

the conversation project

HAVE YOU HAD THE CONVERSATION?

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.

Get the conversation started

Your Conversation Starter Kit

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The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.

We know that no guide and no single conversation can cover all the decisions that you and your family may face. What a conversation can do is provide a shared understanding of what matters most to you and your loved ones. This can make it easier to make decisions when the time comes.

In that spirit, we've created this Starter Kit. It doesn't answer every question, but it will help you get your thoughts together, and then have the conversation with your loved ones.

You can use it whether you are getting ready to tell someone else what you want, or you want to help someone else get ready to share their wishes.

Take your time. This kit is not meant to be completed in one sitting. It's meant to be completed as you need it, throughout many conversations.

The logo for The Conversation Project, featuring the text "the conversation project" in a lowercase, sans-serif font. A stylized, curved line above the word "conversation" suggests a speech bubble or a conversation path.

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Step 1: Get Ready

There are a million reasons to avoid having the conversation. But it's vitally important. And you can do it.

Consider the facts.

60% of people say that making sure their family is not burdened by tough decisions is "extremely important"

56% have not communicated their end-of-life wishes

Source: Survey of Californians by the California Health Foundation (2012)

70% of people say they prefer to die at home

70% die in a hospital, nursing home, or long-term-care facility

Source: Centers for Disease Control (2005)

80% of people say that if seriously ill, they would want to talk to their doctor about end-of-life care

10% have not communicated their end-of-life wishes

Source: Survey of Californians by the California Health Foundation (2012)

82% of people say it's important to put their wishes in writing

23% have actually done it

Source: Survey of Californians by the California Health Foundation (2012)

One conversation can make all the difference.

Remember:

- You don't need to talk about it just yet. Just think about it.
- You can start out by writing a letter—to yourself, a loved one, or a friend.
- Think about having a practice conversation with a friend.
- These conversations may reveal that you and your loved ones disagree. **That's okay.** It's important to simply know this, and to continue talking about it now—not during a medical crisis.

What do you need to think about or do before you feel ready to have the conversation?

Step 2: Get Set

Now, think about what you want for end-of-life care.

What matters to me is ____.

Start by thinking about what's most important to you. What do you value most?
What can you not imagine living without?

Now finish this sentence:

What matters to me at the end of my life is_____.

Sharing your "What matters to me" statement with your loved ones could be a big help down the road. It could help them communicate to your doctor what abilities are most important to you—what's worth pursuing treatment for, and what isn't.

Where I Stand scales

Use the scales below to figure out how you want your end-of-life care to be.

Circle the number that best represents your feelings on the given scenario.

As a patient...

1

2

3

4

5

I only want to know
the basics

I want to know
as much as I can

1

2

3

4

5

Ignorance
is bliss

I want to know how
long I have to live

1

2

3

4

5

I want my doctors to
do what they think
is best

I want to have a say
in every decision

Look at your answers.

What kind of role do you want to play in the decision-making process?

How long do you want to receive medical care?

1

I want to live as long as possible, no matter what

2

3

4

5

Quality of life is more important to me than quantity

1

I'm worried that I won't get enough care

2

3

4

5

I'm worried that I'll get overly aggressive care

1

I wouldn't mind being cared for in a nursing facility if necessary

2

3

4

5

I want to live independently, no matter what

Look at your answers.

What do you notice about the kind of care you want to receive?

How involved do you want your loved ones to be?

1

I want my loved ones to do exactly what I've said, even if it makes them a little uncomfortable

2

3

4

5

I want my loved ones to do what brings them peace, even if it goes against what I've said

1

When the time comes, I want to be alone

2

3

4

5

I want to be surrounded by my loved ones

1

I don't want my loved ones to know everything about my health

2

3

4

5

I am comfortable with those close to me knowing everything about my health

Look at your answers.

What role do you want your loved ones to play? Do you think that your loved ones know what you want, or do you think they have no idea?

What do you feel are the three most important things that you want your friends, family and/or doctors to understand about your wishes for end-of-life care?

1. _____
2. _____
3. _____

Step 3: Go

When you're ready to have the conversation, think about the basics.

Mark all that apply:

Who do you want to talk to? Who do you trust to speak for you?

- | | | |
|---|--|---------------------------------------|
| <input type="checkbox"/> Mom | <input type="checkbox"/> Partner/Spouse | <input type="checkbox"/> Doctor |
| <input type="checkbox"/> Dad | <input type="checkbox"/> Minister/Priest/Rabbi | <input type="checkbox"/> Caregiver |
| <input type="checkbox"/> Child/Children | <input type="checkbox"/> Friend | <input type="checkbox"/> Other: _____ |
-

When would be a good time to talk?

