Supplemental Module to *Intellectual Disability and Dementia: A Caregiver's Resource Guide for Rhode Islanders*

TALKING ABOUT DEMENTIA

A Guide for Families and Caregivers and Adults with Intellectual Disability

DRAFT v-4b

Seven Hills Foundation

The Arc

ntg National Task Group on Intellectual Disabilities and Dementia Practices

Talking about dementia

Dementia is hard to talk about. It is scary to think about what will happen as dementia progresses. This fear makes it hard to talk about ~~it~~ with other people, especially adults with intellectual disability (which includes those adults with Down syndrome).

Often, we avoid hard conversations with our loved ones. We do this because the information seems scary, we don't know if they will understand, or because we don't know how to start the conversation. This discussion is most effective "in the moment" of a related experience by someone close to them (grandparent, others) or in a personal situation. The more real we can make the explanation the better for everyone to relate to and understand.

Our goal of this booklet is to share information and resources to help you have this conversation about dementia. There is also a section for adults with intellectual disability which explains dementia. It provides a guide on helping friends who may have dementia. You can use this section with adults when you talk about dementia. Also included is a sample easy-read and understand advance directive for use by an adult with an intellectual disability. It provides instructions for recording their health care wishes for when advanced dementia is present.

PART 1: WHAT HAPPENS WHEN SOMEONE HAS DEMENTIA?

Dementia is a group of symptoms that occur when a person has a disease or condition that affects the brain. It changes the way the person thinks, feels, and acts. Some causes of dementia are treatable and others are not treatable. Many adults with Down syndrome have a high risk for dementia.

Want to learn more?

The more you know about dementia, the more you can help your loved one understand it. To prepare, you may want to read the section in the 7HRI Caregivers' Guide on 'Learning About Dementia'. Then, you may want to watch these two short videos that are available via YouTube. One explains Alzheimer's disease, and the other explains the difference between Alzheimer's disease and dementia:

- View "*What is Alzheimer's Disease?*" at https://www.youtube.com/watch?v=9Wv9jrk-gXc (runs *3:15 minutes*)

- View "*What is the Difference Between and Alzheimer's Disease and Dementia?*" at https://www.youtube.com/watch?v=RT907zjpZUM (runs *2:45 minutes*)

PART 2: HOW TO TALK ABOUT DEMENTIA WITH ADULTS WITH INTELLECTUAL DISABILITY

Many of us struggle with how much to tell our loved one about the diagnosis of dementia. We also struggle with when and how to start talking about dementia.

Below are some talking points and ways to have this conversation. Remember there is no set way to have this conversation. Where you begin depends on how well your loved one understands what you are saying. Adults who have difficulty understanding the meaning of words, often understand best by seeing and doing.

Consider When and How to Present Information About Dementia

Think about what you want to tell your loved one about dementia. Some people will have difficulty understanding the typical explanation about Alzheimer's disease or dementia. For them, understanding the disease might not be as important as recognizing or experiencing the symptoms. This you will have to decide. One way does not meet everyone's understanding.

Making that decision to have this conversion may be hard. You may wonder, 'what should I do if my family member receives a diagnosis of Alzheimer's disease and I do not want to tell him or her?' Does my family member have a right to know his or her diagnosis? You may be concerned about how discussing this topic may impact your loved one and your family. If you decide to go ahead to discuss it, it may be useful to think about how you feel about these questions and how you might handle them.

- How do I share the diagnosis?
- How can I help my loved one understand their new diagnosis?
- How can I validate the person's frustrations and worries while supporting and encouraging them?
- How do I talk to their partners or others about the diagnosis?
- What can I do to help the person stay independent as long as possible?
- What is my loved one's life story? How does their life story fit into their ability to maintain relationships and access long-term care?

Some questions to think about as you have this discussion.

- Has the person heard about Alzheimer's disease or dementia?
- What does he or she know about it? What do they see happening?
- Does the person know someone who has it? (*Use stories about these people to help your discussion*.)
- What does he or she think about what's happening to the person that they know?
- What does he or she think is going on with his or her own life?
- Does the person ask questions as to why he or she is feeling or doing things differently?

