

# Planning for Life (and death) with Dementia

## *What are your values & priorities?*

Dementia is a general term for changes in the brain that affect language, thinking, memory and personality and are severe enough to interfere with daily activities. While there are many types of dementia, Alzheimer's disease is the most common, especially for adults over 65.

Although there is no cure for dementia, dementia is rarely treated as the terminal disease it is. As a result, people with dementia often receive aggressive, potentially burdensome and unwanted treatments that show little benefit.

### **Honoring Your Wishes**

Every end-of-life plan should start with thinking about your values and wishes. Your priorities. For example, what will be most important to you in the final weeks or days of life? What does "quality of life" mean to you? How do you feel about the use of life-sustaining

treatments (such as artificial nutrition, breathing assistance, medications) if diagnosed with a terminal illness?

What if you are living with dementia?

If you are experiencing cognitive changes or are diagnosed with dementia, one of the most important things you can do (for yourself and your loved ones) is discuss what is most important to you, document your wishes and develop a plan for the future.

An advance directive is a legal document that allows you to document the type of care you want and how treatment decisions should be made (and by whom), in the event you are unable to make your decisions.

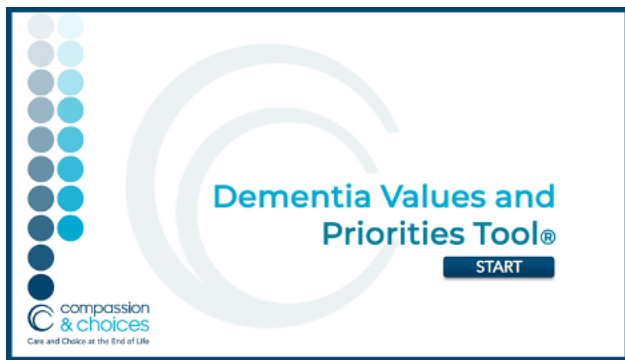
A dementia directive is an addendum for your advance directive that addresses the unique and specific issues that can arise with the progression of dementia.

Life with dementia can be unpredictable, life-changing and different for everyone

## The Dementia Values & Priorities Tool

The Dementia Values & Priorities Tool is designed to help you communicate and document your wishes regarding future care if you are living with dementia.

The Dementia Values & Priorities Tool will guide you through a series of questions based on end-of-life issues and the changes commonly seen in the progression of all types of dementia.



The tool is offered by Compassion & Choices at no cost; both online and by paper. The online version is interactive and includes informative videos to explain important concepts, such as “comfort care” and “artificial hydration.”

Once you have answered all the questions and the Dementia Values & Priorities Tool is complete, the document should be signed in front of a witness or notary. Copies should be saved with your advance directive and most importantly, shared and discussed with your healthcare team and surrogate decision maker(s).

Laws regarding witness signatures and what makes a document valid vary from state to state. This tool does not meet every state's

specific requirements. If you have questions or want to ensure you have taken all necessary steps, share your completed document with an attorney licensed in your state.

By doing the hard work of preparing and documenting your end-of-life wishes, it lessens the responsibility of your loved ones to make tough decisions later.

Compassion & Choices is working to ensure people can plan for the life (and death) they want if living with dementia. Our goal is to empower people to take action, consider what matters most and discuss those wishes.

## Other Resources to Consider

In addition to the Dementia Values & Priorities Tool, Compassion & Choices offers a variety of resources to help you plan for the type of end-of-life experience you hope for.

- **Dementia Decoder** is an online tool to help you plan for appointments and time with your physician.
- **My End-of-Life Decisions** is an advance planning guide and toolkit, full of information, resources and checklists to help you identify your priorities and wishes.
- **End-of-Life Consultation** provides resources, information and answers to your questions.

For these resources and more, visit [CompassionAndChoices.org](https://CompassionAndChoices.org)