





Take Time To Listen...

Those with Alzheimer's  
Disease

by  
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# Begin to listen early

- As soon as the diagnosis has occurred

# Maximize the Patient's Involvement

- Opportunity to consider options
- Allow for choices, both great and small
- Participate in shaping care plan



Advance care planning is  
an essential part of good  
care for those diagnosed  
with Alzheimer's Disease

- Honoring a legacy
- Keeping one's memory alive
- Incorporating spiritual and other values

# Advance care planning should accommodate for:

- A lengthy progressive illness
- Changing roles and family situations
- A slow decline in capabilities
- A sudden or a lingering death

# The Hardest Part

- Raising the subject in the first place



# A Difficult Discussion

- The information is difficult to convey
- The emotions triggered by impending prolonged incapacity and death are often intense and unpredictable

# Must meet individual intake style and need

- Denial
- Curiosity
- Acceptance
- Oral
- Written



Listen

- To the Words
- To the Tone
- To the Cadence
- To the Volume

Watch

- The Face
- The Hands
- The Body Language
- The Care Partner's Reactions

# Typical Fears

- How long do I have?
- How sick will I be?
- What will others think?
- Will my family be embarrassed of me?

- What will happen to my family?
- What will happen to my future?
- Who will take care of me?
- Will I be able to stay in my own home?
- How will I pay for my care?

- Will I be a burden to my family?
- Should I take my own life **NOW** and avoid it all?

# Understand the Context

- Do not assume anything, but
- Be prepared to listen with your heart
- Document the words

# Some suggestions to initiate discussion

- What concerns you most about your diagnosis?
- What does this diagnosis mean to you?
- How is your treatment going so far?
- What is the best/worse thing that might happen as a result of your diagnosis?

- What are your hopes/fears about the future?
- How is this diagnosis impacting your quality of life?
- If you had a short time before you became incapacitated, how would you want to spend the remaining time?

- What is the best way to ensure you have support?
- What are some of the most helpful things others can do for you right now?
- Do you like to make your own decisions or get input from others?

- The answers to these kinds of questions can assist you in charting the course for the length, intensity and depth of the ongoing discussion
- The discussion will need to be titrated based on level of capacity

# Discussion about Agents

- Who would you trust the most to make decisions for you if you could not decide for yourself?
- If that person were not available, whom would you choose?
- How much leeway would you want your agent to have?

- Do you want your agent to adhere strictly to your advance directives or do you prefer to allow for flexibility?
- How would you want your agent to make a decision if it involved a medical treatment or situation you had not previously discussed with your agent?
- How would you feel if your agent made the wrong decision about a medical treatment?

# Of Special Importance

- More than most illnesses, Alzheimer's Disease involves more than the individual so the care plan should also foster caregiver endurance, reliability and loyalty



# Common Decisions in the Course of Alzheimer's Disease

- What would you want your agent to do if you were so sick you couldn't tell your doctor/family what you wanted and decisions had to be made about...

- Participating in a clinical trial or other type of research
- Allowing you to drive
- Needing someone to help you at home
- Managing your pain, agitation and behavioral issues, depression, etc.
- Needing to place you in assisted living
- Needing to place you in a nursing home

- CPR
- Treating you for acute illness and infection
- Feeding you if you no longer could eat or didn't want to eat
- Hydrating you
- Hospitalizing you if you were near death

# More General Questions

- What would you want the goals of your treatment to be?
- What makes life worth living for you?
- Can you imagine any situation in which life would not be worth living?

- What if the doctor wasn't sure if a treatment would work, what would you want your agent to do?
- How do you think you would feel if your agent made the wrong decision?

# Empower a Personal Legacy

- Keep a journal
- Design a photo album/collage
- Research a family tree
- Plant a garden
- Engage in a life review

# The Goal

- To provide the dignity of shaping decisions about the future NOW while participation is still possible
- To provide the confidence that a rich legacy of thought and deed is possible

# "Anthem"

Ring the bells that still can  
ring. Forget your perfect  
offering. There's a crack, a  
crack in everything. That's  
how the light gets in.

-Leonard Cohen

