Who can be a health care agent or conservator?

Patients who have capacity can name almost anyone they trust to be their health care agent. (Someone's doctor or other health care provider can't also be their agent.) If a patient no longer has capacity, a family member or friend can ask the court to make them a conservator of the person (guardian) for that patient.

What health care agents or conservators can do depends on the situation. If you are an agent or conservator, ask for help from your doctor, your Care Team Navigator, or a lawyer if you are not sure. In most cases, health care agents and conservators can do many things on behalf of the patient, such as:

- Talk to the doctors and say *yes* or *no* to treatments for the patient.
- Read the patient's medical records and give access to others.
- Decide where the patient gets health care, such as in the patient's home, a nursing home, or hospital.
- Make decisions about food, clothing, personal care, and social outings.
- Decide whether the patient can be in a research study.

What makes a good health care agent or conservator?

For health care agents, the most important thing is to listen to what the patient wants. Patients should choose agents they can talk to honestly, and who will respect the patient's wishes even if they disagree.

For both health care agents and conservators, it is also important to:

- Involve the patient as much as possible in decisions, even after they lose capacity.
- Know the patient and his or her values well.
- Not be afraid to ask doctors or other people questions.
- Be available to talk with doctors and other people caring for the patient.
- Be able to handle tough decisions.
- Be in good enough health to take on the role.
- Be willing to do all of these things for the patient.

Care Ecosystem

Navigating Patients and Families Through Stages of Care

Planning for Health Care Decisions

Why is it important to plan?

Different people have different values. Some treatments are right for some but not for others. This is why all patients should get care that matches their **own values and wishes**.

If you are a patient with dementia

You may still be able to make your own health care decisions. Later on you probably will need help making these choices. By planning, you can help your caregivers make decisions that are **right for you**.

If you live with or care for a patient with dementia

Making decisions for your loved one can be stressful. We want you to have a good plan that helps you feel more confident and prepared.

Who can still make decisions for themselves?

Some patients can still make their own decisions. Others can't. Usually a doctor or lawyer will decide if someone understands their choices well enough to make a decision.

We say that a patient has **capacity** if they can still make their own decisions. If possible, it's best to start planning while patients can make their own plans.

What are the different stages of dementia?

There are different kinds of dementia, such as Alzheimer's disease, vascular dementia, and Lewy body disease. Your doctor can tell you more about which kind you have and what to expect. Most dementias get worse slowly over several years.

Mild (early-stage) dementia

In mild dementia, people start having trouble with memory and thinking. Most can still do many daily tasks on their own. They may need help with things like driving, cooking or paying bills.

Moderate (middle-stage) dementia

This is usually the longest stage and often lasts for years. People may get confused and might need help with daily tasks like dressing and bathing. Most can still talk and engage in social activities. Many have behavior changes like irritability, trouble sleeping, or paranoid ideas.

Advanced (late-stage) dementia

In the late stage, patients lose the ability to talk and move. Most will need help around-the-clock. Many develop trouble swallowing and can have problems with pneumonia and other infections.

What are "goals of care"?

Because we can't predict exactly what will happen in the future, patients should think about the overall goals that are important to them.

For example, some people want to live as long as possible. These people would want to be kept alive on machines even if they were in pain or could never talk. Other people want to focus on comfort. These people wouldn't want to be kept alive if they were in pain or couldn't talk to others.

Some people don't know what their goals are. Talking with your doctor and family can help all of you to think together about what is right for you.

What are Advance Health Care Directives?

These are legal forms signed by **patients with capacity**. They say how decisions should be made if patients can't make decisions themselves. There are two types, though many advance directives include both:

Durable Power of Attorney for Health Care

This names a **health care agent** (also called a *proxy, surrogate,* or *medical decision-maker)* to make decisions if the patient no longer can. This is **the most important document** for patients to have.

Living Will

This lists treatments (like CPR or breathing machines) that someone would or wouldn't want in different situations. Living wills can also describe the patient's goals of care.

What other documents should I know about?

Conservatorship of the Person (Guardianship)

If someone doesn't have a health care agent, they may need to go through *conservatorship* (in some states called *guardianship*). This means that a judge will decide whether the patient can make decisions on his or her own. If he or she can't, the judge will choose a **conservator of the person** (in some states called a *guardian*) to make decisions about their health care, food, clothing, and housing.

DNR (do-not-resuscitate) order

An order written by a doctor in a health care facility. A DNR says that if a patient's heart or breathing stops, the staff should not try CPR or machines to restart it. DNR orders usually are not valid if the patient moves from one facility to another.

POLST (Physician Orders on Life-Sustaining Treatment)

These only exist in some states (in Iowa they are called *IPOST*) and are printed on pink paper. These say whether the patient should receive CPR or other treatments at the end of life. They are valid wherever the patient goes. They can't be used to name a health care agent.