



Your Conversation Starter Kit

For Families and Friends of People
with Alzheimer's Disease or Other
Forms of Dementia



Institute for
Healthcare
Improvement

the conversation project

CREATED BY THE CONVERSATION PROJECT AND THE INSTITUTE FOR HEALTHCARE IMPROVEMENT

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.

We developed the original Conversation Starter Kit as a useful tool to help people have conversations with their family members and friends about their wishes.

After we posted the Conversation Starter Kit on our website a few years ago, several people contacted us about the need for an additional resource: **a Starter Kit specifically designed to help families and friends of people with Alzheimer's disease or another form of dementia are looking for guidance on how to "have the conversation."**

We responded eagerly — partly because we, too, have personal experience of caring for family members and friends with Alzheimer's disease and other forms of dementia. We appreciate the difficulty — and the importance — of having these conversations. We hope you find this new Starter Kit helpful in beginning, and continuing, these conversations with your family members and friends.

NAME

DATE

It's not easy for anyone to begin the conversation about how they want to live at the end of their lives — about the care they want, and the care they don't want. But it's both more difficult and more important to have this talk as soon as possible if your family member or friend has Alzheimer's disease or another form of dementia.

The reason for this is simple: as your family member or friend's disease progresses, and his or her ability to think and share thoughts declines, it will become more difficult for your family member or friend to express his or her wishes. And yet, knowing those wishes will be a critical guide to help you through the many decisions that you may have to make.

This guide will not only help you to begin these talks in the early stages of decline. We will also share some ways to use the Starter Kit on your family member or friend's behalf even when the illness is so advanced that he or she cannot express his or her own thoughts.

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Thanks to Julie Michaels, Andrea Kabcenell, Ellen Goodman, Barbara Moscovitz, Constance Holden, Jean Abbott, Carol Loria, Susan Mitchell, and Ruth Kandel for sharing their stories, experience, and wisdom. Their invaluable contributions are at the heart of this document.

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Step 1 Get Ready

“Should I have the conversation with my family member or friend?”

- What if he insists that “there’s nothing wrong” with him?
- What if she says she doesn’t want to have the conversation?

We know how hard it can be to start conversations about end-of-life care with a family member or friend. The primary reason we give for postponing the conversation is telling ourselves that “it’s too soon.” But as we say in The Conversation Project, “It’s always too soon until it’s too late.”

This is especially true when the people we care about begin to lose their memory, their cognitive ability — word by word, step by step — along with their ability to function in the world. And at no time is the need to have these conversations greater.

We often hesitate because it may seem unkind to suggest to the people we care about that they are losing their mental ability. We are often so afraid ourselves when we see the clues, the symptoms, and then hear the diagnosis. It’s normal to be held back by our own fear of the future, afraid of loss, or what will happen.

We may feel alone. And we may fear that our family member or friend’s response would be that of denial, anger, or depression. It is tempting to postpone the talk until tomorrow, or the next doctor’s appointment, or after the holidays. It seems easier to talk around the person, to pretend that the memory lapse is normal at his/her age, and to join in a conspiracy of denial. Indeed, we may want to protect our family member or friend from the judgment, and even ridicule, of others in their world.

Having the conversation lets your family member or friend know that you will be there for them.

There is no single way that people with Alzheimer's disease or another form of dementia think about or react to their symptoms. But most are far more aware than we think. Some choose denial. Some worry privately. Many, perhaps most, people who are experiencing cognitive decline — who lose their way home, who cannot work the TV remote or figure out the tip on the bill — become frightened themselves. Without a trusted confidant, they may feel extraordinarily vulnerable and increasingly lonely as the disease progresses.

Having the conversation about care, and especially care at the end of life, isn't an intrusion, nor is it unkind. On the contrary, it may be the most intimate way to promise your family member or friend that you will be there for them. By listening carefully and respectfully, you share their worries and promise that even when they lose the capacity to make decisions, you will be their voice; that you will respect them and their wishes, that they will not disappear.

