



End-of-life planning with loved ones can be hard. Here's where to start.

How to make sure you know what they want so you can honor their wishes without having to guess.

By Marin Cogan | @marincogan | Sep 30, 2022, 7:00am EDT



Denis Novikov/Getty Images

Confronting the fact that our loved ones will someday die — that we all will — is one of the hardest parts of being human. Most of us don't like to think about death, and as long as it doesn't feel urgent, it's easy to avoid discussing it with family and friends.

Avoiding the reality, though, is risky. It increases the likelihood that we'll be unprepared to make medical decisions when we need to make them. If we're forced to make choices for

an incapacitated loved one and don't know what they want, we might agonize over whether or not we've made the right choice.

Over the last few years, I've been talking to my parents about death, in part because of my dad's health complications, which include a pneumonia infection that nearly killed him last year. In my family, almost no subject is taboo, including death; often, my dad is the one who brings it up. I know that he has advanced directives and long-term care insurance, and that he doesn't want overly invasive medical treatment, especially if it's just delaying the inevitable. I know that he would prefer a quick death to a drawn-out decline. I also know — as does he — that we can only plan for so much, and that most of us don't ultimately get to choose how we die.

Help inform the future of Vox

We want to get to know you better — and learn what your needs are. [Take Vox's survey here.](#)

Still, there's a lot that can be planned for, and it goes beyond **estate planning and establishing a will** (more on that below). The advances in medicine over the last several decades mean that people have more decisions to make about their end-of-life care than they ever have before. That makes it even more important for individuals to start considering what's most important to them now.

Not everyone feels ready to have these sorts of conversations with their loved ones. But waiting too long can create a different kind of anxiety. So I spoke with four experts — a **doctor specializing in neurology and palliative care**, a **death doula**, a **bioethicist**, and the **leader of an initiative** to help patients and their families discuss end-of-life wishes — about how to start having these crucial conversations.

Consider what you hope to learn from a conversation, but don't be too attached to an outcome

It's helpful to think about what you might want to have come out of an initial conversation. There's plenty to consider when trying to prepare for end-of-life plans, and **lots of online resources** with different checklists. Most involve establishing a will, which lays out where a person wants their assets to go after they've passed away; another option is to establish a trust, which is a legal entity to which a person can assign a trustee to manage assets after they've passed.

But for the first conversation, experts say, you shouldn't focus on any of that. You want to keep it general and get a sense of where the person is at. What you're really doing is gauging whether they're open to talking about what they want from the end of their lives, what kind of planning they've already done, and how you can best support them in the process.

If they seem open to it, you might try to find out whether they've appointed what's sometimes called a **health care proxy**, or a health care agent, or a **durable power of attorney**. Different states and institutions sometimes use different terms to describe this person, but essentially, it's someone who can make medical decisions for a patient if they're incapacitated or unable to speak for themselves. You may also ask whether they've established an advance directive: a document that **lays out a patient's specific wishes** regarding the use of medical procedures and devices like ventilators and feeding tubes.

If you're feeling nervous or worry they might not be ready to discuss these topics with you, understand that it's fine — and probably even preferable — to initiate with open-ended questions and to prioritize being open to your loved one's thoughts over trying to check things off a list.

That might mean letting go of expectations and keeping things in the realm of the general at first. "It's easier to talk about how you want to live your life through the end, as opposed to how you want to die," says Kate DeBartolo, who runs **the Conversation Project**. On the Conversation Project's website, there are **guides** to help people begin those conversations. They focus on introspective prompts and questions, such as, "What does a good day look like to you?" and, "What matters to me through the end of my life is ..."

The idea, DeBartolo says, is to get people thinking about their values, which can help clarify what kind of say they'd like to have in their medical care. "We talk to people who want every measure taken — every trial drug, every curative treatment until the end — and other people who absolutely don't want that," says DeBartolo. There's no right or wrong answer to those questions. "The emphasis is on living well through the end, and what matters to you, not what's the matter with you. Making sure that those conversations don't get too medical or legal right away can be helpful," she says.

Find an opening

There's no perfect way to start this kind of conversation, but there are ways to make it easier, says Jamie Eaddy Chism, director of program development for the **International**

End-of-Life Doula Association. Sometimes, it helps to take the pressure off of loved ones by talking about yourself. “Something like, ‘I’ve been really thinking today about how I want people to remember me, and what I want people to do and say when I’m not here anymore,’” Eaddy Chism says. “Using yourself as an example disarms the person a bit because they don’t immediately have to think about their own situation. Then you can ask a question like: How would you want people to remember you?”

