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Advance Care Planning and Health Care Decisions: Tips for Caregivers and Families

Knowing what matters most to your loved one can help you honor their wishes and give you peace of mind if they become too sick to make decisions. Unfortunately, only one in three people in the United States has a plan for their future health care in place. There are steps you can take to help your friend or family member navigate future medical decisions — and to be prepared to make decisions for them, if needed. This is part of [advance care planning](#), which involves preparing for decisions about future medical care and discussing those wishes with loved ones.

Create your own plan

NIA's new email series, *Ready, Set, Plan! A Weekly Guide to Advance Care Planning*, will help you start planning for your future health care over seven weeks.

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How to start the conversation about advance care planning

One of the best things you can do as a caregiver is to discuss your loved one's care and treatment preferences in advance. Starting the conversation early is especially important if the person has been diagnosed with a condition that affects their cognitive health, such as Alzheimer's disease or another form of dementia. Here are some ways you might start the conversation:

- **Start simple.** Talking about specific medical treatments or decisions can be scary and overwhelming. Instead, try asking about any concerns they may have, what decisions they may need to make, and who they might trust to make decisions for them.
- **Share what's important to you.** Your loved one may feel more comfortable discussing their preferences if you talk about what matters to you, as well.
- **Remind them why it's important.** Talk about the benefits of having these conversations and creating an advance care plan. By documenting their wishes, they are more likely to get the care they want, and it



[Share this infographic](#) about steps to take after a dementia diagnosis.

can also help loved ones feel less burden, guilt, and depression.

- **Try to be understanding.** After a recent diagnosis or health change, it can be overwhelming and difficult to discuss future health care needs. The person may feel more comfortable talking with someone else such as a doctor or someone in their spiritual community. You can also encourage the person to think about their potential needs and plan to discuss them another time.
- **Keep the conversation going.** Listen carefully to what the person says and encourage them to continue sharing.

If the person is open to creating an advance care plan, you can provide them information on [how to get started](#). It's possible your loved one may not want to put a plan in place. Still, talking to them about their preferences can help you prepare for future decisions. You may also be able to help prepare in other ways, for example by [getting important papers in order](#).

Advance Care Planning: A Conversation Guide

Want to learn more about advance care planning? NIA's guide offers conversation tips, worksheets, and more.



Download or order for free

How to serve as a health care proxy

Most people ask a close friend or family member to be their health care proxy. A health care proxy is typically responsible for talking with doctors and making decisions about tests, procedures, and treatments if a person is unable to speak for themselves. The types of decisions a proxy can make should be outlined clearly in the durable power of attorney for health care, a legal document that names the proxy.

If someone has asked you to be their health care proxy, it's important to consider whether the role is right for you. You may have to discuss sensitive topics, make difficult decisions, and advocate on the person's behalf. Ask yourself:

- **Can I honor this person's wishes and values about life, health, health care, and dying?** Sometimes this can be challenging if your values are not the same.
- **Am I comfortable speaking up on the person's behalf?** It's okay if you don't know a lot about health care, but it's important that you are willing to ask questions and stand up for the person.
- **Are you comfortable dealing with conflict?** A proxy may need to uphold the person's wishes even if other family members, friends, or loved ones don't agree.

If you have agreed to be someone's health care proxy, consider these tips:

- **Talk to the person about their values.** Learn what matters most to them when it comes to life, health care, and dying.
- **Learn about their current and future health concerns.** The more you understand their wishes, the more prepared you will be to make decisions for them when the time comes. Ask if they have any plans in place, like a [living will](#), and walk through it together.
- **Ask for a copy of their advance directives.** This often includes a living will and durable power of attorney for health care forms.
- **Keep a copy of important information.** Make sure to have contact information for the person's health care providers and family members.
- **Ask about other considerations.** For example, is there anyone other than the medical team that you should talk with when making decisions? Are there spiritual, cultural, or religious traditions the person wants you to consider?
- **Continue the conversation.** Have conversations each year and as major life changes happen, such as a divorce, death, or change in their health.

Even when you have a person's decisions in writing and have talked about their wishes, you may still face difficult choices or not be able to follow the person's wishes exactly. Try to reflect on your discussions and do your best to honor the person's wishes to the extent possible.

Learn more about the [role of a health care proxy](#).

What to do when your loved one can no longer make decisions

If your loved one can no longer make their own decisions, you may need to make decisions on their behalf. This can be difficult if you haven't discussed their preferences before. Even if you have, there may be unexpected situations and decisions that arise. Talking with close loved ones and the person's health care team can help you prepare and feel more supported when decisions arise. Try to:

- Talk to family members, friends, or others who know the person well.
- Think about how the person lived their life. What values and wishes did they express in the past? What did they find most meaningful in life?

- Talk with the doctor and health care team about what to expect and the types of decisions you may need to make.

Learn more about [making decisions for someone at the end of life](#)

Tips for navigating the health care system

When a person becomes too sick to make decisions for themselves, family members and caregivers may need to navigate the health care system and find ways to advocate for their loved one's care — especially if a proxy was not named. Use these tips:

- **Ask questions.** If you are unclear about something you are told, don't be afraid to ask the doctor or nurse to repeat it or to say it another way.
- **Make the person's wishes clear.** Share copies of the person's advance directives and the proxy's contact information with the health care team, nursing home staff, or others caring for the person. If the person is still living at home, you can put this information in a colorful envelope near their bed or on the fridge for emergency responders.
- **Write down contact information.** Ask for a specific person on the medical team that you can contact for questions or if the person needs something.
- **Choose one person to make health care choices.** Deciding on a main point of contact for the medical team can help everyone stay more organized, coordinate upcoming appointments, and manage medications or changing medical needs.
- **Keep family members looped in.** Even with one person named as the decision-maker, it is a good idea to have your family agree on the care plan, if possible. If you can't agree, you might consider working with a mediator, a person trained to bring people with different opinions to a common decision.
- **Try to decide on an end-of-life approach.** When it becomes clear the person is nearing the end of life, the family should try to discuss the desired end-of-life care approach with the health care team. This might include [hospice care](#). Discussing the options and making decisions as early as possible can help with planning.
- **Remind the health care team who the person is.** Remind them that the person is not just a patient. Tell them about the person. Share what they were like, discuss the things they enjoyed most, and post pictures in their room.

There may also be people in your community who can help you navigate the health care system. Some hospitals have a patient advocate or care navigator, or you may consider working with a [geriatric care manager](#).

You may also be interested in

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- Learning more about [preparing a living will](#)
- Reading about [organ donation](#) and [brain donation](#)

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www.americanbar.org

CaringInfo

National Hospice and Palliative Care Organization

800-658-8898

caringinfo@nhpco.org

www.caringinfo.org

The Conversation Project

866-787-0831

<https://theconversationproject.org>

National POLST

202-780-8352

info@polst.org

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PREPARE for Your Care

info@prepareforyourcare.org

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