"I know it's important to have the conversation as early as possible — but what if my family member or friend insists that 'there's nothing wrong' with him? What if he doesn't want to have the conversation?"

Be gentle. Sometimes it's really difficult for people to talk about the end of their lives — because it means facing the reality of our mortality. This can be especially true for someone who has recently been diagnosed with early-stage Alzheimer's disease or another form of dementia. It's normal for people to be in denial — to insist that "there's nothing wrong" with them or to be suspicious of why you want to have the conversation.

How to deal with this? Make it clear that the conversation is for everyone — not just for them. Have the conversation "both ways" — both of you tell each other what your wishes are for end-of-life care. Or if the conversation seems overwhelming or confusing, ask if they would rather have a trusted family member or friend make these decisions for them.

REMEMBER

- People in the early stages of Alzheimer's disease or another form of dementia will often express some anxiety about memory loss or loss of their ability to do things they used to be able to do easily. It's important to not to simply dismiss this — *"Oh Dad, we all forget things as we get older."* Instead, **this may be an opening to establish yourself as someone they can really talk to — "Tell me more."** It can be an opening to begin a longer conversation.
- **Even though dementia is a long and steady decline, there are "moments"** when a person with dementia may remember certain things (like music or distant memories) better than more recent events (like what they ate for breakfast). Use one of those moments to carry on the conversation if you wish to ask for more input about care wishes.
- With cognitive decline especially, **it's important to have this conversation in small bites. And keep it simple.** People with Alzheimer's and other forms of dementia get overwhelmed rather quickly. Don't expect to go through several pages of the Starter Kit in one conversation. And when you return to the conversation, you'll likely have to repeat the questions you went through before.
- **It is critical to do this as soon as possible.** While you can. There's a great deal you can do to help your family member or friend have as good a quality of life for as long as possible. Yet, remember that Alzheimer's and other forms of dementia are terminal illnesses. The sooner you can start having the conversation, the better.
- This is hard for you, too. You are talking about losing a family member or friend before you actually lose him/her. **Having this conversation is important for you, too** — to avoid the kind of guilt and uncertainty and depression that can accompany making these decisions on your own, without knowing what your family member or friend would have wanted. Remember that you are doing the best you can. Get help; share this experience with a trusted family member or friend rather than hiding it.

A WIFE

"He doesn't want anybody to know about his dementia. He sees an old friend at the gym who doesn't know he's sick, and so then he gets in a problem with a conversation and has trouble with it but is just embarrassed and doesn't tell them he has Alzheimer's disease."

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A SISTER

"I was in a state of great relief when my sister's doctor finally told her she had Alzheimer's and I said to my husband, 'Now we can finally talk about it.' But of course then the next day she had forgotten — because she had Alzheimer's."

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A SISTER

"I remember when I had to tell my sister that she could no longer make speeches or travel out of town. We were sitting at the kitchen table. I was talking truth to powerlessness. She looked up and said, 'If I believed that, I'd jump out the window.' That's the sort of thing that makes us terrified to talk about it. But she didn't jump out the window."

Yes, you should have the conversation with your family member or friend — the sooner, the better. Having the conversation is in your family member or friend's best interest — and in your best interest too. It's not easy, but remember: you're doing this out of care and concern.

? What do you need to think about or do before you feel ready to have the conversation with your family member or friend?

Step 2 Get Set

“Okay, I’ve decided that I want to have the conversation with my family member or friend. But how do I begin?”

Again, everyone is different. And each person with Alzheimer’s or another form of dementia will react differently to the disease. If your family member or friend can still express his/her wishes, then you can use the Starter Kit as a guide to the conversation.

