



# Learning about Living and Dying

70/FACES  
MEDIA



MJHS®  
HOSPICE AND PALLIATIVE CARE



# Contents

## **SECTION 1: Hospice and Judaism**

Must-Know Words and Phrases Related to End-of-Life Care.....	6
Judaism, Hospice and Palliative Care: Questions and Answers.....	11
Jewish Perspectives on End-of-Life Care.....	15
Writing an Ethical Will: How to Get Started.....	19
Jewish Ethical Wills (Tzava'ot).....	21
How to Talk to Loved Ones About Your End-of-Life Wishes.....	24
Why Jews Need to Talk About Death.....	28
End-of-Life Care in the Bible.....	32

## **SECTION 2: Personal Stories**

9 Tips for Visiting Someone in Hospice.....	36
Bringing Joy and Therapy to Hospice Patients Through Jewish Music....	38
The Surprising Thing that Helped My Mom Live Longer Than Anyone Thought She Would.....	41
The Surprising Connection Between Childbirth and Death.....	43
If I'm Ever in a Coma, Please Thread My Eyebrows.....	45
My 9-Year-Old Daughter Embraced Life Until the Day.....	47
Talking About Death Over Dinner with Strangers.....	49

The following articles were originally published by 70 Faces Media and appeared as part of a series supported by MJHS Health System, 70/Faces Media and UJA-Federation of New York to raise awareness and facilitate conversations about end of life care in a Jewish context.

---

MJHS Health System was founded in 1907 by The Four Brooklyn Ladies and has one of the largest historically Jewish hospice and palliative care programs in the region. Because our patients and their loved ones have different levels of religious observance, we offer a unique way of caring that acknowledges each person's cultural beliefs, life experiences and religious values. If desired,

- our clinicians are sensitive to Jewish religious and cultural practices
- a rabbi is available to provide spiritual counseling, caring conversations and to address end-of-life issues
- we provide a *halachic* pathway so patients, their families and their chosen rabbinic advisor, or *Posek*, will be included in the medical decision-making process
- a creative arts therapist or volunteer may visit to help provide additional support
- we can assist with funeral planning and work with funeral homes and the *Chevra Kadisha*
- we have the unique ability to obtain electronic death certificates, which facilitates burial within 24 hours of the patient's passing
- grieving family members may receive bereavement support up to 13 months after the loss of their loved one, because we know how emotional milestones—such as birthdays, anniversaries and holidays—can be.

MJHS Hospice and Palliative Care is particularly aware of, and attuned to, the unique needs of Holocaust survivors stemming from the emotional, social and psychological pain and discomfort they experienced during the war years. We educate our clinicians and professional caregivers about how past traumas often resurface during the end of life. And we extend that compassion, dignity and respect to second- and third-generation survivors.

The stories included in this booklet will make you laugh, cry and reflect.

We hope they also spark conversations with your family and friends. When you need us, we'll be here to help you focus on what matters most: life's joys and comforts.

Sincerely,

MJHS Hospice and Palliative Care  
(212) 649-5555  
[www.mjhs.org](http://www.mjhs.org)

## Section 1

# Hospice and Judaism

Must-Know Words and Phrases Related to End-of-Life Care.....	6
Judaism, Hospice and Palliative Care: Questions and Answers .....	11
Jewish Perspectives on End-of-Life Care .....	15
Writing an Ethical Will: How to Get Started .....	19
Jewish Ethical Wills (Tzava'ot).....	21
How to Talk to Loved Ones About Your End-of-Life Wishes .....	24
Why Jews Need to Talk About Death .....	28
End-of-Life Care in the Bible.....	32

# Must-Know Words and Phrases Related to End-of-Life Care



General and Jewish terms you'll want to know at this critical time.

BY RABBI JASON WEINER

Navigating any stressful and significant situation requires effective communication and clear understanding. All the more so when that scenario involves life-and-death decisions and the stress, guilt, grief and unfamiliar surroundings that often entails.

To help you better understand the various issues that may arise, both in a general and Jewish context, the list below explains terms you are likely to encounter. [Click here](#) to skip directly to the Jewish terms. You also may want to review our [Must-Know Jewish Death and Mourning Terms](#).

## General Terms

**Advance Directive:** A document that is legally binding (if signed by witnesses or notarized), in which one makes one's healthcare goals, values and preferences known. There are different types of written advance directives used in healthcare: the "living will," "health care proxy" or "MOLST/POLST." Each fulfills a different role, and hence a different need.

- **Living Will:** This type of advance directive document includes specific instructions regarding one's goals, values and preferences as they relate to various treatment options and circumstances. This was the very first

kind of advance directive, developed in the 1960s, and it is what many people think of when they hear the phrase "advance directive." There are various versions of "living wills," including Jewish living wills issued by different denominations.

- **Healthcare Proxy:** This is a document in which an individual assigns another person or persons the authority to serve as his or her surrogate — that is, to speak on one's behalf when one lacks the capacity to do so — and hence to represent the patient when medical decisions need to be made and values-based input from and about the patient is crucial.
- **Combined "living will" and "healthcare proxy" documents:** Often referred to as "advance healthcare directives," these documents combine the two above types into a single document. Most documents used nowadays in the United States are of this type, including those encouraged by various

state laws. The current Orthodox forms are this type of document; their primary goal is simply to appoint a proxy, but they also include some mention of the patient's values.

- **MOLST/POLST (Medical/Physician's Order for Life-Sustaining Treatment):** A physician-initiated medical order form that begins with a conversation between the patient and doctor, based on the patient's current condition. It assures the patient's wishes regarding life-sustaining treatment will be carried out and is generally used for patients who are seriously ill. The MOLST is a durable form that travels with the patient and is honored across different care settings.

**Chaplaincy/Pastoral Care:** Most hospitals and hospices in the United States have chaplains available to provide spiritual care. Chaplains are clergy members who are ordained in their own faith tradition but have also undergone rigorous training to become interfaith practitioners. They function as an integral part of the interdisciplinary healthcare team. A professional chaplain can become board certified through various professional chaplaincy organizations including the Jewish chaplaincy organization, Neshama: Association of Jewish Chaplains." Chaplaincy is based on the understanding that healing involves the whole person — body, mind and soul — and it attempts to support patients, their loved ones, and staff. This is done by spending time with patients and families and providing a compassionate, non-anxious, non-judgmental presence. Chaplains are trained to listen deeply and help patients and families sort through their spiritual and emotional distress and questions. At times, chaplains may provide a spiritual perspective, prayer or blessing if the patient or family so desires. At other times the chaplain participates in lifecycle events, holiday observances, healing rituals and

celebrations. Chaplains who share a patient's religion can often offer more specific rituals and interventions, but even chaplains of another faith tradition can often provide general support.

**Code Status:** Code status refers to the level of medical interventions a patient wants to have started if their heart or breathing stops. A code is called when a patient goes into cardiac or respiratory arrest. If a person chooses "DNR" (see below), that is also known as "no code." There are also numerous other codes which vary based on the situation and healthcare setting often with a name, and sometimes a corresponding color code.

**Curative Care:** As opposed to hospice, which focuses on symptom and pain management, "curative care" is any medical intervention seeking to treat patients with the intent of curing them, not just reducing their pain or stress. An example of curative care would be chemotherapy, which is often used to cure cancer patients.

**DNR:** A DNR (Do Not Resuscitate), or sometimes referred to as "DNAR" (Do Not Attempt Resuscitation), is a medical order indicating that if the patient's heart stops beating (cardiac arrest), the medical staff should not initiate CPR (cardiopulmonary resuscitation) through chest compressions or electronic defibrillation, but should instead allow death to occur naturally. Similarly, a DNR order usually indicates that if the patient stops breathing (respiratory arrest), the medical staff will not initiate artificial (mechanical) respiration by inserting a tube into the lungs (intubation) and then connecting that tube to a mechanical ventilator. Natural death is then allowed to occur.

**Healthcare Agent** (also sometimes referred to as "surrogate decision maker"): A healthcare agent is someone close to the patient who the patient

trusts to communicate his or her healthcare wishes and make sure that the patient always has a say in their treatment plan. Different states have varying rules regarding who is the automatic decision maker on behalf of a patient if nobody has been selected ahead of time. If you are unable to (or choose not to) participate in decision making about your healthcare, your healthcare agent plays a very important role. Some of the things a healthcare agent may be asked to do include meeting with medical providers to talk about your health, medications and interventions, and then deciding when/where you will get care. A healthcare agent will also be the one to ensure that your wishes are followed (or speak on your behalf, if you have not expressed your wishes) about medical interventions, organ donation, autopsy and funeral arrangements etc. The healthcare agent should be identified in a patient's Advance Directive.

**Hospice Care:** This service is specifically designed for patients who are expected to live six months or less. Hospice focuses on managing the pain and symptoms associated with dying, and patients being cared for by hospice must generally forgo all major curative treatments. However, hospice patients can in most cases still receive routine medical care, such as nutrition and hydration, as well as antibiotics and other medical interventions, if they choose to. Hospice commonly takes place in a patient's home, but a hospice patient can also be in a setting such as a nursing home, residential hospice facility or inpatient hospice unit in a hospital.

**Life Support:** This refers to various forms of medical technology/interventions utilized when one's vital organs, such as brain, lungs, heart or kidneys are not functioning properly. The goal of life support is to serve as a bridge to help a critically ill patient survive an acute

experience until they can recover. Unfortunately, not everyone on life support improves and can survive the withdrawal of life support. This often leads to an ethical dilemma regarding what should be done. When the family of the patient decides to withdraw life support, that act is sometimes referred to as "pulling the plug."

**Palliative Care:** This is interdisciplinary care that focuses on decreasing pain (both physical and emotional) and improving quality of life in order to provide additional support to patients. In contrast to hospice care, palliative care can be initiated at any point during the course of illness, including at the time of diagnosis, and for patients of any age who are living with any serious illness. In addition, palliative care may be provided along with all life-prolonging and disease-directed interventions. Thus, palliative care should not be viewed as pertaining only to end-of-life care, nor should it be assumed that palliative care implies that there is no hope for recovery or improvement in a patient's condition. Palliative care is most frequently utilized in hospitals, but it can also be part of care in other settings, such as clinics, cancer centers, nursing homes and, increasingly, as part of home care.

**Terminal/life-limiting illness:** There is no standard clinical definition of "terminal," although in contemporary medicine the word is often loosely used to refer to the prognosis of any patient with an incurable fatal disease. In hospice care, it is often defined as an illness expected to leave the afflicted with six months or less to live. Many clinicians suggest that "terminal illness" should be applied only to the condition of those patients who experienced clinicians expect will die from a lethal, progressive disease despite appropriate treatment and in a relatively short period of time, measured in days, weeks, or at most several months.

## Jewish Terms

**Bikkur Cholim** (“bee-KOHR khoh-LEEM”): This refers to visiting the sick. In addition to being a nice thing to do, it is a mitzvah [meritorious religious act], assuming the patient is indeed up for visitors. Bikkur Cholim can be fulfilled in a variety of ways — in person, by phone, via Skype/Facetime or by sending a gift or a card. The goal should be providing support, assistance and companionship in the way that is most meaningful and beneficial to the patient. Many synagogues and Jewish communities have “bikkur cholim societies,” whose members visit the sick on behalf of the community.

**Birkat Hagomel** (“beer-KAHT ha-goh-MELL”): The “thanksgiving blessing,” traditionally recited by a person who has survived a life-threatening situation. It is often said in synagogue during the Torah service within a few days of one’s recovery. Find the text of the Birkat Hagomel here.

