







# What Matters to Me

## A Workbook for People with Serious Illness

**NAME** _____

**DATE** _____

ARIADNE LABS

the **conversation** project

**This document does not seek to provide legal advice.**

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## This Workbook is designed to help people with a serious illness get ready to talk to their health care team (doctor, nurse, social worker, etc.) about what is most important to them.

This Workbook is NOT about making specific medical decisions. It's about thinking about what matters most to you — and sharing your goals and preferences with your health care team. Then together you can choose the kind of care that is right for you.

### DO THIS

- **Do the Workbook by yourself or with someone else.** Choose the way that works best for you.
- **Take your time.** You don't need to complete the Workbook all in one sitting. It's okay to skip questions — or come back to them later.
- **Share it with your health care team.** Bring the filled-in Workbook to your next appointment so you can talk over your answers and questions.
- **Be prepared.** Even if you don't have an appointment soon, or you won't be seeing a family member soon, doing the Workbook will help YOU be clear about what matters to you.

### TWO WAYS TO SHARE

1. If you are doing the Workbook on your computer, be sure to save it to your computer before typing in your answers. Otherwise, what you type will not be saved.
2. Many people find it easier to write their answers in the printed document, then make copies of the filled-in document to share with others.

### FOR CAREGIVERS

If you are helping someone else complete this Workbook, here are some things to keep in mind:

- **Explain why this will help.** You might say, "I want to make sure we know what's most important to you, so we can have a more useful conversation with your health care team."
- **Take it in small pieces.** It's always okay to skip a question. You can even let the person pick the questions that appeal to them. If they get tired or overwhelmed, take a break and come back to it later.
- **If the person is prone to confusion, keep the number of helpers small.** Having many people present can increase pressure on the seriously ill person. Have one or two people assist in completing the Workbook, then share it with others.

# My Health

**What is your understanding of your current health situation?**

**How much information about what might be ahead with your illness would you like from your health care team?**

# About Me

**MY GOOD DAYS** • What does a good day look like for you?

**Here are some things I like to do on a good day:**

EXAMPLES

*Get up and dressed • Play with my cat • Make a phone call • Watch TV • Have coffee with a friend*

**MY HARD DAYS** • What does a hard day look like for you?

**These are the toughest things for me to deal with on a hard day:**

EXAMPLES

*Can't get out of bed • In a lot of discomfort • No appetite • Don't feel like talking to anyone*

**MY GOALS** • What are your most important goals if your health situation worsens?

**These are some things I would like to be able to do in the future:**

EXAMPLES

*Take my dog for a walk • Attend my child's wedding • Feel well enough to go to church • Talk to my grandchildren when they come to visit*

# My Care

Everyone has their own preferences about the kind of care they do and don't want to receive. Use the scales below to think about what you want at this time.
*Note: These scales represent a range of feelings; there are no right or wrong answers.*

- **Answer where you are right now.** For each scale below, think about what you want now. Revisit your answers in the future, as they may change over time.
- **Use your answers as conversation starters.** Your answers can be a good starting point to talk with others about why you answered the way you did.

**As a patient, I'd like to know…**

Only the basics about my condition and my treatment — All the details about my condition and my treatment

**When there is a medical decision to be made, I would like…**

My health care team to make all the decisions — To have a say in decisions whenever possible

**What are your concerns about medical treatments?**

I worry that I won't get enough care — I worry that I'll get too much care

**How much medical treatment are you willing to go through for the possibility of gaining more time?**

Nothing: I don't want any more medical treatments — Everything: I want to try any medical treatments possible

**If your health situation worsens, where do you want to be?**

I strongly prefer to be in a health care facility — I strongly prefer to be at home, if possible

**When it comes to sharing information about my illness with others…**

I don't want those close to me to know all the details — I do want those close to me to know all the details

## MY FEARS AND WORRIES • What are your biggest fears and worries about the future with your health?

**These are the main things I worry about:**

EXAMPLES

*I don't want to be in pain • I'm worried that I won't be able to get the care I want • I don't want to feel stuck someplace where no one will visit me • I worry about the cost of my care • What if I need more care than my caregivers can provide?*

## MY STRENGTHS • As you think about the future with your illness, what gives you strength?

**These are my main sources of strength in difficult times:**

EXAMPLES

*My friends • My family • My faith • My garden • Myself ("I just do it")*

## MY ABILITIES • What abilities are so critical to your life that you can't imagine living without them?

**I want to keep going as long as I can…**

EXAMPLES

*As long as I can at least sit up on the bed and occasionally talk to my grandchildren • As long as I can eat ice cream and watch the football game on TV • As long as I can recognize my loved ones • As long as my heart is beating, even though I'm not conscious*

**If you become sicker, which matters more to you: the possibility of a longer life, or the possibility of a better quality of life? Please explain.**

## MY WISHES AND PREFERENCES • What wishes and preferences do you have for your care?

**If my health situation worsens, here's what I want to make sure DOES happen:**

EXAMPLES

*I want to stay as independent as possible • I want to get back home • I want my doctors to do absolutely everything they can to keep me alive • I want everybody to respect my wishes if I say I want to switch to comfort care only*

**And here's what I want to make sure DOES NOT happen:**

EXAMPLES

*I don't want to become a burden on my family • I don't want to be alone • I don't want to end up in the ICU on a lot of machines • I don't want to be in pain*

**Is there anything else you want to make sure your family, friends, and health care team know about you and your wishes and preferences for care if you get sicker?**

## MY QUESTIONS • What questions do you want to ask your health care team?

EXAMPLES

*How will you work with me over the coming months? • What treatment options are available for me at this point — and what are the chances they'll work? • What can I expect if I decide I don't want more curative treatment? • If I get sicker, what can you do to help me stay comfortable? • What are the best-case and worst-case scenarios?*

# My People

**Are there key people who will be involved in your care (family members, friends, faith leaders, others)?** For each person you list, be sure to include their phone number and relationship to you.

**How much do they know about your wishes and preferences? What role do you want them to have in decision making? When might you be able to talk to them about your wishes?**

**Which person would you want to make medical decisions on your behalf if you're not able to? This person is often called your health care proxy, agent, or surrogate. See the Guide to Choosing a Health Care Proxy for help.**

*Name, phone number, relationship to me*

I have talked with this person about what matters most to me. ◉ Yes ○ No

I have filled out an official form naming this person as my health care proxy. ○ Yes ◉ No

I have checked to make sure my health care team has a copy of the official proxy form. ○ Yes ◉ No

# My Health Care Team

Who are the key clinicians involved in your care?

| | | |
|---|---|---|
| My primary care provider | *Name* | *Phone number* |
| My social worker | *Name* | *Phone number* |
| My main specialist | *Name* | *Phone number* |
| Other | *Name* | *Phone number* |

# Next Steps

**Now that you have completed the Workbook, what's next?**

- **Talk it over with someone else.** If you filled out the Workbook on your own, make a time to share your answers and questions with a family member, a friend, or another person. You might want to give them a copy of the Workbook with your answers written in. See the Conversation Starter Guide for help.
- **Talk it over with your health care team.** Make an appointment to talk over the Workbook, sharing your answers and asking any questions. If your primary care doctor or main specialist works with a social worker, that person can be an excellent place to start. You might want to give your health care team a copy of the Workbook with your answers written in before your appointment. See the Guide for Talking with a Health Care Team for help.
- **Pick a proxy**. This is the person you choose to make medical decisions for you if you are not able to make them for yourself. See the Guide to Choosing a Health Care Proxy for help.
- **Keep talking**. People's preferences often change as their health changes or as time goes by. Revisit the Workbook over time to see if your answers have changed. And be sure to keep your health care team updated so they know what is most important to you.

This document has been modified by the following organization:








# Your Guide to Choosing a Health Care Proxy

How to choose an advocate who could speak for you — and help you have a say in your health care.

Institute *for* Healthcare Improvement

the **conversation** project

# A Proxy: Your Health Care Advocate

We can't plan for everything. But we can talk about what is most important — in our life, and in our health care — with those who matter most.

Talking with the important people in our life can bring us closer together. It also helps us create the foundation of a care plan that's right for us — a plan that will be available when the need arises.

The Conversation Project wants to help everyone talk about their wishes for care through the end of life, so those wishes can be understood and respected. An important step in that conversation is to choose a health care proxy (also known as a health care agent, power of attorney for health care, or surrogate decision-maker). That's the one person who speaks on your behalf if you can't make your own health care decisions. If you were unable to speak due to an accident or illness, your proxy would advocate for you. That's why it's really important to plan now, since we can't predict the future.

