

Your Conversation Starter Kit

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

Institute for Healthcare Improvement



CREATED BY THE CONVERSATION PROJECT AND THE INSTITUTE FOR HEALTHCARE IMPROVEMENT

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.

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 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.

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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**:

90% of people say that talking with their loved ones about end-of-life care is important.

27% have actually done so.

Source: The Conversation Project National Survey (2013)

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 HealthCare Foundation (2012)

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.

7% report having had this conversation with their doctor.

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

One 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.)

REMEMBER:

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- 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.**

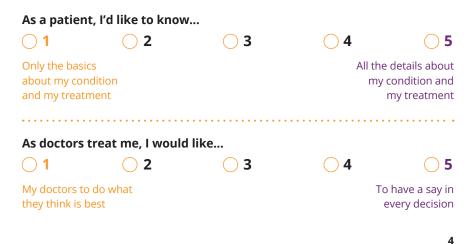


Now finish this sentence: What matters to me at the end of life is... (For example, being able to recognize my children; being in the hospital with excellent nursing care; being able to say goodbye to the ones I love.)

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



lf l had a te	rminal illness, l v	vould prefer to		
◯ 1	2	3	4	05
Not know how it is progressi		estim	v doctors best ation for how g I have to live	
	t your answers. ind of role do you	want to have in th	e decision-making	process?
How long d	o you want to red	ceive medical car	e?	
1 Indefinitely, n	2 o matter	3	4	5 uality of life is
how uncomfo treatments ar				important to than quantity
What are ye	our concerns abo	ut treatment?	-	_
1 2 I'm worried that I won't get enough care		() 3		ed that I'll get gressive care
What are ye	our preferences a	about where you	want to be?	
◯ 1	2	3	4	5
	nd spending my health care facility			t to spend my days at home
	t your answers. o you notice abou	t the kind of care y	you want to receive	2?

5

How involved do you want your loved ones to be?				
◯ 1	2	3	◯ 4	5
l want my loved one do exactly what l've even if it makes the little uncomfortable	said, m a	what bring	ed ones to do s them peace, t goes against what l've said	
When it comes t	o your priv	vacy		
◯ 1	2	<u> </u>	◯ 4	5
When the time com I want to be alone		e surrounded ny loved ones		
When it comes t	o sharing i	nformation		
◯ 1	<u>2</u>	3	◯ 4	5
I don't want my loved ones to know everything about my health				nfortable with o me knowing out 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 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?				
 Mom Dad Child/Children Partner/Spouse Sister/Brother 	 Faith leader (Minister, Priest, Rabbi, Imam, etc.) Friend Doctor Caregiver Other: 			
 WHEN would be a good time to ta The next holiday Before my child goes to college Before my next trip Before I get sick again 	 alk? Before the baby arrives The next time I visit my parents/ adult children At the next family gathering Other: 			
WHERE would you feel comfortable talking?				
At the kitchen table	Sitting in a park			

- At the kitchen table
- At a favorite restaurant
- At my place of worship

Other:

- In the car
- 🗌 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.*)

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 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 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?

This list doesn't cover everything you may need to think about, but it's a good place to start. Talk to your doctor or nurse 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.
- 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, here are some legal and medical documents you should know about. Use them to record your wishes so they can be honored when the time comes.

Advance Care Planning (ACP) The process of planning for your future care—exactly what you have been working on here.

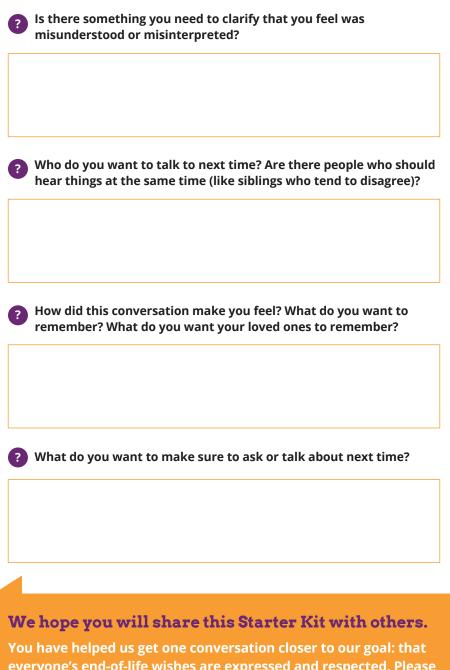
Advance Directive (AD) A document that describes your wishes.

Health Care Proxy (HCP) 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.

Living Will

Specifies which medical treatments you want or don't want at the end of your life, or if you are no longer able to make decisions on your own (e.g., in a coma). 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 on the following page to collect your thoughts about how your first talk went, and then look back to them when you prepare for future conversations.



everyone's end-of-life wishes are expressed and respected. Please send us your feedback or request additional information at conversationproject@ihi.org.