

END OF LIFE

Understanding Health Care Decisions at the End of Life

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It can be overwhelming to be asked to make health care decisions for someone who is dying and is no longer able to make his or her own decisions. It is even more difficult if you do not have written or verbal guidance (see [Advance Care Planning: Health Care Directives](#)). How do you decide what type of care is right for someone? Even when you have written documents, some decisions still might not be clear since the documents may not address every situation you could face.

Two approaches might be useful. One is to put yourself in the place of the person who is dying and try to choose as he or she 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 would be best for the dying person. This is sometimes combined with substituted judgment.



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 decided to say no, and his mother died peacefully a few hours later.

Ali and Wadi's Story

Ali's father, Wadi, is 80 and has lung cancer, as well as advanced Parkinson's disease. He is in a nursing facility and doesn't seem to recognize Ali when he visits. Wadi's doctor suggested that surgery to remove part of a lung might slow down the course of the cancer and give Wadi 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 would not improve his father's quality of life but would cause him pain and discomfort.

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:

- Has the dying person ever talked about what he or she would want at the end of life?
- Has he or she expressed an opinion about how someone else was being treated?
- What were his or her values in life? What gave meaning to life? Maybe it was being close to family—watching them grow and making memories together. Perhaps just being alive was the most important thing.

As a decision-maker without specific guidance from the dying person, you need as much information as possible on which to base your actions. 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?
- Why is this new test being suggested?
- Will it change the current treatment plan?
- Will a new treatment help my relative get better?
- How would the new treatment change his or her quality of life?
- Will it give more quality time with family and friends?
- How long will this treatment take to make a difference?
- If we choose to try this treatment, can we stop it at any time? For any reason?
- What are the side effects of the approach you are suggesting?
- If we try this new treatment and it doesn't work, what then?
- If we don't try this treatment, what will happen?
- Is the improvement we saw today an overall positive sign or just something temporary?

It is a good idea to [have someone with you](#) when discussing these issues with medical staff. Having someone [take notes](#) or remember details can be very helpful. 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 that does make sense to you. Keep asking questions until you have all the information you need to make decisions. Make sure you know how to contact a

member of the medical team if you have a question or if the dying person needs something.

Sometimes, the whole family wants to be involved in every decision. Maybe that is the family's cultural tradition. Or, maybe the person dying did not pick one person to make health care choices before becoming unable to do so. That is not unusual, but it makes sense to choose one person to be the contact when dealing with medical staff. The doctors and nurses will appreciate having to phone only one person.

Even 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 you can't agree on a care plan, a decision-maker, or even a spokesperson, the family might consider a mediator, someone trained to bring people with different opinions to a common decision.

In any case, as soon as it is clear that the patient is nearing the end of life, the family should try to discuss with the medical team which end-of-life care approach they want for their family member. That way, decision making for crucial situations can be planned and may feel less rushed.

Common End-of-Life Concerns

Maybe you are now faced with making end-of-life choices for someone close to you. You've thought about that person's values and opinions, and you've asked the health care team to explain the treatment plan and what you can expect to happen.

But, there are other issues that are important to understand in case they arise. What if the dying person starts to have trouble breathing and a doctor says a ventilator might be needed? Maybe one family member wants the health care team to do everything possible to keep this relative alive. What does that involve? Or, what if family members can't agree on end-of-life care or they disagree with the doctor? What happens then?

Here are some other common end-of-life issues. They will give you a general understanding and may help your conversations with the doctors.

If someone says "do everything possible" when someone is dying, what does that mean? This means that if someone is dying, all measures that might keep vital organs working will be tried—for example, using a ventilator to support breathing or starting dialysis for failing kidneys. Such life support can sometimes be a temporary measure that allows the body to heal itself and begin to work normally again. It is not intended to be used indefinitely in someone who is dying.

