Six Steps to "Now Care Planning"

➔ "**Now Care Planning**" is for patients who: (A) have already reached the advanced stage of dementia; (B) depend on another's hand to put food and fluid in their mouth; and (C) have lost capacity so they cannot complete a new living will or revise their existing living will that is, in their physician's opinion, **not adequate** or **not effective** to write the orders they would want.
Definitions: A living will is *adequate* if it clearly informs future physicians and others "**when**" the patient would want to be allowed to die of her underlying disease. A living will is *effective* if "**what**" it offers (its intervention) allows patients to have a **private**, **peaceful**, and **timely** dying—by a means that physicians and others in authority accept. Unfortunately, few living wills meet both criteria. A possible sad result: loved ones feel helpless for years as they watch the patient endure prolonged dying with possible suffering.

➔ These **Six Steps** expand the traditional protocol of **Substituted Judgment**, which is widely accepted as legal and ethical. The "**Now Care Planning**" Protocol strives to present robust data and key points to treating physicians, along with several layers of safeguards designed to prevent premature dying. The Protocol requires a counseling healthcare provider who guides the legally designated currently active proxy/agent and two or more proxy/agent alternates and concerned others—as they strive to make the same treatment decisions the patient would have made, if the patient still possessed decision-making capacity to judge his/her present condition.

Step 1: Do concerned individuals who know the patient's values, think the patient qualifies for "Now Care Planning"? Are these individuals legally and clinically qualified to serve as members of a new patient's Decision Committee? Are they willing to give their informed consent to serve?

How it works:

Potential members of the patient's Decision Committee in the process of being formed, including the legally designated currently active proxy/agent, all designated alternates, and identified concerned others **complete an online program** entitled:

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"**Are you concerned about someone who has dementia, is dying slowly, and might be suffering?**" This program is available without a password at the link: **https://www.surveymonkey.com/r/Now-Care-Planning-for-Dementia**

This online program **informs** potential members of the patient's Decision Committee about the Protocol requirements; then it asks for their **consent**.

This online program also introduces the Protocol to concerned persons who are seeking a way to help reduce a loved one's suffering.

Counseling healthcare providers can evaluate the patient's living will using two checklists that ask, "*On its face,* is the patient's living will likely to be **not adequate** or likely to be **not effective**?" (Such an evaluation may help overcome the treating physician's resistance to writing the orders the patient would want.)

BENEFIT:

"Now Care Planning" is, to our knowledge, the only legal, ethical way to spare advanced dementia patients an unwanted, prolonged dying with possible suffering if their living wills are not adequate or not effective. Awareness of this Protocol may eliminate the need for loving, devoted spouses or children to consider mercy killing, thus sparing them from suffering great emotional angst even if they would never carry out such an act.

Why this step is unique:

To our knowledge, no other protocol insists on criteria for advanced dementia patients, and on criteria for potential surrogate decision-makers to form a Decision Committee of three or more qualified individuals for making Substituted Judgments regarding the patient's end-of-life treatment decisions, which include withdrawing assistance with spoon-feeding.

Step 2: Does (or did) the patient show resistance to being spoon-fed?

How it works:

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Potential Decision Committee members who complete Step 1 will automatically be directed to the second online program. Its title is:
“Now Care Planning: Does your loved one resist spoon-feeding?”
This program is available without a password at the link:
https://www.surveymonkey.com/r/Relative-resist-spoon-feeding .

BENEFIT:

Observing feeding behavior that *seems* resistant to spoon-feeding may help motivate qualified individuals to become members of the patient’s Decision Committee and to serve as active advocates. The data generated may also help motivate treating physicians to write the orders needed to allow patients to die naturally from their underlying disease.

Why this step is unique:

The online program explains why the interpretation of observed feeding behavior is subject to false negatives and false positives, and why some state laws require honoring patients’ requests for life-sustaining treatment. Admitting these facts may initially seem discouraging. Yet such frankness could paradoxically increase the motivation of those concerned to spend the time and effort to serve as Decision Committee members and follow the recommended “Now Care Planning” Protocol. (Typically, it takes two or three hours.)

Step 3: Each Decision Committee member completes the online *patient decision aid* “My Way Cards” to express an opinion about each of 49 conditions. Their task is to answer this question: “If the patient had capacity, would s/he judge this condition —by itself—causes severe enough suffering to want others to allow him/her to die of his/her underlying disease?”

How it works:

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Each person whom other members and the counselor accept as a member of the Decision Committee members by finishing Steps 1 and 2 consults with the counseling healthcare provider who provides them a unique link and password to this online program entitled:
“**Now Care Planning for Loved Ones and Caregivers**.”