**Chevra Kadisha** (“KHEV-ra ka-DEESH-uh”): This literally means “holy society.” It refers to the Jewish sacred burial society responsible for all matters related to ritual preparation of a body for burial.

**Gosses** (“GO-ses”): A dying person in their final moments or days of life, as their body begins to shut down. Jewish tradition mandates the utmost respect of a dying individual, particularly once they have been given the status of “gosses.”

**Mi Sheberakh** (“MEE-sheh-BAY-rakh”): Literally translated as “may the God who blessed...” referring to the first words of the prayer, a Mi Sheberakh is the traditional Jewish prayer for healing. Although commonly recited in a synagogue, it can be said anywhere, and

typically includes a space to insert the name(s) of the person being prayed for. There is a classic Mi Sheberakh text, as well as many contemporary ones, in addition to numerous beautiful tunes that have been composed to its words. Find the words and listen to different versions here.

**Neshama** (“neh-shah-MAH” or neh-SHAH-mah): One of the Hebrew words for “soul.” Other words include “nefesh” and “ruach.” Judaism traditionally teaches that humans are made up of both body and soul, and that the immortal soul is our true self. The word neshama, in particular, refers to a human being’s animating life force, innermost essence and intellectual capacity, believed to have come directly from God having breathed life into our bodies. The Torah says in the account of creation: “God formed human out of the dust of the ground, and breathed into his nostrils a soul-breath of life (Nishmat Chaim). Human [thus] became a living creature (Nefesh Chaya).” (Genesis 2:7)

**Nigun** (“NEE-goan or nee-GOON”): A traditional Jewish melody, usually with no words, just the hum of various sounds. It is traditionally believed that because a nigun doesn’t have words, it isn’t constrained by the limitations of language and can thus be the holiest type of singing.

**Olam Haba** (“oh-LAHM hah-BAH”): These words mean “world to come” and refer to the afterlife, or heaven. While individual Jews and different denominations take varying positions on the existence of an afterlife, traditional Jewish belief affirms the notion of a spiritual world to come. What exactly that existence will be like, who gets to go there and who doesn’t, and various other questions are hotly debated. Judaism encourages us to maintain focus on this world and this life, which may be why the

Torah doesn't directly reference an afterlife. Nevertheless, the fact that historically Judaism does believe in an afterlife provides comfort for many people.

**Shemirah** (“sheh-MEE-rah or SHMEE-ruh”): Shemirah means to “guard” or “watch.” It refers to the traditional Jewish practice of ensuring that the deceased is not left alone prior to burial, by arranging for a shomer (guard) to watch over the body and recite psalms and prayers.

**Siddur** (“see-DOHR or SIDD-ur”): A Jewish prayer book. There are many types and formats and they contain various sorts of prayers. The word “siddur” comes from the root “seder,” meaning order, thus referring to the fact that it is a book containing the entire order of the prayers, including prayers for various occasions.

**Tahara** (“tah-HAR-ah”): This is the ritual washing of the body which is done by members of the chevra kadisha to prepare the body for burial. The word “tahara” literally means “purification” and includes cleansing, ritually washing and dressing the deceased's body in burial shrouds (tachrichim). As tahara is being performed, it is customary to recite special prayers, asking God to bring the person's soul to eternal rest in heaven.

**Tehillim** (“teh-HILL-im”): This literally means “praises” and refers to the biblical Book of Psalms. It is an ancient Jewish custom to recite various psalms during times of need or fear. Some believe that reciting psalms is so holy that even if one doesn't understand what they are saying, simply reciting the words has power. Others have found comfort in relating their sorrow to the anxiety expressed by King David, who is traditionally credited with having written many of the psalms during challenging moments of his life.

**Tzavah** (“TZAH-vah”): Also known as an “ethical will,” this is an ancient Jewish practice in which a dying person documents the wisdom and lessons they have learned in their life, as well as their hopes and dreams for their family. An ethical will is often seen as both an opportunity to summarize one's values and as a gift to one's family to enable them to continue to learn from their loved one and be aware of what that person would want from them, even after he or she has left this world.

**Viddui** (vee-DOO-ee (oo as in boot”): This literally means “confession,” and it generally refers to the prayer traditionally said at the end of life, in order for the dying person to leave this world in a state of purity, and to proclaim faith in God and God's justice. Viddui is viewed as a way to repent, make amends and get one's affairs in order before dying. The traditional Viddui text includes the hope that the patient will recover, such that Viddui may be recited again at a later point when necessary, and even many times throughout one's life. Saying the Viddui can be seen as an opportunity to relieve some of the emotional burdens of unresolved conflicts or unrealized hopes so that one can experience a lightness of spirit and removal of regret. Viddui can be said as a beautiful and intimate prayer of affirming one's beliefs, hopes, and values as one reaches a potential crossroads and focusing on making peace above and below. Find a Viddui text here. ■



# Judaism, Hospice and Palliative Care: Questions and Answers

What you need to know about Jewish approaches to end-of-life care.

BY MY JEWISH LIFE

Hospice is an approach to caring for individuals who are suffering from terminal illnesses and are expected to live for six months or less. Patients are typically referred to hospice care when further medical treatment is not expected to reverse the course of their disease. Patients who choose hospice care opt to forego aggressive medical care aimed at curing them in favor of therapies geared toward reducing pain and sustaining the highest quality of life for as long as possible. The decision to choose hospice care is a personal one, as is the amount in which Jewish tradition informs one's choices for end of life care. The following is a general overview of contemporary Jewish perspectives on the topic.

## **Does Judaism require life-prolonging interventions in all cases?**

No. While some Jewish authorities are very stringent in these matters, there is ample support in Jewish tradition for ceasing interventions that offer no hope of cure and serve merely to delay death. The Talmud

(Avodah Zarah 18a) offers support for this idea in the story of the second-century sage Rabbi Hanina ben Teradion, whom the Romans wrapped in a Torah scroll and set afire as punishment for teaching Torah. A damp piece of wool was placed on his chest to prolong the agony of his execution. When the executioner

asked the rabbi if removing the wool and allowing the rabbi to die faster would grant the executioner a life in the world to come, the rabbi said yes. At that point, the executioner removed the wool and leaped into the flames. After both of them perished, a divine voice called out that both the rabbi and the executioner had been granted life in the world to come.

A similar idea is conveyed in the ruling of Rabbi Moshe Isserles, known as the Rema, who in his commentary on the Shulchan Aruch writes that while it is strictly forbidden to take any active steps to hasten death, it is permissible to remove obstacles to the soul's departure. The example given is of a sound — for example, the noise from a woodchopper — that can be stopped if it is preventing a dying person from departing.

### **Does Judaism allow a person to turn down medical intervention?**

Jewish tradition generally requires that every effort be made to sustain and extend life, but that position is not absolute. In cases where diseases cannot be cured and medical interventions would be risky, painful, of uncertain efficacy or serve merely to prolong a life of unbearable physical or psychic pain, there is support in Jewish law for an individual's right to reject such treatment.

Within the Conservative and Reform movements, the autonomy of individuals to make decisions concerning their health care, including the right to refuse such care, is given broad standing. Two 1990 Conservative papers allow a patient to refuse treatment if the patient believes they cannot bear it and its efficacy is in doubt. In 2008, the Reform movement's rabbinic authorities stated that a lung cancer patient was not obligated to undergo treatment that offered only three months of life extension

while causing significant pain and suffering. "One is obligated to accept treatment that offers a reasonable prospect of therapeutic effectiveness, the attainment of an accepted medical purpose," the statement read. "The purchase of an additional three months of life in a pain-filled and dying condition does not, in our judgment, meet that standard."

The 20th-century American Orthodox authority Rabbi Moshe Feinstein ruled that "those individuals whom the physicians recognize cannot be cured . . . but could receive medications to extend their lives, in which they would suffer, should not be given such medications." The late Israeli authority Rabbi Shlomo Zalman Auerbach issued a similar ruling, stating that "it is reasonable that if the patient experiences great pain and suffering, or even extremely severe psychological pain . . . it is permissible to withhold medications that cause suffering to the patient if the patient so demands." (Most Orthodox authorities do not consider nutrition, hydration and oxygen, even if artificially provided, to be medical treatments and generally do not permit them to be discontinued.)

### **Does hospice mean I'm giving up?**

For many, the term "hospice" connotes resignation in the face of death and seems to run counter to the Jewish imperative to seek life and preserve it. However, various studies suggest that hospice patients often live longer and do better than those who opt for more aggressive treatment. A 2011 study of lung cancer patients found that hospice patients fared better on average than those who received more aggressive care. A 2007 study found that hospice patients diagnosed with congestive heart failure, lung cancer, pancreatic cancer and marginally significant colon cancer lived "significantly longer" than counterparts

undergoing aggressive medical treatment. A 2010 study published in the New England Journal of Medicine found that for patients suffering from non-small-cell lung cancer, early palliative care after diagnosis appeared to prolong their life expectancy even as they received less aggressive end-of-life treatment.

“Any good hospice program is geared to stretch or lengthen or try to manage one’s time based on the limitations,” says Rabbi Charles Rudansky, the director of pastoral care at MJHS Hospice and Palliative Care. “There’s no hospice that’s accredited that is hastening anyone’s demise.”

### **How do I ensure that hospice decisions are made in accordance with my wishes – Jewish or otherwise?**

Hospice professionals advise patients to take a range of preparatory steps well before major decisions need to be made, including speaking with family, identifying priorities for end-of-life care and naming a health care proxy and possibly a rabbinic adviser to assist in ensuring decisions are made in conformity with religious requirements. Choosing a specifically Jewish hospice program may also make it easier to ensure that Jewish traditions and customs are respected.

A number of Jewish organizations also offer advance directive forms (sometimes known as a living will or health care proxy) that allow patients to declare particular rabbinic advisers who should be consulted in making critical end-of-life care decisions.

**Rabbinical Council of America (Modern Orthodox)**

**Agudath Israel of America (Haredi Orthodox)**

**Rabbinical Assembly (Conservative movement)**

**Living Wills for specific states**

### **Is hospice discussed in Jewish texts?**

Not explicitly. The modern concept of hospice care has been around only since the 1970s. However, in addition to the passages noted above, several other sources are commonly cited in support of a compassionate approach to palliating pain and allowing for a peaceful death.

Among the most frequently cited is a story recorded in the Talmud (Ketubot 104a) about Rabbi Yehuda Hanassi (Judah the Prince), the chief compiler of the Mishnah, who was dying of an apparent stomach ailment. The rabbis were praying for his recovery, but Rabbi Yehuda’s maidservant, noticing her boss’ distress, prayed for his death. Seeing that the prayers of the rabbis were acting as a sort of spiritual life-support keeping Rabbi Yehuda alive the maidservant ascended the roof of the house and threw down a jug — momentarily silencing the prayers and allowing the ailing rabbi to die. Commenting on this passage, the 14th-century Catalan Talmud scholar Rabbenu Nissim observed: “There are times when one should pray for the sick to die, such as when the sick one is suffering greatly from his malady and his condition is terminal.”

Another story, recorded in the Yalkut Shimoni, a compilation of Midrashic commentaries on the Bible, concerns a woman who came before the second-century sage Rabbi Jose ben Halafta and complained that she was old and sick, could no longer taste food and drink, and wished to die. The rabbi asked her which commandment she is grateful to perform each day, and she responded that it is the commandment of going to synagogue. The rabbi instructed her not to go for three days, the woman complied, and on the third day she died. ■

### Is hospice compatible with Judaism?

Jewish tradition regards every moment of human life as infinitely valuable.

