New Advance Health Care Directive Developed
For those Who Fear Dementia

An advance health care directive to avoid prolonging late stage dementia has been developed by End of Life Choices New York. The Advance Directive for Receiving Oral Food and Fluids in the Event of Dementia was written with the help of physicians, palliative and hospice care experts, lawyers, and others with concerns about dementia care. This Advance Directive permits those who retain decision making capacity to document specific choices about future assisted oral feeding in the event they develop an advanced stage of dementia. The Directive will be of use for those in the earliest stages of dementia as well as those who fear a future diagnosis due to a significant family history of the disease.

“Dementia is a terminal illness that follows a long progression of suffering,” said Judith Schwarz, Clinical Director for End of Life Choices New York (EOLCNY) and lead author of the document. “Through thoroughly informed and thoughtful choices those afflicted with dementia can use the Advance Directive to anticipate and diminish the suffering that comes with end stages of the disease.”

EOLCNY has developed the advance directive in response to growing demand for clear language to address specific needs not adequately covered by health care proxies and living wills. The directive for receiving assisted oral feedings has two options: Option A refuses all oral assisted feedings once the patient is in an advanced stage of dementia and the ability to self-feed and make decisions has been lost. Option B permits assisted oral feeding in advanced dementia but limits that provision to comfort focused feeding that must be stopped when the patient becomes disinterested or unwilling to be fed.

The feeding options would be implemented only when a patient is diagnosed with moderate or severe dementia, defined as Stages 6 or 7 (the last two stages) of the widely used Functional Assessment Staging Tool (FAST). At those stages patients would be unable to feed themselves or make health care decisions.

“There is unfortunately no cure for Alzheimer’s, but such advance care directives can potentially limit unwanted suffering and indignity that can last for years in the late stages of this disease,” said Dr. Timothy Quill, Palliative Care Physician and Professor at the University of Rochester School of Medicine. “These new directives provide an opportunity for patients to make their wishes about assisted feeding known to family members and clinicians in advance should they develop significant cognitive impairment in the future. It is a potentially important addition to standard Living Will and Healthcare Proxy documents for those who would like to set these limits.”

“People live well with dementia for several years, but when the disease has progressed to the point that they can no longer toilet, speak or swallow, many individuals and families feel the disease enters a time of needless suffering and indignity,” said Dr. Anne Kenny, Geriatrician and Professor at University of Connecticut Medical School. “These clear directives are welcome support to families who face difficult medical decisions for another late in life. People can keep a voice in their values and choices and limit the consequences of advanced dementia by making their treatment wishes known while they still have the ability to do so.”
Without an advance directive most individuals with advanced dementia are spoon fed, often for months or years. Only when patients begin to cough and aspirate liquids into their lungs are efforts to provide assisted oral feedings stopped. EOLCNY developed this advance directive to provide clear documentation that the patient decided, while still mentally capable, to refuse all life prolonging measures, including assisted oral feedings, once their dementia became advanced.

Laurie Leonard, Executive Director of End of Life Choices New York, said, “Currently some 6 million Americans have Alzheimer’s disease and that number is expected to increase to 14 million by 2050. Many people fear living for years in late stage dementia after losing the ability to communicate, dress themselves, understand their surroundings and recognize loved ones. End of Life Choices New York has developed this advance directive so that people can do everything possible to avoid extended time in late stage dementia, while they still have the mental capacity to make a choice.”

EOLCNY recommends that their new advance directive be used together with other forms of advance directives such as a health care proxy and, if appropriate, a MOLST form (Medical Orders for Life Sustaining Treatment). EOLCNY strongly advises open discussion of these personal decisions with the family attorney, loved ones, medical care providers and caregivers.

Jill Godmilow, Professor Emerita of the University of Notre Dame said, “After a ‘six-months to live’ cancer diagnosis eight years ago I scrambled to produce a will, a living will, and a MOLST. I didn't die but recently when I saw the new directive on spoon-feeding if moderate or severe dementia should occur I felt I should make changes in my preparations. I have chosen Option A and have sent it to my lawyer to update my will. It is a great relief to know that I can direct my health care proxy to end life-sustaining treatments when I no longer can self-feed, recognize friends and family, and make decisions for myself.”

By bringing forward the issue of feeding in dementia the advance directive seeks to clarify a critical issue in end of life care, a frequent point of debate and anxiety. EOLCNY welcomes a broader discussion, including judicial review, of options to expand choice for people as they encounter challenges in the end stages of life.

End of Life Choices New York is a nonprofit organization working to improve end of life care so that people can have a good quality of life in their final months and a peaceful death. It educates health care professionals, students, and the general public about end of life options; provides one on one counseling to patients and families; and advocates to get laws passed in New York State to improve end of life care. End of Life Choices New York can be reached by telephone at 212 726-2010 or info@endoflifechoicesny.org.


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