What can be done if someone's heart stops beating (cardiac arrest)? CPR (cardiopulmonary resuscitation) can sometimes restart a stopped heart. It is most effective in people who were generally healthy before their heart stopped. During CPR, the doctor repeatedly pushes on the chest with great force and periodically puts air into the lungs. Electric shocks (called defibrillation) may also be used to correct an abnormal heart rhythm, and some medicines might also be given. Although not usually shown on television, the force required for CPR can cause broken ribs or a collapsed lung. Often, CPR does not succeed in older adults who have multiple chronic illnesses or who are already frail.

What if someone needs help breathing or has completely stopped breathing (respiratory arrest)? If a patient has very severe breathing problems or has stopped breathing, a ventilator may be needed. A ventilator forces the lungs to work. Initially, this involves intubation, putting a tube attached to a ventilator down the throat into the trachea or windpipe. Because this tube can be quite uncomfortable, people are often sedated with very strong intravenous medicines. Restraints may be used to prevent them from pulling out the tube. If the person needs ventilator support for more than a few days, the doctor might suggest a tracheotomy, sometimes called a “trach” (rhymes with “make”). This tube is then attached to the ventilator. This is more comfortable than a tube down the throat and may not require sedation. Inserting the tube into the trachea is a bedside surgery. A tracheotomy can carry risks, including a collapsed lung, a plugged tracheotomy tube, or bleeding.

How can I be sure the medical staff knows that the patient has a DNR (Do Not Resuscitate) order? Tell the doctor in charge as soon as the patient or person making health care decisions decides that CPR or other life-support procedures should not be performed. The doctor will then write this on the patient’s chart using terms such as DNR (Do Not Resuscitate), DNAR (Do Not Attempt to Resuscitate), AND (Allow Natural Death), or DNI (Do Not Intubate). DNR forms vary by State and are usually available online.

If end-of-life care is given at home, a special non-hospital DNR, signed by a doctor, is needed. This ensures that if emergency medical technicians (EMTs) are called to the house, they will respect your wishes. Make sure it is kept in a prominent place so EMTs can see it. Without a non-hospital DNR, in many States EMTs are required to perform CPR and similar techniques. Hospice staff can help determine whether a medical condition is part of the normal dying process or something that needs the attention of EMTs.

DNR orders do not stop all treatment. They only mean that CPR and a ventilator will not be used. These orders are not permanent—they can be changed if the situation changes.

Should pacemakers (or similar devices) be turned off when someone is dying? A pacemaker is a device implanted under the skin on the chest that keeps a heartbeat regular. It will not keep a dying person alive. Some people have an implantable cardioverter defibrillator (ICD) under the skin. An ICD shocks the heart back into regular rhythm when needed. The ICD should be turned off at the point when life support is no longer wanted. This can be done at the bedside without surgery.

What does it mean if the doctor suggests a feeding tube? If a patient can’t or won’t eat or drink, the doctor might suggest a feeding tube. While a patient recovers from an illness, getting nutrition temporarily through a feeding tube can be helpful. But, at the end of life, a feeding tube might cause more discomfort than not eating. For people with dementia, tube feeding does not prolong life or prevent aspiration.

As death approaches, loss of appetite is common. Body systems start shutting down, and fluids and food are not needed as before. Some experts believe that at this point few nutrients are absorbed from any type of nutrition, including those received through a feeding tube. Further, after a feeding tube is inserted, the family might need to make a difficult decision about when, or if, to remove it.

If tube feeding will be tried, there are two methods that could be used. In the first, a feeding tube, known as a nasogastric or NG tube, is threaded through the nose down to the stomach to give nutrition for a short time. Sometimes, the tube is uncomfortable. Someone with an NG tube might try to remove it. This usually means the person has to be restrained, which could mean binding his or her hands to the bed.

If tube feeding is required for an extended time, then a gastric or G tube is put directly into the stomach through an opening made in the side or abdomen. This second method is sometimes called a PEG (percutaneous endoscopic gastrostomy) tube. It carries risks of infection, [pneumonia](#), and nausea.

Hand feeding (sometimes called assisted oral feeding) is an alternative to tube feeding. This approach may have fewer risks, especially for people with dementia.