Rabbis from the more liberal denominations view hospice as a legitimate Jewish option for those suffering from terminal disease. The Reform movement has long endorsed hospice as a practice consistent with Jewish values. And both of the Conservative movement's major papers on end-of-life care, adopted in 1990, endorse hospice as a life-affirming and, perhaps, even Jewishly preferable option.

“One may not choose hospice so as to die more quickly, but, rather, only in order to live one's remaining days in the best way possible,” Rabbi Avram Reisner wrote in one of the Conservative documents. “As such, instructions to the hospice should clearly state that while only palliation is in order for the immediate incurable condition, other unrelated and curable conditions that may arise, such as infections, should be treated in line with standard medical care. Jewish hospice must be an attempt to live one's best with dignity, not an attempt to speed an escape into death.”

Some authorities hold that hospice is antithetical to Jewish tradition since it entails rejecting aggressive medical interventions to cure terminal disease in favor of a focus on pain reduction and enhanced quality of life. These authorities often cite sources in Jewish law indicating that efforts to extend human life should be made even in cases where life can be extended only by a few moments. The Shulchan Aruch rules that the Torah mandates healing and that a physician who withholds such treatment is guilty of causing harm.

Many contemporary authorities, however, argue that Jewish tradition allows a focus on comfort and pain reduction and the eschewing

of aggressive medical interventions in certain circumstances. Rabbi Moshe Feinstein ruled that a patient may be referred to hospice if he or she requests it and is experiencing such intense physical or psychological pain that his or her quality of life is severely diminished.

### Does hospice raise any other Jewish concerns?

Yes. Jewish law generally mandates that a patient never be deprived of the most elemental forms of human sustenance — food, water and oxygen — even if they are artificially provided. (This position is not universal — some authorities consider feeding tubes and the like to be forms of medical intervention that can be withdrawn or rejected under certain conditions.) For hospice patients concerned about complying with Jewish law, it may be necessary to ensure that hospice care continues to provide intravenous fluids and hydration as religiously required.

Jewish tradition also raises concerns about fully disclosing to a patient the fact that a condition is terminal, lest the patient be deprived of a will to live. Some contemporary religious authorities are emphatic that a patient should never be told explicitly that their condition is hopeless — a position that clashes with contemporary medical ethics, which considers patient autonomy a cardinal principle. Medical professionals familiar with the requirements of Jewish law in this respect are often able to transition a patient to hospice without fully disclosing the particulars of their diagnosis. ■

# Jewish Perspectives on End-of-Life Care

Jewish approaches to medical decision-making for the terminally ill.

BY MY JEWISH LIFE

Decisions concerning medical care in the final stages of life present a range of Jewish ethical and legal conundrums. They are often messy and complicated, and they have vexed ethicists, medical professionals and religious leaders alike.

**W**hile Jewish tradition maintains that human life is of infinite value and that its preservation and extension overrides virtually every other religious imperative, relieving pain and allowing for the soul's peaceful departure are also values well-established in Jewish tradition. Of course there is a moral distinction between hastening death and removing obstacles to its natural progression, but in practice the difference isn't always easy to discern.

Below is a general overview of a number of issues that commonly arise at life's end — and how Jewish authorities have weighed in on them. Jewish thinkers often emphasize that specific cases vary substantially and must be considered individually. And while weight is always given to a patient's wishes, those who are concerned about complying with Jewish

law are always urged to consult with trusted advisers.

## Artificial Nutrition/Hydration

For patients unable to eat or drink, doctors can provide food and water intravenously or through a feeding tube. This is a common situation faced by those with advanced-stage dementia. Most Orthodox authorities generally consider nutrition, hydration and oxygen — even if artificially provided by a feeding tube or ventilator — to constitute essential human needs that should never be discontinued as long as they are effective. This position was also reflected in the 1990 paper on end-of-life care authored by Conservative Rabbi Avram Reisner. However, the Conservative movement's religious law authorities also endorsed a paper by Rabbi Elliot Dorff, who advanced several possible justifications for

removing artificial nutrition and hydration for the terminally ill, among them the contention that a medically administered treatment that conveys food and water to the patient by tube is more properly regarded as medicine than as simple food and water.

### **Hospice**

Hospice is a form of medical care for people suffering from terminal illnesses with a life expectancy of six months or less. Patients are typically referred to hospice care when further medical treatment is not expected to reverse the course of their disease and they elect instead to focus on therapies geared toward reducing pain and sustaining the highest quality of life for as long as possible. Jewish hospice programs are typically equipped to provide hospice services while abiding by Jewish traditions. Because hospice focuses on a patient's quality of life rather than aggressive medical treatment, some Orthodox rabbis do not believe hospice conforms with Jewish tradition. However, not all Jewish authorities agree. Many contemporary Jewish authorities argue that Jewish tradition allows a focus on comfort and pain reduction and the eschewing of aggressive medical interventions in certain circumstances.

### **Do Not Resuscitate Orders**

Known as DNRs, these are legally binding directives signed by doctors ordering medical professionals to withhold CPR or advanced life support in the event a patient's heart stops functioning. DNRs are typically requested by patients who are elderly or are suffering from an advanced terminal illness that makes it unlikely they would survive CPR without a severely diminished condition. Some Jewish authorities consider these orders extremely

problematic, as a patient needing CPR is in acute distress and could be saved, even for a brief period, with proper treatment. But given the often low success rate of resuscitation and the high likelihood of adverse effects for the elderly or those weakened by terminal illness, some authorities permit DNRs under certain conditions. Reisner, in his 1990 paper on treatment for the terminally ill, writes that it is proper to respect a patient's DNR request in cases where it is not possible to restore "a full measure of life."

### **Advance Directives**

These are documents specifying a person's wishes concerning medical care in the event they are unable to make such decisions for themselves and/or appointing a health care proxy to make decisions on their behalf. The laws concerning advance directives vary considerably from state to state. A number of state-specific forms are available here. In addition, both Conservative and Orthodox Jewish versions of advanced directives are available, some of which explicitly state a person's desire to have Jewish law and custom respected in their health care choices. There is typically also space to name a specific rabbi to be consulted when making such choices.

### **Experimental Therapies**

While most Jewish authorities would require a patient to submit to a therapy if it is known to be effective at curing their condition, this is not the case with respect to experimental treatments whose success rate and potentially adverse side effects are not known. These can include treatments whose effectiveness has yet to be demonstrated in clinical trials, or new drugs whose safety and effectiveness have not yet been established. Jewish authorities from

across the denominational spectrum support the right of a patient to refuse treatment that is risky or of unproven value. Equally, a patient who desires to undertake an experimental therapy in the hope of being cured is permitted to do so even if there are risks involved. According to some authorities, this is even the case with a hazardous treatment that may itself result in death. Dorff writes that it is permissible to undertake a hazardous therapy if it presents a “reasonable chance” of cure, even if it simultaneously poses a risk of hastening death if it fails.

### Refusing Treatment

Jewish tradition generally requires that every effort be made to sustain and extend life, but that position is not absolute. In cases where diseases are incurable, and medical interventions would be risky, painful, of uncertain efficacy or serve merely to prolong a life of unbearable physical or psychic pain, there is support in Jewish tradition for an individual’s right to reject such treatment. This was the reasoning behind the Reform Rabbinate 2008 ruling that a lung cancer patient did not have to submit to chemotherapy that could extend her life by three months, but only at a cost of significant pain and suffering. Within the liberal denominations, there is broad respect for individual autonomy in making decisions concerning health care, including the right to refuse care if the patient feels it would not be effective or would be too painful. Among Orthodox authorities, there is also support for refusing treatment in situations where it would not cure the patient but would only prolong individual suffering.

### Praying to Die

Taking active steps to hasten death are prohibited in Jewish law, but praying for death is another matter. The 14th-century Catalanian Talmud scholar Rabbenu Nissim, commenting on the talmudic story in which the maidservant of Rabbi Yehuda Hanasi prays for his death, observes: “There are times when one should pray for the sick to die, such as when the sick one is suffering greatly from his malady and his condition is terminal.” (Nedarim 40a:2) The Jewish bioethicist J. David Bleich has formulated it this way: “Although man must persist in his efforts to prolong life, he may, nevertheless, express human needs and concerns through the medium of prayer. There is no contradiction whatsoever between acting upon an existing obligation and pleading to be relieved of further responsibility.”

### Withdrawing life support

Many Jewish legal experts believe it is permissible to withhold advanced life-support measures from terminally ill patients. However, once such measures have been provided, withdrawing them to let natural death occur becomes more problematic. While there are grounds in Jewish law for withholding advanced life-support measures from terminally ill patients, once such measures have been provided, withdrawing them to let natural death occur becomes more problematic. As a general rule, withdrawing life support is not permitted in traditional readings of Jewish law. However, there are many contemporary Jewish authorities who consider a person to be dead if activity in their brain stem stops. If such a patient were kept “alive” only by means of medical machinery, these authorities would permit those machines to be disconnected. For those seeking to adhere to more traditional interpretations of Jewish law,

there have been some interpretations used by rabbinical medical experts, that have been applied to withdraw treatment in cases where a patient is entirely dependent on machines for breathing and blood circulation and has little hope for recovery. However, it must be considered on a case by case basis, informed by accurate information between the physician, rabbi and family.

### Organ Donation

Jewish authorities from across the spectrum of religious observance, from Reform to ultra-Orthodox, support the lifesaving potential of organ donation, with some authorities going so far as to suggest that Jewish tradition mandates organ donation. Traditional requirements — such as burying the dead quickly, avoiding defilement or benefit from a dead body — that would seem to preclude organ donation are superseded by its lifesaving potential. The Halachic Organ Donor Society (an organization for Jews who want to strictly comply with Jewish law) offers an organ donor card that specifically states that any transplant procedures be conducted in consultation with the deceased's rabbi. The Conservative movement has a similar card.

### Euthanasia/Assisted Suicide

Most Jewish authorities adamantly reject euthanasia or assisted suicide of any kind. Taking active steps to hasten one's death is considered tantamount to suicide, while assisting another to do so may be considered murder. A number of Reform rabbis have challenged this view, questioning the validity of the commonly drawn distinction between active measures to hasten death and merely withholding treatment or removing impediments to death. Peter Knobel, a prominent Reform rabbi and past president

of the movement's rabbinical association, has argued that in certain cases, active euthanasia may even be a praiseworthy act, however this remains a decidedly minority view. Over the years, the Reform rabbinate has repeatedly reiterated its opposition to euthanasia and assisted suicide.

### Truth-Telling

While honesty is a well-established imperative in Jewish tradition, there is ample precedent for the idea that full disclosure of a terminal diagnosis ought to be withheld from a patient since it may sap their will to live. Various biblical sources are cited in support of this idea, including the prophet Elisha's response to the query of Ben Haddad, in which the prophet told the king he would recover from his illness though he knew the opposite was true. The Shulchan Aruch rules that, while a person near death is instructed to confess their sins, they must also be reassured that many have confessed their sins and not died. (Yoreh Deah: 338) Bleich has gone so far as to suggest that a doctor not only refrain from conveying information that might cause a patient to despair and thereby hasten their death, but he must continue to "feign medical aid even though there is no medical purpose in his ministrations."

End-of-life decisions can be challenging, particularly for those who wish to ensure that the decisions comply with traditional Jewish law. And, while there are areas of consensus, there are also differences in how Jewish leaders interpret relevant Jewish teachings and texts. While the article provides an overview, we encourage families concerned with abiding by Jewish practices and beliefs when facing these difficult decisions to consult with trusted spiritual leaders for advice. ■



# Writing an Ethical Will: How to Get Started

Exercises and tips for creating this document to share with your loved ones.

