

Your Conversation Starter Guide

For Caregivers of People with Alzheimer's or Other Forms of Dementia

How to understand what matters most to someone living with Alzheimer's or another form of dementia, and help them have a say in their health care.



the **conversation** project

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.

We know it can be hard to start conversations about health care through the end of life with someone you care for. It can be even harder when the person has Alzheimer's disease or another form of dementia.* Over time, they begin to lose their memory, capability to independently perform daily routines and tasks, or reasoning ability.

As dementia progresses, it will become harder for the person you care for to express their wishes for care. Having conversations early and often can help you know their values and wishes. Then, you will be better informed to make health care decisions on their behalf.

That's why it's best to start a conversation before any treatment decisions need to be made. Sometimes, we might avoid the conversation by telling ourselves, "it's too soon." But it always seems too soon, until it's too late.

Caring for someone with dementia is a long-term commitment that can have many challenges. This guide was created to help you, someone who cares, prepare yourself and others to make health care decisions for the person you are caring for as 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.

* To keep it simple, this guide uses the term "dementia/dementias" to refer to both Alzheimer's and other forms of dementia.

We'll take it step by step.

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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.

Understanding Alzheimer's and Dementia

Alzheimer's and other forms of dementia are diseases. Unlike other diseases like cancer or heart disease, dementias affect thinking and behavior.

Dementias are terminal, which means people with advanced dementia usually die from health problems caused by the disease. Because the disease may last a long time, many people do not understand that dementia is a terminal illness. It can help to think about a person who dies from cancer. If someone with cancer dies from an infection or eating problems caused by the weakness of their body from having cancer, most people would still say they died from cancer.

In the same way, people with dementia often have infections or eating problems near the end of life because their bodies are weakened. Dementia is the illness that leads to their death.

Each person living with dementia is unique. Different forms of dementia may affect different parts of the brain. Some people mostly have memory loss, while others have changes in personality, hallucinations, or other changes. To learn tips that can help you communicate, try asking the health care team for resources or websites about the specific kind of dementia your person has.

It is important to understand that unlike many other illnesses, dementia often makes people become unable to see the effects of the illness on their life and the people around them. Starting a conversation early on can help your person have a say in their care.

Adapted from "Advanced Dementia: A Guide for Families," created by an interdisciplinary team from Hebrew SeniorLife and Beth Israel Deaconess Medical Center: Susan L. Mitchell, MD, MPH, Angela G. Catic, MD, Jane L. Givens, MD, MSCE, Julie Knopp, APRN, MSN, and Julie A. Moran, DO.

STEP 1

Prepare

To get ready to talk with someone you care for about their wishes for care through the end of life, put your ideas together first.

Here are some helpful ways to think about it.

> What if I feel afraid to talk?

It may seem unkind to suggest to the person you care for that they are losing their mental ability. You may feel sad, afraid, or alone. You may be worried that the person you care for will be upset, depressed, or angry. Dementia causes changes in the brain, often making it hard for someone with the illness to know they have it. What may look like denial is often a lack of awareness. The goal is to learn about the person's values and needs, and to document them. That way, other people can understand and support these values and needs. It is not necessary for the person to acknowledge their diagnosis.

Fears can make it feel more comfortable to wait to have a conversation “until next time.” It may seem easier to talk when the person isn't there, or to pretend that memory problems or other changes are not a big deal or aren't happening. You may want to protect yourself and the person you care for, which is understandable.

These feelings are common. And it's important, for your sake and the sake of the person you care for, to start the conversation now.

> What if they insist “there's nothing wrong” ? What if they don't want to have the conversation?

Sometimes it's difficult for people to talk about a terminal illness. This can be especially true for someone with dementia. They might insist that “there's nothing wrong,” and may be suspicious of your reasons for having the conversation.

Make clear that the conversation is for everyone — not just for them. Remember that dementia can make it hard for them to see what is happening. It can be helpful to have the conversation “both ways” — where both of you talk about your wishes for health care through the end of life.

If the conversation seems overwhelming or confusing, you can ask about their concerns. Listen carefully to their worries, change your approach if needed, and gently try to move the conversation forward. You can also ask if there is someone else they trust who they would prefer to make these decisions for them if needed.

> What if I'm worried that my questions are unkind?

