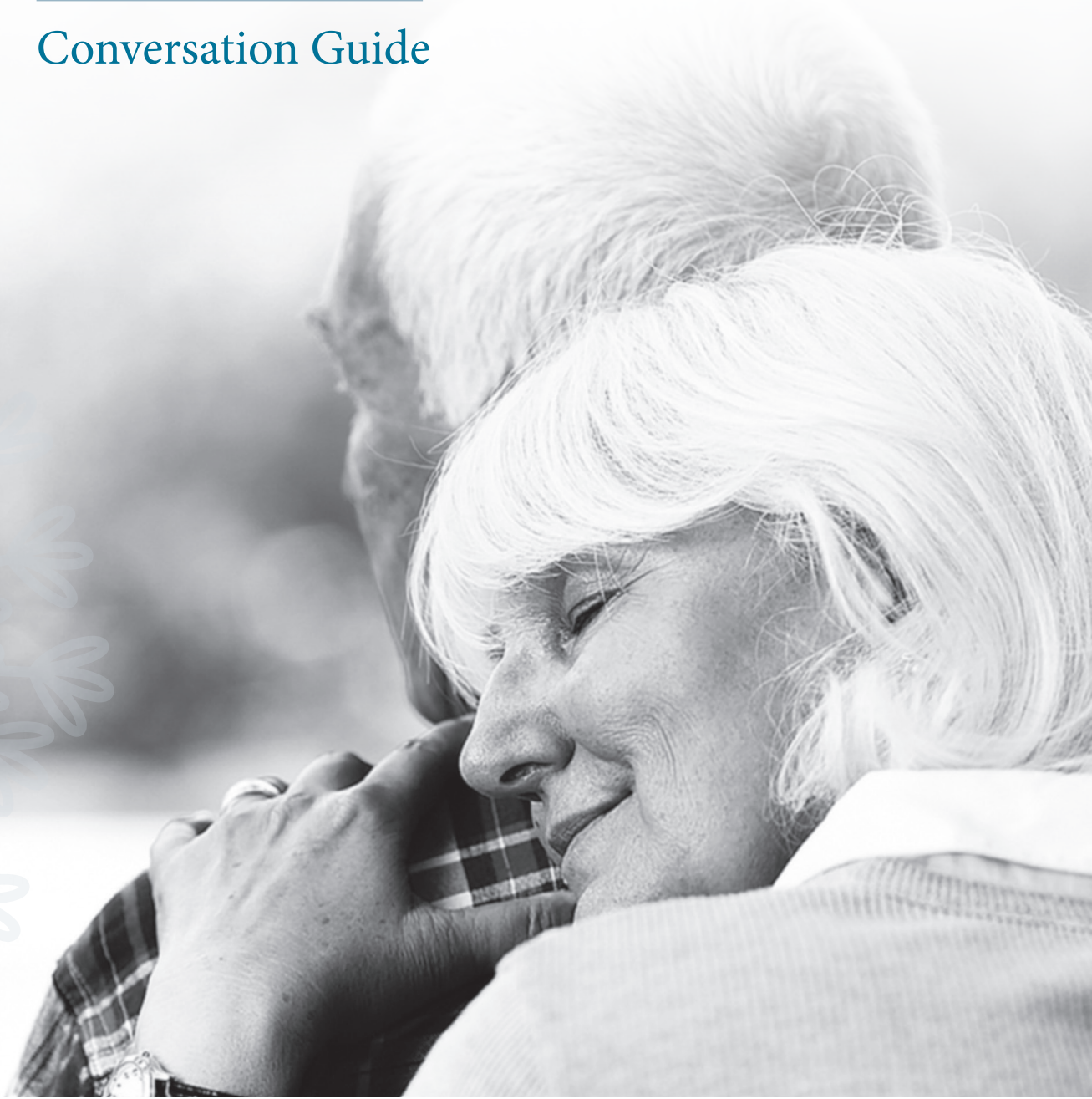




Voice *your* Choice

Conversation Guide



*Hospice of Southwest Ohio and CareBridge
are dedicated to helping people talk about
their wishes for end-of-life care.*



Hospice
of Southwest Ohio
A Servant Leadership Organization



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Voice *your* Choice

Voice *your* Choice is an important and timely initiative focused on helping individuals plan for end-of-life. Death and dying are a natural part of life's journey. The more we as a society discuss this universal stage of life, the better educated and empowered we will be to navigate our own final days and those of our loved ones. When we have these conversations outside the context of imminent death, we can more thoroughly understand our options allowing us to clearly communicate our wishes.

Talking about end-of-life issues can be difficult for anyone. One way to approach the subject is to discuss why you have decided to think about these issues. Sometimes sharing your personal concerns, values, spiritual beliefs or views about what makes life worth living can be as helpful as talking about specific treatments and circumstances. Voicing your Choice with your loved ones will also help them ensure your wishes are followed.