BY RABBANIT ALISSA THOMAS-NEWBORN

Writing an ethical will can feel like an overwhelming process. How does one begin to summarize a lifetime of lessons and beliefs? Where should the focus of the message be?

**R**abbi Jodie Gordon, a Reform rabbi who leads the Hevreh of the Southern Berkshires and teaches a class there on ethical will writing suggests beginning simply with one's thoughts and a pen and paper (or computer). She adapted the following exercises from the book *What Will They Say About You When You're Gone* by Rabbi Daniel Cohen to help her congregants craft their ethical wills.

In addition to Cohen's book, Rabbi Gordon also recommends reading *Having the Last Say*, Bruce Feiler's "This Life" column: *The Family Stories That Bind Us*, and Susan Garland's "Your Money" column: *Telling Their Life Stories, Older Adults Find Peace in Looking Back*.

## **Exercise A: Reflect on courageous choices you have made over a lifetime.**

### **Consider the following:**

- 1.** What are three core values in your life?
- 2.** Identify three courageous choices you made that were driven by your values in your personal, work and communal life.
- 3.** Recall an experience when your values were challenged and you fought to uphold them.
- 4.** Think about private ways you remain connected to your past.
- 5.** Identify a past and present moral dilemma in your life and chart the impacts of making a courageous decision versus a convenient decision.

### Exercise B: Reflections on how you prioritize your life.

#### Consider the following:

1. What gives my life meaning?
2. If I had my life to live over again, what would I do with it?
3. What ideals, if any, would I be willing to die for?
4. What would bring me more happiness than anything in the world?

### Exercise C: Focus on creating memories for your family.

#### Consider the following:

1. Great companies possess a statement of values or mission. What is yours? Craft a family declaration of values.
2. Family heirlooms: Look around your house. Do you have an object that was passed down to you that reflects the legacy of your family? Write down the story for your children and grandchildren.
3. Craft a family genealogy chart. The process may reveal stories, connections and a sense of generational transcendence.

### Exercise D: Explore inspired storytelling.

Consider the following:

1. Describe an out-of-the-ordinary event in your life. What led to it?
2. Describe an experience when initial disappointment was transformed into gratitude. How did your understanding of the event change? Why?
3. Identify three significant events in your life and trace their path to fruition. Were the events by chance or design?
4. Identify three people who have made a difference in your life. How did you meet them? By chance or design?
5. Share an experience in which you saw God's hand in your life.

#### More Resources for Creating an Ethical Will:

Step By Step Directions: How to Write an Ethical Will in Six Easy Steps

*Ethical Wills: The Gift of a Heart* – Robert G. Alexander

*Ethical Wills – What They Are And How To Write One* – Kari Berit

Ethical Will Resource Kit

*Ethical Wills and How to Prepare Them* – Rabbi Jack Riemer and Dr. Nathaniel Stampfer ■



# Jewish Ethical Wills (Tzava'ot)

A rich tradition, these free-form documents can provide comfort to the dying and their loved ones.

BY JAMIE RUBIN

For centuries, Jewish parents have passed down wisdom and values to their children by crafting end-of-life documents called *tzava'ot* or “ethical wills.” Much as a legal will enables one to dole out assets and possessions to one’s heirs, an ethical will gives the writer an opportunity to share their wealth of wisdom: lessons they’ve learned over a lifetime, where they found meaning in their lives, and what they may want for their loved ones going forward.

**T**raditionally, Jewish ethical wills contained a number of items, including burial instructions, debts and obligations to be paid, requests that family members carry on specific religious traditions, and blessings over the family. But modern ethical wills are less about accounting and instruction and more about imparting wisdom or wishes or simply reviewing one’s life. They are often written in the form of a letter and addressed to one’s children, but they can take many forms. There is no halachic (Jewish law) template or script they must follow.

## Ethical Will Origins

In biblical times, ethical wills were often instructional and became a record of a person’s

final wishes. Near death, the patriarch Jacob blessed his children and told them where he wanted to be buried. Rabbi Charles Rudansky, pastoral director for MJHS Health System in New York City explains that Jacob was setting a model of preparation for a Jewish death. “His example was to get your house in order and begin to convey to the next generations your wishes, your legacy, your hopes, your blessings, and in some cases, your rebuke,” Rudansky explains. “Jacob’s messages to his children are the starting points in terms of what Jewish tradition feels should be discussed at the end of life.”

The Talmud contains references to verbal ethical wills or deathbed instructions left by

sages and scholars. As Rabbi Eliezer, a notable scholar of the Talmud, lay dying, he criticized his students for not taking advantage of the opportunities they had to learn from him. His aim was to move his students to learn from his teachings even after his death. (Sanhedrin: 68)

In the Middle Ages, ethical wills were shared privately among families. One of the most famous ethical wills from this time was written by Spanish Jewish physician and scholar Judah ibn Tibbon to his son, Samuel when he died in France in the 12th century. It ran over 50 pages long and covered a wide range of topics, from the importance of books — he wrote the familiar line “let books be your companions; let bookcases and shelves be your pleasure grounds and gardens” — to a harsh rebuke of his son whom he felt wasn’t living up to his expectations.

### Ethical Wills During the Holocaust and Beyond

Zippora Birman, a member of the Jewish Underground in the Bialystok ghetto in Poland, left an ethical will to future generations of Jews before she died in 1943. Birman’s notes, discovered after the war, included a call to action for “Vengeance, vengeance— with no mercy, with no sentimentality.”

Yad Vashem, the Holocaust Museum and Memorial in Israel holds a number of ethical wills hastily written by Jews before they were killed at the hands of the Nazis. Like Birman’s will, many also call for vengeance. Others thank the writer’s parents, ask for a proper Jewish burial and express an unending love for God.

After the Holocaust, ethical wills became a tool to help future generations understand how Jews who survived held onto their faith despite the suffering they endured and to impart the

message of why they felt supporting Israel, a Jewish state, was so important. Today, some secular Jews use this medium to convey to their children why they believe it’s important to stay connected to a Jewish community even if Judaism is not at the center of their lives. For examples of ethical wills written by contemporary American Jews, see Rabbi Jack Riemer and Dr. Nathaniel Stampfer’s *Ethical Wills and How to Prepare Them*.

### The Universality of Ethical Wills

In his book *Ethical Wills: Putting Your Values on Paper*, author Barry Baines notes that Christian texts also contain illustrations of verbal ethical wills. He points to John 15-17, a recounting of Jesus’s parting advice and blessings to his followers. Baines concedes that the term “ethical will” is of uncertain origin but offers his interpretation of the name: “as writing became more common, attachments to legal wills were discovered that contained the title of “Teachings of the Fathers.” While legal wills provided instructions on what to do with material assets, the “ethical” sections contained instructions on how to lead a moral and upright life. I like the analogy: legal wills bequeath valuables, while ethical will bequeath values.”

A number of secular groups also encourage people to write ethical wills. One such group is Celebrations of Life, which strives, through its website and podcast, to give all people the tools to create an ethical will. There are also professional writers who can explain the process, share sample ethical wills, and help clients write their own ethical will.

Ethical will writing is a key part of end-of-life or hospice care, with many hospice nurses or social workers encouraging their patients to write one. An ethical will is usually intended for

the benefit of family members after a parent or grandparent has died, but the process of ruminating on one's own legacy and what one values most can be an emotional and healing experience for a person coming to terms with their own mortality. Proponents of ethical wills say it can end up being just as meaningful for the author to write an ethical will as it is for their intended audience to read it. Doctors and other palliative care professionals often "prescribe" or suggest their terminal patients engage with ethical-will writing as a comforting component of their end-of-life care.

### Receiving and Reading an Ethical Will

Writing an ethical will can be challenging, and similarly, reading an ethical will is not always an easy thing to do in the aftermath of a loved one's death. In *Ethical Wills: A Modern Jewish Treasury*, Riemer and Stampfer describe the feeling of receiving an ethical will as "sort of like reading a love letter from the beyond. There is a sense of being a voyeur, of eavesdropping on an intimate conversation." They recommend recognizing the privilege of being given an ethical will, holding it in perspective and treating it with reverence and gratitude, even if the will presents the reader with a burden or sense of guilt.

### How Can I Create an Ethical Will?

Ethical wills are not legal documents so they can take any shape the writer wishes. In most cases, they are written or typed, but they can also be shared widely through video platforms and social media. An ethical will may contain photographs or illustrations or take the form of a collage. It can read like a letter or a laundry list of ideas. It can be addressed to one's children and grandchildren, to a friend, or anyone and everyone else you think should read it.

There is no template for an ethical will; however, a number of rabbis, synagogues and JCCs offer courses in ethical will writing. Hospice workers and colleges can also be a resource. Find some exercises to help you get started here.

If a person near death is unable or uninterested in writing an ethical will on their own, hospice workers can step in and help their patients with verbal ethical wills. These are nonjudgmental, non-threatening conversations social workers or chaplains have with dying patients that are either recorded with audio or video, or simply transcribed after talking to the patient about their life. This is often an easier way for a person who is uncomfortable talking about certain subjects or memories to leave a legacy for their families.

### Additional Resources

Much like sitting shiva or watching over the dead before burial, writing an ethical will is one of a number of rituals where Jews can find meaning and spirituality while engaging with their own mortality. Consider the links below to get started writing your own.

*Step By Step Directions: How to Write an Ethical Will in Six Easy Steps*

*Ethical Wills: The Gift of a Heart* – Robert G. Alexander

*Ethical Wills – What They Are And How To Write One* – Kari Berit

*Ethical Will Resource Kit*

*Ethical Wills and How to Prepare Them* – Rabbi Jack Riemer and Dr. Nathaniel Stampfer ■

# How to Talk to Loved Ones About Your End-of-Life Wishes

Do's and don't's for broaching the most difficult of topics.

BY RABBI RICHARD ADDRESS

Conversations about end-of-life decisions are delicate, personal and unique — and rarely if ever, begun and completed in one sitting. One thing is certain, given the mobility of our society, the advances in medical technology and the continuing cultural denial of death: The need for these conversations has never been more profound.

**H**ow to begin? There is no one way, no “one size fits all.” Family gatherings such as Thanksgiving, holidays and birthdays can be a good time to have the conversation.

In addition to Cohen's book, Rabbi Gordon also recommends reading *Having the Last Say*, Bruce Feiler's “This Life” column: The Family Stories That Bind Us, and Susan Garland's “Your Money” column: Telling Their Life Stories, Older Adults Find Peace in Looking Back.

It is important to prepare for the conversation. Start by letting people know that you plan to have this conversation, how important it is to you and that you need cooperation, understanding and support.

We've compiled 8 Do's and Don't's that will help you have the most productive and meaningful conversation possible with your loved ones.

## 8 Do's and Don't's

Consider the following:

### 1 Do your homework ahead of time.

Before you sit everyone down, you should designate a health care proxy and complete, or at least review, the relevant documents that express your wishes in cases when you are unable to speak for yourself. Important documents, which you can learn more about at the resources listed below, include:

- Your will
- An advance medical directive which states your wishes for end-of-life care.
- Health Care Proxy which is a legal and enduring form designating a health care agent to speak for a person if they can no longer speak for themselves.



- POLST (Physician's Order for Life-Sustaining Treatment) or MOLST (Medical Order for Life-Sustaining Treatment) forms. This is not recognized in all states, but it supersedes an advanced directive. Please note that the creation of these documents expressing your wishes has been supported by every major Jewish denomination.

