
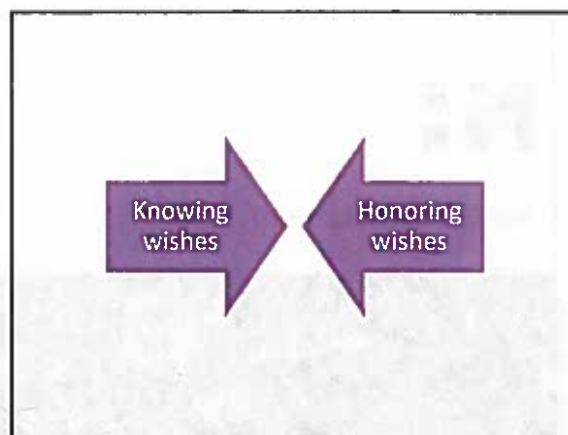


N:
Having difficult conversations

**Knowing and Honoring
 Patients' Wishes**
www.novanthealth.org/choicesandchampions

Making it work with novant. 2015

Advance Care Planning – a way of thinking

Shift from Advance Directives to Advance Care Planning



Emphasis on Health Care Power of Attorney rather than Living Will

Knowing your options, making your choices

Selecting the right agent, letting them know your wishes and their role


Focus on the conversation, not the document – Provide resources to help

Its about the conversation





Advance Care Planning is about.....

-telling your champion about your values and wishes**
-naming a champion and documenting your healthcare wishes**
-making forms accessible**
-having resources available**




Communicating with patients with advance cancer:



Your work will be helpful and rewarding!

- **Some are very sick patients with an uncertain future – very different from clients in an attorney's office**
- **They may not know very much – their approaches to their illness will vary**
- **Potential for emotional responses or resistance**
- **Some may have family members or friends with them who differ with the patient**
- **Some will be medically and legally 'illiterate'**

Thank you for volunteering to do this important work!



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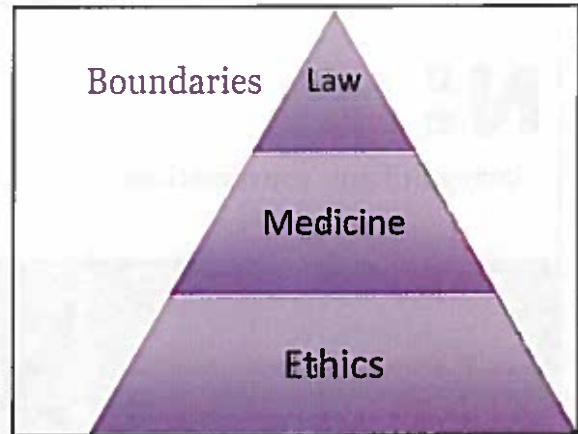
During the appointment:

Focus on the conversation

Emphasize the HCPOA over the Living Will

Assess for readiness

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Know when to make a referral

- You are not an attorney – yet.
- You are not their therapist.
- You are not their physician.
- You are not their minister.
- What do you think your role will be?

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The 20th Century: A Century of Change

1910's: Endotracheal intubation	1950's: Mechanical ventilation
1920's: Noninvasive ventilation	1960's: CPR; hospice; LW; TPN
1930's:	1970's: ICUs Propagate
• Radiation	• ACLS guidelines; DNR; Bioethics committees
• IV Nutrition	1980's: PEG tube
1940's: Hospitals proliferate	1990's:
• Renal Dialysis; Defibrillation; Chemotherapy	• Hospitalist Specialty
	• Laryngeal mask ventilator

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Discussion Questions

How do you think they feel navigating today's healthcare system?

What do you think their expectations of the Advance Care Planning session might be?

What would you tell them about the importance of having advance directives in place?

Describe the barriers and/or challenges you might encounter

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In Patient Focus Groups what aspects of communication were most important to them?

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Focus Group results

- 137 patients with AIDS/COPD/Cancer, bereaved family members, physicians, non-MD providers
- Qualitative analysis
- Examples: surgeon, minister, ER doc

6 important domains

- Talking in an honest, clear and straightforward way
- Willingness to talk about end-of-life care choices
- Giving bad news sensitively
- Listening
- Encouraging questions
- Sensitivity to when patients are ready to talk about dying

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What do you imagine patients' primary fears might be?

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Patients' primary fears included:

Patient Concern	%
The possibility of being vegetable-like	73
Not having the chance to say goodbye	73
The possibility of great physical pain	67
How family or loved ones will be cared for	65
Thinking that your death will be the cause of inconvenience and stress for others	64

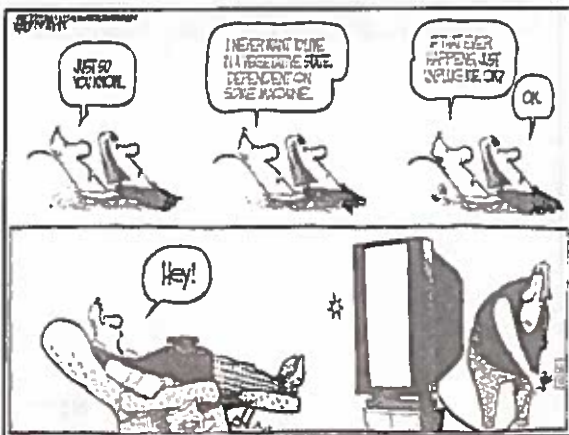


How might advance care planning help mitigate those fears?

The right conversations done at the right time with the right people involved do not always occur. Assessment helps. Triageing issues to the right source is sometimes best.



How are these conversations handled in families?




Addressing their concerns

- MD's/RN's underestimate and do not elicit full range of patient concerns – Why?
- Insufficient open-ended/empathic responses – Why?
- Blocking/distancing behaviors
- Patients don't disclose concerns – Why?
- Thus, inaccurate assessment of patient distress – including physical, mental and emotional distress


Maguire et al. *Eur J Cancer*. 1996
 Ford et al. *Soc Sci Med*. 1996
 Heaven et al. *Pall Med*. 1993



The doctor waits for the patient to bring it up.
 The patient waits for the doctor to bring it up.
 The conversation is often delayed until it is too little, too late.




Language matters!
 Compare....
 "We have some papers for you to fill out and sign."
 vs.
 "Your doctor and loved ones want to know and honor your healthcare wishes. Getting these forms in place will help make that happen."
 "Think of it as a gift to your family."




Pitfalls

- Responding to distress with more information
- Distancing/blocking behaviors
- Encouraging completion of documents before they are ready




Eliciting Concerns: More listening, less talking

- What is most important to you right now?
 - Goals, values
- What is the hardest part of this for you and your family?
 - Fears
- When you think about the future, what concerns you most?
 - Quality of life; expenses; unfinished business?




Ask-Tell-Ask Model

- Ask about their current understanding
- Tell what you need to communicate; answer their questions
- Ask them to tell you what they heard to see if they understood
- Helps introduce a difficult conversation



Tell Me More....

- Great when stuck!



When families disagree.....



Honoring Patients' Wishes

How we deliver care at end of life will forever shape the narrative of the decedent's life story and color the grieving process of the patient's loved ones.



Thank You