REMEMBER

- **Keep it simple.**
- **The most important thing is to find out who your family member or friend wants to make medical decisions for her when she is not able to make them for herself.** (This is called the “substitute decision maker.”)
- **It’s best to be concrete rather than open-ended:** *“If you’re unable to speak out and you want someone to tell the doctor what to do, I’m your gal.”* *“If you think Charlotte would fight hardest for your wishes, she’s your pick.”*
- **Be specific:** *“What do you worry about most — that you won’t be able to stay at home? That you won’t recognize your children? That you’ll be a burden to your family? That you won’t be able to afford a caregiver?”*
- **Knowing your family member or friend’s wishes will help guide and protect you and your family member or friend through the many decisions to come.**

NOTE: The questions and the “Where I Stand” scales on the next few pages are taken directly from the original Conversation Starter Kit. If your family member or friend cannot or does not want to answer these questions, the family should do their best to answer the questions as they think their family member or friend would answer.

As you answer these questions, remember that you are speaking for your family member or friend — not for yourself.

What's most important to you as you think about how you want to live at the end of your life? What do you value most? Thinking about this will help you get ready to have the conversation.

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

Sharing your “what matters to me” statement with your family members or friends could be a big help down the road. It could help them communicate to your doctor what abilities are most important to you — what’s worth pursuing treatment for, and what isn’t.

WHERE I STAND SCALES

Use the scales below to figure out how you want your end-of-life care to be. Select the number that best represents your feelings on the given scenario.

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

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

Only the basics
about my condition
and my treatment

All the details about
my condition and
my treatment

.....

As doctors treat me, I would like...

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

My doctors to do what
they think is best

To have a say in
every decision

If I were in the terminal phase of Alzheimer's or another form of dementia, I would prefer to...

☐ 1

☐ 2

☐ 3

☐ 4

☐ 5

Not know how quickly it is progressing

Know my doctor's best estimation for how long I have to live

? Look at your answers.

What kind of role do you want to have in the decision-making process?

How long do you want to receive medical care?

☐ 1

☐ 2

☐ 3

☐ 4

☐ 5

Indefinitely, no matter how uncomfortable treatments are

Quality of life is more important to me than quantity

What are your concerns about treatment?

☐ 1

☐ 2

☐ 3

☐ 4

☐ 5

I'm worried that I won't get enough care

I'm worried that I'll get overly aggressive care

What are your preferences about where you want to be during your last days?

☐ 1

☐ 2

☐ 3

☐ 4

☐ 5

I wouldn't mind spending my last days in a health care facility

I want to spend my last days at home

? Look at your answers.

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

How involved do you want your family members or friend to be in care decisions?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

I want my family member or friend to do exactly what I've said, even if it makes them a little uncomfortable

I want my family member or friend to do what brings them peace, even if it goes against what I've said

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When it comes to your privacy...

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

I want to be alone when the time comes

I want to be surrounded by my family member(s) or friend(s)

.....

When it comes to sharing information...

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

I don't want my family member or friend to know everything about my health

I am comfortable with those close to me knowing everything about my health

? Look at your answers.

What role do you want your family members or friends to play? Do you think that your family members or friends know what you want, or do you think that they have no idea?

? What do you feel are the three most important things that you want your friends, family, and/or doctors to understand about your wishes and preferences for end-of-life care?

1.
2.
3.

What if the illness is so advanced that my family member or friend is not able to express his or her wishes?

If your family member or friend is no longer able to have the conversation, then it's up to you and your family to do your best to understand his wishes and make sure they are respected. They have a disease that makes it no longer possible for them to answer these questions — so you need to do your best to answer them as you think he would. This is not about your opinion versus your siblings' opinion. It's about all of you doing your best to express and respect what your family member or friend would want.

Gather the family members and do your best to fill out the Starter Kit as if your family member or friend were filling it out.

