

Talking About Dementia:

A Guide for Families, Caregivers
and Adults with Intellectual Disability



A Supplemental Module to

Intellectual Disability and Dementia: A Caregiver's Resource Guide for Rhode Islanders



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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 for whom you provide care.

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Source

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The *Intellectual Disability and Dementia: A Caregiver's Resource Guide for Rhode Islanders* can be accessed at the following web sites:

<http://aadmd.org/sites/default/files/8.5.17%20SHRI%20Resource%20Guide.pdf>

<http://www.sevenhills.org/uploads/SHRI-IDD-ADRD-Resource-Guide.pdf>

<http://rrtcadd.org/wp-content/uploads/2017/07/Intellectual-Disabilities-and-Dementia-A-Caregivers-Resource-Guide-for-Rhode-Islanders-Final-7-3-17.pdf>

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TALKING ABOUT DEMENTIA

Often, we avoid challenging conversations with our loved ones with intellectual disabilities. We may 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. Talking about dementia is hard. It is scary to think about what will happen as dementia progresses. This fear makes it difficult to speak about with other people, especially adults with intellectual disability (which includes those adults with Down syndrome).



Discussion about dementia is most effective *in the moment*. When someone close to the person has dementia (grandparent, aunt, uncle, friend, or others), you can talk about times your loved one has been with that individual. Any conversation about dementia will be better understood if there is a real-life incident to which your loved one can relate.

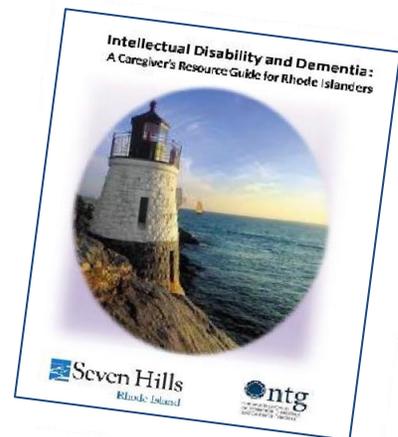
Our goal in this module is to share information and resources to help you have this conversation about dementia. There is also a section which explains dementia for adults with intellectual disability. It provides a guide to help friends who may have dementia. You can use this section with adults when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

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, while others are not. Many adults with Down syndrome have a high risk for dementia.

The more you know

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 on "Learning About Dementia" in the Seven Hills Rhode Island book, *Intellectual Disability and Dementia: A Caregiver's Resource Guide for Rhode Islanders*.

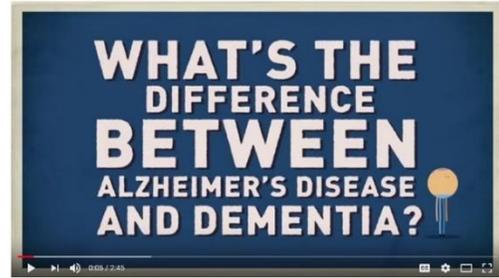


You may also want to watch these two short videos that are available on YouTube. One explains Alzheimer's disease, and the other explains the difference between Alzheimer's disease and dementia.



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)



TALKING 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 the decision to have this conversation may be hard. You may be concerned about how discussing this topic may impact your loved one and your family. As you decide to have that discussion, it may be useful to think about your reactions to these questions and how you might handle them.

Here are some questions you may consider as you decide to have this conversation.

- 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 friends or others about the diagnosis?
- What can I do to help the person stay independent for 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 about why he or she is feeling or doing things differently?

Try asking these questions:

- “Do you ever feel this way or do these things?” (give examples of some of the feelings or actions that the person has mentioned previously.)
- “Do you have any questions about how you are feeling or why you are doing things differently?”

Consider Who Should Be Part of the Conversation

- Would it be best to first 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. Ask your family member who they want to be there when you talk about the changes in their life. Consider inviting people your loved one likes, respects, and with whom they feel comfortable.
- 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?



Consider When It Would Be 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. One adult with intellectual disability told us, "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 may just happen, 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.

