

Conversations Before the Crisis: Reframing Advance Care Planning

By Kathy Brandt, MS

When will we ever learn?

How many times have you sat on the fence concerning an important decision or looming deadline that you just couldn't bring yourself to address? It is an experience we can all relate to even though we also know that postponing the big decisions and difficult tasks is usually a recipe for disaster.

One of the most disastrous examples of this that comes to my mind was the case of Terri Schiavo.

As Terri lay dying in a Florida hospice, the Supreme Court, Congress and the entire country debated her fate because she hadn't made her end-of-life preferences known to her entire family. The Schiavo/Schindler conflict was the ultimate illustration of what can go wrong when this difficult task is not addressed, when a family member's wishes are not shared or documented.

Yet, despite all the media attention surrounding this case, a PEW survey conducted less than a year after Terri's death found that only 30 percent of Americans had completed an advance directive. Can the barriers to advance care planning ever be overcome?

Hospices have long played an integral role in educating communities about the importance of advance care planning and teaching people how to complete the legal documents.

To increase awareness at the national level, a coalition of national, state and community organizations, including NHPCO and many state organizations and local hospices, also came together to create [National Healthcare Decisions Day](#) (NHDD) on April 16. This past April marked NHDD's fifth-year anniversary and drew participation from more than 110 national organizations and 1,100 state and local organizations which participated in events to increase awareness.

Even with this national effort, however, the percentage of Americans who have completed advance directives still hovers between 25 and 30 percent of the nation's adult population. This begs the question: What will it take to get every other adult American to complete his or her advance care directive?

The Known Barriers

The common barriers to advance care planning are both widely known and documented:

- Our death-denying culture
- A pervasive belief that advance care planning is for the very old and very sick

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- Individual reluctance to discuss such an “unpleasant” or “uncomfortable” topic
- General confusion about the necessary documents—Living Will, DNR, Healthcare Surrogate, Advance Directive—as well as where to find them and how to complete them
- Unfamiliarity with the medical terminology
- Fear of receiving “no care” if a living will is signed
- Lack of trust that the document will be honored
- State-specific directives and laws which make portability of directives difficult

As NHDD shows us, even the presence of a diverse coalition of organizations working together to mitigate these barriers and increase understanding through a national day of awareness has not resulted in a higher completion rate. Given this, is it time to change our strategy?

Reframing Our Goal

As hospice professionals, we often talk about helping the patients and families we serve “reframe hope.” Perhaps we also need to “reframe success” when it comes to advance care planning. Rather than think about success as a percentage of Americans with an advance directive, what if, instead, we focused on and measured a more specific aspect of advance care planning? What if we focused our community-based advance care planning efforts on naming a healthcare surrogate? The reasons for doing so paint a persuasive picture.

In looking at the known barriers to advance care planning, focusing on the importance of naming a healthcare surrogate, and not on creating a living will, is probably far more palatable to many Americans and makes many of the other known barriers a non-issue.

For example, naming a healthcare surrogate is not directly tied to end-of-life care, but is appropriate for individuals having surgery, people with chronic conditions, and others. Thus, our “death-denying society” as well as the belief that advance directives are only for the “very old or very sick” become non-issues. Since the healthcare surrogacy document doesn’t require individuals to make decisions about specific treatments, “understanding medical terminology” also becomes a non-issue.

If individuals name someone as their surrogate who has similar values or thoughts related to beginning, continuing, or stopping treatment, then the known barrier related to “fear of receiving no care” is also eliminated.

When it comes down to it, the piece of paper that lists treatment options (e.g., CPR or no CPR, artificial nutrition or not, artificial hydration or not) does not account for the endless number of subtleties that reflect the realities of the medical conditions that precipitate these decisions. No single document, no matter how it is structured and how many questions it asks, can anticipate the unique set of circumstances and the context of a complex, serious medical situation.

Naming a healthcare surrogate obviates the need to think about the many “what if’s” and how to document a person’s preferences (e.g., “try for a little while...”). Naming a surrogate is entrusting the decision making to someone who knows the individual well enough to make those decisions on his or her behalf. While it isn’t perfect (sure it would be better if the surrogate had the living will to guide every step), it is far better than doing nothing.