We created this guide to help you choose a health care proxy. Read our Conversation Starter Guide for guidance on starting and continuing conversations about your care through the end of life.

This document does not seek to provide legal advice.

# We'll help you choose a proxy step by step.

You can take your time! It's all about what works best for you.



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.

STEP 1

# Learn About Choosing a Proxy

Getting the kind of health care that works for you — now and through the end of life — means talking about what matters to you with the people who matter most. It also means choosing the one person you'd want to speak for you, and advocate for the care that's right for you, if you're unable to speak for yourself. That person is a health care proxy.

## What does it mean?

Your proxy can talk with your doctors, nurses, and other members of your care team, and read your medical records. They would use what they know about the health care you want to make decisions about tests, procedures, and treatments if you became too sick to make those decisions yourself.

There are three steps in naming a health care proxy:

1. Picking a person
2. Having a conversation with that person
3. Adding that person's information to your official documents

It's important to know that although your proxy's decisions on your behalf could have some financial impact, the proxy does not make financial decisions for you — they only speak for you about health care decisions.

A health care proxy may also be called: health care agent, power of attorney for health care, or surrogate decision-maker.

The legal document that allows a proxy to speak for someone else may be called a health care proxy form or an advance directive. The advance directive document includes both a health care proxy form and a living will, where specific medical treatments a person would or would not want can be listed.

## Why do you need one?

We can't predict the future, or what it might mean for our health and our ability to receive the health care that's right for us. The COVID-19 pandemic and unexpected accidents have shown us that even healthy people can suddenly need someone else to speak for them and help make health care decisions. And as we get older, we're less likely to be able to make decisions for ourselves: half of all people over 65 admitted to a hospital need help from someone else.*

"It always seems too soon, until it's too late."

## When do you need one?

Everyone over age 18 needs a proxy. Up until then, a parent or legal guardian is automatically considered a child's proxy. But after age 18 that is no longer the case. In fact, in most places, if you are over 18 and have not filled out a proxy, the legal system will choose one for you.

That's why it's so important to choose a proxy for yourself, as soon as you can. It's also a good idea to review your proxy choice:

- At the start of each decade of your life: when you turn 20, 30, 40, 50, etc.
- Around a major life event, like going to college; getting married, divorced, or widowed; or the birth or adoption of a child
- If you are planning to go on a major trip
- If you are diagnosed with a serious illness

* Torke AM, Sachs GA, Helft PR, et al. Scope and outcomes of surrogate decision making among hospitalized older adults. JAMA Intern Med. 2014;174(3):370-377.

STEP 2

# Think About It

Now that we've explained why it's so important to have a proxy, let's help you think about how to choose a proxy.

First, there are some things you need to know about the best people to choose as your proxy. You may be considering a spouse/partner; family member like an adult child, sibling, cousin, niece or nephew; friend; neighbor; or community member.

Here are some things to think about as you make your choice:

› It's best to choose just one person as your proxy.

- Different states and countries have different rules — some only allow you to name one proxy, while others let you name more than one.
- In general, since different proxies could disagree about a situation, it's best to keep things simple with one proxy.
- It's a good idea to name an alternate proxy in case your main proxy is unavailable for some reason.

There are some laws that could affect your choice.

The rules can vary between states and countries, so it's best to check your local laws. In the United States, here are examples of how some states decide who you can choose to be your proxy:

- Your proxy must be over 18. In Alabama and Nebraska, your proxy must be over 19.
- Patients who live or stay in a health care facility, such as a long-term care facility, can't choose an employee of that facility (unless the person is a relative).
- You can't choose a member of your current health care team (your doctor, nurse, etc.) as your proxy.

If you aren't sure who to choose as your proxy, it's still a good idea to fill out an advance directive.

- Even if you don't name a specific person when you fill out your advance directive, you can still have a say in your care by listing medical treatments that you would or would not want if you became seriously ill or unable to make your own decisions.
- You can then choose a proxy later. For some people, it's not possible to choose a family member — and you don't have to. For example, it could be a friend, a more distant relative, or someone at your place of worship.
- If you don't name your proxy and you are married, in most states your spouse may automatically become your legal proxy. If you think your spouse might find it too difficult to make decisions such as starting or ending treatments if you were seriously ill, it's probably a good idea to choose someone else as your proxy.

STEP 3

# Pick Your Person

Now that you know more about what's involved in choosing a proxy, it's good to think about the best qualities of a proxy as you make your decision. Your proxy is the person who will make medical decisions for you if you can't speak for yourself. They may have to make tough, quick decisions on your behalf — including decisions about treatments, procedures, or even life support. Some people are more comfortable with that than others.

Here are some things to help you think about who you will ask to be your proxy:

- Will the person make decisions that follow your wishes?
  - Your proxy may need to make certain decisions on your behalf — even if their own wishes are different from yours. This may be emotionally difficult for some people.

- Will the person be comfortable making quick decisions in a changing situation?
  - Your proxy doesn't need to be a medical expert, but they may need to make quick decisions as information becomes available about your care, such as whether to give you antibiotics for an infection or insert a feeding tube if you can't eat.
  - That's why your proxy should be someone who could understand your values and wishes in any situation. That way, they can make decisions more easily about the kind of care that's right for you. Will the person be comfortable speaking up on your behalf?
  - Your proxy may need to ask doctors and other members of your care team questions to make sure they understand the situation.
  - Your proxy may need to advocate strongly on your behalf to get you the care that's right for you — not only with your health care team, but with others in your life who may not agree with the proxy's decision for you.

## What if I don't want to pick a family member?

- That is OK! Sometimes a spouse, adult child, sibling, or other family member may not be the best choice to follow your wishes.
- Your proxy doesn't need to be someone local; the person you choose can act as your proxy and make choices for you over the phone.
- If you do choose someone who's not a family member, certain members of your family may have questions. It's a good idea to let family know who your proxy is, and why you made that decision, before a medical problem happens.
- You can say something like, "I want you to be able to focus fully on our time together, rather than on health care decisions that may cause you stress."

## Here are some people you can consider.

- Parent
- Spouse/partner
- Adult child (at least 18 years old)
- Sibling
- Cousin
- Friend
- Trusted neighbor
- Member of a faith community

Who is the one person you would want to choose?

Who is your alternate choice, as your backup proxy?

STEP 4

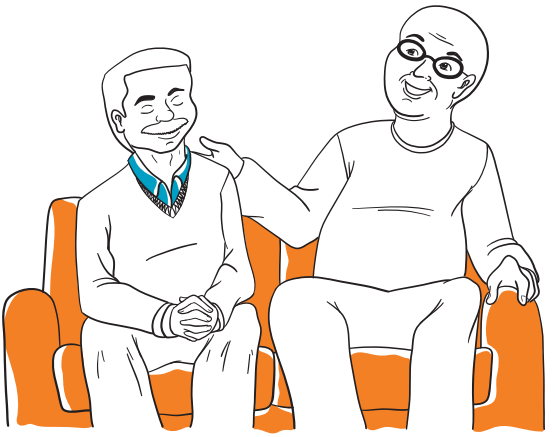
# Talk About It

Once you've chosen a proxy, it's time to talk about it with the person you chose. Here are some tips to help you have that conversation.

- Start by asking if the person is comfortable taking on this role.
  - You can say, "I'd like you to be my health care proxy. That means you would be the person who would make medical decisions for me if I can't make them for myself. I would share what matters to me in my care, so you wouldn't have to guess. Is this something you would be comfortable doing?"
  - Ask, then sit back and listen to their answer. Do your best to answer any questions they might have. And tell them it's OK if they need to say no.
- Talk about what it means to be a proxy.
  - They would have the legal power and responsibility to make medical decisions for you if you're unable to make them for yourself.
  - They can talk with your doctors, read your medical records, and make decisions about tests, procedures, and other treatment.
  - In the United States, they are entitled to full access to your medical information under federal privacy laws (known as HIPAA).
  - They will need to ask questions and get information to make decisions for you, and at times may need to advocate for you.
  - You can give the person our Guide to Being a Health Care Proxy for more information about what it means.

Make sure your proxy understands what matters to you.

- It's really important to talk to your proxy about what matters to you — about the kind of health care you'd want now and through the end of life.
- When these conversations happen before a health challenge or crisis, it will be easier for your proxy to make decisions for you if it becomes necessary.
- Our Conversation Starter Guide is a good place to start. You can work through that guide yourself first, then talk over your answers to the questions with your proxy so that you can have a detailed conversation about what matters to you.
- You can also use your own state's or country's proxy/advance directive form to talk about more specific medical scenarios and what would be right for you.
- If you are diagnosed with a serious illness, you could ask your proxy to join an upcoming doctor's appointment in person or by phone, so they understand your diagnosis, treatment, and decisions.



