Prolonging Life in the Shadow of Death
WHERE HALACHA GUIDELINES AND MEDICAL EXPERTISE MEET

RABBIS AND DOCTORS. Communicating Effectively

A seriously ill patient in a hospital unit takes a dramatic turn for the worse. The patient's son, Mr. Ploni, is approached by his father's doctor, who urges him, the patient's official "health care proxy," to sign a "Do Not Resuscitate" (DNR) order. The doctor, with apparent sincerity and compassion, states that in his medical opinion, to resuscitate the patient would be futile. The patient's daughter is convinced that they cannot give up—that by the power of tefilos recited on behalf of her father, his condition will most certainly improve. She implores her brother to do everything possible to extend their father's life in hope that a miracle will occur. At the same time, their mother (the patient's wife) is in tears, lamenting over her husband's great suffering, and asks her son, "Why should we mucher1 him anymore?"

Mr. Ploni's head is spinning with questions that have no immediate answers. What is the right thing to do? He wishes to fully follow halacha, but he is emotionally distraught, not wanting to inflict needless suffering on his father. Perhaps a miracle will occur. Doctors are only human. How can they know when a person's time is destined to end? What are the motives that drive doctors' decisions, anyway? Kabdehu vechasheidehu (show respect but question motives, as well). The doctor intensifies his request to the son to sign a DNR, as time is running out. Mr. Ploni is feeling pressured and unsure of what to do, as everything is happening so quickly. He turns his tear-filled eyes heavenward—Ribbonsa shel Olam, guide me in what to do....

Medical miracles occur each day, providing countless opportunities to see the greatness of our Creator. At the same time, tragic medical realities are also often encountered, wherein hoped 1 Yiddish for putting a strain on him for miracles are replaced with words of nechama (consolation), reinforced by our emuna that ultimately everything is the will of G-d. This life dialectic, while reconciled through emuna, can also be eased by making sure that decisions at the end of life are guided by the same halachic principles that guided decisions throughout life.

When finding out that a loved one has a life-threatening or terminal disease, we often feel great confusion, anxiety and fear. The lack of preparation for this type of news can be immobilizing and often throws normal life into disarray. When we do not know how to proceed and are not even sure of our options, the potential is there to make poor decisions and we feel a loss of control at a time when any form of control is sorely needed.

As a result, interactions between Orthodox families and doctors at the end of life are frequently difficult. A confusing and emotionally intense situation is exacerbated by western medical ethics and halachic considerations often conflict, putting family members and patients in crisis. Pressure on families to make quick medical decisions at the time of a rapid or sudden decline of a...
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family member's condition can create both confusion and anguish.
What is particularly unfortunate about these situations of end-of-life conflict is that often, much of the confusion and anguish could have been avoided. Learning when to start planning for a crisis, how to communicate effectively, whom to involve in the discussion, and what Orthodox-friendly services are available can improve the medical decision making process and its related outcome.
For the last three years, Metropolitan Jewish Health System (MJHS), through a grant from UJA-Federation of New York, has researched and developed programs that answer the unmet challenges of Orthodox families facing serious illness at end of life. Our work has brought together an extraordinary network of leading rabbis from virtually every stream of Orthodoxy, physicians, and community leaders from the New York area and beyond. In March 2007, MJHS organized a rabbi-doctor educational series in collaboration with Maimonides Medical Center in Brooklyn. The participants in this program included twelve mid-career doctors and a cross section of twelve rabbis from the various Orthodox Jewish communities in the New York Metropolitan area. In this training session, called "Creating Healing Conversations," a communication model was adapted and customized to facilitate a family conference for the purpose of medical decision making for Orthodox patients. More broadly, in programs that we regularly conduct in synagogues, hospitals, and other settings, we find that the problems encountered in the story of Mr. Ploni are sadly almost universal in the Orthodox world.

