



Your life. Your death. Your choice.

## ABOUT MY INSTRUCTIONS FOR ORAL FEEDING AND DRINKING

The purpose of *My Instructions for Oral Feeding and Drinking* is to stop attempts to give you food and water if, because of progressive dementia such as Alzheimer's disease, (1) you become unable to feed yourself and you lose interest in eating or drinking, or (2) instead of swallowing food and water, you breathe them into your lungs. Eventually, nearly everyone with progressive dementia will get to this point (unless they die of something else first). It's important to understand that this document does not apply to people with dementia who still get hungry and thirsty and want to eat and drink.

Most adults have legal rights to decide how they want to be treated. This includes a right to refuse medical treatment they don't want — even if they would die without it. If, because of dementia, you become unable to say how you want to be treated, you can empower someone else to make decisions for you. You can do that by making a durable power of attorney for health care. But the law *doesn't* say that the person you want to make decisions for you can tell a caregiver to stop offering food and drink. Likewise, the law *doesn't* say that a caregiver who is told to stop offering food and drink is allowed to do so. However, the law does not require a caregiver to offer food and drink to a person who does not want them.

*My Instructions for Oral Feeding and Drinking* attempts to (1) empower you, and the person you choose to make decisions for you later on, to stop offering food and drink during advanced dementia in circumstances you describe in the document, and (2) communicate your choice to your care providers. Be sure to discuss your document with your decision maker and health-care provider(s), and consider sharing your decisions with immediate family.

*My Instructions for Oral Feeding and Drinking* does not replace other advance directives, such as [End of Life Washington's Durable Power of Attorney for Health Care and Health Care Directive](#) or the [Physician Orders for Life-Sustaining Treatment \(POLST\) form](#).

### Signing and Witnessing of Your *Instructions*

1. Do not sign and date your *Instructions* until you are in the presence of valid witnesses.
2. Sign your *Instructions* in the presence of two adult witnesses. The two witnesses cannot be:
  - Related to you by blood or marriage.
  - Entitled to any portion of your estate through the operation of law or through any will or codicil.
  - A person who has a claim against your estate.
  - Your attending physician or an employee of your attending physician.
  - An owner, operator, administrator, or employee of a health care facility in which you are a patient at the time you sign your *Instructions*.

## How to Make Your *Instructions* Work

1. If you already made a Health Care Directive (also known as a living will), look for any language about getting food and drink by mouth that contradicts your *Instructions*. If you find contradictory language, End of Life Washington recommends that you make a new Directive to correct any contradictory language. You cannot cross out parts of a directive after it has been signed and witnessed.
2. Copies of your *Instructions* should be just as good as the original. Keep the original in a secure place that is accessible. Don't give the original to your attorney or put it in a safe deposit box. The person who will have the right to make decisions for you should know exactly where to look for your *Instructions*. Tip: Ask the person who will make decisions for you to keep a copy of your *Instructions* and other advance directives in the glove box of their car, if they have one, so the documents will be available when needed. Documents can also be photographed and kept on smartphones. Your *Instructions* and advance directives are useless if they can't be found.
3. Give copies of your *Instructions* to family members, other loved ones, caregivers, and medical and long-term care providers. Ask the person who will have the right to make decisions for you to make sure there is a copy of your *Instructions* on file at your nursing home or memory care facility and at your local hospital.
4. It is extremely important for you to tell people about your *Instructions* and talk to them about your decision to stop feeding and drinking. Make sure the person who will have the right to make decisions for you, your immediate family members, and your physician understand your reasons. Try to get them to promise to honor your wishes. If a person who will have the right to make decisions for you and your immediate family members don't all agree with your *Instructions*, they are not likely to be honored.
5. Tell the person who will have the right to make decisions for you, family members, and other important people that you don't want them to disregard your wishes because they think your quality of life is still okay or because you appear to be comfortable.
6. Cooperation of the nursing home, memory care facility, or other long-term care facility where you intend to be (or where you are now) is extremely important. If possible, choose a facility that will honor your *Instructions* before you need to be admitted. If you can't, instruct the person who will have the right to make decisions for you to try to find a facility that will.
7. Changes in leadership, ownership, and affiliation of long-term care facilities can result in changes to policies related to oral food and water. If a facility that agreed to honor your *Instructions* changes its policy, make sure the person who will have the right to make decisions for you understands that you want to be transferred to a facility that will, or that you want to go home, if appropriate care can be provided there.