We want you to be the expert on your end-of-life wishes and those of your loved ones. We want you to Voice *your* Choice.

your Choice

*It's not just medical decisions at end-of-life:
we each have personal preferences.
This often needs time and thought.*

Three points to keep in mind:

Thinking about your end-of-life can be exhausting and emotional.

Thinking through what's important often means having 'Aha!' moments about yourself.

Determining personal choices at end of life can give you and yours peace of mind.

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)



The process of considering options, making decisions and communicating with family and physician emerges as the most potent factor in a peaceful death. As you consider how your values and beliefs might influence your decisions for the future, this guide will help you voice your choices.

Perhaps you already understand the importance of completing an advance directive. Regardless of age or health status, none of us know when a future event might leave us unable to speak for ourselves. If you become unable to make or communicate health care decisions, talking with your loved ones, appointing a representative and preparing a written record of your wishes will be invaluable.

the Basics

There is no question that western medicine has made amazing advances in recent decades, but for people whose illness cannot be cured, this medical progress presents a modern dilemma.

Only you can decide how much treatment is enough, where the line is between therapeutic and futile treatment, and the most difficult decision for many—how long your life should be prolonged after it has ceased to be “life” as you define it. These questions don’t have any easy answers.

Advance Directive is a generic term for documents that typically include a written statement of preferences and durable power of attorney for health care. These documents allow you to provide instructions relating to your future health care, such as when you wish to receive treatment or when you wish to stop or refuse life-sustaining treatments.

The part often referred to as the **living will** is a place for you to specify what kinds of treatments and care you would or would not want if you were unable to speak for yourself. A living will is a good tool to use for writing down your wishes. The most important piece is the conversation you have with your loved ones.

The other part, often called a **durable power of attorney for health care**, allows you to appoint someone to act on your behalf in matters concerning your health care when you are not able to decide for yourself due to illness or incapacitation. This document covers health issues only; it does not include finances, estate or business concerns. T

Your advance directive is very helpful to your physician, family, and your health care agent when they must make choices on your behalf. It is important to understand that these documents alone do not guarantee enforcement. The more you can do to prevent conflicting opinions about your wishes, the greater the likelihood those wishes will be followed.



At a Glance

A **living will** is a document that lets people state their wishes for end-of-life medical care, in case they become unable to communicate their decisions.

A **durable power of attorney for health care**, also known as a **health care proxy**, allows you to name a person to direct your health care when you cannot do so. Choose who will follow your instructions and insist that your end-of-life wishes be respected.

Together these documents make up your advance directive.

Living Will + Durable Power of Attorney = Advance Directive

It is not enough just to have an advance directive and durable power of attorney for health care. Discuss your choices with your doctor and your family.

Who Will You Appoint?

In your durable power of attorney for health care, you appoint a health care agent to carry out your wishes. This legal document gives the person you appoint the right to direct your health care if you are unable to make or communicate decisions. Your agent can be anyone you choose who is at least 18 years of age—your next of kin or another family member, or someone outside the family. To prevent conflicts of interest, avoid choosing your primary care physician or any other health care practitioner involved in your care.

You will also want to name an alternative agent, and cover the same questions with that person. The alternative agent will step in if your first choice is unavailable.

As you consider potential agents, ask yourself, “Are they assertive? Do they live nearby? Are they comfortable talking about death? Will they respect my values?” In any case, your family should know and understand how you have instructed your agent and whom you have appointed as your agent. Whatever you say, make sure to explain things in detail.

Discuss Your Wishes Early

Discuss your end-of-life wishes with your family and loved ones now — before a crisis hits. This is essential to ensuring that your end-of-life care wishes are met. You may want to use the following occasions as opportunities for having this conversation:

- Around significant life events, such as marriage, birth of a child, death of a loved one, retirement, birthdays, anniversaries, and college graduation;
- While you are drawing up your will or doing other estate planning;
- When major illness requires that you or a family member move out of your home and into a retirement community, nursing home, or other long-term care facility; or
- During holiday gatherings, such as Thanksgiving, when family members are present.

Have regular discussions about your views on end-of-life, since they may change over time. And don’t forget to discuss your end-of-life wishes with your doctor.



your Wishes



As you gather courage to think through personal decisions regarding your end-of-life, it can help to acknowledge it is a fearful topic, and that it's often hard to know where to start. You don't need to have the conversation just yet. It's okay to just start thinking about it. You can start 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. Below are some items you'll want to consider.

What worries you?

Sometimes the best starting point for end-of-life contemplations is to think about what worries you. For others, the starting point is considering who is important to you.

What's important?

On a personal level, what's important can include relationships to (try to) mend, for others knowing the most common regrets can offer a chance to live life out without any.

What to consider?

Often, it's hard to know what you should consider, when planning what you'd like to have in place before the end. For some its repairing relationships, for others it's paperwork.

How much do I want to know?

How much do you already know about your health? Different health conditions, and those with more than one health condition, can well have several decision or crisis points along their journey.

You are the boss

Remember – your end of life wishes can be changed as often as you want, as long as you're considered 'competent and capable' of consenting to treatment. While it may seem simple and obvious to determine whether you're of sound mind, with certain medical conditions your competence can change from hour to hour.