Putting the Idea into Action

Reframing our approach to advance care planning doesn't require a change in the forms or documentation.. It does require a change in the way we talk about this subject—and perhaps the language we use to describe the process.

What if we used the terminology of NHDD, referred to the process as making “healthcare decisions” and encouraged people to just name a surrogate? Nothing more. No talk about resuscitation, tube feedings or ventilators.

If our presentations to community groups or at health fairs started and ended with, “Who would you want to make healthcare decisions for you in the event that you couldn't talk for yourself?” The discussion could include what happens when a decision maker isn't named, the qualities you should seek in an effective advocate, and how to ask someone to be a surrogate. Wouldn't that change the way people think about decision making? All we are asking them to do is name one person who they trust could speak to doctors if they are unable to.

The next time you are talking with a person or group about the topic, call it “healthcare decision making” and ask them to think about who in their circle of friends and family would make a good advocate—someone who could:

- Ask their doctor questions without feeling intimidated or bothersome;

- Talk to other family members who might have different opinions or questions and can keep an even temper so as not to fuel disagreements;

- Make decisions based on the individual's values or beliefs—and always keeping that at the forefront of all healthcare discussions.

If you are able to engage a person or people in this discussion and you get to the point where you show them the document, you can mention the living will. Certainly tell them that they can complete it if they want, but that it isn't required in order to name a surrogate.

The last important step in this new approach—and any advance care planning discussion for that matter—is to encourage individuals to talk with their chosen healthcare surrogate, family members and friends to ensure that everyone knows who the primary decision maker is. And then, as we've always done when educating people about advance care planning, make sure they give copies of the documents to all parties who might need access to them in an emergency.

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Resources:

[Caring Connections](#)

[Choosing Wisely](#)

[National Healthcare Decisions Day](#)

**Coming April 23:
Free ACP Symposium
Moderated by Eleanor Clift**

On April 23rd, NHPCO president/CEO, Don Schumacher will be joined by *Newsweek* contributor, author and political analyst, Eleanor Clift, to moderate a free, half-day symposium on “Conversations Before the Crisis: The Intersection of Family, Faith and Policy in Advance Care Planning.”

The symposium will be held in Washington, DC, in conjunction with the NHPCO Management and Leadership Conference, and is being hosted by the NHPCO Hospice Action Network (HAN) and NHPCO’s new Mary J. Labyak Institute for Innovation.

The event will include non-partisan panels comprised of policy makers, faith leaders, caregivers, hospice experts and journalists who will explore:

- Avoiding family conflict through advance care planning
- Exploring faith and spiritual aspects of end-of-life decision making
- Acknowledging the economic realities of providing care in the last years of life.

Mark your calendars and look for further details in January. Immediate questions can be directed to Cozzie King at cking@nhpco.org.

**Choosing Wisely:
An Opportunity to Expand
the Conversation**

Choosing Wisely is a national initiative that seeks to promote conversations between physicians and patients by helping patients choose care that is supported by evidence; not duplicative of other tests or procedures already received; free from harm; and truly necessary.

NHPCO is currently working with Consumer Reports, AARP and other groups to promote Choosing Wisely and inform consumers about lists of tests and procedures that patients and families should discuss to determine both their efficacy and the impact on a patient’s quality of life.

**EOL Lists and Guidance
in the Works:**

In early 2013, the American Academy of Hospice and Palliative Medicine, the American Geriatrics Society and other medical specialties will be releasing new lists of evidence-based recommendations that patients and physicians should discuss to ensure that care decisions reflect the patient’s goals and individual situation.

Consumer Reports will take these lists and prepare easy to understand information that patients can use to engage their physicians in conversations and ask questions about what tests and procedures are right for them.

As part of this initiative, consumer-friendly resources related to care near the end of life will be developed.

Your Role:

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When people understand what questions to ask their physicians, they are better prepared to make decisions about their treatments and, hopefully, also name a healthcare surrogate before they are faced with a crisis.

As part of your organization's advance care planning outreach, please share this new resource with members of your community—and avail yourself of the materials as well! Choosing Wisely provides hospices with another series of tools to help reframe discussions about care decisions and empower patients.

Visit [Choosing Wisely](#) now.