Who, Me?

Starting THE Conversation

Nancy Flowers, LCSW
Social Work Manager
Rainbow Hospice and Palliative Care
nflowers@rainbowhospice.org
847-685-9900
Objectives

• Clarify the importance of advance directives for all adult patients
• Discuss barriers to talking with patients about advance directives
• Understand personal barriers
• Employ strategies to talk with patients/families
“I don’t mind dying. I just don’t want to be there when it happens.”

– Woody Allen
How Most Americans View Death
More Americans Making Plans

• 42% of Americans have had a friend or relative suffer from a terminal illness or coma in the last 5 years
• By 8-to-1 margin, public approves of laws that let terminally ill patients make decisions about whether to be kept alive through medical treatment
• In 2005, 29% had living will, up from 12% in 1990
Fact v Fiction

Fantasy:
• “Not going to happen to me”
• “Wake up dead”

Reality:
• 7 out of 10 Americans will die from a chronic conditions they’ve had for more than 5 years...and for which they’ve run out of treatments
Cases in Point

Karen Ann Quinland

Nancy Cruzan

Terri Shiavo

“If everyone had an advanced directive, it would save $1.7 billion a year in health care expenses,” according to a 2006 estimate.
Fears About Death

Fears in 1970s Gave Rise to Advance Directives

• Lingering deaths
• Intense, painful suffering
• Tubes, machines, interventions
• Tremendous burdens on family
• No control over end-of-life treatment

Goal of Advance Directives

• To allow patients to retain control over the life-prolonging treatment they receive when the benefits and burdens of treatment are complex.
For Patients:

Why Plan for End of Life Care?

• End bedside guessing game and guilt
• Create a plan before a crisis occurs
• Get the care you want and deserve – even if you can no longer make your own decisions
Who, Me? Why Me?

9 Different Physicians in the Last 6 Months of Life
Barriers to Advance Directives

- Cultural
- Voicing the fear might make it real
- Medical hierarchy— “doctor’s job”
- Intimate subject
- Fear of patient/family reactions
- Personal views/fears
Stages of Advance Care Planning Over the Life Time of Adults

**First Steps**
ACP: Create POAHC and consider when a serious neurological injury would change goals of treatment.

Healthy adults between ages 55 and 65. (Planning would occur earlier if patient has serious, progressive illness.)

**Next Steps**
ACP: Determine what goals of treatment should be followed if complications result in “bad” outcomes.

Adults with progressive, life-limiting illness, suffering frequent complications

**Last Steps**
ACP: Establish a specific plan of care expressed in medical orders using the POLST paradigm guided by goals of care.

Adults whom it would not be a surprise if they died in the next 12 months.

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Who, Me?

Someone needs to start this discussion:

- Who “should” do it?
- Protocol or workflow helps
- What about back-ups?
  - Communicate well with team
  - Offer chance to resume conversation
Before you start...

What are your own feelings?
Will they help or hinder this discussion?
Can you use them to guide the process?
Being aware of them provides you with background
“We’d like to help you plan.”

Think about what you would want if you were in that bed—

• A friend
• An advocate?
• Someone who is honest?
• A medical team that will lay out all the options
“You’ve got six months, but with aggressive treatment we can help make that seem much longer.”
How do I Start?

- Gather facts
- Be sure you are organized—it increases confidence
- Arrange a time
- Who else does the patient want there?
- Arrange the environment
Planning

Step 1:

• Set up the appointment

• Purpose:
  – “We need to do some planning...”
  – “We want this stay to go as smoothly as possible.”
  – “You know this person best, and we like to involve families in planning and in care.”
Step 2: Ask open-ended questions

• What have the doctors told you about your progress and prognosis?
• What would you wish to see happen, going forward?
• What are your fears for the future?
Establish the context

Step 4:

• Briefly summarize the clinical situation
• Elicit from the patient/family their own history with situations like this
• Have they had theoretical discussions?
• Has the patient expressed wishes, on paper or verbally?
• Who will the decision-maker(s) be?
A Case Study

• Mr. Jones, a 71-year-old man with severe chronic obstructive pulmonary disease and mild dementia, was admitted for weaning from the ventilator after an exacerbation of his disease process.
• Mr. Jones had several hypoxic episodes that necessitated increased vent pressures and rates over the first few days. He also began to show symptoms of pulmonary edema.
• The Jones family had seen the transfer to the LTAC as the next step toward full recovery. The patient had been driving and fully independent before this episode.
• On day 3, chest X-ray confirmed pulmonary edema and lab results showed the beginning of renal insufficiency.
• Now is the time to talk with the family.
Role Playing Exercise

The Meeting

Please watch for the following:

• How does the team member open the meeting with the family?
• How does she handle their hopes?
• How does she establish a context?
• What options were explained?
• What could have been done better or differently?
• Did she leave anything out?
A Case Study

Gather your facts:

– On admission, the family was asked about advance directives; they had not signed a DNR
– Prognosis appears guarded; patient is showing some signs of decline
– You know the family has been informed of this decline
– You also know that they have transferred him here expecting a full recovery
Two Volunteers

• Spouse
• Daughter
The Meeting

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Metaphor for Medical Interventions

- **Stop**: Patient Refusal
- **Caution**: Limited Treatment
- **Go**: Full Treatment
<table>
<thead>
<tr>
<th></th>
<th>Advance Directives</th>
<th>POLST</th>
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<tbody>
<tr>
<td>Population</td>
<td>All adults</td>
<td>Any age with advanced, progressive illness</td>
</tr>
<tr>
<td>Timeframe</td>
<td>Future care</td>
<td>Current care</td>
</tr>
<tr>
<td>When complete</td>
<td>In any setting</td>
<td>In medical setting</td>
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<tr>
<td>Guidance for ER process</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Role of HC PoA</td>
<td>Cannot complete</td>
<td>Can consent if patient lacks capacity</td>
</tr>
<tr>
<td>Portability</td>
<td>Patient/family responsibility</td>
<td>Provider responsibility</td>
</tr>
<tr>
<td>Periodic review</td>
<td>Patient/family responsibility</td>
<td>Provider responsibility</td>
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Many physicians indicate a reluctance to place a DNR order on the chart. They fear the patient may not get the care or treatment that is desired. Staff are distressed about exercising aggressive resuscitative measures for the dying patient. DNR does not indicate Do Not Treat but... how far should we go? Consider benefit vs. burden.
Questions?

• Contact us 24 hours a day, 7 days a week at: (847) 685-9900

• www.rainbowhospice.org

Rainbow Hospice and Palliative Care
1550 Bishop Court
Mount Prospect, IL  60056
Resources

• The Five Wishes (advance directive)  
  www.agingwithdignity.org

• National Hospice & Palliative Care Organization  
  www.nhpco.org

• Disease related organizations: American Cancer Society, American Heart Assn., Alzheimer’s Assn.