate within Jewish circles. Whether a DNR is relevant to a case, or at which point in the illness it should be signed, are literally questions of "life and death" proportions and require consultation with a *rav*.

It is in everyone's best interest to first explore whether the *rav* involved with the case is in favor of resuscitation and, if so, under what circumstances. The next step is to find out whether the hospice feels that they can abide with these halachic requirements.

It is vital to consult with a competent rav *before* making out *any* type of advance directives. In particular to hospice care, it should be clarified in advance whether the hospice will honor specific halachic/medical dictates.

Is admitting a patient to a hospice program an act of giving up hope, both on the part of the family and the patient?



This fear is probably the biggest impediment to opting for hospice care. Two points are crucial to analyzing this concern:

1) A terminal prognosis does not preclude continuing to hope for remission or recovery. Though relatively rare, patients may be discharged from hospice care if their condition markedly stabilizes or improves. As Dr. Ira Byock, president of the American Academy of Hospice and Palliative Medicine, points out, "No one's life is over simply because a terminal prognosis has been

given. There are people who don't die [despite medical predictions]. Some people enter a hospice because of a terminal diagnosis, stabilize, and leave the hospice. Some live far longer than anyone ever anticipated."[15]

2) "Hope" may mean different things to different people. Hospice staff try to work with patients and families to expand their definitions of hope: looking forward to being free from pain, a visit from a loved one or an impending family gathering may make life a bit more bearable at such a critical time.

...Medical treatment may hinge on what directives have, or have not, been given.

Potential Jewish concerns The issue of whether hospice encourages "giving up" really hits at the crux of the program's philosophy. The Talmud states, "One should never despair of Heavenly mercy, even if a sharpened sword is lying across your neck" (Berachot 10a). This concept has become ingrained within Jews worldwide over the millennia, regardless of religious affiliation. With proper sensitivity to religious concerns, a hospice should be able to help patients and families maintain whatever degree of hope they aspire to. Whether encouraging hope for recovery may, for some patients, eventually result in a sense of false hope (which can prove demoralizing and counterproductive) is a question which families need to address on an individual basis.

As mentioned above, hospices can help foster an atmosphere in which a patient's remaining time is spent with as much meaning as possible. In Jewish life, the ongoing cycle of Shabbatot and Yomim Tovim often provides built-in short-term goals – looking forward to attending upcoming events, such as a family wedding or bar mitzvah, may serve as a strong incentive for maintaining hope for some patients. Helping patients and families to focus on living life to its fullest, regardless of illness or prognosis, is very much in accord with Torah values.

Still, critical questions may remain. For example, is it appropriate to encourage families to give their loved ones "permission to leave," as many hospices espouse? Again, these types of issues may require much personal introspection, family discussion and halachic consultation.

Ideally, the philosophy and services of the hospice should be discussed *prior* to admission. If any of the views or practices do not meet with the family's cultural or religious beliefs, it is best to clarify this with the hospice administration *in advance*. Staff members may need to be reminded of family instructions before speaking with the patient, especially during the initial stages of hospice care.

Weighing both the "spirit" and the "letter" of Jewish law

Clearly, hospice care may entail serious issues of *halachah* and hashkafah. Deep thought and discussion among family members, as well as consultation with a qualified rabbi and the program being considered, should be conducted before placing a patient under hospice care. With the proper sensitivity to both the "spirit" and the "letter" of Jewish law, services can be designed to serve Jewish patients, even when the program is not under formal Jewish or halachic auspices. Aided by knowledgeable rabbis and organizations, Jewish families may be able to negotiate a partnership with their local hospice to ensure that their loved one will benefit from comforting care which is compatible with Jewish life and law.

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The author wishes to acknowledge Aliyah Gordon, RN, MA, Administrator of The Jewish Hospice of Greater New York, for her contributions to this article.

Notes

1. The term "opioid phobia" has been coined to describe what is viewed as some physicians' "irrational fear of opioids." See J. Lander's "Fallacies and Phobias about Addiction and Pain" (*British Journal of Addiction*, 1990), cited in Dr. Elyse Singer's "Advances in Managing Terminal Pain in AIDS" (*Annals of Long-Term Care*, December 1998). Some of the factors which are often cited include "fear of addiction and exaggerated concern about side effects" (Daniel Brookoff's "The Case for Opioids" in *Hospital Practice*, September 15, 2000); as well as "concerns about legal, regulatory … and insurance reimbursement issues" (David Joranson's "Are Health-Care Reimbursement Policies a Barrier to Acute and Cancer Pain Management?" in *Journal of Pain and Symptom Management*, Vol. 9(4) 1994).

2. As a case in point, a recent British study concluded that "there is no connection between *competent* symptom control and euthanasia" ("Opioid Use in Last Week of Life and Implications for End-of-Life Decision-Making" in *The Lancet* medical journal, July 29, 2000).

3. From his article "Euthanasia" (an excellent resource for *halachot* and *hashkafot* related to end-of-life care) in *Medicine and Jewish Law*, volume 1.

4. *Iggrot Moshe, Yoreh De'ah*, 2:174.

5. For halachic discussion of this scenario, see the responsa of Rav Shlomo Zalman Auerbach *zt"l* (*Minchat Shlomo*, vol. 2/3, 86:2). Certainly, a rabbi knowledgeable in this field should be consulted in the event that such circumstances are anticipated by medical staff.

6. Dr. Abraham's essay outlines the progressive stages of terminal illness and their halachically prescribed interventions, based primarily on his understanding of the

rulings of Rav Moshe Feinstein, *zt"l*, and Rav Shlomo Zalman Auerbach, *zt"l*. Individuals or professionals grappling with such cases should consult with physicians and *rabbanim* knowledgeable of the issues at hand.