STEP 5

# Write It Down and Share It

Now, it's a good idea to record your conversation with an important legal document to be sure your choices are followed. This is called an advance directive. It has two parts.

### 1. Your Health Care Proxy

This is the part of the advance directive where you name the person you have chosen to make health care decisions on your behalf, if needed, as well as an alternate if your first choice is unavailable. Be sure to have a conversation — and keep talking — with these people to be sure they understand what matters to you.

### 2. Your Living Will

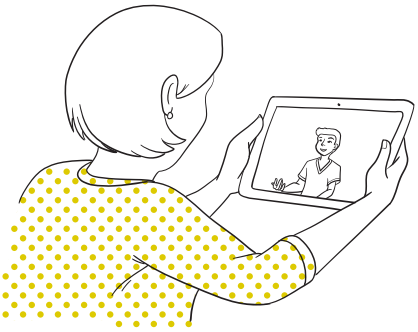
This is the part of the advance directive where you describe your preferences and wishes for your health care if you cannot speak for yourself. These are many of the same things that you have thought about and discussed throughout this guide.

› You can fill out your advance directive yourself!
Here's how to get one in the US.

- Every state and most countries have their own advance directive forms. In the United States, the NHPCO (National Hospice and Palliative Care Organization) can help you find the right forms in your state (nhpco.org/advancedirective).
- Most states need two witnesses to sign your proxy, saying that they have seen you sign the form. In most states and countries, your proxy cannot sign as a witness. In many states, you may have your advance directive notarized instead of signing before two witnesses. Some states require a notary and two witnesses. Check the above site for more information about your own state.

- Once you complete your advance directive, make sure your proxy has all the information they need, so they are prepared to speak for you if needed.
  - Give your proxy a copy of the health care proxy form and any other advance directive documents you completed.
  - Give your proxy a list of names and contact information for your primary care doctor and any other important members of your health care team.
  - Give your proxy's name and contact information to your primary care doctor and any other important members of your health care team.

- Tell other important people in your life who you've selected as your proxy.
  - It's important to share your advance directive with more than your proxy alone, and provide copies to anyone who may need them.
  - For example, if you pick an adult child to be your proxy and you have other children, they should all be aware of what matters to you in your health care and know who you have chosen as your proxy.
  - Talk to anyone who may have a say in your care through the end of life. Talk to those you don't want to have a say, too — and let them know who will be speaking for you instead.
  - Talk to anyone who can help you have a say in your care through the end of life and provide copies of your advance directive to anyone who may need them.
  - If you want tips on talking about what matters to you with your health care team, visit our Guide for Talking with a Health Care Team.



STEP 6

# Keep Thinking and Talking

Sometimes, situations or relationships change, and you may choose to change your proxy. It's OK to change your proxy. In fact, it's a good idea to think regularly about whether your proxy is still the right person.

If you do want to make a change

- Fill out a new form and tell the people close to you, along with your health care team, about the change.
- File and keep your previous advance directive form, noting the date when it was replaced by the new one.
- Let your previous proxy know you've decided to make a change. You can say, "I've been thinking about it, and I've decided to change my proxy. Thank you for agreeing to do this for me, but I won't need you to take on this responsibility anymore."

No matter who your proxy is, keep talking.

- It's important to keep the conversation with your proxy going.
- From time to time, think about the questions in our Conversation Starter Guide, and tell your proxy if anything changes about the health care that works for you — now and through the end of your life.
- As stated above, it's good to have a new conversation around certain events, such as the arrival of a baby, the start or end of a marriage, or a new decade of life.

# Stories About Picking a Proxy

Here are some real-world examples of how a proxy can be chosen and named.

## Siblings and Partners

When Andre set out to choose his proxy, he thought about choosing his sister. They were extremely close. He realized, however, that if something unexpected were to happen to him she would be devastated, and he didn't want to put her in that position. He'd want her nearby for comfort.

Andre decided to pick his partner Dylan, who would be equally upset, but was more comfortable talking to doctors and making decisions like this. At first, he felt guilty, but then realized he'd be putting his sister in a potentially difficult position if he'd chosen her.

## The Just-Right Answer

Joy, a married mother of grown children, needed to choose her proxy. She talked to her husband first. He told her, "I could never unhook you from anything. I will hold your hand for 20 years even if you're too sick to respond."

Joy then went to her son. He said, "Got it, Mom — I know you don't want any extreme measures to save your life. I'll never let anyone hook you up."

Finally, Joy went to her daughter, who said, "I hear what's important to you, and I know any choice I would make should depend on your prognosis and chances for recovery."

After hearing that her daughter had really listened to her, while her husband and son weren't able to put aside their own thoughts and feelings in decision-making, Joy chose her daughter as her proxy.

## Chosen in Good Faith

Sofia, age 59, and Alex, age 42, attended a Conversation Starter Workshop at their church. Sofia had health issues and knew she needed a proxy — but was single, with no kids, and estranged from her family. Alex was a healthy single person with two brothers — neither of whom she'd be comfortable asking to be her proxy.

At the end of the workshop, the speaker encouraged attendees to choose a proxy. He added that if people didn't have an obvious choice in their lives, they might find someone in the group capable of serving. Sofia and Alex had sat next to each other many times in church, so they turned to each other and started talking. After meeting for coffee several times and talking about what matters to them and what's important in a proxy, they felt comfortable choosing each other.

Choosing a proxy and sharing what matters to you is an important step to getting the health care that's right for you. For more help having the conversation, visit our Conversation Starter Guide.

## Learn more and share

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# Your Guide to Being a Health Care Proxy

How to be an advocate for someone you care about, as their proxy — and help them have a say in their health care.

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# A Proxy: A Health Care Advocate

We can't plan for everything. But we can talk about what is most important — in our life, and in our health care — with those who matter most.

Discussing what matters most can bring us closer to the people who matter most, and help them make sure they get the kind of health care that's right for them, now and through the end of life.

The Conversation Project wants to help everyone talk about their wishes for care through the end of life, so those wishes can be understood and respected. An important step in that conversation is to choose a health care proxy (also known as a health care agent, power of attorney for health care, or surrogate decision-maker). You may be reading this because someone has asked you to speak on their behalf, as their proxy, if they become unable to make their own health care decisions. It's an honor to be asked to fill this role for someone. It shows their trust in you to make important decisions for them, and it can deepen your relationship.

You may need to advocate for this person if they have a serious accident or illness and cannot speak for themselves. That's why it's really important to understand your role now, since we can't predict the future.

We created this guide to help you be the best possible health care proxy. It's a good idea to read this along with our Conversation Starter Guide. For more information, see our Guide to Choosing a Health Care Proxy.

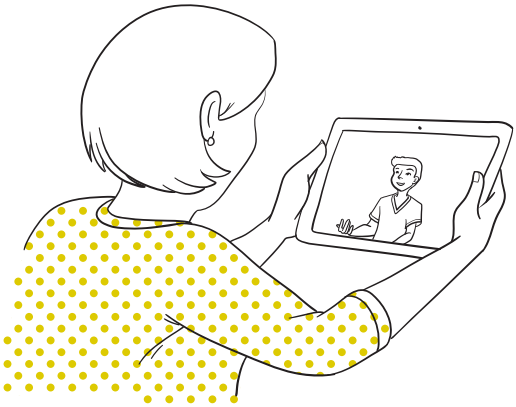
We'll help you learn to be a proxy step by step.



This document does not seek to provide legal advice.

STEP 1

# Learn
## About It



First, let's review what it means to be someone's proxy.

As a proxy, you can talk with doctors, nurses, and other members of the care team, and read medical records to help make decisions for the person you're representing. By talking with this person now about the kind of health care that works for them, you can prepare to make decisions about tests, procedures, and treatments if they became too sick to make those decisions themselves.

It's important to know that although decisions you make on behalf of the person you are representing could have some financial impact, as a proxy, you do not make financial decisions. You only speak about health care decisions.

A health care proxy may also be called: health care agent, power of attorney for health care, or surrogate decision-maker.

The legal document that allows a proxy to speak for someone else may be called a health care proxy form or an advance directive. The advance directive document includes both a health care proxy form and a living will, where specific medical treatments a person would or would not want can be listed.

STEP 2

# Think
## About It

Someone has asked you to be their health care proxy. It's an honor to be asked to take this step for someone. How can you be prepared to answer them and possibly act as their proxy?

### Things to consider:

As you think about whether you'd be comfortable acting as a proxy, it's helpful to understand the role of a proxy.

