# Advance Care Planning:

## Considerations for Dementia

May 18, 2020
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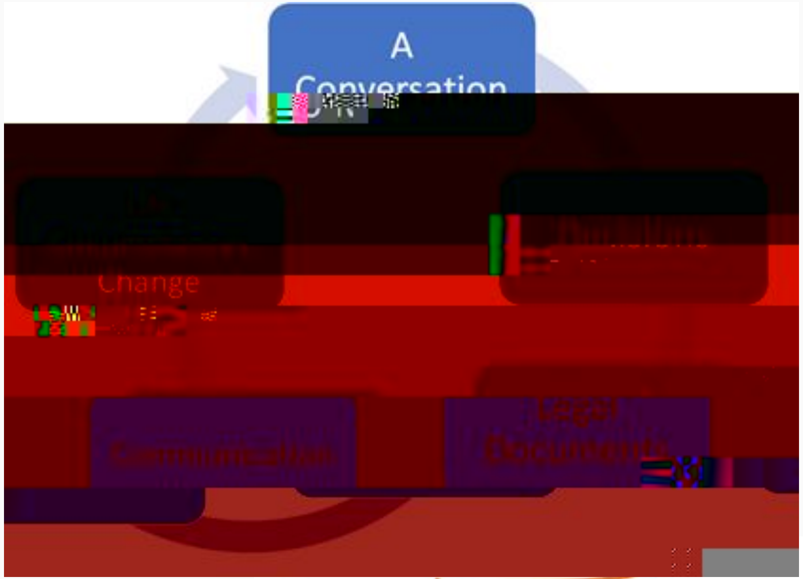
"I have an advance directive, not because I have a serious illness, but because I have a family."

Gateway

the conversation project

# Gjwf!Tufqt!Up!Bewbodf!Dbsf!Qmboojoh

1. A Conversation
2. Decisions
3. Legal documentation
    - -Advance Directive (AD)
    - -Durable Power of Attorney for Health Care/Agent
    - -DNR/DNAR/POLST/MOLST/TPOPP
4. Communication
5. Life circumstances change



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# Efǹojoh!Pvs!Ufsnt

**Advanced Care Planning (ACP)**: a process of reflection, discussion, and communication of treatment preferences in the event of future loss of decision-making capacity (DMC).

**Advance Directive (AD)**: an oral or written statement in which a person declares one's treatment preferences in the event he/she loses decision-making capacity (DMC).

**Difference**:

ACP is a process whereas ADs are documented preferences.

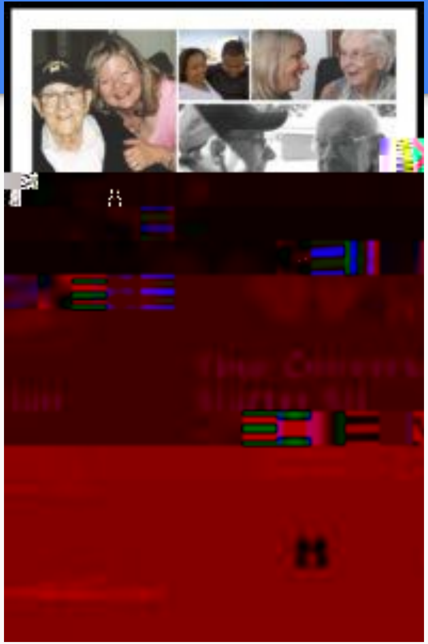
**Durable Power of Attorney for Health Care /Agent/Proxy:** a legal document that names someone to express your wishes and make health care decisions if you lose decision making capability.

# The Conversation Project Founder Ellen Goodman

# Uif!Dpowfstbujpo!Qspkfdu!Gps!Mpwfe!Poft!Xjui!Efnfoujb

- It’s not easy for anyone to begin the conversation
- The conversation is even more important if your loved one has dementia
- As dementia progresses it becomes more difficult to express wishes
- A person’s wishes will be a critical guide to help with many decisions
- What if your loved one insist that “there’s nothing wrong” with them
- What if they say they don't want to have the conversation

# Tufq!2!Hfu!Sfbez!



# I bwjoh!Ui f!Dpowfstbujpo!Mfut!Zpvs!Mpwfe!Pof!Lopx!Zpv!Xjmm!Cf!Uifsf!Gps!Uifn/

- Talking about care at the end-of-life isn’t an intrusion or unkind
- It may be a way to promise your loved one you will be there for them
- Listening, sharing their worries, promising you’ll be there voice if they can’t
- Assuring them you will respect them and their wishes

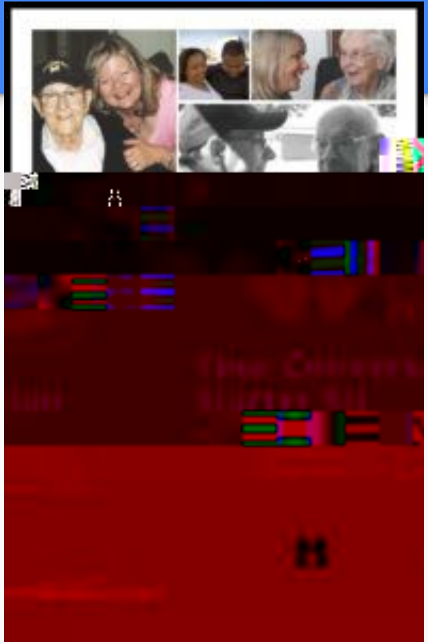
# Pwfsdpnjoh!Sftjtubodf

- Be gentle
- Make the conversation for everyone - not just for them

# Sfnfncfs

- Don't dismiss anxiety about memory loss
- Establish yourself as someone they can really talk to,"Tell me more"
- There are "moments" when a loved one can think more clearly

# Tufq!3!Hfu!Tfu



Gateway

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# Start By Asking Questions

- What’s most important to you as you think about how you want to live at the end of your life?

