

Second Thoughts Connecticut

Advocates against the legalization of assisted suicide

Testimony regarding SB 413, An Act Concerning the Department of Public Health's Recommendations Regarding Medical Orders for Life-Sustaining Treatment

Senator Gerratana, Rep. Johnson, and members of the Public Health Committee:

We in the disability community have a motto: Nothing About Us Without Us. Last year we opposed a bill to establish a MOLST pilot, in part because a policy that affected not only our lives, but also our deaths, was being made without our input. I am happy to say that the Department of Public Health got the message and has fully included us in the process. I want to thank Suzanne Blancaflor in particular for her support of our concerns. I am also happy to say that we are here to support SB 413 conditioned on the new language in the bill.

Others from the field of hospice and palliative medicine will be testifying regarding the potential benefits of MOLST. We at Second Thoughts Connecticut are here to offer balance and show why the new safeguards and guidance in SB 413 are absolutely essential. These safeguards are adapted from attorney Jason Manne's model POLST statute, available online at <http://polst-views.blogspot.com/2013/10/model-polst-statute-updated.html>. As we noted last year, there are significant problems with the POLST paradigm nationally, and it is vital that Connecticut learn from the mistakes of other states.

SB 413 limits the use of MOLST to people who are nearing the end stage of a serious life-limiting illness or are in a condition of advanced chronic progressive frailty, unlike the dangerous POLST laws of New Jersey (<http://polst-views.blogspot.com/2013/07/new-jerseys-new-polst-law-and-risk-of.html>) and Nevada (<http://polst-views.blogspot.com/2013/08/nevadas-new-polst-statute-one-more-step.html>), which recommend POLST for people with five years life expectancy. Nevada mandates that doctors promote POLST for anyone with either five years life expectancy or whose condition falls under that state's expansive definition of "terminal," encompassing many people with long-term disabilities. As Manne (whose doctoral thesis was on the POLST) points out on his excellent blog, POLST: Critical Analysis and Comment (<http://polst-views.blogspot.com>), the risk of unintended death is significant when used with people who could live a long time. Someone who fears a lingering death may refuse life-sustaining treatment, wind up in a car accident or go into anaphylactic shock the next day, and be denied what would have been wanted lifesaving care.

Moreover, to further minimize this risk, the legislation mandates that patients be fully informed of the risks as well as the benefits of MOLST in documenting their treatment preferences. Unlike an advance directive, MOLST is an immediately effective set of medical orders. If an advance directive may not be powerful enough, MOLST may in some circumstances be too powerful, risking denial of wanted and beneficial care. It is particularly important that patients give fully informed, stable (over both time and different scenarios), and authentic consent to MOLST.

Section (e) of SB 413 requires the signature of the patient or surrogate on the MOLST form as a safeguard against both forgery and unilateral physician completion. The latter is a significant issue. Disability Rights California (California's Protection and Advocacy agency) issued a scathing report of a case where a hospitalist wrote out a unilateral POLST for comfort care only overriding the patient's POLST and repeatedly expressed wished for full treatment, resulting in the patient's premature death: <http://www.disabilityrightsca.org/pubs/702601.pdf>. Moreover, no one was held accountable for disregarding the patient's wishes and killing him. We would appreciate a clarification that such behavior by medical staff should be a criminal offense, and will seek explicit criminal penalties if and when we get to statewide implementation.

Section (e) also requires nuanced conversations about goals of care before filling out the MOLST form. While MOLST is supposed to be about having these conversations, this is all too often not the case in other states. Both the California Association for Nursing Home Reform (which has documented many problems with POLST in that state: http://www.canhr.org/reports/2010/POLST_WhitePaper.pdf) and Susan Hickman, formerly of the National POLST Paradigm Task Force (<http://polst-views.blogspot.com/2013/08/i-think-its-way-too-easy-for-polst-to.html>) have noted the widespread tendency to use the POLST as a checklist, foregoing these critical conversations.

The same section requires that these conversations genuinely elicit patient preferences and not use biased information to steer people away from otherwise wanted and beneficial care. We have seen training videos from California (<http://www.uctv.tv/shows/POLST-Having-the-POLST-Conversation-18360>) and New York (<http://www.youtube.com/watch?v=dSZ3UGAlwl>), a "cue card" from California (<http://med.fsu.edu/userFiles/file/POLST%20Cue%20Card-short%20version%20with%20Doc%20Tool.pdf>), and a number of "fact sheets" which are clearly aimed at manipulating patient choices toward refusing life-sustaining treatment. Perhaps the most egregious are two "fact sheets" regarding tube feeding (<http://www.hospiceofcincinnati.org/downloads/Tube%20Feeding%20-%20What%20You%20Should%20Know.pdf>) and breathing support (<http://www.hospiceofcincinnati.org/downloads/BiPaP%20and%20Ventilators%20-%20What%20You%20Should%20Know.pdf>) put out by Gunderson Health System's "Respecting Choices" program out of La Crosse, Wisconsin, widely used with POLST programs nationally. Recently our organization and many other groups and individuals in the disability community, including the CT Office of Protection and Advocacy and The Arc of the United States, signed on to an open letter from Not Dead Yet to Dr. Bud Hammes which we helped draft, demanding the recall of these biased "fact sheets":

Open letter: <http://www.notdeadyet.org/national-disability-letter-of-living-with-feeding-tubes-and-breathing-support>

Press release: <http://www.prweb.com/releases/2013/12/prweb11442713.htm>

This extreme bias against tube feeding, CPAP and BiPAP breathing devices, and ventilators is life-threatening to tens of thousands of people with disabilities, including members of our organization, who use these devices long-term to live happy and productive lives.

