

Being Mortal
Kol Nidre 5776
Rabbi Joel Mosbacher

Jacob, Phoebe, Ari, and Alex come up to Cantor's podium during the singing of Oseh Shalom.

Rabbi: The question comes in a two forms:

Jacob Jaffe: Rabbi, what should we do?

Phoebe Lachenauer: Rabbi what does Judaism say we should do?

RABBI: Like Jews do, I answer the question with a question:

What does your mother/father/ son/ daughter/ brother/ sister/spouse want?

The answer comes in four forms:

Jacob: Do you think we should ask her, rabbi?

Phoebe: We're afraid to ask him. We could handle that question, but we think he's too fragile—it would upset him. He'd think he was dying. We don't want him to give up hope. Maybe there'll be a miracle.

Ari Lachenauer: We don't know. We're lost. She's unconscious and we can't ask her. We wish we would have asked her when we had the chance, but we never did, and now it's too late. Some of us think she would have wanted X. Some of us don't think she ever would have said that. What should we do?

Alex Anesetti: Well, dad told us years ago that what was most important to him was to spend time with his family; he said that he wanted the doctors to be honest, and that when the best we could realistically hope for was to keep him comfortable, he didn't want to be hooked up to any machines or have any extraordinary measures. He didn't want hail Mary surgeries or treatments that could shorten whatever time he had left. He said that he didn't want to be in pain. He told us all years ago that his priorities were to die at home, if at all possible.

All these questions and answers, as you can imagine, come from real life conversations I have with families all the time.

This sermon is going to be challenging for some in this room, I am sure. If you've had to make end of life decisions in recent times with me, or with or for your loved ones, the emotions may still be raw, and I welcome the opportunity to process them with you in the coming days. I am not here today or any day of my rabbinate to pass judgments on anyone for any question they ask. I do not stand here tonight to judge anyone, including

myself, for the answers we have given to the questions that our rabbis, doctors, or other advisors have asked us in response to our questions. But here at BHSS, we don't avoid the hard conversations. We embrace them, wrestle with them, and strive to support each other through them.

There is likely no more difficult conversation to have than the impending death of a loved one. Whether your relationship with that person is beautiful, loving, and committed, or complicated, messy, or even ugly, making decisions with and for them at the end of life is something we'd all rather avoid.

All I want to do tonight is tell you something you already know. You can't avoid it.

Yom Kippur is not just any day of the year. On this day, we pray to be inscribed in the Book of Life. Yom Kippur is perhaps the quintessential liminal moment because it forces us to truly confront our mortality. And this is no small task, especially when we, so many of us, are afraid to die, afraid to talk about death, afraid to talk to our loved ones about death. Afraid of the word death.

The human fear of the inevitable is so prevalent that I found one website with 213 euphemisms for death and dying. Here are some of my favorites: in addition to usual ones like, "he bought the farm" or "she kicked the bucket," there's "sleeping with the fishes," "cooking for the Kennedys," "joining the majority." Or, "he's left the building," "mailing in his warranty," "pushing up the daisies," "wearing concrete galoshes" or, appropriate in the computer age: "he's been reformatted by God." We chuckle when we hear that Mark Twain once remarked, "Reports of my death have been greatly exaggerated" or that Oscar Wilde proclaimed on his deathbed: "It's either the wallpaper or me. One of us has to go."

Of course we joke about death, because it's our way of coping with the reality of it.

But we must ask ourselves, how often are we coping with the **reality** of death as opposed to **disconnecting** ourselves from that reality? How many of us are simply in denial, thinking that if we don't talk about it, it will never happen?

The psychiatrist Elisabeth Kubler-Ross put it this way: "It is the **denial** of death that is partially responsible for people living empty, purposeless lives; for when you live as if you'll live forever, it becomes easy to postpone the things you must do. . . . In contrast, when you fully understand that each day you awaken could be the last [one] you have; you take the time that day to grow, to become more of who you really are, to reach out to other human beings."

My friends, it is not the "Jewish way" to deny death. Our tradition recognizes death as the necessary antecedent to life. And yet, even our sages grappled with their own anxieties about death. Rav Nachman once related that the moment of dying itself is as painless as "removing a hair from a cup of milk." The fear of death though, he explained, is eminently more painful.¹

¹ Babylonian Talmud, *Moed Katan 28a*

But for one day, one extended moment, each year, we stare death in the face. Yom Kippur forces us to confront the reality of death-- that today may truly be our last on this earth.

In point of fact, Yom Kippur is more than a reminder of death; it is a dress rehearsal. We fast, as the dead have no need for sustenance. Sex, too, is a luxury of the living. We avoid pampering ourselves with life's usual trappings: leather shoes, perfumes and long hot showers. Even our clothing changes. The traditional garment of Yom Kippur is the *kittel*—the same garment we are traditionally buried in.

So, who is ready for rehearsal?

Have you prepared your lines?

Do you know how to hit your entrance on time? Your exit?

I don't know any of those things, either.

There are some subjects we never want to discuss with those we love. Sometimes, there's an old hurt we're afraid to broach; sometimes, it's an old emotional wound we fear reopening.

