Ethics of Self-Determination: Empowering Older Adults to Make Their Own Life Decisions

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It can start with a phone call like this...
Advanced Care Planning
Health Care Power of Attorney

- Appoint someone to be your decision maker
Living Will

Details the care you want
When do your directives start?

- When you lack capacity, and
- You can’t communicate your wishes
When do the directives end?

- When you revoke them
- When a court invalidates them
- When a court revokes your agent’s authority
- When you get a divorce
- After your death
Having that critical conversation

The notions of autonomy and self-direction do not only apply when people are healthy
Having that critical conversation

Too often, people are excluded from medical decision-making because they are presumed to be incompetent and/or not capable by the sheer virtue of their label as an older adult...particularly if they have had any cognitive issues or events.
Having that critical conversation

Trying to gather information and plan at the eleventh hour when a critical decision is staring us in the face makes no sense, is immensely difficult, is fraught with emotion that often leads to poor judgment, and is a poor response on our part as a system.
Medical Goals and Family Decisions

3 Goals of Medical Treatment

- Cure
- Stabilization of functioning
- Preparation for a comfortable and dignified death

Family Decisions

- CPR
- Artificial hydration/nutrition
- Hospitalization
- Palliative or comfort care only
Pearl’s Surgery
Too often people are presumed to be incompetent and/or not capable because they have the label of some kind of cognitive or intellectual disability
Self-direction and autonomy do not stop as one gets older and/or develops a critical, chronic, or terminal illness.
Six years later...
What Could Have Happened?

- We could have gone through the “emergency Healthcare Power of Attorney” process again.
- We could have gone to court and request to have a Guardian appointed immediately.
- We could have looked to “the system” for a decision.
The dreaded phone call...
Issue 3

Eleventh-hour planning is not planning; it is an ineffectual response to our lack of process for thinking ahead.
Need for Advanced Directive Planning Training

Statistically, it is estimated that only 18% to 36% of Americans have an Advance Directive
Which brings us to tools that can assist in communicating...

Person Centered Profiles
Relationship Maps
What People Like and Admire about Ruth

- Such a “grandmother”
- A true lady
- Has the gift of gab ~ can hold a conversation with anyone!
- Always dressed so nice ~ everything always matches, right down to socks and earrings
- Very liberal thinker for her age

What is Important to Ruth

- Living with granddaughter and grandson-in-law
- Being warm and feeling safe with caregivers
- Having “a little pour” before bed (rum and tea)
- Being a part of whatever is going on at home ~ being in the middle of it!
- Sweets during the day!

Supports Ruth Needs to be Happy, Healthy and Safe

- Needs people to ask frequently if she is warm enough and help her put on sweater/sweatshirt if she is not (she’ll be cold when you’re not)
- Must have assistance with her medications ~ knows them by color but you need to dole them out and keep track of times
- Needs assistance with bathing and dressing ~ will tell you what clothes she wants to wear for the day/event
- When bathing, no water on face ~ she will wash with cloth
- Must talk with daughter 2-3 times a week on the phone ~ will need you to dial for her
- Must see her doctor right away if she has cough, fever or is “off balance” ~ indications of systemic infection that will grow quickly!

Supports, continued

- Must feel safe with her caregivers
- Must always have her wheelchair with her in case she gets tired
- Someone to sit with her during thunder storms
Three ways to have a conversation

Linear:

Branching:

Meandering:
A few tips for getting the best information and understanding motivations:

- Make it personal
- Make it empowering
- Make sure it comes from a trusted source
- Make it self-directed
- Make it solution-oriented
What about people with cognitive decline?

Do you think someone with cognitive decline should be able to make healthcare decisions?

Discuss why or why not with a partner.
Guidelines for Decision-Making Capacity:

- Understanding of right to choice
- Understanding of being asked to make a choice
- Can apply personal values
- Can offer a justification for the decision
- Makes the same decision over a period of time
Communication Challenges

- Remember the potential difficulties with cognition and interaction
  - Paying attention, remembering
  - Logical thinking and planning
  - Following the flow of a conversation and responding accordingly
  - Understanding social cues and norms
Adapting Professional Communication

- Do not use jargon.
- Express one thought or idea at a time.
- Expect missed cues; repeat information as needed, ask questions in different ways.
- Use reminders creatively.
- Work to maintain trust and a positive alliance.
For more information, contact:

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