

# Advance Care Planning Information Being a Healthcare Agent for a Person Living with Dementia

## **Advance Care Planning**

Advance Care Planning is the process of thinking and talking about future medical decisions if you had a sudden event, like a car accident or illness, and could not make your own decisions. The best time to make these decisions is when you can choose for yourself.

# Healthcare Agent

A Healthcare Agent is the person you choose to make medical decisions on your behalf if you are unable to make your own decisions. Discussing and sharing your wishes with your Healthcare Agent is important.

## Advance Directive for Healthcare

A Healthcare Agent is the individual you choose to make medical decisions on your behalf if you are unable to make your own decisions. Discussing and sharing your wishes with your Healthcare Agent is important.

For more information about creating an Advance Directive, contact your healthcare team or the Idaho Healthcare Directive Registry staff at the Department of Health and Welfare.

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Dementia is a terminal illness, which means there is no cure. Dementia will affect a person's ability to think, express thoughts, and make decisions.

Given all that is known about dementia, the person will also experience physical changes that will make it hard or impossible to take care of themselves. If you have been chosen as a person's Healthcare Agent, you may be called on by their healthcare team to make medical decisions when the person is unable to do so.

You may have questions and uncertainty about how much and how quickly the illness will affect a person. You can find reliable and respected information about what to expect from:

- ☐ Alzheimer's Association (www.alz.org / 1-800-272-3900)
- ☐ The person's doctor and other members of their healthcare team

Participating in advance care planning early with the person is important. It will help you be prepared for your role. Discussing the person's goals and values and preferences for future care will help you make decisions that honors and supports the person's wishes when dementia leaves them unable to express them.

#### How do I start?

Take this one step at a time. You don't have to do this all at once!

- ☐ Talk with the person about what is important to them. (See more information on the other side).
- ☐ You can find help on how to start the conversation at:
  - The Conversation Project Conversation Starter Kit for Families and Loved Ones of People with Alzheimer's Disease/Dementia
  - Discuss the person's goals and values and preferences for medical care. Ask the person to share this information with their healthcare team and other people that should know.
  - Ask the person to write down his or her preferences in an Advance Directive. Ask the person's healthcare team to document these same preferences in the person's medical record.

Taking these steps early prepares you to continue involving the person in discussions about their goals and preferences as the illness evolves.

# **COMMON QUESTIONS:**

Knowing the person's wishes will help guide you through many decisions to come.

Talk with the person about what matters at different stages of the illness. The Conversation Project has a free 'Starter Kit' that can be useful throughout a person's dementia illness. You'll find information on talking with the person at different stages, and how to include family members in these important conversations.

Talk with the person's healthcare provider. The person's doctor and healthcare team can help answer questions you may have about dementia.

What if I am not able to talk with the person about their wishes? Gather as much information from the person's family and friends about what matters to the person. Ask yourself how the person would answer the questions suggested to the right.

Should the person complete an Advance Directive document? If possible, yes. The section that names the Healthcare Agent (Durable Power of Attorney for Healthcare) is the most important. If the person can also complete the Living Will section, their goals and values for future medical care will also be documented.

## What is my role as Healthcare Agent?

You have been chosen and authorized to make healthcare decisions on the person's behalf if that person cannot communicate or make decisions.

Decisions you may be asked to make include: ☐ Starting, continuing, or stopping medical care or services, such as tests, medications, treatments, and surgery ☐ Life-prolonging treatments, like decisions about hydration and nutrition, help with breathing, and CPR (cardio-pulmonary resuscitation) ☐ Releasing medical records ☐ Choosing where and how the person receives care ☐ Assisting with funeral arrangements The best way to prepare for these important decisions is to talk with the person to understand their wishes for future healthcare. It is important to talk early because the person will become less able to discuss their wishes as the illness progresses. But even as the illness progresses, it's important to include the person in decisions about their medical care, when possible. What should I talk about with the person? Their values: ☐ What is most important to them as they think about how they want to live? ☐ What matters to them at the end-of-life? What brings them comfort? ☐ How much do they want to know about their illness? ☐ What cultural, religious, or spiritual beliefs, if any, might help them choose the care they want or don't want? ☐ What fears or concerns do they have related to their illness? ☐ What abilities are so important to them that they can't imagine living without them? Their treatment goals: ☐ How involved do they want me to be in their healthcare decisions? Do they want me to do exactly as they have said in conversations or written in an Advance Directive or do, they want me to have some flexibility in future care decisions?  $\square$  Is it more important to live as long as possible or is quality of life more important than quantity? What treatments will support their goals? ☐ Do they want everything possible done to be kept alive and for how long? For instance, if they can no longer feed themselves, do they want nutrition and/or hydration given artificially or offered by hand? If they have trouble breathing on their own, do they want a machine

### Tough Times — Ask for Support

There may be tough times and decisions ahead. Thinking about the person's goals and values- what is important to them- will help guide decisions you may need to make. It is important to ask for support from the person's healthcare team. They can provide information and facts about the benefits and burdens of treatment

benefits and burdens of treatment options to help you make decisions that support the person's goals and values.

or medication to help them breathe?

☐ Where do they prefer to spend their last days?