Sometimes, pop culture provides an opening. Look for TV shows, books, or movies that everyone is reading or talking about that deal with death. They can be great conversation starters for families because they aren’t inherently personal but might invite further reflection — the season finale of ***This Is Us***, which aired earlier this year, was a great conversation starter, Eaddy Chism says. There’s also ***Extremis***, a short documentary on Netflix, that explores the tough choices that patients and family members have to make about whether or not to pursue more aggressive medical treatment near the end of their lives, and ***Being Mortal: Medicine and What Matters in the End***, Atul Gawande’s 2014 bestseller about the challenges that advances in medicine have posed to patients, doctors, and caretakers.

Context can be crucial, too. Cultural backgrounds, religious beliefs, prior experiences with the health care system, and even a family’s unique culture and communication style might play a role in how you start a conversation. Some family members might not like the term “death,” but may prefer terms such as “transitions” or “passing away.” “Understanding how language fits into the conversation is important,” Eaddy Chism says, “so you choose your wording in a way that invites people into the conversation.”

Listen — and be aware of your preconceived notions

A good conversation “starts with really listening,” says Alan Carver, who specializes in neurology and palliative care at Memorial Sloan Kettering Cancer Center. “You really want to give the people that you care about the opportunity to share how they feel — and it can be hard to do if you’re doing all the talking.”

Active listening means being open to any kind of response, even if it’s a dismissive one. You can’t force someone to prioritize a conversation if they share different values, and that’s important to listen for, too. “Different people respond very differently,” says Mildred Solomon, president of the Hasting Center, a bioethics research institute. “I know some people who are desperate for their children to hear their preferences, and they feel their children are refusing to talk about anything about the parent’s death,” she says. “On the

other hand, I know people who don't want to anticipate the possible downward trajectories and want to live in the moment. I respect that whole range."

It's important, when talking to elder loved ones, not to try to predetermine how we think they might react. Adult children, for example, tend to think they know their parents well, including their weaknesses, their biases, and their anxieties. But it's key to remember that our parents have their own complex experiences and histories, and no matter how well we think we know them, we still mainly know them in the context of child and parent, meaning there is a lot we might not understand about them. Going in with preconceived notions about how they'll respond makes it harder to hear what someone wants — and makes it more likely that conversations will become unproductive. "Listening requires you to catch your assumptions as they come so you can remain present with the person," Eaddy Chism says. "It's about giving people the freedom to be discovered, and giving yourself permission to discover new things."

What if your loved one reacts poorly or refuses to engage? Apologize and try not to get defensive, says Eaddy Chism. She suggests you try something like: "I'm so sorry that this conversation made you feel like this. I know this was really uncomfortable, and I also know that I want to honor you. Can we try again later?" If they seem calm enough, you might try exploring why they reacted so strongly. Or you can redirect to something that might seem less scary, like: "I know you don't want to talk about whether you want to be buried or cremated, but can we talk about hospital stays? What would you want in a hospital stay?" Still, she says, there's only so much you can do with a family member who doesn't want to engage. "Let's be completely real in this, there are some conversations that we never return to, that people avoid and that we never have again. Don't take that on as your own baggage," she says.

Pace yourself

The benefit to having these conversations with loved ones early is that it ensures that the person's wishes are respected and that decision-making is easier for loved ones. But it doesn't need to happen all at once, nor is it something that families have to handle by themselves. If someone is sick, Carver says, their doctor can and should work closely with patients and families to identify how much information they want about the course of an illness, what their priorities are, and to help with decision-making. Sometimes it means letting a family know they should move a wedding date earlier, or take a planned vacation in the next calendar year rather than indefinitely putting it off.

It's also important to understand that while there may be several decisions to be made, there are resources available to help them do it; it's not going to be easy or practical to try to do everything at once. "These are conversations to have over time," Carver says. "It's not like you sit down once and do it and then it's over. It's really over the course of a lifetime."

For more prompts and resources from the Conversation Project, click [here](#). Check out INELDA's website [here](#).

***Even Better** is here to offer deeply sourced, actionable advice for helping you live a better life. Do you have a question on money and work; friends, family, and community; or personal growth and health? Send us your question by filling out this [form](#). We might turn it into a story.*

Our goal this month

Now is not the time for paywalls. Now is the time to point out what's hidden in plain sight (for instance, the hundreds of election deniers on ballots across the country), clearly explain the answers to voters' questions, and give people the tools they need to be active participants in America's democracy. Reader gifts help keep our well-sourced, research-driven explanatory journalism free for everyone. By the end of September, we're aiming to add 5,000 new financial contributors to our community of Vox supporters. **Will you help us reach our goal by making a gift today?**