Disclosures

No Relevant Financial Relationships with Commercial Interests

No Conflicts of Interest

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May 30, 2018
Objectives:

- Obtain a broad understanding of available tools and models to ensure patients’ wishes are respected throughout the care continuum
- Learn about community-wide partnerships promoting patient-centric advance care planning practices
- Understand user needs and state activities to progress access to advance care planning tools
- Identify common challenges, opportunities, and focus areas for statewide efforts
Objectives:

• Compare and contrast Goals of Care conversations, Advance Directives & MOLST/POLSTs
• How are these related?
Case Study
George 64 y/o M, multimorbid

- 64 y/o man with DM2, HTN, CHF, CAD, ESRD on HD with an AICD.
- He has arthritic pain in his knees and hips, neuropathy in his feet.
- He is in your office for f/u of HTN & CHF and pre-op evaluation for knee replacement.
George 64 y/o M, multimorbid

- What questions might you ask?
- What anticipatory guidance will you provide?
- Is he Terminally Ill?
- Surprise question?
Healthcare Today: Technology
Advance Care Planning: Communication Pointers
What is Advance Care Planning (ACP)?

- **Process** of planning for future medical care where:
  - Patients values and goals are explored
  - Proxy decision maker identified
  - Conversation documented
    - A communication process, not a legal process
- **Process** of creating “Advance Directives”
- **Not a one time event**
Benefits of ACP:

- Promotes patient autonomy & control
- Creates trust between clinician & patient
- Avoids future confusion and conflict
- Increases patient peace of mind
Joan Rivers’ Living Will:

Melissa explained: "She had written in specifically that she was to be able to go onstage. For an hour. And be funny.

'It was an amazing gift to give me, knowing exactly how she wanted her life to be. Not that it's ever an easy decision, but I knew I was making the right one."

"Joan Rivers' daughter knew she was right to switch off her mother's ventilator because the 81-year-old star had a living will which explained the quality of life she wanted."

-- People Magazine
When should ACP be addressed?

Can we hard-wire assessment into standard work-flows?
– On all intake forms?

Introduce the topic at routine times?:
– New patient evaluations
– Complete physicals/annual exams
– Pre-op physicals
– New or worsening significant diagnoses or test results

Create a culture of normality and ownership by all?
What should be addressed?

Routine, healthy patients?
- Healthcare Proxy
- General goals and values discussion
- Evaluate presence of living will, etc.

Serious or chronic illness? Evolving disease?
- Confirm Proxy
- Refinement in goals of care discussion
- Document discussion & Encourage living will

Terminal disease
- Confirm Proxy
- Re-evaluate goals of care & their priorities
- Review living will and/or prior documentation
What are “Goals of Care?”
Goals of Care = Patient Values

- Cure disease
- Avoid early death
- Maintain or improve function
- Prolong life
- Avoid pain
- Avoid disability
- Avoid dependence
- Maintain alertness
- Improve life quality
- Stay in control
- Support family

*Goals may change as an illness evolves

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YES INDEED, I'D WANT A NATURAL DEATH... JUST A FEW LIGHT SHOCKS, SOME GENTLE CHEST COMPRESSIONS, A TRACHEAL TUBE TO BREATHE, SEVERAL ROUNDS OF EPINEPHRINE, AND IF IT'S NOT WORKING, WELL THEN JUST LET ME GO PEACEFULLY.
“Orders” but do not allow for description or caveat.

Do not define “Quality of Life”

NOT Advance Care Planning!
“Moms living will”

To My Dear Family

This is to ask you — should there be a medical emergency — if the situation is such that recovery will leave me a vegetable — please give me the right to die as I choose — with dignity if possible — to be drawn out affairs that is offensive and heart-breaking to everyone. This note is to remove the responsibility of the choice from your hands and leave it in mine.

