

# State Initiatives in End-of-Life Care

Issue 3, April 1999

Focus: Oregon's POLST Program

## Implementing End-of-Life Treatment Preferences Across Clinical Settings

Since the late 1980s, out-of-hospital Do Not Resuscitate protocols have spread like wildfire, according to Charles Sabatino, Assistant Director of the American Bar Association's Commission On Legal Problems of the Elderly (see map on page 2).

Now operational in 41 states, these protocols protect people from unwanted, aggressive life-sustaining treatment by Emergency Medical Service personnel. Since EMS responders are required to take heroic measures unless otherwise directed by valid physician orders, advance directives will generally not stop the uncoiling spring of high-tech EMS "rescue."

In Oregon, as in many other states, the first impetus for change came from family and health provider reports of tragedies caused when "rescue" mandates overrode documented patient wishes to die in familiar settings without extraordinary life support:

- an 84-year-old nursing home resident in advanced heart failure is transported to the hospital, given CPR en route, dying a painful death among strangers;
- a 91-year-old nursing home resident with dementia fractures her hip, is appropriately transported to the



*The POLST (Physician Orders for Life-Sustaining Treatment) form accompanies patients so that their end-of-life treatment preferences do not get "lost" when transfer occurs or care givers change.*

hospital for surgery, but then is sent to an ICU for pneumonia (where she later dies on a ventilator), instead of being sent back to the nursing home for palliative care;

- a frail 90-year-old man in adult foster care has a massive stroke during a weekend; fearful of being deemed negligent, the on-call doctor orders hospital transport and aggressive treatment; the man survives but never regains his previous level of functioning.

As members of the Consortium of Oregon Ethics Resources began sharing such stories and related systems

problems, the idea of portable physician orders that could operate as a summary plan of care in all clinical settings was born. In 1990, Oregon's Center for Ethics in Health Care convened the multidisciplinary POLST Task Force, and, in 1995, launched POLST as a voluntary, statewide protocol.

More than a form, POLST is a program that comprises the Task Force's continuing leadership, scientific research, education for providers, and a set of strong health care resources to support families and patients who choose to die out of hospital.

Implementing End-of-Life Treatment Preferences Across Clinical Settings  
*Continued*

**Developing POLST**

“We began by choosing representatives from all sectors and developing relationships of trust with people and institutions,” says Patrick Dunn, M.D., chair of the POLST Task Force. “Creating the POLST form and implementing it were secondary steps. We listened closely. Our attitude was, ‘How can we be of service to you,’ not, ‘Have we got a plan for you!’”

This approach also reflected the Task Force’s very pragmatic decision to bypass the Oregon State Legislature. “We explored the legislative route,” says Dunn, “but worried the outcome might not be as comprehensive.”

Instead, the Task Force successfully sought to modify an Oregon Board of Medical Examiners’ administrative rule defining the scope of practice for emergency medical technicians (EMT), first responders, and supervising physicians. The revised rule directs providers to respect patient wishes regarding life-sustaining treatment and comply with treatment orders (such as POLST) executed by a

physician. Strongly supported by the EMT community, the rule provides both a mandate and a legal shield.

Although not intended specifically for POLST, a 1993 overhaul of the state’s advance directive statute helped enable the protocol by establishing a liberal surrogacy provision, mandating comfort care in explicit terms, and rescinding presumed consent for tube feeding.

The Task Force’s chief focus was on perfecting the protocol through research, pilot-testing, successive revisions, and intensive training for EMS personnel.

Evaluation played a seminal role in POLST development. In 1992-94, Dunn spearheaded provider focus groups to refine the form and then asked cohorts of 87 acute and long-term care providers to indicate their treatment approaches to three different simulated protocol scenarios. The question: Would anything on the form promote undertreatment or negligence? The study demonstrated overwhelmingly that providers liked and

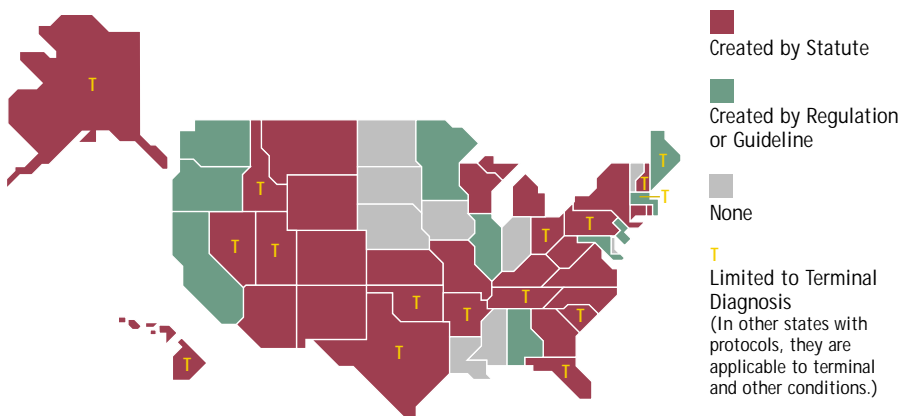
would use the form and that it was helpful rather than harmful in making decisions about life-sustaining treatment (JAGS 44:785-791, 1996).

