

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 you support.

The National Task Group on Intellectual Disabilities and Dementia Practices

Contents

| | |
|---|-----------|
| HOW TO USE THIS RESOURCE GUIDE | i |
| INTRODUCTION | 1 |
| Becoming A Healthcare Advocate | 2 |
| <i>Advocating for a loved one.....</i> | <i>2</i> |
| <i>Preparing for a medical appointment.....</i> | <i>2</i> |
| <i>Following up after a medical appointment.....</i> | <i>2</i> |
| LEARNING ABOUT SCREENING, ASSESSMENT AND DIAGNOSIS | 4 |
| <i>Screening, Assessment and Diagnosis... What are the differences?.....</i> | <i>4</i> |
| <i>Screening an individual with an intellectual disability.....</i> | <i>5</i> |
| <i>Collecting personal best information about your loved one</i> | <i>6</i> |
| <i>Preparing for an assessment</i> | <i>7</i> |
| <i>Finding diagnostic help in Rhode Island.....</i> | <i>7</i> |
| LEARNING ABOUT DEMENTIA..... | 8 |
| <i>Discovering various types of dementia</i> | <i>8</i> |
| <i>Recognizing signs & symptoms of dementia</i> | <i>9</i> |
| <i>Understanding the risk of Alzheimer’s in people with an intellectual disability.....</i> | <i>10</i> |
| <i>Observing dementia in adults with intellectual disability</i> | <i>10</i> |
| <i>Staging Alzheimer’s</i> | <i>11</i> |
| <i>Dementia Stages and Symptoms</i> | <i>12</i> |
| WORKING WITH THE HEALTHCARE PROVIDER..... | 13 |
| <i>Communicating with healthcare providers, caregivers, and the support team</i> | <i>13</i> |
| <i>Telling your loved one.....</i> | <i>14</i> |
| <i>Giving consent</i> | <i>14</i> |
| <i>Making decisions</i> | <i>15</i> |
| <i>Helpful Rhode Island Booklets.....</i> | <i>16</i> |
| PROVIDING CARE | 17 |
| <i>Determining next steps.....</i> | <i>17</i> |
| <i>Learning about caregiving</i> | <i>17</i> |
| <i>Offering ongoing care.....</i> | <i>18</i> |
| <i>Talking with other family members.....</i> | <i>19</i> |
| <i>Thinking about legal and financial issues</i> | <i>19</i> |
| <i>Planning for end-of-life care</i> | <i>21</i> |
| <i>Sound Practices</i> | <i>22</i> |
| CAREGIVING TIPS..... | 23 |
| <i>Dealing with confusion and forgetfulness</i> | <i>23</i> |
| <i>Home Safety</i> | <i>24</i> |
| <i>Wandering.....</i> | <i>25</i> |
| <i>Brain Health.....</i> | <i>26</i> |
| <i>Healthy Aging: Nutrition, Exercise, and Mental Activity</i> | <i>27</i> |
| <i>Behavior Changes.....</i> | <i>29</i> |
| <i>Meaningful Day.....</i> | <i>33</i> |
| GETTING ASSISTANCE IN RHODE ISLAND..... | 34 |
| <i>Learning about eligibility</i> | <i>34</i> |

| | |
|---|-----------|
| <i>Accessing and paying for services</i> | 34 |
| <i>Considering guardianship and other legal options</i> | 35 |
| <i>Thinking about end-of-life planning</i> | 35 |
| LEARNING MORE: LOCAL, NATIONAL & INTERNATIONAL RESOURCES | 36 |
| <i>Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia</i> | 40 |
| <i>The National Task Group on Intellectual Disabilities and Dementia Practices Consensus Recommendations for the Evaluation and Management of Dementia in Adults with Intellectual Disabilities</i> | 40 |
| TERMS & DEFINITIONS | 42 |

HOW TO USE THIS RESOURCE GUIDE

This guide, while written for families of adults with intellectual disability, is a useful tool for anyone who provides care. Caregivers play an important role in the overall wellness of individuals they support. Our goal is to provide information that will be helpful to anyone who cares for adults with intellectual disability.