Elizabeth J. Usher 1-1-91
Elizabeth J. Usher 1-1-92
Elizabeth J. Usher 1-1-93
Elizabeth J. Usher 3-95
Elizabeth J. Usher 1-1-96
Elizabeth J. Usher 1-6-87
Elizabeth J. Usher 1-2-88
Elizabeth J. Usher 4-14-72
Elizabeth J. Usher 1-1-83
Elizabeth J. Usher 1-1-84
Elizabeth J. Usher 1-1-85
Elizabeth J. Usher 1-1-86

P.S. Remember — no plastic flowers or — step back — 1-11-78 1-15-77
Elizabeth J. Usher 1-1-1990
Elizabeth J. Usher (3-12-75) 1-11-74 3-10-76

Ps. With all my love, mother.

Elizabeth J. Usher 2007-3-4 2018-4-5
# Advance Directives vs. MOLST

## Differences between POLST and advance directives

<table>
<thead>
<tr>
<th>CHARACTERISTICS</th>
<th>POLST</th>
<th>ADVANCE DIRECTIVES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>For the seriously ill</td>
<td>All adults</td>
</tr>
<tr>
<td>Time frame</td>
<td>Current care</td>
<td>Future care</td>
</tr>
<tr>
<td>Who completes the form</td>
<td>Health care professionals</td>
<td>Patients</td>
</tr>
<tr>
<td>Resulting form</td>
<td>Medical orders (POLST)</td>
<td>Advance directive</td>
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<tr>
<td>Health care agent or surrogate role</td>
<td>Can engage in discussion if patient lacks capacity</td>
<td>Cannot complete</td>
</tr>
<tr>
<td>Portability</td>
<td>Provider responsibility</td>
<td>Patient/family responsibility</td>
</tr>
<tr>
<td>Periodic review</td>
<td>Provider responsibility</td>
<td>Patient/family responsibility</td>
</tr>
</tbody>
</table>

POLST = Physician Orders for Life-Sustaining Treatment

Goals of the ACP:

NOTE: Goal is **NOT** to get the DNR!

- Goal is to understand the patient, their values, and hopes
  - “Goals of care” for health is much broader than resuscitation status!
  - Use patient’s values to guide your medical recommendations

- Establish decision maker
Evolution in Advance Care Planning

- Movement away from fixed statements about future medical treatments
  - E.g.: “No intubation if I am in a “terminal state”
  - Definitions are challenging
  - Living wills never cover every situation
Evolution in ACP

• Movement towards discussion of Goals:
  1) Acceptable functional outcomes
     • “Life is worth living as long as I can still sing in the choir.”
     • “I want to talk and make sense.” “Sail my boat”
  2) Milestone events
     • “I want to live long enough to see my daughter’s graduation”

• Once elicited, medical treatments can be tailored to reach patient’s goals
ACP in the Clinics/Admission:

- Be straightforward, calm & positive
- Incorporate in your Routine

**Social History:**

“Do you smoke or drink alcohol?”

“What do you do for a living?”

“Do you have a *living will, advance directive* or other healthcare wishes I should respect when caring for you?”

**Proxy:**

“If sickness ever makes it such that you cannot speak to me, who should I call who knows you best, and can speak on your behalf?”
“I want to help you achieve what you want out of your health care, & I have some questions to ask:”

• “What are your most important hopes? What are your biggest fears about your health?”
• “What makes life worth living? What if you could no longer do these things?”
• “Would there be any circumstances under which you would find life not worth living?”
• “Has anyone close to you ever died? What are your feelings about that experience?”
• “What brings you joy? What makes you smile?”
George 64 y/o M, multimorbid

• Healthcare Proxy is son
• Goals:
  – Reduce pain
  – Increase ambulation
  – Increase exercise
  – Improve health by exercising more
  – Maintain independence
  – Avoid being a burden
Phrases to Avoid:

• “Do you want us to do everything?”
• “Do you want us to start your heart if it stops?”
• “If we do CPR we will break your ribs and you will need to be on a breathing machine – you don’t want us to do that – do you?”
• “Will you agree to discontinuing care?”
• “There is nothing more we can do…”
Phrases to Avoid:

• “If your heart stops, do you want us to use electrical shocks and chest compressions to try to get it beating again? Or if you stop breathing, do you want us to put a tube down your throat into your lungs and attach you to a breathing machine to help you breathe?”

