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Dementia Living Will Extension

Legal Disclaimer:
The primary purpose of the ***Dementia Living Will Extension*** *is to provide information to the healthcare surrogate regarding the medical choices of the individual signing this document. The completed document, signed and witnessed, should be regarded as a valid statement of advance care planning in addition to a completed living will in the State of Florida.*

This document is intended as an extension to your Living Will and Designation of Healthcare Surrogate documents. It is designed to provide clear, detailed information about your preferences for care should you have or develop dementia. This extension should be kept with your living will and discussed with your healthcare surrogate, loved ones and physicians.

The most important part of the advance care planning process is to **choose a healthcare surrogate** who will advocate and speak out for your medical choices. A good healthcare surrogate will respect and honor your choices, even if he/she does not entirely agree with them. The strength of this dementia living will extension depends upon the ability of your surrogate to clearly understand and advocate for your personal choices.

Your words matter. **Provide detailed answers to questions. Add explanations for your choices to help your surrogate understand your reasoning and decisions.** Remember, the more detail you provide, the more useful this document becomes to those caring for you.

Discuss your choices and this document with your surrogate so they fully understand your decisions and values. Share this document with your loved ones so they are aware of your choices before a crisis.

You will be asked to place your initials in the _____ *next to the statements with which you agree. You may place an X through statements with which you disagree.*

Declaration

I _____, understand that my living will reflects my medical choices
(Your name)
if there should come a time when I can no longer make my own medical decisions and I am in a terminal condition, persistent vegetative state or coma, or end-stage disease process.

This extension to my living will reflects my medical choices should I develop moderate or severe dementia but my living will does not yet apply. It is meant to assist my healthcare surrogate, physicians and loved ones with understanding my authentic wishes, personal values, and goals for care. If I develop mild dementia, I will make my own healthcare decisions with the support of my loved ones and healthcare providers.

I understand that dementia is a gradually progressive, terminal disease that will eventually cause symptoms that may last for months or years. I understand that I may lose the ability to communicate. I may lose my appetite, the ability to feed myself, and ultimately, my ability to chew or swallow. I may develop complications that would normally require hospitalizations and/or surgical treatments and I have the right to refuse such treatments if I develop moderate or severe dementia.

Since important decisions about medical care/hospitalizations and eating/drinking may be difficult for my loved ones, I want to communicate some of these decisions in this document. I understand that these and other medical choices may need to be modified by my healthcare surrogate and physicians many times as my dementia worsens**.**

I cannot anticipate every condition, but I request that my surrogate respect and honor the choices made by me in this document.

My General Statement on Quality of Life versus Length of Life

*Initial **ONE** of the following statements (or cross out the entire box if you do not wish to choose):*

_____I believe that the quality of my life is more important than the length of my life. I am fully aware that I may be declining medical treatments that could extend the length of my life. ***My choice is to request care that focuses on quality of life, avoidance of pain and suffering, and a natural death.***

OR

_____I believe that it is important to stay alive for as long as medically possible. I am fully aware that I may be choosing medical treatments with limited success rates that may cause pain and suffering and may prolong my dying. ***My choice is to request care that focuses on extending the length of my life.***

Hospitalization

There are both benefits and risks associated with hospitalization for individuals with dementia. This section describes some potential reasons for hospitalization, risks associated with hospitalization, and the levels of care available.

Hospitalization can be common and frequent for people who are in moderate to severe stages of dementia. Reasons for hospitalization include falls, aspiration pneumonia, urinary tract infections, bedsores, psychological distress or behavioral issues, pain or shortness of breath.

There are risks associated with repeat hospitalizations. Extended bed rest can lead to the loss of physical strength and abilities. The risk of a hospital acquired infection rises with repeated hospitalizations. Most importantly, prolonged hospitalization places the person in an unfamiliar environment that frequently results in an increase in dementia symptoms (confusion and disorientation) and a decline in ability to function. It is common that the person does not return to a previous level of function after being discharged from the hospital.

Three Levels of Hospital Care

1. **Full Care** provides all available means to preserve life, including cardio pulmonary resuscitation (CPR) if the heart and/or breathing stops. This level of care could include admission to an intensive care unit (ICU), surgery, dialysis and breathing machines. Full Care also includes the care listed in the Intermediate and Comfort Measures Only levels below.

2. **Intermediate Care** provides hospitalization with a focus on basic, non-invasive medical interventions. Common treatments at this level include antibiotics, intravenous fluids, non-invasive testing, monitoring and airway support via a pressurized mask (CPAP & BiPAP). The ICU is avoided at this level. Intermediate Care also includes all of the care listed in the Comfort Measures Only level below.

3. **Comfort Measures Only** provides symptom management and the maintenance of comfort. Treatments include management of pain and other symptoms, oxygen and wound care. Hospitalization is avoided unless symptoms cannot be managed outside the hospital. Hospice care may be considered.

Hospitalization Choices

The boxes below are a general guide for understanding the symptoms one might face in mid-stage to severe dementia. The symptoms may overlap between stages. They are not intended as a means of diagnosing dementia. Please see a physician for a medical diagnosis.

