

Advance Care Planning: Considerations for Dementia

May 18, 2020

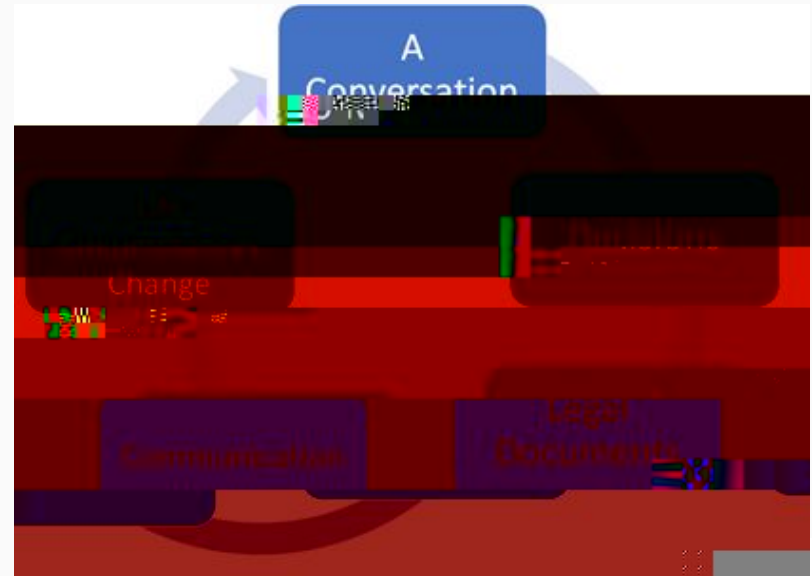
Joan Bretthauer and Kim Gladstone



"I have an advanced
directive, not because I
have a serious illness,
but because
I have a family."

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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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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



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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



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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



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Be gentle

Make the conversation for everyone - not just for them



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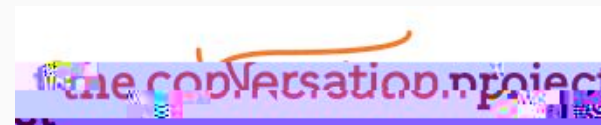
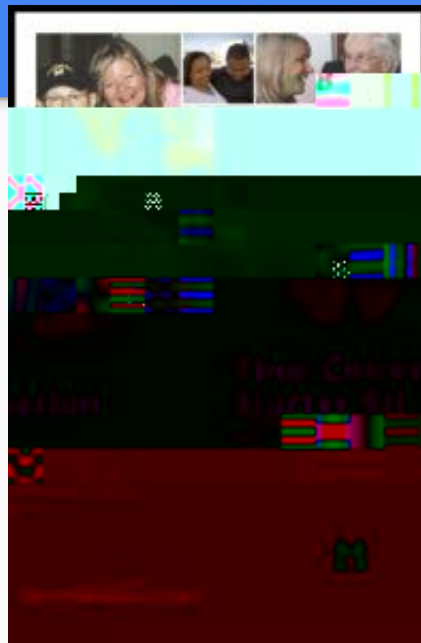
Don't dismiss anxiety about memory loss

Establish yourself as someone they can really talk to, "Tell me more"

There are "moments" when a loved one can think more clearly



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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



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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



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Try reminiscing to determine wishes

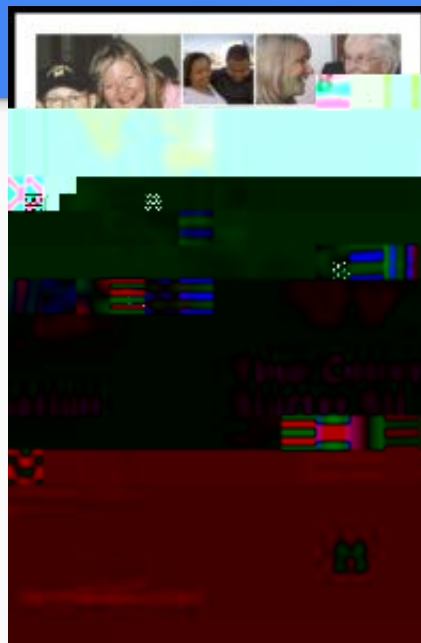
Gain support from the rest of the family

If a proxy hasn't been designated, families should discuss who will make decisions in the future as they are needed





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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



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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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