This online program uses the *patient decision aid,* **My Way Cards** that has been used for about ten years for “Strategic Advance Care Planning.” Each card describes one condition clearly and specifically. Its words are written at the 4th grade level of reading comprehension. A line drawing adds clarity. When all 49 conditions are considered, they strive to be comprehensive by reflecting what people dread most about enduring a prolonged dying in advanced dementia and similar terminal illnesses. Decision Committee members can complete this program on their computer, tablet, or cell phone. (A “real” card version of this *patient decision aid* can be used on a desk or kitchen table.)

In Step 3, each Decision Committee member *independently* answers the key question based on knowing the patient’s values. (In Step 4, members discuss their answers in a group discussion with other members and the counseling healthcare provider.)

The online program explains “Natural Dying” and summarizes key arguments designed to convince those in authority why they can **accept** this intervention as being clinically appropriate (even compelling) as well as legal, ethical, moral, and consistent with the teachings of major religions. (Note: An expanded, counselor-version of this online program has additional detailed arguments with citations. It is available by invitation at: www.surveymonkey.com/r/Now-Care-Planning-Counselors.)

The Now Care Planning Protocol generates a form that summarizes the independent opinions of each Decision Committee member. Its title is:

“Now Care Planning”: MY Substituted Judgments of _ _/_ _/20_ _
for ____________________ ____________________, born _ _/_ _/_ _ _ _.”

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BENEFIT:

The goal of the Protocol—to let patients have a peaceful and timely—can be attained only if physicians write orders to stop oral feeding. Often, arguments about writing such orders are based on too narrow a view of the harms and burdens of the act of oral feeding *itself.* A relevant example is, the patient has a high risk of aspiration pneumonia. The benefit of using the *patient decision aid* **My Way Cards** is to view suffering more broadly so that various types of severe suffering could be considered enough for the patient to want other to allow him/her to die of his/her underlying disease.[1] In addition to physical pain about which the patient is unable to complain, which may therefore go unrecognized and untreated, some types of suffering are difficult to treat. Examples: disruption of one's life narrative, and loss of existential meaning in one's life. These types of suffering often result from losing the ability to communicate and relate to others.

The "Now Care Planning" Protocol adopts a broad concept of suffering and uses the high bar of a condition causing **suffering severe enough**. The goal is to present substituted judgments that physicians and others will find **convincing** and **compelling**.[2]

The criterion "severe enough suffering" has significant advantages over other criteria proposed for dementia-specific living wills, such as patients' feeding behavior, stage of disease, "quality of life," and "loss of dignity." *Behavior* must interpreted, and is prone to false negatives and false positives. *Stage* is arbitrary and perhaps discriminatory. Using *quality of life* or *loss of dignity* could begin a

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[1] Opponents may argue that if patients feeding behavior *seems* resistant, they deserve greater effort from caregivers to provide them nourishment—not giving up and allowing them to die. Why? Because spoon-feeding provides an obvious, great, benefit: it allows patients to live. This Protocol strives to overcome this argument by something even more compelling: **severe enough suffering**. For other arguments to continue nutrition and hydration, see those expressed by Pope John Paul II in "Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas" (March 20, 2004), no. 4, that were used to argue that Terry Schiavo's tube feeding should continue, and the "Ethical and Religious Directives for Catholic Health Care Services, 5th edition" (2009), especially #58.

[2] The expanded concept of suffering requires four paradigm shifts that are detailed in the application for a patent pending for Now Care Planning Protocol sent to the USTPO.

dangerous slippery slope that could end in authorizing others to judge whether a patient’s life is worth living.

Another potential benefit of the Protocol is to lower the emotional toll of Decision Committee members. The *patient decision aid* educates surrogate decision-makers about various types of suffering caused by 49 clinical conditions. If a member delays rendering an opinion, dying will likely be prolonged and new sources of suffering may emerge as others increase. This perspective permits members to view their request to treating physicians to write orders for Natural Dying as a helpful and positive act because its intent is purely to spare the patient prolonged, increased suffering. (Step 4 lists additional reasons why the Protocol may reduce the emotional toll of surrogate decision-makers.)

Why this step is unique:

Traditionally, treating physicians ask ONE currently active proxy/agent to make ONE decision for ONE condition (or set of) current clinical conditions. Then, if the physician and proxy/agent agree that the harm and burdens of treatment outweigh the benefits, even life-sustaining treatments can then be withdrawn and withheld. The Now Care Planning Protocol uniquely asks surrogate decision-makers to express their opinions for patient’s treatment decisions for about 49 conditions—whether or not the patient is currently in one of these 49 conditions.

The Protocol argues that the orders for Natural Dying do not necessarily hasten the patient’s death because food and fluid are never withheld and one physician order is: “Always place food and fluid in front of the patient and within the patient’s reach.” This order provides the opportunity for patients to resume self-feeding and drinking that may occur due to the reduction of brain swelling from medical dehydration. (Admittedly, this may occur infrequently.)

