

NOW Care Planning—a Caring Advocates Protocol

NOW Care Planning is a legal, ethical, moral protocol to respectfully decide and effectively implement a **treatment of last resort**—a medical intervention considered only after less drastic options failed to relieve a patient’s severe, irreversible (refractory, untreatable) end-of-life suffering. The protocol strives to be consistent with the patient’s lifelong values and treatment preferences; that is, to provide “goal-concordant care.” Often, strategies are needed to overcome challenges to implement these interventions because they are controversial. A possible, foreseen, but unintended outcome is attaining a peaceful, timely dying—but its primary goal is to relieve suffering, **not** to hasten death.

NOW Care Planning is designed for patients who have already reached an advanced stage of dementia or other terminal illness that has rendered them unable to speak for themselves: they lack decision-making capacity (**DMC**) *and* they did **not** previously complete an **effective** living will to attain their goals for their current condition.

The protocol serves two types of patients. Neither depends on high-tech medical treatment that can be withdrawn or withheld to allow them to die naturally. They have “No plug to pull.”

(A) Those with **severe** refractory suffering who depend on another person’s hand to put food and fluid in their mouth to survive—a treatment that is legal to refuse.

(B) Those with **exceedingly severe** refractory suffering for whom all reasonable non-sedating methods of treatment have failed (or would likely fail) to provide relief, who can still eat and drink independently (without another’s hand assistance).

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(C) Note: NCP is **not** needed for patients at risk for contracting aspiration pneumonia—a way to die that can be unpleasant—for which it is legal to withhold food and fluid.

Benefit: NOW Care Planning can make it possible to avoid prolonged suffering for several months or years that includes suffering from sources that **cannot be observed or be treated**.

Two treatments of last resort:

Natural Dying (ND): This intervention refuses assisted oral feeding and hydrating by another person's hand while always offering food and fluid by placing them within the patient's reach. Unless the patient resumes eating and drinking, which is possible but would be surprising, dying by medical dehydration usually occurs within two weeks of beginning a total fast of food and fluid. The process of dying is most often peaceful with minimal medication. Spoon-feeding, like any other invasive treatment that violates a patient's bodily integrity, can be viewed as legal, ethical, and moral to refuse.

Moderate Anesthesia (MA): Using medications to sedate patients to either relieve the offending symptoms (for example, psychiatric symptoms), or to make patients unaware of these symptoms due to deliberately diminishing their consciousness.

Consent: The legally designated, currently active proxy/agent must sign a consent form on behalf of the patient that acknowledges being adequately informed by the physician/provider about two foreseen but unintended possible side effects:

(A) The patient might die earlier with either ND or MA as the treatment of last resort.

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(B) The patient may not regain consciousness before dying with Moderate Anesthesia.

To be effective, living wills must be **acceptable** to authorities who have the power to agree to implement orders and let those orders stand. Otherwise, any requested intervention would be effective only in theory—not in practice. **Effective** means a physician or provider promptly (without conflict) writes and implements a clinically appropriate **POLST** that contains the medical orders the patient needs.

Reasons why POLSTs are well-suited for NOW Care Planning: (POLSTs were formerly called Physician Orders for Life-Sustaining Treatment although their names varied among American states):

- (A) POLSTs have the authority and power of physician/provider orders (that exceeds an instruction in a living will or from a proxy/agent)
- (B) POLSTs are immediately actionable, so there is little time for conflicts to emerge
- (C) Orders apply in all treatment settings including home, long-term residences such as memory units, assisted living facilities, and skilled nursing homes, and hospitals.

The ethical process: Treating physicians/providers must diligently discuss POLSTs with the legally recognized proxy/agent regarding whether the POLST is clinically appropriate. They must also adequately inform them of the implementation's benefits and risks. To implement the POLST, both must sign the POLST form—an act that indicates the proxy/agent consented on behalf of the patient after the physician/provider shared adequate relevant

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information.

How the treatment decision is made:

Substituted Judgment (SJ) is a widely accepted bioethical practice of making treatment decisions for a person who lacks DMC. The goal is to make the same treatment decisions for the current condition that patients would have made for themselves if they had DMC.

NOW Care Planning expands the traditional process in two ways: by the number of people asked for their SJ opinion, and by the number of conditions they are asked to judge regarding how much suffering they would cause.

Traditionally, one individual (the currently acting proxy/agent) is asked just one question about treatment for just one clinical condition (the patient's current condition).

“In your opinion, what specific treatment would the patient want **now**—given his/her present clinical condition(s)—if s/he had been asked a few years ago, when s/he possessed decision-making capacity (DMC)?” (This is the classic **SJ** question.)

