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Week 2

Plan & Manage – Advanced Care Planning and Essential Conversations

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Learning Objectives

1. Advanced Care Planning
2. Tools for having difficult conversations
3. Discussing Hydration and Nutrition
4. Discussing EOL at LTC

Materials

1. SPIKES
2. Approaches to Goals of Care Discussions/Wish, Worry, Wonder
3. Suggested Responses

A Palliative Approach to Care – Plan & Manage

What is ACP?

Two essential components:

1. A reflection on values and wishes for EOL care

2. Formally identifying a person(s) to make decisions on one's behalf if one is unable to do so

Share these discussions
Document them
Only activated when capacity lost

Advanced Care Planning in Relation to Goals of Care and Health Care Decision Making

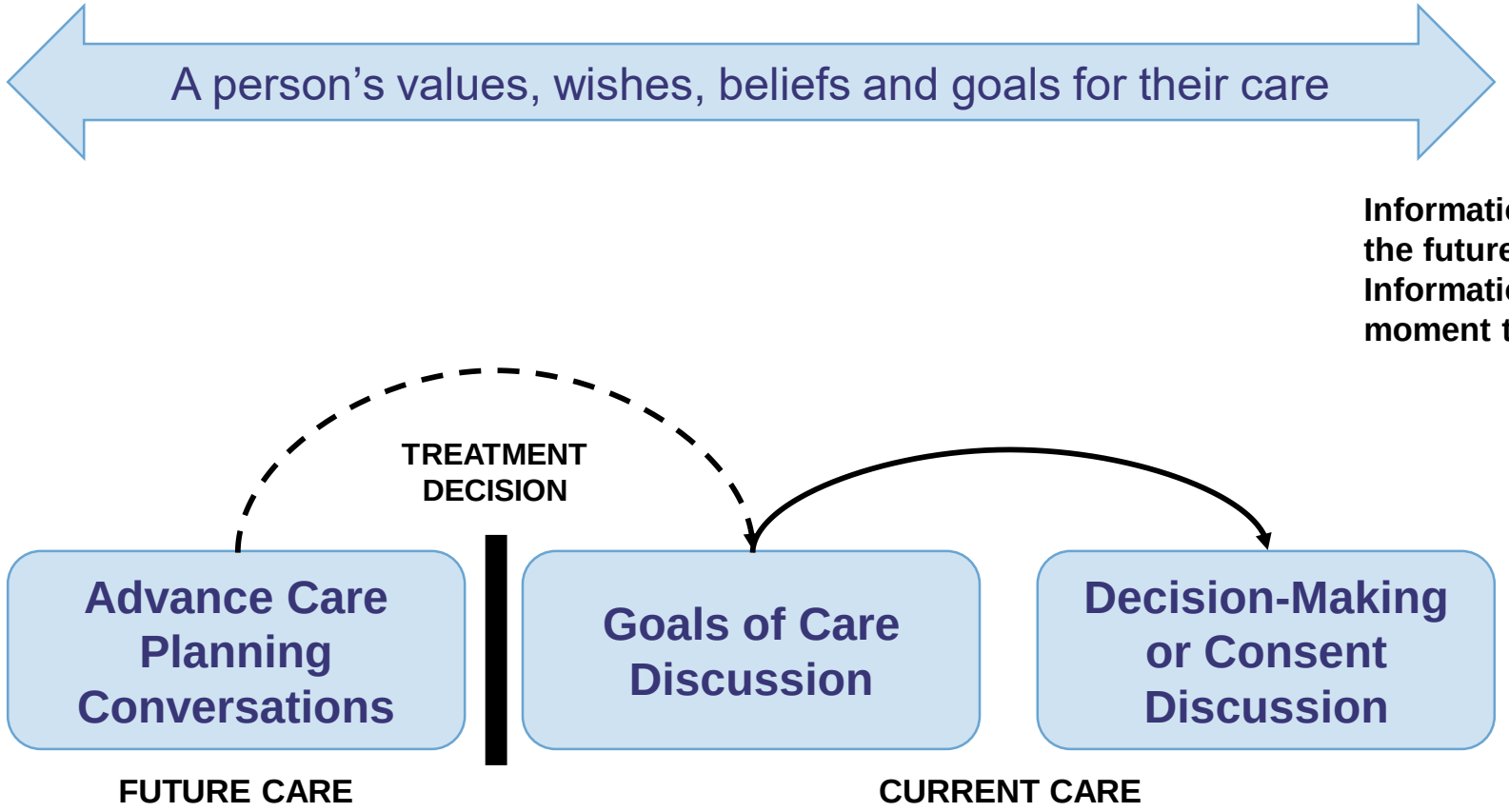


Figure: Relationship between three key discussions as components of informed consent

Cardio Pulmonary Resuscitation is a treatment option…

- CPR is a medical treatment to restart the heart or lungs
- CPR may include compressions, intubation, drugs, defibrillation
- About 10% survive of those requiring CPR; statistics decline with comorbidities and frailty
- Out of that 10%, 5 will have some form of brain injury
- Side effects – broken bones, impaired mental function, pain

If no CPR – natural process of death occurs

DNR will not change your other care

Approaches to Goals of Care Discussions

Goals of Care – Conversation suggestions[i,ii,iii]	
Conversation flow	**Suggested conversation starters**
To begin the conversation Introduce idea and benefits Ask permission	• If it is okay with you, I'm hoping we can talk about where things are with your illness and where they might be going. • As you begin treatment [or settle into a routine], it is a good time to discuss your goals and preferences.
1. Explore Illness Understanding Confirm the individual's understanding of the serious nature of their illness	• I'd like to hear from you about your illness, and what it means for your health and quality of life? • What is your understanding of what lies ahead with your treatment and overall health? • It would be helpful to hear what has been going on from your perspective (or in your own words…) so I know what other information you might still need
2. Inform Assess individual's interest in knowing more about prognosis	• What information about what lies ahead would you like me to share? How do you like to get information? • Would you like statistics? Would you like to talk about the big picture? • Sometimes people with a life-limiting illness think about how long they might have. Is that something you are thinking about?
Normalize uncertainty of prognosis	• We cannot fully predict what is ahead and there is often some uncertainty. Based on your health status and the best available information, I would say about [provide estimated prognosis]… . It could be longer or shorter, though.
