

April 2016

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Dear Friends,

14 years ago my mom was diagnosed with non-Hodgkin's lymphoma; she died 11 months later. Her death was peaceful and, fortunately, she had capacity until the end, which allowed my mom to give us her final gift of sparing us decisions to second guess - something that I'm sure helped my dad, my sisters and me in the grieving process.



Amy Vandenbroucke

Over the last 14 years, I've realized we were incredibly fortunate but also that we should have been talking earlier. A fundamental component of successful end-of-life care is that of the conversation: between health care professionals and their patients, as well as, patients and their families. We need to get comfortable with the conversation - specifically:

- **How to start it** - probably the hardest part;
- **The language we need to use** - for example, care vs. treatment (they are *not* the same!);
- **Identifying goals of care** - treatments should not automatically be what is most aggressive or cutting edge, but, instead, influenced by what goals of care the patient has given his/her specific circumstances; and
- **How patients can share treatment decisions** in way that health care professionals can honor them (e.g., having comfort with the differences between an advance directive and a POLST, what each does, and when it is appropriate to use those tools).

There is other work to be done but focusing on the conversation is primary - we need to make sure time, energy and resources are dedicated to education and training for the conversation elements, actually having the conversation with all patients, and easily sharing advance care planning documents so they are readily accessible during a medical crisis. There are a lot of opportunities to make this happen!

[National Healthcare Decisions Day is April 16th!](#) In addition to the

work the National POLST Paradigm Office is doing, I will once again email my friends and family members to encourage them all to have these conversations and make sure their advance directives are updated. What will you be doing?

Take care,



Amy Vandembroucke, JD, Executive Director
Executive Director

Our News

National POLST Paradigm exhibited at AAPHM Annual Assembly

This past March, the National POLST Paradigm exhibited at the AAHPM Annual Assembly in Chicaco, Illinois, for the first time. Amy Vandembroucke, Executive Director of the National POLST Paradigm, was profoundly impressed by the level of interest in POLST Paradigm, citing that individuals from **about 32 states** stopped by the booth. **"I want to thank the proponents of the National POLST Paradigm** because this shows how wonderfully effective they've been in raising the level of POLST awareness. People were asking questions that weren't simply, *What is POLST?* but more advanced questions showing a true depth of engagement." Great job and many thanks to all of you out there!

[Learn more: AAHPM & HPNA Annual Assembly](#)

Featured News

Be a champion for National Healthcare Decisions Day, April 16th.

National Healthcare Decisions Day (NHDD) is an annual event that serves to remind all of us to prioritize our healthcare decisions for the sake of ourselves and the ones we love. It takes place on April 16th. Below, are some actions that others are planning for NHDD. What will YOU do?

Here are some ideas to help inspire you!

- **Watch this 3-minute video about NHDD.** It's charming, and available both [in English](#) and [in Spanish](#). Share it with others!
- **Check out NHDD on social media.**
 - **Twitter:** Search and retweet [#NHDD on Twitter](#).
 - **Facebook:** Like and Share [NHDD's Facebook page](#).
 - **Pinterest:** Follow [NHDD on Pinterest](#).
- **Watch the documentary *Being Mortal*.** Think you are not prepared to give a presentation or lead a discussion? You don't have to. [Just watch this free 1-hour video online](#) with your friends and colleagues. The discussion will come naturally.
- **Read a great book**, perhaps with friends or a book club, such as [Being Mortal](#) or [When Breath Becomes Air](#), and discuss.
- **Check out the NHDD website** for *plenty* of other ideas! Visit www.nhdd.org.

The theme for this year's campaign is *It always seems too early, until it's too late*. Let's take that to heart and lead the way by example.

National POLST Paradigm awarded John A. Hartford Foundation grant

The John A. Hartford Foundation recently approved a \$3.5 million initiative to create a collaborative to bring together a "dream team" which includes the National POLST Paradigm and several other organizations, all dedicated to caring for the seriously ill or those at end of life.

[Read more about the John A Hartford grants](#)

Free upcoming Webinar (5/25/16): All about New York's eMOLST

The National POLST Paradigm Office is pleased to announce the first of its 2016 Webinar series, to be presented on May 25, 2016. Patricia Bomba, MD, FACP, and Katie Orem, MPH, will discuss their electron POLST Registry system, eMOLST, in their presentation *Digital Transformation of NY MOLST an End-of-Life Care Transition Program*.