An alternative **SJ** question is: “In your opinion, what specific treatment would the patient want **now**—given his/her present clinical condition(s)—if somehow (magically) the capacitated version of the patient could return long enough to observe the current state of the patient and to make a deliberative decision now?”

The **NOW Care Planning** Protocol expands the effort to gather a robust set of data upon which life-determining decisions can then be made. These are the **6 steps**:

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1. The currently acting proxy/agent forms a new Patient Decision Committee (**PDC**) by inviting all alternate designated proxies/agents. The PDC can also include individuals who know the patient well such as other family members and those whose specialized background may be helpful. They can offer their advice, but they are not asked to vote based on their substituted judgment.
2. When anyone believes the patient's suffering has become severe, all available PDC members should schedule a meeting to discuss if other interventions possibly need to be implemented now.
3. To help PDC members decide, they can complete one or both of Caring Advocates' free forms. One is: "**Are you concerned about someone who is dying slowly from dementia, and might be suffering?**" This is available at:
<https://www.surveymonkey.com/r/Now-Care-Planning-for-Dementia>

Another form is: "**Now Care Planning: Does your loved one resist spoon-feeding?**" This is available at:
<https://www.surveymonkey.com/r/Relative-resist-spoon-feeding>.

4. Each PDC member then uses the patient decision aid, **My Way Cards**, to render their opinion based on their substituted judgment and their knowledge about the patient's lifelong values and treatment preferences to judge the severity of each of 49 conditions.

There are four levels of severity, four possible interventions, and four corresponding POLSTs. They start with Selective/Limited Treatment—first with, and then without CPR (DNR).

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Natural Dying and Moderate Anesthesia are two treatments of last resort.

Example: If there are 5 currently acting proxy/agent, including four designated alternates who complete the patient decision aid **My Way Cards**, then there will be 5 X 49 or 245 pieces of data.

Presenting the results—if there is agreement—may help persuade a future physician/provider to implement the appropriate POLST.

5. An ACP counselor will review all questionnaires and My Way Cards data and hold a conference with the available PDC members. They can discuss the results, debate differences, change their minds, and possibly reach a “consensus of substituted judgment.” If they cannot agree, they must wait until the patient’s clinical condition changes further.

If PDC members agree that one or more conditions are **now** causing severe suffering, then they can authorize the currently acting proxy/agent to advocate for implementing the **Natural Dying POLST** in a shared decision-making/POLST Conversation with the treating physician/provider.

If PDC members agree or that two or more conditions are **now** causing exceedingly severe suffering and the patient can still eat and drink without assistance, they can then authorize the currently acting proxy/agent to advocate to implement the **Moderate Anesthesia POLST** in a shared decision-making/POLST Conversation with the treating physician/provider.

6. The ACP counselor can provide the currently acting proxy/agent a blank POLST form to which the needed orders for the treatment of last resort have already been added (for the convenience of the

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treating physician/provider).

The ACP counselor can also print a cover letter summarizing the consensus of substituted judgment data that appears in a Table in this letter, and a boilerplate letter that the physician/provider can optionally modify, sign, and send to a bioethicist or independent clinician to request a second opinion regarding the appropriateness of implementing the requested treatment of last resort.

When the currently treating physician/provider is comfortable with implementing the treatment of last resort, the signed completed POLST can be implemented.

Safeguards and Strategies:

- (A) The robust set of data collected can be combined with convincing arguments to persuade treating physicians/providers to comply with patients' wishes. These arguments can be in several fields, including medicine, geriatrics, dementia, end-of-life suffering, bioethics, law, philosophy, and religion.
- (B) A counseling healthcare provider can guide the legally designated currently active proxy/agent and alternates, and concerned others, through the protocol. It is essential that the goal of substituted judgment is understood: It strives to arrive at the same set of treatment decisions for the current condition that patients would have made themselves, if they had capacity. It is **not** what the surrogate would do for himself or herself, or what the surrogate thinks is best for the patient. It is what the patient would have decided (worth repeating).

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- (C) If the currently treating physician/provider delays or refuses, the currently acting proxy/agent can seek another provider and/or follow one of several strategies from Strategic Advance Care Planning that may be applicable.
- (D) One advantage of the NOW Care Planning Protocol is to spread the responsibility among several people for making a life-determining treatment decision for another human being. This is in addition to emotional support, that is likely enhanced by having a group meeting with the ACP counselor. It is also likely that the decision arrived at, and when to implement it, are more accurate than if only one surrogate had been asked. Finally, the treating physician/provider may be impressed by the number of surrogates who agree with one another and that they asserted they know no one who may have legal standing who would oppose implementing a treatment of last resort.
- (E) In NOW Care Planning, every patient and their proxies/agents are different; hence the approach needs to be personalized. That makes the above a general guide regarding what to expect.