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At the end of this session...

You will be able to understand the role of advance directives in end-of-life decision-making and learn a new approach to advance care planning.
Overview

• We have focused too much on a piece of paper as opposed to a process of communication and formation of a plan to ensure preference are honored.

• **There is not one communication strategy.** Rather, tailor your advance care planning to the disease trajectory and needs of that patient and family.
No CPR
No G-tube,
NO Feeding Tubes
No Vent
Advance Directives

Legal document that allows a competent person to state their preferences and values in advance of a future period of incompetence.
Advance Care Planning

Process of ongoing communication that clarifies the patient’s goals and values.

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Advance Care Planning (cont’d.)

Based on this, a health care provider formulates a plan of care that honors patients’ goals and values.
Case

- Did not involve discussion with a health care provider...
- Not informed
- Did not consider time-limited trials
Brief History: 1969

“That when an event occurs wherein it appears that I am physically or physiologically irreversibly ill...I then direct...that I be given an appropriate method of EUTHANASIA.”

Luis Kutner proposes the Living Will
Three Key Court Cases
Case 1: What happened?

- 21-year-old-female who collapsed at a party, April 15, 1975
- Alcohol and valium
Case 1: What happened? (cont’d)

- Anoxia,
- Persistent Vegetative State (PVS)
- Father requested guardianship to discontinue mechanical ventilation
Case 2: What happened?

- 25-year-old female in motor vehicle accident in 1983
- Anoxia
- Resuscitated in the field
- PVS

Nancy Cruzan
Case 2: What happened? (cont’d)

- Husband consented to feeding tube placement
- Parents obtained guardianship
- Parents requested removal of feeding tube
Case 3: What happened?

- 26-year-old-female with cardiac arrest, February 1990
- Anoxia, PVS
- Husband designated guardian
Case 3: What happened? (cont’d)

- Treatment for 3 years
- Requests removal of feeding tube
- Parents object, seek guardianship
Legal implications of 3 cases
1. Karen Quinlan
Right to privacy

In Re: Quinlan

We think that the State's interest contra weakens the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims. **Ultimately there comes a point at which the individual's rights overcome the State interest.** It is for that reason that we believe Karen's choice, if she were competent to make it, would be vindicated by the law.
Surrogate Decision-Making

In Re: Quinlan

“It is for this reason that we determine that Karen's right of privacy may be asserted in her behalf, in this respect, by her guardian and family under the particular circumstances presented by this record.”
Aftermath of Quinlan

• Father had right to order removal of mechanical ventilation

• Legal only in New Jersey

• Nurses, physicians successfully weaned her
Aftermath of Quinlan (cont’d)

- Died 1987
- Evolution of hospital ethics committees
- States enact living will legislation
2. Nancy Cruzan

Cruzan v. Director, Missouri Dept. of Health (1990)
Missouri Court Decisions

• Court affirms right to refuse treatment
• Right to privacy has restrictions
• Missouri living will statute specifically prohibits withdrawal of feeding, hydration
• Without a living will, parents cannot assume her wishes regarding termination of treatment
U.S. Supreme Court Decisions

Upheld Missouri Court decision, referred back to Missouri, but:

- Competent person can refuse feeding, hydration
- “Artificial feeding cannot readily be distinguished from other forms of medical treatment” (Justice O’Connor)
- State can adopt standard require “clear and convincing” proof of incompetent person’s preferences
Aftermath of Cruzan

• Former roommate claimed Cruzan said she would not want life-sustaining treatment
• MO Supreme Court ruled that it had sufficient evidence of her wishes, reversed prior opinion
• Feeding, hydration withdrawn
Aftermath of Cruzan (cont’d)

• Died Dec 26, 1990
• Patient Self-Determination Act of 1991
• Durable power of attorney, H.C. Proxies
3. Terri Schiavo
2002 C.T. Scan shows cerebrospinal fluid replacing large portions of Schiavo’s cortex.
Schiavo background

• 15 years in persistent vegetative state

• Florida law—spouse default decision-making that states that husband can decide but her parents and siblings are opposed.
Claims

• Over the past four decades, we have focused on a piece of paper and “do not resuscitate order.”

That was wrong.