3. Elicit values and define goals Ask the patient about their past experiences, hopes, values and priorities	• What are your hopes or personal goals as the illness progresses? • Are there any milestones you have in mind that you would like to achieve? • We want to make sure the care you receive honours what is important to you. What sort of quality of life would you find acceptable and what would you find unacceptable? • When you think about the future, what do you worry about? • If time were limited, what would be most important for you? Where would you want to be cared for? • What would you want to make your final days be more peaceful for you and your family? • What has been the hardest part of this illness for you? What about your (wife, husband, partner, children)? • What do I need to know about you, or your personal, cultural or spiritual background that could help us provide you with the best possible care? • What are you hopeful for? Do you have any fears?
After clarifying values, determine overall Goals of Care	• Given what you have told me and what I know about your illness, it sounds like [insert what you've heard, e.g., "trying to prolong life" or "focusing on comfort" or "a mixture of…"] is important to you now. Have I understood your Goals of Care correctly?
4. Plan and Document Discuss treatments in relation to identified goals and values	• Based on what you said, it seems like [propose treatments that you do recommend] would be in your best interest. How do you feel about this? • Given what you have told me about yourself and what I know of your medical condition, I do not think that [treatments that you do not recommend] are right for you because of the following reasons… • We want to help you with your goals. There are different things that we can do to help you feel better. Let's talk about the options, and figure out which ones will help you meet your goals
5. Revisit the conversation Update the Goals of Care and Plan of Treatment accordingly	• We have talked about your goals and priorities before; I'm checking in now to see whether you've changed your mind about anything we discussed.
If the conversation is not going well at any time	• I talk with all of my patients about this. I am asking these questions because I care about your health, and I want to be open with you • I understand this is a difficult topic. When people get sicker, they often lose the ability to tell their healthcare providers about the kind of care they want. This leaves families and providers guessing about your goals, which can be distressing for everyone. Can you help us understand what is important to know about you so that we can give you the best care for you now and in the future?