The Protocol uniquely strives to be comprehensive by broadening the concept of suffering so that it includes what people dread most about a prolonged dying in advanced dementia (and similar terminal illnesses).

The Protocol is uniquely pragmatic. If surrogate decision-makers agree that the patient would have judged a condition causes severe enough suffering, then physicians do **not** need to assess patients’ current suffering; physicians do **not** need to predict patient’s future suffering. Physicians need only do this: Assess if the patient has reached the clinical criteria of this condition.

Step 4: All members of the Decision Committee have a discussion that the counseling healthcare provider facilitates, to answer two questions:

(1) Have members reached a Consensus of Substituted Judgments for at least one of the 49 conditions for which the patient would want Natural Dying?; and,

(2) Do Decision Committee members and the treating physician agree the patient has reached at least one such condition, *NOW*?

How it works:

All members of the patient’s Decision Committee meet with the counseling healthcare provider at the same time. If a member cannot meet in person, he or she can use a HIPAA-compliant Internet video application. Members discuss their Individual Substituted Judgments for each of the 49 conditions. Sometimes, the knowledge and perspective shared by one member leads other members to change their opinion about whether the patient would have judged a condition caused “severe enough suffering.”[3]

After the meeting, the counselor finalizes the summary of all final Individualized Substituted Judgments in a form entitled:

“Now Care Planning”: Summary of <u>OUR</u> Substituted Judgments of _ _/_ _/20_ _ for __________________ _____________________, born _ _/_ _/_ _ _ _.”

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[3] Steps 3 and 4 can be combined in an alternate procedure: All Decision Committee members meet together. For each condition, others wait until every member has formed his or her independent Substituted Judgment opinion. Then, they reveal and discuss their individual opinions, make revisions if warranted, and then move on to the next condition.

The counselor reviews the summary to determine if Decision Committee members have reached a "**Consensus of Substituted Judgments**"; that is, "Do all Decision Committee members agree the patient would want Natural Dying for at least one condition?" The counselor also asks, "Do Decision Committee members and the treating physician agree that the patient *now* meets the criteria for (at least) one of these conditions?" If the answers to both questions are "Yes," then the time has come for the currently active proxy/agent to ask the physician to engage in a "shared decision-making" conference so the currently active proxy/agent can ask the physician to write orders for Natural Dying (in Step 5).

BENEFIT:

There is usually safety in numbers: the treatment decision that all Decision Committee members reach via a Consensus of Substituted Judgments is more likely to reflect the same decision that the patient would have made, compared to asking only one proxy/agent to make one Substituted Judgment decision. The degree of agreement among Decision Committee members may be revealed by considering not just the patient's current condition but by considering all 49 conditions in the *patient decision aid*.

The Protocol may further reduce the emotional toll of Decision Committee members by sharing the awesome responsibility of making a life-determining treatment decision with other members after diligently discussing the decisions with an experienced and knowledgeable counselor. This contrasts with a common proxy/agent lament: "After the physician asked me, I found it really hard to say, 'Yes' to pull the plug from Grandma."[4]

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[4] This statement and others in this section, seem plausible *on their face*, but they have not yet been proven by empirical research. Note: traditional substituted judgment may be accurate only about two-thirds of the time; however, several frequently cited studies did not focus exclusively on severe, end-stage conditions. See: Shalowitz, David & Garrett-Mayer, Elizabeth & Wendler, David. (2006). The Accuracy of Surrogate Decision Makers: A Systematic Review. Archives of internal medicine. 166. 493-7. 10.1001/archinte.166.5.493. Others report better results with acute stroke patients: Bryant, J., Skolarus, L. E., Smith, B., Adelman, E. E., & Meurer, W. J. (2013). The accuracy of surrogate decision makers: informed consent in hypothetical acute stroke scenarios. *BMC emergency medicine*, *13*, 18. doi:10.1186/1471-227X-13-18

Why this step is unique:

Traditionally, ONE surrogate decision-maker makes ONE treatment decision about ONE condition (the patient's current condition), in response to a request from the treating physician—which generates ONE data point. In contrast, the Now Care Planning Protocol directs three (or more) surrogate decision-makers to proactively make 49 treatment decisions about 49 conditions, which generate 147 (or more) data points.

Step 5: The currently active proxy/agent and likely, the counselor, attend the "shared decision-making" conference. The currently active proxy/agent delivers four items to the physician: (A) a cover letter; (B) a Table summarizing the Decision Committee's Consensus of Substituted Judgments; (C) a POLST or medical order form with pre-printed orders for Natural Dying; and, (D) a boilerplate letter the physician can modify and send to a bioethicist or independent clinician to request a second opinion.

