Six Steps to “Now Care Planning”

- “**Now Care Planning**” is for patients who want a peaceful, timely dying, but 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 mental capacity so they cannot either complete a new living will or revise their existing living will that is **not adequate** or **not effective**.

  Defining what makes living wills **adequate** and **effective**:

  A living will is **adequate** if it clearly informs future physicians and others precisely “**when**” patients would want others to allow them to die of their underlying disease.

  A living will is **effective** if (i) the intervention it offers (its “**what**”) can allow patients to have a **private**, **peaceful**, and **timely** dying, and if (ii) physicians and other authorities can view the intervention as **acceptable**.

  Unfortunately, few living wills meet these criteria and the results can be sad. Loved ones may feel helpless for years as they watch patients 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 convincing arguments to treating physicians. It also includes several layers of safeguards designed to prevent premature dying. A counseling healthcare provider is required to guide the legally designated currently active proxy/agent and two or more proxy/agent alternates and possibly concerned others through the Protocol. The intermediate goal is to make the same treatment decisions patients would have made—if patients had been asked when they still possessed decision-making capacity to judge if their present condition would cause “severe enough suffering.”

  The ultimate goal is to convince a physician to write the orders for Natural Dying so the patient can avoid a prolonged dying with severe suffering by having a private, peaceful, and timely dying that is based on their values.

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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:

First, the concerned individual asks the counseling healthcare providers to evaluate the patient's living will using two checklists. They ask, "*On its face,* is the patient's living will likely to be **not adequate** or likely to be **not effective**?" If not:

Potential members of the patient's Decision Committee, which includes the legally designated currently active proxy/agent, all designated alternates, and identified concerned others all complete a **FREE online program** entitled: "**Are you concerned about someone who is dying slowly from dementia, and might be suffering?**" at:
https://www.surveymonkey.com/r/Now-Care-Planning-for-Dementia

This online program introduces the Protocol to concerned persons who are seeking a way to help reduce a loved one's suffering. It **informs** potential members of the patient's Decision Committee about what qualifies the patient as appropriate for Now Care Planning, and what qualifies them to be a surrogate decision-maker. Then it asks for their **consent**.

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. Using this Protocol may change surrogate decision-makers' treatment decisions for loved ones in middle dementia. If surrogate decision-makers know they can avoid a prolonged dying with suffering and burdens, then they may request treatment for patients who contract a life-threatening urinary tract infection or pneumonia, to let the patient possibly return to enjoying simple pleasures of life. Using this Protocol may also eliminate loving, devoted spouses or children from considering mercy killing (that could be considered "murder")—thus sparing them great emotional angst and possible criminal prosecution, or at least suffer from anxiety and guilt because they think about but cannot carry out such an act even though they are certain they patient would no longer want to live.

Why this step is unique:

To our knowledge, no other protocol insists on qualifying criteria for advanced dementia patients, and on qualifying 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 hand-feeding and hand-hydrating (spoon-feeding).

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

How it works:

Potential Decision Committee members who complete Step 1 will automatically be directed to the second FREE online program whose title is:
"Now Care Planning: Does your loved one resist spoon-feeding?" and is at: 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 that *seems* resistant or *seems* to cause the patient *distress* is subject to false negatives and false positives, and that 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 to follow the recommended “Now Care Planning” Protocol, which can take two or three hours.

At this point, the concerned individuals, who have become Decision Committee members, can engage the healthcare counseling provider on a limited basis to receive feedback in Step 3.

Step 3: Each Decision Committee member completes the online *patient decision aid* “My Way Cards” to express an opinion about each of 49 conditions by answering this key question for each condition: “If asked before losing capacity, would the patient have judged 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:

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—if the patient and the surrogate decision-maker qualify, and the currently active proxy/agent engages the counselor’s services: “**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. Taken together, these 49 conditions strive to be comprehensive by reflecting what people dread most about enduring a prolonged dying in advanced dementia and other 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. The counselor facilitates this group meeting.)

The online program explains “Natural Dying” and summarizes the main 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.
The counselor returns the forms to each committee member and holds a telephone conference to review his/her opinions.

The title of this form is:

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

BENEFIT:

The goal of the Protocol—to let patients have a peaceful and timely—can be attained only if physicians write an order to stop oral feeding. Some physicians refuse to write this order because they hold too narrow a view of the harms and burdens of suffering. Many limit their view of suffering to the act of oral feeding itself; for example, the high risk of aspiration pneumonia because food may go down the wrong way into the lungs.

The benefit of using the *patient decision aid* **My Way Cards** is to view suffering more broadly so that various types of severe suffering can be considered severe enough for patients to want others to allow them to die of their underlying disease.[1] In addition to physical pain about which the patient is unable to complain, which may therefore go unrecognized and untreated, patients often experience severe emotional suffering that can be difficult to treat. Other types of severe suffering include disruption of one’s life narrative, loss of existential meaning in one’s life, and imposing huge burdens on their loved ones, which are difficult or impossible to treat.