More specifically, we have found two critical problems in how the Orthodox community interacts with the medical system at the end of life. First, there is ignorance within the Orthodox community about how to handle medical decisions so that they conform to halacha. Second, there has been a lack of halachically compatible end-of-life and hospice services, so that Orthodox families feel that they have to choose between halacha and access to needed end-of-life support services.
This article summarizes what we have learned about how to ameliorate or prevent each of these problems. These lessons can be incorporated into an action plan that families discuss prior to an emergency. While it is the nature of emergencies to surface unexpectedly,
we can take steps to minimize loss of control and to create a state of readiness for serious illness.

Handling Medical Decisions: Techniques and Approaches for Orthodox Families.

1. Get a Rav Involved

One of the most important lessons that we learned from our research relates to the role of the rav in medical decisions. As assertive medical consumers, Orthodox Jews are typically quick to look for a second opinion on important medical questions — but Orthodox families often need a second opinion from more than just a doctor. Since according to halacha, great emphasis is placed on the sanctity of life, we need the assistance and guidance of a rav who has expertise in medical situations, knows how to ask the right questions of the doctor, and has knowledge of the patient’s wishes. It is important not to make assumptions about what halacha demands — we learned that some families falsely assume that they must pursue aggressive care under all circumstances, whereas poskim (recognized authorities) have clarified that each case requires its own halachic judgment. Partly because of these misunderstandings, some Orthodox families are afraid to ask questions of a rav who has not been involved throughout the patient’s illness, for fear that they will get an answer that may inflict additional suffering on the patient. In our experience, however, this rarely occurs when the rav has been adequately informed of the medical situation by the physician and family.

The responsibility of the medical decision making process is a shared one. Collaboration in this process between rabbinim, doctors and families should be encouraged. Once a serious or potentially life threatening diagnosis is determined, it is important to share this information with your rav and it is equally important to give permission to and encourage your rav and your physician to speak directly. The importance of bringing the rav into the communication process cannot be overstated — it is critical, as the rav will know which questions to ask the physician in order to render a decision. We have seen again and again that placing a family member in the role of liaison between rabbi and doctor is a less than ideal choice. The family member is typically preoccupied with so many caregiving responsibili-

2. Have a Family Conference

In order to make important decisions, you must bring together the parties who have a say in the decision making process. Many medical providers call this kind of meeting a family conference — for a typical Orthodox patient, it should include at the least the patient (if possible), the family member or friend who is the health care proxy (that is, the person designated to make health care decisions if the patient is rendered incapable of making his wishes known), as well as the physician and family rav, who may also bring in a respected posek should there be a need. The family conference approach gives key members of the family and caregiving team a chance to share information directly. The goal is to arrive at a medical decision that respects halacha and the wishes of the patient while considering the best medical practices possible.

The “LEARN Model” in the box on page 43 is adapted from a classic article for doctors about treating people from different backgrounds. It provides a guide to key objectives for the family meeting.

Any member of the caregiving team can initiate a conference and can make a contribution to the decision making process. It can be very helpful to have a chaplain or other mediator participate, who can take a non-judgmental and value-neutral stance that respects the religious values of the patient and the medical realities of the situation at hand.

If an individual important to the conference cannot be physically pres-
ent, then convening a phone conference is the next best option. The keys are a "live" conversation that will not be misinterpreted or misrepresented when discussed at a later time, and the information exchange between rabbi and doctor and, subsequently, the ability of the rav to help the family understand the halachic ruling and its implications.

The family conference must yield an action plan and implementation process. If the medical facts change, the plan must allow for modification, at which point a new decision may be needed. A successful first conference will pave the way for collaboration in the future. The kiddush Hashem that can be accomplished by such a coordinated effort is another important outcome.

3. F ind a Hospice that knows how to work with Orthodox Jews, or look into "palliative care" as an alternative

Hospice—covered by Medicare and many other insurance plans—can be a wonderful service for patients near the end of life, but can also be problematic for Orthodox families. Hospice programs receive an all-inclusive daily fee from the health insurer, in return for which they manage and pay for virtually all medical care (with an emphasis on comfort care), in-home assistance from an aide as needed, medications, medical supplies, and spiritual and other kinds of support. As an enrollment criterion, a physician must certify that the life expectancy of the patient is six months or less should the disease run its normal course.