Consider Where the Most Comfortable Place is to Talk

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 a video call like Skype or FaceTime. 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 attribute]." "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 Dementia Clearly

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, forgetting, or being 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’s time for your favorite TV show,” because you know they enjoy a particular TV program but have lost track of time.
- You can say, “It’s 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 exercises and additional resources beginning on page 7 that may help you.

Preparing for the Questions

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





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 OK to be frustrated or upset when they are confused or forgetful. If someone else has dementia, it is also OK 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 get 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.

A breakthrough in understanding what dementia is can sometimes happen as 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 things that are difficult to talk about. Sometimes our loved ones more easily understand when they get information in small chunks. Try not to overwhelm them with too much at one time.





Seeking Help from A Local Agency

Many adults live independently. 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 concerns about their behavior, have a conversation with the agency staff about what you are sensing or seeing in your loved one. It may be that the staff are seeing the same things.

If there is a suspicion that changes are occurring, it is important that you stay in close contact with any people who provide services and support to your family member. Most parents have been involved for many years in service planning for their sons and daughters and continue to be involved as their child becomes an adult. Brothers and sisters often become even more involved as their family member gets older. Make sure that meetings related to the service plan are held at a time when you can attend. Ask questions, and let the staff know what information you need to be kept aware of – things like behavior changes, more fatigue than usual, difficulty walking, wanting to leave, etc. Confirm how the agency will handle future changes caused by the dementia. It will also be important that there is clear understanding about who will take the lead on any dementia related conversations with your family member.

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 this conversation, as well as giving guidance on how to answer many of the questions you or your loved one may have.

EXERCISES TO EXPLAIN DEMENTIA TO PEOPLE WITH AN INTELLECTUAL DISABILITY

The next section contains an exercise you can use to talk about what it means to remember or have memories. You will find full size photos of the illustrations used in this section in the Attachments. You can substitute any food that may be more familiar to the person or any other articles of clothing. In this exercise you are trying to tap the person’s understanding of memory.

What is memory? How does our brain work?

Memory is the basic idea that we need to help people understand before explaining how dementia may affect a person’s recollections. 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 favorites?”

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 the person may only say, *“Because it is,”* or *“I don’t know.”*

Continue the discussion with questions and comments similar to these.

“How are they alike?” *How are they different?”*

“Why do you like one better than the other?”

“Pizza is usually round, but if it is square is it still a pizza?”

“Does pizza tastes better than a hamburger?”

“Hamburger buns are round, does that make it the same as a pizza?”

This second exercise helps with finding how they recognize things, and how they use the information from their memory.

Show the 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 should start a discussion like 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 remember all the things we have learned.

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.

RESOURCES

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

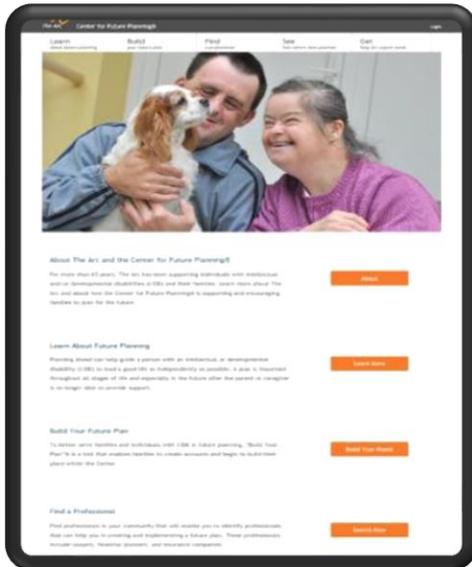
Reading about Dementia

There are a 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***. This booklet is designed for use by a person with an intellectual 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>



Planning for the Future

A useful online resource is ***The Arc’s Center for Future Planning***.



This site has a guide to help a person with an intellectual disability 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 for Future Planning can be found at: <https://futureplanning.thearc.org/>

Tool Kit on Understanding Memory

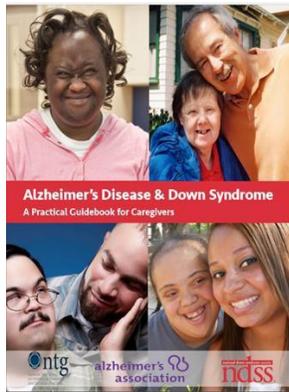
The **Center on Aging, Dementia and Longevity** at the Orange Grove Habilitation Center, Chattanooga TN, has a tool kit that can help explain memory and other related functions.

