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The Scholl Institute of Bioethics is a nonprofit, Judeo-Christian organization that addresses bioethical issues including euthanasia, physician-assisted-suicide, the withholding or withdrawing of food and water from non-dying patients, brain death, organ transplantation, genetic engineering, and the rights of disabled or mentally ill persons.

Advanced Directives: How to Protect Yourself and Your Loved Ones

By Alexandra Snyder, Executive Director for Life Legal Defense Foundation

Life Legal was founded nearly thirty years ago and since that time, we have handled thousands of inquiries involving the denial of life-sustaining care. In the last few years, however, the number of these types of cases has skyrocketed.

I am not sure whether to attribute this to the Affordable Care Act and its inevitable rationing of health care or whether the cause is a changing culture that increasingly views human life in terms of purely utilitarian value. I suspect it is a little of both.

Whatever the cause, the effect is that we have not only seen an overall escalation in the number of such cases, but an increasing number of calls to Life Legal involve denial of life-sustaining care to patients who are simply not allowed sufficient time to recover from their injuries.

Some of those cases shock the conscience—like that of 32-year-old Jessica, who suffered a heart attack that left her temporarily incapacitated. Within 4 days of being admitted to the hospital, Jessica's doctors and mother decided she wouldn't want to live "this way," and committed her to a hospice facility without nutrition. The plan was to starve her to death. Two days after entering hospice, Jessica began moving one arm and a day later, she uttered her first words since her injury: "I'm hungry."

The hospice physicians refused to feed her. David, Jessica's fiancé, had been trying to get information about Jessica's prognosis and the hospice's "treatment" plan, but because he and Jessica were not married, he had no legal standing to make medical decisions—or even inquiries—on her behalf.

David called Life Legal and we worked with a local attorney to obtain a court order compelling the hospice facility to immediately transfer Jessica back to the hospital so she could receive food, water, and proper medical care. With therapy, Jessica was able to recover most of the functions she had prior to her injury.

So how can you protect yourself and your loved ones from a health care system that is willing to make life and death decisions

about patient care based on a highly subjective "quality of life" determination?

If Jessica had signed a document prior to her heart attack indicating that she wanted full treatment in the event she was rendered unable to make her own health care decisions, she

would not have been at risk of being starved to death—at least not so soon after becoming incapacitated. There are a number of ways you can make your health care wishes known so you are not at the mercy of someone else's view of whether your life is worth sustaining.

One of those ways is through a POLST, or Physician's Order for Life Sustaining Treatment. In some states, the form is called a MOLST

(Medical Order for Life Sustaining Treatment). For purposes of this article, I will simply refer to them as POLST.

As its name indicates, a POLST (or MOLST) is a doctor's order for a specific type or level of treatment.

There has been no small amount of controversy surrounding the use of POLST forms. The forms were initially developed as a means to allow individuals to request the *withholding* of extraordinary medical treatment, most typically artificial ventilation. Some individuals also used the forms to expressly state that they did not wish to receive artificial nutrition and hydration in the event that they became incapacitated.

Note that the provision of food and water by any means should not be considered treatment as such; rather food and water are part of ordinary care and should not be withheld unless they pose a health risk to patients. In any case, some people still view POLST forms with suspicion, believing they inherently diminish the availability of life-saving medical treatment. This is not necessarily accurate. There are several reasons why an individual may want to consider a POLST—for example, if he or she does not have a trusted family member or loved one to designate as a health care agent or proxy.

As we enter into an era where extraordinary—and even

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ordinary—medical treatment and care are provided for shorter periods of time and where patients are removed from ventilators or hydration within days or hours of a disabling event, POLST forms can be a means of expressing the type and extent of care a person *wants*, as opposed to the type of care he or she does not want.

In a culture that increasingly views life in terms of utility, health care providers often consider artificial nutrition and hydration a form of extraordinary care that, absent specific instructions to the contrary, may be withdrawn at their discretion. People need to be aware of this and plan accordingly.

