THOSE CRITICAL CONVERSATIONS: 
Death Discussion and Advance Planning

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Learning Objectives:
- We will explore the healthcare decisions that everyone must address and how to discuss them. These decisions include:
  a) the qualities of life that we value
  b) the kinds of treatment [tube feeding, CPR, ventilators...] that we do or do not want.
  c) the choice of who will speak for us, when we can no longer speak for ourselves
- We will discuss how these questions pertain to people who have the capacity to make their own decisions and people with dementia who cannot make these decisions.
- We will review the hierarchy of surrogates for Arizona and discuss medical powers of attorney. We will discuss which surrogates may address stopping artificial nutrition and hydration.

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Crucial Conversations: Facilitating Health Care Decisions

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Learning Objectives

Upon completion of this course, learners will be able to:
• Describe the AZ advance care planning forms.
• Initiate an ACP discussion with your family or clients
• Include appropriate resources in the ACP discussion.
• Recognize unique characteristics of discussions with clients living with Memory Impairment
Why Advance Care Planning?

The facts about how we die are clear:
- Most of us will die after experiencing a chronic, progressive, and ultimately fatal illness
- Approximately 80% of deaths will occur under the care of health professionals in some type of health organization.
- When the time comes to make important end-of-life decisions, approximately 50% of people are incapable of participating in those decisions.
- When health professionals are uncertain about what decisions to make, the default is to treat.
- If health professionals or loved ones have not spoken with a patient about end-of-life issues, they cannot reliably predict what the patient would have chosen and they find the decision making responsibility burdensome and stressful.

Reasons for the Conversation

- 70% of people say they prefer to die at home. 70% die in a hospital, nursing home, or long term care facility.
  - Source: Centers for Disease Control (2005)
- 60% of people say that making sure their family is not burdened by tough decisions is “extremely important.” 56% have not communicated their end of life wishes.
  - Source: Survey of Californians by the California HealthCare Foundation (2012)

More Reasons to Initiate Conversation

- 82% of people say it's important to put their wishes in writing. 23% have actually done it.
  - Source: Survey of Californians by the California HealthCare Foundation (2012)
- 80% of people say that if seriously ill, they would want to talk with their doctor about end of life care. 93% report never having had an end of life conversation with their doctor.
  - Source: Survey of Californians by the California HealthCare Foundation (2012)
Advance Care Planning

What Advance Care Planning is: It is a conversation that takes place between loved ones on end-of-life care wishes and preferences. It is a process that identifies what is most important to you concerning quality of life and living. There is no “right” or “wrong” in advance care planning. Your decisions and values are simply your preferences for end-of-life care.

- What is your personal and/or professional experience with advance care planning?
- How many of you have an advance care plan?
- Why health care professionals should have these documents.

Resources

- HonoringChoicesMN.org
- Primetime End of Life planning
- Bill Moyers PBS
- www.AZAG.GOV
Educating and Exploring Ideas on Treatments

- CPR
- Intubation/Ventilation
- Nutritional Support
- Dialysis
- Antibiotics
- IV Hydration
- Pain Management

- You may want to discuss your specific health issues with your provider prior or during your drafting process

When Should Advanced Care Plans be Reviewed?

- Major Illness
- New Diagnosis
- Change in treatment plan
- Client’s wishes change
- Transfer from one care setting to another

Your Advance Care Plan

Completing Your Advance Directive

- Advance Care Plan form
- How to complete
- Involvement of family
- Common Problems with Plans
  - Technical errors/gaps
  - Ambiguous statements/phrases
  - Miscommunication
Meet Mary

• Mary Smith is an 83 year old woman who has always been healthy and active. She has no chronic or life-limiting illnesses.
• She has lived alone in her own home since her husband died 20 years ago.
• She drives to visit friends and relatives around the state.
• She has 2 adult children who get along well with each other. Among the 3 of them, they have 5 graduate degrees past the bachelor’s degree.