Try asking these questions:

- "Do you ever feel this way or do these things?"
- "Do you have any questions as to why you are feeling or doing things differently?"

Who Should Be Part of the Conversation?

- Would it be best to first to talk with your loved one alone or should others also be part of the first conversation?
- Think about who should be part of the conversation. Consider inviting people your loved one likes, respects, and with whom they feel comfortable. Ask them who they want to be there when you talk about the changes in their life.
- Who could help you start the conversation or join the discussion at another time? Siblings are very powerful allies. Should they have a role when discussing these changes or feelings? What about a friend who has gone through this within his or her family?

When is a Good Time to Talk?

Try to find a time to talk when your loved one is most open to talking (for example, when watching a show or a movie on TV) or when a behavior or life-change occurs because of dementia (for example, someone is having trouble with their memory or their daily habits change).

It is best to approach a person before symptoms of the disease are apparent or before the disease has progressed. Talking early on is important so that people can deal with changes and grief related to the diagnosis, develop plans for

the future, and adapt to the situation. But for many adults with intellectual disability this may not work. For some, 'thinking about how I will feel in the future or even the next day can be difficult'.

You may need to have more than one discussion about dementia and changes that happen. You may have one initial conversation and then need to have follow-up discussions when questions are asked or as changes occur. This disease is a progression, not an event. It evolves over time. You need to be aware that having this discussion cannot always be planned. The moment just happens and you need to be prepared to take advantage of it.

Before you begin, think about the words you want to use for this discussion. 'Dementia' may be too abstract and unfamiliar, but 'thinker problems' or 'forgetting problems' might be easier conversation starters.

Where Do I Feel Comfortable Bringing This Up?

Think about the places where this discussion might best happen. Starting the conversation while engaged in some activity can be helpful. However, when you want to focus on it, find a quiet place where you and your loved one can talk that is comfortable and there are no distractions. If possible, it is best to have this conversation in person and very near an incident that can be an example of what you want to talk about. If you live out of the area, start the conversation by phone or via Skype. Conversations do not have to be long, often brief 'in the moment' talks work best.

Breaking the Ice

Here are examples of things you can say to your loved one to get the conversation started:

- "I noticed that you are having some problems answering questions." "You seem to be more confused [or other feature]." "You seem to be having problems going up and down the steps."
- "Let's talk. Grampa has what we call dementia. I want to talk with you about what this is and how this will change things."
- "You seem to be worried about your friend who is having memory problems …"
- "I need to talk with you about something … do you have a few minutes for us to talk?"
- "When we visited the doctor, they asked you about your memory. They think you have something called dementia. I want us to talk more about what that is and some things we can do."

Describing Clearly What is Dementia

Do your best to describe what is dementia, how it changes thinking, memories, and decisions, and how a person's behavior changes. You may also want to talk about feeling 'confused' or 'forgetting' or afraid.

You may want to give some examples.

- You can say that some adults might need a reminder like "drink some water with your dinner" … because they often forget to drink liquids with their meals.

- You can say that some adults may need to be told, "it is time for your favorite TV show" … because you know they enjoy a particular TV program but have lost track of time.

- You can say that it is "time to get ready for bed, your pj's are on your bed" … because some adults have problems finding things they are familiar with and will get frustrated when they cannot find them.

We have some resources in Part 3 to help you do this.

Preparing for the Questions

Your loved one may be worried about what having dementia may mean. He or she may have some questions as to what will happen. It is good to have thought about these ahead of time and be prepared to address them. These questions may include:

- Will you still love me?
- Where will I live … can I stay here?
- What will happen to me?
- Can I still go to work?
- How long will I have dementia?
- Can I still see my friends?

Removing the Blame

Assure your loved one that dementia is not something he or she caused or made up. It is not something they can "catch" from another person or pass on to another person.

Also, let them know that – if they have dementia – it is okay to be frustrated or upset when they are confused or forgetful. If someone else has dementia, it is also okay to be frustrated or upset when that person is having a bad day or a hard time remembering.

Being Positive About the Future

Make sure that your loved one knows that people with dementia continue to enjoy their favorite activities, and they should be included and have fun. Assure them that you will be there for them.

Even though a person may get confused if things gets busy or noisy, people with dementia are still loved, helped, and included. This will be the same for your loved one.

