Impact of COVID-19 Pandemic on Advance Care Planning and Re-setting Goals of Care in Nursing Homes

National Consumer Voice for Quality Long-Term Care
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Webinar
HOST and FACULTY

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Global Impact and National Crisis

CORONAVIRUS

HEALTHCARE

free resources - personal assistance - expert interviews
Devastating Effects

Impact of Physical Distancing/Separation
Threat to Intimacy and Integrity
Insidious nature of contagion
Vulnerability of our Population
What can we do?

What ought we do

How can we help?
Caring Conversations® in a Pandemic

Linda Ward
Caring Conversations®

• **Relevant information** free resources for consumers to help sort out complex situations

• **Educational programs** about advance care planning
Caring Conversations®

• Relevant information free resources for consumers to help sort out complex situations

• Educational programs about advance care planning
Having an opportunity to reflect *before there is a crisis* can make the difference between:

– A family torn apart by disagreements over “what Mom would have wanted”

*OR*

– The peaceful, dignified end that we all want for ourselves and those we love.
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
- Variety of tools to guide you through this process
COVID-19…

• The world’s turned upside down…
• Americans are death averse under normal circumstances—especially when it comes to our own
• We all agree making an advance care plan is good, but only 1/3 of us actually do it.
• Easy to say death is a long way off. We can do this later.
Mistaken Beliefs

“I’ll always be able to make my own decisions.”

Not only will we not necessarily be able to make our own decisions, but with crisis standards, decisions may be made for us.
Reasons for Caring Conversations®

• 85% of us will die without capacity to make decisions/on life support—BEFORE COVID
• It can get complicated—even under normal circumstances and these are NOT normal…
Reasons for *Caring Conversations®*

• How we die is changing

In a pre Covid19 world, we could say that most of us will die…

– of complications from chronic illnesses
– with slow and uncertain disease paths
– affected by dementia
Reasons for Caring Conversations®

- We had the luxury to fret about the difficulties in the process:
  - Legalistic forms are limited in what they can anticipate and how well they guide agents.
  - Anticipating all the “what ifs” can seem like an infinite puzzle—so we used a frame to help us narrow down the possible ways we will die.
Pictures of Illness

• The four basic ways a person might experience an illness or serious health condition
Non-Pandemic ACP

More relaxed process—
Reflect on your own values, what does a good life followed by a good death look like to me?
What would I want and not want as I die?
Who is the best person to speak for me when I cannot speak for myself?
Act on your reflections

- “Talk” with that person
- Get their commitment
- Discuss likely scenarios
- Document
- Share your wishes with anyone who might have a point of view about your care
- Revisit annually or when your health changes
Values and Goals

• Even before the pandemic, lots of people (including some close to you) are getting closer to changes in physical and sometimes mental capacity…

• And we know, taking the hard step of clarifying values, naming someone to speak for us, talking about it, can help.
Conversations first and here’s why

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
– Higher patient satisfaction  Detering BMJ 2010
– Less non-beneficial care and costs  Wright 2008, Zhang 2009
Lesson from ACP...

What we want  v.  What we get

Dying at home...  
Surrounded by loved ones

ICU  - Isolated from family (waiting room)
Brave New World…

• Timeline will be significantly compressed for hundreds of thousands of us through this pandemic – Accelerated discussions
• Usual health events including injuries will continue—without regard to COVID19
• ACPs used to be all about maintaining some control of our final days
• Options are narrowed now through scarce resources
How can we retain some control of this?

• Don’t delay — the time is now
• Do your own work first
• Use Facetime to talk with YOUR family
• Go slowly – technology will not promote the kind of intimate conversation required but it is better than nothing
Don’t assume

My family already knows my wishes.

• last conversation was…
Mistaken Beliefs

My doctor knows best…

I’ve written it down, so I don’t need to talk.
Some suggestions for the talk

- Glad you are doing OK so far
- Acknowledge it’s a scary (terrifying?) time
- We know many people will get this virus
- No one is exempt
- “I want to share with you how I’ve been thinking about this for myself and hope you will share your thoughts, too....”
Who needs an ACP?

 Anyone 18 and older needs to identify a health care proxy
Reasons for Caring Conversations®

• Family and friends are often unwilling and/or uncertain agents

• Don’t assume…

call from the waiting room…
Caring Conversations®
Workbook (overview)

Free to Consumers
Downloadable
Or order large quantities online
What’s next...