[i] Mandel EI, Bernacki, RE, Block SD. Serious illness conversations in ESRD. Clin J Am Soc Nephrol. 2017;12:854-63.
[ii] Speak Up Ontario. Just ask: a conversation guide for goals of care discussions [internet]. Canadian Researchers at the End of Life Network. [undated; cited [2017 September]. Available from: http://www.advancecareplanning.ca/wp-content/uploads/2015/09/acp_just_ask_booklet-rev-july20_final-web2.pdf.
[iii] Goals of Care E-Learning Module created by Leah Steinberg and Christine Soong (Sinai Health System, Toronto, ON).

I Wish, Worry, Wonder Framework

Wish

- "I wish… your health would improve"
- I wish allows for aligning with the patient's hopes

Worry

- "I worry… if things do no improve"
- I worry allows for being truthful while sensitive

Wonder

- "I wonder… if we can plan if your health does decline"
- I wonder is a subtle way to make a recommendation

SPIKES

SPIKES protocol for delivering bad news:

- **S** **S**etting up the interview
- **P** Assessing the patient's **P**erception
- **I** Obtaining the patient's **I**nvitation
- **K** Giving **K**nowledge & info to the patient
- **E** Addressing patient's **E**motions with empathy
- **S** Strategy and **S**ummary

Case Study # 1: Resident Mr. K

- 92 year old male with end stage Liver disease
- No CPR order in place based on patient's expressed wishes. Spouse having a hard time with his decision; but accepting; end of life discussions started with family
- Condition is worsening; difficult to rouse; not expected to survive for more than a few days; Daughters ask about starting hydration

What would you say?

Diet and Comfort Feeding

- In the dying process, as the metabolism slows down, residents usually show less interest in food and fluids
- Family members may fear that the resident is ‘dying of starvation’
  - › Distinguish that starvation implies the withholding of food when hungry vs the lack of desire of food these residents experience
- Teaching: ***“food is no longer nourishing and in fact, it may cause discomfort”***
  - › Expenditure of energy is so little, the required intake is also little
- If the resident/family chooses comfort feeding, explain the risk of aspiration
  - › Advise on safest techniques possible – thickened fluids, head of bed up, patient awake and requesting it

Hydration

- Families often request hydration; education about its appropriateness is key
- Some residents may benefit from hydration (eg. Delirium), therefore, fluid provision should be assessed on an individual basis
- Hydration will NOT prolong life OR add to comfort ***once*** a resident shows signs of peripheral shutdown, also known as terminal dehydration
    - › Over hydration can cause harm causing peripheral and pulmonary edema and oropharyngeal secretions and pain
- For a gentler compromise - Hypodermoclysis

Case Study # 1: Resident Mr. K (cont'd)

- You are walking into the home, the resident is in bed and looking very different from when you saw him last
- The resident is noted to be confused and drowsy. He has now developed a congested cough. He rouses to your voice and falls asleep quickly
- You estimate his PPS to be 20%
- Wife and daughters are present in the room. Youngest daughter is 32 weeks pregnant and having a hard time with his decline. They are asking you what is going on

What would you say?