**2 Do educate yourself.**

Take the time to become familiar with the terms associated with these documents and, equally as important, your local laws as they relate to decision making. It is important to understand the possible tax implications of your estate (if applicable) and the potential challenges of “spending down” as your situations change. These issues are important especially if you are

in a second marriage or if you are living with a partner. Also, be aware that some of these laws vary from country to country and from state to state. Consulting with trusted advisers such as an elder care attorney, financial adviser, accountant, and if desired, your rabbi is strongly recommended.

**3 Don't just fill out these forms and forget about them.**

You should review all documents and directives at least every five years. Why? Because we all change, and we may change our mind on certain treatments. Also, the pace of medical technology is rapid, often outpacing society at large and so what was frontier medicine years ago may now be standard practice.

**4 Do share any documents you develop with as many people as possible.**

This can include your family, doctor, lawyer, and anyone else you deem appropriate. If or when you enter an assisted-living facility or nursing home they will also need copies. Make sure that these people, especially your proxies, know your wishes and are up to date on your thoughts. They may be called upon to make serious life and death decisions.

**5 Do be firm in your resolve to have these discussions.**

Some family members may have already witnessed situations in which no advance planning has taken place and thus be more inclined to participate. Others may push back. That's OK; it's important, and you need to do it.

**6 Do remember that having these conversations will help your children, even if they don't agree with everything you say.**

Differences of opinion may emerge as to your wishes and the thoughts and feelings of your loved ones. Jewish tradition has the concept of stewardship, which, in the spirit of the 5th Commandment to honor and respect the wishes of parents, says that adult children should honor the wishes of their adult parents, assuming the wishes of the parents have been made in full knowledge and clarity. Having these conversations and documenting your wishes will help, in moments of crisis and stress, alleviate guilt and

give clear direction, especially in cases where you may not be able to make your wishes known. Clarity of wishes and acknowledgment of those wishes (even if some may harbor other wishes) is a powerful and necessary act.

**7 Do speak in a language of love, affirmation and concern.**

These conversations look at your choices and your belief in your quality of life. Try to avoid language that relates to being or not being a “burden.” Remember, that your loved ones who care for you are adults and that just below the surface, these conversations raise the reality of our mortality and the evolving concern over the issue of loss and legacy.

**8 Do understand that these conversations may raise all kinds of psychosocial – and spiritual – issues.**

Our society does not do a good job of embracing our aging or accepting our own mortality. Yet the conversations you will have with your loved ones are discussions about just this. We have these conversations and sign these documents and, in doing so, accept in a very real way, the reality of our own mortality. This is a spiritual issue.

For spiritual guidance, Jewish sources, sample forms, and other related information visit Jewish Sacred Aging.



### **Books That Can Help Your Conversation**

*Being Mortal*, by Atul Gawande

*On Matters of Life And Death*, by Rabbi Elliot Dorff

*A Jewish Guide to Practical Medical Decision Making*, by Rabbi Jason Weiner

*Navigating The Journey*, edited by Rabbi Peter S. Knobel

### **More Resources for Your Conversation**

The Conversation Project

National Health Care Decision Day

The Five Wishes

The Coalition to Transform Advanced Care  
[YourLifeYourWishes.com](http://YourLifeYourWishes.com)

# Why Jews Need to Talk About Death

Conversations about end-of-life wishes are easy to procrastinate. But you shouldn't.

BY RABBI RICHARD ADDRESS

It's not easy to face our own mortality, and perhaps even harder to imagine losing our loved ones. Which is why many of us just avoid the issue.

Whether your reticence comes from anxiety, religious superstition or fear of engaging with a morbid subject, experts advise everyone to consider these issues earlier rather than later, even when you are young and healthy. Some rabbis even encourage newly engaged couples to discuss advance care planning before their wedding and to revisit the topic when a child is born or around other lifecycle events.

## Why You Shouldn't Wait

Why the rush? If you delay thinking about what you want for the end of your life, you and your loved ones may end up forced to make difficult decisions very quickly and under duress. And you may be in no condition at that point to articulate your decision, leaving your loved ones to guess about your preferences. According to a recent report by the Pew Charitable Trust, 70 percent of Americans over the age of 60 had to make a decision about treatment during their last week of life but were physically unable to communicate their wishes to family or clinicians. Only about 1 in 3 has completed an advance care plan for the end of their life.

"Too often, we see families stuck in situations they could never have imagined, as a result of not having had conversations before loved ones lose the ability to make decisions for themselves," says Melanie Levav, a rabbinical student at the Jewish Theological Seminary in New York who works as a hospice chaplain. "Gaining clarity on how we wish to live as we approach death is a vital conversation; none of us will survive death, but all of us have the chance to live well."

## What The Talk Should Include

End-of-life conversations can include a number of issues, such as who we want making decisions about our health when we are unable to do so on our own, where we want to be treated (At home? In a hospital?), how many medical interventions we want doctors to use and where (or if) we want to be buried. Toby Weiss, director of cultural sensitivity and Jewish programming for MJHS Hospice and Palliative Care in New York advises family members to check in about these topics often and alter their previous plans if their feelings have changed. Not only is it important to draft an advance



directive in which you designate a health proxy to speak for you, Weiss says, but you have to actually speak with your proxy — and yourself. “The hardest conversation to have is the one you have with yourself first,” Weiss says. “That’s the one people avoid most.”

There are a number of reasons to push past the discomfort, however. Rabbi Charles Rudansky, director of pastoral care for MJHS Hospice and Palliative Care, counsels families to discuss these issues sooner rather than later to allow “the person that is dying the opportunity to make decisions on their own terms.” He wishes there wasn’t “such a taboo among Jews who feel they shouldn’t talk about death or dying or that we are a religion that should only focus on life.” He wishes these kinds of conversations were at the front and center of Jewish life, not just in nursing homes and in hospice but well before that time.

One of the most important reasons to discuss these issues before it’s too late is to remove any sense of guilt one’s family members might feel if they are forced to make decisions for a loved one without an advance care directive. Simple questions like whether or not to install a feeding tube can create anxiety and uncertainty for

family members. And modern medical advances can add to the difficulty.

Dr. Alex Hakim, director of the ICU at Providence: Little Company of Mary Hospital in Torrance, California explains, “Medicine was easier when the loved ones of a patient came to the physician and said ‘do everything you can,’ because ‘everything’ meant a limited set of procedures and medications. Now that we can literally bypass failing hearts and lungs with mechanical devices or chemically maintain the pulse and blood pressures of near brain dead individuals, patients who are actively dying can be maintained in a near death state for months and sometimes years at a time. From my experience, having the discussion with your immediate relatives and friends about what you would accept in an end-of-life situation and what life and a ‘good death’ mean to you are immensely beneficial.”

End- of- life conversations can go beyond plans for medical care and touch on the realities of where participants want to be buried, whether they are comfortable with cremation, what they want their funeral to look like, and how they want to be remembered once they are gone. It can also give loved ones the opportunity to

share with each other feelings that are often reserved for eulogies and never heard by the family member when they are gone.

### **How To Start The Conversation**

There are a number of ways to initiate an end-of-life conversation with your family or friends, and it doesn't have to be awkward or uncomfortable.

It's sometimes helpful to bring in a third party like a trusted social worker, doctor, or rabbi to help families engage in end-of-life discussions. Medicare will pay for advanced care planning conversations between doctors and patients, so this is something to consider bringing up when accompanying family members to their medical appointments.

Another resource is the Death Over Dinner project, which helps facilitate group conversations on death, offering explanatory invitations sent to guests and guided discussion topics for the hosts. With her husband, Sarah Benor, professor of contemporary Jewish studies at the Reform movement's Hebrew Union College-Jewish Institute of Religion, hosted a Death Over Dinner event for friends while their kids were away at sleepaway camp. "Even though it's talking about death, the way it's set up is also talking about life, how you want to be remembered, and what you want to do in your life," she said. "We talked about bucket list things, and there were also people who had lost parents and other loved ones who talked about their losses. It was a little bit about life and a little bit about mourning and a little bit about how we expect to want to die. It made me feel closer to my friends to hear about their mourning experiences. These are really personal things, things you don't share with a lot of people, so

I guess it was a bonding experience for us, a community building exercise."

Elizabeth Saiger was motivated to host an end-of-life conversation for a group of parents from her daughter's nursery school after attending a how-to seminar through Ikar, her synagogue in Los Angeles. "We talked about what our eulogies might be like, what we hoped people would say about us, and we shared a story or a moment we hoped would be definitional of who we were," she said, adding, "While I think a conversation around medical interventions and end-of-life care can be fruitful, it was nice to take it up a level and talk about what we valued." Saiger and her invitees created such a bond after their initial meeting that they decided to keep the group going and have since met monthly, branching out into other difficult-to-talk-about subjects.

These discussions don't have to be depressing, notes Melanie Levav, the rabbinical student and chaplain. "Taking care of the business of death lifts up the sacredness of life," she says.

### **Resources To Help You Get Started**

#### **The Death Over Dinner Project**

The website allows you to plan a dinner party, invite guests with a customized scripted letter, send them related reading materials to engage with before meeting, and select conversation starters to help introduce the topic and why it's worth talking about. There is also a Death Over Dinner: Jewish Edition available.

### **Attend a Death Cafe**

A gathering, usually of strangers, who come together over a cup of coffee and talk about death. There is no formal script to follow; the goal is to create a space where people can talk about death in order to better appreciate life. Social workers often agree to host these conversations. You can look for one near you on their website.

### **The Five Wishes Brochure**

This document helps families organize these conversations by asking specific questions (meant to be answered and recorded) about end-of-life care, like who the person wants making health care decisions for them, what kind of medical treatment they want, how comfortable they want to be and how they wish to be treated.

### **Talk to a Rabbi**

A rabbi can help you initiate these conversations with your family members and give you suggestions on some “opening lines” to begin these talks drawing from their own personal experiences with your loved ones.

### **The Conversation Project**

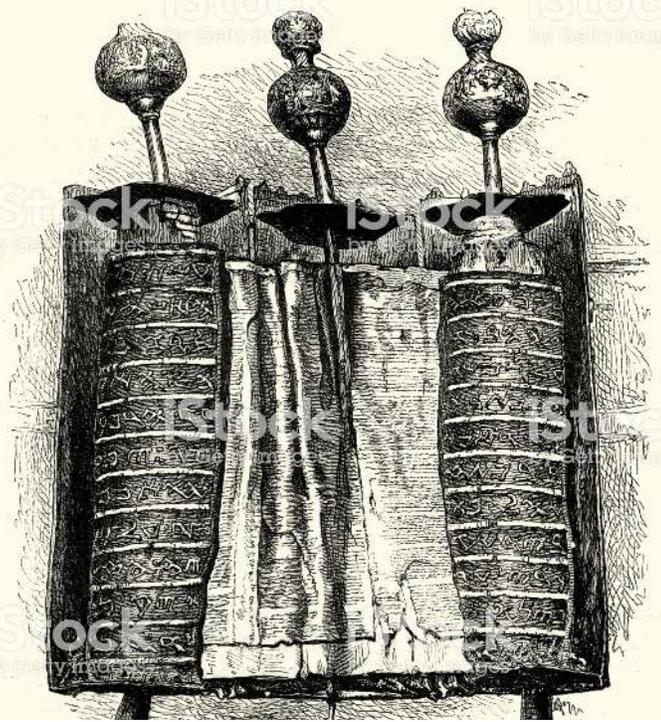
If you don't have a rabbi, begin the process yourself with something like The Conversation Project which offers a starter kit for these talks.

After you've had these conversations, a website like Gyst.com can help you put together a living will, an estate will and order life insurance. ■

# End-of-Life Care in the Bible

What we can learn from Jacob, Sarah and Moses' final moments.