As individuals with an intellectual or other developmental disability age, you may see changes that are confusing and upsetting. It can be frightening not knowing what is happening to them or how to best support him or her.

This guide was designed to provide caregivers of individuals with an intellectual disability an overview of dementia, as well as provide information about caregiving and support options available in Rhode Island.

A note about Alzheimer’s disease and dementia. Alzheimer’s is a disease of the brain which causes a person to lose his or her memory and ability to function. Those losses are termed dementia. Alzheimer’s is not the only cause of dementia – see the glossary at the end for the different causes.

We hope that you will find this guide to be a foundation for your knowledge as we have included some commonly used words and phrases, a basic overview of the disease process, some tips for caregiving, as well as local Rhode Island and national organizations that offer training and services. In no way should this guide take the place of consulting with your loved one’s healthcare provider.

The guide is divided into sections, each with a different focus to aid you on your caregiving journey. You do not need to read this guide from cover to cover, rather it has been written so that you can find information you need related to the questions or concerns you may have at any time during an individual’s journey through dementia.

The following icons may be helpful as you read this guide:



This icon indicates you may find additional information on the web.



The Rhode Island icon indicates there is information or a resource specific to the state of Rhode Island.



TOC

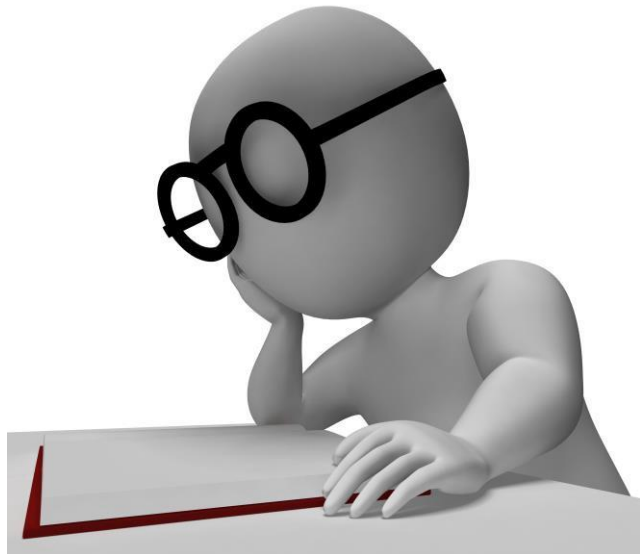
If you are reading an electronic copy of this guide, the TOC button at the bottom of each page will return you to the Contents page (Table of Contents).

INTRODUCTION

The fact that you are reading this guide means there is someone with an intellectual disability who you care about and who has you concerned. You may be seeing changes in his health or behaviors that are unusual for him. Your loved one's healthcare provider may have mentioned the possibility of him having a type of dementia.

If you are a family member, know that your support is extremely important to your loved one. You are taking the right step by learning all you can about aging in people with intellectual and developmental disabilities.

If you are a direct support professional, know that caring for someone outside your family is an important job. You may be the one who best understands this person, the one person who knows her medical history, the one person who knows what brings her joy or what causes her pain. Learning about the health issues your person may face as she ages can have a very positive impact on her quality of life.



Sometimes, it can be difficult finding answers when life begins to change. Unfortunately, there has not been a lot of information available up until now. We do know that as people with intellectual disability age, changes will occur. The best thing you can do is learn as much as you can, advocate whenever it's needed, and support your loved one to live his best life.

Let this guide be a tool you can use to go through the days and months ahead supporting your loved one aging with an intellectual disability.

BECOMING A HEALTHCARE ADVOCATE

A healthcare advocate can help present information to a healthcare provider in support of a person with whom they have a trusted relationship. For someone with an intellectual disability, a healthcare advocate may share the individual's medical history, changes in functioning, and symptoms that are related to the reason the person has a medical appointment.

