FUTURE MEDICAL PLANNING IN DEMENTIA – PROMISES AND PITFALLS

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Outline

- Approaches to medical care planning
- Identifying resources
- Discussing common challenges of being a decision maker

Who are you? (Part One)

- Who here has a written Living Will or Medical Power of Attorney?
- How many of you have designated someone to speak for you - an "agent"?
- How many of you are the "agent" for someone else?
- How many of you have talked about what is important to YOU at the end of your life?

Who are you? (Part Two)

- How many of you are living with cognitive issues?
- How many are living with a loved one with cognitive issues?

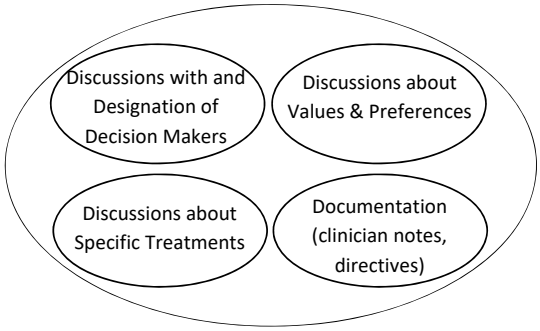
Briefly - What questions would you like to talk about today?

WHAT IS ADVANCE CARE PLANNING?

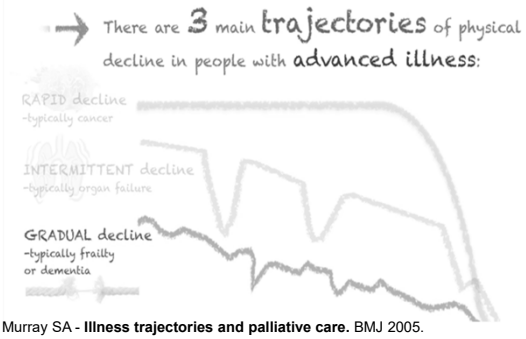
What does it mean to you?

Why does it matter?

Advance Care Planning

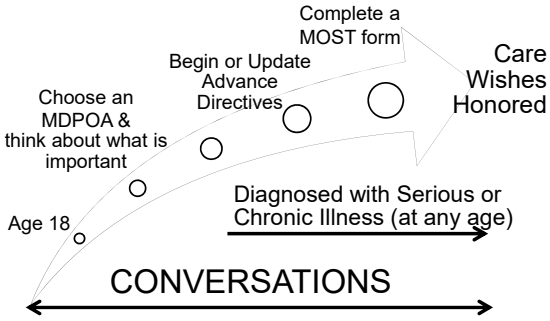


How does dying happen?



Murray SA - **Illness trajectories and palliative care.** BMJ 2005.

Where does Advance Care Planning Fit?



The Goal: To Honor Preferences

- Many (but not all) people are more concerned about quality than quantity.
- Many….want to die surrounded by loved ones, in a familiar situation.
- For some, meeting family needs may be what is most important to the individual.

IT IS ALWAYS TOO SOON TO START THE CONVERSATION… UNTIL IT IS TOO LATE

Ellen Goodman

What is important to you?

Reflect on your values and personal beliefs:

- Family and upbringing experiences
- Spirituality and faith
- Life legacies
- Meaning
- Periods/experiences of growth

The Conversation Project

Questions to consider for end of life care:

- What matters to me in life is _____.
- Would you prefer to spend your days and receive medical care?
- Are you worried about too little care or too much medical care?

the conversation project

A Question for Discussion:

- Your doctor wants to know…..
- ***What do I need to know about you as a person to give you the best care possible?***

What do people say they want?

- To not be a burden
- To maintain some control
- To not be in pain
- To have time to share and reach closure
- Peace of mind may be *more* important than what medical treatments are given or not given

BEING THE DECISION MAKER

What are common challenges of being a decision maker for someone with dementia?

Making Informed Decisions

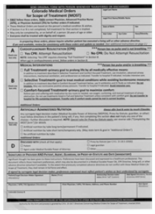
- Focus on the person's wishes
- Stay true to the person's values and beliefs
- Weigh pros and cons of treatments
- Understand the difference between withholding treatment and Medical Aid-in Dying

Questions to ask the doctor about end-of-life-care

- What is the treatment for?
- How will it help?
- What are the physical risks or discomforts?
- What are the emotional risks or discomforts?
- Does the treatment match what the person would have wanted?
- Are we doing all we can to uphold dignity?
- Are we doing all we can to give the person the best quality of life?
- Is he or she in pain? What can be done to ease the pain?
- When is the best time to ask for hospice care?