Why am I crying?

Sometimes these explorations can bring on bouts of grief. This is normal, although often exhausting and overwhelming.

How will I be remembered? Is it important to you to think about how you'll be remembered?

Sometimes memories are preserved in loving conversations, sometimes it's memorabilia, and sometimes it's a legacy effort with more than one person in your family or communities. In this digital age, there are many services to help you preserve or create your own memories of life.



Consider the facts.

90% of people say that if seriously ill, they would want to talk to their doctor about wishes.

7% report having had this conversation with their doctor.

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)



Voice your Choice

Experts agree that the time to discuss your views about end-of-life care, and to learn about the end-of-life options available, is before a life-threatening illness occurs or a crisis hits. This greatly reduces the stress of making decisions about end-of-life care under duress. By preparing in advance, you can avoid some of the uncertainty and anxiety associated with not knowing what your loved ones want. Instead, you can make an educated decision that includes the advice and input of loved ones.

RESOURCES

Values Worksheet

Questions to Consider Worksheet

How to Start the Conversation Handout

Talking to Your Doctor/Caregiver

Legal Forms

- Living Will
- Durable Power of Attorney

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.)

Step
1

What's important

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...

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.

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

☐ 1

Only the basics about my condition and my treatment

☐ 2

☐ 3

☐ 4

☐ 5

All the details about my condition and my treatment

As doctors treat me, I would like...

☐ 1

My doctors to do what they think is best

☐ 2

☐ 3

☐ 4

☐ 5

To have a say in every decision

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

☐ 1

Not know how quickly it is progressing

☐ 2

☐ 3

☐ 4

☐ 5

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 play in the decision-making process?

How long do you want to receive medical care?

☐ 1

Indefinitely, no matter how uncomfortable treatments are

☐ 2

☐ 3

☐ 4

☐ 5

Quality of life is more important to me than quantity

What are your concerns about treatment?

☐ 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

What are your preferences about where you want to be?

☐ 1

I wouldn't mind spending my last days in a hospital

☐ 2

☐ 3

☐ 4

☐ 5

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

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

When it comes to your privacy...

☐ 1

When the time comes, I want to be alone

☐ 2

☐ 3

☐ 4

☐ 5

I want to be surrounded by my loved ones

When it comes to sharing information...

- ☐ 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 2
Get ready

When you're ready to have the conversation, think about the basics.
Mark all that apply:

Who do you want to talk to?

- ☐ Mom
- ☐ Sister/Brother
- ☐ Doctor
- ☐ Dad
- ☐ Faith leader (Minister,
- ☐ Caregiver
- ☐ Child/Children
- ☐ Priest, Rabbi, Imam, etc.)
- ☐ Other:
- ☐ Partner/Spouse
- ☐ Friend
-

When would be a good time to talk?

- ☐ The next big holiday
- ☐ On a walk
- ☐ Other:
- ☐ Before my child goes to college
- ☐ Sitting in a park
-
- ☐ Before my next trip
- ☐ 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 ways you could break the ice:

- "I need your help with something."
- "Remember how someone in the family died—was it peaceful or difficult and restless? 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're looking for more end-of-life care questions.

the
Conversation

Having the conversation, “before the crisis” is not only much easier, it is much more valuable. If you can begin to talk about the end of life while people are still healthy, you will have made a significant contribution to your family, and you will discover important information for yourself. Understanding family includes understanding hopes and fears around illness and dying. Conversations before the crisis help a family cope with inevitable loss; preparing for death helps those who live on most of all.

Talk is the single most important thing that family and friends can do to prepare for the end of life of someone they love. Always difficult, the end of life can be amazingly rich. Learning, insight and love are possible to the last breath, and beyond. Talking about this time make a rich ending more likely.

Read our *How to Start the Conversation Handout* with helpful steps



We can't control everything about our death. But if we communicate effectively, we make it more likely that our wishes for the end-of-life will be known and respected.



Discuss Your Wishes Early

Discuss your end-of-life wishes with your family and loved ones now — before a crisis hits. This is essential to ensuring that your end-of-life care wishes are met. You may want to use the following occasions as opportunities for having this conversation:

- Around significant life events, such as marriage, birth of a child, death of a loved one, retirement, birthdays, anniversaries, and college graduation;
- While you are drawing up your will or doing other estate planning;
- When major illness requires that you or a family member move out of your home and into a retirement community, nursing home, or other long-term care facility; or
- During holiday gatherings, such as Thanksgiving, when family members are present.
- When a friend or another family member is facing illness or an end-of-life situation

Have regular discussions about your views on end-of-life, since they may change over time. And don't forget to discuss your end-of-life wishes with your doctor.



GET STARTED

Contact Hospice of Southwest Ohio Foundation at
(513) 770-0820
www.hswo.org

Join our Voice your Choice Classes to learn how to plan and discuss your choices.
Information about classes and how to sign up are available on our website.



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