Mission Critical: How to Plan Your Wonderful Life to the Very Last Breath

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April 24, 2018
Advance Care Planning: Redux

- This is a “one step at a time” process
- When you are healthy
- When you become seriously ill
- When you decline
- End of life
- Each of these life events are signposts along the path of advance care planning
Advance Care Planning Terminology

Prognosis: 1-2 Years
- 18+, Healthy
  - Identify Health Care Proxy (HCP)
  - Conversation about care preferences
- Diagnosis of Serious or Chronic Illness(es)
- Progression of Serious or Chronic Illness(es)
  - Have Serious Illness Conversation
- Serious Illness
  - Condition worsening
  - Revisit Serious Illness Conversation
  - Goals of Care Discussion (if clinical decision)
- Crises & Decline
  - Poor Prognosis
  - Revisit Serious Illness Conversation / Goals of Care Discussion
  - MOLST / POLST
- End of Life

Advance Care Planning = Planning in Advance of Serious Illness
Serious Illness Care Conversation = Planning in the context of progression of serious illness
Goals of Care Discussion = Decision making in context of clinical progression / crisis / poor prognosis
18+, Healthy

• Identify Health Care Proxy (HCP)
  – Who will make decisions for you in the event you can’t?
  – The Conversation Project Video
    • https://theconversationproject.org/who-will-speak-for-you/

• Conversation about care preferences
  – Well illustrated in the video
It’s Life: Things Happen

• People have accidents – like Kathy
  – Protect yourself, plan ahead

• People get chronic illness
  – Learn more, manage your health
  – Revisit your plans for proxy & goals
  – Advance Care Planning increasingly important before you become seriously ill

• People get seriously ill
  – Planning becomes more focused
  – Health care provider should be involved
ACP Conundrum

• People are reluctant to think or talk about serious illness, goals of care and death
• Especially when things are going well and people feel pretty good
• But this is exactly the time to have these conversations and make plans
• DO NOT wait until you are seriously ill
• There are a variety of tools to guide you through this process
What is Caring Conversations®?

For everyone, especially those dealing with advanced illness or responsible for loved ones:

- Consultation/coaching
- Advocacy if needed
Why Caring Conversations®?

Aging population—Beginning in 2011, every day in America, 10,000 baby boomers turn 65 (2,200 a month in KC Metro Area) - continues to happen for 20 years (2031)

Lots of people with changes in physical and sometimes mental capacity

Clarifying values, naming someone to speak for us, talking about it, can help
• Relevant information about resources to help you sort out complex situations

• Educational programs about advance care planning—getting clear on your goals and values and making sure your healthcare preferences are known and honored
Reasons for Caring Conversations®

• 85% of us will die without capacity to make decisions/on life support—it can get complex
Reasons for Caring Conversations®

• How we die is changing

Most of us will die…
– of complications from chronic illnesses
– with slow and uncertain disease paths
– affected by dementia
Pictures of Illness

- The four basic ways a person might experience an illness or serious health condition
When we die:
What we want  vs.  What we get

Die at home:
Surrounded by loved ones

ICU:
Isolated from family (waiting room)
What we want vs. what we get...

• Pain free (symptoms managed) vs. hooked up to tubes and machines (often in pain)
• Wishes known and honored vs. family and care-provider disputes
• Psycho-social needs of family met vs. isolation
Reasons for Caring Conversations®

- Family and friends are often unwilling and/or uncertain agents
Reasons for Caring Conversations®

• Physicians are often without knowledge of patient’s goals and values

• Hospitalists the norm now
Mistaken Beliefs

• I’ll always be able to make my own decisions.
• My family already knows my wishes
• My doctor will know what’s right
• I’ve written it down so I don’t need to talk
Tools to Help Start the Conversation

Workbook
Conversation Aid
Bracelet
Caring Conversations® Workbook (overview)

- Reflect
- Talk
- Appoint
- Act
Think About

• What is important to you about care you receive at the end of life.
• What does it mean to die well?
• What does “a good death” look like to you?
Your Homework