Mary

• Recently, Dr. Smith has begun to “feel my age”.
• She now believes that she would be better off living in an apartment in a life care community, where she would not be responsible for the house and where she would have services available when she starts to need them.
• The community that she has chosen has given her many forms to fill out, including their own Advance Directives.
• They also request a copy of her regular Advance Directives.
Mary

- She and her son have been staring at the forms for several days, reading and re-reading the questions.
- They cannot seem to answer questions about the care that she would wish to receive or forgo.
- A major stumbling block is the information that was provided to them suggests that indicates that there is a “5% RISK of SURVIVAL” with out-of-hospital resuscitations.
- Another problem is that her son suggests answers based on his own wishes, without asking his mother what she would want.

- How would you facilitate the discussion?

Advance Directives

- Hospital vs No hospital [Orange Form]
- CPR vs no CPR
- Artificial Hydration / Nutrition?
- Other treatments: Ventilators, ICU care, dialysis...
- Medical Power[s] of Attorney
- Facility Forms
Conditions/ quality of life that trigger these decisions:

- Advanced dementia, vegetative state
- Inability to communicate
- Inability to recognize loved ones
- Inability to live independently, requiring SNF/LTAC care
- Ventilator dependence
- Inability to play tennis, walk, drive...

Mary

- Advance Directive forms document Dr. Smith’s values, wishes and beliefs.
- The first step is for her to determine what her values and wishes are, in consultation with family and others.
- When she knows and can communicate these values to others, she can document them in a form.

Surrogate list for AZ

- *Patient, medical power of attorney, guardian
- Surrogates
  - Spouse
  - Majority of adult children
  - Parent
  - Domestic partner
  - Brother or sister
  - Close friend
  - Physician + ethics committee, 2 physicians
Mary

• Until these forms are executed, the family/surrogates can make sure that her wishes are honored.
• It is so important that Dr. Smith determine her wishes that she should not be pressured into signing forms.
• However, Advance Directives may be revoked at any time, by declaring her new wishes and executing new forms. So, if the facility requires that their form be filled out before move-in, she may choose all treatments, with the understanding that the form will be updated.

Starting point for discussion of values

• Are there prior Advance Directives? Have you worked through these issues before?
  – Where are they?
  – What do they say? Are these your current values?
• Who is [are] the Medical Power[s] of Attorney?
  – How are they designated? [A and B vs A or B…]
  – Are they willing and able to always honor your wishes, and always act in your best interest?
• Do you want to make any changes?

Arizona Statutes on nutrition/hydration

• 36-3201. Definitions
  – 2. "Artificially administered" means providing food or fluid through a medically invasive procedure.
• 36-3203. Surrogate; authority; responsibilities; immunity
  – D. A surrogate who makes good faith health care decisions for a patient is not subject to civil or criminal liability for those decisions… For the purposes of this subsection, “good faith” includes all health care decisions, acts and refusals to act based on a surrogate’s reasonable belief of a patient’s desires or a patient’s best interest if these decisions, acts or refusals to act are not contrary to the patient’s express written directions in a valid health care directive.
  – E. A surrogate who is not the patient’s agent or guardian shall not consent to or approve the permanent withdrawal of the artificial administration of food or fluid.
• Laws on non-artificial feeding/hydration
  – None
• Is the “5% risk of survival” a Freudian slip or an indication that there are instances in which survival would be undesirable?
Meet Betty

85 y.o., female living at home with extended family
• Late moderate stage of Alzheimer’s disease; CHF; HTN; Chronic pain due to DJD

• Needs assistance with all ADLs
• Incontinent bowel/bladder most of the time
• Moderate to severe aphasia
• MMSE = 11/30

• Advance Directive: “DNR”

Recent Developments

• Swallowing difficulties with meals resulting in choking episodes
• Urine C/S shows current UTI (3 UTIs in < 10 months)

Family wants to discuss and plan for possible treatment options for these issues
• Consider placing a feeding tube in the future as swallowing problems increase?
• Continue offering Antibiotics for UTIs?

Family’s Concerns

“When she took care of her mother with dementia, she told us several times that she’d never want to live like this. But, we love her and couldn’t stand to watch her suffer....”

