

# Op-Ed Beware the rush to help people die

By **BEN MATTLIN**

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**T**he Medical Society of New Jersey, the state's largest physicians group, opposed a recently tabled bill for physician-assisted suicide. But it is pushing an alternative that may be just as bad: the Practitioner's Orders for Life-Sustaining Treatment, or POLST.

POLST is a legally binding form with medical instructions that other healthcare providers, such as paramedics and nursing home staff, must follow if the patient is unable to speak because of illness. It gives more specific instructions than a living will or advance directive, and is said to be more effective because it comes from — and is signed by — a medical authority, such as the patient's doctor. Ideally, the patient gives permission for the form, but if the patient is unable to, a designated proxy can do so.

"POLST has teeth," as a 2013 NPR segment put it: "It overrides the legal obligation of an EMT or a hospital to provide CPR and other emergency care that for old and sick people can lead to a long, miserable hospital stay."

But is POLST really a good idea? POLST has been gaining ground nationwide, in various forms, since it was launched in the 1990s in Oregon, the first state to legalize physician-assisted suicide. It's now been implemented or is under development in all but seven states. New Jersey introduced its version in February 2013, but Larry Downs, the head of the medical society, said in news reports that "it's going to take a few years" to be adopted.

I don't need to wait to weigh in on it. I can't help but feel a deep-seated distrust and dread over POLST and any assisted-suicide laws. I have lived all of my 51 years on the cusp of death because of a genetic neurological condition called spinal muscular atrophy. I have never been able to stand or walk, and I lost the use of my hands 16 years ago. I was not expected to live beyond my teens but am a Harvard graduate, a writer, a husband and the father of two. And with the help of a motorized wheelchair, a voice-recognition computer and attendants, I live a full life.

In fairness, the attention being given to end-of-life choices is a good sign for those of us who are concerned about patients' rights. I'm simply leery of the push for a better death before we've done all we can to promote a better life for those of us on the fringe.

Last month, the Journal of the American Geriatrics Society published a study by Oregon Health & Science University validating the success of Oregon's POLST program. "Almost everyone in our study who wanted to be with family and avoid an unwanted terminal hospitalization, as long as their comfort could be managed, got their wish," concluded the study's senior author, Susan Tolle.

I agree that too many people die in hospitals rather than at home where they'd prefer to be. Nevertheless, POLST is the wrong solution. The forms are standardized, not tailored to the patient. It is unlikely that a doctor would suggest any hypothetical, extreme treatment on such a form, so it is inherently skewed toward the patient not opting for potentially lifesaving care. In fact, there's no provision to ensure how well informed you are at the time to make such a decision.

I don't like my care choices hemmed in by pre-planned institutionalized parameters. I know firsthand how important it is to remain flexible regarding medical care, and how common it is for conditions to be dangerously misunderstood and deemed terminal.

Seven years ago, I spent three months in the ICU after an error in routine surgery. I was in a coma. My wife was asked, given my severe physical limitations, whether I felt my life was worth saving. She had to insist that every measure should be taken to preserve my life.

It took another six months after I was home before I was back in the swing of life. During that time, my wife learned how to keep clueless home nurses on task. She would say, "Doctor's orders." It's a powerful phrase that says, "This must be obeyed precisely. Don't argue." But just as "doctor's orders" can save the day, they can also be harmfully rigid.

Physician orders written in advance can't possibly cover every real-world eventuality. Sometimes you have to render decisions on the spot, in response to new information such as an allergic reaction — or a change of heart.

At other times, a doctor's orders are simply wrong. Reasonable doctors can and often do disagree. That's why we seek second opinions.

To be sure, POLST and assisted-suicide advocates aim to alleviate misunderstandings and honor patients' desires and tolerance limits. But what I want most when I'm at my worst physically is to feel better. So if a doctor asks a patient about some future treatment, "Do you prefer to refuse treatment and let nature take its course?" — or words to that effect — it might well sound like a recommendation. After all, aren't doctors supposed to know what's best?

Worse still, some POLST programs don't even require a doctor's input. A nurse practitioner simply has to indicate that various treatment options were discussed with a patient — "Do you

want to go on a ventilator?" "How do you feel about blood transfusions?" "Would you like to a feeding tube?" No one witnesses how that was done, how well the patient understood the options or how clearly the patient answered. If a patient declines to answer, is that taken as permission to forgo life-sustaining treatment?\*

The subtle pressures to go along — to avoid costly treatments — can easily lead to acquiescence, especially if the patient is confused. Believe me, we may say anything under the influence of pain or morphine or in the isolation of an ICU.

POLST merely hastens uninformed decision-making based on fear, just as assisted suicide's medically monitored poisoning is based on fear. Both have equally insufficient safeguards against coercion.

*Ben Mattlin is the author of "Miracle Boy Grows Up: How the Disability Rights Revolution Saved My Sanity."*

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\* Maryland not only doesn't require a doctor's input, the patient or surrogate never actually signs the [MOLST](#) form to affirm that he even comprehends, much less consents to, these a la carte life-and-death choices. DNR forms get no patient/surrogate signature either, and an unauthorized [DNR](#) was placed in my father's chart culminating in his euthanization (see [HolyCrossHealth.com](#)).