The Tool Kit is useful 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

<https://www.ndss.org/about-down-syndrome/publications/caregiver-guide-order-form/>

SEEKING 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.

ATTACHMENTS

The following pages contain the images used in the discussion on memory and remembering. Remember, you can use pictures of different food and clothing items that will be more well known to your family members.

TOOLS FOR PEOPLE WITH AN INTELLECTUAL DISABILITY

The final section of this book can be used as a pull-out and either given to the person to read or you can read it to him or her. This section helps explain what dementia is, and what might the person do to help a friend or relative who has dementia.









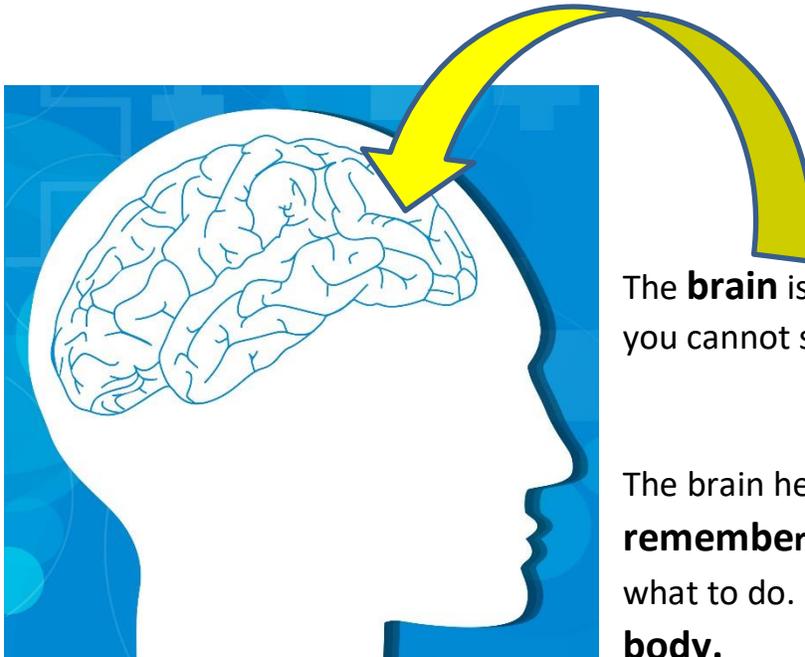
Learning About Dementia



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



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:

