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Community Conversation: Advance Care Planning - NOTES

Northwest Life Passages Coalition

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About 45-50 participants

Commitment #1 - to educate our community about the importance of Advance Care Planning
(Marie Eaton)

BARRIERS/CHALLENGES:

- It's hard to get started.
- It's scary, especially when being prompted by illness or injury and it's a crisis time
- The language or phrases we use to describe this process – e.g., “end of life” – may put some people off, particularly younger people. It doesn't feel like it applies to them. What might draw them in?

IDEAS/SUGGESTIONS/OPPORTUNITIES:

- Important to normalize language when reaching out to younger generations. Make the language more personal and real.
- Debbie Ahl described possible bill that would authorize Centers for Medicare and Medicaid Services (CMS) to pay \$75 to Medicare recipients for completing their advance directives.
- More outreach to young people, e.g., colleges
- Work within the smaller communities we all belong to – book club, yoga group, etc.

Commitment #2 - to provide assistance in the development and completion of Advance Care Plans
(Mary Ann Percy & Adrienne Doucette)

BARRIERS/CHALLENGES:

- Waiting until you are close to dying, and then you're trying to complete AD in a crisis
- Forms may be too complicated.
 - Prepare for your Care is written in 4th grade language, has videos and steps through the process in a self-paced way. Videos are in English and Spanish.
- Lack of understanding of the impact of my choices. What does it really mean if I make these choices?
 - This is particularly a problem with those forms that focus on the procedures rather than the quality of life.
 - The “Chinese menu” of interventions is less effective than the conversation about “life is worth living for me when I....”
- Need to educate about the importance of conversations with all loved ones who might show up at the bedside about goals of care.
- People think they have to go to a lawyer to complete AD
- Doctors/health care and lawyers/legal services are “different universes”
- Lawyers often do the legal documents with clients, but aren't always knowledgeable about advance care planning
- Going to a lawyer is expensive, and the resulting documents are often hard to understand

IDEAS/SUGGESTIONS/OPPORTUNITIES:

- Have tables at each Death Cafe to educate how to get started with your advance directives
- Create a chart outlining the various AD documents that list key features of each to help people decide which form to use.
- The conversations need to be specific and detailed, e.g., what does “be able to communicate” mean to you? Able to talk, to write, to squeeze a hand?
- “My Directive” is an app with good resources for tips how to have good conversations
- Work more with legal offices, since some people have advance directives done there
- Share information at a continuing education event for lawyers
- Peace Health’s new lawyer has an interest in Advance Care Planning and Directives and might be able to help reach out to legal community.
- Consider doing a Financial Power of Attorney as part of planning

Commitment #3 - to assure that Advance Care Plans are complete and clearly understood by both you and any provider

(Hilary Walker, Sharmon Figenshaw & Marv Wayne)

BARRIERS/CHALLENGES:

- People aren’t always clear on what their own Advance Directive says. Do YOU understand what your document says?
- “A good conversation leads to a completed document. A completed document rarely leads to a good conversation.”
- Challenges with multiple forms available, not knowing how they are different from each other or which one is “best”.
- Misunderstanding/confusion between a POLST form and an Advance Directive.
 - Not against the “rules” for patient to ask for a POLST. It’s a patient right to ask for one, but they are often not appropriate for a healthy group
 - POLST does not replace AD and does not establish DPOA
 - New POLST does not negate the prior AD so it’s important to make sure the decisions all match

IDEAS/SUGGESTIONS/OPPORTUNITIES:

- Some movement for a statewide registry for both POLST and ADs.
- Clarification that POLST is not *in place of* an AD. They should support each other.
 - Make sure the POLST and AD match.
 - POLST is primarily for someone who is facing what is likely to be their last illness.
 - POLST forms are especially important if a person is choosing DNR, DNI, or limited treatment, because the “default” is for EMS and providers is to do more
- Dr. Wayne talked about EMS which “hopes to offer great patient care and great patient caring.”
 - Spoke to the importance of the POLST from in EMS response. Grey areas don’t work well in crisis situations. “Is it a *yes* or a *no*?” We need better education about when to call 911 in a crisis. An insistant family member will trump the form.
 - Also, everyone around the person needs to know where their POLST is and what it says.
 - A copy of a POLST form is valid
 - Tattoos and bracelets are not legal documentation of treatment choices
- Audience concern about EMS response if they are not at home with access to the POLST during an emergency.
 - What about a sticker on driver’s license?

Commitment #4 - to develop and maintain a system to store Advance Care Plans until necessary (Hilary Walker)

- Hilary outlined changes in the PeaceHealth storage process in Medical Records to ensure ADs are placed in the correct place in the “chart” (electronic medical record, EMR)
 - training everyone who touches the documents
 - better consistency in where they are stored
- “Refresher” training is happening in clinics on finding the AD in patient records
- Working toward patient being able to see their AD via “My PeaceHealth” patient portal

Commitment #4 - to appropriately follow your Advance Care Plan (Berdi Safford)

- Culture of medicine is changing. More doctors are interested in the conversations about goals of care and what patients really want.
- Talking frankly and death is challenging for doctors for several reasons:
 - not being *100% certain* of a prognosis
 - possible malpractice threat – this threat is greater if there is conflict among the patient’s family members about care decisions. Suits are best avoided by having good conversations with all family members.
 - it is generally a very emotional time for everyone.
 - Knowing what makes life most meaningful and worth living for a patient helps the health care provider muddle through the gray areas.

OTHER DISCUSSION

“5 D’s” – when to review update Will and Living Will or Advance Care Plan: *Suggested by the American Bar Association*

Decade – each decade birthday

Divorce

Diagnosis – a change in health status

Death – friend or family member

Decline in health

The group suggested a sixth “D” to add

Decision – major life decision, e.g. moving, changing jobs, getting married, having a child

Gundersen model’s success [La Crosse WI, with very high rates of completed ADs] is built on payer and provider collaboration. Are there opportunities for that here?

Some other comments that were submitted in writing:

From community members:

1. We need to have data on completed ADs to quantify what is happening with ADs in the community. Concern has been raised about the lack of data on the success of our local ACP programs and perhaps an over-reliance on the success of the LaCrosse program.
2. Do we need two major initiatives in Advance Care Planning? “Personally, I can't see the need for two programs on advance care planning in such a small venue. I think it undercuts WAHA. I'd prefer to see PeaceHealth support WAHA.”
3. I like EOL Washington's advanced directive because it specifically addresses dementia.
4. In order to get more folks signed up - and earlier, could we make it a part of the new drivers' licensing procedure? This could be an opportunity to get teenagers to think about EOL decisions. They could then go home and ask their folks about their EOL decisions...

From a local attorney:

5. “I would note that I have many physician (MD) clients, and most of them agree (and one adamantly argues) that when it comes to a “living will”, they want less text and not more. The adamant doc said that the only form people should have is the tear-off back of the WSMA pamphlet. The reason, I think, is that the “many options” forms can tend to focus the decision-makers too much on the “if this, then that”, when the MD wants to talk about “here’s where we are”. The MD like the form to be a general expression of consent, instead of specific direction. That said, I understand that a primary benefit for people of working through the process is so that family generally and the health care proxy especially are prepared for a decision not to continue treatment. And a longer “many choices” form can encourage more conversation and understanding.