- | | | |
|--|--|---------------------------------------|
| <input type="checkbox"/> The next big holiday | <input type="checkbox"/> Before my next big trip | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> At Sunday dinner | <input type="checkbox"/> Before I get sick again | |
| <input type="checkbox"/> Before my kid goes to college | <input type="checkbox"/> Before the baby arrives | |
-

Where would you feel comfortable talking?

- | | | |
|---|--|---------------------------------------|
| <input type="checkbox"/> At the kitchen table | <input type="checkbox"/> On a walk or hike | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> At a cozy café or restaurant | <input type="checkbox"/> Sitting in a garden or park | |
| <input type="checkbox"/> On a long drive | <input type="checkbox"/> At my place of worship | |
-

What do you want to be sure to say?

If you wrote down your three most important things at the end of Step 2, you can use those here.

How to start

Here are some things you could say to break the ice:

- “I need your help with something.”
- Remember how someone in the family died—was it a “good” death or a “hard” death? How will this be different?
“I was thinking about what happened to _____, and it made me realize...”
- “Even though I’m okay right now, I’m worried that _____, and I want to be prepared.”
- “I need to think about the future. Will you help me?”
- “I just answered some questions about how I want the end of my life to be. I’d like to talk about my answers with you.”

What to talk about

- When you think about the last phase of your life, what’s most important to you? How would you like this phase to be?
- Do you have any particular concerns about your health? About the last phase of your life?
- Who do you want (or not want) to be involved in your care? Who would you like to make decisions on your behalf if you’re not able to? *(This person is your health care proxy.)*
- Would you prefer to be actively involved in decisions about your care? Or would you rather have your doctors do what they think is best?
- Are there any disagreements or family tensions that you’re concerned about?
- Are there circumstances that you would consider worse than death? *(Long-term need of a breathing machine or feeding tube, not being able to recognize your loved ones)*
- Are there important milestones you’d like to meet if possible? *(The birth of your grandchild, your 80th birthday)*

- Where do you want (or not want) to receive care? (*Home, nursing facility, hospital*)
 - What kinds of aggressive treatment would you want (or not want)? (*Resuscitation if your heart stops, breathing machine, feeding tube*)
 - When would it be okay to shift from a focus on curative care to a focus on comfort care alone?
 - What affairs do you need to get in order, or talk to your loved ones about? (*Personal finances, property, relationships*)
-

This list doesn't cover everything you may need to think about, but it's a good place to start.

Don't feel like you have to cover all of these questions in a single conversation. Start wherever you want, and feel free to skip around.

Talk to your doctor, nurse, or other health care provider if you'd like more guidance.

Remember:

- Be patient. Some people may need a little more time to think.
- You don't have to steer the conversation; just let it happen.
- Don't judge. A "good" death means different things to different people.
- Nothing is set in stone. You and your loved ones can always change your minds as circumstances shift.
- Every attempt at the conversation is valuable.
- This is the first of many conversations—you don't have to cover everyone or everything right now.

Now, just go for it!

Each conversation will empower you and your loved ones. You are getting ready to help each other live and die in a way that you choose.

Step 4: Keep Going

Congratulations!

Now that you have had the conversation, the next steps are putting it on paper and continuing to talk. You can use these legal and medical documents to write down your wishes so they can be honored when the time comes.

- **Advance Care Planning:** the *process* of thinking about your preferences for care at the end of life—exactly what you have been working on here.
- **Advance Directive:** the *document* that describes your preferences for care in case you are unable to make health care decisions on your own. It is also known as a **living will**.
- **Health Care Proxy:** identifies your health care agent (often called a “proxy”), the person you trust to act on your behalf if you are unable to make health care decisions or communicate your wishes. In some states, this is called the Durable Power of Attorney for Health Care. This is probably the most important document. Make sure you have many conversations with your proxy.

You can find more information about these documents from the link in the “Keep Going” section of the website Starter Kit at www.TheConversationProject.org.

Remember, this was the first of many conversations.

You can use the questions below to collect your thoughts about how your first talk went, and then look back at them when you prepare for future conversations.

Is there something you need to clarify that you feel was misunderstood or misinterpreted?

Who do you want to talk to next time? What other family members might you want to talk to so that everyone's on the same page?

**How did this conversation make you feel? What do you want to remember?
What do you want your loved ones to remember?**

What do you want to make sure to ask or talk about next time?

We hope you will share this Starter Kit with others. You have helped us get one conversation closer to our goal: that everyone's end-of-life wishes are expressed and respected.