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Community Conversation: Advance Care Planning

Northwest Life Passages Coalition

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COMMUNITY CONVERSATIONS

In 2014, a community task force wrote a [Blueprint](#) that outlines steps to make Whatcom County a community of excellence for those with serious illness or facing death and their families.

The Blueprint has five pillars: Advance Care Planning, Clinical Care, Provider Training, Community Culture and Activation and Financial Sustainability.

Many organizations are involved with implementing various aspects of the Blueprint. The Northwest Life Passages (NWLP) Coalition provides a platform for Blueprint implementation by strengthening partners' shared commitment to the vision, facilitating coordination among programs and initiatives and fostering ongoing learning and innovation.

As part of those goals, the NWLP Coalition hosts community conversations on Blueprint pillars several times a year. Our intent is to share the progress that has been made and the challenges we still face, and to listen to community members' ideas, suggestions and concerns.



COMMUNITY CONVERSATION: ADVANCE CARE PLANNING

March 26, 2018

Health Education Center, Bellingham, WA

About 45-50 people participated.

NOTE: The Five Commitments used as a framework for this Community Conversation are a modified version of the Respecting Choices® [Five Promises of an Advance Care Planning System](#).

WELCOME

Marie Eaton, Chair of the Northwest Life Passages Coalition, welcomed participants explained the purpose of the Coalition and its Community Conversations.

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
- Should prepare a handout that explains how the AD forms are different from each other, with key features of each one. This would help people understand the benefits and limitations of the different forms and decide which one 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 & Dr 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 (Physicians Orders for Life Sustaining Treatment) form and an Advance Directive (AD).
 - POLST does not replace AD and does not establish Durable Power of Attorney (DPOA)

- A new POLST does not negate the prior AD – make sure the decisions all match
- Not against the “rules” to ask for a POLST. It’s a patient right to ask for one.
- Good to introduce the concept of POLSTs to healthy group so folks know when the POLST is appropriate.
- Question sometimes arises: What if my doctor doesn’t want to use that form? – Refer to the Whatcom Medical Association.
- End of Life Council WSMF is going to sponsor a Conference on *Physician Agency in Dying* in collaboration with the Medical Ethics and School of Law at UW in 2019

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?”
 - Public needs better education on when to call 911. Screaming person often trumps 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 #5 - To appropriately follow your Advance Care Plan (Dr 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*
 - **D**ecade – each decade birthday
 - **D**ivorce
 - **D**iagnosis – a change in health status
 - **D**eath – friend or family member
 - **D**ecline in health
 - The group suggested a sixth “D” to add: **D**ecision – 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?

Additional Comments 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. [Others have also raised concern 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.”

ADDENDUM

The following was discussed by the Advance Care Planning “Disappearing Task Force” (an ad hoc committee of NWLP Coalition) when it debriefed about the Community Conversation.

1. Data collection is biggest challenge.

- a. PeaceHealth still struggles to provide number of ADs filed.
 - i. perhaps because they are entered into EPIC as ‘media?’
 - ii. Need to develop an entry process that can be queried.
 - iii. Gib Morrow is following up to see if there are ways around the current EPIC limitations.
 - iv. Is there a way to identify a ‘slice’ of data and hand gather the data on completion? E.g., all folks with a last name that starts with H.
- b. FCN has better access to those data. About 20% of patients have ADs?
 - i. Nancy agreed to clarify if this is all patients or patients in a specified age demographic (50 & older?)

2. Chuckanut Health Foundation grant to WAHA to collect data on AD implementation and success.

- a. Need to agree on some metrics to share commonly. Here’s some suggested. There may be more that would be helpful.
 - i. Number of “touches”
 1. people attending classes
 2. people attending large events
 3. articles or letters in media
 - ii. ACP CPT codes billed
 1. Michelle Lott (WSMA) is coming to PeaceHealth to provide training for providers around the CPT code
 2. There is a quick reference guide – on Honoring Choices PNW website.
 - iii. Follow up surveys on barriers and best practices (using the same protocol as the first PCI study. See attached.)
 1. Might use the Eleanor Apartment sub-group as the first follow-up group.
 2. Perhaps WAHA facilitators can conduct the surveys?