Being Patient and Realistic

Your loved one may not be ready to discuss dementia when you first bring it up. It is important to be patient. Try talking another time.

Often the meaning of dementia is complex and difficult to understand. You may need to try to approach this conversation from a different perspective or using different words. Try to explain in a way that this will mean something to your loved one.

Understanding sometimes is best talked about as the behavior changes occur. Everyone understands and recognizes changes in their own way.

Taking a Break

Your conversation about dementia does not have to be long. At first, it can just cover the basics, maybe just introduce the words or explore the feelings.

You want to let the person know there is more to talk about and you can talk again. Also let them know that they can ask questions any time they want. Time will help. People eventually gain an understanding of difficult to talk about things. Sometimes our loved ones will understand more easily from getting less information than more. Try not to overwhelm them with too much information at one time.

Seeking Help from A Local Agency

Many adults live independently on their own. In such situations they might not have anyone to tell if they feel confused doing certain things. If your loved one is in this type of setting, and they are linked to a local disability services agency, they may have a "service plan" that guides the services and supports they receive.

If you have suspicions about their behavior, have a conversation with the agency worker about what you are sensing or seeing in your loved one. It may be that the agency staff are seeing the same things. Agree on who may have that conversation with your loved one.

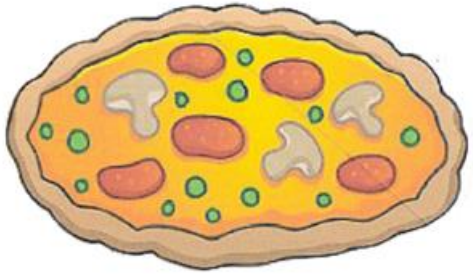
Get involved with your loved one's "service plan". Ask to attend meetings about the "service plan" and raise questions. Look for help with getting a diagnosis. Confirm how the agency will handle future changes caused to the dementia.

If your loved one is still living with you, contact a local disability agency and seek help with getting supports for your caregiving. They can also help you with having that conversation, as well as giving advice on how to answer many of the questions you or your loved one may have.

PART 3: EXERCISES TO EXPLAIN DEMENTIA TO PEOPLE WITH AN INTELLECTUAL DISABILITY

What is memory? How does our brain work?

Memory is a basic idea that we need to help people understand before explaining how dementia may affect a person's memory. Very simply, memory is remembering. You can use this exercise to help the person grasp the concept of memory. Once they understand, you can then explain how dementia affects memory.



You can show the person these two pictures – one of a pizza and one of a hamburger.

Ask, "*What are these*?" *Are one of these your favorite?*

If the person gives you an answer. Then, ask "*how do you know or why*?"

This could start a discussion of shape and taste, or maybe the person may only say, "*because it is*", or "*I don't know*"

Follow-up with a discussion of how they are similar or different or why do you like one better than the other. Pizza is usually round, but if it is square is it still a pizza? Pizza tastes better than hamburgers. Hamburger buns are round, does that make it the same as a pizza? What is different?

This second exercise helps with getting at how they recognize things … and how they use the information from memory

Show two other pictures, one of a shirt and one of a pair of pants. Or you can point to what they are wearing? Ask, "What are these?" Wait for the answers, and then ask, "How do you know?"

This will start a discussion similar to the one about the food items. After a bit, the person may say, "*I remember what they are…*" or a something similar. You can then say, "*Great, you are using your memory*!"

If they don't figure this out, you can say, "*When you were young you learned the names for these things. You remembered what they are called… this means you are using your memory*."

You can explain that memory helps us learn and remember all the things we know.

These exercises help explain what 'memory' is and can lead you into a discussion of how dementia affects memory.

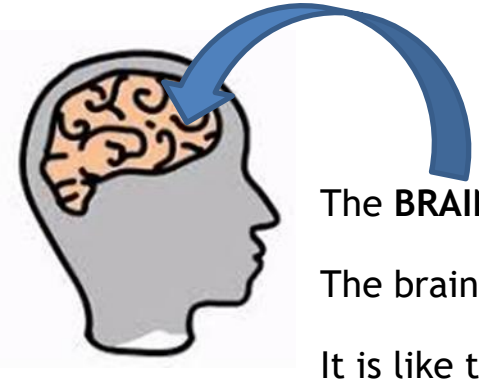
As one adult said, he felt his "*thinker was not working*," meaning his memory and ability to make decisions was affected.