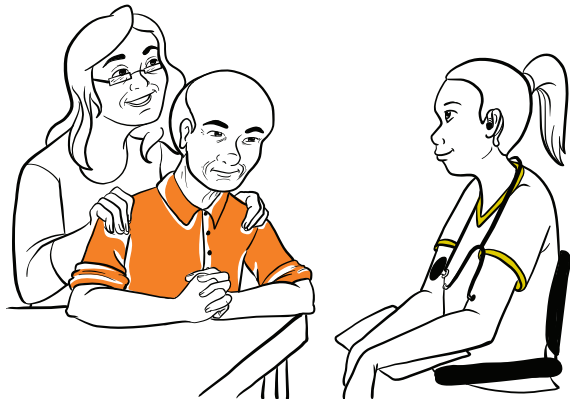
Helping someone with dementia have a say in their health care through the end of life is an act of kindness and caring. In fact, it may be the most meaningful way to show the person you care for that you will be there for them. By listening carefully and respectfully, you can understand their worries and reassure them that even when they lose the ability to make decisions, you will respect them and speak about their wishes. They will continue to have their wishes heard, through you.

Conversations clarify. They can give back some control during a time when things may feel out of control.

> What if they react negatively or think I'm trying to upset them?

Different people with dementia think differently about their illness, and one person may think or act differently at a different stage of illness. Because of changes in the brain, they may or may not understand they have dementia. Whether they worry or not, the reaction is often about their own thoughts and feelings, not about you. Many people who have thinking or memory problems — whether that means losing their way home, forgetting how the TV remote works, or figuring out how to pay a bill — may feel afraid, vulnerable, or lonely. Dementia can also affect people's emotional reactions.

It can be helpful to focus on feelings, not facts. In other words, if the person is upset, try to respond to their feelings rather than arguing. Dementia may change the way the world seems to them. Focus on listening, showing respect, caring, and helping them to feel safe.



➤ What if they don't want to talk or have a hard time getting started?

That's okay. Pay attention to your tone. This is a time to be gentle, curious, and humble. Don't pressure someone into talking. Remind yourself that they may not be able to see any changes in themselves.

Take note of situations that might invite conversations such as the experience of friends and family, or illness and death in TV or books.

The idea of one big conversation can be overwhelming. Instead, you can have several short conversations. Pick just one question at a time. There are some ideas on the following pages.

The person may be willing to answer a few yes/no questions about what matters. For example, "I think that something you really value is _____ Does that sound right to you?"

Confirm who will make decisions. Try saying, "I understand you don't like talking about this. Are you comfortable with me making decisions if you can't speak for yourself? Is there someone else you want to make decisions?"

Use whatever language feels right to help your person be more comfortable. For example: "I need your help with something." "What does a good day look like for you?" "I want to make sure I know how you feel." "We'll figure this out together." "What do you think about _____" when a relevant situation comes up.

If the person really doesn't want to talk, take a pause. Keep the door open for more conversations in the future. The person may or may not remember the previous conversation.

When communication becomes more limited, these questions may be hard for the person to understand. You can use other ideas in this guide to reflect on what matters to the person.

You're not alone; it's normal to feel afraid.

It's also normal for the person you care for to feel afraid.

Conversations show the person that you care and you will be there for them.



Tips for your talk

- People in the early stages of dementia will often share that they are nervous about losing their memory or their ability to do things they used to be able to do. It's important not to ignore this — for example, by saying, “Oh, Dad, we all forget things as we get older.” In fact, saying something like “tell me more” can be an opening to begin a longer conversation.
- Even though dementia makes a person lose their thinking abilities over time, there might be moments when the person you care for can remember certain things (like music or older memories) better than more recent events (like what they ate for breakfast). Use one of those moments to continue the conversation and ask more questions about their health care wishes.
- When someone is living with dementia, it's important to approach a conversation about their health care in small pieces. Keep it simple. People living with dementia may need more time to process complex information. Too much information, too fast, could feel overwhelming. It's better not to go through too many pages of this guide in just one conversation. When you return to the conversation next time, it could be helpful to review the information you talked about before.
- Having a conversation about health care through the end of life may be difficult for you, too, as a caregiver. But it's also important for you. It can help you feel less guilty, uncertain, and worried when you make decisions for the person you care for, since you will know what they would want. You are doing the best you can. It can also help to share the experience with someone you trust, who can listen and offer ideas.



