Strategies for Avoiding Advanced Dementia

Selected resources mentioned in my presentation for the Hemlock Society of San Diego on November 18, 2018

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Planning

Tool 1

End of Life Choices
NEW YORK

ABOUT THE ADVANCE DIRECTIVE FOR RECEIVING ORAL FOOD AND FLUIDS IN DEMENTIA

Introduction

There are two purposes to completing an Advance Directive for Receiving Oral Food and Fluids In Dementia*.* The first is to document your wishes about when to stop efforts to provide assisted oral feeding because of an advanced dementia. The second is to ensure that your appointed health care agent is empowered to honor and implement those choices if you suffer from advanced dementia.

The accompanying Directive (beginning on page 4) provides two alternatives concerning assisted oral feedings:

A. The Directive permits you to direct, in a particular clinical situation, that ALL assisted feeding of food and fluid be stopped.

B. The Directive also permits you to direct, in that same clinical situation, that comfort-focused feeding be provided.

You may sign the Directive with the directions in A **or** B, not both.

A person who is diagnosed with Alzheimer's or another incurable dementing disease may wish to have control over the circumstances and timing of his or her death. While Alzheimer's is considered a terminal disease, because the duration of the disease can be long, the terminal stage of the disease may not occur for many years, and long after decision-making capacity and the ability to self-feed are lost. The average time from diagnosis to death is 7 years, but many individuals live considerably longer. So long as those with advanced dementia receive good physical care and are assisted with eating and drinking, it can be difficult to predict when death will finally occur.

In the final, 'terminal' stage of all dementias, a person may become unable to swallow what is placed in his or her mouth, and lose the ability to ambulate, speak, recognize loved ones, and control bowel or bladder functioning. Individuals with Alzheimer's disease who contact End of Life Choices New York want to know how they can avoid the final stages of this disease. It is for those individuals, and others who fear being diagnosed with dementia in the future, that the Directive about assisted oral feeding has been created.

Appointing Your Health Care Agent

If you are age 18 or older, we recommend that you complete a health care proxy form appointing someone (and an alternate) as your health care agent who will be the advocate for your wishes. The agent will be authorized to make all health care treatment decisions for you if and when you lose your decision-making capacity. Your agent is instructed to assume this responsibility and to make future treatment decisions as you would decide, if you were able to make that decision. Health care providers are expected to honor decisions made by an appointed health care agent.

Other Documents

You might also consider completing a MOLST (Medical Orders for Life-Sustaining Treatments) with your primary care physician. That document includes your **current** wishes about receiving cardiopulmonary resuscitation (CPR) if your heart stops or being placed on a mechanical ventilator (breathing machine) should your breathing becomes compromised.

If you complete a MOLST, be sure to add a stipulation that your instructions in your directive about assisted feeding should take precedent and be followed. You should add that stipulation in the space for OTHER INSTRUCTIONS in Section E of the MOLST form.

Although completing a MOLST is recommended, if you do not do so, you should obtain from your physician a signed Out of Hospital Do Not Resuscitate Order. You should also discuss with your physician your Advance Directive for Receiving Oral Food and Fluids In Dementia in the event that you suffer from advanced dementia. Provide a copy of this document to your primary care physician. Be sure there is no conflict between instructions in these various documents about your wishes to be fed.

Your Advance Directive for Receiving Oral Food and Fluids In Dementia does not replace your completed Health Care Proxy or MOLST form, but it is an important additional tool to empower you and your appointed agent to make decisions about receiving oral assisted feeding, in the event that you suffer from advanced dementia. Your completed Directive should be photocopied, discussed, and provided to all family members, loved ones, other health care professionals and care-givers.

Instructions for Execution of the Advance Directive

1. Sign and date the Directive when you are in the presence of two witnesses who are 18 or older. A witness may not be your health care agent or an alternate agent. The agent may not be your primary physician.

2. Have two witnesses who are age 18 or older (preferably persons who know you well) sign and add their printed names, addresses and phone numbers.

3. Executing one copy of the Directive is sufficient, but additional copies can be executed, if that is convenient for everyone. (Photocopies are generally accepted by health care providers.)

Additional Steps to Consider After the Directive is Signed

1. You might find it helpful to meet with your family attorney to review the Directive, to explain your wishes and to provide her or him with a copy of the Directive along with your concerns and your reasons for completing it.

