

hat happens when someone can no longer make choices about medical care? If someone can no longer speak for themselves, how can family and medical providers know their wishes? If preparations are not made ahead of time, this situation can lead to disagreements, dissention and distress. Fortunately, there are ways to prepare. Legal documents called advance directives have been developed to answer these questions. These documents are a way to protect a person's wishes and choices by putting them into writing.

### WHAT ARE ADVANCE DIRECTIVES?

Advance directives are legal documents that state a person's wishes about medical care and who they want speaking for them if they cannot speak for themselves. These documents are only used when a person is no longer able to make their own medical decisions. Laws about these documents vary from state to state. Depending on the state, an advance directive may include:

• A durable power of attorney for healthcare. This allows a person to designate someone they want to make medical decisions for them if they lose the ability to make decisions for themselves.

- A living will. This allows a person to outline
  what care they want or do not want in the case
  of certain terminal or irreversible illnesses or
  medical conditions.
- **Do not resuscitate (DNR) orders.** These state that a person does not want CPR if their heart stops.

Each state may allow only certain types of advance directives. See the sidebar for organizations that can help you get the information you need for your state.

### WHY ADVANCE DIRECTIVES ARE ESSENTIAL

What gives life meaning? What makes a person happy to be alive? What physical and mental abilities are essential to quality of life? These can be hard questions to answer, especially for someone else. A person's beliefs, value system and life experiences all help shape their opinion about a life well-lived. But, often, these thoughts are not openly discussed. The process of developing an advance directive encourages conversation around these issues, bringing to the fore important information that can be vital when decisions need to be made. Advance directives put wishes and beliefs into writing, helping ensure that they will be respected and carried out.

# DURABLE POWER OF ATTORNEY FOR HEALTHCARE

Not every decision can be anticipated ahead of time. Many states allow a person to designate someone they trust to make medical decisions for them if they are unable to decide for themselves. This person is called their agent. The agent's role—and moral duty—is to make decisions according to the preferences of the person they are speaking for. They must decide as they believe the person would decide, putting aside their own opinions and values. The agent should be someone who will support a person's wishes and stand up for them.

Each state has its own rules about who can be an agent and what an agent can and cannot do. In most states, an agent can:

- Choose or refuse life-sustaining treatment
- Consent to treatment and stop it if needed
- Access and release medical records
- · Choose where care is provided

#### START THE CONVERSATION NOW

The ability of someone with Alzheimer's disease to understand the issues and be able to speak their wants and needs often declines as the disease progresses. So, it's best to start the discussion as early as possible. It's never too soon. Even at later stages of the disease, it may not be too late to get these documents into place.

Setting up advance directives does mean discussing issues that many people would like to avoid, but these are important issues. Choose a nonstressful time to talk; avoid busy times of the year, such as around the holidays. Find a quiet, comfortable place for everyone involved in the conversation to sit and express their concerns and feelings, without judgment. Keep in mind that in the end, it is the person at the center of the decision-making whose wishes must be followed. It's their life, and the choices are theirs to make.

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<b>Putting Things in Order</b>
Have discussions about wishes and values.
Designate an agent and backups as needed.
Obtain and fill out the documents that are legal in your state. Be sure they are signed.
Make copies of documents. Place at least one set of copies is in a safe place and make sure that people know where to find them. Distribute the other copies to providers to be put into the person's medical files.
Review these documents regularly and make updates, as needed.

## **Getting the Help You Need**

It's a good idea to talk with an expert who is familiar with your particular state's laws around advance directives and durable power of attorney. An eldercare attorney or other law expert is ideal. Healthcare providers and social workers may also help point you in the right direction. These organizations can also help:

- Fisher Center's Resource locator: www.alzinfo.org/resource-locator/
- National Academy of Elder Law Attorneys: www.naela.org/findlawyer
- CaringInfo: www.caringinfo.org; 800-658-8898
- Eldercare Locator: www.eldercare.acl.gov; 800-677-1116
- American Bar Association Commission on Law and Aging: www.abanet.org/aging/ toolkit/home.html: 202-662-8690
- The Conversation Project: www.theconversationproject.org