We urge people to print out a copy of their state's POLST form and carefully read through the various levels of care options. Typically, the form will first ask whether you want a do not resuscitate (DNR) order in the event of incapacity. A DNR means you will not receive life-saving measures such as cardiopulmonary resuscitation (CPR) if you have a heart attack or stroke, but rather you will be allowed to die a "natural death."

We witnessed this with my father-in-law who, unbeknownst to my husband and I, had a DNR in place. When he had a stroke, his wife was instructed not to call the hospital; instead she was informed that a home health nurse would arrive the following day to administer pain medication. I am not a medical professional and do not know whether timely emergency intervention may have saved my father-in-law's life. I do know that he lay writhing on his couch, in and out of consciousness, for a week before he died. It may have been "natural," but we have often wondered if it was a needlessly premature death.

The POLST form describes three levels of care:

1. "Full Treatment" provides patients with the most care and treatment, including ventilation and artificial nutrition and hydration.
2. "Selective Treatment" provides limited medical treatment such as antibiotics and IV fluids, but not so-called "burdensome" measures like ventilation and artificial nutrition and hydration. Selective Treatment typically does not include intensive care.
3. "Comfort-Focused Treatment" only provides care to keep patients comfortable. Often patients who select a DNR and Comfort-Focused Treatment are not taken to the hospital, but are provided palliative care in a home or hospice setting.

Most POLST forms have a separate section that allows you to select whether you would like to receive artificial nutrition and hydration, including feeding tubes, and whether you would like it to be continued long-term, for a trial period, or not at all.

I certainly cannot dictate what type of care another individual would like to receive. People with very severe health concerns, for example, may not be good candidates for aggressive resuscitative measures. However, I have encouraged my family and loved ones to select the highest level of care, including full treatment, and long-term nutrition and hydration. Too often I have seen cases where life-sustaining care was abruptly withdrawn once the hospital discovered that

the patient had requested select or comfort-focused treatment on the POLST.

It should be noted that the POLST is a legal document that is fully executable as soon as it is signed by you and your doctor. The form becomes part of your medical record.

If you have someone you trust to make your health care decisions for you in the event of incapacity, it is likely preferable to execute an advance directive over a POLST, as an advance directive gives you more options regarding your care and is not as rigid as a POLST.

The websites of State Attorneys General often have advance directive forms available that you can modify to suit your needs. You can fill out all or part of the form, which typically becomes fully executable as soon as it is signed by two witnesses and/or acknowledged by a notary public. In some states, one of the signers must be a "disinterested witness," that is, an individual who is not related to you and who does not stand to benefit from your estate. Each state's advance directive laws are different, so familiarize yourself with the requirements for your state.

It is important that any documents expressing your health care wishes be consistent. If you have signed a trust document, health care power of attorney, living will, and/or POLST in the past, review the documents to make sure they still reflect your true wishes. For example, living will templates may include boilerplate language that authorizes the withdrawal of treatment, including food, water, and ventilation. You can change this language if you want to receive life-sustaining treatment, but you will have to properly amend the documents.

It is essential to have a thoughtful conversation with your chosen health care agent to communicate your desires as well as the religious or philosophical grounds for your choices in care and treatment. I would also encourage you to have such a conversation with your close friends and family so that they too know what type of care you want in order to avoid any potential conflicts in decision-making.

It is important to familiarize yourself with key terms and concepts involved in health care decision-making. And be aware that serious brain injuries resulting in incapacitation can take time—often months or even years—to heal. If you select a low level of treatment, whether through a POLST or an advance directive, treatment that could sustain and even save your life will likely be withheld from you.

It is not pleasant to imagine yourself in an incapacitated state such that you are not able to make real time health care decisions for yourself. But thinking about your health care goals and wishes ahead of time and executing the proper documents to protect those wishes is far preferable to having a stranger make life and decisions for you based on a highly subjective interpretation of your "quality of life."

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