As a caregiver for a person living with dementia, what do you need to think about or do before you feel ready to have a conversation with them about their health care wishes through the end of life?

STEP 2

Talk



Dementia affects people differently and often varies for each person over time.

When the disease progresses and communication becomes more limited, questions may be hard for the person to understand. You can use other ideas in this guide to reflect on what matters to the person.

EARLY-STAGE DISEASE

In early-stage dementia, the symptoms can be subtle. The person may not yet have a formal medical diagnosis. In fact, many people never get one. Even without a formal medical diagnosis, it can be helpful to talk together with their health care team about memory or behavior changes. Routine tasks can become difficult, and the person may need some help with daily activities.

The questions below are a good place to start the conversation. You can encourage them to think about their goals and what matters to them in their care through the end of life. That way they can share this information with you and others who will be involved with making decisions for them.

MIDDLE-STAGE DISEASE

In this stage, communication may be more limited. The person may be confused or not understand what is happening around them. There may still be moments when it's possible to remind the person with dementia about their experiences with someone at the end of life ("Remember when grandma died?"), ask how they felt about it, and learn their preferences for their own experience. You might want to ask questions from the ideas below that seem most important to you for understanding their preferences. Remember that the person might have trouble understanding or answering the questions. They might be irritable, frustrated, or angry.

LATER-STAGE DISEASE

In this stage, the person often does not recognize loved ones, can no longer care for themselves, and cannot express their wishes. As you and others start making decisions on their behalf, it can be helpful to think about how they lived their life, and what values and wishes they expressed in the past. You and trusted family members and friends can review the questions below to help you think about what the person would want.

- > What if the illness is so advanced that the person I care for cannot answer these questions?

The following questions and scales will help you understand the wishes of the person you care for, whether they are able to answer them with you or you answer them based on their past wishes.

Note that the use of “me” and “you” in the questions refers to the person with dementia. If they are unable to answer them with you, it’s best to answer these questions as you think they would. It can help to ask others who know this person well, or may also be involved in their care, to help you think about it and answer the questions.

- > First, finish this sentence:
What matters to me through the end of my life is...

FOR EXAMPLE Being in the hospital receiving treatments, being able to spend time with the people who matter most

Sharing your “what matters to me” statement with those you care about could be a big help down the road. It could help them communicate to your health care team what abilities, such as taking care of yourself or doing activities you enjoy, are most important to you — what’s worth pursuing treatment for, and what isn’t.

- > What are the most important things you want your friends, family, and health care team to understand about what matters most to you through the end of life?

Note: These scales represent a range of feelings; there are no right or wrong answers.

➤ If you become sick with another illness, how much medical treatment do you want to try?



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

➤ If you weren't able to speak for yourself, would you want people to follow all your wishes or do what they think is best in the moment?



I want the people I trust to do exactly what I've said, even if it makes them uncomfortable

I want the people I trust to do what brings them peace, even if it's different from what I've said

➤ 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

➤ When I die...



I want to be alone

I want to be with other people

- Based on your responses, what do you notice about the kind of care you prefer to receive?

- Is there anything else the people who care for you should know about your wishes, so they can make the best decisions for you?

➤ More tips for your conversation

- Thinking about these topics and recognizing the wishes of the person you care for will help guide and protect you as you make the many decisions ahead.
- Keep questions and statements simple and specific.
- If they haven't already, now is a good time for the person to choose and name a health care proxy. The proxy is the person who can officially make medical decisions for them when they can no longer make those decisions themselves. They can also record their wishes as part of advance care planning. For more information, visit our [Guide to Choosing a Health Care Proxy](#).

- If you're a caregiver, this is not about what you would want for yourself in this situation. Think about and write down what the person you care for would want.

It can be helpful to ask, "How would [this person] answer this question? What matters most to them?" You can also think about past situations the person you are caring for has gone through, and how they reacted or what they said about it, for clues.

Here are some questions you, and others caring for this person, can ask yourselves:

- Would they worry about not getting enough care? Or that they would get overly aggressive care?
- Would they be OK with spending their last days in the hospital? Or would they really want to spend their last days at home or in a home-like environment?
- Would they want us to take care of all their needs ourselves, or would they want us to get some help from professionals?
- Would they prefer to be alone most of the time? Or would they prefer to be surrounded by people they care about?
- What are the three most important things they would want us to know about their wishes for care through the end of life?
- What were they especially worried about? What was really important to them?
- What kinds of treatment would they want (or not want)?

