

## The Right to Die / Yom Kippur 2022

Rabbi Yaron Kapitulnik

Good morning. As many of you are aware, for the past 10 years, on Yom Kippur morning, in lieu of a sermon directed to the congregation, I write my four children a letter. This year is no exception. But before I begin sharing it, I would be remiss not to thank Rabbi Ed Feinstein whose words and wisdom inspired me to write this letter.

Dear Roni, Tom, Danielle and Yonatan,

Judaism is a religion that focuses on and celebrates life.

We lift a glass of wine and say, “L’chaim!” We say “She’hechiyanu,” thanking God for the gift of life. We wear jewelry with the word *Chai* – meaning life, and use its numerical value - 18 – when giving tzedakah.

But Yom Kippur is an exception.

Yom Kippur is the only day of the year in which we focus on death.

Today, we literally rehearse our own deaths. In our white attire, mimicking a death shroud, we abstain from activities that bring us pleasure. Throughout the day, we recite the Vidui, the confessional prayer, just as one does before death. And we fast -which for many Jews may be worse than death.

Yom Kippur helps us fight the deepest taboo in our human consciousness- one which we all invest enormous mental energy to push away, the reality of our own finitude.

As a rabbi, I have met with so many people who refuse to talk about their own death. In fact, just last week I had a heart-to-heart conversation with a member I also consider a friend. He has a terminal illness. He is fighting it with inspiring courage. I asked him if he has spoken to his family about what happens when all the experimental drugs stop working. To my surprise he said, "When I get to that bridge, I will cross it." If only I could tell him of all the times, we never make it to the bridge, when the surge of the storm carries away the bridge. Leaving us with regret that we did not have the conversation earlier.

So many of us have forgotten what Henri Nouwen teaches when he says, "I have a deep sense, that if we could really befriend death, we would be free people. So many of our doubts and hesitations and insecurities are bound up with our deep-seated fear of death that our lives would be significantly different if we could relate to death as a familiar guest instead of as a threatening stranger."

Yom Kippur confronts us with this reality, and the prayer that probably has the greatest power to do so is known as the "Unetaneh Tokef" – when time after time we ask who will live and who will die?

And we want to believe that the answer is "NOT ME".

But this past year, it could in fact have been me.

As you know, after experiencing shortness of breath during beach Shabbat (And I thank Dr. Dan Goldstein for being on the beach that day,) I finally went to that forever postponed doctor's visit, and thank God I did, because that appointment showed a 95% blockage in my main left artery. A widow maker waiting to happen.

I will never forget the feeling, laying in the cath lab, fully awake, looking at my heart beating on the monitors as the doctor was inserting a stent into my artery, and thinking to myself how little it would take for this story, my story, to end differently. In those moments, the reality of my own death became very real, and it made me realize there is still more I need to share with you.

My dear kids, you well know that I talk about death a lot. Quite often during a family adventure you will hear me saying, "make sure this goes into my eulogy" or "make sure this doesn't." I share with you lessons I have had the privilege to learn by holding hands of people on their deathbeds, and those of mourning widows, children and family members. And I do so because I believe we can learn much about life by having a better perspective of death.

So today, I need, and want, to talk to you not just about the importance of befriending death, but perhaps even more importantly, about the right to choose how to die, and when to die.

Look at the "Unetaneh Tokef" prayer again and, as terrifying as it is, listen to the different ways it describes how we might die. Do you see what they all have in common? They are all sudden and unexpected. Fire, water, sword, beast, earthquake, famine, thirst, and various sorts

of violence, all come with little or no warning and mostly without remedy.

For most of human history, that's how most people died. During a war or by natural catastrophe, by accident or injury, of an incurable illness. People died quickly, often by conditions we consider trivial. George Washington developed a throat infection on December 13, 1799, and was dead the next evening. Women commonly died in childbirth. Newborns were taken by whooping cough or diarrhea. People died of diseases we barely know today thanks to advances in public health and vaccinations: cholera, tuberculosis, typhoid, measles. Disease came without warning and without remedy. There was little anyone could do.

That's not how we die today. Yes, sudden, catastrophic illness, accidents, terrible injuries still happen. But most people today die after long medical struggles, often with an incurable condition – like cancer, heart or kidney or liver failure, Parkinson's and Alzheimer's disease, complications from a stroke, or failure to thrive as we reach a ripe old age. While death is still certain, the timing isn't.

In fact, today as soon as a malady is detected, modern medicine goes to its battle stations. It's actually awesome to witness. Medical interventions, such as CAT scans, MRIs, blood tests, cameras in pill form or at the end of a wire scan, pharmacological and nuclear medicine, immunotherapies are all amazing. We have so many ways to medically manage our lives to go to war against death.