- There is no perfect proxy.
  - As a proxy, you will only need to try your best. No one expects you to be perfect.
  - A proxy bases decisions on what they know matters to the person they're representing.
  - In any situation, your goal will be to give a voice to what you know about the person's values.

- You would need to speak for the person if they were unable to speak for themselves.
  - That means putting aside your own priorities and preferences and thinking about what the person you are speaking for would want.
  - You would need to be able to answer the question, "If they could speak and make their own decision, what would they say?"

- As a proxy, you would have certain legal responsibilities.
  - As a proxy, you would have the legal power to make medical decisions for the person if they can no longer make them for themselves.
    - In order to do that, you would have full access to the person's medical information under the health care privacy law known as HIPAA.
    - You would talk to the person's doctors and gather information on their condition so you could make an informed decision about tests, procedures, and other treatment for the person.
  - Serving as a proxy does not make you responsible to pay for that person's care.

- Preferences aren't always possible.
  - Sometimes it's not possible — physically, medically, or financially — to follow every one of someone's health care preferences, and that's OK.
    - For example, someone might prefer to spend their last days at home, but their condition may make that impossible.
    - In that case, you would do your best to make a decision based on the information you have, and try to find other ways to meet the person's preferences based on what matters most to them. For example, if they have to enter a nursing facility to get medical support that is not available at home, you may be able to choose a facility that lets the person have a beloved pet with them.

- It's OK to say no.
  - Although it's an honor to be asked, there are many reasons that being a proxy may not be right for you. Maybe you're just not comfortable with the person's preferences, or making such a big decision for them. Or maybe it's just not something you can take on at this time.
    - In that case, it's best to be honest and kind.
    - Thank the person for asking you, tell them you are honored, and let them know why it won't work for you, if you feel comfortable sharing this information.

STEP 3

# Talk About It

If you've said yes to being someone's proxy, you can feel proud of the role you will play in reassuring the person that someone will be there for them to make health care decisions now and through the end of life.

We will help you feel prepared. When you've agreed to be someone's proxy, it's important to understand your person's preferences. That way, if you need to represent them, you can help them get the kind of health care that works for them.

It's a good idea to set up a time right away to talk with this person about what matters to them and how you can best advocate for them. Allow for plenty of time to talk — it's important not to rush these conversations, and they can happen in multiple sittings.

## Understand what matters.

- Our Conversation Starter Guide is a helpful resource for you to use in speaking with the person you've agreed to represent. It can help you understand what matters most to them in their life and in their care through the end of life.
- You can go through the guide with them and talk over their answers to questions that would help you make informed choices for them.
- It's also a good idea to talk to the person you will represent about their advance directive — specific instructions for their care preferences in certain situations.
- It's important to have these conversations before a medical crisis — so you can be ready to make decisions for the person if the time comes.

- Here are some things you can say to start a conversation and get the information you need to fulfill your important role as a proxy. You can see our Conversation Starter Guide for more ideas.
    - Do you have any worries about your health?
    - What do you need to address to feel more prepared (examples: finances, property, legal documents, relationships, health care situations)?
    - Do you have any fears, concerns, or mistrust about where or how you receive health care?
    - Who do you want (or not want) to be involved in your health care?
    - When you look ahead to the future, are there important events or dates you hope you're there for?
    - Are there kinds of treatment you would want or not want (examples: resuscitation attempts, ventilation, feeding tube)?
    - If your health condition changed, when would it be OK with you to shift from trying to cure an illness to trying to enjoy the end of life as much as possible?

› Speak up if you need to.

- If there's something you don't know about what matters to the person you will advocate for, have another conversation with them and ask questions.
- If the time comes when you need to speak for the person as their proxy, it is important to speak up with doctors, nurses, and other members of the care team. That way, you can make sure you understand the situation and can make the best possible decisions for the person.
- You can ask the care team to repeat information, explain things that aren't clear, and help you understand the details of a certain test or treatment. For example, you could say:
    - I'd like to speak to you about (person you represent)'s wishes.
    - I don't understand what you just said.
    - I have some questions I would like to ask you. When would be a good time for you?
- You may want to write down questions in advance, so you remember them.

Since your role as a proxy is so important and it can bring you closer to the person you represent, make sure to have all the information you need to answer the question, "What would they want?"

For more information on becoming a proxy from the American Bar Association, visit Making Medical Decisions for Someone Else: A How-To Guide.

## Learn more and share

VISIT US
theconversationproject.org

EMAIL US
conversationproject@ihi.org

FOLLOW US ON SOCIAL MEDIA
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Institute *for* Healthcare Improvement

the **conversation** project

# PALLIATIVE CARE OR HOSPICE?

## The right service at the right time for seriously ill individuals

| QUESTION | PALLIATIVE CARE | HOSPICE |
|---|---|---|
| **What is the focus?** | Palliative care is not hospice care: it does not replace the patient's primary treatment; palliative care works together with the primary treatment being received. It focuses on the pain, symptoms and stress of serious illness most often as an adjunct to curative care modalities.<br><br>It is not time limited, allowing individuals who are 'upstream' of a 6-month or less terminal prognosis to receive services aligned with palliative care principles. Additionally, individuals who qualify for hospice service, and who are not emotionally ready to elect hospice care could benefit from these services. | Hospice care focuses on the pain, symptoms, and stress of serious illness during the terminal phase. The terminal phase is defined by Medicare as an individual with a life expectancy of 6-months or less if the disease runs its natural course.<br><br>This care is provided by an interdisciplinary team who provides care encompassing the individual patient and their family's holistic needs. |
| **Who can receive this type of care?** | Any individual with a serious illness, regardless of life expectancy or prognosis. | Any individual with a serious illness measured in months not years.<br><br>Hospice enrollment requires the individual has a terminal prognosis. |
| **Can my patient continue to receive curative treatments?** | Yes, individuals receiving palliative care are often still pursuing curative treatment modalities.<br><br>Palliative care is not limited to the hospice benefit. However, there may be limitations based on their insurance provider. | The goal of hospice is to provide comfort through pain and symptom management, psychosocial and spiritual support because curative treatment modalities are no longer beneficial.<br><br>Hospice should be considered at the point when the burden of any given curative treatment modalities outweighs the benefit coupled with prognosis. Other factors to consider and discuss, based on individual patient situations, are treatment modalities that no longer provide benefit due to a loss of efficacy. |
| **What services are provided?** | Pain and symptom management, in-person and telephonic visits, help navigating treatment options, advance care planning and referrals to community resources. | Pain and symptom management, 24-hour on-call service, in-person visits, medical equipment, related medications, inpatient care, continuous care in the home, respite care, volunteer services, spiritual care, bereavement and counseling services.<br><br>There are four levels of care that can be provided to patients per CMS regulations (routine, inpatient, continuous, and respite care). |
| **Where are services provided?** | Palliative care may be provided in any care setting.<br>▮ Home<br>▮ Hospice facility<br>▮ Skilled Nursing Facility<br>▮ Long-term Care Facility<br>▮ Long Term Acute Care Facility<br>▮ Assisted Living Facility<br>▮ Hospital<br>▮ Group Home<br>▮ Clinics | Hospice care can be provided in most care settings.<br>▮ Home<br>▮ Hospice facility<br>▮ Skilled Nursing Facility<br>▮ Long-term Care Facility<br>▮ Assisted Living Facility<br>▮ Hospital (inpatient levels of care only)<br>▮ Group Home |

