

What if your relative reaches the advanced stage of dementia without an effective Living Will?

Why we need a new way to make end-of-life decisions for some patients.

Some patients do not plan ahead at all. Others only designate a person to speak for them (a surrogate decision-maker, such as a proxy or agent) but leave no Living Will to reduce others' doubts that they are certain they want specific end-of-life options. Although many do not realize this, the vast majority of Living Wills are unlikely to be effective for Advanced Dementia. Some reasons are: When Advance Directive statutes were first passed by states, legislators were cautious. They considered only two kinds of patients: Those who were or near death *in time* (the terminally ill) and those near death *in brain function* (coma or Persistent Vegetative State). Twenty-five years ago, dementia did not loom as great a threat to individuals and society as it does today, with these current projections: By mid-Century, dementia may affect 16 million patients and on average, three times as many loved ones. Traditional Living Wills do not effectively deal with two significant challenges: 1) What options are available if the dying patient does **not** depend on life-sustaining treatment; that is, has "No Plug To Pull"? And, 2) How do surrogate decision-makers decide "WHEN" to implement an appropriate option? Current and proposed Death With Dignity Acts that legalize Physician-Assisted Dying offer nothing to Advanced Dementia patients, as these patients are not competent and are expected to live longer than six months. In terms of refusing food and fluid, some people adamantly argue that such "basic care" cannot be refused on legal, ethical or moral grounds. Thus planning to attain a peaceful and timely dying, which means avoiding a prolonged dying after reaching Advanced Dementia, can be very challenging.

It takes time for society's morals—both secular and religious—to catch up with the implementation of new medical technology. A relevant example: In 1999, there was already adequate evidence that proved feeding tubes could not benefit Advanced Dementia patients. In 2013, the American Geriatrics Society and AMDA (The Society for Post-Acute and Long-Term Care Medicine) partnered with the American Board of Internal Medicine to publish and to distribute their definitive position statement, as part of the *Choosing Wisely Campaign*.¹ It thus took prominent medical organizations 14 years to definitely recommend careful hand-feeding rather than feeding tubes. Now others, including the present author, believe the proposal for "**Comfort Feeding Only**" protocol² will likely lead to very slow dying by starvation with hunger, while such feeding provides no benefit to most Advanced Dementia patients. So now the question is: How long will it take medical organizations to lead society by acknowledging the fact that, at a certain point in the devastating trajectory of dementia, even careful hand-feeding can harm the patient while not providing the patient benefit? The alternative is a total fast of both food and fluid, with adequate Comfort Care, especially to the mouth to decrease the symptom of thirst. Called "**Natural Dying**," this end-of-life option may be, for some patients, the best way to attain the goal of a peaceful and timely dying.

How have we previously decided WHEN it is time to die? By default, some dementia patients live for as long as 20 years. In contrast, for 70% to 80% of medical ICU patients, the timing of death is determined by when their surrogate decision-makers and their physician decide to withdraw and to withhold all life-sustaining treatments; that is, when they "plug the plugs." But most Advanced Dementia patients have "No Plug to Pull." Furthermore, physicians are **not** likely to initiate the

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conversation as to when “that time has come.” So surrogate decision-makers must know what their loved ones would have wanted, and then take action.

Traditionally, for patients who did **not** leave clear and specific written set of conditional directions such as an effective Living Will, one physician will ask one surrogate decision-maker to make one treatment decision that may allow the patient to die of her underlying disease. The person speaking for the patient need only state that she knows the patient’s values and treatment preferences and thus what the patient would have decided—if the patient could understand the treatment options, appreciate each option’s pros and cons, and use reasoning to express a consistent answer. This last sentence defines decision-making capacity. Unfortunately, dementia patients usually lose this capacity years before they reach the stage of Advanced Dementia. For patients who cannot speak for themselves and do not have a clear and specific Living Will, physicians usually honor the ethically accepted standard of “**Substituted Judgment.**” Unless (as sometimes happens), another relative comes forward to object, physicians have no legal incentive to spend any effort to try to determine if another person might be a more appropriate surrogate decision-maker; that is, to make sure this person is making the same treatment decision that the patient would have wanted, or to consider if this surrogate has a conflict of interest. Here’s why: most states have passed laws that provide immunity to physicians. These statutes state that if the physician acts in good faith by believing the person making a treatment decision on behalf of the patient has authority, then the physician cannot be sued in any civil or criminal court or be sanctioned by the medical board. Also, there are typically no financial incentives for physicians or the institutions they work in, to advocate timely dying.

It usually takes a strongly motivated relative to approach a physician to make treatment decisions that she feels truly reflect the patient’s wishes. Such decisions can be very difficult, especially if the decision-maker is plagued with doubt or ambivalence due to a potential conflict of interest that is inherent in the role. To explain, the person closest to the patient—who is usually in a position to initiate the decision that may allow the patient to die—is often the same person who will gain the most relief—if the patient does die. The huge burdens of caregiving extend to the emotional, financial, and physical areas. Emotions can override reason, as exemplified in this sad case:

Charlotte Fitzmaurice gave up everything else in her life to provide total care for her daughter, Nancy. Group B Streptococcus had seriously damaged Nancy’s brain before birth. At best, Nancy functioned at the level of a six-month old. But for two years, Nancy was “screaming and writhing in agony for 24 hours a day” due to a post-surgical infection operation for kidney stones. U.K. Justice Eleanor King ruling permitted Charlotte to stop Nancy’s feeding tube. Nancy died in August 2014, at the age of 12. Charlotte subsequently reflected, “The last day was the hardest of my life. It was absolutely horrifying. I miss my beautiful girl every day and **although I know it was the right thing to do, I will never forgive myself.** It shouldn’t have to be a mother’s decision to end their child’s life.”³

Guilt from being a proactive decision-maker often leads to prolonged bereavement reactions that include depression. Negative emotions can be further fueled by criticism from other relatives who were not part of the decision-making process.