Exercises such as this can help explain these ideas.

You will find page size images of these two exercise items at the back of this booklet.

PART 4: TOOLS FOR PEOPLE WITH AN INTELLECTUAL DISABILITY

What is Dementia?



The **BRAIN** is a part of your body that you cannot see and is inside your head.

The brain helps you think, feel, remember things, and tells your body what to do.

It is like the boss of your body.

Some people when they get older have an illness in their brain.

This illness is called dementia.

Dementia causes you to forget things and forget how to do things.

Dementia can also make you do things that you would not usually do.

This illness in the brain causes people to change. People with dementia may:

- feel confused
- forget things
- get lost
- get upset and don't know why
- do things differently
- have problems walking

Over time, dementia may cause other changes. A person may

- Feel different, get mad or sad about something that they did not before
- Forget words for things they know
- Have problems talking
- Get slow in doing things
- Have trouble dressing
- Want to sleep at different times
- Have problems walking
- Forget the faces of people they know

What Can I Do to Help A Friend or Parent with Dementia?

Sometimes you may not know what to do to help a person with dementia. Here are some things you can do to help:

- Be nice and smile at them
- Keep your voice calm and soft when you are speaking
- Be nice to them when they are confused or talk funny
- Be patient if they have trouble remembering things
- Patiently answer their question, even though they just asked it a few minutes ago
- Talk to them about what is going on around them
- Help them remember who you are… show them pictures of you two together or doing activities
- Talk with them about things they like to do or things you like to do together
- Spend time together… you can make an album of pictures and other mementos to remember people, events, trips, and activities
- Sit with them and enjoy a favorite snack or meal together
- Listen to music and dance

- Keep the TV or radio sound low so it is not noisy and they can relax
- Try to make sure things are quiet and peaceful

What Should I Do if I Am Feeling Different in My Thinking and Often Feel Confused?

- Tell someone you trust if you are forgetting things or often get confused or lost. This could be your family or your caregiver.
- Forgetting things does not always mean you have dementia. Sometimes, these problems come from what you eat, your medicines, another illness, or sad things that have happened.
- A doctor can help figure out what is wrong and make you feel better. You may be given pills or just have a talk with you. The doctor may also want to see you again to see how you are doing.
- The doctor will speak with you, and with your permission speak to people you trust about what is wrong.

What Should I Do If I Am Told I Have Dementia?

- Talk with a person you trust or your doctor about what this means to you. Ask what dementia is and what may happen to you as the years go by.
- Make a plan so that your doctor and people you love know what you want when you get sicker.

If you want help with deciding what to do, ask a friend. You can learn more about deciding at this website – https://futureplanning.thearc.org

Having dementia makes you think about questions… it is good to ask a parent or friend to help with answering these. Answers to these questions can help you know more about dementia.

- What can happen when dementia harms the brain?
- If I think I am having trouble remembering things or if my brain doesn't work like it used to, whom should I tell?
- What will the doctor do if I think that I am having some changes in my brain?
- What kinds of decisions will I have to make if I am told I have dementia?
- What kind of support and assistance will I need and still live my life?
- How can I stay independent for as long as possible?
- What if I feel afraid, who will help me?
- What kinds of things can help me stay calm?
- What kinds of things can help me remember?
- What do I want people to know about me if I cannot remember things about myself.
- What should I tell my friends?
- Who will take care of me if I cannot take care of myself?

How Can I Plan for What Doctors May Do with Me in the Future?

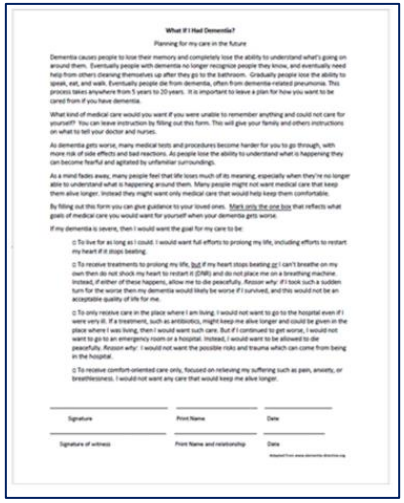
Be prepared for when you meet with your doctor. Write down information on how you want to be cared for and what decisions you want made about your health care when you get older.