The “Now Care Planning” Protocol’s broad concept of suffering strives to comprehensively include what people dread most about prolonged dying with suffering in advanced dementia and other terminal illnesses. The Protocol also insists on using this high bar: the patient is now in a condition that s/he would have judged as causing **severe enough suffering**. The goal is to present the data of surrogate decision-makers’ substituted judgments that physicians and others will find **convincing** and **compelling**.[2]

The criterion “the patient would have judged this condition to cause severe enough suffering” has significant advantages over other criteria proposed for dementia-specific living wills, including 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 dangerous

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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.

slippery slope that could lead to 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 of various types. (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 one set of current conditions). Then, if the physician and proxy/agent agree that the harm and burdens of treatment outweigh the benefits, it is ethical and moral to withdraw/withhold all life-sustaining treatments. The Now Care Planning Protocol uniquely asks surrogate decision-makers to express their opinions about how the patient, when capacitated, would have judged each of 49 conditions—even for conditions that the patient is currently not in.

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 is unique in striving to be comprehensive by broadening the concept of suffering so that suffering can include 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 the patient's current or likely future suffering. Physicians need only assess if the patient has reached the clinical criteria of this particular condition.

Step 4: All members of the Decision Committee have a discussion that the counseling healthcare provider facilitates, to answer two questions: (1) Have committee members reached a Consensus of Substituted Judgment 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:

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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.

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"Now Care Planning": Summary of <u>OUR</u> Substituted Judgments of _ _/_ _/20_ _ for ____________________ ________________________, born _ _/_ _/_ _ _ _."

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 any condition?" The counselor also asks, "With input from the treating physician, do Decision Committee members agree 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" meeting where the currently active proxy/agent will 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, their Consensus of Substituted Judgment, 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, which reflects knowledge of patient's values, may be revealed by considering all 49 conditions in the *patient decision aid*, in addition to the patient's current condition.

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 this common proxy/agent lament: "After the physician asked me, I found it really hard to say, 'Yes, 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-

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 point of data. 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) points of data.

Step 5: The currently active proxy/agent and counselor, and perhaps others, attend the "shared decision-making" meeting, at which the currently active proxy/agent hands the physician four items:

(A) a cover letter that summarizes the data and lists the attachments;
(B) a Table summarizing the Decision Committee's Consensus of Substituted Judgment;
(C) a POLST or medical order form with pre-printed orders for Natural Dying; and,
(D) a boilerplate letter that 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 or trusted advisor attended the "shared decision-making" meeting, the currently active proxy/agent can ask the physician if this person can also attend, with this understanding: only the currently active proxy/agent has legal standing.

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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

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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.) This letter, in turn, refers to and explains the Table that summarizes the Decision Committee's Consensus of Substituted Judgment. The Table refers to the members' individual Substituted Judgments that are attached. Finally, the letter asks the physician to sign the POLST or medical order form that has pre-printed, the orders for Natural Dying.

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

For the Now Care Planning Protocol to be widely accepted, all must feel certain that 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 may inherit some 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 opinions about the patient's judgments may be self-serving.
2. The counseling healthcare provider, who hears the opinions of all Decision Committee members twice.
3. The treating physician, who is responsible for the patient and 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 was asked to evaluate the ethical/clinical (and legal) appropriateness of applying the Now Care Planning Protocol in this case after taking the patient's particular circumstances into consideration.

BENEFIT:

The protocol defines success as the treating physician writes the orders that honor what the patient wanted, which can include the four orders for Natural

Dying. The Protocol is design to make convince the physician by the counselor's explanation of "severe enough suffering" and the data of the Consensus of Substituted Judgment. The physician is responsible 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 all 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 start a lawsuit later.[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 the currently active proxy/agent moral angst.

In contrast, the Now Care Planning Protocol supports the currently active proxy/agent in various unique ways: The presentation of data designed to convince the treating physician may also convince members of the Decision Committee; support from other committee members; sharing by an experienced, knowledgeable, and articulate counselor; and the second opinion of a bioethicist or independent clinician.

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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 a week or two, the lawsuit carried on for about 6 years."

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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 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 will try to transfer the care of the patient to another clinician who is willing to write the orders for Natural Dying. If that fails, the currently active proxy/agent can petition a court of law to compel a physician to write an order. While to our knowledge, no judge has ruled on any similar case, a provocative fictional account does exist, and perhaps someday, life will have been predicted by art.[6]

BENEFIT:

Bioethics consultations can be expedited to answer challenging questions whose answers may allay fears about unwanted, premature dying as well as about profound ethical and philosophical issues.

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

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[6] “The Mighty Rogues.” Boston Legal. Season 4, Episode 16. April 15, 2008. Its official description is: “Shirley makes a bold decision to help her father end his suffering when he reaches the final stages of Alzheimer’s, but needs Alan’s help to convince the court to allow it.”

decision-making protocol **requires** a bioethics (or second clinical) consultation for **every** patient, regardless of specific circumstances. (It is possible that someday, if the Protocol becomes widely and routinely accepted, and especially if those with experience write clinical guidelines, then bioethics consultations may be needed only if a new challenge emerges.)