This bill also recognize that issues of undertreatment affect not only people with disabilities, but also others, including African-Americans, Latinos, and those of lower socioeconomic means.

In addition to what is spelled out in SB 413, DPH is also issuing guidance to further prevent misuse of MOLST. We have developed a guidance document regarding proper use of MOLST for people with disabilities. Many people with significant disabilities are often misperceived as having end-of-life conditions. We clarify that MOLST is inappropriate for use with people with long-term stable or mildly progressive disabilities who are not approaching an end-stage condition. This has been a problem in other states. John Kelly, New England Regional Director of Not Dead Yet and director of Second Thoughts Massachusetts, was recently "MOLSTed" by Massachusetts MOLST; he and others with disabilities were presented with the MOLST form as if it were mandatory. He writes of his experience: <http://alexschadenberg.blogspot.com/2013/11/john-kelly-responds-to-iom-online-survey.html>

Three months ago, my nurse brought me the Massachusetts MOLST form, with its preferences for certain treatments in extremis. She had been told that they were to complete these forms with every disabled person she follows. I found the form oppressive, and have never in my life seen a questionnaire in which "No" was on the left and "Yes" was on the right. I thought these forms were for people near death.

I asked her what she had been instructed about the form, and whether there were any materials for me. A few minutes earlier, she had given me the notification form for my annual flu shot. But nothing to accompany the MOLST form. She didn't receive any training, either. And while I was confident filling out the form, others may not be. I believe people should receive notice that they will be hit with this kind of form, and be able to have another person present when the discussion happens.

I know people in my community who have been badgered about having a DNR. We hear stories in the media about disabled children having DNRs slapped on them. We have friends who use ventilators, and don't think that they are extreme interventions. Two of my best friends – a writer and a playwright – used ventilators for years.

The characterization of a feeding tube as "artificial" is insulting. I am very happy with my suprapubic tube, a simple rubber catheter that takes care of my urological needs very well. My writer friend also got a feeding tube and she loved it for keeping her alive. The food that went into it was cooked with just as much love as anything someone else would put in their mouth.

One of my friends works for a man with a head injury. When the nurse approached him with the MOLST form, he became extremely agitated, as this kind of harassment has gone on for years. He says over and over that he wants to stay alive, and gets angry when questioned on that decision.

In contrast to Massachusetts and most other states, Connecticut will be consistently listing full treatment first on the MOLST form.

I hope this lengthy discussion shows why we need the safeguards in section (e) in particular of SB 413. That is why we are piloting MOLST first, prior to full statewide

implementation. It will require a lot of educating of the medical profession to get this done right. We need to test for the "klutz factor" and to see that people actually do get the treatments they want. Current research on the POLST paradigm is unfortunately contaminated by investigator bias, with POLST advocates doing almost all of the research claiming to support the paradigm. While the evidence tends to indicate that refusal orders are usually honored, the same cannot necessarily be said regarding full treatment orders. There will be an independent evaluation of the pilot to see that patient wishes are consistently honored.

Having noted a number of major problems with the POLST paradigm, I do want to emphasize that it is very much in our interest to solve the problem of overtreatment. As staunch opponents of assisted suicide / "aid-in-dying," we want to make it clear that people have the right to refuse unwanted and burdensome life-sustaining treatment. In this area, MOLST should help to ensure this right is respected in practice.

Finally, I would suggest three changes to the bill. In section (e)(4)(D), there is a comma missing between "language" and "disability" which changes the intended meaning and needs to be added so these read as separate categories. In the same section, regarding awareness of factors that may affect use of MOLST, I would also suggest adding "religious affiliation" to the list, as religious belief and practice significantly affect the use of MOLST. The debate over POLST among Catholic authorities tells us that this is a major issue, though it certainly affects people of other faiths whose need for flexibility and nuance may well conflict with the checkbox format on the MOLST form. I would also suggest that the pilot extend to two years, to October 1, 2016. One year is insufficient time to train medical personnel and evaluate a pilot in which MOLST is intended for people with 6-12 months life expectancy.

Connecticut should be proud of being the first state in the nation to fully include people with disabilities in designing its POLST paradigm program and doing so in a careful and thoughtful manner. These are complex issues; it is important to take the time to get them right.

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