What If I Had Dementia?

Planning for the future

Alzheimer's disease is one of the most common problems people face in their 70's and 80's. One of the most important things you can do is tell people who would be taking care of you what you would want for medical care if you were to develop worsening dementia.

What is dementia?

Over 5-20 years, people with Alzheimer's (and other forms of dementia) lose their memory and eventually lose the ability to understand what's going on around them. In late stages, people with dementia no longer recognize people they know, and need help from others with their own basic body functions. At times they might still enjoy some experiences. At other times they can become quite agitated.

There is no known cure for dementia. Gradually people lose the ability to speak, eat, and walk. Eventually people die from dementia, often from dementia-related pneumonia. This process takes anywhere from 5 years to 20 years. The ***average*** time it takes dementia to progress to a severe form (of not being able to dress or feed oneself) is about 8 years.

One of the most important questions to consider is:

What kind of medical care would you want if you were to develop worsening dementia?

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Why it's important to express your wishes

People with advancing dementia lose the ability to make decisions for themselves. Their families need to make medical decisions for them.

Giving family members guidance about what kind of care you'd want if you were to develop worsening dementia can ease the burden of their decision making and make you feel more secure that you'll receive the care that you would want.

Your guidance today will help the people taking care of you in the future.

What kinds of guidance can you give?

As dementia gets worse, many medical tests and procedures become harder for people to go through, with more risk of side effects and bad reactions. As people lose the ability to understand what is happening they can become fearful and agitated by unfamiliar surroundings.

As their mind fades away, many people feel that life loses much of its meaning, especially when they're no longer able to understand what is happening around them. At points along the way, many people might not want medical care which would keep them alive longer. Instead they might want only medical care that would help keep them comfortable.

On the following pages are descriptions of the stages of dementia. By filling out this form you can give guidance to your loved ones. Read the description of each stage, then mark the box that reflects what goals of medical care you would want for yourself if you were at that stage of dementia.

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Stage 1 -- Mild dementia

People may often lose ability to remember recent events in their lives.

Routine tasks become difficult (such as cooking.) Some tasks can become more dangerous (such as driving.)

If you were to be at this stage of dementia what level of medical care would you want for yourself?

Select one of the 4 main goals of care listed below to express your wishes. Choose the goal of care that describes what you would want at this stage.

If I had <u>mild</u> dementia then I would want the goal for my care to be:

☐ **To live for as long as I could**. I would want full efforts to prolong my life, including efforts to restart my heart if it stops beating.

☐ **To receive treatments to prolong my life, but if my heart stops beating or I can't breathe on my own then do <u>not</u> shock my heart to restart it (DNR) and do <u>not</u> place me on a breathing machine**. Instead, if either of these happens, allow me to die peacefully. Reason why: if I took such a sudden turn for the worse then my dementia would likely be worse if I survived, and this would not be an acceptable quality of life for me.

☐ **To only receive care in the place where I am living. I would not want to go to the hospital even if I were very ill,** and I would not want to be resuscitated (DNR)**.** If a treatment, such as antibiotics, might keep me alive longer and could be given in the place where I was living, then I <u>would</u> want such care. But if I continued to get worse, I would <u>not</u> want to go to an emergency room or a hospital. Instead, I would want to be allowed to die peacefully. Reason why: I would not want the possible risks and trauma which can come from being in the hospital.

☐ **To receive comfort-oriented care only, focused on relieving my suffering such as pain, anxiety, or breathlessness**. I would <u>not</u> want any care that would keep me alive longer.

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Stage 2 -- Moderate dementia

People lose the ability to have conversations, and communication becomes very limited.

People lose the ability to understand what is going on around them.

People require daily full-time assistance with dressing and sometimes toileting.

If you were at this stage of dementia what level of medical care would you want?

Select one of the 4 main goals of care listed below to express your wishes. Choose the goal of care that describes what you would want at this stage.

If I had <u>moderate</u> dementia then I would want the goal for my care to be:

☐ **To live for as long as I could**. I would want full efforts to prolong my life, including efforts to restart my heart if it stops beating.

☐ **To receive treatments to prolong my life, but if my heart stops beating or I can't breathe on my own then do <u>not</u> shock my heart to restart it (DNR) and do <u>not</u> place me on a breathing machine**. Instead, if either of these happens, allow me to die peacefully. Reason why: if I took such a sudden turn for the worse then my dementia would likely be worse if I survived, and this would not be an acceptable quality of life for me.

☐ **To only receive care in the place where I am living. I would not want to go to the hospital even if I were very ill,** and I would not want to be resuscitated (DNR)**.** If a treatment, such as antibiotics, might keep me alive longer and could be given in the place where I was living, then I <u>would</u> want such care. But if I continued to get worse, I would <u>not</u> want to go to an emergency room or a hospital. Instead, I would want to be allowed to die peacefully. Reason why: I would not want the possible risks and trauma which can come from being in the hospital.

☐ **To receive comfort-oriented care only, focused on relieving my suffering such as pain, anxiety, or breathlessness.** I would <u>not</u> want any care that would keep me alive longer.

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Stage 3 -- Severe dementia

People are no longer able to recognize loved ones and family members. People may be awake through the night, disruptive, and yelling.

Some may be calm or serene most or all of the time, but many become angry and agitated at times, and sometimes even violent toward people they love.

People need round-the-clock help with all daily activities, including bathing and assistance with all basic body functions.

If I had <u>severe</u> dementia then I would want the goal for my care to be:

☐ **To live for as long as I could**. I would want full efforts to prolong my life, including efforts to restart my heart if it stops beating.

☐ **To receive treatments to prolong my life, but if my heart stops beating or I can't breathe on my own then do <u>not</u> shock my heart to restart it (DNR) and do <u>not</u> place me on a breathing machine**. Instead, if either of these happens, allow me to die peacefully. Reason why: if I took such a sudden turn for the worse then my dementia would likely be worse if I survived, and this would not be an acceptable quality of life for me.

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_____ _____ _____

Signature Date Print Name + Date of Birth

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