[Register now online.](#)

California POLST 2016 Form is now available in 12 languages

The 2016 California POLST Form is now available in 12 foreign language translations: Armenian, Simplified Chinese, Traditional Chinese, Farsi, Hmong, Japanese, Korean, Pashto, Russian, Spanish, Tagalog, Vietnamese. Braille forms may also be requested.

[More about the 2016 California POLST Form](#)

We suggest that you do at least one activity this week (perhaps choosing from the above list), and one the following week - And, *as importantly*, share what you're learned with friends and family by email, Tweet, Facebook or other media. Make a difference. Spread the word. That's what it's all about.

Featured Resource

National POLST Paradigm Frequently Asked Questions (FAQs) Guide is available online

The National POLST Paradigm Office recently released a *Frequently Asked Questions*, or *FAQs* document addressing many of the most commonly asked questions about POLST.

The questions addressed include:

1. What is the POLST Paradigm?
2. What is a POLST Form?
3. Why do I need a POLST Form?
4. Should I have a POLST Form?
5. Who can complete a POLST Form?
6. Does a POLST Form replace a Do Not Resuscitate order?
7. Does a POLST Form replace an advance directive?
8. What happens if the patient's medical condition changes? Can s/he change his/her POLST Form?
9. Does a POLST Form limit the type of treatment I can get? What if I develop a simple infection?
10. Does a POLST Form allow for basics like food and water?
11. Can my loved one use a POLST Form to request physician-assisted suicide?
12. What else should I know about a POLST Form?
13. Where can I get a POLST Form?
14. Is a POLST Form required?

Also included in this document is a table comparing POLST and Advance Directives in detail.

This document is a great way to review the questions and answers that are most often asked about POLST. Formatted as a PDF, it's ready for you to download and print to have copies on hand. With the update to the new website (coming this summer) this information will even be easier to find.

[Download the National POLST Paradigm POLST FAQs Document](#)

Featured Research

Study: End-of-Life discussions in nursing home improve outcomes, reduce odds of dying in

Institute of Medicine (IOM) Renamed to the Health and Medicine Division

On March 15, 2016, the former Institute of Medicine (IOM), the division of the National Academies of Sciences, Engineering, and Medicine (the Academies) that focuses on health and medicine, was renamed the Health and Medicine Division (HMD). The new name is intended to emphasize its increased focus on a wider range of health matters.

[Read about the name change of IOM to HMD](#)

Participate in the National Academy of Medicine Survey

The National Academy of Medicine is conducting a nationwide survey to assess progress since the release of the [Dying in America](#) report, and to inform the work of a new Roundtable on Quality Care for People with Serious Illness. Please participate and encourage your friends and colleagues to take the survey as well.

[Take the National Academy of Medicine survey](#)

hospital.

A study conducted in France was recently published in *Age and Ageing*, aimed at (1) estimating the frequency of physician-conducted end-of-life issues with nursing home residents, and (2) investigating how end-of-life discussions affected care outcomes for these patients.

Participating physicians were asked to indicate whether they discussed with the patient and/or family each of six topics in the last months before death: (i) the course of the disease and the prognosis; (ii) the approaching end of life; (iii) the possibility to withdraw treatments; (iv) options in terms of palliative care; (v) psychological problems and (vi) spiritual and existential problems.

In 32.8% of the cases, no discussion about end-of-life topics ever occurred with either the patient or patient's family. The 2 most frequently discussed topics - the course of the disease and psychological problems - were only broached with 21.7% of the patients during their last few months of life.

The two least frequent issues - the possibility to withdraw treatments and spiritual and existential problems - were discussed with 11.9 and 12.6% of patients, respectively.

Older people with severe dementia were less likely to have discussed more than three of the six end-of-life topics investigated, compared with residents without dementia. In the last month of life, discussing more than three end-of-life issues with the residents or their relatives was significantly associated with reduced odds of dying in a hospital facility and with a higher likelihood of withdrawing potentially futile life-prolonging treatments.

The study authors concluded that during the last months of life, discussions about end-of-life issues occurred with only a minority of nursing home decedents, although these discussions may improve end-of-life care outcomes.

[Discussing end-of-life issues in nursing homes: a nationwide study in France](#)

Age and Ageing 2016; 0: 1-7. doi: 10.1093/ageing/afw046

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