



## 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, and a notary, if you are having your *Instructions* notarized (see below).
2. Sign your *Instructions* in the presence of two adult witnesses (and a notary, if you elect to have your document notarized). 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*.
3. Although notarizing is not required, the *Instructions* include a notary statement because we believe that notarization may provide legal support for your document. Notarizing must take place at the time your

*Instructions* are signed, meaning that you, your witnesses, and the notary must all be present when you sign. Notaries can be found at your bank, insurance office, or some office supply stores (call ahead to make sure they will be present). End of Life Washington provides free notarization of this document and advance directives in our Seattle office.

## 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.*