In 1995-96, as POLST was being put into practice, a second study asked a group of health care providers and a few patients to rate the form’s user-friendliness. Since much of the form’s early language had been taken directly from statute, the news was not good, so Task Force members made sweeping changes. “We still use medical terms,” says Susan Tolle, M.D., director of the Center for Ethics in Health Care, “but how we emphasize comfort care is different; if you are refusing treatments you may fear abandonment, so we wanted to create opportunities for saying more than ‘NO,’ opportunities for patients to lay claim to dignity and comfort.”

Task Force members and health care providers say POLST was initially piloted in the Portland Metro Area, in Bend (central Oregon), and in the coastal area of Coos Bay. Now most Oregon nursing homes and hospice programs are using POLST, and several major managed care systems, including Kaiser Permanente, have adopted the protocol for patients in long-term care. While acute care hospitals typically respect POLST forms (for patients being admitted), they rarely initiate the form’s use. The Center has distributed 185,000 forms within the state, but no comprehensive data on patient use exist.

“It takes tremendous effort to change the culture to use this instrument,” says Dunn. “Not just years—decades. We need to plug away at the education and implementation piece. But we are over the hump: POLST is evolving into Oregon’s standard of care.”

EMS-DNR Protocols Statewide (March 1999)



Source: Charles Sabatino, Assistant Director, Commission On Legal Problems of the Elderly, American Bar Association. These data are drawn from a report titled, *A Survey of State EMS-DNR Laws and Protocols*, forthcoming in May 1999. For a copy, call the Commission at (202) 662-8690 (web site: [www.abanet.org/elderly](http://www.abanet.org/elderly)).

### The Hot Pink Form: Special Features and Clinical Use

POLST is designed first and foremost to help patients near the end of their lives reflect on the goals of their treatment. Each set of options in sections A-D demarcates the same clear fork in the road: "Given my health as it is now, do I want comfort or curative measures if I experience a serious medical event?" Taken together, patient choices become a summary plan of care that goes well beyond narrow EMS-DNR orders (Section A) to provide clear treatment directions (Sections B-D).

POLST's brevity, simplicity, high visibility, portability, and authority as physician orders help ensure that patient preferences, once recorded, can be operationalized quickly and will not be lost or overridden.

To be ethical and effective, the form must create occasions for meaningful, non-coercive discussions among patients, surrogates, and care givers. Are such conversations occurring? According to Task Force members and health care personnel, nurses, social workers, admissions coordinators, and nursing home administrators are typically the front-line implementors of POLST. They facilitate POLST discussions at the time of admission (or sometime later), record patient preferences, and then refer the form to the physician for signature. Anecdotal evidence suggests that these "admissions" discussions elicit and respect patient preferences; less is known about the communication that may occur between doctor and patient. "As long as POLST facilitates discussion and communication of preferences—and is updated when the clinical situation changes—it's great,"

says Ira Byock, M.D., Research Professor of Philosophy, University of Montana (Missoula). "If not, it's a problem."

### Evaluating POLST's Effectiveness

Does POLST really help systems of care honor dying patients' treatment preferences?

To begin to answer this question, Tolle, Dunn, and researchers Virginia Tilden, D.N.Sc., R.N., and Christine Nelson, R.N., M.S., from the



*From left to right: Rhonda Rabus, social worker, and Catherine Frolof, resident at Porthaven Health Care Center, Portland, Oregon, review Mrs. Frolof's POLST form.*

*"I think POLST is a very good idea. I don't believe in a lot of this extra—maybe some oxygen to make you comfortable. But not resuscitation. There's just more lingering—and more worry and sadness for our children and grandchildren."*

Catherine Frolof

Program of Research on End-of-Life Care (Oregon Health Sciences University) tracked for one year 180 adults with completed POLSTs from eight geographically diverse long-term care facilities. The study sought to determine whether DNR and "Transfer Only if Comfort Measures Fail" orders were heeded and whether POLST led to more or less attention to comfort measures, such as the use of opioids to control pain.