Modern medicine is a miracle. It has doubled our life expectancy within a century. But with miracles come responsibilities. And today,

we find ourselves with responsibilities unanticipated by the Jewish tradition; unanticipated by American culture; unanticipated by most of us personally. Once, it was God who decided who would live and who would die. Now it is us - we have to decide. How and when.

Seventy-five percent of Americans say they want to die at home. They want to avoid suffering, they want to be with family, have the touch of others, be mentally aware, and avoid becoming a burden. However, in reality, only twenty-five percent do. In fact, more than 70% of people die in a hospital or care facility, on stiff hospital sheets, beneath cold fluorescent lights, often under heavy sedation, unable to say “I love you” or “good-bye.”

Fulfilling those end-of-life desires requires us to have brutally honest conversations about our right to choose how to die. As Doctor Haider J. Warraich describes in a recently published article in The Washington Post, “Dying with dignity, at home, is not as easy as we think it is. It's possible but it requires preparation, it requires hard conversations and so many of us are not willing to have that conversation.”

I am.

And so today, let me be clear, I want to make my own decision about my death.

Last night on Kol Nidrei, I shared a story about David, and my personal regret for not visiting him one last time before he died. David was the first person I ever met who made a decision to not accept treatment when he was diagnosed with lung cancer. During our

proceeding conversations, he shared with such clarity, how he wanted to end his life in dignity, with minimal pain, not connected to tubes in a hospital but rather at home, with his wife Shirley by his side, reading his books and listening to his extensive collection of Yiddish music. And that is exactly how he did, in her arms.

In his book, *How We Die*, Dr. Sherwin Nuland, chief of surgery and Professor of Medicine at Yale University Hospital, shares a very different and deeply personal confession about his brother - a cautionary tale.

His brother, Harvey was an New York City accountant. He loved his work, was the president of his shul, and his greatest joy, his treasures, were his family, having been married only at the age of 40 and having two children later in life. Harvey was generally healthy, but when he turned 62, he was diagnosed with cancer.

While Harvey's surgery was successful the cancer had spread widely throughout his body. When he awoke from the surgery, Harvey turned to his brother, the famous doctor, for guidance. At that time, his well-educated brother knew there was no cure. But yet, he could not admit to his brother that there was no hope; that there was nothing to be done. He could not admit it to the family. He could not admit it to himself. He confesses:

“I could not face my brother and speak the words that should have been said; I couldn't tolerate the immediate burden of hurting him, and so I exchanged the possibility of comfort that may come with an unhampered death for the misconceived hope I thought I was giving him.”

Instead, Dr. Nuland arranged for an experimental, and brutal protocol, which demanded extensive hospital stays. The treatment ravaged Harvey's body, brought tremendous suffering, and robbed him of his precious family time. And it didn't stop the cancer. In the end, Dr Nuland admits,

“Where my own brother was concerned, I had forgotten or at least forsaken the lessons learned from decades of experience. Thirty years earlier, when there was no chemotherapy, Harvey would probably have died at about the same time that he eventually did, of the same causes, but his death would have been without the added devastation of futile treatment and the misguided concept of hope that I had been reluctant to deny him and his family, as well as myself.”

I understand that there are times when we should sacrifice the quality of our life today – to gain time tomorrow– to live longer. I see it all the time. People are willing to go through extensive and expensive efforts, pain, discomfort. I admire their courage and at temple we celebrate their many victories.

However, there comes a time when I believe we need to change direction. There comes a time when the fight to prolong life is impractical, when the chance is minimal, and the collateral damage – the discomfort, disability, indignity – robs us of life's quality. We pray for *refuat ha-nefesh v'refuat ha-guf*, for healing of body and healing of spirit. But there comes a time when we must choose between them....to give up the fight...to let the body go and to tend to the soul....to stop worrying about what's coming later and provide the fullest possible life now... to be at home and not in the hospital; to be free of pain and discomfort; to be mentally aware and alert and not

sedated into delirium; to be with loved ones and friends and not surrounded by impersonal strangers; to be able to share final words and wisdom and to say goodbye.

There comes a time when the soul is more important to us. *Ki hem chayeynu v'orech yameynu*, because this is what life is for – to share family, friendship, love, wisdom.

In my thirteen years as a rabbi, I have seen many examples of both choices. Brave people who make the choice to fight or the choice not to fight. And let me be clear – I am not judging anyone's decision – each person has his or her unique circumstances none of us can fully understand. My Jewish wisdom teaches me very well not to judge any person until I have been in their shoes.

But I think it is critical to remember that while the choice is theirs, that we must respect their choice. While there is no good or bad decision, there are mistakes made – mistakes in the form of not sharing with loved ones what our decision is, while we can still share it. Mistakes in leaving that impossible decision to spouses, children and family members.