Instead of thinking about what you think would be best for your family member or friend, try to “bring your family member or friend into the room” — honor her by focusing on what she would want; what she would say if she were able to. Ask, *“How would mom answer this question?” “What matters most to Mom?”* **Do your best to fill in the “Where I Stand” scales with the answers she would have given:**

- Would she worry about not getting enough care? Or that she would get overly aggressive care?
- Would she be okay with spending her last days in the hospital? Or would she really want to spend her last days at home?
- Would she want us to take care of all her needs ourselves, or would she want us to get some help from professionals?
- Would she prefer to be alone most of the time? Or would she prefer to be surrounded by family members and friends?
- If we had to list the three most important things she would have wanted us to know about her wishes for end-of-life care, what would they be?
- What was she especially concerned about?
- What was really, really important to her?
- What kinds of treatment would she want (or not want)?

Ask yourselves, “If we could hear Mom’s voice, how would she answer these questions?”

Using the Conversation Starter Kit at Different Stages of the Disease

- **Upon diagnosis of a condition such as Alzheimer's disease that will result in cognitive decline**, the affected person may wish to use (or be encouraged to use) the Starter Kit to identify values and facilitate conversations with chosen decision makers and other family members who are likely to wish to participate in later decisions about medical care. Appointment of a substitute decision maker and documentation of these wishes is highly recommended. As part of this phase, families and friends may seek more information about what to expect in later stages of dementia and what decisions they are likely to come up against.
- **In the mid-stages of the disease**, there may still be moments when it's possible to remind the person with memory loss about a prior situation of death or dying ("Remember when Mom died?" "Remember when Dad was on a ventilator?"), and reminisce about how that felt.
- **In the later stages of the disease**, when family members or friends are no longer able to express their wishes, families or friends may find it helpful to use the Starter Kit as a guide to come together to reach consensus about the values expressed in the past by the person who has memory loss. It may also be helpful to reflect on how he/she lived his/her life. Remembering family events and the values and opinions the family member or friend expressed in those situations can help anchor such discussions.

It is wise to do this proactively, before any actual treatment decisions need to be made. If substitute decision maker(s) (SDM) have been previously designated, that person might choose to use this process to gain support from the rest of the family. If an SDM hasn't been designated, families should discuss who will make decisions in the future as they are needed.

In Ontario someone will be appointed to act as an SDM according to the following ranked order: the Power of Attorney(s) they appointed when capable; a representative appointed by the Consent and Capacity Board (friends or family may apply to the Consent and Capacity Board to act as an SDM (1-800-461-2036)); a spouse/co-habiting partner of one year or more; an adult child(ren); a parent who has a right to access; a sibling(s); any relative by blood, marriage, or adoption, or a Public Guardian and Trustee.

A Public Guardian and Trustee will be appointed if no person falls under any of the categories listed.

Step 3 Go

Now that you've had the conversation — or you've gathered family members and done your best to fill out the Starter Kit as if your family member or friend was filling it out — you have a good idea of what matters most to him or her when it comes to end-of-life care.

- You're in a good position to make sure the team caring for your family member or friend knows what's most important to him.
- You're in a good position to make sure your family member or friend's wishes are respected as much as possible.

In short, you are the keeper of your family member or friend's wishes — and his or her most important advocate.

This step is about making sure your family member or friend's care team knows his or her wishes — and follows them as closely as possible. In the cases of people with Alzheimer's or another form of dementia, this can be particularly difficult, for a variety of reasons. The complexity of dealing with end-of-life issues for people with dementia is not to be underestimated.

To make sure your family member or friend's wishes are known, provide a written statement of wishes to staff at the assisted living facility, to the primary care provider, to family members — and even leave it in an envelope on the fridge for emergency medical technicians.

Families and friends of people with Alzheimer's or other forms of dementia may feel that the health care system is not there to help them.

A SOCIAL WORKER

"I'm appalled still about the abandonment at every stage along the way for people with Alzheimer's. The essential experience is that one gets that diagnosis of 'mild cognitive impairment' and the advice, 'Don't worry, eat well and exercise. Here is the Alzheimer's Association pamphlet and see you in six months for another round of testing.' Families are literally sent, in my experience, out in shock."

