Advance Care Planning: Conversations Do Change Lives!

Susan E. Nelson, MD, FACP, FAAHPM

NATIONAL PACE ASSOCIATION
Advancing Programs of All-inclusive Care for the Elderly
www.NPAonline.org | (703) 535-1565
Allows patients and families to discuss and document treatment plans that are important to them.
Decreases PTSD in family members who don’t have to guess about what someone wanted or did not want. Promotes consensus and discussion!

Advance care planning documents are:
Living will or advance directive/health care power of attorney and POLST type document. May use 5 wishes or other documents!
Why do PACE programs do it better??? See literature!

Physician Barriers
- Less time constraints
- More comfort with the discussion

Patient/Family Barriers- we know the family dynamics better than most situations!
- DETOXIFY the discussion!
- This is just a part of providing better care
- Is not a “one size fits all” discussion
- Must be individualized to patient readiness and stage of health
- Use examples
- Ask about their own experiences/observations
- Complete your own advance directive (i.e. Practice what you preach.)

But wait, there’s actually good news....ACP discussions are covered by Medicare since January 1, 2016 (so patients might be entering PACE having heard of ACP discussions!)
Living Will

- Patient Self Determination Act (PSDA) in 1990
- Gives patients the “right to make choices and decisions about the types and extent of medical care they wish for themselves”.
- Patients can specify if they want to accept or refuse specific medical care
- A legal document that requires physician interpretation
- May not need a lawyer to complete
- May not need to be notarized

PSDA mandated that we all must be given the opportunity to document our wishes in a living will. Everyone is asked this when they go to any facility that takes federal $. Advanced directives or living wills are documents that are USUALLY written in advance of illness that outline the kinds of care that you would want when you cannot speak for yourself. The recommendations are that all of us have this kind of document but in reality, less than 25% of us have one.
The second document that is available and more important that a living will is the power of attorney for health care or “who you want to make decisions for you if you can’t speak for yourself”! This is a very important person who knows your goals and values so there are a lot of issues in just the naming of this crucial person!! It should be someone that the patient has talked to about what is important to them and what types of treatments and outcomes that are acceptable. It should be someone who can make decisions especially in the face of adversity. These decisions are usually made during times of crisis and require advance knowledge of the kind of care they would want in this situation.

If no one identified then state law decides the order of “authority”. See reference provided.
There are 3 stages of ACP ....
Normalize this conversation!

How to Initiate ACP Conversations

PACE is great with this!

- Patient history / intake assessment: “Do you have a POAHC or Living Will?
- Annual assessment/reassessment : “I talk with all of my patients about this each year... we talked a little about this last year…”
- As part of chronic disease discussion: “This particular illness can have a fairly predictable course... here are some things you need to think about ahead of time…”
- Following emergency department visits or hospital admission: “You were in the hospital... What did the other doctors say... What did you think?”
PACE programs have implemented documents like this to document what someone would want today and when they “get worse”. This helps the family and team adjust their care plans based on the goals outlined. Sometimes, this is difficult to get documented or even have the conversation with the right family member.
It is for patients with health conditions that are life limiting and physicians should consider completing the document with patients who want to avoid or receive life sustaining treatments, reside in long term care facilities or require similar services or might die within the next year—what we call the “no surprises” question. “Would you be surprised if the patient died in the next 12 months?”

**POLST** ([www.polst.org](http://www.polst.org))

- Translates a patient’s end of life wishes into a physician order
- Transfers with the patient across care settings
- Helps physicians, nurses, health care facilities and emergency personnel **honor** patient wishes regarding life-sustaining or emergency treatments
- Can be completed by the patient or the surrogate decision maker if the patient is unable to participate
- Is neither for nor against treatment
- Is complementary with Advance Directives
When to have the POLST conversation

• Patients with serious life-limiting illness whose decision making could be compromised some time in the not-too-distant future

• The surprise question: “Would you be surprised if this patient died in the next year?”

• Not available in all states!
This is what the document looks like in Louisiana. Other documents are available at www.POLST.org
Ask, Tell, Ask

1. **ASK** the patient of their understanding of their medical situation and treatment options
   - Determine if they are able to comprehend their situation
   - Ask how has condition changed over the last 6 months?
   - If the patient is unprepared or appears to need support defer to next visit (schedule soon!!)
Ask, Tell, Ask

2. **TELL** the patient in straight forward language what you need to communicate
   - Clarify any misunderstandings the patient might have
   - Tell the truth
   - Avoid vagueness – well intended efforts to soften the news may lead to misunderstanding
   - Pause frequently
Ask, Tell, Ask

3. **ASK** the patient what they understood you to say
   - Ask what worries they have about their illness or medical care
   - Ask what fears they have about their illness or medical care
   - Ask what is important to them to live well
   - Ask if they have values and preferences

This allows for shared decision making and developing consensus on a treatment plan.
Questions to Elicit a Patient’s Story

• How do you see the situation you and your family face? (Understanding)
• What are your past experiences in caring for others who are seriously ill or have died? (Past experiences with illness/death)
• What are you hoping for in the coming days? Weeks? Months? (Hopes)
• What are you concerned about (worried) afraid of)? (Fears)
• Where do you draw strength to get through each day? (Coping)
• Do you have a core “family” who supports you through your illness? (Important relationships)
• Is there anything else about who you are or what you believe that we should know? (Beliefs/values)
Advance Care Planning websites and articles

- [www.lhcqf.org/lapost](http://www.lhcqf.org/lapost)
- [www.closure.org](http://www.closure.org)
- [www.compassionandsupport.org](http://www.compassionandsupport.org)
- [www.caringinfo.org](http://www.caringinfo.org)
- [www.theconversationproject.org](http://www.theconversationproject.org)
Contact Information:

- Susan E. Nelson, MD, FACP, FAAHPM
- Medical Director, Franciscan PACE (Louisiana)
  - Susan.nelson@fmolhs.org
  - 225-490-0604