• Process and plans are more important
“...at that time, the patient’s wife expressed concern that the patient not be kept alive if there was no hope of recovery, that those were his wishes, and she wanted to honor them... her question was how would she know when to stop?”
LESSONS FROM THE US ADVANCE DIRECTIVE MOVEMENT

I believe that the important issue is “when” or “At what point, do you make a transition in the goals of care?”
New Framework for Advance Care Planning
New framework

• Emphasis on communication and negotiation regarding goals and likely outcomes

• Specificity targeted to age and patient’s condition

• Anticipate the disease trajectory
New framework

• Not a single conversation, but **occurs over time**

• Conversations should **meet the needs of the dying patient and family**

• Should formulate plans to **ensure preferences are honored**.
Overall Strategy: Eliciting and Respecting **Choice**
Step 1

• "Where is the patient in their disease course?"
• “Have they reached a critical turning point?”
Step 2

Communicate and Negotiate—what are their goals of care?
Step 3

Develop contingency plans to honor those preferences
One Targeting Possibility

- “Healthy” persons
- Serious Illness
- Death is likely outcome
For the “healthy” person

Content should focus on:

• Naming a proxy
• Stating undesirable outcome states
• Unusual preferences
For the “healthy” person (cont’d)

Action Items:

• Discuss surrogate for this and all categories

• Document in chart

• Possibly complete Advance Directive
Communication Strategies for “Healthy” Persons
Offer Choices

“There are many ways to control hypertension…”
Proxy

“If you were too sick to talk with me about your health care decisions, who would you like me to speak with?”
Communication Strategies for Limited Life Expectancy
Formulate a plan of care

Specifics are essential

“Mrs. M, you have said it important that your medical care focuses on your comfort. Even if you get more short of breath, you want to stay at home...Is that correct?...

“Now if you do get short of breath and it does not respond to usual treatment, we will use morphine. And, you can call....”
2 Examples:
Different disease trajectories,
Different communication needs
Mattie: A young patient with short bowel syndrome, marked cachexia and near death
Ruth: An elderly woman with advanced dementia now pocketing and choking on food
Mattie’s story

- 49-year-old woman with Stage IV colorectal cancer, short bowel syndrome, and refusing increasing morphine

- Nurse: “Can you convince her to increase morphine?”
Buckman’s Six Steps

1. Getting physical context right
2. Find out how much information they already know
3. Find out how much information they want to know
4. Share information—**align and educate**
5. Empathy
6. Closure and next steps
1. Getting the context right

• Introduce yourself and your role in the medical care of their loved one.
• Find a quiet setting if at all possible
2. How much do the patient & family know

- Where is the patient in their disease trajectory?
- Quality of Life?
- Listen carefully- how do they describe the illness? patients' prognosis?
- Through carefully listening, you will learn how to tailor the information that you present to the special needs of this patient and their families.
3. How much do they **want** to know?

Some may not want to know information on prognosis or even undertake advance care planning.

Yet, treatment goals and plans should be discussed.
4. Share information

Align and educate

- What is their mental model?

- Educating and clarifying misperceptions are often an important part of sharing information
5. Empathy

One must be cognizant of how far one can push a patient or family in decision making if they have not fully come to terms with their emotional response to their situation
Mattie’s story

- 49-year-old woman with Stage IV colorectal cancer, short bowel syndrome, and refusing increasing morphine

- Nurse: “Can you convince her to increase morphine?”
Applying Buckman’s 6 Steps to Mattie’s Story
1. Getting the context right

• Sat down with Mattie & her husband in a quiet room
• Listened to them
• What is their understanding of her medical illness?
2. How much do the patient & family know

Where is the Mattie in her disease trajectory? Quality of Life?

- Mattie understood about compassionate trials of chemotherapy
- She understood her condition and prognosis
- Poor Quality of Life
3. How much do they want to know?