Finally, a very important component of a peaceful, dignified death from dementia is palliative (comfort) care from hospice. Despite how helpful it is for people with dementia and their families, very few receive hospice care. Make sure the person who will have the right to make decisions for you understands that you want hospice care as soon as you qualify. Some long-term care providers and adult family home administrators may say they can provide the same level of palliative care as hospice and may attempt to discourage involving hospice providers. Do not accept that; you have the right to receive hospice wherever you reside.

If you have questions or need guidance in preparing your *Instructions for Oral Feeding and Drinking*, please call the End of Life Washington office at 206.256.1636, and a staff member will be glad to assist you.

*Please consider providing End of Life Washington with a tax-deductible donation to help us continue to provide our free services to people who are planning ahead or facing the end of life.*



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## MY INSTRUCTIONS FOR ORAL FEEDING AND DRINKING

I am making this document because I want my medical and long-term care providers, caregivers, family, and other loved ones to honor my wishes regarding oral feeding and drinking.

If I become unable to make decisions about my health care and I stop feeding myself due to Alzheimer's Disease or other progressive dementia, I want oral food and fluids to be provided to me under certain circumstances.

If I accept food and drink (comfort feeding) when they're offered to me, I want them. I request that oral food and fluids be stopped if, because of dementia, any of the following conditions occur:

- I appear to be indifferent to being fed.
- I no longer appear to desire to eat or drink.
- I do not willingly open my mouth.
- I turn my head away or try to avoid being fed or given fluids in any other way.
- I spit out food or fluids.
- I begin a pattern of coughing, gagging, or choking on or aspirating (inhaling) food or fluids.
- The negative medical consequences or symptoms of continued feeding and drinking, as determined by a qualified medical provider, outweigh the benefits.

I want the instructions in this directive followed even if the person who has the right to make decisions for me and my caregivers judge that my quality of life, in their opinion, is satisfactory and I appear to them to be comfortable. I have given considerable thought to this decision and want my wishes to be followed.

No matter what my condition appears to be, I do not want to be cajoled, harassed, or forced to eat or drink. I do not want the reflexive opening of my mouth to be interpreted as giving my consent to being fed or given drink or misinterpreted as a desire for food or drink.

Before I am admitted to a long-term care facility, I want that facility to affirm its willingness to honor these instructions. If the long-term care facility where I already reside will not honor these instructions, I want to be transferred to one that will.

I want my wishes for life-sustaining treatment, including medically assisted artificial nutrition and hydration (for example, tube feeding, nasogastric tube, total parenteral nutrition) to be honored as documented in my health care directive or my Physician Orders for Life-Sustaining Treatment (POLST) form. If I did not make a health care directive or POLST form or they cannot be located, I want my health care agent's or other legal surrogate decision maker's decisions about life-sustaining treatment to be honored, including those addressing medically assisted artificial nutrition and hydration.

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Signature

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Printed Name

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Date

**Statement of Witnesses**

The afore-named person is personally known to me, and I believe him/her to be of sound mind and to have completed this document voluntarily. I affirm I am at least 18 years old, not related to by blood, marriage, or adoption, and not the health care agent named in an Advance Directive for Health Care. As far as I know, I am not a beneficiary of his/her will or any codicil, and I have no claim against the estate. I am not directly involved in his/her health care, and I am not an employee of the physician or a health care facility where the person making this document may reside.

**WITNESS 1**

**WITNESS 2**

\_\_\_\_\_  
Signature                      Date

\_\_\_\_\_  
Signature                      Date

\_\_\_\_\_  
Printed Name                      Phone

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Printed Name                      Phone

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