Advance Care Planning in Dementia

- Similar to ACP for everybody
  - What is most important at the end of life?
  - Can be a conversation in early dementia
  - May need to be asked by family through sharing history
- Discuss ranges of treatment intensity
  - Full treatment
  - Selective treatment
  - Comfort-focused treatment
- Identify how much Flexibility for the agent



How do People with Dementia Die?

- Falls (and hip fractures)
- Infections
  - Sepsis
  - Pneumonia
  - Urinary tract infections
- Underlying diseases
  - Heart failure
  - Renal failure
  - Chronic lung disease
  - Strokes
  - ….

Approach to Advance Care Planning in Early Dementia

- Early diagnosis, or even before diagnosis
  - Lose some memory of recent events
  - Routine tasks become more difficult (cooking, driving)

- Advance Care Planning Steps:
  - Upstream conversations about Values and Wishes
  - Choosing your decision-maker; completing an MDPOA
  - Think about goals:
    - Live as long as possible
    - Treatment to prolong life but no resuscitation or intubation
    - Comfort-oriented care only

What is the ability to make a decision?

- Able to communicate
- Understand care choices
- Share the consequences of those choices
- Explain why you are making the choice you are making

- *Not all-or-nothing*
- *Varies over time*
- *Not the same as legal "competence"*

Approach to Advance Care Planning as Dementia Progresses:

- Middle Dementia or Moderate Dementia
  - Think about small parts of ACP at a time
  - Have family conversations
    - Reflect on prior discussions of values
    - Support the agent

  - Again reflect on the person's overall goals for life
  - Recognize that the agent will have a larger role in decision making

Approach to Advance Care Planning in Advanced Dementia:

- Late-stage dementia
  - How did she live her life?
  - What was important to her?
  - How did she react to other deaths?
  - What would she say if she were sitting next to us now?

Is Medical Aid-In-Dying an Option in Dementia?

No, not legal in dementia.

Patients Must:

- Be 18 years or older
- Demonstrate residence in Colorado
- Be capable of making and communicating their own health care decisions
- Have a terminal diagnosis; prognosis six months or less

A Question for Discussion:

- Your doctor wants to know…..
- ***What do I need to know about you as a person to give you the best care possible?***

Breaking the Ice or Next Steps

HOW DO YOU TALK ABOUT THIS?

- We often don't talk about plans for dying due to:
  - not understanding
  - not knowing wishes or situation
  - being uncomfortable with topic
  - wishing to protect others from uncomfortable situations.

Thoughts on Starting Conversations

- Talk Early – It's NEVER Too Soon!
  - Encourage everybody you care for as a professional
  - Fold in all "interested persons"
  - Pivot off of news, personal experiences

Over half of older adults will not be able to participate in healthcare decisions near the end of our lives!

Navigating Family Conflicts

- Prevention:
  - Conversations help avoid confusion/ guilt/ uncertainty
    - Keep loved one at center of conversations.
    - Be open / communicate
    - Have loved one pick MDPOA
- Out of town family
- Conflicting goals or beliefs of family members
  - How to come to resolution or a way forward?
- [Do you want an autopsy, examination of brain.]

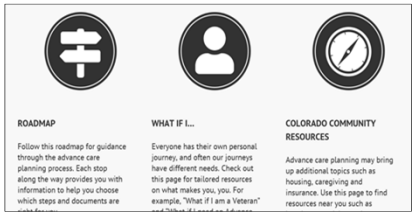
CONCLUSIONS

- Early conversations about values and wishes are critical.
- Dementia doesn't automatically rob a person of their ability to make or give input into decisions.
- Discerning values after the person loses capacity can be difficult, but can also represent a time when loved ones come together.
- It is very important to recognize overarching "goals and values" to make intervention decisions, since the benefit vs. burden balance changes.

Colorado Care Planning

COLORADO CARE PLANNING

Website to help Coloradans find information for future medical planning, including choosing a medical decision maker.



https://coloradocareplanning.org/

Handouts & Websites

- Colorado specific: www.ColoradoCarePlanning.org
- Conversation Project:

  www.theconversationprojectinboulder.org
- Dementia Directive: www.dementia-directive.org
- POLST information: www.POLST.org