- Fully-involved
- Control in decision-making
4. Share information

- Note Academic background—very knowledgeable
- Yet, I needed to educate about use of medications
5. Empathy

- Acknowledge the “injustice” of the situation

- Told her that she was in charge of what we would do regarding the morphine drip

- **The body was the final teacher**
6. Next Steps & Closure

- Draw labs
- Start hydrating IV
- Would re-discuss in 24 hours
- She should tell me when
Ruth’s Story:
A study on dementia
Ruth’s Story

83-year-old woman with dementia

• Eating problems

• Losing weight

• Multiple urinary tract infections with worsening delirium and disruptive behavior
Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life
CASCADE: Eligibility

• Age 65 and older
• At least 30 days length of stay in a nursing home
• Severe cognitive impairment—Global Deterioration Scale of 7
• Proxy
CASCADE: Aims

To establish a cohort of nursing home residents with advanced dementia and their proxies (families), follow repeatedly for 18 months:

1. **Clinical Course**
2. **Decision-Making**
3. Satisfaction with End-of-Life Care
4. Complicated Grief
## Resident characteristics

### Characteristic (N=323)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years) (mean ± SD)</td>
<td>85.3 ± 7.5</td>
</tr>
<tr>
<td>Female (%)</td>
<td>85.4</td>
</tr>
<tr>
<td>White (%)</td>
<td>89.9</td>
</tr>
<tr>
<td>Alzheimer’s disease (%)</td>
<td>72.4</td>
</tr>
<tr>
<td>Vascular dementia (%)</td>
<td>17.0</td>
</tr>
<tr>
<td>Other dementia (%)</td>
<td>12.7</td>
</tr>
</tbody>
</table>
- N=177/323 (55%)
- Median = 478 days
- 6-months = 25%
- 93% die in Nursing Home

*Adjusted for age, gender, disease duration*
Probability of $\geq 1$ pneumonia: 41% (N=132/323)

6-month mortality after pneumonia: 47%
6-month mortality after pneumonia: 47%
Probability of eating problem: 86% (N=278/323)
6-month mortality after eating problem: 38.6%
A proposal for a new order to allow for persons and/or family with neuro-degenerative disorder to select feedings for their comfort, but not to the point of distress.
Concerns

• Focus on what persons want
• Families struggle with stopping feedings
• Staff fears of regulatory citation regarding weight loss
Evidence

Observational data that feeding tubes vs. careful hand feeding does not improve survival, or patient related outcomes.
Practice

• Substantial variation in prevalence and insertion rates
• Low rates of orders to forgo Artificial Nutrition and Hydration (ANH)
Society

- Being sick and Mom’s chicken soup
- Care vs. No Care
- Nursing home fear of regulatory scrutiny
Comfort Feedings Only

An order either where a competent nursing home resident or legally approved proxy decision maker indicates a preferences to forgo, withdraw, or limit the use of a feeding tube or other artificial means of nutrition and develop a plan for ensuring the appropriate level of comfort feeding.
Comfort Feedings Only (cont’d.)

Key is what steps are taken to ensure **patient is comfortable** and individualized feeding plan developed
Key processes

Prior to implementing comfort feeding only

• **Medical Evaluation**—including speech therapy and dental consultation, if needed
• Change diet and timing
• Increase intensity of feeding efforts (if safe) for short period of time—*if dementia and the patient unable to consume sufficient calories, consider hospice consultation*
Communication Strategy 1

• Learn what the Husband understands about the treatment and prognosis of dementia
• Ask what he has observed about his wife’s condition
• Educate about risks (restraints both physical and chemical, health care transitions) and limited benefits
Communication Strategy 2

Another option is to focus on keeping your wife comfortable through feeding her by hand instead of through a tube. We call this order **Comfort Feeding Only**.
Communication Strategy 2 (cont’d.)

Goal of a Comfort Feeding Only Order:

To focus on your wife’s comfort and provide feeding to her as long as she is not showing signs of distress such as choking or coughing.

If oral feeding is causing her distress, the person feeding her will stop the feeding.
Communication Strategy 2 (Cont’d.)

Over time her ability to eat orally will likely decline further. This is the natural progression as someone approaches the end-of-life. However, it is important for you to understand that this order of Comfort Feeding Only places a premium on her comfort during meals, but is unlikely to keep her from losing weight.
Summary
What is Advance Care Planning?

• An ongoing process of communication

• Negotiation to formulate a patients’ goals and values.

• Based on that understanding, one can formulate an advance directive, a legal document that states preferences and/or names a proxy or surrogate, and develop contingency plans
Key

- Tailor to the patient’s age and know disease trajectory
- Anticipate common problems
- Tailor your communication strategies to the needs of the patient and family
- Once there is clear preference, ensure that there is a set of plans to ensure those preference will be honored.
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