# When The Illness Is So Advanced Your Loved One Is Not Able To Express Their Wishes

- It’s up to you and your family to do your best to understand their wishes
- Think about what your loved one would want
- It is not about your opinion versus your siblings’ opinion

# I bwjoh!Ui f!Dpowfstbujpo!Vqpo!Ejbhoptjt

- Early in the disease process, the Starter Kit may work
- Appointment of a power of attorney health care/agent/proxy and documentation is highly recommended.
- Seek more information about what to expect in later stages

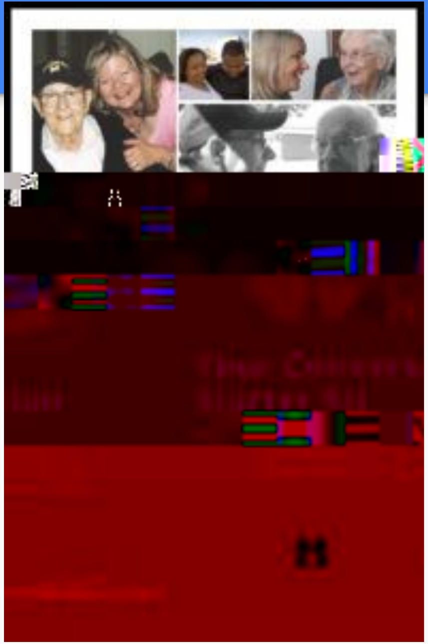
# Ibwjoh!Uif!Dpowfstbujpo!Jo!Uif!Nje!Tubhf

- Try reminiscing to determine wishes
- Gain support from the rest of the family
- If a proxy hasn’t been designated, families should discuss who will make decisions in the future as they are needed

# Ibwjoh!Uif!Dpowfstbujpo!Jo!Uif!Mbufs!Tubhft

- Use the Starter Kit as a guide to come together to reach consensus
- Reflect on how they lived their life
- Remembering family events and the values and opinions the loved one expressed in those situations can help anchor such discussions
- Do this proactively, before any actual treatment decisions need to be made

# Tufq!4!Hp



# Dpnnvojdbujoh!Xibu!Nbuufst!Nptu

- You’re in a good position to make sure the team caring for your loved one knows what’s most important to them
- You’re in a good position to make sure your loved one’s wishes are respected
- End-of-life issues for people with dementia should not be underestimated
- Written statements will help communicate wishes

# Advanced Dementia Is A Terminal Illness

- Patients commonly die from complications caused by this disease.
- Some people have a hard time understanding that dementia is a terminal illness.

# Keep Going

**Once you** understand that “having the conversation” with your loved one isn’t harmful-far from it.  It could be the most important gift you could share with your loved one-and your loved one could share with you.

**Then**, you actually “had the conversation”-the first of many. You listened carefully to whatever your loved one wanted to talk about-and you let the conversation go where they wanted to take it. If your loved one is no longer capable of having the conversation, you gathered family members together and “brought your loved one into the room”-you did your best to answer the questions as your loved one would.

**And**, you embraced your role as your loved one’s advocate. You made sure your loved one’s care team knew what mattered most to your loved one and your family-and did your best to make sure your loved one‘s wishes were respected.

**Step 4 is a hard one: Keep going. It means being there for your loved one no matter what…even as they become sicker and face death.**

# It Helps When Everyone Knows

- Dementia is a brain disease
- Treat it like a disease
- Don’t treat it like a stigma
- When families are ashamed about what’s happening and embarrassed, they don’t get help

# Tbnqmf!Mfuufs!Gspn!B!Gsjfoe

**Special directives in the event of dementia or other degenerative brain and/or mental conditions.**

I know that dementia is prevalent in my family. I watched my own mother; both grandfathers and two aunts go through a protracted period of cognitive failure. I personally witnessed the mental anguish that came from the fear of not being able to make sound decisions, the frustration of not being able to deal with the world they lived in and the breakdown of lifelong loving relationships as memory and reason slipped away. I also saw the guilt they felt for the trauma they were putting their loved ones through.  This is a process that I want to avoid if possible, or at least to minimize.

I wish to provide specific guidance in the event I am diagnosed with Alzheimer’s, other dementia and/or a degenerative mental condition for which there is no reasonable expectation that my mental capacities will improve, and I am no longer able to make informed decisions about my care....

# Being Prepared In The Time of Covid-19

- Pick your person to be your health care decision maker (Durable Power of Attorney for Health Care/Agent)
- Talk about what matters most to you
- Think about what you would want if you became seriously ill with COVID-19
    - If you became very sick, would you prefer to stay where you live or go to the hospital
    - If you chose to go to the hospital, would you want to receive intensive care in the hospital
    - When you speak with your healthcare provider, ask if completing a POLST/MOLST form would be appropriate so others know what treatments to use or avoid

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