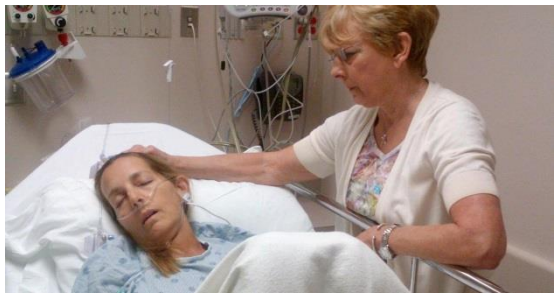
Explain to Family the Signs of Approaching Death

Urine output decreases & may become tea-coloured

Decreased awareness, insight and perception

Heart rate - increased, irregular, thready

Incontinence of urine or stool may occur



Sleeping increases, patient may appear uncommunicative, with decreased socialization

Restlessness & agitation

Changes in skin temperature and colour (e.g., cold, blue “mottled” extremities)

Eating & drinking decrease or stop

Eyes might be slightly open

Breathing shallow, apnea, terminal secretions

Oral & ocular mucosal dryness

Suggested Responses (Registered Staff/ PSW)

What will the end be like?	*"What do you believe will happen at the end?"*
Why aren't you feeding them?	*"Loss of appetite is common and natural as the body begins to shut down"*
How long do I (they) have?	*"We are very inaccurate at predicting life expectancy and are often wrong. Sometimes we overestimate and sometimes we underestimate.*
Why are they making that rattling sound?	*"it might seem like they are uncomfortable, but it's just like snoring, the person who is snoring is not in any distress"*

Case Study # 2

- 84 year old female with advanced dementia
- Her PPS score is 20-30%. You note that she has been having difficulty swallowing and coughing when she is drinking water
- She had had a recent pneumonia and treated with antibiotics at the LTC home
- Her son is her SDM whom visits and calls regularly

What do you do next?

Case Study # 2 (cont'd)

Step 1: Identify

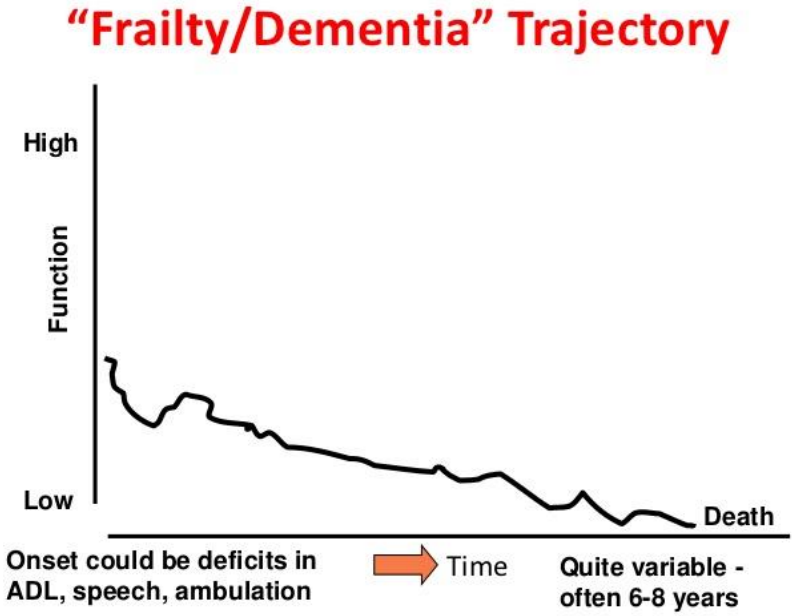
- "Would you be surprised if the patient were to die in the next year?"

Step 2: Assess

- What tools can you use in your assessment?
- What "essential conversation" will you have with this family?

Step 3: Plan/Manage

- What will you put in place for this patient?
- What additional resources can you offer?



Case Study # 2 (cont'd)

- Her son visits and you open a conversation about her wishes and goals
- When you ask him about what he thinks is happening with her health. He tells you they are quite religious and tells you "God will heal her"

What do you say?

Case Study # 3

- 89 year old male with a diagnosis of prostate cancer
- His disease is progressing with metastases to his bone, lung and liver
- You want to have a conversation about DNR and CPR

What do you say?

Changing My Practice

- ✓ Understanding Advanced Care Planning
- ✓ Have ‘essential conversations’ early
- ✓ Document these conversations and involve the SDM
- ✓ Update and renew wishes regularly
- ✓ Acknowledge these are only used as guides for future care

Thank you

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