BY RABBANIT ALISSA THOMAS-NEUBORN



The Torah is called *Etz Chayim*, a tree of life, because it provides values, ethics and laws by which Jews are commanded to live. But how we die is also part of how we live. And so when we face death, our biblical ancestors can serve as models for how we approach the end of life. Below are some key examples from the Torah and what they teach us about dying.

## Jacob

Is there such a thing as a good death? Today much of the research around this question says yes, and it looks like this:

- Death at home or in one's place of choice
- Death surrounded by loved ones or whomever one desires
- Death with closure in all relationships

Hospice organizations, palliative care teams and family members of those who are dying are finding that these components can ease anxiety and pain and create peace at the end of life.

In the Torah, Jacob has a famously good death. Not only does he know that his death is imminent, he has the mental clarity to call each of his children to his bedside to bless them and give them advice for life after he is gone. (Genesis 47:28) He rebukes those who

need it and tells his own life story. Jacob even tells his children exactly where to bury him — alongside his ancestors. In contemporary terms, he models a life review and legacy work, and provides an ethical will — all things that healthcare professionals, therapists and clergy so often encourage. Jacob does not get the life he wanted — as he says to Pharaoh: “Few and evil have been the days of the years of my life.” (Genesis 47:9) But he does get the death he wanted. He ties up his loose ends and makes sure everyone he needs to speak with hears him. He does this all in the comfort of his home.

Of course, the type of death Jacob has is not always possible. Some deaths are unexpected and unplanned. Some deaths happen in the hospital because that is the only place a person is able to get the care they need. Sometimes a person who is dying is no longer conscious or

cognitively capable of imparting their wishes. And because we don't know what our own death will be like, it is important to prepare for it as early as possible, even before we are ill. Telling a loved one whom we want at our beside or what medical measures we want to be taken or how we want to be remembered can be done at any age. These conversations are uncomfortable, but they are also the ultimate expression of love.

There is wisdom for us all in Jacob's death. There is even a famous teaching (Rashi on Genesis 49:33) that says Jacob did not really die. The lesson being: When we leave behind instructions, a legacy, and blessings, we never truly die.

### **Sarah**

Can a person die of a broken heart? In the Torah, Sarah does.

After struggling to bear children, Sarah finally gives birth to her beloved son, Isaac. One day God commands Sarah's husband, Abraham, to sacrifice this cherished child as a test of faith. When Sarah finds out that her son was being prepared for slaughter, "her soul went out from her and she died" (Rashi on Genesis 23:2) although Isaac would not, ultimately, be harmed or killed. The Torah portion in which Sarah dies is called, "Chayei Sara," or "The Life of Sarah," underscoring that how she died reveals much about how she lived and how she is to be remembered.

What can we learn from Sarah's death? Rabbi Kalonymus Kalmish Shapira, a 20th-century Polish rabbi known as the Aish Kodesh in the Warsaw Ghetto, tells us that Sarah's death is a prayer to God — and a plea that a person should not be expected to suffer unlimited pain and anguish. If Sarah, one of the most virtuous, giving and faithful people in our tradition, could

not withstand such pain, no one can or should have to. The story of her death is a prayer to God to step in and hold us, comfort us and save us when we cannot continue on.

When we are faced with unbearable sorrow in our own lives, perhaps as we face our own illness and death or that of a loved one, we can think of Sarah. We can imagine her sitting with us in our pain, holding our hand — and maybe even crying along with us. When we have nothing to say to God, Sarah is our voice, demanding that God make our lives and deaths better than hers. Let us learn from her story and say in our prayers, "God, this is enough! Please give me the strength to get through this. Please let Sarah's death not be for nothing. Please heal my broken heart."

### **Moses**

"It is not up to you to finish the work, but you are not free to desist from it." (Pirkei Avot 2:16)

We often think that we have to do everything ourselves, that if we don't, it won't get done. At the end of his life, Moses — a leader used to doing it all — learns that this way of thinking is counterproductive.

To this day, we say that no one will ever be like Moses in his character or in his relationship with God. But even Moses was human and died. If Judaism had ended with Moses, if the work stopped with him, we would not be here today. If the Torah only existed in the life of one person, it would not be eternal. And so, in the final moments of his life, Moses is told by God to focus on passing his leadership on to Joshua. (Deuteronomy 31:14) He has to accept that he will not, in his lifetime, get to enter the land of Israel; in this acceptance, Moses learns that passing on the tradition is the greatest way of keeping it.

Our job is not to finish the work, but to be a link in the chain. This is a lesson we often accept only when we face death — and thus the loss of time, opportunities and dreams. And yet this same tough realization is a source of hope. There is more than just now; we are part of a greater story. We do not have to worry about finishing everything because we will have help from future generations. This truth is humbling and freeing. It allows us to let go.

At the end of life, sometimes a person feels tethered to this world, worried about children or a spouse, unable to let go of the things he or she wants to finish or take care of. Or perhaps a loved one will not leave the bedside or practice self-care for fear that no one else will look out for the patient. In such situations, it is a wise and compassionate gift to ourselves and to our loved ones to give permission to let go and accept help.

In your own life right now, reflect on letting go and accepting that your unfinished work will be carried on by others. What would it feel like to say (to yourself at the end of life or to a loved one at the end of life): “You did not desist from the work. You did it every moment of your life. You took care of everyone and are loved. But you don’t need to finish it, you don’t need to do it all yourself. Your legacy will continue; your story will go on. I give you permission to let go.”

Though in death we lose life in this world, we also gain the gift of legacy, of a story that is greater than ourselves. By passing on his leadership, Moses made sure we could do the same. ■

## Section 2

# Personal Stories

9 Tips for Visiting Someone in Hospice .....	36
Bringing Joy and Therapy to Hospice Patients Through Jewish Music ....	38
The Surprising Thing that Helped My Mom Live Longer Than Anyone Thought She Would.....	41
The Surprising Connection Between Childbirth and Death .....	43
If I'm Ever in a Coma, Please Thread My Eyebrows.....	45
My 9-Year-Old Daughter Embraced Life Until the Day.....	47
Talking About Death Over Dinner with Strangers .....	49

# 9 Tips for Visiting Someone in Hospice

BY JENNIFER MODLINGER

No matter your feelings about extravagant weddings and the British royal family, I think we can all agree that they did a beautiful mitzvah by turning the flowers from Prince Harry and Meghan Markle’s wedding into bouquets for hospice patients.

And whether or not you are of royal blood, visiting a loved one who has entered hospice care can be a nerve-wracking experience. But it doesn’t have to be. There are things you can do to bring comfort and joy to a person in hospice. We pulled together the following tips from the hospice nurses, social workers, and clergy at MJHS Health System.

## 1 Timing is Everything

Plan the time of your visit carefully. Find out when your friend or relative is feeling most energetic: morning, midday, or night? When do medications need to be taken? Speak with the patient, family caregiver, hospice staff, or close friend to determine the best time of day to visit. And make sure to double check that it is still a good day and time to visit before heading over.

## 2 Comfort Food – Or Not

Don’t just show up with your specialty brisket or noodle kugel without checking in first. Find

the patient is craving something. If he or she is on a liquid diet, you could bring a smoothie or milkshake. If martinis were a favorite but alcohol is no longer an option, make a toast over water in martini glasses. Sometimes smelling a favorite food can be a comfort, even if it can no longer be eaten — the aroma of a freshly baked challah or a fragrant pot of chicken soup can bring back beautiful memories even if they can’t be tasted. But again, ask first.

## 3 Technology Can be a Powerful Tool

Even if the patient can no longer travel, he or she can still be part of a family simcha. Facetime, Skype, and live streaming are all ways to help someone be a virtual guest at a Bat Mitzvah, a bris or a wedding.

## 4 Think Twice About Bringing Decorations

Fragrant flowers are beautiful but can be majorly problematic for someone with respiratory issues; a giant bunch of balloons



something particularly meaningful — and not too large — that you can bring. Homemade cards and drawings, as well as family photos, are always a good choice.

#### **5 Don't Bring an Entourage**

If you planned to come alone, don't decide on a plus-one — or two! — at the last minute. Additional guests can be overwhelming and can make a room feel crowded.

#### **6 Children are a Blessing — Usually**

Kids can bring lots of energy and joy into the room — but only if that energy and joy will not overwhelm the patient. Exuberant hugs and kisses may be welcomed, or they can exacerbate existing pain. Let the patient be your guide.

#### **7 Keep an Eye on the Clock**

Don't overstay your welcome — patients often tire easily. You may be having a lovely visit and dreading what could be a final farewell, but be mindful of any cues you may be getting from the patient or family members.

#### **8 No Surprises**

This isn't the time to try and mend fences or settle a long-standing family feud unless

specifically requested by the patient. He or she may have already made her peace with whatever quarrel or drama happened in the past, and resurfacing matters may do more harm than good.

#### **9 Don't Take It Personally**

Don't take offense if a patient doesn't express delight over a thoughtful gift or painstakingly crafted card or drawing. He or she may be too tired to be effusive about the gift. The same goes for not talking during the visit, ending the visit suddenly, or seeming apathetic about a holiday or celebration.

The bottom line when visiting someone in hospice is to let the patient be your guide, to be present and in the moment, and remember that it isn't about you. Visiting a loved one who is in hospice care for a life-limiting condition is going to bring up all sorts of emotions, and it may be hard to squish those emotions down — particularly if you aren't having the kind of visit you envisioned. In the end, remember that you are doing a huge mitzvah — even if you aren't bringing a leftover bouquet from the royal wedding. Like so many things in life, it's about showing up and showing you care. ■



# Bringing Joy and Therapy to Hospice Patients through Jewish Music

BY SARAH SELTZER

It's a bitterly cold winter morning in Brooklyn, but Brenda, a 101-year-old woman in a Jewish hospice facility suffering from severe short-term memory loss, has a special group of visitors show up in her warm room.

Joelle Missry, a creative arts therapy intern, arrives with her guitar slung over her back and with her licensed music therapy supervisor by her side. She sits beside Brenda's bed.

For the next 20 minutes, Missry holds Brenda's hand and sings a combination of old Yiddish songs with help from her team and Brenda's home health aide, who has learned some of the songs. But Brenda is largely sleepy and unresponsive, despite Joelle's best efforts. After going through a songbook that ranges from "You are My Sunshine" to

the Yiddish favorite "Tumbalalaika," the group gets up to leave.

Just as they're about to exit, however, Brenda's eyes pop open. Suddenly fully alert, she begins to croon the Yiddish standard "Bai Mir Bist Du Shoen," looking straight at Missry. She goes through the song a few times, tapping her feet and looking very pleased.

This is the kind of moment for which the music therapy program at MJHS Health System, a Jewish health care service provider in New York, was designed.

Hospice care, which is playing an increasingly central role in end-of-life arrangements, isn't just about administering palliative medical care and making sure loved ones are comfortable. It's also about relieving patients' pain through meaningful interactions and experiences. Proponents of music therapy say singing has medical benefits while also enhancing patients' social and emotional health.

"Music therapy programs brings human dignity back into the picture," Missry says.

Music therapy is considered so important that MJHS Hospice now employs five full-time music therapists, as well as interns and part-time workers, all trained in a songbook that covers many of the languages and cultures in New York's five boroughs. For aging Jews, that means the Yiddish and Hebrew songs that bring back warm memories. The MJHS songbook ranges from American standards like "What a Wonderful World" to Hebrew songs like "Jerusalem of Gold" and "Hatikvah."

The therapy itself is considered an "integrative therapeutic intervention" – non-medical treatment that can have therapeutic results. Studies show that a joyful singing experience can ameliorate pain and a patient's symptom burden without the use of drugs. It has an exercise component, encouraging healthy physical movement, such as feet-tapping and hand-waving. Hospice workers say it also can help relax patients before treatments, like a blood draw or IV infusion, that might cause agitation or anxiety.