*(continued on reverse...)*

National Hospice and Palliative Care Organization

NHPCO, 2019

| | | |
|---|---|---|
| **Who provides these services?** | Palliative care may be provided by an interdisciplinary team. However, most palliative services are provided by a physician, nurse practitioner or nurse with consultative support from social worker and chaplaincy services.<br><br>These services are performed in collaboration with the primary care physician and specialists through consultative services or co-management of the patient's disease process. | Hospice care is provided by an interdisciplinary team that is led by a physician and includes nurses, social workers, chaplains, volunteers, hospice aides, therapy disciplines and others.<br><br>These services are performed in collaboration with the attending physician. |
| **What types of health care organizations may provide these services?** | Palliative care is not dependent on care setting or type of medical practice. Services are performed in collaboration with the patient's primary care physician, other specialists, and health care settings they may be receiving services from.<br>▮ Palliative Care Practices<br>▮ Licensed Home Health Agencies<br>▮ Licensed Hospice Agencies<br>▮ Nursing Facilities<br>▮ Healthcare Clinics<br>▮ Hospitals | Hospice organizations<br>▮ State licensed and/or Medicare-certified Hospice providers<br>▮ Non-Medicare certified Hospice providers<br>▮ Veteran Affairs Hospice |
| **How long can an individual receive services?** | Palliative care is not time-limited. How long an individual can receive care will depend upon their care needs, and the coverage they have through Medicare, Medicaid, or private insurance.<br><br>Most individuals receive palliative care on an intermittent basis that increased over time as their disease progresses. | As long as the individual patient meets Medicare, Medicaid, or their private insurer's criteria for hospice care. Again, this is measured in months, not years. |
| **PAYMENT** | | |
| **Does Medicare pay?** | Palliative care is covered through Medicare Part B. Some treatments and medications may not be covered.<br><br>May be subject to a co-pay according to the plan. | The Medicare Hospice Benefit pays all related costs associated with the care that is related to the terminal prognosis as directed by CMS.<br><br>There may be some medications, services, and/or equipment that are not included in the Medicare Hospice Benefit. |
| **Does Medicaid pay?** | Palliative care is covered through Medicaid. Some treatments and medications may not be covered.<br><br>May be subject to a co-pay according to the plan. | In most states Medicaid pays all related costs associated with the care related to the terminal prognosis as directed by CMS.<br><br>There may be some medications, services and/or equipment that are not included in the Medicaid Hospice Benefit. |
| **Does private insurance pay?** | Most private insurers include palliative care as a covered service. Each payer is different, and their palliative services will be outlined through the insurer's member benefits.<br><br>Some treatments and medications may not be covered. May be subject to a co-pay according to the plan. | Most private insurers have a hospice benefit that pays all related costs associated with the care related to the terminal prognosis.<br><br>There may be some medications, services and/or equipment that are not included in the individual's policy.<br><br>May be subject to a co-pay according to the plan. |
| **When should I refer?** | Patients with advanced chronic illness that have received maximum medical therapy and are at risk of using the hospital for decompensation. | If you would not be surprised if this patient died within the next 12 months, they are likely appropriate for hospice. Patients that have received maximum therapy and focus has shifted to symptom management and comfort care. |

# The Difference between the Advance Directive and POLST

The Advance Directive and the POLST are really different. Still, it is easy to confuse the two. This chart shows you the differences.

| | **Advance Directive** | **POLST** (stands for Portable Order for Life Sustaining Treatment) |
|---|---|---|
| **Who is it for?** | Everyone 18 and older. | People with a serious illness or who are very old and frail. |
| **What kind of document is it?** | It is a legal document. | It is a medical order. |
| **Who signs it?** | You fill it out and sign it. Also, your health care representative signs it and witnesses or a Notary. | Your doctor fills it out with your input. Then signs it. |
| **Do I need a lawyer?** | No. | No. |
| **Who keeps the form?** | You keep the original where loved ones can find it. You give a copy to your health care representative and your doctor. | Your doctor's office keeps it and enters it into the electronic Oregon POLST Registry. They give you a copy that you post at home in a visible place like the fridge. |
| **Can I change the form if I change my mind?** | Yes. You can tear up the old one. Then write a new one where loved ones can find it. You give a copy to your health care representative and your doctor. | Yes. You can ask for an appointment with your doctor to change it. |
| **What if there is a medical emergency and I cannot speak for myself?** | Your health care representative speaks for you and honors your wishes. | The ambulance staff, hospital staff and doctors look for the medical orders in the electronic data base and follow them. |

# Oregon Advance Directive for Health Care

**This Advance Directive form allows you to:**

- Share your values, beliefs, goals and wishes for health care if you are not able to express them yourself.
- Name a person to make your health care decisions if you could not make them for yourself. This person is called your health care representative and they must agree to act in this role.

**Be sure to discuss your Advance Directive and your wishes with your health care representative.** This will allow them to make decisions that reflect your wishes. It is recommended that you complete this entire form.

**The Oregon Advance Directive for Health Care form and Your Guide to the Oregon Advance Directive are available on the Oregon Health Authority's website.**

- In sections 1, 2, 5, 6 and 7 you appoint a health care representative.
- In sections 3 and 4 you provide instructions about your care.

**The Advance Directive form allows you to express your preferences for health care.** It is not the same as Portable Orders for Life Sustaining Treatment (POLST) as defined in ORS 127.663. You can find more information about the POLST in Your Guide to the Oregon Advance Directive.

**This form may be used in Oregon to choose a person to make health care decisions for you if you become too sick to speak for yourself** or are unable to make your own medical decisions. The person is called a health care representative. If you do not have an effective health care representative appointment and you become too sick to speak for yourself, a health care representative will be appointed for you in the order of priority set forth in ORS 127.635 (2) and this person can only decide to withhold or withdraw life sustaining treatments if you meet one of the conditions set forth in ORS 127.635 (1).

**This form also allows you to express your values and beliefs with respect to health care decisions and your preferences for health care.**

**If you have completed an advance directive in the past, this new advance directive will replace any older directive.**

**You must sign this form for it to be effective.** You must also have it witnessed by two witnesses or a notary. Your appointment of a health care representative is not effective until the health care representative accepts the appointment.

**If your advance directive includes directions regarding the withdrawal of life support or tube feeding,** you may revoke your advance directive at any time and in any manner that expresses your desire to revoke it.

**In all other cases,** you may revoke your advance directive at any time and in any manner as long as you are capable of making medical decisions.

# Advance Directive Form

| 1. About me | | |
|---|---|---|
| Name (first, middle, last): | | Date of birth: |
| Telephone numbers: Home | Work | Cell |
| Address: | | E-mail: |

| 2. My health care representative | | |
|---|---|---|
| I choose the following person as my health care representative to make health care decisions for me if I can't speak for myself. | | |
| Name (first, middle, last): | | Relationship: |
| Telephone numbers: Home | Work | Cell |
| Address: | | E-mail: |

I choose the following people to be my alternate health care representatives if my first choice is not available to make health care decisions for me, or if I cancel the first healthcare representative's appointment.

| **First alternate health care representative** | | |
|---|---|---|
| Name (first, middle, last): | | Relationship: |
| Telephone numbers: Home | Work | Cell |
| Address: | | E-mail: |

| **Second alternate health care representative** | | |
|---|---|---|
| Name (first, middle, last): | | Relationship: |
| Telephone numbers: Home | Work | Cell |
| Address: | | E-mail: |

## 3. My health care instructions

This section is the place for you to express your wishes, values and goals for care. Your instructions provide guidance for your health care representative and health care providers.

You can provide guidance on your care with the choices you make below. This is the case even if you do not choose a health care representative or if they cannot be reached.

### A. My health care decisions

There are three situations below for you to express your wishes. They will help you think about the kinds of life support decisions your health care representative could face. For each, choose the one option that most closely fits your wishes.

a. **Terminal condition**
This is what I want if:

- I have an illness that cannot be cured or reversed

  **AND**

- My health care providers believe it will result in my death within six months, regardless of any treatments.

| **Initial one option only** | |
|---|---|
| _____ | I want to try all available treatments to sustain my life, such as artificial feeding and hydration with feeding tubes, IV fluids, kidney dialysis and breathing machines. |
| _____ | I want to try to sustain my life with artificial feeding and hydration with feeding tubes and IV fluids. I do not want other treatments to sustain my life, such as kidney dialysis and breathing machines. |
| _____ | I do not want treatments to sustain my life, such as artificial feeding and hydration with feeding tubes, IV fluids, kidney dialysis or breathing machines. I want to be kept comfortable and be allowed to die naturally. |
| _____ | I want my health care representative to decide for me, after talking with my health care providers and taking into account the things that matter to me. I have expressed what matters to me in section B below. |

b. **Advanced progressive illness**
This is what I want if:

- I have an illness that is in an advanced stage.
  **AND**
- My health care providers believe it will not improve and will very likely get worse over time and result in death.
  **AND**
- My health care providers believe I will never be able to:
  - » Communicate
  - » Swallow food and water safely
  - » Care for myself
  - » Recognize my family and other people

| Initial one option only | |
|---|---|
| _____ | I want to try all available treatments to sustain my life, such as artificial feeding and hydration with feeding tubes, IV fluids, kidney dialysis and breathing machines. |
| _____ | I want to try to sustain my life with artificial feeding and hydration with feeding tubes and IV fluids. I do not want other treatments to sustain my life, such as kidney dialysis and breathing machines. |
| _____ | I do not want treatments to sustain my life, such as artificial feeding and hydration with feeding tubes, IV fluids, kidney dialysis or breathing machines. I want to be kept comfortable and be allowed to die naturally. |
| _____ | I want my health care representative to decide for me, after talking with my health care providers and taking into account the things that matter to me. I have expressed what matters to me in section B below. |

c. **Permanently unconscious**
This is what I want if:

- I am not conscious.
  **AND**
- If my health care providers believe it is very unlikely that I will ever become conscious again.

| Initial one option only | |
|---|---|
| _____ | I want to try all available treatments to sustain my life, such as artificial feeding and hydration with feeding tubes, IV fluids, kidney dialysis and breathing machines. |
| _____ | I want to try to sustain my life with artificial feeding and hydration with feeding tubes and IV fluids. I do not want other treatments to sustain my life, such as kidney dialysis and breathing machines. |
| _____ | I do not want treatments to sustain my life, such as artificial feeding and hydration with feeding tubes, IV fluids, kidney dialysis or breathing machines. I want to be kept comfortable and be allowed to die naturally. |

_____ I want my health care representative to decide for me, after talking with my health care providers and taking into account the things that matter to me. I have expressed what matters to me in section B below.