• With whom should I discuss my Caring Conversations® workbook?
• “The drive home…” exercise
Talk to Others

• Talk to those close to you
• Talk to your doctors
• Share your workbook with family, doctors, clergy and attorney
• Talk to us if you need help.
  – 816-221-1100
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- MOLST / POLST

Prognosis: Weeks to Months
- End of Life

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DANA-FARBER CANCER INSTITUTE

CENTER FOR PRACTICAL BIOETHICS
GUIDANCE AT THE CROSSROADS OF DECISION
Doctors

• You may not see your doctor if you are hospitalized, as most are staffed by hospitalists.
• You might see a palliative care doctor in the hospital.
• Don’t wait. Talk to your primary care doctor about your serious illness, your goals of care and your likely health trajectory.
• At CPB we work closely with Dr. Karin Porter-Williamson, KU palliative care doctor. Next few slides are from her.
Conversations are too little, too late, not great

- Multiple studies show patients with serious medical illnesses do not discuss EOL preferences, or first discuss them only in the last days to month of life  
  Wright 2008, Dow 2010, Halpern 2011

- Among patients with advanced cancer:
  - First EOL discussion occurred median 33 days before death  Mack AIM 2012
  - 55% of initial EOL discussions occurred in the hospital
  - Only 25% of these discussions were conducted by the patient’s oncologist  Mack AIM 2012
So, when is it time to start Serious Illness Care Planning?

• Asking the “surprise question” can help
  – Would it surprise me if this person were to die in the next year? (answer of “no” means it’s time)
  – NOTE: NOT the same as saying someone has a prognosis of a year or less
  – NOTE: for cancer and renal patients, surprise question does a better job of predicting mortality than our current Medicare Hospice Certification criteria

• Recognizing functional trajectories can help
It’s Time to Rename and Reframe

• Need to get away from the idea of “End of Life” discussions/wishes
  – These conversations are about a person’s priorities for how they want to LIVE
  – These conversations are intended to help someone prepare over a course of months, even a year or two
  – This is not about people at the end of life, it is about people living with serious illness
Conversations are Key

Earlier conversations about patient goals and priorities for living with serious illness are associated with:

- Enhanced goal-concordant care [Mack JCO 2010]
- Improved quality of life
- Reduced suffering
- Better patient and family coping [Detering BMJ 2010]
- Higher patient satisfaction
- Less non-beneficial care and costs [Wright 2008, Zhang 2009]
A New Approach

• Developed at Ariadne Labs at Harvard
• Guide for use by physicians
• Consider how important this conversation is to physician, patient and family
• This is what a meaningful serious illness conversation looks like.
**CONVERSATION FLOW**

1. **Set up the conversation**
   - Introduce the idea and benefits
   - Ask permission

2. **Assess illness understanding and information preferences**

3. **Share prognosis**
   - Tailor information to patient preference
   - Allow silence, explore emotion

4. **Explore key topics**
   - Goals
   - Fears and worries
   - Sources of strength
   - Critical abilities
   - Tradeoffs
   - Family

5. **Close the conversation**
   - Summarize what you’ve heard
   - Make a recommendation
   - Affirm your commitment to the patient

6. **Document your conversation**

**PATIENT-TESTED LANGUAGE**

1. **Set up**
   - “I’m hoping we can talk about where things are with your illness and where they might be going — is this okay?”

2. **Assess**
   - “What is your understanding now of where you are with your illness?”
   - “How much information about what is likely to be ahead with your illness would you like from me?”

3. **Share**
   - Prognosis: “I’m worried that time may be short.”
     - or “This may be as strong as you feel.”

4. **Explore**
   - “What are your most important goals if your health situation worsens?”
   - “What are your biggest fears and worries about the future with your health?”
   - “What gives you strength as you think about the future with your illness?”
   - “What abilities are so critical to your life that you can’t imagine living without them?”
   - “If you become sicker, how much are you willing to go through for the possibility of gaining more time?”
   - “How much does your family know about your priorities and wishes?”

