

The Agent's Role in End-of-Life Care

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The person we designate to make decisions and speak for us in our dying days, called a health care agent, may have no idea how complicated and difficult the role may ultimately be. Indeed, much research—including a recent study funded by the Robert Wood Johnson Foundation—suggests that this is the case.

However, the study also offers practical suggestions on how to be a good agent—and an effective advocate for the wishes of the person who is dying.

Definitions and Terms

Advance directive: A general term that refers to your oral and written instructions about the care you will receive if you become unable to speak for yourself. Advance directives are regulated state by state. There are two types of advance directives: a living will and a durable, or medical, power of attorney. It is important to have both.

Agent: Someone appointed by you to make decisions about your medical care if you cannot make those decisions yourself. Most often, agents are close friends or family members. An agent may be appointed either as a person (the principal) becomes ill, or long before the person needs someone to represent him or her in medical decisions.

Durable, or medical, power of attorney: Also called a health care proxy, this is a written document in which you appoint an agent to make medical decisions for you if you lose the capacity to do so. This form is important because appointing an agent ensures a flexible form of decision making, since the agent can respond to unanticipated problems that a written document may not predict.

Living will: A written document that states your wishes about what type of medical treatment you want to receive if and when there is a time that you are unable to communicate.

Principal: The person — ultimately the patient — who creates the advance directive and who appoints the agent.

Shifting capacity: Due to illness or dementia, moving in and out of lucidity.

Checklist: How to Choose and Work With an Agent

Most often, people appoint a friend or a family member to be a health care agent. The agent will make decisions for you if you are unable to make them for yourself. Here are some things to consider when choosing and working with an agent.

- Not everyone makes a good agent. The ideal agent is assertive and not afraid to ask questions. Keep this in mind when choosing an agent to represent you.

- Don't designate an agent without knowing whether that person wants the responsibility. If possible, designate an alternate agent, in case your first choice is unable to serve when the time comes.
- Clarify to your health care providers the role you want your agent to play if you get ill.
- Prepare and sign the appropriate forms for your state. Make sure that your agent, physician and anyone else involved with your care has a copy.
- Ask your physician how he or she has worked with agents in the past. What problems arose? How can you ensure that such problems won't occur with your agent?
- Talk to your agent to communicate your wishes regarding end-of-life medical treatment. Clarify how much treatment you would want at the end of life. Have your agent repeat your words back to you to ensure that he or she understands your desires. Such conversations may help to diminish the agent's potential guilt and anguish over whether he or she is doing the right thing when the time comes.

Checklist: How to be a Good Agent

A health care agent is an important role and, ideally, one that is taken on only after much thought. Here are some things to consider.

- The agent has the power to make medical decisions—not only end-of-life ones—if the patient loses the ability to do so on his own. This may vary state to state. Carefully read the form that appointed you as an agent to see if there are requirements or limitations imposed by the state, such as needing knowledge about the patient's wishes regarding artificial nutrition and hydration (tube feeding).
- Have open discussions with the person you will represent to ensure you understand his wishes. What are the person's views on medical technology? How much medical care would the person want if he were diagnosed with a terminal or irreversible illness, and unlikely to speak again?
- Educate yourself about the patient's illness to help you anticipate potential decisions you may ultimately have to make.
- A good agent is assertive. Don't be intimidated to ask questions. If you don't understand the medical terminology a provider uses, ask for clarifications.
- Speak up if you feel that health care providers are not respecting your role as an agent.
- Find what type of support you will get from the hospital, and who to go to if you run into problems while acting as an agent.
- Make sure that your role as agent is clear not only to the medical community, but to the person's family as well to avoid conflict when difficult end-of-life decisions must be made.