You may write in the space below or attach pages to say more about what kind of care you want or do not want.

**B. What matters most to me and for me**

This section only applies when you are in a terminal condition, have an advanced progressive illness or are permanently unconscious. If you wish to use this section, you can communicate the things that are really important to you and for you. This will help your health care representative.

This is what you should know about what is important to me about my life:

This is what I value the most about my life:

This is what is important for me about my life:

I do not want life-sustaining procedures if I can not be supported and be able to engage in the following ways:

**Initial all that apply**

_____ Express my needs

_____ Be free from long-term severe pain and suffering

_____ Know who I am and who I am with

_____ Live without being hooked up to mechanical life support

_____ Participate in activities that have meaning to me, such as:

If you want to say more to help your health care representative understand what matters most to you, write it here. (For example: I do not want care if it will result in…)

### C. My spiritual beliefs

Do you have spiritual or religious beliefs you want your health care representative and those taking care of you to know? They can be rituals, sacraments, denying blood product transfusions and more.

You may write in the space below or attach pages to say more about your spiritual or religious beliefs.

## 4. More information

Use this section if you want your health care representative and health care providers to have more information about you.

### A. Life and values

Below you can share about your life and values. This can help your health care representative and health care providers make decisions about your health care. This might include family history, experiences with health care, cultural background, career, social support system and more.

You may write in the space below or attach pages to say more about your life, beliefs and values.

### B. Place of care

If there is a choice about where you receive care, what do you prefer? Are there places you want or do not want to receive care? (For example, a hospital, a nursing home, a mental health facility, an adult foster home, assisted living, your home.)

You may write in the space below or attach pages to say more about where you prefer to receive care or not receive care.

**C. Other**

You may attach to this form other documents you think will be helpful to your health care representative and health care providers. What you attach will be part of your Advance Directive.

You may list documents you have attached in the space below.

**D. Inform others**

You can allow your health care representative to authorize your health care providers to the extent permitted by state and federal privacy laws to discuss your health status and care with the people you write in below. Only your health care representative can make decisions about your care.

| | | |
|---|---|---|
| Name (first, middle, last): | | Relationship: |
| Telephone numbers: Home | Work | Cell |
| Address: | | E-mail: |

## 5. My signature

My signature

Date

## 6. Witness

Complete either A or B when you sign

## A. Notary

State of _____

County of _____

Signed or attested before me on _____ by _____
Date

_____

Notary Public State of Oregon

## B. Witness Declaration

The person completing this form is personally known to me or has provided proof of identity, has signed or acknowledged the person's signature on the document in my presence and appears to be not under duress and to understand the purpose and effect of this form. In addition, I am not the person's health care representative or alternative health care representative, and I am not the person's attending health care provider.

_____
Witness name (print)

_____ _____
Signature Date

_____
Witness name (print)

_____ _____
Signature Date

## 7. Acceptance by my health care representative

I accept this appointment and agree to serve as health care representative.

**Health care representative:**

Printed name

Signature or other verification of acceptance | Date

**First alternate health care representative:**

Printed name

Signature or other verification of acceptance | Date

**Second alternate health care representative:**

Printed name

Signature or other verification of acceptance | Date

**Document accessibility:** For individuals with disabilities or individuals who speak a language other than English, OHA can provide information in alternate formats such as translations, large print, or braille. Contact the Health Information Center at 1-971-673-2411, 711 TTY or COVID19.LanguageAccess@dhsoha.state.or.us.

# Advance Directive for Voluntary Stopping of Eating and Drinking (VSED Directive)

My name is _____. My date of birth is _____.

As an adult with decision-making capacity, I have the right to direct my treatment and care, even if those choices lead to an earlier death. This includes the right to refuse medical treatment and the right to refuse oral food and drink. I have thought carefully about the circumstances in which I would want to stop prolonging my life with eating and drinking.

This directive instructs my health care agent or other legal decision-maker ("decision-maker") and all caregivers how to act on my behalf to ensure that my wishes for stopping eating and drinking are carried out.

**1. Voluntary stopping of eating and drinking (VSED)**

When I meet the conditions I have selected in section 2 (below) and can no longer feed myself:

- Do not help me with eating and drinking (by spoon-feeding, for example).
- Do not verbally or physically encourage or persuade me to eat or drink.
- Do not put food or liquids in my mouth.

**2. Conditions for starting VSED**

I want to start VSED when I have a serious and irreversible illness or chronic condition that will not significantly improve (even if it is not terminal), and when I meet (*initial one*)

__ **at least one** of the conditions I select below.

__ **all** of the conditions I select below

(*initial all that apply*):

__ I cannot communicate with others beyond a few words, eye movements, etc.

__ I do not recognize close family and friends.

__ I am indifferent to being fed, no longer want to eat or drink, and show no signs of enjoying eating and drinking.

__ I do not open my mouth to receive food and drink, or I turn my head away when offered food or drink.

__ I usually refuse food or drink

__ I frequently inhale or choke on food or drink.

__ The following additional conditions or situations:

_____

**3. If my decision-maker thinks my quality of life is still good when it is time to start VSED**

If my decision-maker thinks my quality of life is still good enough and I seem comfortable or happy, my decision-maker (*initial one*):

__ **must follow this directive and start VSED.** I have given a lot of thought to this decision and insist that my wishes be followed.

__ may choose **not** to follow this directive. **I understand this means some or all of my choices may not be honored.**

**4. Palliative care – relief from pain and discomfort**

If food and drink are being withheld, I want palliative care to manage any pain or discomfort from my illness and from not eating and drinking (relief from dehydration, for instance).

I want palliative sedation if necessary to manage pain and discomfort (*initial one*):

__ **even if** it makes me unconscious.

__ **but not** to the point of unconsciousness.

**5. If I express the desire to eat or drink**

If eating and drinking has stopped, but I repeatedly show by words or gestures that I want to eat or drink, I want my caregivers to reassess my palliative care and (*initial one*):

__ continue to withhold all help with eating and drinking.

__ give me only enough food and drink to avoid discomfort, even if it's not nutritionally adequate (also known as 'minimal comfort feeding'). **I understand this approach will likely prolong my dying process.**

**6. Medical facilities and providers that will not honor this directive**

**Before** I receive care from a medical facility or provider (including my physician or residential hospice, or long-term care facility), I want the facility or provider to confirm it will follow the instructions in this directive. If the medical facility or provider will not follow the instructions in this directive due to moral, ethical, or other reasons, my decision-maker should make all reasonable efforts to make sure I get care from a facility or provider that will.

(*Initial if selected*)

__ **After** I am admitted or receiving care, if a facility or provider will not honor the instructions in this directive, my decision-maker should make all reasonable efforts to make sure I get care from another facility or provider that will. I understand this means I may be transferred to another medical facility or living situation that might cost more or be less convenient.

If a medical facility or provider will **not** follow this directive due to legal or institutional barriers, I want to be given only enough food and drink to avoid discomfort even if not nutritionally adequate (also known as 'minimal comfort feeding').

**7. Dispute resolution**

My decision-maker will resolve any disagreement about the instructions in this directive and/or whether the conditions I have chosen have been met.

If no decision-maker is available, then I want my medical providers to make these decisions if that is legally allowed.

If any part of this directive is determined to be legally invalid, all other parts should be honored.

**8. Health care decision-maker**

__ I have named a health care decision-maker in the following legal document (*initial one and attach a copy, if possible*):

__ Power of Attorney for Health Care

__ Other document (*name*): _____

__ I have **not** yet named a health care decision-maker.

**9. Other advance planning**

I intend this directive to supplement any existing documents about my end-of-life care. This directive does not revoke any existing documents except with respect to receiving food and liquid by mouth, in which case this directive shall govern.