How it works:

Most physicians prefer to deal with one, legally designated surrogate decision-maker. But if the Decision Committee believes success is more likely if another member attends the "shared decision-making" conference, then the currently active proxy/agent can ask the physician if both can attend although only one has legal standing.

The cover letter is entitled: "**A request to sign a POLST form with additional orders to honor the patient's end-of-life wishes**." (POLST is the Physicians Orders for Life-Sustaining Treatment.)

The boiler plate letter is entitled: "**Treating Physician's Letter to a Bioethicist or Independent Clinician**."

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For the Now Care Planning Protocol to be widely accepted, all must feel certain adequate safeguards were taken to make premature dying extremely unlikely. This is particularly relevant if there is a known potential conflict of interest. Examples include: the proxy/agent is (A) a recipient of the patient’s estate; is reeling from the huge burden of caregiving; or, resides in the patient’s home.

Summary of safeguards to prevent premature dying includes oversight by . . .

1. Other members of the Decision Committee, who may call out a member whose decisions seem self-serving.
2. The counseling healthcare provider who hears the opinions of all Decision Committee members.
3. The treating physician who is responsible for the patient, whose societal duties include preserving life and reducing suffering although both goals may not be possible as life nears its end.
4. A bioethicist or independent clinician (and possibly a healthcare attorney) who are asked to evaluate the ethical/clinical (and legal) appropriateness of the Now Care Planning Protocol that surrogate decision-makers followed, taking into consideration, the patient’s particular circumstances.

BENEFIT:

The protocol defines success as the treating physician writing the four orders for Natural Dying—if that is what the patient would have wanted. To maximize success, the Decision Committee can ask another member to attend the “shared decision-making” conference. The currently active proxy/agent or counselor can present data, explain the “severe enough suffering” criterion and the Consensus of Substituted Judgments; and then ask treating physician to confirm that the patient *NOW* meets the clinical criteria of one or more of such conditions. The counseling healthcare provider can share his or her professional experience and knowledge that can include citing relevant clinical, legal, and religious authorities. The counselor can also assure the physician that all members of the Decision Committee were previously asked to list the names of other concerned individuals who might have legal standing and want their opinions heard. This may reduce physicians' fear of being sued by a person who might otherwise not be identified.[5]

Why this step is unique:

Traditional currently active proxy/agents act alone as they attempt to motivate physicians to write orders that honor the patient's wishes. Lacking support may be one reason such requests are so often thwarted. Success may cause moral angst.

In contrast, the Now Care Planning Protocol supports the currently active proxy/agent in various unique ways: A presentation that includes data that strive to be convincing; a group of alternate surrogate decision-makers; an experienced, knowledgeable, and articulate counselor; a boilerplate letter that has had previous success, a pre-printed POLST form that includes the requested orders; and, the reasonable request that the physician ask for a second opinion from a bioethicist or independent clinician.

Step 6: The treating physician requests a consultation from a bioethicist, holds a conference, and then may write the orders for Natural Dying.

How it works:

"**Treating Physician's Letter to Bioethics Committee**" is a boilerplate form letter that the treating physician can modify and send to a bioethicist or second clinician (and a legal consultant). This letter has a suggested minimum set of questions for

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[5] See: *Conservatorship of Wendland*, 26 Cal.4th 519, 524, where the court concluded, "…a conservator may not withhold artificial nutrition and hydration from such a person absent clear and convincing evidence the conservator's decision is in accordance with either the conservatee's own wishes or best interest." A 20-member ethics committee voted unanimously that the patient's wife could refuse surgical reinsertion of a feeding tube after Robert Wendland, who was in the Minimally Conscious State, pulled out his feeding tube for the fourth time. But then, the patient's previously estranged mother showed up. Instead of dying in about a week, the lawsuit carried on for about 6 years."

the bioethicist/clinician to answer. The physician can of course ask other questions and the bioethicist can expand the scope of his/her opinion.

If the treating physician is not willing to write the orders for Natural Dying, the Protocol suggests several ways to inform, educate, and motivate the physician. If unsuccessful, the currently active proxy/agent and counselor may be able to transfer the care of the patient to another clinician who is willing to write orders to allow the patient to die of her underlying disease in a private, peaceful, and timely way.

BENEFIT:

Bioethics consultations can be expedited to answer challenging questions whose answers may allay fears about unwanted, premature dying; and about other ethical, and philosophical questions.

Why this step is unique:

This step is proactive compared to traditional requests for bioethics consultations that arise from unanticipated situations. To our knowledge, no other end-of-life decision-making protocol **requires** a bioethics (or second clinical) consultation for **every** patient, regardless of specific circumstances. (Perhaps, if the Protocol becomes widely and routinely accepted someday, and those with experience write clinical guidelines, then bioethics consultations may be needed only if a new challenge emerges.)