You can meet with someone you trust to tell about what options you have. If you cannot read or write ask someone you trust to help you. Make sure you understand and agree with what they

wrote and read back to you. No one is going to mad at you for what you say. You are the boss and in charge of yourself.

Such a paper with the information on how you want to be cared for is called an **Advance Health Directive**. Someone you trust or your doctor can help you get the right paper. Advance Directives tell other people

- what you want to have happen with your health in the future.
- what are your wishes if you can't tell people what you want, how you want to be taken care of, or what kind of medical care you may want
- whether you want someone to restart your heart if it stops
- whether you want people to make your life longer or more comfortable



What If I Had Dementia?

Planning for my care in the future

Dementia causes people to lose their memory and completely lose the ability to understand what's going on around them. Eventually people with dementia no longer recognize people they know, and eventually need help from others cleaning themselves up after they go to the bathroom. 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. It is important to leave a plan for how you want to be cared from if you have dementia.

What kind of medical care would you want if you were unable to remember anything and could not care for yourself? You can leave instruction by filling out this form. This will give your family and others instructions on what to tell your doctor and nurses.

As dementia gets worse, many medical tests and procedures become harder for you 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 a 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. Many people might not want medical care that keep them alive longer. Instead they might want only medical care that would help keep them comfortable.

By filling out this form you can give guidance to your loved ones. Mark only the one box that reflects what goals of medical care you would want for yourself when your dementia gets worse.

If my dementia is severe, 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 not shock my heart to restart it (DNR) and do not 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. If a treatment, such as antibiotics, might keep me alive longer and could be given in the place where I was living, then I would want such care. But if I continued to get worse, I would not 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 not want any care that would keep me alive longer.

Signature | Print Name | Date

Signature of witness | Print Name and relationship | Date

You can ask people you trust to help you fill out the paper. They can help you keep the paper and can share your Advance Health Directive with your doctor so he or she will know what you want.

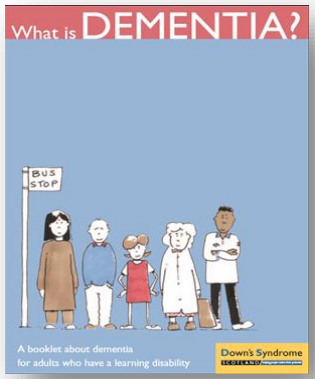
An Advance Health Directive asks you to make a decision about how much medical care you want when you have advanced dementia. Advanced dementia means you are very ill, cannot remember anything, and will not get well.

Sometimes, you may not know what to do. It can take time to understand and think about these kinds of things. Ask a person that you trust to help you as the words may be hard to understand.

There is a sample Advance Health Directive included in the back of this booklet. Your loved one can help you with filling it out. Save this in a safe place and share it with your doctor.

PART 6: RESOURCES

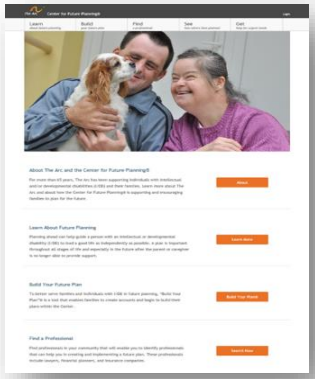
There are many helpful resources found on the Internet. Searching for 'dementia and intellectual disability' reveals a wealth of useful information for family members and caregivers. Not all provide specific information on having 'that conversation,' but do provide tips on helping adults with intellectual disability who have been diagnosed with dementia.



Reading about Dementia

There are few materials that can help an adult with intellectual disability understand dementia and its effects. One excellent publication is ***What is dementia? A booklet about dementia for adults who have a learning disability***. It was developed by Down's Syndrome Scotland and can be accessed in the US from www.aadmd.org/ntg/resources or https://aadmd.org/sites/default/files/whatisdementiabooklet.pdf

This booklet is designed for use by a person with an intellectual disability.