Sometimes, families agree not to talk about business, money, or politics at the break the fast. Sometimes, there's no such agreement, and you might wish there were!

In my experience in my pastoral role as a rabbi, though, the subject that THE most number of people don't want to talk about is: death.

Fortunately, we live in a time of positively miraculous medicine. As he writes in his new book, Being Mortal: Medicine and What Matters in the End, surgeon Atul Gawande says that the dangers of childbirth, injury, and disease have been transformed, "from harrowing to manageable."²

People live longer and better than at any other time in history. But scientific advances have turned the processes of aging and dying into medical experiences—matters to be handled by health care professionals. And medical professionals, armed with all of the incredible tools of modern medicine, tend to see a patient's death as a failure. And since we rightfully hold medical professionals in such high regard, we see death as a failure, too. And that directly informs the choices and options we and our loved ones are willing to allow for ourselves when it comes to death and dying.

Death, of course, is not a failure. Death is normal. Death may be the enemy, but it is also the natural order of things.

² Being Mortal. Inside flap.

So many of you have told me difficult stories in the quiet of my office. And I read so many other moving stories in Gawande's powerful book.

Doctors, uncomfortable discussing patients' anxieties about death, can fall into a trap of providing false hopes and treatments that may actually be shortening people's lives instead of improving them.

And family members, desperate to do the right thing, terrified to have hard conversations with those they love, not knowing what their now-incapacitated loved one would have wanted, tend to go along with whatever the doctor orders.

I've heard stories from you that facilities in which some of our loved ones reside, which are devoted above all to safety, sometimes argue with residents over the food they are allowed to eat and the choices they are allowed to make.

When doctors are afraid to have hard conversations with the patient—afraid even to use the word, “death,” and family members are scared to have those same conversations, that combination bodes poorly for the prospects of giving the **patient** what **they** actually want.

Atul Gawande makes the case that our **ultimate** goal as humans is not a good **death**, but a good **life**, all the way to the end, and he provides guidance for how we might best reach for that good life.

When we are making decisions for our loved ones, we tend to focus on making sure that, above all, they'll be safe, and that they will live as long as we can possible help them live. And those aren't bad inclinations.

But when we are the patient, it turns out, a life of safety, a life of being protected from falling, a life with as many days in it at all costs, might not **actually** encompass the sum **total** of what every person really **wants** for themselves. But how do we **know** what they want, unless we ask?

Gawande outlines 5 questions that, he argues compellingly, we need to be comfortable asking each other. It needs to be normal to ask these questions, especially when someone is faced with a serious illness, and especially when we know that we're aging and becoming frail. The questions are these:

1. What is your understanding of your current medical condition?
2. What are your fears or worries for the future?
3. What are your goals and priorities?
4. What outcomes are unacceptable to you? What are you willing to sacrifice and not?

And ultimately,

5. What would a good day look like?

Asking these questions increases the likelihood that loved ones and medical professionals will really understand what the goals are — what we are really working and fighting for. In some cases, it may be for the maximum number of days or years. In other cases, it might be for the best **quality** of time, even if that seems likely to mean less time.

I recently sat with a family in the congregation who was struggling with a difficult decision about whether or not to pursue an aggressive form of treatment for their father, let's call him David, who had been diagnosed with cancer. They, like so many of us, didn't know what to do. They were like the person at the beginning of this sermon who was afraid to ask the patient, afraid that they would scare him.

When they asked David these questions, a few things became obvious. First of all, David knew about and understood his situation much more clearly than anyone thought he did.

And secondly, David was very clear that what was most important to **him** was to have a **social** life, and that he didn't want aggressive treatment that would prevent him from being social. So if his tumor was going to make him a quadriplegic, he didn't want to be on a ventilator or have a feeding tube. He chose spending the best time he could with those he loved over the prospect of more time with less chance to live the way he wanted.

One more thing was clear in this case and, I would submit, might be true more often if we asked Gawande's 5 questions of our loved ones. David's choice might **not** have been the choice his **family** would have made **for him**; they might well have chosen whatever option was most likely to **extend** his life. But when they asked **him**, they realized that his goal wasn't "give me the most days possible at any cost." His goal was, "give me the best days possible, even if it means fewer of them." To David, a good day was a social day. That was his priority. And so he was willing to risk a potentially shorter life for one with opportunities to be able to converse with his family and friends.

Let me be clear: there are no perfect solutions to the problems inherent in bodily decline, and there is no pat answer to the question, "What are your goals and priorities?" Given all of the information about their situation, some may choose to exhaust all medical options available, and some may make other choices.

Gawande simply challenges us to commit ourselves to creating the best range of options, and to doing our best to allow our loved ones to make choices with the goal of a purposeful life in mind, however they might define that.

What's also true, though, is that we rarely consider how our own discomfort may be preventing us from starting that difficult conversation. Rather than deal with or accept that we are avoiding our own potentially unpleasant experience, we project our own challenges onto the other person.

In other words, we tell ourselves that we would be able to handle the conversation, but the other person cannot or will not be able to deal with it, so best to just avoid it altogether. Powerful research that deals with end-of-life conversations provides a compelling story as to why we may want to reconsider this perspective.