Symptoms of Mid-Stage Dementia

- Significant loss of short-term memory
- Loss of ability to work and drive safely
- Decline in ability to perform daily activities (dress, hygiene, chores)
- Loss of ability to make complex decisions
- Unable to be left alone for a significant time due to confusion, fear or danger to self
- Significant changes in social behavior (words and actions)
- High risk of wandering, falls and injury

Symptoms of Severe to End-Stage Dementia

- Severe memory loss (short and long term events, friends; eventually loss of recognition of family and self)
- Possible loss of ability to walk or sit upright
- Severe speech difficulty, possible total loss of the ability to speak
- Severe to total dependence for all care
- Incontinence
- Loss of interest in eating and progressive difficulty with swallowing and weight loss
- Eventual aspiration of food and liquid into the lungs and risk for pneumonia
- Eventual death

If I have **mid-stage dementia**, I prefer the following level of care:
(Initial one)

_____Full Care _____Intermediate Care _____Comfort Measures Only

My reasons for choosing this level of care include: _____

_____

_____

_____

If I have **severe to end-stage dementia**, I prefer the following level of care:
(Initial one)

_____Full Care _____Intermediate Care _____Comfort Measures Only

My reasons for choosing this level of care include: _____

_____

_____

_____

Food and Fluids

Changes in sense of taste, loss of appetite and weight loss are often a normal part of the process of severe to end stage dementia.

Artificial nutrition (tube feeding) may be suggested by healthcare providers to surrogates or loved ones due to loss of appetite, weight loss or a decline in the ability to swallow. Swallowing difficulties may also increase the risk for choking and/or aspiration pneumonia.

Medical research consistently shows that tube feeding for dementia patients:

- usually requires surgical placement of a feeding tube
- can increase the risk for aspiration over careful hand feeding
- may lead to increased hospitalizations
- may lead to a person being restrained if he/she pulls at the feeding tube
- typically will not extend life longer than careful hand feeding

There is no legal requirement to place feeding tubes in patients with dementia or other terminal illnesses.

Food and Fluids Choices

(Initial the boxes for the statement(s) with which you agree.)

☐ **I want my caregivers to offer me food and liquids regularly and encourage me to eat.** Assist me, as needed, and hand feed me if I am unable to feed myself or drink. Provide ice chips or sips of liquids to always keep my mouth moist. Clean my mouth and teeth regularly.

☐ **I want my caregivers to respect my preferences when I indicate that I do not want to eat.** For example, if I clench my teeth when being fed, or otherwise avoid taking food, please do not push food into my mouth, pry my mouth open, or pressure me to eat. Do continue to offer me food and fluids at other times if I accept them.

*(Initial only **ONE** of the boxes below.)*

Based on my personal, cultural or spiritual values:

_____ **I DO NOT want** a feeding tube for food and fluids or artificial nutrition, including surgery (feeding tube through the abdomen), a nasogastric tube (nose to stomach) or an I.V.

OR

_____ **I want** my surrogate and healthcare providers to consider if a feeding tube, (artificial nutrition), is appropriate for me.

Additional comments about hospitalization and receiving food and liquids that I want my healthcare surrogate to know:

_____

_____

_____

_____

_____

_____

Other Personal Statements about My Care

What fears or worries do you have about dementia or loss of mental capacity? (When a healthcare provider knows your fears, they are better able to avoid those things.)

_____

_____

_____

_____

_____

_____

What do you want others to know about things that make you comfortable and happy, even if you can no longer ask for them? (For example: spiritual or other rituals, moving around, grooming, music, pets, types of food, temperature of the room, who is with you, etc.)

For My Healthcare Surrogate

My signature on the next page demonstrates my commitment to this document and my medical choices. If I develop dementia, you will need to make decisions about my healthcare on a regular basis. Some of these decisions will not be easy. By following this document, you will make the choices I would have made for myself. While no one can predict everything that might happen in detail, the spirit of my choices should guide all of your decisions about my medical care. You do not need to feel guilty or anxious about making choices because I have already made them. ***Thank you for being my voice when I can no longer speak for myself.***

Making it Legal

I fully understand the meaning of this Dementia Living Will Extension. I am emotionally and mentally capable of signing this document. This document reflects my personal medical choices should I be diagnosed with moderate or severe dementia.

My Signature	**Print name**	**Date**

Witness 1:

Signature	**Print name**	**Date**

Witness 2:

Signature	**Print name**	**Date**

NOTE: Your healthcare surrogate(s) cannot serve as witnesses to this dementia living will extension. At least one witness must be someone other than your spouse or a blood relative. The Empath Choices for Care Living Will Extension is legal under Florida Law and is compliant with Florida Statute 765 regarding advance directives. If using this extension outside of Florida, please consult your state's advance directive laws.

Communicating Your Plan

- ✓ Communicate your choices with your healthcare surrogate and alternate surrogate.
  - o It is important they know and understand the choices listed in this extension.
- ✓ Discuss your Dementia Extension with your healthcare providers and loved ones.
- ✓ Keep signed and witnessed extension with your completed living will.
- ✓ Keep the original copy where it can easily be found.
- ✓ Review this extension and your living will on a regular basis. Both documents can be changed at any time. The hospital and your physician will always honor the one with the most recent date as long as they have a copy.