May 6, 2014

State of Illinois
S.B. 3076
***in the* House Health Care Licenses Committee**

Prepared Testimony of Catherine Glenn Foster, Esq., Alliance Defending Freedom

My name is Catherine Glenn Foster. I serve as litigation counsel in the Washington, DC, office of Alliance Defending Freedom, a non-profit legal organization based in Scottsdale, Arizona, and with offices around the country and world. I have been involved in numerous cases relating to denial of care and have had the opportunity to advise clients and my fellow attorneys about proposed legislation and compliance with state laws. I write today based on my experience as a patient advocate to express my concerns about the wisdom of this bill.

S.B. 3076 on Practitioner Orders for Life-Sustaining Treatments ("POLST") would amend certain Illinois statutes: 20 ILCS 2310/2310-600, 210 ILCS 45/2-104.2, 210 ILCS 50/3.57, 210 ILCS 85/6.19, and 755 ILCS 40/65. In relevant part, it would amend the prior form of "physician orders for life-sustaining treatments" to "practitioner orders for life-sustaining treatments," expanding the law to allow any attending health care practitioner (defined as an Illinois-licensed physician, advanced practice nurse, physician assistant, or licensed resident in practice at least one year, attending the patient and with primary or co-responsibility for the patient's treatment and care) to execute a POLST or other advance directive form. Further, it would mandate that the Department of Public Health ("DPH") develop and publish a uniform form for practitioner cardiopulmonary resuscitation (CPR) or life-sustaining treatment orders (a change in terminology from the prior "physician do-not-resuscitate orders"), and require the Department of Public Health to include POLST in its publication of advance directive law. Senate Committee Amendment No. 2 would provide only the limited protections that no person can be required to execute a POLST and that advance directives, including POLST, ought to be reviewed annually and upon a change in condition.

S.B. 3076 would greatly expand the number of individuals who could be called upon to set perceived patient preferences in stone: not just physicians with the many years of advanced and specialized training that title entails, but also advanced practice nurses, physician assistants, and residents with only one year of practical experience. It would allow a flood of new potential POLST executors, who may not be adequately

trained in end-of-life or crisis decision-making, and in particular nuanced and sensitive advance directive decisions, to sign off on POLST forms that the patient may not even know about, since Illinois law allows either the patient or a surrogate – not limited to a medical power of attorney ("MPOA") – to sign the advance directive. 755 ILCS 40/65(b). And S.B. 3076 would promote POLST and other advance directives. While S.B. 3076 was proposed with the best of intentions, in the real world this bill would nonetheless carry very dangerous unintended consequences.

Advance directives assume that an individual's preferences will remain substantially the same throughout their lives, or that the patient will amend their preferences in writing. Advance directives purport to offer patient autonomy, but block the patient from the fully informed consent that would yield true patient autonomy. Life, and medical treatment in particular, are simply more nuanced than can be captured in an advance directive.

Two of the most common complications that can arise after a person commits to an advance directive are misdiagnosis and a change of mind by the patient. More than 40% of patients with disorders of consciousness are misdiagnosed;[1] this rate has not changed despite medical advances over the last 15 years.[2] Overall, it is estimated that up to 15% of diagnoses are incorrect in most areas of medicine.[3] In my legal practice I have seen patients who were clearly misdiagnosed, and even communicating, but whose hands were bound by their advanced directive. The results are often tragic.

And even with accurate diagnoses, patients frequently change their minds. The circumstances in which patients are handed an advance directive form vary, but individuals in a physically or mentally vulnerably position can frequently be coerced into signing the advance directive or pressured into certain choices. This bill tries to reduce that risk by having trained health care professionals present both benefits and risks, but a limited training session cannot adequately protect against real-world abuses.

Upon reflection, or over a period of time, nearly half of patients change their mind or beliefs.[4] This is even more relevant once the person is in the context of a situation

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[1] *See, e.g.*, Martin M. Monti et al., *Willful Modulation of Brain Activity in Disorders of Consciousness*, 362 NEW ENGLAND J. OF MED. 579 (2010) (noting that the rate of misdiagnosis of disorders of consciousness is approximately 40%); K. Andrews et al., *Misdiagnosis of the Vegetative State: Retrospective Study in a Rehabilitation Unit*, 313 BRITISH MED. J. 13 (1996) (finding a 43% misdiagnosis rate, even among long-term patients).

[2] *See* Caroline Schnakers et al., *Diagnostic Accuracy of the Vegetative and Minimally Conscious State: Clinical Consensus Versus Standardized Neurobehavioral Assessment*, 9 BMC NEUROLOGY 35 (2009).

[3] *See* Eta S. Berner & Mark L. Graber, *Overconfidence as a Cause of Diagnostic Error in Medicine*, 121 AM. J. MED. S2 (2008).