I have the following other documents about advance planning or end-of-life wishes:

Name: _____

Name: _____

Name: _____

Name: _____

**10. Liability Waiver**

I voluntarily assume any and all risk associated with my choice to use VSED as an end-of-life option. I release all persons, including my health care decision-makers, medical providers, caregivers (including but not limited to my physicians, nurses, care facilities, doulas, or personal care providers, etc.), and family members and other loved ones from any and all liability that could result from any and all actions they may take in good faith reliance on my wishes as described in this directive. This includes my express release of civil liability and my strongly held wish that they **not** be subject to any criminal or disciplinary sanctions.

Further, I direct my estate to hold harmless and indemnify my health care decision-makers, medical providers, caregivers, family members, and other loved ones for acts done according to this advance directive in good faith.

Finally, I wish to make it clear that I am making this directive of my own free will and am doing so intentionally to ensure that my medical care is consistent with my stated wishes. As a result, I regard any action taken to undermine my wishes as described in

this directive as medical battery and authorize my surrogate and/or my estate to pursue such a claim on my behalf.

**11. Capacity**

I am making this VSED Directive because if I cannot make decisions for myself, I want my decision-makers, medical and long-term care providers, caregivers, family, and other loved ones to honor every part of this directive.

I am of sound mind. I am voluntarily signing this VSED Directive and understand what it means. I make this advance directive of my own free will, and I have the mental and emotional capacity to do so.

I understand that honoring this directive might cause me to die sooner than if I received help with eating and drinking.

**[Sign only in the presence of a notary or qualified witnesses]**

_____ ▶ _____

Date My Signature

_____

Print name

## ➢ Notarization and Witnessing

While it is best to have this document both notarized and witnessed, in most places this document is legally binding with either one or the other.

**Notarization**

State of _____

County of _____

Signed or attested before me on (*date*): _____

by (*name*):_____.

▶ _____

Signature of Notary

Notary Public for the State of Washington.

My commission expires _____.

**Statement of Witnesses**

I, the witness, declare that the person who signed or acknowledged this VSED Directive:

- Is personally known to me
- Signed or acknowledged this VSED Directive in my presence
- Appears to be of sound mind and under no duress, fraud, or undue influence

I also declare that I am over 18 years of age (19 in Alabama) and that I am:

- **Not** the person's health care agent, decision-maker, or alternate decision-maker
- **Not** the person's health care provider, including an owner or operator of their long-term care, residential, or community care facility
- **Not** an employee of the person's health care provider
- **Not** financially responsible for the person's health care
- **Not** an employee of a life or health insurance provider for the person
- **Not** related to the person by blood, marriage, or adoption
- **Not** a beneficiary of any legal instrument, account, or benefit plan of the person
- **Not** a creditor of the person or entitled to any part of their estate under a will or codicil, by operation of law

(*Some states may have different rules about who may be a witness. Unless you know your state's rules, please follow the above.*)

**Witness 1**

▶ _____
Signature

Print name: _____

Address: _____

_____

Phone: _____

**Witness 2**

▶ _____
Signature

Print name: _____

Address: _____

_____

Phone: _____

# Advance Directive for Living with Dementia

My name is _____. My date of birth is _____.

I am a person with decision-making capacity. I voluntarily sign this mental health directive under RCW 71.32.260. If I cannot make decisions for myself, my relatives, friends, agents, and medical providers should fully honor every part of this directive. If any part of this directive is invalid, the rest should be honored. I revoke any Advance Directive for Living with Dementia that I have signed in the past.

This directive instructs my health care agent or other legal decision-maker ("decision-maker") and all caregivers how to act on my behalf.

1. **I have written this advance directive because:**
   - ☐ Skip this section.
   - ☐ I have a current diagnosis of dementia and want to plan ahead.
   - ☐ I have **no** current diagnosis, but want to plan ahead.
   - ☐ Other (*Example: I've seen others with dementia and know what I would want*):

     _____
2. **Start date.** This directive is effective (*check one*):
   - ☐ Now.
   - ☐ Only if I can't make decisions for myself (if I'm incapacitated).
   - ☐ When my decision-maker determines that any of these circumstances, symptoms, or behaviors have occurred (*check all that apply*):
     - ☐ I can no longer communicate verbally.
     - ☐ I can no longer recognize people who are important to me.
     - ☐ I put myself or others in danger because of my actions or behaviors.
     - ☐ Other (*describe*): _____

       _____
3. **End date.** I want this directive to remain in effect until revoked.
4. **Revocation.**

   As your dementia progresses, you may worry you'll reject the decisions and preferences you've made in this directive. If so, select the first option below. This means you **can't cancel** this directive unless you're able to make decisions for yourself (you have **capacity**).

   I can cancel (revoke) this directive (*check one*):
   - ☐ **Only when I can make decisions for myself (when I have capacity).** I understand this means I can't cancel this directive unless I have capacity. It means I may receive the medical and personal care listed in this directive even if I object at the time.
   - ☐ **Even if I cannot make decisions for myself (if I'm incapacitated).** I understand this means I can cancel this directive at any time. This means I may not get the medical and personal care listed in this directive when I am incapacitated.

**5. Health care decisions**

I want whoever makes dementia care decisions for me to do as I would want in the circumstances, based on the choices I express in this directive. If my wishes are not known, then I want decisions to be made in my best interest, based on my values, this directive, and information provided by my health care providers.

**6. Personal history and care values statement**

☐ None.

☐ Attached.

## ➢ Preferences and instructions about my care and treatment

**7. Care in my home**

☐ Skip this section.

☐ If I need personal care and assistance in my home, I want these people to provide it: (*Check all that apply*)

☐ Volunteer caregivers who are friends or family.

☐ Volunteer caregivers who are **not** friends or family.

☐ Paid caregivers who are friends or family.

☐ Paid caregivers who are **not** friends or family.

Other details about who I want to provide care in my home (*Example: Specific people you do or **don't** want involved. It's okay to leave this blank.*)

_____

_____

**8. Out-of-home placements**

☐ Skip this section.

☐ If I can't receive care in my home, I want to receive care in the following place/s, if possible: (*Check all that apply.*)

☐ A friend or family member's home.

Name (*optional*): _____

☐ Adult family home.

Name and/or location (*optional*): _____

☐ Assisted living facility.

Name and/or location (*optional*): _____

☐ Nursing home.

Name and/or location (*optional*): _____

☐ I know that it may not be possible for me to receive care where I want, given my needs and circumstances at the time. I trust my healthcare decision-maker/s and know that they will make the best decisions for me after considering my values, and consulting with my loved ones and care providers.

Other details about where I want to receive care (*Examples: If one of these options is your first or last choice, if there's anywhere you **don't** want to live, or if you prefer a memory care facility. It's okay to leave this blank.*)

_____

_____

**9. Cultural, religious, and/or gender preferences about my care and assistance**

☐ Skip this section.

☐ (*Describe*) _____

_____

_____

_____

_____

**10. Assessment.** If someone needs to do an assessment or make recommendations about my ability to remain in my home, I prefer this be done by the following person/s or agencies:

☐ No preference.

☐ (*Name/s*) _____

**11. Psychiatric Hospitalization**

Sometimes people with Alzheimer's or dementia become aggressive, assaultive, or combative, despite good care. If this happens, emergency or other treatment may be necessary. You can consent to psychiatric hospitalization in advance. If you don't consent, someone would have to get a court order for your involuntary commitment to a psychiatric hospital.

***Important!*** By consenting to inpatient mental health treatment now, while you are well, you may get treatment sooner if you decompensate.

☐ Skip this section.

☐ Check one *(sign if consenting):*

☐ **I consent** to voluntary admission to inpatient mental health treatment for (*up to 14*) _____ days if my mental health care agent and treating medical providers decide it is appropriate. I prefer to receive treatment in a facility specializing in Alzheimer's/dementia care to reduce my behavioral symptoms and stabilize my condition.

▶ _____

My signature (*in front of a notary or witnesses*)

☐ **I don't consent** to inpatient mental health treatment.

**12. Psychiatric hospital or other facility preferences**

☐ Skip this section.

☐ If I need hospitalization, I prefer to go to a specialized dementia care unit at:

_____

☐ If I need hospitalization, I **don't consent** to these hospitals or facilities:

_____

☐ I want treatment from trained caregivers who know me and my history, and who know how to handle the situation.

**13. Financing my care**

☐ Skip this section.

☐ I know that the cost of my care could become high over the course of my illness. I have the following preferences about financing my care (*check one*):

☐ Please use my income, assets, and savings to buy the highest quality private care forme, even if this requires selling my home and other property.