2. You should also give a copy to your primary physician and ask him or her to make it a part of your medical records.

3. You might consider videotaping a statement explaining why you have completed the Directive, what your values and wishes are regarding this choice, and that you have made this decision without coercion. Doing so might facilitate a legal defense of the document, should the need arise. Copies of the video can also be provided to your health care agent, your physician and family members. A videotape is the most powerful way to explain why you have completed the Directive, but you can also add a separate page to the directive to explain in writing your reasons for signing it.

4. Be sure to tell all those who care about you that you are depending on them and your agents to honor your requests. Ask them to promise NOT to ignore or disregard your Directive because ***they*** think your quality of life is satisfactory or because you appear to be comfortable. Their job is to represent your wishes and preferences.

5. If you anticipate moving to a long-term care or memory care facility at some point, it is important to explore whether the administrators of the facility will honor your Directive before you are admitted. This may take some time as this document about limiting assisted oral feeding is currently a somewhat novel approach to advance care planning. Get help from those who care about you and your wishes.

6. Be sure that your health care agent and the alternate agent, family members, and all health care professionals know that you want to receive good symptom management and that they are aware of your directive about oral feeding. Thus access to hospice or palliative medical oversight should be provided at the appropriate time.

Please note that this Directive has not received judicial review in New York State. If you have questions or need assistance in completing the Directive, please call the End of Life Choices New York consultation service number at 212-252-2015, and we will be pleased to assist you.

To learn more about End of Life Choices New York, please go to our website at www.endoflifechoicesny.org.

ADVANCE DIRECTIVE FOR RECEIVING ORAL FOODS AND FLUIDS IN THE EVENT OF DEMENTIA

I, _________________________, residing at _________________________ ____________________, am creating this document because I want my health care agents, medical providers, caregivers, family members, and other loved ones to know and honor my wishes regarding assisted oral feeding of food and fluids if I am in an *advanced* stage of Alzheimer's* or other incurable, advanced dementing disease and:

1. I am unable to make informed decisions about my health care, and
2. I am unable to feed myself.

Why I Am Documenting My Instructions Concerning Oral Feedings

Under the conditions that may be imposed upon me by advanced dementia, including my inability to communicate comprehensively with loved ones or care givers, and my physical dependence on others for all aspects of bodily care, continuing life would have no value for me. In those conditions, I would want to die peacefully and as quickly as legally possible to avoid a drawn-out, prolonged dying that would involve unnecessary suffering for me and for those I love.

This Advance Directive is intended to supplement any instruction I may have given in a health care proxy, living Will or other document.

Choose the provisions of either Option A OR Option B by entering your initials in the corresponding space below.

OPTION A

The provisions of this column are selected ______ (initial)

Medications and Life-Sustaining Treatments

If my appointed health care agent concludes, after consultation with my primary health care provider, that I am suffering from advanced dementia and conditions 1 and 2, above, are met, I want all medications and treatments that might prolong my life to be withheld or, if already begun, to be withdrawn,

OPTION B

The provisions of this column are selected ______ (initial)

Medications and Life-Sustaining Treatments

If my appointed health care agent concludes, after consultation with my primary health care provider, that I am suffering from advanced dementia and conditions 1 and 2, above, are met, I want all medications and treatments that might prolong my life to be withheld or, if already begun, to be withdrawn including cardio-pulmonary resuscitation and the provision of nutrition and hydration whether provided artificially or medically or by hand or by assisted oral feeding.

Assisted Hand Feeding

If I am suffering from advanced dementia and appear willing to accept food or fluid offered by assisted or hand feeding, my instructions are that I do NOT want to be fed by hand even if I appear to cooperate in being fed by opening my mouth.

including cardio-pulmonary resuscitation and the provision of *medically* provided nutrition and hydration. I would want to receive assisted oral feedings *only* under the following circumstances:

1. So long as I appear receptive and cooperate in eating and drinking by showing signs of enjoyment or positive anticipation of eating and drinking, I want to receive assisted or hand oral feedings.

2. I would want to be fed only those foods I appear to enjoy, in any texture I prefer, and in whatever amount I readily accept.

3. I would want all attempts to provide assisted oral feedings stopped when I no longer seem to enjoy or appear willing to eat or drink, or if I begin to cough, choke or aspirate oral feedings into my lungs.