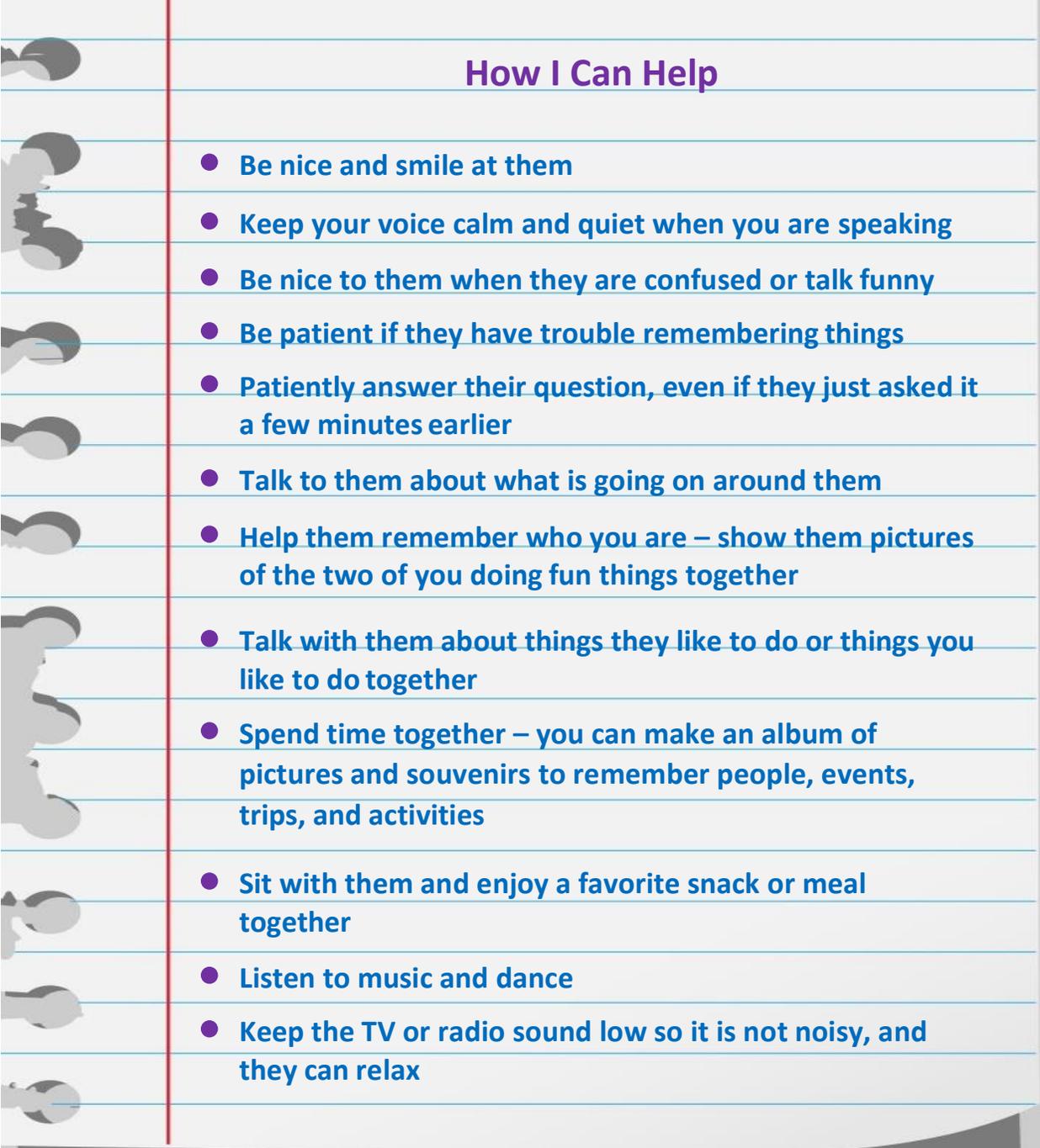
-  **Feel confused**
-  **Forget things**
-  **Get lost**
-  **Get upset and not know why**
-  **Do things differently**
-  **Have problems walking**

Over time, **dementia may also cause people to:**

-  **Forget words** for things they know
-  **Have problems talking**
-  **Do things** more slowly
-  **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 a Parent with Dementia?

If you have a **friend**, a **parent** or **another relative** who has dementia, they may need some help. You might be able to **do things that can help them** and it is very easy. You can **pick one or two – or try to do them all**. Just know that **whatever you do** will help your friend or relative feel good.



How I Can Help

- Be nice and smile at them
- Keep your voice calm and quiet 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 if they just asked it a few minutes earlier
- Talk to them about what is going on around them
- Help them remember who you are – show them pictures of the two of you doing fun things together
- 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 souvenirs 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

What Can I Do if My Thinking is Different or I Get Confused?

There may be times when you feel different than you normally do. Or you might find that you get confused. That **can be upsetting** for you. Here are **some ideas** you might try if this happens to you.



Tell someone you trust if you are **forgetting things** or **often get confused** or **lost**. This **could be your family** or **your caregiver**.

