

# 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 medical care you think you would want if you were to develop worsening dementia.

**What is dementia?** Over many years, people with Alzheimer's (and other forms of dementia) lose the ability to understand what is going on around them. In later stages, people with dementia no longer recognize people they know. They need help from others with their own basic body functions. At times they might still enjoy some experiences. At other times they can become angry and confused.

There is no 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 can take anywhere from 5 years to 20 years.

**One of the most important questions to consider is:** what kind of medical care do you think you would want if you were to develop worsening dementia?

**Why it is 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 type of care you would want can help ease the burden of their decision making and help you feel more secure that you will receive the care that you would want.

**Some people may not want to give this type of guidance,** but would rather trust their families to make decisions. For those people, this Directive may not be helpful. However, many people do want to provide some guidance for their family, even if it is hard to know exactly what your future situation might be.

**What kinds of guidance can you give?** You can say, ahead of time, what you would want the focus of your medical care to be. At what point would you still want everything done to keep you alive longer? At what point might you want only hospice-type care focused mainly on treating your symptoms and keeping you comfortable?

# INSTRUCTIONS

**1. On the following pages are descriptions of the stages of dementia.** Read the description of each stage. Then mark one box under each stage that most closely fits what you would want the goals of your care to be if you had that stage of dementia.

**2. Once you have filled out the Directive, the most important thing you can do is discuss these wishes with your closest family members.** This is the most important thing you can do. In the future, if you have dementia, your closest family members will be the ones making medical decisions for you. Let them know what your wishes are, so if needed they will be able to honor them.

**3. Make sure you give each of your closest family members a copy of your Dementia Directive.** That way they will have it to refer back to, if needed, to help them better honor your wishes.

**4. Finally, mail a copy of your Dementia Directive to your health care provider,** so that it can be a part of your medical record.

Fill in the address of your health provider, to mail them a copy:

Name of Health Provider

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← Address

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## Stage 1 -- Mild dementia

With mild dementia, people may often lose the ability to remember what just happened to them. 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 medical care would you want?

Select **one** of the 3 main goals of care listed below to express your wishes. Choose the goal of care that best describes what you would want if you had Mild Dementia.

If I have **mild dementia** then I would want the main goal for my care to be:

- To live for as long as I can.** 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 I would **not** want my heart shocked to restart it and I would **not** want to be put on a breathing machine. **(DNR and Do Not Intubate)** Instead, if my heart stops or I can't breathe on my own, allow me to die peacefully.

**Why you might choose this goal:** If your mind were already not working well due to dementia, and something suddenly happened which stopped your heart or made you unable to breathe on your own, the chances are high that even if you survived the ICU, your brain would be more damaged. So some might say, "If I would likely be worse off if I survived, then I would prefer to die peacefully."

- To receive comfort-focused care only.** (Including DNR and Do Not Intubate) I would only want medical care to relieve symptoms such as pain, anxiety, or breathlessness. I would not want care to keep me alive longer. It would be important to me to avoid sending me to a hospital or ER, unless that was the only way to keep me more comfortable, because trips to the hospital when someone has dementia can be quite traumatic.

## Stage 2 -- Moderate dementia

In moderate dementia, 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 often toileting. They can sometimes become quite confused and agitated and paranoid. Some people appear to be content much of the time.

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

Select **one** of the 3 main goals of care listed below to express your wishes. Choose the goal of care that best describes what you would want if you had Moderate Dementia.

If I have **moderate dementia** then I would want the main goal for my care to be:

- To live for as long as I can.** 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 I would **not** want my heart shocked to restart it and I would **not** want to be put on a breathing machine. **(DNR and Do Not Intubate)** Instead, if my heart stops or I can't breathe on my own, allow me to die peacefully.

**Why you might choose this goal:** If your mind were already not working well due to dementia, and something suddenly happened which stopped your heart or made you unable to breath on your own, the chances are high that even if you survived the ICU, your brain would be more damaged. So some might say, "If I would likely be worse off if I survived, then I would prefer to die peacefully."

- To receive comfort-focused care only.** (Including DNR and Do Not Intubate) I would only want medical care to relieve symptoms such as pain, anxiety, or breathlessness. I would not want care to keep me alive longer. It would be important to me to avoid sending me to a hospital or ER, unless that was the only way to keep me more comfortable, because trips to the hospital when someone has dementia can be quite traumatic.

## Stage 3 -- Severe dementia

In severe dementia, people are no longer able to recognize loved ones and family members. Some people with severe dementia may be calm and serene much of the time, but many go through periods of agitation. They can be awake through the night. They can be angry, disruptive, and yelling. People need 24-hour help with all daily activities, including bathing and assistance with all basic body functions.

Select one of the 3 main goals of care below you'd want if you had Severe Dementia.

If I have severe dementia then I would want the main goal for my care to be:

- To live for as long as I can.** 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 I would not want my heart shocked to restart it and I would not want to be put on a breathing machine. **(DNR and Do Not Intubate)** Instead, if my heart stops or I can't breathe on my own, allow me to die peacefully.

**Why you might choose this goal:** If your mind were already not working well due to dementia, and something suddenly happened which stopped your heart or made you unable to breath on your own, the chances are high that even if you survived the ICU, your brain would be more damaged. So some might say, "If I would likely be worse off if I survived, then I would prefer to die peacefully."

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Signature

Date

Print Name + Date of Birth

## **Dementia Directive -- Frequently Asked Questions**

### **Why consider a Dementia Directive?**

Many people have clear ideas about the medical care they would want if they were to develop dementia. But standard advance directives (also known as living wills) do not cover dementia. Dementia is the most common reason people lose the ability to guide their own care, so expressing and documenting these wishes is very important.

A Dementia Directive is a simple way to communicate your wishes if you were to develop dementia. It is a way to be more sure that if you develop dementia that you'll get the type of medical care you would want.

Families often face difficult medical decisions if their loved one has dementia. Having a Dementia Directive to refer to can help them feel clearer that the decisions they make reflect what their loved one would have wanted.

### **When is the best time to fill out a Dementia Directive?**

Ideally, everyone should be given the chance to fill out a Dementia Directive before they develop dementia. It is especially recommended after age 65. It can be difficult for someone to complete a Dementia Directive once they are already experiencing signs of cognitive impairment.

### **How does a Dementia Directive relate to other advance directives?**

A Dementia Directive can be used as a stand-alone document to communicate one's wishes. It can also be included as a supplement, attached to a standard advance directive form.

### **Is a Dementia Directive legally binding?**

The Dementia Directive is a form of written communication to help guide those who might need to make medical decisions on your behalf in the future. As such, it is a way to record your wishes. The guidance it provides is not legally binding, however. If someone has lost the ability to make medical decisions, family members will still need to address clinical situations as they arise and decide how a dementia directive might provide guidance in a given situation. That is why it is important to talk to those closest to you (who might later help make decisions about your care) about your wishes, so that they understand as clearly as possible what your wishes would be.

### **Should I get the Dementia Directive notarized or witnessed?**

If you are worried someone might challenge your dementia directive in the future, then it is reasonable to sign it in front of a notary or in front of witnesses. These signatures can be added as an additional page if desired. But having it witnessed is not required.