Contrary to popular belief, hospices in the US are not simply an alternative place where dying patients receive their care, rather than remaining in a hospital. Hospices are coordinated programs—programs to assist families in providing care to patients with serious and potentially life-limiting illnesses. Hospice care focuses on managing the pain and other symptoms, and the strain on the caregivers that results from the illness. Most hospice care is delivered in the patient’s home, whether that home is a private residence or a nursing home. Each hospice program must also have a provision to care for inpatients when it is necessary.

These are extraordinary benefits, and it is therefore important for Orthodox families to be able to access them.

The aim of hospice care is to provide the best possible quality of life, and to relieve pain and other symptoms during the final days, weeks or months of a person’s life, at a time when the underlying disease can no longer be cured. As a result, hospice programs are essentially barred from pursuing curative treatment.

There are a variety of medical treatments that are not curative but can still prolong life under some circumstances. Issues of withholding medical interventions that can prolong life even briefly are particularly sensitive in halacha. True halachic hospice differs from how hospices normally practice, primarily in decisions regarding providing or withholding life prolonging non-curative treatment.

In our own hospice – Metropolitan Jewish Hospice – we have developed a formal (copyrighted) Halachic Pathway that is offered to every Jewish individual enrolled. This serves as a health care proxy that ensures that a Jewish person will have any and all medical decisions made in consultation with the rav of the patient’s choice, should he so desire. If the patient does not designate a rav, he may opt to have the halachic advisor of the hospice2 fill that role. This simple intervention incorporated into the enrollment process goes a long way toward achieving comfort and confidence when arriving at a point in the disease process when hospice becomes a recommended option.

It is important to reiterate, however, that in a truly halacha-friendly hospice program, there is a commitment to bearing the financial burden of continuing treatments such as intravenous nutrition and hydration when halachically mandated.

A number of other issues should be

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2 Rabbi Meyer Schemberg נב"א was the Halachic Advisor for Metropolitan Jewish Hospice.
addressed in a halachic hospice program. Hospice staff should not inform the observant patient of the six-month prognosis. If asked by the patient, a culturally competent hospice program is trained in how to respond in non-definite terms so as not to go against halacha, and possibly bring despair to the patient. Some or all staff should be trained in traditional Jewish practice and particularly regarding kashrus, Shabbos and tznius laws.

An alternative to hospice in some cases is palliative care treatment. In recent years, palliative care medical programs have developed that allow continued treatment that is intended to be curative but offers the same emphasis on symptom relief and psycho-social support as hospice. These programs are offered in many hospitals and are becoming increasingly available for in-home or office-based treatment as well. Palliative care is initiated earlier in the course of a serious illness, can be utilized with traditional or curative care, can be accessed in conjunction with other health care providers, and does not require a six-month prognosis for admission. It can happen that a patient seeking quality of life and symptom management will have palliative care for a prolonged period of time. It is also possible that the patient may advance into a hospice program should their condition deteriorate to an end stage process.

A Different Kind of Challenge

This article began with the case, based on a true story, of Mr. Ploni. We will conclude with a case that occurred in early 2007 with similar circumstances but a significant difference in the way it was handled.

The Case of Mrs. Almoni

Mrs. Almoni is Orthodox, 85 years old, suffering from advanced Alzheimer’s disease and colon cancer and has a feeding tube. She has been residing in the dementia wing of a nursing home for 18 months, and was moved to the hospice

The LEARN Model for Orthodox families dealing with medical decisions

I – Listen and dispel unwarranted assumptions
- Listen to the clinical perspective of professionals without assuming that the health care system will automatically oppose your interest in following halacha.
- Respectfully state your needs or concerns based on religious values.