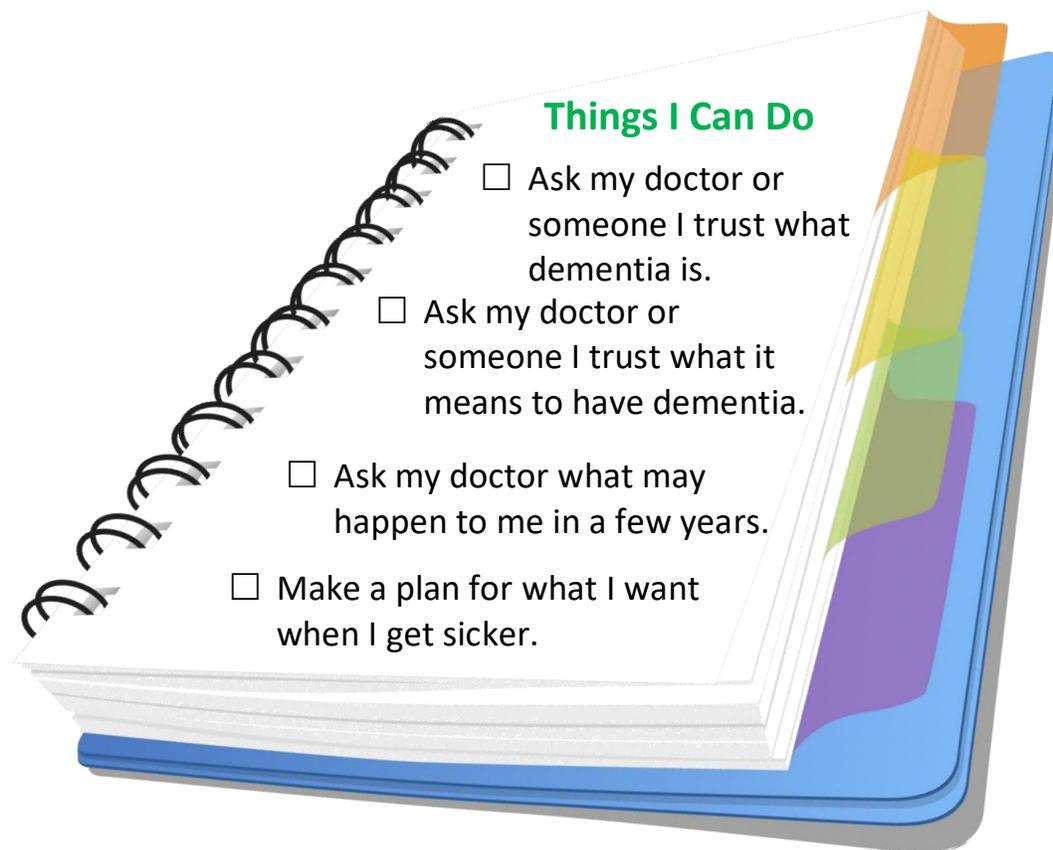
Forgetting things does not always mean you have dementia. Sometimes, these problems come from **what you eat, your medicines, another illness, or sad things** that have happened.



A doctor can help figure out what is wrong and **help you feel better**. He may **give you 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 **talk with you**, and **may ask your permission** to **speak to people you trust** about what is wrong.

What Should I Do if I Have Been Told I Have Dementia?

There may be times when you feel different than you normally do. Or you might find that you get confused. That **can be upsetting** for you. Your **doctor** or someone else may have **told you that you have dementia**. You **may have a lot of questions** about what that means. **It can be scary when you don't know** what might happen. The best thing you can do is **get some answers**. Asking questions and making plans may **help you feel more at ease** about what is happening. Here are **some ideas for things you can do**.



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 can make you think of **lots of questions**. When you do, it is good to **ask a parent or friend to help you get the answers**. When your questions are answered you will **know more about dementia** and you can **understand what is happening** to you. Here are some questions you might want to get answered.

- ★ **What can happen** when dementia hurts my brain?
- ★ If I think I am having trouble remembering things, or if my brain doesn't work like it used to, **who should I tell?**
- ★ **What will the doctor do** if I think that my brain is changing?
- ★ **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 to still **be able to 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 for Me in the Future?

You can **make decisions about** how you want to your doctor and others to **care for you in the future**. This is called **future planning**. It is a good idea to **talk about your choices** with **someone you trust a lot** – like a **parent, your sister or brother, or a caregiver who has known you for a very long time**.