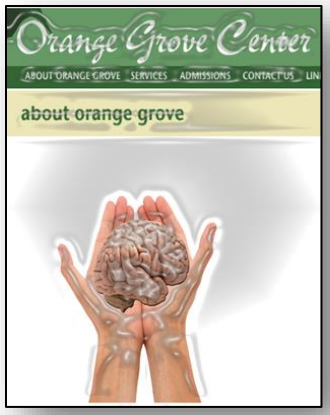


Planning for the Future

A useful resource is ***The Arc's Center for Future Planning***. Future Planning has a guide for a person with an intellectual disability to lead a good life as independently as possible and to age according to his or her own wishes. Such a plan is important throughout all stages of life and especially in the future after a parent or caregiver is no longer able to provide support.

The guide notes that a person-centered future plan should reflect the wishes of the person, as well as his or her parents, siblings, extended family members and friends, and other important people in his or her life. A plan should include information about all aspects of a person's life including long term medical and health care and an advance directive.

The website for The Arc's Center is https://futureplanning.thearc.org/

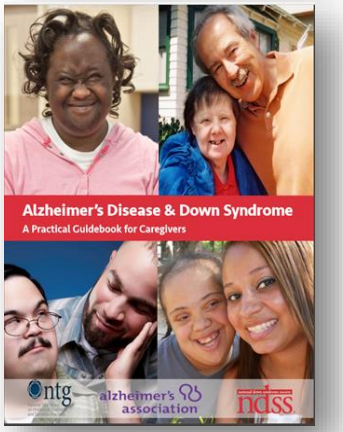


Tool Kit on Understanding Memory

The ***Center on Aging, Dementia and Longevity*** at the Orange Grove Habilitation Center, Chattanooga TN, has a tool kit that can help explain memory and other related functions.

The Tool Kit contains useful things to use to help assess an adult's understanding of these sometimes complex and difficult to comprehend ideas.

You can access the tool kit at **www.aadmd.org/ntg/toolkit**



Booklet on Alzheimer's Disease and Down Syndrome

The ***National Down Syndrome Society***, in collaboration with the National Task Group on Intellectual Disabilities and Dementia Practices and the Alzheimer's Association, has produced an informational booklet on a variety of aspects of how Alzheimer's disease affects adults with Down syndrome.

The booklet can be accessed and copies downloaded at **http://www.ndss.org/wp-content/uploads/2017/11/NDSS_Guidebook_FINAL.pdf**

Who can I contact for help with this discussion?

In Rhode Island, you can seek help from the **Rhode Island Chapter of the Alzheimer's Association**
Their 24-hour Helpline number is 1 (800) 272-3900

Also, you can call the **Rhode Island Division of Elderly Affairs**
Their information number is 1 (401) 462-0570

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To the many families and professional caregivers who will be using this guide, appreciation is offered for the tireless hours of quality care you provide. Our hope is that this resource guide will provide you with the foundation you need to begin the conversation in planning supports for the individuals you support.

Citation

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Source

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Health Directive for Intellectual Disability and Dementia

What If I Have Dementia?
Planning for my care in the future

Dementia causes people to lose their memory and completely lose their ability to understand what is going on around them. Eventually people with dementia no longer recognize people they know and need help from others for everything they do. They lose the ability to speak, eat, and walk. Eventually people die from dementia, often from dementia-related pneumonia. This process with someone who has an intellectual disability can take anywhere from between 2 and 20 years.

What kind of medical care would you want if you were unable to remember anything and could not care of yourself? You can leave instructions by filing out this form. This will give your family and others instructions on what to tell your doctor and nurses.

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.

By filling out this form you can give guidance to your loved ones. Mark only the box that reflects what goals of medical care you would want for yourself when your dementia gets worse.

If I have 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 not shock my heart to restart it (DNR) and do not 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.** If a treatment, such as antibiotics, might keep me alive longer and could be given in the place where I was living, then I would want such care. But if I continued to get worse, I would not 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 not want any care that would keep me alive longer.

Signature	Print Name	Date
Signature of Witness	Print Name and relationship	Date

Adapted from "Health Directive for Dementia" – www.dementia-directive.org (2018)

Memory Exercise Images