7. For discussions of the various medical/halachic issues which may arise in end-of-life care, see Rabbi J. David Bleich's "Treatment of the Terminally Ill" (*Bioethical Dilemmas: A Jewish Perspective*) and Rabbi Yosef Stern's "Can Hospice have a Jewish Heart?" in *The Jewish Observer*, March 1998, in addition to the above-mentioned article by Dr. Abraham.

8. "The mechanism of denial [may operate] as a helpful and hope-giving coping strategy…Data suggests that denial is increasingly used as the prognosis grows poorer."

"Denial, Misinformation and the 'Assault of Truth' " by Phyllis Butow, Stewart Dunn and Martin Tattersall in *Topics in Palliative Care*, vol. 1.

9. Derek Kerr, MD, CNA ("Complementary Therapy in Russian Hospice Care" in *The American Journal of Hospice and Palliative Care*, January/February 1997) posits some possible explanations for this strong taboo: "The Soviet system propagandized images of vitality, productivity and durability. The wondrously preserved cadavers of Lenin and Stalin displayed in Red Square carried such triumphalism to extremity. The health care system was state-controlled … and atheistic, with little interest in the least productive member of society – the dying."

10. "Each survivor has outlived a sentence of death – facing death at this time is (like) dying the second time around" (Maria Rosenbloom's "Lessons of the Holocaust for Mental Health Practice" from the book *The Psychological Perspectives of the Holocaust and its Aftermath*). "Illness, hospitalization or institutionalization may reawaken Holocaust-related feelings of helplessness and powerlessness" (Maria Rosenbloom's "The Holocaust Survivor in Late Life" in *Journal of Gerontological Social Work*, Spring 1985). Numerous studies have been made of this phenomenon.

11. See *Yoreh De'ah* 337 and 338:1 (Shach, subsections 1 and 2) regarding the concept of "*tiruf hadaat*" (loosely translated, "mental anguish"), which mandates the avoidance of disclosing information which may prove harmful to the recipient. From personal experience, I have learned that even when such information should be provided, it can be stressed to the patient that: a) providing an accurate prognosis is an imprecise science, and b) physicians have been wrong on countless occasions in which people have long outlived their prognoses (and sometimes their physicians as well!).

12. Butow, Dunn and Tattersall, ibid.

13. *Yoreh De'ah* 335:7. Also see *Orech HaShulchan* 335:10, which includes the theme of optimism so strongly expressed near the very end of life in the *Vidui*. (See note 13.)

14. In *Yoreh De'ah* (338:1) it is advised that to help alleviate a patient's fears, *Vidui* be introduced in the following manner: "We say to the person, 'Many have said *Vidui* and not died, and many who did not say *Vidui* have died. On the merit that you say *Vidui*, you may hopefully be rewarded with an extension of life. Whoever says *Vidui* earns a portion in the World to Come.' "

Part of the text recited (*Yoreh De'ah* 338:2) includes the acknowledgement that "both my cure and my death are in Your hands. May it be Your will to heal me completely; and if I die, let my death to be an atonement for my sins…. and grant me my portion in *Gan Eden* and allow me to merit the *Olam Habah* that is reserved for *tzaddikim*."

Despite (or because of) the patient's dire situation, Judaism compassionately holds out two types of hope to the patient: a) optimism for recovery, and b) potential for the utmost in eternal reward in the event one does not recuperate.

15. From an interview with author Wesley J. Smith in *Forced Exit: The Slippery Slope from Assisted Suicide to Legalized Murder*. JA

Avraham Avinu's Eishel

The modern day hospice movement traces its roots to the church-sponsored "hospices" of the Middle Ages that served as way stations for weary travelers. Our Jewish tradition of hospitality goes back much further — to the Torah itself: "(And Avraham) planted an *eishel* in Beer Sheva, and proclaimed there in the name of Hashem, God of the universe." (Bereshit 21:33)

The Talmud (*Sotah* 10a) debates the exact nature of this "*eishel*." Some say that it was an inn, while others maintain that it was an orchard. The commentary *Iyun Yaakov* opines that perhaps *both* approaches are accurate: in the winter, his guests were housed at the inn, while in the summer they camped outside in the grove, "where Avraham would take them for walks as well." Clearly, Avraham understood that there is a hierarchy of needs when caring for others: first attend to the person's physical welfare, then progress to soothe his emotional distress.

He was then able to address his guests' spiritual needs as well: "And (Avraham) proclaimed there in the name of Hashem" – i.e., Avraham *caused others* to proclaim Hashem's name (*Sotah*, above). When his guests thanked him for his extreme kindness and hospitality, he adroitly focused them on the *chesed* of Hashem, the true Source of the food and drink they had enjoyed. Avraham didn't force religion on his visitors; rather, he framed the issues with such clarity and sincerity that they could not help but connect with the Almighty.

Even this level of care did not suffice for Avraham. The Talmud points out that after his guests were reinvigorated, he was careful to escort them on their way, recognizing his role as a conduit to their ultimate destination.

When we speak of Jewish hospice care, we are speaking of no less than the application of Avraham's model of hospitality to every patient's needs. Striving to go above and beyond the norm, a hospice should make patients and families feel as comfortable as possible. Patients should be viewed in a holistic sense, with their full range of physical, emotional and spiritual needs addressed. Hospices can help patients and their families focus on the fact that every moment of life is precious, and despite the travails of terminal illness, personal growth may be attainable. And finally, hospices have the unique status of serving as a way station of sorts, easing some of the patients' pain and despair as they straddle their personal *Olam Hazeh* and *Olam Habah*.