• If something happens to her, isn’t sending her to the hospital the best thing to do?
• If we don’t provide a feeding tube, will she starve to death?
• If we don’t choose antibiotics, does that mean she will be in pain until she dies?”
Advance Care Directives for Persons with Dementia (PWD)

• What are the common details associated with end-of-life decisions for PWD?

Background

Most adults report they would not want aggressive medical interventions if they had advanced dementia.

Most proxy decision-makers report that comfort is the primary goal of care for their person with advanced dementia.

And yet

Gozalo et al, 2011; Hanson et al, 2011; Volandes et al, 2009; Volicer, 2005

Background

People with end-stage dementia have

– Fewer completed advanced directives
– More distressing symptoms amenable to treatment (pain, neuropsychiatric symptoms)
– More costly & burdensome interventions with little to no clinical benefit (antibiotics, IVs, feeding tubes, restraints, lab tests)
– More transitions of care that can be avoided (Emergency room visits, hospitalizations, ICU)
– Less use of hospice services

Mitchell et al., 2012; Shega et al., 2008; 2009; Teno et al, 2011; Unroe & Meier, 2013
The Critical Question…
How do we bridge the gap between the care people say they want and what they actually receive?

Clarifying Goals of Care
Be Careful HOW you pose the questions......

When clarifying the goals of care with the MPOA or surrogate decision-makers, do not ask questions like “what do you want us to do for your mother?”

• Posing a question in this manner places the burden of decision-making on the proxy.

Instead.....

Ask what would the **patient** want?

“Given the state of your mother’s’ condition, what would **she** choose at this point if she could tell us?”

“…Would it be to have life prolonged with medical means even though she has a terminal condition, or would she ask simply to be kept comfortable?”

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What are the goals of care?

There are no right or wrong answers.

The question simply focuses on the unique desires & values of the individual.

Facilitate Informed Decision-Making

Provide patients & families with education about options and realistic outcomes related to the details of advance care directives:

- CPR
- Hospitalizations
- Antibiotics
- Feeding Tubes

Resuscitation

- CPR is 3 Xs LESS LIKELY to be successful in a person with dementia as compared to others their age, and those who initially survive are taken to an ICU where most die within 24 hours.

(Volicer, 2005)
Hospitalizations for PWD are Hazardous

Increased risks for complications, injuries, discomfort and distress

Hospitalized PWD are more likely to have adverse outcomes:
  - Delirium
  - Incontinence
  - Pressure sores
  - Infections
  - Inadequate pain control
  - Physical and chemical restraints
  - Deconditioning
  - Increased Long Term Care (LTC) placements
  - Decreased Quality of Life (QOL)

(Fulton et al., 2011; Phelan, 2012)

If the person wants to receive antibiotics or other treatments, remember….

Infections & co-morbidities can be effectively treated in long-term care facilities or outpatient settings
  - Labs, x-rays, & IVs can be done on site

(Fulton et al., 2011)

Antibiotics (ABX) for Pneumonia in PWAD

N = 323
91% of PWAD who had pneumonia were given some form of ABX

Survival was prolonged for up to 9 mos, BUT comfort was not. More aggressive care was associated with more discomfort (associated w/ parenteral ABX & hospitalization)

*Oral ABX agents are best choice. No difference in outcomes r/t route of administration; less costly; less burdensome

(Givens et al., 2010)
**Tube Feedings in PWAD**

- Do not prolong survival or improve quality of life
- Do not prevent aspiration pneumonia, malnutrition, wt loss, muscle wasting
- Associated w/ complications (e.g., restraints, leakage, infections)

Carefully hand fed patients had similar survival rates & increased satisfaction.

(Teno et al., 2011; Teno et al, 2012)

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**Best Times to Discuss Health Care Decisions**

- **Begin early** in the course of dementia when the pt has the ability to understand & provide input.
- Discuss HCDs details at a time when things are relatively stable rather than in crisis.
- Review the HCD periodically as dementia progresses and complications arise

(Fulton et al., 2011)

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