E – Evaluate the practical information
- Gain a clear picture of the medical facts, current condition of the patient and impending medical issues or treatment decisions in need of resolution.
- Know if there are any advanced directives (DNR) in place and consult your halachic advisor (rab, poseik) for guidance.
- Consider any significant emotional/spiritual/mental health factors impacting the patient or family.

A – Ask the right questions to the right people
- Determine who is best positioned to convene a family conference and who should participate. Potential participants – Doctors, family rav and or poseik, chaplaincy staff, social workers, nursing staff, healthcare administrator, family friends, legal representatives or experts.

R – Reach a consensus
- Identify a facilitator, skilled in collaborative dialogue and conflict resolution, who can lead a value-neutral conversation, with all decision making parties present.
- Arrange for a telephone conference if all relevant parties cannot be present.

N – Negotiate a plan
- Define an action plan or system for future decision making, as changes can occur suddenly, and halacha demands consideration of the medical issues based on current conditions and always on a case by case basis.


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unit of the nursing home four months ago. Her son is her health care proxy and regularly consults with the medical staff and hospice chaplain after changes in his mother’s clinical status regarding goals of care and advanced directives. He realizes that his mother is declining and will not get better medically.

Mrs. Almoni’s dementia leads to erratic behavior. She is unable to remain still and at times lies and crawls on the floor, requiring her to wear a helmet and padding, sometimes even to be restrained.

Although the nursing home staff handles these unfortunate requirements in a loving and respectful way, the son feels that his children should not see their grandmother in this condition, as she cannot respond to them in any meaningful way and it would cause them distress. The son, however, visits on a regular basis.

After several back and forth hospitalizations in a short amount of time, the hospice medical staff suggested a “Do Not Resuscitate” (DNR) order for Mrs. Almoni should she go into cardiac arrest.

The hospice chaplain, an Orthodox rabbi, suggested a family meeting in order to discuss what the DNR is all about, and other advanced directives. The son contacted his community rabbi and asked impressed at his grasp of complex medical facts and moved by his compassion and his ability to translate technical terms to the patient’s family into clearly understood language.

The poseik asked many questions regarding how advanced the cancer was, what treatments had been performed, and the patient’s degree of suffering. He wanted to know if, indeed, the patient were resuscitated, what would the possibilities be of her ever being weaned off the respirator. He inquired as to her condition and the level of function and suffering she would experience.

Ultimately a decision was rendered by the poseik, once he was fully and directly informed by the physician regarding all

**True halachic hospice differs from how hospices normally practice, primarily in decisions regarding providing or withholding life prolonging treatment.**

for advice about the signing of a DNR and other advanced directives.

The son does not want his mother to suffer, nor does he want to hasten her death. It is very important to him to follow halacha, and he knows that this would be his mother’s wish as well. What should he do?

Such a decision, the rabbi replied, must involve a poseik of the highest caliber. He recommended the involvement of his own rav, one of America’s leading experts in halacha.

After speaking with the son, the hospice chaplain decided to convene a tele-conference involving the son, the chaplain, the community rabbi, the hospice medical director and the poseik. The medical director of the hospice is not Jewish, but has been trained in the treatment of Orthodox patients and has experience in and respect for their unique requirements. Nevertheless, the doctor has little experience with outside psikim and was certainly not aware of the poseik’s lofty stature. She was quickly

medical realities. A plan was implemented: not to aggressively revive the patient should her vital energies fail. As the poseik explained to her son, Hashem is calling for the neshama, which is trying to leave.3

A respectful conversation such as the one described in the case of Mrs. Almoni, leading to an agreed upon and halachically acceptable course of action, and allowing for the highest level of hospice care together with a halachically-driven decision making process, should be the standard that Orthodox families expect and work for when facing terminal illness. The model of communication and hospice care described here can serve the halachic community with an approach that honors the kedushas hachayim that we hold dear and cherish. 18

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3 The ruling by the poseik was rendered specifically for this case, and should not be applied to another case. Every medical case should be considered unique and an Orthodox rabbi with expertise in these issues should be consulted.