Dementia Provision (Advance Directive Addendum)

compassion & choices
Care and Choice at the End of Life



The following language can be added to any advance directive. It advises medical providers, healthcare proxies, caregivers, and loved ones of the wishes of a patient with Alzheimer's Disease or some other form of advanced dementia. Once completed and signed, the addendum should be kept with the advance directive.

I, For Discussion Purposes Only, am creating this document because I want my healthcare representatives/agents/proxies, medical providers, family members, caregivers, long-term care providers, and other loved ones to know and honor my wishes regarding the type of care I want to receive if I develop an advanced stage of Alzheimer's Disease or other incurable progressive dementia.[1]

Under the conditions of advanced dementia, including my inability to communicate rationally with loved ones or caregivers, and/or my physical dependence on others for all aspects of bodily care, continuing life would have no value for me. In those conditions, and if my condition is unlikely to improve, I would want to die peacefully and as quickly as legally possible to avoid a drawn-out, prolonged dying that would cause unnecessary suffering.

For this reason, if I have advanced dementia, and I am unable to feed myself due to advanced dementia, I want the following to apply (initial each option that represents your wishes):

For Discussion Purposes Only
(Please print this document and initial with a pen.)

To receive comfort care only, focused on relieving any suffering such as pain, shortness of breath, anxiety or agitation. I would not want any care or treatments that would be likely to extend my life or prolong the dying process. This includes life-sustaining measures like cardiac pacing, cardiopulmonary resuscitation and mechanical ventilation.

(please turn over)

For Discussion Purposes Only
(Please print this document and initial with a pen.)

In the event of an acute infection, I do not wish to be treated with antibiotics and/or antimicrobials in any form but with aggressive pain and symptom relief only, while the illness takes its natural course.

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If I lose the ability to speak for myself and my advance directive is being taken into consideration as written, I also would like it to be clear that if I am currently receiving any medications or treatments that are likely to extend my life or prolong my dying process, I would like those stopped.

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I request that food and fluids in any form, including spoon-feeding, be stopped if, because of dementia, any of the following conditions occur:

- I appear indifferent to food and being fed.
- I no longer appear to desire to eat or drink.
- I do not voluntarily open my mouth to accept food without prompting.
- I turn my head away or try to avoid being fed or given fluids and am clearly repelled by food or fluids.
- I spit out food or fluids.
- I cough, gag, choke on, or aspirate (inhale) food or fluids.
- The negative consequences or symptoms of continued feeding and drinking, as determined by a qualified medical provider, outweigh the benefits.

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If the above statement regarding food and fluids goes into effect for any of the above listed reasons, and as a result I begin to experience delirium, agitation or hallucinations, then I would like my medical team to provide palliative sedation in order to avoid suffering until death occurs.

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

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.

Printed Name _____ Date of Birth _____

Signature _____ Date _____
(Please print this document and sign with a pen.)

For Discussion Purposes Only

We, whose names are provided below, declare that the person who signed this document is personally known to us, appears to be of sound mind and acting of their own free will, and signed this document (or asked another to sign this document) in our presence.

WITNESS 1 Signature _____ Date _____
(Please print this document and sign with a pen.)

Printed Name _____ Phone _____

Address _____

WITNESS 2 Signature _____ Date _____
(Please print this document and sign with a pen.)

Printed Name _____ Phone _____

Address _____

[1] *Defined as Stage 6 or 7, moderately severe to severe dementia, of the Global Deterioration Scale for Assessment of Primary Degenerative Dementia (GDS) and/or the Functional Assessment Staging Tool (FAST) which include severe cognitive decline and the need for extensive assistance for most activities of daily living.*