Note your answers to these questions in the box below.

STEP 3

Advocate

Once you have a good idea about what matters to the person you care for, and what their wishes for health care may be, you (and others) will be able to advocate on their behalf. This means making sure their health care team knows what is important to that person. The health care team may include doctors, nurses, assisted living staff members, and others.

- Advocating for the care of someone with dementia can be challenging. You may feel overwhelmed by navigating the health care system to care for that person through the end of their life.

IT HELPS TO THINK ABOUT IT IN TWO STEPS:

1. Sharing who the person is

Help the health care team see the person in front of them, not just a patient. For example, share what they were like when they were younger, what they care about, what activities they like, what makes them laugh, and what brings them joy. You can share this by talking or by making a collage with pictures that show who they are and hanging it in their room.

2. Making their wishes clear

Help the health care team know and respect the wishes of the person you care for. For example, write down their wishes and share this document with family and friends, the people who work at the assisted living facility, and their doctor or other members of the health care team. If the person lives at home, you can put the document noting their wishes in a colorful labeled envelope on the refrigerator for emergency responders to find, if needed.

To help make sure the wishes of the person you care for are known and respected as much as possible, it's important that you advocate frequently for them with their health care team. You can find many more helpful tips to help you advocate on the Alzheimer's Association website, alz.org.

For more information on advocating for the person you care for, visit our [Guide for Talking with a Health Care Team](#).

STEP 4

Learn from Others

You've prepared to talk with someone who is living with dementia, had a conversation or thought about their wishes, and learned some ways you can advocate for them. Now, here's some advice from people who have cared for someone living with dementia.

FROM A FAMILY MEMBER

"One thing that charmed my mother at the end of her life was watching the birds on a bird feeder. It never would have occurred to me to put into a document like this that 'As long as she can enjoy nature and feel pleasure, she would want to be alive.' But I know that now. In the end, it was the simple things — watching a grandchild play, watching a bird — that mattered most to her."

FROM A SOCIAL WORKER

"I tell families at the beginning that everything about living and loving someone with dementia is counterintuitive. The person with middle-stage dementia has lost their abstract thinking. For example, if you tell someone they have a doctor's appointment in two days, they'll start worrying about it and ask you every five minutes. The counterintuitive advice is to not tell her, but get her dressed."

FROM A DOCTOR

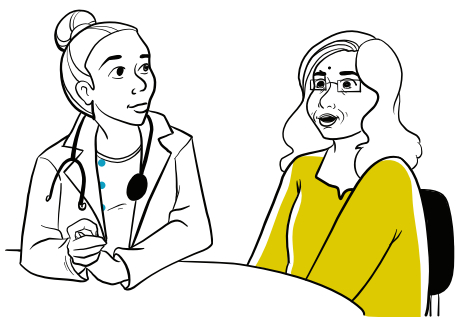
"I get people in the clinic at different stages. Doing it alone — not seeking help or advice — can be so isolating for family members. Connect with others at an earlier stage. There is so much out there."

"Dementia is a disease. It's a disease that you don't have to take personally. We have family members come in and they are angry at their family members because they are doing some things that are bizarre. It's important to help families understand it's not their choice to act this way. They don't have a choice."

FROM A SPOUSE/PARTNER

"What is enormously helpful is the support group. Because you feel that you're the only one this is happening to and a doctor never says, 'That's terrible!' They're not that emotional. In support groups people can say, 'That happened to me.'"

"That's what I learned: share, share, share, and share again."



It's important to keep talking — talk to anyone who can help the person you care for have a say in their care. The role you play in this person's care is very important and will help them live their best life possible.

Learn more about Alzheimer's disease and other forms of dementia through these resources: [alz.org](https://www.alz.org) and [newsinahealth.nih.gov/special-issues/seniors/dealing-dementia](https://www.newsinahealth.nih.gov/special-issues/seniors/dealing-dementia)

Other causes of dementia include Lewy Body Dementia —visit [lbda.org](https://www.lbda.org) to learn more – and Frontotemporal Degeneration — find more information at [theaftd.org](https://www.theaftd.org).

Find more information, including our [Conversation Starter Guide](#), blog posts, personal stories, and more tips for talking at theconversationproject.org

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