You will want to **think about your choices** for **when you get older**. Your **doctor** and **others** may want to **know where you want to be cared for** – your **home** or in a **hospital** or **somewhere else**. **Talk** with the person you have chosen **about your choices**. Sometimes, **you may not know what to do**. It can **take time to understand and think** about these kinds of things.

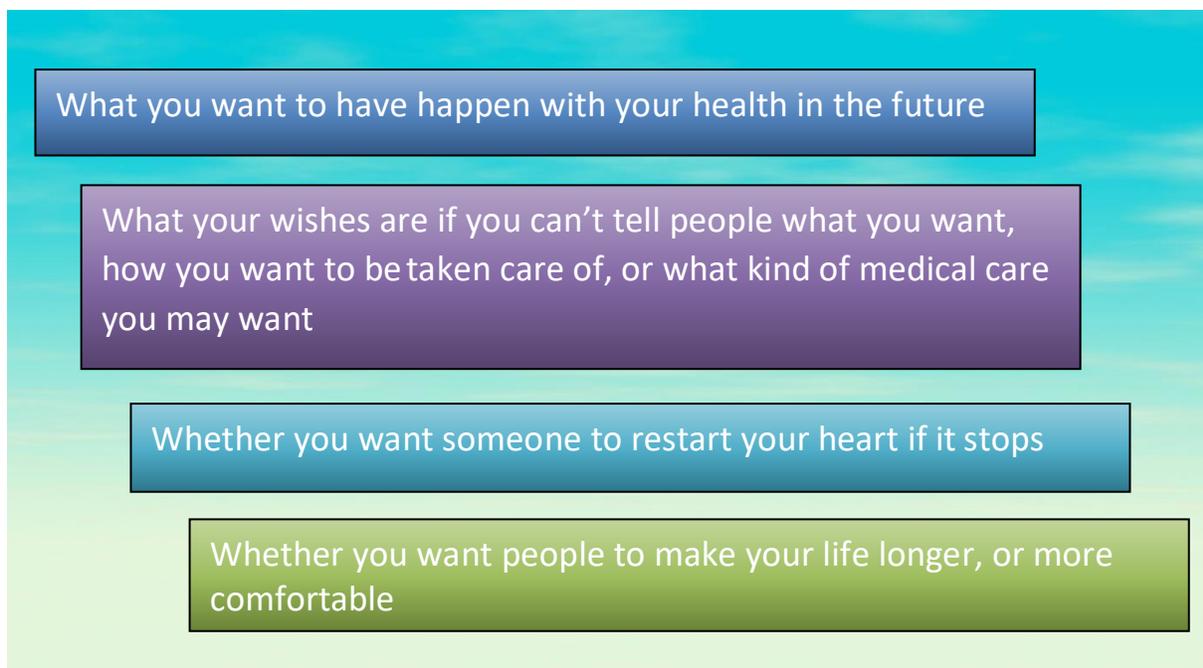
An **Advance Health Directive** asks you to **decide about how much medical care** you want **when you have a serious illness** or **advanced dementia**.

Advanced dementia means **you are very ill, cannot remember anything, and will not get well**.

If you cannot read or write, ask your trusted person to help you. They can **help you with the words that might be hard to understand** and **get the right paper** or form that you need. A **paper** with the information on **how you want to be cared for** is **called an Advance Health Directive**.

Make sure you understand and **agree with what they wrote**. Have them **read it back to you**. **No one is going to get mad at you for what you say**. **You are the boss and are in charge of yourself**.

Your **Advance Health Directive** will tell other people:



There is a **sample Advance Health Directive** included in the back of this booklet. The **person you trust can help** you **fill it out**. When you finish, **sign it** and **save it in a safe place**. Some people keep this paper in a **clear plastic zipper bag in the freezer** or on the **back of their closet door**.

You will want to **let your doctor know what decisions you make**. He or she **may ask you for a copy** of your plan. You might want to **give a copy** of your **Advanced Health Directive** to your **parents or sister or brother**.

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

Notes

