

Making Decisions For Someone At The End Of Life

It can be overwhelming to be asked to make health care decisions for someone who is dying and is no longer able to make their own choices. It is even more difficult if you do not have [written or verbal guidance](#). Even when you have written documents, some decisions still might not be clear.

Addressing A Person's Advance Care Wishes

If the person has written documents as part of an advance care plan, such as a do not resuscitate order, tell the doctor in charge as soon as possible. If end-of-life care is given at home, you will need a special out-of-hospital order, signed by a doctor, to ensure that emergency medical technicians, if called to the home, will respect the person's wishes. Hospice staff can help determine whether a medical condition is part of the normal dying process or something that needs the attention of health care personnel.



For situations that are not addressed in a person's advance care plan, or if the person does not have such a plan, you can consider different decision-making strategies to help determine the best approach for the person.

Decision-Making Strategies: Substituted Judgement And Best Interests

Two approaches might be useful when you encounter decisions that have not been addressed in a person's advance care plan or in previous conversations with them. One is to put yourself in the place of the person who is dying and try to choose as they would. This is called substituted judgment. Some experts believe that decisions should be based on substituted judgment whenever possible. Another approach, known as best interests, is to decide what you as their representative think is best for the dying person. This is sometimes combined with substituted judgment.

These two approaches are illustrated in the stories on the following page.

Joseph And Leilani's Story

Joseph's 90-year-old mother, Leilani, was in a coma after having a major stroke. The doctor said damage to Leilani's brain was widespread and she needed to be put on a breathing machine (ventilator) or she would probably die. The doctor asked Joseph if he wanted that to be done. Joseph remembered how his mother disapproved when an elderly neighbor was put on a similar machine after a stroke. He declined, and his mother died peacefully a few hours later. This is an example of the substituted judgment approach.



Ali And Wadi's Story

Ali's father, Wadi, is 80 years old and has lung cancer and advanced Parkinson's disease. He is in a nursing facility and doesn't recognize Ali when he visits. Wadi's doctor suggested that surgery to remove part of one of Wadi's lungs might slow down the course of the cancer and give him more time. But, Ali thought, "What kind of time? What would that time do for Dad?" Ali decided that putting his dad through surgery and recovery was not in Wadi's best interests. After talking with Wadi's doctors, Ali believed that surgery, which could cause additional pain and discomfort, would not improve his father's quality of life. This is an example of the best interests decision-making approach.



If you are making decisions for someone at the end of life and are trying to use one of these approaches, it may be helpful to think about the following questions:

- Have they ever talked about what they would want at the end of life?
- Have they expressed an opinion about someone else's end-of-life treatment?
- What were their values and what gave meaning to their life? Maybe it was being close to family and making memories together. Or perhaps they loved the outdoors and enjoyed nature. Are they still able to participate in these activities?

If you are making decisions without specific guidance from the dying person, you will need as much information as possible to help guide your actions. Remember that the decisions you are faced with and the questions you may ask the person's medical team can vary depending on if the person is at home or in a care facility or hospital. You might ask the doctor:

- What might we expect to happen in the next few hours, days, or weeks if we continue our current course of treatment?
- Will treatment provide more quality time with family and friends?
- What if we don't want the treatment offered? What happens then?
- When should we begin [hospice care](#)? Can they receive this care at home or at the hospital?
- If we begin hospice, will the person be denied certain treatments?
- What medicines will be given to help manage pain and other symptoms? What are the possible side effects?
- What will happen if our family member stops eating or drinking? Will a feeding tube be considered? What are the benefits and risks?
- If we try using the ventilator to help with breathing and decide to stop, how will that be done?



It is a good idea to [have someone with you](#) when discussing these issues with medical staff. That person can [take notes](#) and help you remember details. Don't be afraid to ask the doctor or nurse to repeat or rephrase what they said if you are unclear about something they told you. Keep asking questions until you have all the information you need to make decisions. If the person is at home, make sure you know how to contact a member of the health care team if you have a question or if the dying person needs something.

It can be difficult for doctors to accurately predict how much time someone has left to live. Depending on the diagnosis, certain conditions, such as dementia, can progress unpredictably. You should talk with the doctor about hospice care if they predict your loved one has six months or less to live.

Cultural Considerations At The End Of Life

Everyone involved in a patient's care should understand how a person's history and cultural and religious background may influence expectations, needs, and choices at the end of life. Different cultural and ethnic groups may have various expectations about what should happen and the type of care a person receives. The doctor and other members of the health care team may have different backgrounds than you and your family. Discuss your personal and family traditions surrounding the end of life with the health care team.

A person's cultural background may influence comfort care and pain management at the end of life, who can be present at the time of death, who makes the health care decisions, and where they want to die.



It's crucial that the health care team knows what is important to your family surrounding the end of life. You might say:

- In my religion, we . . . (then describe your religious traditions regarding death).
- Where we come from . . . (tell what customs are important to you at the time of death).
- In our family when someone is dying, we prefer . . . (describe what you hope to happen).

Make sure you understand how the available medical options presented by the health care team fit into your family's desires for end-of-life care. Telling the medical staff ahead of time may help avoid confusion and misunderstandings later. Knowing that these practices will be honored could comfort the dying person and help improve the quality of care provided.

Discussing A Care Plan

Having a care plan in place at the end of life is important in ensuring the person's wishes are respected as much as possible. A care plan summarizes a person's health conditions, medications, health care providers, emergency contacts, end-of-life care wishes, such as advance directives, and other decisions. A care plan may also include your loved one's wishes after they die, such as funeral arrangements and what will be done with their body. It's not uncommon for the entire family to want to be involved in a person's care plan at the end of life. Maybe that is part of your family's cultural tradition. Or, maybe the person dying did not pick a person to make health care choices before becoming unable to do so, which is also not unusual.

Discussing A Care Plan (cont'd)

If one family member is named as the decision-maker, it is a good idea, as much as possible, to have family agreement about the care plan. If family members can't agree on end-of-life care or they disagree with the doctor, your family might consider working with a mediator. A mediator is a professional trained to bring people with different opinions to a common decision. Clinicians trained in palliative care often conduct family meetings to help address disagreements around health care decisions.

Regardless, your family should try to discuss the end-of-life care they want with the health care team. In most cases, it's helpful for the medical staff to have one person as the main point of contact.

Here are some questions you might want to ask the medical staff when making decisions about a care plan:

- What is the best place — such as a hospital, facility, or at home — to get the type of care the dying person wants?
- What decisions should be included in our care plan? What are the benefits and risks of these decisions?
- How often should we reassess the care plan?
- What is the best way for our family to work with the care staff?
- How can I ensure I get a daily update on my family member's condition?
- Will you call me if there is a change in his or her condition?
- Where can we find help paying for this care?

There may be other questions that arise depending on your family's situation. It's important to stay in contact with the health care team.

We Can Help!

Alzheimer's Orange County

Call 844.373.4400

For more caregiver tips

Visit us at:
www.alzoc.org/resources

Information taken from the National Institute on Aging, part of the National Institutes of Health

<https://www.nia.nih.gov/health> | NIH Dec 2021 | Reviewed by AlzOC June 2022