A study conducted at Massachusetts General Hospital involved hundreds of patients with terminal lung cancer. Half of the group was randomly assigned to receive traditional treatment. The other half received standard care along with visits to the hospital's outpatient palliative care center-- care focused on pain-relieving rather than cause-solving.

Among other things, the group receiving palliative care was asked how they would like their treatment to be modified if their physical health changed. Families may be reluctant to have this conversation, as they may be uncomfortable discussing the possibility of their loved one's condition worsening. However, these possibilities are real. And such discussions empower patients to talk about their preferred care, rather than leaving it solely to medical personnel or family members to make those decisions.

The preliminary results were quite promising. First, significantly more patients receiving palliative care had their resuscitation preferences documented in their medical records than those receiving standard care; an important area to ensure patient wishes are followed at the end of life. Palliative care patients used less aggressive end-of-life care, which included less frequent chemotherapy as well as longer hospice care. These less aggressive treatments resulted in lower costs, which benefited the patients, their families, and the hospital.

Perhaps the most fascinating results related to their psychological and actual physical well-being. Specifically, the palliative care group was less depressed three months after their initial visit, experienced less pain, and reported a higher quality of life than those who received standard treatment alone.

In addition to the psychological benefits, these palliative care discussions also impacted the lifespan of the patients. Researchers found that although patients receiving palliative care chose "less aggressive end-of-life care" these patients lived significantly longer; by an average of 25%.

The only difference between the two groups was the opportunity to have palliative care discussions, which focused on the realities of their disease and the patients' desires for how they wanted they wanted to live their lives at this terminal stage. Despite the gravity of the situation, opening the door to these difficult and deeply personal conversations yielded an opportunity to discuss what mattered most.

The above results begin to suggest that the benefits of such difficult conversations far outweigh the discomfort we may feel when engaging in them.

Dealing with end-of-life matters is one of the most challenging and uncomfortable conversations to have. Yet, when done properly, it can empower and engage the individuals who need it most, resulting in improved physical and emotional well-being.

There's no natural moment to have these difficult conversations, except in a crisis. And that's too late.

Tonight, I say again, I stand here not to judge you or myself for the ways we have handled the lives and deaths of our loved ones in the past. This is the hardest topic I can imagine—it's one of those subjects, along with sex and money, that we don't talk about in polite company.

You know, sometimes I give the sermons I need to hear, hoping, praying, that they'll be sermons that you need to hear, too. My experience tells me that we all need to hear this.

So what should we do, rabbi?

Have the conversation.

Have the conversation with your adult children. Have the conversation with your parents. Have the conversation with your spouse or siblings.

Yes, I know. We're young. We're young in spirit. We're going to live to be 120—isn't that what you wish us, rabbi, when we get our birthday chocolate?

Great! You're young! Have the conversation. Have it once, write it down, and then you'll never have to have it again! And your loved ones will never have to guess, will never have to fight with each other, will never have to ask ME what YOU would have wanted.

Tell your loved ones what kind of medical care you want if you are in a physical state that a doctor asks these questions. Tell them what a good day looks like for you.

Do you want life-sustaining care regardless of your physical or mental state? Or are there circumstances in which you would not want your life prolonged by further medical treatment? And if it's the second, what are those circumstances? Do you wish for artificial fluid and nutrition to be provided? Do you want CPR to be administered? And under what circumstances? Is it important for you that you die at home, if at all possible? Do you want your organs donated, if at all possible?

You don't have to remember all of these questions. Atul Gawande's version of the 5 questions is outlined in his amazing book. It's called Being Mortal. Go to the library. Get it on your Kindle. Read it.

Also, in the foyer tonight, there are packets called "advanced directives" for you to pick up—each state has its own form. We have copies available for New York and New Jersey; if you live in another state, we can help you get those state-specific forms.

And because you might want to know more about what Judaism's view is about these questions, and because you might want to hear more from a medical professional about these decisions before you face a crisis for yourself or others, the Caring Committee is hosting a forum on November 22 at 1 p.m. where a panel of end of life specialists and I will be speaking about the Jewish and medical perspectives on end of life issues and decision-making. I invite you to join us, and bring family and friends.

One of the most moving changes I've come across in our new machzor is in the Avinu Malkeinu prayer. Amongst all the powerful liturgy contained in this prayer is the line, *Avinu Malkeinu, kotveinu b'sefer chaim tovim*. In our previous machzor, this was translated, "Our Father our King, inscribe us for blessing in the Book of Life." Now it says, "Enter our names in the Book of Lives Well Lived."

There's a subtle and yet deeply meaningful difference in these two translations. The **first** implies that the goal is life itself, and who could argue with that? We want to know every single time we gather on this day of days that we will live another year.

But the version here in our new machzor speaks to a related, different need we have: to live the life we have **well**.

In 5776, I pray that our names be entered in the book of lives **well lived**. May we take the time to grow on this Yom Kippur, to become more of who we really are, to reach out to other human beings. And may this be the year we have the courage to have the conversations that will help ensure that we and our loved ones will have a good life, all the way to the end.