I don't want to make that mistake. I have learned from the regrets of so many who failed to have the conversation.

So, I want to share this confession with you. I hate pain. In the few experiences I had, I do not handle pain well. And so, sitting here today, I believe that if I am faced with a choice of a shorter life, one with little or no pain, or a longer one with extensive pain, I would choose to say goodbye earlier.



This is my personal choice for ME, this is my answer for TODAY. I reserve the right to change my mind, and if I do, I will let you know. But I hope that if I am successful in befriending death, if I continue to feel that I have been blessed in my life, the realization of an inevitable painful, undignified end will not push me to make irrational decisions.

I believe you understand my position, my beloved dear children, because this past May, you lost your grandmother, Savta Nurit, whom you loved so much. For close to two years, she fought her cancer with all she had, she was willing to endure pain just so that she could be with you and hug you one more week, just so that she could cook for you one more delicious Shabbat meal - and ooh could she cook. But the last months of her life were an experience no human should have to go through. First, she couldn't get out of bed, and then she couldn't hold on to the cigarette she loved so much, soon after she lost the ability to speak, then to keep her eyes open, and then a slow lingering, painful road leading to her death. I know how much you suffered seeing her suffer this way.

You know, one thing that was so incredible about your grandmother was that, and I think it's safe to say, she loved her dogs just as much (if not more at times) then she loved anything else. And that she, like all of us who love our pets, understands what it means to help our pets die when their time comes, when we see them suffering.

I am furious that we cannot treat our loved ones with the same kindness and mercy.

When the time comes - I want to have the choice to say "enough." I want to have the choice to receive medical help so that I do not suffer.

I want more states to pass dying in dignity laws like we have in Oregon, California and Vermont and I pledge to do all I can, as a rabbi to support these laws when they are presented.

Yes, this might surprise you. I know that traditional Judaism advocates against the right to die, I am familiar with the teaching in the Talmud about Rabbi Chanina ben Teradion who when tortured by the Romans, ignores his students and refuses to do anything to shorten his suffering and hasten his death -proclaiming that no one, but God can make that decision.

However, there is a reason why I am a rabbi in the reform movement and that is because I believe in personal autonomy based on educated decisions. I am one of those students of Rabbi Chanina, supporting our right to end our suffering when it is clear that all that awaits us is a painful death. I know that even traditional Judaism recognizes the existence of a stage in life called GOSES, in which we are alive but not living because life as we know it is no longer considered life. And thus, helping a person who is a Goses die without suffering is not considered a sin but rather a mitzvah.

So, if I am dying, if I am a Goses, allow me to stop eating, don't try to feed me, allow me to stop taking my medication, don't hide them in mushy apple sauce, call in the services of hospice at home, make sure I am not suffering. and God willing, if by then, it is legal, be by my side, and hold my hand, as I take the pill that will allow me to end my suffering. This should be everyone's right and I insist you honor my request.

Roni, Tom, Danielle, Yonatan, don't worry. I'm fine. I'm healthy. But this is exactly the time when I realize we must have these conversations.

In my life, I have had many great teachers whom I have learned from about death -David, Denise, Jayne, Chris, and many others. I have learned valuable lessons through their struggles and their courage and resilience, about what happens when you befriend death and what happens when you don't.

As Jews, we believe there might be an afterlife. And of that, I am certain most days. But of this there is no doubt – there is an after - death. After death, one can either leave a legacy of second guessing, guilt, depression, family turmoil, and blame. I do not wish this after-death legacy to the worst of anyone, so, with your permission I am sharing this letter with my congregation today, I am asking them, begging them, to go home today and have this conversation with their loved ones, I know we all prefer not to, but we have to. We can't take the risk that we will not have the chance to get to the bridge.

I am not willing to take that risk – nor put you children in that situation.

So, here's what you need to know, here is where I draw the line.

I love being your father. I love the people in my life. I love being a rabbi. I love building relationships. This is the tapestry of my life – sewn together by the gift of loving, direct, and meaningful communication.

So, as long as I am the father you know, the one who has a hard time keeping his mouth shut, or his opinions to himself, as long as I am able to crack a joke about anything and at any time, as long as I know who I am, and who you are, I want to fight for my life.

But if I can't discuss an interesting book I read, or movie I saw, if I lose the ability to learn something new or to teach, if I can't understand or remember the story you are telling me, if I can't share your burdens and joys, if I can't tell you I love you....I am telling you now, today, let me go.

Don't feel guilty. Don't argue about it. Don't blame the doctors. Don't blame God. God has given me a life of blessing beyond anything I could have asked for. I am grateful. And I am not afraid.

As the psalm I recite so many times reminds me over and over again, I am not alone.

“Even As I walk through the shadow of the valley of death, I shall not fear, for you are with me”

You are always with me.

With love greater than words, Aba