

Your Conversation Starter Kit

Yale Health is dedicated to helping people talk about their wishes for end-of-life care.

Your healthcare provider would like you to look at this information to start the conversation. The packet contains worksheets for you to use and 2 documents for you to complete and return to Yale Health Member Services.

If you have questions or concerns as you review this information and talk to your family about it, or just need help, please contact Care Management, 203-436-5791. And remember, we are here to support you with this process.

Important note

When you complete:

- ◆ *Appointment of Health Care Representative and*
- ◆ *Treatment Preferences and Living Will*

Keep copies for yourself (and your healthcare representative) and return a copy of each document to Yale Health Member Services.

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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Step 1: Get Ready

There are a million reasons to avoid having the conversation. But it's critically 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 HealthCare 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

7% report having had an end-of-life 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 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 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?

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How long do you want to receive medical care?

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| I want to live as long as possible, no matter what | | | | Quality of life is more important to me than quantity |
| 1 | 2 | 3 | 4 | 5 |
| I'm worried that I won't get enough care | | | | I'm worried that I'll get overly aggressive care |
| 1 | 2 | 3 | 4 | 5 |
| I wouldn't mind being cared for in a nursing facility | | | | Living independently is a huge priority for me |

Look at your answers.

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

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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 a little uncomfortable at first | | | | I want my loved ones to do what brings them peace, even if it goes against what I've said |

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|--|
| When the time comes, I want to be alone | | | | I want to be surrounded by my loved ones |

| 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 |

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?

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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.

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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?
- 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. Talk to your doctor or nurse if you're looking for more end-of-life care questions.

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, 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.

- **Health Care Planning (ACP):** the process of thinking about your wishes—exactly what you have been working on here.
- **Health Care Representative:** 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.
- **Treatment Preferences and 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).

When you have completed these forms return them to Member Services so they can become part of your medical record.

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 to them when you prepare for future conversations.

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

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Who do you want to talk to next time? Are there people who should hear things at the same time (like siblings who disagree about everything)?

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

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

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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.

MEDICAL RECORD NUMBER:

NAME

BIRTH DATE:

Yale New Haven Health

**Appointment of
Health Care Representative**

I understand that, as a competent adult, I have the right to make decisions about my health care. However, there may come a time when I am unable to make my own health care decisions due to illness or incapacity. In these circumstances, those caring for me will need direction from someone who knows my values and health care wishes. By signing this appointment of health care representative, I give the person named below legal authority to make health care decisions on my behalf in such case or at such time.

I appoint – Name _____

Address _____

Phone number _____

Cell phone number _____

to be my health care representative. If my attending physician determines that I am unable to understand and appreciate the nature and consequences of health care decisions and to reach and communicate an informed decision regarding treatment, **my health care representative is authorized to (1) accept or refuse any treatment, service or procedure used to diagnose or treat my physical or mental condition, except as otherwise provided by law, (2) make the decision to provide, withhold or withdraw life support systems and (3) to receive any health care information about me that might be necessary to make these decisions, including information related to my mental health or HIV status.**

I direct my health care representative to make decisions on my behalf in accordance with my wishes as stated in my living will, or as otherwise known to my health care representative. In the event my wishes are not clear or a situation arises that I did not anticipate, my health care representative may make a decision in my best interests, based upon what is known of my wishes.

If this person is unwilling or unable to serve as my health care representative, I appoint:

Name _____

Address _____

Phone number _____

Cell phone number _____

to be my alternative health care representative.

This request is made, after careful reflection, while I am of sound mind.

Patient's Printed Name

Patient's Signature

Date



MEDICAL RECORD NUMBER:

NAME

BIRTH DATE:

Yale New Haven Health

Treatment Preferences and Living Will

I am providing the information below to help my physicians and care team understand my care choices, particularly to help them understand my wishes relating to end-of-life care.

- I already have a Living will or Advance Directive that I wish to be read in conjunction with this document.
- I do not already have a Living Will or other Advance Directive, and would like Part 2 of this document to serve as my Living Will, and be read in conjunction with this document.

Part 1. Information About My Treatment Preferences

If I am no longer able to make my own health decisions, the information I have provided below outlines my goals and preferences for care at the end of life.

Future health situations:

- When you think about your health and health situations you may experience in the future, how do you feel?
 - Life is always worth living no matter what type of serious illness, disability, or pain I may be experiencing.
 - There may be some health situations that would make my life not worth living.
- How do you balance quality of life with medical care? If you had serious illness, what would be important to you?
 - I want medical treatments to try to live as long as possible. I would not want to stop treatment even if I were in pain, could not feed or care for myself, or needed machines to live.
 - I want to try treatments for a period of time, but I don't want to suffer. If after a period of time the treatments do not help or I am suffering, I want to stop.
 - I want to focus on my quality of life and being comfortable, even if it means having a shorter life.

In the event of serious illness:

- If I am terminally ill or so ill that I am unlikely to get better
 - I would not want to receive treatment to try to keep me alive
 - I would want to receive treatment to try to keep me alive
- If my doctors decide that I am likely to die within a short period of time, and life support treatment would only delay the moment of my death:
 - I would not want to receive treatment to try to keep me alive
 - I do want to receive treatment to try to keep me alive
- If my doctors decide that I am in a coma from which I am not expected to wake up or recover, and life support treatment will only delay the moment of my death:
 - I would not want to receive treatment to try to keep me alive
 - I would want to receive treatment to try to keep me alive
- If my doctors decide that I have permanent and severe brain damage, and I am not expected to get better, and life support treatment would only delay the moment of my death:
 - I would not want to receive treatment to try to keep me alive
 - I would want to receive treatment to try to keep me alive