4. I do not wish to receive assisted feedings once I no longer willingly open my mouth or I appear indifferent to being fed, or spit out food or fluids.

5. I do not wish to be coerced, cajoled or in any way forced to eat or drink.

My Hygiene and Comfort

I want to receive good hygiene and other measures to assure comfort and to receive appropriate medications for relief of any signs of anxiety, agitation, insomnia, or pain, with hospice or palliative oversight. I would like my lips and inner surfaces of my mouth and gums to be kept moistened to minimize discomfort. I want to receive medications for pain or anxiety in sufficient dosages and with sufficient frequency to assure effective relief of suffering even though such medication might shorten my life.

I Hope to Die at Home

It is my wish to die at home rather than in an institutional setting, provided this does not impose an unreasonable burden on my family. If an institutional placement becomes necessary, I would like my health care agent to determine whether the facility will honor my wishes concerning hand feeding and other life-prolonging measures as written in these directions. If not, I would like not to be in that facility and instead placed under hospice care in a setting where capable staff will provide compassionate end-of-life care in accordance with these directions.

> * By "advanced Alzheimer's disease" I mean stage 6 or 7 (moderate to severe) of the Functional Assessment Staging Tool (FAST) which includes severe cognitive decline and the need for extensive assistance for most activities of daily living including toileting and eating.

My Signature ______________________________ Date ____________

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 his or her own free will, and signed this document (or asked another to sign this document) in our presence.

Witness 1:

Signature ____________________________________ Date ______________

Printed name _________________________________ Phone _____________

Address ______________________

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Witness 2:

Signature ____________________________________ Date _____________

Printed name _________________________________ Phone ____________

Address ______________________

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Planning
Tool 2

Worried About Getting Stuck in Advanced Dementia?

You are not alone. Some people are so worried that they consider preemptive suicide. Yet dying in early dementia is a great sacrifice…and if unnecessary, tragic.

Try **"Begin to Plan for a Better Ending"** – an excerpt of an online program that generates a living will, which strives to be adequately clear, specific, and effective for Advanced Dementia.

➔ Experience what it is like to make decisions about a dozen conditions

Would one or more conditions cause **severe enough suffering** for you to want to be **allowed to die** of your underlying condition?

➔ Review your emailed **printout** and ask: Do I have enough **confidence** in *this living will so I can… **Plan Now, Die Later—to Live Longer**?*

"**Strategic Advance Care Planning**" strives to overcome this challenge: To write orders that will honor your wishes, *your future physician must*…

1. Feel certain **now is the time** to write the orders for **Natural Dying**; and,
2. Feel comfortable that others can view their medical orders as **clinically appropriate**, **legal**, **ethical**, and **moral**.

A related program, **Now Care Planning**, is designed to help patients who have already reached the stage of Advanced Dementia, but who do not have an adequate and effective living will.

Stanley A. Terman, PhD, MD
Effective Living Wills for Dementia, Etc.

www.CaringAdvocates.org
800 647-3223 *or* 760 431-2233
FAX: 888 767-6322 *Available: HIPAA-compliant Internet video.*

"Begin to Plan for a Better Ending"
surveymonkey.com/r/BeginToPlan

DrTerman@gmail.com
Text: 760 704-7524

On-line brochure about Advance Care Planning: caringadvocates.org/acp/

Planning

Tool 3

from: American Bar Association Commission on Law and Aging, *Advance Directives Counseling Guide for Lawyers*

ADVANCE CARE PLANNING RESOURCE LIST

THE TOOLS BELOW ARE FREE TO THE PUBLIC

ADVANCE CARE PLANNING TOOLS FOR CLIENTS

PREPARE for Your Care™. PREPARE is an online resource in English and Spanish that helps people learn about and prepare for medical decision making. This evidenced-based tool features video stories and examples and guides people as they explore their wishes and learn how to discuss them with family, friends, and medical providers. The result is a 'Summary of My Wishes' document which can be shared with family and friends, caregivers and medical providers. PREPARE also offers easy-to-read, legally-binding advance directives for all 50 states in English and Spanish. www.prepareforyourcare.org.

The Conversation Project, an initiative begun in 2010 dedicated to helping people talk about their wishes for end-of-life care. Their Conversation Starter Kit is a useful tool to help you have the conversation with a family member, friend, or other loved one about your – or their – wishes regarding end-of-life care. It is available in several languages. www.theconversationproject.org.