• Talk to those close to you
• Share your thoughts/workbook with family, staff/doctors, clergy
• Store paper copies where they can be found and upload e-version to cloud through MyDirectives – more tomorrow!
What about the formal written documents?
Tools to Help Start the Conversation

Workbook

Conversation Starter
For information contact the Center:

- 816-221-1100
- lward@practicalbioethics.org
- http://www.practicalbioethics.org
ACP during the COVID-19 Pandemic

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Facts about COVID-19

- Serious health threat to frail and elderly.
- 3x more contagious than influenza
- 10x more deadly than influenza
- No treatment, care is supportive
- Individuals can be carriers, and not become infected
- Virus not a bacterium
- Testing tells us the epidemiology and helps with tracking
- Death is due to respiratory failure, secondary to interstitial pneumonia.
Goals for Advance Care Planning

- Map out plans for future care
- Best before a crisis
- Encourage conversations with family and loved ones.
- Clarify diagnosis, prognosis and life expectancy
- Educate
- Identify individual’s values
POLST and Medical Orders

- Use as a guide or outline for conversation
- Code Status: yes or no
- Degree of Medical Interventions
  - Full, Selected and Comfort
- **Additional Orders**
- Nutrition
Evidence

- CPR
  - Survival rate about 17% when occurring in-hospital.
  - Survival rate 7.5% outside hospital (community setting)
  - Of those who survive CPR in long term care <1%, most die within 120 days.

- Mechanical Ventilation - short term effective, long term high morbidity and mortality.
Evidence

- Tube feedings do not prolong life and may cause more complications.
- Withholding artificial nutrition is neither painful nor uncomfortable. People adapt physiologically to decreases intake of food and fluid.
- Dehydration has a sedating effect.
- IV Hydration-at EOL can increase suffering, fluid accumulation in the tissues, and increased secretions.
- Antibiotics can cause complications and may not be palliative.
  - Pneumonia can be managed through comfort measures.
Assessing life expectancy

- Functional predictors: impairment in ADL
- Cognitive predictors: moderate to severe dementia
- Nutritional predictors: weight loss, fluid accumulation, sarcopenia
- Patients self-report
- Critical Illness in patients with moderate to severe debility = high mortality.
Debility and Critical Illness

- More than half died within 1 month or experienced significant functional decline over the following year with poor outcomes in those who had high levels of pre-morbid disability.

- Does decisions for ICU make sense when we know the outcome is the same?

Ferrante et al: studied functional trajectories in older adults both prospectively and following admission to an ICU
Components of the Goals of Care Discussion

- Introductions
- Take the emotional pulse/empathize
  - Emotional will not be able to listen to the cognitive
- Clarify the purpose of the meeting
  - Define why everyone is meeting
  - Discuss why this meeting is important
  - Include that this is about the planning for future medical care.
• Don’t force a decision
• Start with the basics: DNR, feeding tubes
• Restate “as I understand you, it sounds like you want ___ and do not want ___. Is that correct?
• Based on my understanding of your values and goals and what I think is best, my plan will be to ________. Is that OK?
Ethics during a crisis

- Hospitals and physicians will need to balance individual needs of each patient and larger needs of community.
- Decision to not institute aggressive rescue treatment is ethically allowable as is withdrawal of treatment when it does not achieve goal.
- Emotionally difficult for families to withdrawal treatment.
- The fact that we are facing a crisis is an ethical lesson.
- Allowing for a natural death.
Tools and Resources

CAPC COVID-19 Response Resources
COVID Ready Communication from VitalTalk
POLST and COVID-19
Working with Families Facing Undesired Outcomes (SWHPN)
Tools and Resources

A decision aid for patients considering life support at a time of COVID-19 Univ of CO

Caring Conversations
And tomorrow…
Tomorrow - Electronic Options

MyDirectives and Center for Practical Bioethics are partners offering you a FREE account to upload, store and share your Caring Conversations Workbook and forms.

Click Upload an Existing Document to get started.

Upload an Existing Document
Questions?
THANKS for all you are doing!
STAY WELL

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Consumer Voice: Getting Quality Care

https://theconsumervoice.org/issues/recipients/nursing-home-residents/getting-quality-care/advance-care-planning

Advance Care Planning

Advance care planning is making decisions about the care you would want to receive if you become unable to speak for yourself. These are your decisions to make, regardless of what you choose for your care, and the decisions are based on your personal values, preferences, and discussions with your loved ones. Find information and resources below on advance care planning.

Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life

In Dying in America, a consensus report from the Institute of Medicine (IOM), a committee of experts finds that improving the quality and availability of medical and social services for patients and their families could not only enhance quality of life through the end of life, but may also contribute to a more sustainable care system. This report was recently made into a podcast series available here. For further information, view the Powerpoint given by Judith R. Peres, LCSW-C, on the report at the Consumer Voice Annual Conference.

FAST FACTS: Advance Care Planning

This consumer fact sheet from Advancing Excellence explains the importance of advance planning for care after a debilitating illness or at the end of life.

Making Your Wishes Known: Advance Care Planning and the Legal Landscape

This Powerpoint, presented by Charles P. Sabatino, JD at the 2014 Consumer Voice Annual Conference, covers how laws and regulations influence advance care planning. It covers the legislative history, what advance directives can and can’t do, and several approaches to developing advance directives.
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