Should someone who is dying be sedated? Sometimes, for patients very near the end of life, the doctor might suggest sedation to manage symptoms that are not responding to other treatments and are still making the patient uncomfortable. This means using medicines to put the patient in a sleep-like state. Many doctors suggest continuing to use comfort care measures like pain medicine even if the dying person is sedated. Sedatives can be stopped at any time. A person who is sedated may still be able to hear what you are saying—so try to keep speaking directly to, not about, him or her. Do not say things you would not want the patient to hear.

Are antibiotics helpful when someone is dying? Antibiotics are medicines that fight infections caused by bacteria. Lower respiratory infections (such as pneumonia) and [urinary tract infections](#) are often caused by bacteria and are common in older people who are dying. Many antibiotics have side effects, so the value of trying to treat an infection in a dying person should be weighed against any unpleasant side effects. If someone is already dying when the infection began, giving antibiotics is probably not going to prevent death but might make the person feel more comfortable.

Diego's Story

Diego was 83 and had lived in a nursing home for several years with advanced Parkinson's disease. One day, he choked on some food, causing him to inhale a small amount into his lungs. As a result, Diego developed aspiration pneumonia. The doctors assured his wife that they could keep Diego comfortable without antibiotics, but she wanted them to try treating his pneumonia. He died a few days later despite their efforts.

Do patients have the right to refuse treatment? Choosing to stop treatment that is not curing or controlling an illness, or deciding not to start a new treatment, is completely legal—whether the choice is made by the person who is dying or by the person making health care decisions. Some people think this is like allowing death to happen. The law does not consider refusing such treatment to be either suicide or euthanasia, sometimes called mercy killing.

What happens if the doctor and I have different opinions about care for someone who is dying?

Sometimes medical staff, the patient, and family members disagree about a medical care decision. This can be especially problematic when the dying person can't tell the doctors what kind of end-of-life care he or she wants. For example, the family might want more active treatment, like chemotherapy, than the doctors think will be helpful. If there is an [advance directive](#) explaining the patient's preferences, those guidelines should determine care.

Without the guidance of an advance directive, if there is a disagreement about medical care, it may be necessary to get a second opinion from a different doctor or to consult the ethics committee or patient representative, also known as an ombudsman, of the hospital or facility. [Palliative care consultation](#) may also be helpful. An arbitrator (mediator) can sometimes assist people with different views to agree on a plan.

The doctor does not seem familiar with our family's views about dying. What should we do? America is a rich melting pot of religions, races, and cultures. Ingrained in each tradition are expectations about what should happen as a life nears its end. It is important for everyone involved in a patient's care to understand how each family background may influence expectations, needs, and choices.

Your background may be different from that of the doctor with whom you are working. Or, you might be used to a different approach to making health care decisions at the end of life than your medical team. For example, many health care providers look to a single person—the dying person or his or her chosen representative—for important health care decisions at the end of life. But, in some cultures, the entire immediate family takes on that role.

It is helpful to discuss your personal and family traditions with your doctors and nurses. If there are religious or cultural customs surrounding death that are important to you, make sure to tell your health care providers.

Knowing that these practices will be honored could comfort the dying person. Telling the medical staff ahead of time may also help avoid confusion and misunderstanding when death occurs. 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.

Questions to Ask When Making Health Care Decisions

Here are some questions you might want to ask the medical staff:

- What is the care plan? What are the benefits and risks?
- How often should we reassess the care plan?
- If we try using the ventilator to help with breathing and decide to stop, how will that be

done?

- If my family member is dying, why does he or she have to be connected to all those tubes and machines? Why do we need more tests?
- What is the best way for our family to work with the care staff?
- How can I make sure 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?

Communicating with Your Health Care Team

Make sure 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 have happen).

Read about [this topic in Spanish](#). Lea sobre [este tema en español](#).

For More Information About Health Care Decisions at the End of Life

Association for Conflict Resolution

202-780-5999

www.acrnet.org

Family Caregiver Alliance

800-445-8106 (toll-free)

info@caregiver.org

www.caregiver.org

Society of Critical Care Medicine

847-827-6869

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www.sccm.org/MyICUCare/Home

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Content reviewed: May 17, 2017