"A Prospective Study of the Efficacy of the POLST (1995-1997)" found that, of the 180 subjects, 55 (31%) experienced a serious medical event during the study year. Among them,

- no patient who asked for DNR was resuscitated
- no patient who asked for a focus on comfort received ICU or ventilator support
- only four patients (2%) were hospitalized to extend life

- other hospitalizations were for fractures or wound care
- of the 38 who died, only two (5%) died in hospital (as compared to rates ranging from 18-23% in a comparable state); and, 63% had an order for opioids (the highest rate investigators could identify for nursing home patients nationally).

The study also suggests that the protocol promotes additional comfort measures for residents and families, and that POLST's claims of portability across clinical settings are valid: only 6% of POLST forms were "missing" at the end of the study (JAGS 46:1097-1102, 1998).

"What this shows," says principal investigator Tolle, "is that the POLST form focuses efforts on comfort, creating a positive plan that serves the patient."

## POLST's Implications for Other States

Given the remarkable nationwide growth in EMS-DNR protocols, might Oregon be a bellwether state for advance care planning tools like POLST? End-of-life care reformers in Oregon and elsewhere suggest that the answer to that question is a qualified yes.

With initial leadership from staff of the Midwest Bioethics Center (MBC), two new POLST-inspired pilot projects are under way in Kansas City, Missouri: one in a large retirement facility; the other involving a collaboration between two hospitals with a common ambulance service. "Out-of-hospital DNR is pretty well established in our area," says Don Reynolds, J.D., Director of Special Projects (MBC), "so it's a matter of moving from a good thing to a better thing. These pilots should help us make progress later at the community-wide level. I think POLST has great power."

Bernard Hammes, Ph.D., Director of Medical Humanities at Gunderson Lutheran Medical Center (LaCrosse, Wisconsin) has spearheaded the implementation of a successful regional POLST protocol in western Wisconsin. Covering LaCrosse County and parts of three other counties, the protocol was adopted as an alternative to a statutorily mandated DNR bracelet protocol that Hammes and many physician colleagues vehemently oppose as being "for the convenience of EMT," says Hammes. "It doesn't serve the values of patients and doctors. Our leadership locally has said we will move ahead, further

develop our model, and increase pressure on the state to reconsider existing legislation and regulations."

As in Oregon and Kansas City, LaCrosse's POLST protocol builds on a pre-existing infrastructure—in this case a community-wide advance directive project in place since 1991, and the educational and administrative muscle of the two largest health care systems in the region.

Without such an infrastructure, POLST cannot succeed and could be misused, according to those who have had experience launching the protocol. "I have grave concerns," says Tolle, about the implementation of POLST in states where key support systems are not in place. "I worry that some legislative leaders may find POLST attractive as a money-saving measure. But it would be unethical to implement POLST without ensuring proper education of the public and providers and without appropriate supports for in-home care for people at the end of life who want to avoid hospital admission. And POLST may need to be modified for use in inner-city environments where support systems may be weak and trust in providers low. You can't let people choose to limit care unless they have other real choices." ■

*For more information about POLST or to be connected with a member of the POLST Task Force, fax or e-mail information requests to The Center for Ethics in Health Care at (503) 494-1260 or [ethics@obsu.edu](mailto:ethics@obsu.edu). The Center's web site has a POLST information page and an order form (web site: [www.obsu.edu/ethics](http://www.obsu.edu/ethics)).*

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## Information About the Series

"Implementing End-of-Life Treatment Preferences Across Clinical Settings" is the third in a series of briefs profiling promising Oregon policies and practices in end-of-life care. Profiles of reforms in other states are also being developed.

### Executive Editor:

**Myra Christopher**  
Director, Community-State Partnerships  
to Improve End-of-Life Care;  
CEO, Midwest Bioethics Center

### Researcher and Writer:

**Jeri Spann**  
President, Spann Publications Consulting, L.L.C.  
Pittsburgh, PA

### Designer:

**Rob Henning**  
Rob Henning Design  
for Spann Publications Consulting

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to Improve End-of-Life Care**  
Midwest Bioethics Center  
1021-1025 Jefferson Street  
Kansas City, MO 64105-1329

Telephone (816) 842-7110  
Fax (816) 842-3440  
E-mail [partners@midbio.org](mailto:partners@midbio.org)  
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Fax (609) 452-1865  
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