A growing body of scientific evidence supports the use of music therapies in various medical settings, from neonatal intensive care units to end-of-life and palliative care situations. Music is shown to boost immunity and reduce

stress and pain by increasing the antibody immunoglobulin A and other immune system-boosting cells while reducing the stress hormone cortisol.

"We've found compelling evidence that musical interventions can play a health care role in settings ranging from operating rooms to family clinics," Daniel Levitin, author of the recent book "This is Your Brain on Music," told the American Psychological Association recently. "This is one reason why music is associated with relaxation."

For Alzheimer's patients specifically, a program called Music and Memory, featured in the documentary film "Alive Inside," shows that music therapy can decrease medication usage in patients. The theory is that music can trigger a kind of deep right-brain response, something beyond the reach of linear memory, so that even a patient who can't string a sentence together might be able to remember or at least respond to lyrics from a song.

MJHS Hospice is unlocking memories through music therapy. (Courtesy of MJHS Health System)

Music therapy isn't just about singing old songs. The therapists are trained to deal with issues like hearing loss or agitation, as well as cultural sensitivities.

For some of the elderly Jewish patients under the hospice care, there's an extra benefit to the treatment.

"Often with Holocaust survivors there is a reticence on the part of patient and on the part of family members to allow pain medication," said Toby Weiss, director of cultural sensitivity and Jewish programming for MJHS Hospice and Palliative Care. "There is a lack of trust and there is a prior history of trauma when it comes

to medical issues and health care interventions. So when a patient is experiencing pain, as an example, if a music therapist starts to play a Yiddish song or a lullaby or something else from the patient's childhood, the vital signs change, their affect changes."

Beyond easing pain, the experience of bringing a patient some music from their early life can be powerful bonding tool, allowing a potentially tense family to come together — part of the core mission of hospice care.

"I've done some of the Yiddish songs with the families present, and the family didn't know the person knew this song," said Meredith Ferrel, creative arts therapy Team leader at MJHS Hospice. "You have that chance to have the family connecting or singing together. It's an added gift that the loved one is giving the family Yiddish-language songs at the end of life and sharing songs with their grandchildren. There is a celebration of culture."

Music therapy often offers family members a chance to see a side of the patient that might long have been in retreat. Ferrel recalled how one woman invited all her neighbors into a music therapy session to "meet" her husband with dementia — the music unexpectedly had brought out a glimmer of his former personality.

Charla Burton, a music therapist with MJHS Hospice, said the music sometimes induces primal emotions, catharsis and joy that makes the experience especially meaningful for patients and their families.

"Some people will respond to hearing 'Hava Nagila' as if they're at a bar mitzvah or wedding!" she said. ■





# The Surprising Thing That Helped My Mom Live Longer Than Anyone Thought She Would

BY CHERI LEVIN *As told to Sarah Seltzer*

When many people hear the word hospice they think it is synonymous with “The End.” But hospice is so much more than that. In my family’s case, hospice care was a gift — it helped my mother live an additional year and a half, and it gave my sister and me peace of mind. When she did die, we were able to mourn her without having any regrets about the decisions we made about her care.

Our story began in 2011 when we started to notice changes in my mother. She was diagnosed with a form of dementia and, as her condition deteriorated, we eventually needed home care. However, the quality of the home care attendants was uneven at best, and I found myself calling the agency over and over again looking for replacements. After my mother fell and broke her hip, my dad felt

like he couldn’t care for her at home, even with a home health aide. At that point, she was unable to feed herself. She did not speak much; she often became agitated and started screaming.

We toured several facilities and I always left in tears — I couldn’t deal with the idea of my mother just sitting in a room in a nursing

home. At the same time, my father was afraid that if she came home, she'd be stuck in a bedroom until she died. After some discussion, we realized that I could accommodate her in my home by doing some construction and hiring a home health aide. We built her a bedroom on the ground floor of the house and widened the doors in the house to accommodate her wheelchair. When the weather was nice, we were able to push her outside so she could sit by the pool. It worked for a time, but she kept ending up in the hospital — with a UTI, pneumonia, high blood pressure, and other health problems.

And then she had a heart attack. The doctors didn't expect her to survive, but she did — but they told us that she was close to the end. We were open to the idea of hospice care, but the first facility we met with said that their palliative care procedures did not include giving patients antibiotics for infections. The idea of my mother dying from an untreated UTI seemed unconscionable; even cruel. I called a friend who worked at MJHS Hospice and she told me that they would, without question, give her antibiotics for a routine infection.

Beginning home hospice care was a total game changer. It felt like a huge burden was lifted from my shoulders. We had a home health aide as well as visits from hospice staff, including a nurse, a rabbi, a music therapist, and a social worker who also met with my dad. The music

therapist brought joy to both of my parents, learning some of their favorite songs and having sing-a-longs with them.

No stone was left unturned. We were able to avoid the hospital because routine medical issues were dealt with at home. Someone even came every week to arrange my mother's pillbox.

Hospice care helped my mother survive longer than anyone thought she would. Toward the end of her life, they arranged for a night nurse to sit up with her all night so that I could sleep. (Before that, I would jump up every hour and check the video monitor I had set up in her room.) She received whatever medicines she needed to keep her comfortable around the clock. My mom died peacefully at home surrounded by her family — the way we all hope to leave this world.

After her heart attack, my mom had been given 24 hours to live. Instead, she had another 18 months, during which she was surrounded by loving family. It was nothing short of a miracle. ■



# The Surprising Connection Between Childbirth and Death

BY SARAH SELTZER

Rikki Ward Photography

*Jessica Zitter is a Jewish mother, doctor, and author of “Extreme Measures: Finding a Better Path to the End of Life.” The book details her journey from believing that technology should be used to save a patient at all costs to a more nuanced approach that prioritizes a terminally ill patients’ values and preferences when making care decisions.*

*Using individual patient stories as a backdrop, Zitter explores how doctors, patients, and families can work together to understand the range of treatment options and potential outcomes in order to make informed decisions about the way they want to experience their final days of life. Her work is also highlighted in Extremis, a gut-wrenching Netflix documentary that follows Zitter and her team as they help families make care decisions for their loved ones in the ICU.*

*Zitter spoke to Kveller about the way Jewish values influence her practice, how she speaks about death and dying with her kids, and how the movements to change childbirth practices are connected to these emerging approaches toward death.*

**A lot of your book is about un-learning some of the things you assumed about your calling as a doctor.**

I went into medicine believing that the point of what I was doing was to use fantastic and exciting technologies to save peoples’ lives. I also believed that working in the ICU, like surgery, was somehow more valuable than the more “soft-science” things like geriatric medicine.

**You talk about the role of Jewish philosophy in your decision to become a doctor. Does it animate your life now?**

I’ve always been very Jewishly identified, and my work in palliative care has brought me much closer to my Jewish values. I went into medicine for the reason many young Jewish people do: it’s a big part of our liturgy — life is so precious, saving a life is so important.

What I learned from listening to patients is that machines and technology have a place — but in moments of acute decision making, 95% of our efforts should be about taking care of the human being, not about taking care of the organ. We prioritize technology and the stretching out of every nanosecond of life. But if you look at the Bible, we're taught we should not interfere with death or dying. The story of Jacob shows us the value of preparing and being in control of your final days. We learn from Exodus the importance of autonomy, of not being a slave.

I feel my Judaism is able to flourish now because I'm prioritizing patients' autonomy — as well as values like community support and not treating people like strangers.

**In your book, you mention that for a brief period you considered becoming a rabbi!**

I did. I think part of why I didn't do it was because I wanted a clearer path forward to help. Medicine felt, at first, like a simpler approach. The irony is that as a palliative care doctor, my main job is to be a rabbi-like figure: to listen, to support, to see what's most helpful.

**There's something of a backlash going on against the over-medicalization of childbirth. Do you see parallels between the way we think about death? Can a palliative care team function like doulas and midwives?**

I think there's absolutely a parallel. I think it's really encouraging, too — for so many years people had this magical vision of the doctor as this Norman Rockwell figure who was going to take care of us and had our best interests at heart. But now, whether it's unnecessary cesareans or the end-of-life conveyor belt, there's a similar shift. People are waking up and saying, "I think I need to take control. "

**What do you mean by the "end-of-life conveyor belt?"**

It's the automatic, unquestioning application of increasingly powerful tools and technologies that take over for the patient's organs as they begin to fail when they're dying. If patients and their surrogates are fully aware and making truly informed decisions, that's different. It's only the end-of-life conveyor belt if it's going on without the patient understanding.

The first and foremost is for the parent to do their own work first. You can't really have a conversation with a kid about death and dying if you haven't processed your own feelings.

In my house, we talk about it a lot. In fact, my kids sometimes say: "Mom, can we have one Shabbat dinner where we don't talk about death?" But they know about death, they know it's going to happen, and when it does, they're going to be able to process it because they've had those tracks laid down.

**What's your favorite Jewish custom or tradition?**

Shabbat. On Friday night we always have friends over, with lots of singing and banging on the table. My husband makes us go around the room, and everyone, big and small, talks about their week. I'm grateful for something nice to come home to every Friday.

**What's the last thing you do before bed?**

I probably check the news — not a good habit.

**What TV shows have you binge-watched?**

I've watched *The Office* and *The Americans*.

**Do you have a favorite Yiddish word?**

I'm a big a Yiddish lover. I love *kvelling*, of course...but also, *chazerai*. It's a good one. *Farshtunkeneh* is such a good word too. ■

# If I'm Ever in a Coma, Please Thread My Eyebrows

BY SARA BETH BERMAN



My father, my brothers, and my best friends have all heard the lecture: If I'm in a coma, and it looks like I'm not getting better, pull the plug and give away all my organs — everything that's useful. Save all the lives!

However, if there is any chance that I am going to make it, and it's been more than 14 days, make sure you bring in someone to thread my eyebrows. I am aware that this conversation is not a normal one to have, but then again, nobody has ever accused me of being normal.

For those of you who do not share my genetic predisposition for Sesame Street's Bert unibrow — well, first of all, I envy you. I have delayed dinner plans, considered bangs, and have argued with supervisors about time off for this particular errand. I will do just about anything to keep my eyebrows in the plural. If I am languishing in a hospital bed, I know that people will visit and see just how gross my face can get.

This is unacceptable.

When I was in my 20s, I was engaged to a lovely man, a rabbinical student named Rafi. He had suffered from a variety of ailments due to an underlying disorder. Over our years-long relationship, there were multiple hospital admissions because he needed to be monitored or treated. Yet in all that time it never occurred to me to ask, "What do you want us to do if you're dying?" In hindsight, as his health kept deteriorating, I really should have asked. But I didn't ask. And neither did his family.

This, like my overgrown eyebrows, was also unacceptable. We talked about everything else — the accommodations we would need

to make when he came home with this deficit or that medication, how I thought we should probably get engaged if I was going to be sleeping overnight in a back-breaking chair next to his hospital bed, how maybe it made more sense for me to be the primary breadwinner in our life together, given his hospitalizations.

When he ended up in a coma, we did not know what to do. What would he want? How long would he want us to have his body be an ICU-based battleground for modern medicine? What would he want his end-of-life to look like? What about his funeral? In denial about just how sick he was, Rafi had never told us what he wanted. So family and doctors, clergy and advisors all teamed up to answer these questions as we imagined he may have answered them, were he conscious.