– Does not address treatment outcome or alternatives
– Burden of decision making is on pt/family, without MD guidance
– Does not assess patient goals of care
– Fails to convey patient’s prognosis
– Devoid of empathy

– Time limited trial?
Can We Do Better?

“For someone in your condition, CPR is rarely successful. Most patients die in spite of our best efforts, or may live for a few more hours or days before dying, but they are comatose. I would suggest we make all efforts at preventing your death with antibiotics and transfusions, but if you are on a different path, to focus aggressively on your comfort.”
Summary

• Advance care planning can increase patient control and strengthen the clinician-patient relationship.
• ACP should be anchored in the patient’s values and goals for healthcare.
• Once goals have been illuminated, healthcare efforts can be patient centered, and directed towards goal attainment.

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Thank you for listening!

Questions?

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Your Conversation Starter Kit
When it comes to end-of-life care, talking matters.

How involved do you want your loved ones to be?

1. I want my loved ones to do exactly what I've said, even if it makes them a little uncomfortable.
2. I want my loved ones to do what brings them peace, even if it goes against what I've said.

When it comes to your privacy...

1. When the time comes, I want to be alone.
2. I want to be surrounded by my loved ones.

When it comes to sharing information...

1. I don't want my loved ones to know everything about my health.
2. I am comfortable with those close to me knowing everything about my health.

Look at your answers.
What role do you want your loved ones to play? Do you think that your loved ones know what you want, or do you think they have no idea?
How To Talk To Your Doctor

Discussing end-of-life care with your doctor, nurse, or other healthcare provider.

Your Conversation Starter Kit

For Families and Loved Ones of People with Alzheimer’s Disease or Other Forms of Dementia

Institute for Healthcare Improvement
the conversation project

CREATED BY THE CONVERSATION PROJECT AND THE INSTITUTE FOR HEALTHCARE IMPROVEMENT
PREPARE Advance Directive

Advance directives are legal forms that let you have a say about how you want to be cared for if you get very sick.

Share the advance directives with your family, friends, and medical providers.

Get Your State's Advance Directive

Select your state below to download and fill out your state’s advance directive.

- Maryland

Submit
PREPARE for your care

**TODAY, IN YOUR CURRENT HEALTH**

Put an X along this line to show how you feel today, in your current health.

- My main goal is to live as long as possible, no matter what.
- Equally Important
- My main goal is to focus on quality of life and being comfortable.

**AT THE END OF LIFE**

Put an X along this line to show how you would feel if you were so sick that you may die soon.

- My main goal is to live as long as possible, no matter what.
- Equally Important
- My main goal is to focus on quality of life and being comfortable.

If you want to write down why you feel this way, go to Page 10.

Your Name
PREPARE for your care

### Part 2: Make your own health care choices

**What Matters Most in Life: Quality of life differs for each person. What is important to you?**

**AT THE END OF LIFE,** some people are willing to live through a lot for a chance of living longer. Other people know that certain things would be very hard on their quality of life.

At the end of life, which of these things would be very hard on your quality of life?

Check the things below that would make you want to focus on comfort rather than trying to live as long as possible.

- [ ] Being in a coma and not able to wake up or talk to my family and friends
- [ ] Not being able to live without being hooked up to machines
- [ ] Not being able to think for myself, such as dementia
- [ ] Not being able to feed, bathe, or take care of myself
- [ ] Not being able to live on my own
- [ ] Having constant, severe pain or discomfort
- [ ] Something else

- [ ] OR, I am willing to live through all of these things for a chance of living longer.

**Is religion or spirituality important to you?**

- [ ] Yes
- [ ] No