[4] *See, e.g.*, Terri R. Fried et al., *Changes in Preferences for Life-Sustaining Treatment Among Older Persons with Advanced Illness*, 22 J. GEN. INTERN. MED. 495 (2007) (studying 189 patients over a two-year period and finding that nearly half were inconsistent in their wishes, even among those with stable health, and even among those with an advance directive); *see also* http://www.kevinmd.com/blog/2012/09/patients-deviate-advance-directives.html.

where the advance directive may be enforced, as no advance directive could possibly provide for every clinical scenario. When people are sick or near the end of life, they may suffer "depression, hopelessness and fear of loss of autonomy and control."[5] But with counseling and caring, and proper treatment,[6] there is hope for comfort, and all of these factors may affect a person's wishes.

Patients have expressed their concern about many of these issues: misdiagnosis, sloppy procedures on the part of doctors, a reduction in end-of-life options, and pressure from facilities and families on elder or infirm individuals.[7] They worry that the focus will be on saving money, not saving lives, and their fears are supported by the medical literature.[8] And hospitals can easily develop a reliance on advance directives to shield themselves from wrongful-death and other lawsuits when they choose to deny care to a patient in need.

Concerns such as the high rate of inconsistency in patient desire led Rebecca L. Sudore of University of California, San Francisco, and Terri R. Fried of Yale University School of Medicine to declare,

> [A]dvance directives . . . frequently fail to affect the quality of care received at the end-of-life or improve clinicians' and surrogates' knowledge of patients' preferences. [Despite s]ubstantial improvements . . . , many of these efforts continue to be aimed at . . . the traditional objective of making advance decisions – an objective which is fundamentally flawed.[9]

They propose instead patient preparation for participation in in-the-moment decisions.[10]

In place of S.B. 3076, I submit the following recommendations. First, for patients who do elect to complete advance directives, issue guidance to healthcare professionals and others recommending they prepare and point to such orders in a way that will be eye-catching (e.g., by placing a flag on patient files or printing the orders on brightly colored paper) and transferable between facilities and providers.

Before any other advance directive bills are considered, there must be studies to appropriately inform the public of issues such as the circumstances under which patients

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[5] http://opinionator.blogs.nytimes.com/2012/10/27/four-myths-about-doctor-assisted-suicide/.
[6] *See* http://ethics.missouri.edu/docs/Anderson_Nov_2002.pdf.
[7] *See, e.g.*, https://www.kofc.org/un/en/resources/communications/kofc-end-of-life-debate-ct-survey-032014.pdf.
[8] *See, e.g.*, C.V. Chambers et al., *Relationship of Advance Directives to Hospital Charges in a Medicare Population*, 14 ARCH. INTERN. MED. 541 (1994) (finding that by limiting care to Medicare patients, "an enormous cost savings to society may be realized").
[9] Rebecca L. Sudore & Terri R. Fried, *Redefining the "Planning" in Advance Care Planning: Preparing for End-of-Life Decision Making*, 153 ANN. INTERN. MED. 256 (2010) (emphases supplied).
[10] *Id.*

agree to an advance directive, the average time difference between advance directive preparation and implementation, patients who change their mind and why, the role of advance directives in cases of misdiagnosis, health care professionals who do not adhere to advance directives, and other misuse of advance directives. Only then can the legislature and the public participate in an informed debate on the matter.

Finally, and most importantly, the form of advance directive and decisionmaking least subject to abuse and premature ossification is the full empowerment of a health care representative as MPOA. The stated goal of all methods of advance directive is patient autonomy, and MPOAs allow the patient to choose a trusted individual and fully express his beliefs and wishes over time through nuanced discussions. When needed, MPOA then allows the agent the necessary freedom to use his substituted judgment to advance the patient's wishes. This view is supported by physicians like Rebecca L. Sudore and Terri R. Fried, who believe that when a patient is not able to participate in a decision, the best way to achieve patient autonomy is through a surrogate.[11] The most effective way to ensure patient autonomy and self-determination would be to create a simple, fast way for individuals to designate a trusted medical power of attorney, and truly enable that agent to respond to the nuances of belief and of medical treatment that are absent from "check a box" advance directives.

S.B. 3076 is premature. The State of Illinois should not open the floodgates to a whole host of expanded POLST executors potentially untrained in the delicate and nuanced decisions inherent in any advance directive, without first fully exploring the potential ramifications, and should not put patient lives at risk.

As Muriel Gillick, a geriatrician at Harvard Medical School and researcher in end-of-life care, wrote in the *New England Journal of Medicine*, "Despite the prodigious effort devoted to designing, legislating, and studying of advance directives, the consensus of medical ethicists, researchers in health care services, and palliative care physicians is that the directives have been a resounding failure."[12] The floodgates must be kept closed until each patient is armed with a life preserver to protect her from abuse. S.B. 3076 should be held until we have the research and analysis that will allow us to fully engage in that discussion.

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[11] *Id.*

[12] *See* JEROME GROOPMAN & PAMELA HARTZBAND, YOUR MEDICAL MIND: HOW TO DECIDE WHAT IS RIGHT FOR YOU (2011).