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To avoid potential conflict, a potential surrogate decision-maker may hesitate to act as the patient continues to suffer. Sadly, for the patient, the result is the same as if this relative had deliberately decided to prolong the patient's dying and suffering. Conflicts, when they do occur (and countless do occur without being publicized), can tear families apart. They can also be quite prolonged and costly in both emotions and finances. Merely taking a simple vote among all concerned can lead to a stalemate if one person is aware that he or she is the tie-breaker who therefore feels responsible for "killing grandma."

There is thus a need for a better method to make such end-of-life decisions. This method should strive to put less stress on surrogate decision-makers and have a built-in protocol to strive to resolve family conflicts. Above all, it must strive for authenticity; that is, it must aspire to make the same treatment decision that the patient would have made for the current condition. These are the goals of the **Consensus of Substituted Judgment**.

How it works: Briefly, several people respond to four dozen end-of-life conditions by imagining they are making the treatment decision that the patient would have made for each condition—before the patient became ill. Each of these conditions is described and illustrated in a decisional aid tool that consists of a set of illustrated cards. One option is "Treat & Feed" (to live as long as possible). Another option is "Natural Dying" (to be allowed to die of their underlying disease). (There is a third option for patients/principals who still possess decision-making capacity and are using this tool in advance, to generate their own clear and specific Living Wills; that is, to let their surrogate decision-maker decide, contemporaneously. In effect, the Consensus of Substituted Judgment asks a group of concerned persons to make these decisions contemporaneously, based on knowing the patient well before he or she became ill so they can speak for her life values and extrapolate to her current treatment goals.

If the decisions thereby made by several people have no or minor disagreements, then they will have attained a "Consensus of Substituted Judgment" and they can proceed to make the relevant treatment decision for their loved one. Usually, one or more of the conditions described in the decisional aid tool fit closely enough to the patient's current condition. If not, the basis for agreeing on other conditions can make it possible to agree on the decision that the patient's physician is now asking about or that seems right for the patient.

Various kinds of discrepancies can arise, however. Not infrequently, surrogate decision-makers forget their role: to make the decision that the *patient* would have made, **not** the decision *they* would make for themselves in these particular conditions.

Some surrogate decision-makers have a conflict of interest that consciously or unconsciously biases their decisions. For example, if they have been absent from the patient's life for a long time, they may hope for a miracle that will let the patient become lucid again. Some hope to apologize or find another way to make other amends for their previous long absence. Others may be motivated by

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greed (getting more money, sooner).⁴ Some interpret the teachings of their religion as requiring treatment that continues to prolong life, regardless of the patient's condition or extent of suffering.

In situations where all cannot reach a Consensus of Substituted Judgment, the protocol calls for a clinician-facilitated family session. The goal is to discuss the discrepancies and to try to work them out, if possible. There can be "safety in numbers"; for example, if only one person makes a decision that differs from all the others, then that person has the obligation to prove why their minority opinion should prevail. If this individual insists that his or her view should still prevail, then a local authority such as a religious leader, bioethicist or Ethics Committee can be asked for an objective opinion.

Since all concerned share in the process of making the decision, each may feel less stress, anxiety, uncertainty and guilt. Each may also feel more certain that the decision ultimately made was the right one for the patient and *the one that the patient would have made if he or she could*. As a side benefit, each person may decide that it is time to create a clear and specific Living Will for himself or herself, to avoid this somewhat cumbersome process for their loved ones. They should also be aware that there additional effective strategies are available to them *only* if they do plan ahead.

For more information, view these two videos on YouTube (for general audiences):

Making Hard End of Life Decisions for Your Loved One. Can ALL Agree by Sorting Natural Dying Cards?

(11.5 min; Nov. 2011). <http://youtu.be/twg4TAnF4XE>

Recommended to view first:

For a Living Will Effective for Dementia & Terminal Illnesses, Sort Natural Dying Living Cards

(17 min; Nov. 2011). http://youtu.be/j_hS51AcYmk

This video is for health care professionals:

For Loved Ones with NO or Vague Living Wills: Making End-of-Life Decisions if There's No Plug to Pull

(37 min. Nov. 2012) <http://youtu.be/24jRy7vDfc8> ; Introduces "Consensus of Substituted Judgment."

¹ http://www.americangeriatrics.org/health_care_professionals/clinical_practice/clinical_guidelines_recommendations/choosingwisely (*be sure to use the entire URL*)

² [Palecek EJ](#), [Teno JM](#), [Casarett DJ](#), [Hanson LC](#), [Rhodes RL](#), [Mitchell SL](#): Comfort feeding only: a proposal to bring clarity to decision-making regarding difficulty with eating for persons with advanced dementia. *J Am Geriatr Soc* 2010, 58(3):580-4

³ <http://www.thedailybeast.com/articles/2014/11/04/u-k-courts-grant-mother-right-to-end-her-12-year-old-disabled-daughter-s-life.html> . Note: The mother might benefit from counseling that helps her consider the judge as the one who made the ultimate decision. —Especially, since these are the judge's words: "The love, devotion and competence of her mother are apparent. In her own closed world [Nancy] has had some quality of life. Sadly that is **not** the case now."

⁴ Terman SA (2009). Guest Editorial. The Potential Pitfalls of Advance Care Forms. The Sooner Mother Dies, the Better. *Caring for the Ages*. Dec. 2009: 20a-20b.