Consumer's Tool Kit for Health Care Advance Planning, by the American Bar Association Commission on Law and Aging is available for free download. http://ambar.org/agingtoolkit.

The Stanford Letter Project. This free website offers three tools available in several languages and formats with real patient videos, at http://med.stanford.edu/letter**.**

- The "What-Matters-Most" letter template. Simple letter template any one can use to write to their doctor about their care choices and preference
- The "Who-Matters-Most" letter template. Simple letter template any one can use to complete the seven tasks of life review and write to their loved ones.
- The "I-Matter-Too" tool. Allows patients to identify their life goals from six common choices

CaringInfo, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decisions about end-of-life care and services before a crisis. www.caringinfo.org

The *Go Wish* Game, a card game for sorting out values related to end-of-life decision-making, created by the Coda Alliance. The cards help you find words to talk family or friends about what is important if you were to be living a life that may be shortened by serious illness. Although there is a charge for ordering the card decks, Go Wish can be played online for free. www.gowish.org

MyDirectives.com. MyDirectives is a free web-based service that walks you through the process of creating an “advance digital directive” which can be electronically signed. Includes a smartphone app. The directive is encrypted and stored in their secure database, available to you and your medical treatment providers 24/7.
https://mydirectives.com

Advance Care Planning Decisions, produces short, evidence-based videos exclusively for health care providers to assist patients and providers in decision-making in clinical settings. A limited number of videos for consumers are available free in multiple languages. Topics include: The Conversation; POLST; What is Palliative Care; Talking to Your Doctor; and A Patient Checklist. https://acpdecisions.org/patients**.**

Compassion and Choices - Tools to Plan for your Care. This web page offers a multitude of useful tools aimed at ensuring you get the care you want.
https://www.compassionandchoices.org/eolc-tools/ .

Thinking Ahead: My Way, My Choice, My Life at the End. This workbook and video were created by California advocates with developmental disabilities and distributed by the Coalition for Compassionate Care of California. However, it is a good tool for anyone who wants a simple, easy-to-follow workbook.
http://coalitionccc.org/tools-resources/people-with-developmental-disabilities**.**

GUIDES FOR HEALTH CARE AGENTS

How to Choose a Health Care Proxy & How to Be a Health Care Proxy, by the Conversation Project.
https://theconversationproject.org/wp-content/uploads/2017/03/ConversationProject-ProxyKit-English.pdf

Making Decisions for Someone Else: A How-To Guide, published by the ABA Commission on Law and Aging, this guide is for anyone serving in the role of health care decision maker for someone else: http://ambar.org/agingproxyguide.

GUIDES FOR TALKING TO ONE’S PHYSICIAN

How to Talk to Your Doctor: Discussing End-of-life Care with Your Doctor, Nurse, or Other Health Care Provider. The Conversation Project.
https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-TalkToYourDr-English.pdf

NIH Resources for "Talking to your Doctor," National Institutes of Health, https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/talking-your-doctor

GENERAL END-OF-LIFE CARE REFERENCES (*some require purchase*)

END OF LIFE: What Are Palliative Care and Hospice Care? An online publication by the National Institutes on Aging (NIA) that explains palliative care and hospice options, with links to free related NIA articles. www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care**.**

Handbook for Mortals: Guidance for People Facing Serious Illness by Joanne Lynn, Joan Harrold, and Janice Lynch Schuster (2nd Ed., Oxford Univ. Press, 2011). A comprehensive and readable 320-page guide to dealing with serious, eventually fatal illness. Available for purchase from Amazon or in book stores. Individual chapters are downloadable for free at: http://growthhouse.org/mortals/mor0.html.

Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Measures Only and the Elderly Patient by Hank Dunn (A&A Publishers, 2016) Available for purchase at: www.hankdunn.com. A concise and helpful 80-page booklet on end-of-life decisions concerning resuscitation, food and fluids, hospitalization, and cure versus comfort care.

Fidelity, Wisdom and Love: Patients and Proxies in Partnership
by Joseph J. Fins and Barbara S. Maltby (Weill Medical College of Cornell University, March, 2003). A workbook and video designed as a step-by-step guide that provides everything you need to know about choosing, appointing, or being a healthcare proxy. It contains four medical scenarios designed to foster dialogue between patients and proxies in order to define possible choices for care and to increase patient/proxy understanding and knowledge. Available for purchase from Amazon.com.