



Your Conversation Starter Kit

When it comes to end-of-life care, talking matters.



the conversation project



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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.

NOTE If you are completing this document on a computer, first save it to your desktop with a name you can easily find again. Then open your saved document and type in your answers. (Otherwise, what you type will not be saved.) Completing it on your computer will create a digital document that you can easily share with others.

NAME

DATE

HOW TO USE THE STARTER KIT

This Starter Kit doesn't answer every question, but it will help you get your thoughts together, and then have a 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.

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Why talking matters

Sharing your wishes for end-of-life care can bring you closer to the people you love. It's critically important. And you can do it. **Consider the facts:**

92% of people say that talking with their loved ones about end-of-life care is important.

32% have actually done so.

Source: The Conversation Project National Survey (2018)

21% of people say they haven't had the conversation because they don't want to upset their loved ones.

53% say they'd be relieved if a loved one started the conversation.

95% say they are willing or want to talk about their end-of-life wishes.

Source: The Conversation Project National Survey (2018)

80% of people say that if seriously ill, they would want to talk to their doctor about wishes for medical treatment toward the end of their life.

18% report having had this conversation with their doctor.

Source: Survey of Californians by the California HealthCare Foundation (2012) and Kaiser Family Foundation Serious Illness in Late Life Survey (2017)

97% of people say it's important to put their wishes in writing.

37% have actually done it.

Source: Kaiser Family Foundation Serious Illness in Late Life Survey (2017)

A conversation can make all the difference.

Step 1 Get Ready

You will have many questions as you get ready for the conversation. **Here are two to help you get started:**



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



Do you have any particular concerns that you want to be sure to talk about? (For example, making sure finances are in order; or making sure a particular family member is taken care of; or any fear or mistrust you may have in the health care system.)

REMEMBER:

- You don't need to have the conversation just yet. It's okay to just start thinking about it.
- You can start out by writing a letter—to yourself, a loved one, or a friend.
- You might consider having a practice conversation with a friend.
- Having the conversation 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.
- Having the conversation isn't just a one-time thing. It's the first in a series of conversations over time.

Step 2 Get Set

What's most important to you as you think about how you want to live at the end of your life? What do you value most? **Thinking about this will help you get ready to have the conversation.**

? Now finish this sentence: **What matters to me through the end of life is...**

(For example, being able to recognize my children; being in the hospital receiving treatments; being able to say goodbye to the ones I love.)

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 health care team 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. Select the number that best represents your feelings on the given scenario.

As a patient, I'd like to know...

- 1 2 3 4 5
- Only the basics about my condition and my treatment
- All the details about my condition and my treatment

As I receive care, I would like...

- 1 2 3 4 5
- My health care team to do what they think is best
- To have a say in every health care decision

If I had a terminal illness, I would prefer to...

- 1 2 3 4 5

Not know how quickly
it is progressing

Know my doctor's
best estimation for
how long I have to live

? Look at your answers.

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

How much medical treatment do you want to try?

- 1 2 3 4 5

I want to try every
treatment available,
no matter how
uncomfortable I become

Quality of life is
more important to
me than quantity

What are your concerns about medical treatments?

- 1 2 3 4 5

I worry that I won't
get enough care

I worry that I'll get
too much care

What are your preferences about where you want to be?

- 1 2 3 4 5

I want to spend
my last days in a
health care facility

I want to spend my
last days at home

? 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

2

3

4

5

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

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

When it comes to your privacy...

1

2

3

4

5

When the time comes, I want to be alone

I want to be surrounded by my loved ones

When it comes to sharing information about my illness with others...

1

2

3

4

5

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

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 health care team to understand about your wishes and preferences 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 now?

- | | |
|--|---|
| <input type="checkbox"/> Parent(s) | <input type="checkbox"/> Faith leader (Minister, Priest, Rabbi, Imam, etc.) |
| <input type="checkbox"/> Chosen family member(s) | <input type="checkbox"/> Trusted friend |
| <input type="checkbox"/> Child/Children | <input type="checkbox"/> Health care provider |
| <input type="checkbox"/> Spouse/Partner(s) | <input type="checkbox"/> Caregiver |
| <input type="checkbox"/> Sibling | <input type="checkbox"/> Other: <input type="text"/> |

? WHEN would be a good time to talk?

- | | |
|--|--|
| <input type="checkbox"/> The next holiday | <input type="checkbox"/> Before the baby arrives |
| <input type="checkbox"/> Before my child goes to college | <input type="checkbox"/> The next time I visit with family |
| <input type="checkbox"/> Before my next trip | <input type="checkbox"/> On a video or phone call |
| <input type="checkbox"/> Before I get sick again | <input type="checkbox"/> Other: <input type="text"/> |

? WHERE would you feel comfortable talking?

- | | |
|---|--|
| <input type="checkbox"/> At the kitchen table | <input type="checkbox"/> Sitting in a park |
| <input type="checkbox"/> At a favorite restaurant | <input type="checkbox"/> At my place of worship |
| <input type="checkbox"/> In the car | <input type="checkbox"/> Other: <input type="text"/> |
| <input type="checkbox"/> On a walk | |

? 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 ways you could 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 yours 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 want you to see my answers. And I'm wondering what your answers would be."

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?
- What affairs do you need to get in order, or talk to your loved ones about? *(Personal finances, property, relationships)*
- 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.)*
- Are there any disagreements or family tensions that you're concerned about?
- Are there important milestones you'd like to be there for, if possible? *(The birth of your grandchild, your 80th birthday.)*
- Where do you want (or not want) to receive care? *(Home, nursing facility, hospital)*

- Are there kinds of treatment you would want (or not want)?
(Resuscitation attempts if your heart stops, breathing machine, feeding tube)
- When would it be ok shift from a focus on care that cures to a focus on care that comforts?
- Anything else: _____

This list doesn't cover everything you may need to think about, but it's a good place to start. Talk to your health care team if you'd like them to suggest more questions to talk about.

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 change.
- Every attempt at the conversation is valuable. Keep trying.
- This is the first of many conversations—you don't have to cover everyone or everything right now.
- Try emailing the guide, or your thoughts, so someone at least has access to it if needed.

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! You have had “the conversation” — hopefully, the first of many. You can use the following questions to collect your thoughts about how your first talk went, and to think about what you’d like to talk about in 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? Are there people who should hear things at the same time (like siblings who tend to disagree)?

? 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?

Now that you have had the conversation, you're ready to think about **completing two important legal documents** to make sure your wishes are clearly stated — and respected when the time comes.

□ Choose a Health Care Proxy

A health care proxy (also known as a **durable power of attorney for health care**) is a legal document in which you appoint another person (a proxy or agent) to express your wishes and make health care decisions for you if you cannot speak for yourself. Choose someone who knows your wishes well — a person you trust to speak for you if you're not able to speak for yourself.

□ Complete an Advance Directive

An Advance Directive, also known as a **Living Will**, is a legal document in which you state your wishes regarding end-of-life medical care — including the types of treatments you do and do not want — in case you are no longer able to make decisions or communicate your wishes. (Note: This is different from your Last Will and Testament, which is used to distribute assets.)

Every state has its own Advance Directive forms.

See this website for more information: <https://www.nhpco.org/patients-and-caregivers/advance-care-planning/advance-directives/downloading-your-states-advance-directive/>

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