Dementia Values & Priorities Tool®

Every end-of-life plan should start with thinking about your values and wishes. 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?

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

Instructions

1. Take your time to answer the questions on the following pages, providing as much detail as you wish.
2. Sign and date your completed document. It is recommended you sign in the presence of a witness.
3. Share your completed document and discuss your wishes with your surrogate decision maker(s), healthcare provider(s).
4. Save a copy of your completed document with your existing advance directive.

Important note: 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.

For more information or to complete an electronic version of the Dementia Values & Priorities Tool, visit compassionandchoices.org

Dementia Advance Directive

I, _____ am completing this document because I want my surrogate decision maker(s), physicians and health care team, family, caregivers and loved ones to know my wishes regarding the type of care I want if I am living with dementia.

Care Preferences

For the questions below, select one of three options to indicate your desired care preferences.

Live as Long as Possible - My goal is to live as long as possible and receive aggressive medical care and life-saving treatments. This could include calling 911, going to the hospital, CPR, nutrition support, artificial hydration or breathing assistance if needed.

Treat me but not Aggressively - I want to continue medication for chronic health conditions (e.g. diabetes, heart disease) and treatment for illness (e.g. pneumonia and infections). I want to avoid surgery, long-term feeding tubes, aggressive treatment and other life-prolonging care.

Allow a Natural Death – Focus on comfort care, avoiding medications and treatments that prolong life. This could include stopping dialysis or blood transfusions, avoiding surgery, turning off a pacemaker or withdrawing treatment for heart disease, diabetes and other health conditions.

If my physician or health care provider has determined my dementia has progressed to advanced or late stage then I want	Live as Long as Possible ○	Treat me but Not Aggressively ○	Allow a Natural Death ○
If I require around-the-clock (24 hour) assistance and supervision, then I want	Live as Long as Possible ○	Treat me but Not Aggressively ○	Allow a Natural Death ○
If I no longer recognize my loved ones, then I want	Live as Long as Possible ○	Treat me but Not Aggressively ○	Allow a Natural Death ○

If I am unable to walk or move safely without assistance from a caregiver then I want	Live as Long as Possible ○	Treat me but Not Aggressively ○	Allow a Natural Death ○
If I am unable to bathe and clean myself without assistance from a caregiver, then I want	Live as Long as Possible ○	Treat me but Not Aggressively ○	Allow a Natural Death ○
If I am unable to remain at home and have to live in a nursing facility, then I want	Live as Long as Possible ○	Treat me but Not Aggressively ○	Allow a Natural Death ○
If I no longer have control of my bladder (urinary incontinence) or bowels (bowel or fecal incontinence), then I want	Live as Long as Possible ○	Treat me but Not Aggressively ○	Allow a Natural Death ○
If I am no longer aware of my surroundings (where I am, the date/year, who is with me), then I want	Live as Long as Possible ○	Treat me but Not Aggressively ○	Allow a Natural Death ○
If I am unable to clearly communicate my thoughts or needs (words and phrases do not make sense), then I want	Live as Long as Possible ○	Treat me but Not Aggressively ○	Allow a Natural Death ○

Interest in Hospice Care

If my physician or health care provider determines I have six months or less to live, then	I am interested in Hospice Care to support me and my loved ones. I would like to enroll as soon as I am eligible ○	I am not interested in hospice ○	I am unsure at this time. My surrogate can make that decision on my behalf when the time comes ○

Food and Drink

If the changes caused by dementia result in any of the following: • I no longer appear to desire food or drink, turn my head or otherwise avoid being fed or giving fluids • I do not open my mouth to accept food or drink without prompting and all food or drink must be provided by a caregiver (hand or spoon-feeding) • I am unable to safely swallow food or drink (cough, choke or aspirate/inhale) • The negative consequences of continued food or drink as determined by a medical provider, outweigh the benefits Then I request all food and drink be stopped, including nutrition support and hydration	Yes ○	No ○

Flexibility for surrogate

This document will help guide my medical team and surrogate decision maker(s). I authorize them to be flexible and make decisions based on what they feel is in my best interest. ☐	This document should serve as clear and precise direction to my medical team and surrogate decision maker(s). My wishes should be followed as much as possible, even if they would personally prefer another option. ☐

Additional Information Important to You

For example, do you have additional wishes that were not included? Is there any person you would not want to be consulted about your care? Are you interested in clinical trials (if eligible)? Would you want your representative to advocate for hospice and the possibility of palliative sedation if you are experiencing severe distress or pain?

_____

_____

_____

_____

_____

_____

_____

Signature

Signature: _____ Date Signed: _____

Print Full Name: _____ Date of Birth: _____

Witness 1

Signature: _____ Date: _____

Print Name: _____ Relation: _____

Witness 2

Signature: _____ Date: _____

Print Name: _____ Relation: _____

Signing in the presence of a witness is optional but recommended

Additional Information Regarding Advance Directives

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.

The individual you choose as your surrogate decision maker will work closely with your medical team to make decisions and communicate on your behalf when you become unable. Think carefully about who you choose for this role.

A good surrogate is someone who:

- Is willing to take the time to understand what is important to you
- You trust to carry out your wishes, even if they differ from their own
- Knows how to advocate and will speak up in a crisis
- Will be able to make difficult decisions in stressful situations
- Will be comfortable navigating family dynamics if needed

Tips and reminders for your advance directive:

- Discuss your wishes and provide a copy of your advance directive to your surrogate decision maker, loved ones and medical team.
- Review your advance directive annually and update when any one of the "5 Ds" has occurred: **D**eath of a loved one, **D**ivorce, a new **D**iagnosis, **D**ecline in health or you reach a new **D**ecade.
- Keep your advance directive in a place where it will be easily found by your surrogate decision maker and/or loved ones.
- Make sure your advance directive will be honored in all states you receive care or frequently visit.
- Talk with your medical team about completing a POLST (also known as a MOLST) form.