Having difficult conversations

Knowing and Honoring
Patients’ Wishes
www.nananhealth.org/choicesandchampions

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

It's 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!
During the appointment:
Focus on the conversation
Emphasize the HCPOA over the Living Will
Assess for readiness

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?

The 20th Century: A Century of Change
- 1910's: Endotracheal Intubation
- 1920's: Noninvasive ventilation
- 1930's:
  - Radiation
  - IV Nutrition
- 1940's: Hospitals proliferate
  - Renal Dialysis; Defibrillation; Chemotherapy
- 1950's: Mechanical ventilation
- 1960's: CPR; hospice; IV; TPN
- 1970's: ICU/Propagates
  - ACLS guidelines; DNR; Bioethics committees
- 1980's: PEG tube
- 1990's:
  - Hospitalist Specialty
  - Laryngeal mask ventilator

"In my day, people died"
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.

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

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

What do you imagine patients’ primary fears might be?
Patients' primary fears included:

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

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. Timing issues to the right source is sometimes best.

How are these conversations handled in families?

"There's no easy way I can tell you this, so I'm sending you to someone else to tell you..."

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/distingating behaviors
- Patients don't disclose concerns – Why?
- Thus, inaccurate assessment of patient distress – including physical, mental and emotional distress

Masuhr et al. Eur J Oncol 1995
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