5. **Close**
   - “It sounds like ________ is very important to you.”
   - “Given your goals and priorities and what we know about your illness at this stage, I recommend...”
   - “We’re in this together.”
Advance Directives: Not Enough

- Focus on potentially life-prolonging treatments in limited set of circumstances
- Does not translate into medical orders for present circumstance
- Completion rate low
- Reliance on surrogate decision maker
- Not available
TPOPP is a program designed to improve the quality of care received at a end-of-life by translating patient’s treatment preferences into medical orders.
# Our Region’s POLST Paradigm

The POLST (Physician Orders for Life-Sustaining Treatment) paradigm helps to ensure that patient wishes and preferences for care are documented and followed. The form includes sections for patient preferences, medical interventions, and transportable orders. The form is designed to be easily transportable and to facilitate communication among healthcare providers.

### Transportable Physician Orders for Patient Preferences

- **A.** Code: 21589 - Cardiopulmonary Resuscitation (CPR): Person has no pulse and is not breathing. If patient is not in cardiopulmonary arrest, follow orders in B and C.
  - Attempt Resuscitation/CPR
  - Do Not Attempt Resuscitation

- **B.** Code: 21569 - Medical Interventions: Person has pulse and/or is breathing.
  - Ventilation
  - Administration of fluids
  - Administration of medications

- **C.** Code: 21568 - Medically Administered Nutrition: Offer food by mouth if feasible and desired.
  - Enteral administration
  - Parenteral administration

- **D.** Code: 21580 - Information and Signatures.
  - Signed: Date/Signature
  - Affidavit: Date/Signature

### References

[Center for Practical Bioethics](https://www.cpb.org) provides guidance at the crossroads of decision.
TPOPP: Transportable Physician Orders for Patient Preferences

• Medical order form designed for patients with serious illness and advanced frailty
• Converts treatment preferences into written physician orders
TPOPP: Transportable Physician Orders for Patient Preferences

• Based on conversations among health professionals, patient, and/or agent
  – about treatment goals for informed decision making

• Form travels with patient across care settings to ensure wishes are honored throughout health care system
## Advance Directive vs. TPOPP

<table>
<thead>
<tr>
<th>Advance Directive/ health care proxy</th>
<th>TPOPP</th>
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<tbody>
<tr>
<td>For all adults</td>
<td>For those with chronic progressive illness or may die within the year</td>
</tr>
<tr>
<td>Complete for the future</td>
<td>Applies to person’s current situation. Medical orders for now.</td>
</tr>
<tr>
<td>In effect when decision-making capacity is lost</td>
<td>Not conditional on decision-making capacity</td>
</tr>
<tr>
<td>Contains no medical orders</td>
<td>Set of medical orders</td>
</tr>
<tr>
<td>May not be available in all settings</td>
<td>Accompanies patient across settings</td>
</tr>
</tbody>
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Based on Serious Illness Conversation

• Timely discussions
• Facilitated by trained professionals
• Helps establish medical goals of care
• Provides information on treatment options
• Builds decision making consensus among patient, family and medical team.
Target populations

Those who:

• Live with serious illness or advanced progressive disease.
• Are terminally ill.
• Physician would not be surprised if patient died within the year.
• Wish to further define their care wishes.
But it’s not for everybody

- TPOPP is not appropriate for person with stable medical condition or disabling problem with **years** of life expectancy.
- TPOPP is voluntary decision.
Community Coalition Model

- Community Coalitions work locally to implement based on a standard of care and clinical consensus approaches
  - 14 active local coalitions
  - 12 additional interested communities
Bi-State Task Force Inclusion

• Broad representation: state, regional, local
  – Hospitals, LTC, EMS
  – Hospital Association
  – Long-term Care Associations
  – Hospice and Home Health
  – Medical Societies / Physician Organizations
  – Bar Associations
  – Foundations