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A SISTER

"It was the failure of a system with good people in a good place. The checklist system graded providers on whether they fed someone who was having trouble swallowing; on whether they weighed, measured, and took blood pressure; when all she needed to do was lie down and get warmed up. When we put her in hospice care, they were the first ones to say, 'Yes, of course your sister is dying.'"

"When my sister was in nursing care, we had a 'family meeting' with the whole team. **They talked about her care, but not about her personhood. I stopped the meeting and said, 'I'd like to tell you about my sister.' Finally, hello, good morning — there's a person here.**"

Alzheimer's and other forms of dementia are diseases — but unlike other serious diseases like breast cancer or heart disease, they're diseases that affect cognition and affect behavior.

A SOCIAL WORKER

"It's useful to make reference to dementia as 'a brain disease' — one that eventually affects the whole body. We know cardiac disease. We know orthopedic disease. But because we know dementia as a disease of behaviors, that is what causes in so many families and patients and employers that confusion and blaming. When you say the brain is diseased, at the least the diagnosis is received and people can move forward."

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A BROTHER

"Sometimes health care facilities, with the best of intentions, keep treating Alzheimer's patients, even at the end, as if they had other diseases ...treating them for infections, pneumonia, cancer... admitting them to the hospital, for example. It's important to make decisions and distinctions between the health care that will keep him comfortable and that which would add other treatments — some painful or confusing — that would add no time...indeed might add stress to the confusion."

IS ADVANCED DEMENTIA A TERMINAL ILLNESS?

Yes, dementia is a terminal illness. This means that patients with advanced dementia commonly die from complications caused by this disease. Some people have a hard time understanding that dementia is a terminal illness. It may help to imagine a patient who died with widespread cancer. If this patient had pneumonia or eating problems in the last few weeks of life from the weakened state caused by the cancer, most people would still consider cancer the underlying cause of death. In the same way, the bodily functions and defenses of patients with end-stage dementia are weakened. As a result, they often get pneumonia or eating problems near the end of life, but advanced dementia is still the underlying major illness leading to these complications and death.

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 4 Keep Going

In Step 1, you began to understand that “having the conversation” with your family member or friend isn’t harmful — far from it. It could be the most important gift you could share with your family member or friend — and your family member or friend could share with you.

In Step 2, you actually “had the conversation” — the first of many. You listened carefully to whatever your family member or friend wanted to talk about — and you let the conversation go where he/she wanted to take it. If your family member or friend is no longer capable of having the conversation, you gathered family members together and “brought him/her into the room” — you did your best to answer the questions as he/she would.

In Step 3, you embraced your role as your family member or friend’s advocate. You made sure that your family member or friend’s care team knew what mattered most to your family member or friend, and to your family — and did your best to make sure your family member or friend’s wishes were respected.

Step 4 is a hard one: Keep going. It means being there for your family member or friend no matter what... even as he or she becomes sicker, and faces death.

Advice from People Who Have Been There

“What do you know now that you wish you had known then?”

A BROTHER

“Don’t be as afraid of invading her privacy. And recognize that Alzheimer’s is a terminal disease.”

“When you start seeing something going wrong with someone’s cognitive function, you feel protective of mental status, rather than reaching out to others. When something’s going wrong, it can go really wrong. My sister almost lost her health insurance because a bill wasn’t paid. And that was the least of it.”

A SOCIAL WORKER

"I tell families at the beginning — 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."

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A WIFE

"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."

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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."

A SISTER

“The shame involved is very parallel to mental illness. There is a lot of shame involved — the more proud or accomplished the people are, the more shame is involved. The behavior can be so off the charts that you want to both protect and hide.”

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A DAUGHTER

“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.”

Alzheimer’s is a brain disease. Treat it like a disease. Don’t treat it like a stigma. As long as you’re ashamed and embarrassed about what’s happening, you don’t get help.

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