After nearly two weeks of adjusting what appeared to be an uncomfortable breathing tube, we learned that the medical team had left his beard untouched, assuming (given his rabbinic training) he was too religious to shave it off. We didn't even know we had to tell them it would be fine with him to have his beard removed for this purpose. They shaved it off within the hour of this revelation.

In the end, there was nothing more anybody could do. He was going to die, and we were doing our best to answer those end-of-life questions for him, authorizing beard removal and, later, ventilator removal. Unlike the landmark Terri Schiavo case — in which family members fought over whether or not to remove a feeding tube from a woman in a persistent vegetative state — all concerned parties reached the same conclusion: It was time to end care and eschew heroic measures. After a monthlong coma, after a life filled with thousands of hours teaching and inspiring, epic amounts of friendship and love, and a million what-ifs, my fiancé became my

dearly, departed fiancé, dying just a few days short of his 28th birthday, and a few months short of our wedding.

In the years that followed, I have endured arguments with family members about my end-of-life wishes. My father, a doctor, is practical, and my mother refuses to discuss these things with me. I have expressed feelings about comas, about terminal illness, about organ donation, about traumatic injuries, and, of course, about my eyebrows. None of these things are written out on paper. They are neither formalized or notarized. They are, instead, in the brains of my father and a few of my closest friends.

They should be on paper. They really should be on paper.

People don't want to think about unwanted body hair, but most agree that what they do with body hair is an individual's choice and that many of the removal options are painful or unpleasant. And that's just body hair. There are plenty more consequential decisions to make, and write down, too. If a person can have such particular feelings about eyebrow maintenance, then shouldn't they also express their feelings about hospice? Palliative care? Organ donation? Medication? Medically induced comas? What a person considers to be the tipping point in determining quality of life after a traumatic injury?

It is painful, and sometimes nearly paralyzing, for people to talk about their own and loved ones' future deaths. But everybody is going to die, and how you deal with that is also a choice. If you don't make your choices known, you may very well be leaving your loved ones in the lurch, with an extra layer of pain, just as you leave them on this earth.

Let's all go out and get our living wills finalized, shall we? ■



# My 9-Year-Old Daughter Embraced Life Until the Day She Died

BY PAULA SKELLEY

Several weeks into chemotherapy and proton therapy, Lydia lost most of her hair. At 7-and-a-half my daughter was diagnosed with Rhabdomyosarcoma. It turned out that her night terrors and toothache were really symptoms of a tumor growing under the surface of her right jawbone, a tumor that started in the connective tissue.

**A**s Lydia's hair thinned more and more, I offered to shave her head. "Are you kidding me?" she said, hand on her hip and a death-ray stare in her eyes. "It's bad enough that I've lost most of my hair, and now you want to take away the little I have left?" Prior to cancer, Lydia's golden hair flowed to her waistline. Where I saw unsightly strands of hair here and there, Lydia saw the remnants of former glory and determinedly wore what she had left with pride.

Lydia felt about her hair the way she felt about her life. She did not want to shave off days just because she looked like she was in bad shape. Resolutely, she wanted to live until she died. She wanted to be treated like Lydia, not like a child dying of cancer.

Early on in Lydia's cancer treatment, we overnights in Boston Children's Hospital and shared a room with a mother and her toddler. With nothing but a curtain dividing our spaces, I remember listening to Mary teaching Sara the ABCs. "Repeat after Mama,

Sara. ABCDEFG..." Sara sang in reply. At that moment it dawned on me: Parenting does not stop when cancer begins. You parent as if your child will live as long as anyone else, no matter the odds the doctors have given.

So, as Lydia battled cancer, we lived life as normally as possible. Lydia attended school between chemotherapy and hospital visits when she could and Skyped in when her immune system was vulnerable. She had playdates with friends and a tutor over the summer. As a mother, I learned to balance my fears that Lydia would end up in the hospital if she hung out with other kids and Lydia's need and desire to see her friends and do normal kid activities.

But even in this "balance," I made everyone who entered our home use hand sanitizer and I gave Lydia clear boundaries to follow to keep her safe while hanging out with friends: "No bike riding today, your platelets are low from chemo and a scrape from a fall may mean a trip to Boston for a blood transfusion."

After the first 10-month treatment protocol failed, and Lydia's tumor continued to grow, we tried another. It too failed. And Lydia was placed on a third trial protocol because there is no "cure" for this type of cancer, only chemotherapy trials with lists of possible side effects that sound every bit as bad as cancer itself and actually include the possibilities of secondary cancers.

By the time this third protocol began, Lydia often experienced terrible headaches. That's when the hospital offered palliative care. At the time, I was unfamiliar with this term and associated it with hospice and death. I was wrong. Palliative care meant pain relief! Pain relief meant that a year and a half into a 25-month battle with cancer, Lydia was able to enjoy her Make-A-Wish trip to Disney World with her family.

Lydia's Make-A-Wish trip made a difference! For a week our entire family was able to focus on Lydia and her brother, Luke, living and loving life. The week, however, was not without stress. The third protocol of chemotherapy had also failed to stop the growth of Lydia's tumor and as we vacationed, we contemplated the next options to treat this indestructible cancer. I could see the tumor slightly grow beneath her right jaw bone each day during our time at Disney World.

As we lived in the shadow of death, Lydia bravely broached the subject. "If I die now, do you think God would let me see myself as a teenager?" she asked one day.

"If you ask, I'm sure he would..."

From that day on, our conversations were open, honest and covered everything

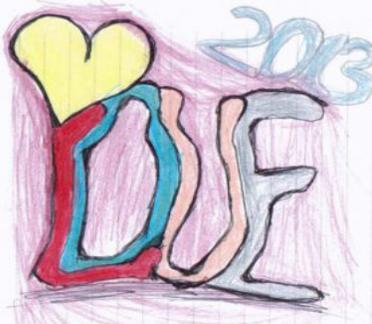
from life and death to the past and a much longed for future. "If I'm lucky enough to live and have children" Lydia said, "I'll make sure they read Robert Munsch. Especially "Love You, Forever" and "Stephanie's Ponytail." She giggled and said, "Ug-i-ly, ug-i-ly, veeeeery ug-i-ly!" She imitated Robert Munsch's voice from a recording she had of "Stephanie's Ponytail." I laughed too, remembering a carefree moment before cancer touched our lives.

By November, 2012, we had placed Lydia on hospice care. It was a difficult decision made easier by the fact that a child on hospice was eligible for pediatric concurrent care, which also allowed continued treatment of the disease to some extent. In my mind, it was not a complete giving into death so much as it was a way to receive some of Lydia's care without a 60-mile drive to Boston in traffic. Every day through April 30, 2013, the day she died at the age of 9, Lydia found a reason to smile through pain.

She found a way to live — loving her family and friends, devouring books (including all 586 pages of "The Mark of Athena" in just three days) and drawing in her journal. She drew the food she wished she could still eat but was unable to. She drew flowers, hearts and funny faces. She expressed herself in her art. She wrote love letters to important people in her life.

On her last hospital stay, she said "I love you," to nurses to whom she'd formerly just waved out of her room when they were finished caring for her.

Lydia spent her last five days of life at home — throwing me kisses and holding my hand. "I'm dying," she said to me. Again, she bravely opened the door to truth. We proclaimed our love for one another and comforted each other. She patted my back and told me, "You can cry as much as you need too, Mom." ■



# Talking About Death Over Dinner With Strangers

BY SARA SHAPIRO-PLEVAN AND TEHILAH EISENSTADT



Dinner with strangers can be awkward. It can be even more awkward if you're there to talk about death. And even more so when the death is your own.

**W**e were a group of Jewish educators gathered together for Death Over Dinner, a two-hour, facilitated conversation about something most of us aren't talking about at all — death and dying.

The Jewish version of this gathering, made possible by Reboot and IKAR, includes remembering our dead, studying Jewish texts on death and dying, learning some practicalities of supporting loved ones through preparing for and living through death, and mindfully imagining the impossible: our own deaths.

Sounds like the most uncomfortable dinner party ever, right? Why would anyone sign up for that?

Because talking about death — and specifically one's own death — can help us to avoid suffering now and later, and honor both our loved ones and ourselves. It is an important conversation that can't happen as fully in the moments directly preceding or following death. And our own experiences with traumatic death in our respective families and communities illuminated how crucial it is to have these conversations.

The dinner began with a l'chaim — a toast. Each of us took turns raising our glasses in memory of a loved one who changed our lives. We told these stories over a lit yahrzeit (memorial) candle. We gave ourselves permission

as a group, and as individuals, to mourn people who we felt we had not previously or adequately mourned — maybe because we thought others had more “official rights” to mourning, or because we felt anger that was best left unshared at the time of death, or because we hurt too much at the time to mourn the way we needed.

The gathering became a sort of sacred space and akin to a *yahrzeit* (an annual commemoration of a loved one’s death). We were a group of people who may never gather again sharing stories of tremendous intimacy.

Each of us had a chance to tell stories of our loved ones, of losses old and new. We acknowledged that we are all part of a larger story and that our loved ones — in fact, all people — are kept alive through stories that we tell. As Jews, we are accustomed to keeping memories alive through the telling of stories. Reading the weekly Torah portion and retelling the story of the Exodus from Egypt during the Passover seder are just two examples of how we use stories to maintain the collective memory of the Jewish people.

By this point, you must think we’re obsessed with death. Quite the contrary. As Jewish educators, we each had our own professional and personal experiences of being called to support others as they transitioned through the phases of life. We were aware of the abundance of available resources on death and of the need to cultivate and curate resources for people of all ages.

We asked ourselves: When do we talk about death? Do we wait for a moment when the conversation is specifically needed? Or do we tackle it as a community? How do we treat other kinds of loss, like pets? Over dinner, we worked together to develop a personal and Jewish vocabulary for these hard feelings

so that we are prepared to be present in the moment when more urgent traumas emerge.

We came away with the realization that we can’t hold on to traditional definitions of mourning anymore. Modern psychology reinforces the wisdom of Jewish grief rituals, but it also shows us that pain is not limited to the people defined by Jewish law as mourners (typically immediate family members) or limited to the timeframes prescribed by Jewish law. The dinner gave us a framework to redefine what family means, to open up new and perhaps controversial ideas about who constitutes a mourner and how long we can mourn. What if our best friend dies? Can we sit shiva for them? What if a sibling or a newborn dies and we want to mourn them in a manner that goes beyond the traditional Jewish timeline? What if we want to say the Mourner’s Kaddish with a virtual minyan online instead of a real-life one?

Redefining mourning today within new formulations of community gave us permission to recognize our families as bigger and less bounded, our pain as real, and our voices as authentic. We were changed by this experience and think that you might be too. We highly recommend participating in a Death Over Dinner or Death Over Dinner Jewish Edition gathering.

You can also try it at home. Here are some questions to get you started.

When and how might I speak to my loved ones about death? What resources could assist me, and how might I access them?

How might I speak to my loved ones about my preparations for my own death? What resources could assist me?

How might I speak to my loved ones about preparations they might have already undertaken in preparing for their own death? What resources could assist me? ■



**70 Faces Media** is a not-for-profit digital media company that aspires to connect as many people as possible to all sides of the unfolding Jewish story.

Learn more at [70facesmedia.org](https://70facesmedia.org)

---

For more than 100 years, **UJA-Federation** has brought New Yorkers together to solve some of the most pressing problems facing our community.

Learn more at [ujafedny.org](https://ujafedny.org)

---

**MJHS Health System** is a not-for-profit organization that serves the home care, hospice and palliative, rehabilitation and nursing care, as well as health plan needs of people across all five boroughs of New York City, Long Island, Westchester and Hudson Valley.

Learn more at [mjhs.org](https://mjhs.org)