☐ I want to preserve my income, assets, and savings for my partner/spouse, children, and heirs, if possible. Please use all available planning options to meet this goal, including, but not limited to (*check all that apply*):

☐ Medicaid planning

☐ Gifting

☐ Divorce or legal separation

☐ Changing estate planning documents

☐ Tax planning

☐ Other: _____

_____

**14. Future intimate relationships – partner or spouse**

☐ Skip this section.

☐ My partner or spouse is (*name*):_____.

**a. Preferences about continuing our intimate relationship** (c*heck all that apply*):

☐ My intimate relationship with my partner/spouse is important to us.

☐ We want to maintain our sexual relationship for as long as possible.

☐ I completely trust my partner/spouse to make any judgments about continuing our intimate relationship, including when to stop if they're no longer comfortable.

☐ I want to maintain our sexual relationship even if we divorce or end our legal domestic partnership for financial reasons.

☐ If I need nursing home care, I request the privacy needed for us to continue our relationship, as required by law.

☐ I know that I may forget my partner/spouse as my Alzheimer's or dementia progresses. If this happens (*check one*):

☐ I want to continue to be intimate for as long as my partner/spouse wants to and feels comfortable doing so.

☐ I **don't** want to continue to be intimate with my partner/spouse.

☐ Other preference/s: _____

_____

**b. Preferences about my partner/spouse having relationships with someone else** (c*heck one*):

☐ I want my partner/spouse to seek companionship and intimacy when I can no longer provide that in our relationship if they wish to do so. I would not consider this a violation of our vows or commitment to each other. I understand that my illness may last a long time, and that I may no longer recognize or be able to function emotionally or sexually with my partner/spouse.

☐ I **don't** want my partner/spouse to pursue a relationship outside our partnership/marriage or other committed relationship.

Other preference/s, if any: _____

_____

**15. My future intimate relationships**

☐ Skip this section.

☐ Whether or not I have a current partner or spouse (c*heck one*):

☐ I know that residents at long-term care facilities sometimes develop intimate or romantic relationships with each other. I am not opposed to having such a relationship if my caregivers or medical providers believe the relationship improves my mental health and I am not coerced in any way.

☐ I **don't consent** to any intimate relationships, even if the relationship improves my mental health, except as stated in section 14 if I have a spouse or partner.

Other preference/s, if any: _____

_____

**16. Driving**

☐ Skip this section.

☐ If it's unsafe for me to drive, I agree that people can take steps to stop me from driving including hiding my keys, disabling my car, and denying me access to my car.

The decision about whether I'm safe to drive can be made by (*check all that apply*):

☐ My legal decision-maker/s.

☐ A qualified professional who can test my visual and mental acuity.

**17. Pets**

☐ Skip this section.

☐ I don't have any pets.

☐ When I can no longer care for my pets, I prefer (*describe who you want to care for them or if someone has agreed to adopt them*):

_____

_____

**18. Participation in experimental Alzheimer's or dementia drug trials** (*check one*):

☐ Skip this section.

☐ **I consent** to participation in any clinical drug trials for drugs that might improve the symptoms of Alzheimer's/dementia or prevent the full onset of the disease. I am willing to participate in the trial even if it could lead to my earlier death. I would rather die sooner but with my memory more intact.

☐ **I don't consent** to participation in any drug trials.

**19. Durable Power of Attorney for Mental Health Care**

> ***Important!*** *A general power of attorney for health care can't authorize mental health hospitalization. If you want your power of attorney to be able to consent to this (in section 10, above), you must complete the power of attorney for mental health care section below. You should appoint the same person as your agent for mental health care as for general health care to avoid confusion.*

☐ I am **not** appointing a power of attorney **for mental health care**.

☐ I am appointing a power of attorney for mental health care as follows. I revoke (cancel) any other power of attorney **for mental health care** documents I signed in the past.

**a. Agent.** I choose (*name*): _____ as my agent with full authority to manage my mental health care.

☐ **Alternate.** If the agent named above is unable or unwilling to act, I choose (*name*): _____ as my agent with full authority to manage my mental health care.

☐ **2nd Alternate.** If both the agent and alternate named above are unable or unwilling to act, I choose (*name*): _____ as my agent with full authority to manage my mental health care.

**b. Spouse or partner.**

☐ Does not apply. I didn't name my spouse or partner as an agent or alternate.

☐ One of the agents or alternates named above is my spouse or domestic partner. If we divorce or legally separate (*check one*):

☐ Their authority to act as my agent is revoked.

☐ They will continue to have authority to act as my agent.

**c. My Rights.** I keep the right to make mental health care decisions for myself if I am capable.

**d. Durable.** My agent can use this power of attorney to manage my affairs even if I become sick or injured and cannot make decisions for myself. My disability will not affect this power of attorney.

**e. Revocation.** I understand that I may revoke this power of attorney at any time by giving written notice of revocation to my agent.

**f. Powers.** My agent shall have full power and authority to make mental health treatment decisions on my behalf, consistent with any instructions and/or limitations in this directive. If my agent does not know my wishes, I authorize my agent to make the decision that my agent determines is in my best interest.

g. **Nomination of Guardian.** I nominate my agent as my guardian for consideration by the court if guardianship proceedings become necessary.

h. **HIPAA Release.** I authorize my healthcare providers to release all information governed by the Health Insurance Portability and Accountability Act of 1996 (HIPAA) to my agent.

**20. Other documents**

In planning for my health care, estate, and potential incapacity, I have signed the following documents (*check all that apply and attach copies, if possible*):

☐ Durable Power of Attorney for Health Care (**not** mental health)

☐ Durable Power of Attorney for Finances

☐ Health Care Directive ("Living Will")

☐ Other (*Examples: POLST, Advance Directive for Voluntary Stopping of Eating and Drinking (VSED)*):

_____

_____

I understand the purpose and effect of this Advance Directive for Living with Dementia. I understand consent to treatment or admission in this directive constitutes my informed consent. I am signing of my own free will for the purposes stated in this document.

▶ _____ _____

My signature (*in front of a notary or witnesses*) Date

**Notarization (preferred)**

State of Washington
County of _____

This document was acknowledged before me on (date) _____

by (name) _____.

▶ _____

Signature of Notary

Notary Public for the State of Washington.

My commission expires _____.

**Statement of Witnesses (only if you cannot find a notary)**

On (*date*): _____, (*name*): _____ signed this Advance Directive for Living with Dementia in my presence. This person is personally known to me or provided proof of identity. I believe they are able to make health care decisions, to understand this document, and to have signed it voluntarily. They don't appear to be acting under duress, undue influence, or fraud.

I am **not**:

- A person designated to make medical decisions for them
- A health care provider or professional directly involved in their care at the time the directive is made
- An owner, operator, employee, or relative of an owner or operator of a health care facility or long-term care facility where they are a patient or resident
- A person related by blood, marriage, or adoption to them
- In a dating relationship with them (see RCW 7.105.010)
- A minor or incapacitated person
- A person who would benefit financially if they undergo mental health treatment

**Witness 1**

▶ _____
Signature

Print Name: _____

Address: _____

_____

Phone: _____

**Witness 2**

▶ _____
Signature

Print Name: _____

Address: _____

_____

Phone: _____

# Advance Directive for Living with Dementia
# Attachment: Contact info

## My information

My name _____

My date of birth _____

My phone number _____

My email address _____

My mailing address _____

_____

My primary care medical provider

_____

## Power of attorney

☐ I have a **Durable Power of Attorney for Health Care** that let someone else (an "agent") make health care decisions for me if I'm not able.

## My health care agent (if any)

Name _____

Relationship to me (*Examples: friend, partner, spouse, sister, etc.*)

_____

Phone _____

Email _____

## My alternate health care agent (if any)

Name _____

Relationship to me (*Examples: friend, partner, spouse, sister, etc.*)

_____

Phone _____

Email _____

## My 2nd alternate health care agent (if any)

Name _____

Relationship to me (*Examples: friend, partner, spouse, sister, etc.*)

_____

Phone _____

Email _____

## Record of Directive

I've given a copy of this directive to the following people:

# Advance Directive for Living with Dementia
# Optional Attachment:
# Personal History and Care Values

I want my caregivers, family, and friends to know and remember who I am and what is important to me for when I may not be able to remember or fully express this.

**Important people in my life:**

**My education, work history, skills, accomplishments:**

**Things I love to do or to experience:**

**Important events in my life:**

**How I would like caregivers, family, and friends to treat and care for me if I can no longer say** (*Examples: Treat me as an adult, not a child; allow me privacy when dressing, bathing, and toileting; help me maintain my personal hygiene and appearance.*):