Advocating for a loved one

Even without a medical background you can be a good healthcare advocate for your loved one. Families are the greatest source of information about their loved ones with intellectual disability. You are the expert on your family member, having spent a lifetime with him. Your knowledge will help identify what is happening and lead the medical professionals to the most accurate diagnosis. As you continue to develop a partnership with your healthcare provider(s) you will feel more confident in the importance of the information you provide.

Your loved one's healthcare provider will appreciate the valuable information you have and will use it to help determine the best course for evaluations, assessments, and interventions. Healthcare providers are human and sometimes have stressful days with little time for each appointment, so do not get discouraged if the first appointment is not as successful as you would like. It takes time to build a successful partnership. If there continues to be a pattern of unwillingness to listen to you, then you may want to have a family member with a medical background or an agency representative accompany you. If none of this helps, it may be time to look for a new provider, if possible. Remember, the ultimate outcome is to assure that a thorough examination be conducted to make an accurate diagnosis and provide you with suggestions for care of your family member.

Preparing for a medical appointment

Keep a list of questions you have and make notes of concerns you have. The more information you can give to the healthcare provider, the better he will be able to determine what needs to be done. Speak with others who provide care for your loved one or those who spend time with her, such as other family members. They may have observations that you are unaware of and that would be helpful to share.

Following up after a medical appointment

The healthcare visit is just the beginning of identifying the underlying cause(s) for changes you are seeing in your loved one. Assessment and treatment is an ongoing process so it will

be important to continue to observe and document any changes noticed after the visit, especially those that may be related to the interventions provided, such as side effects of new medications. Pay close attention to subtle changes in behavior and any changes in communication skills (such as losing the ability to carry on a conversation). Watch for significant changes in functioning, such as skill loss including activities of daily living, loss of appetite and/or weight loss, refusal to participate in previously preferred activities and events, as well as changes in social interaction such as forgetting the names of people who your loved one has known for years. All behavior is a form of communication and much can be learned from changes in typical daily behavior.

Be sure to document and take notes during the appointment and keep in a safe place so you can refer to them later, if needed. Contact other family members and those who provide care to your loved one to give them information they may need to know. If changes need to be made to supports and services your loved one receives, contact her case manager. And, most importantly, make sure your loved one is included in any discussion about her care.

It might be helpful to create a checklist for any tasks or appointments that need to be completed before a next appointment.

Take each day as it comes; don't let yourself get overwhelmed with all there is to do. Don't get discouraged! You are helping to make a positive difference in the life of your loved one.

LEARNING ABOUT SCREENING, ASSESSMENT AND DIAGNOSIS

It can be confusing when a medical professional says she wants to do a lot of tests with your loved one. Screening and assessment are tools used to help a medical provider reach a diagnosis.

Screening, Assessment and Diagnosis... What are the differences?

Screenings are used to identify the possible presence of an as-yet-undiagnosed disease in individuals who are showing no signs or symptoms. For example, a check of your blood pressure is considered a screening. A screening is often a first step in the diagnosis of a potential health concern. The expectation is that if a problem is identified it can be treated early and possibly eliminated or, at least, managed.



For the general population, a screening for dementia may involve asking some basic questions that can help identify someone who may be having some changes in their thinking and behavior. However, for many people with intellectual disability, this type of dementia screening may not be appropriate.

It will be important to get a baseline screening while your loved one is functioning at her best. Most screenings can be completed by a family member or agency staff. A dementia screening for your loved one will look at changes in:

- Health
- Behavior
- Language skills
- Personality
- Function
- Emotional strengths

Documentation of the skills your loved one has developed will serve as a screening tool. Screenings should be done annually or at any time there is a change that creates a concern.

Assessment is an evaluation that includes a health and social history, physical examination, review of medications lab work and possibly imaging. It is the next step in the process to reach a diagnosis. An assessment in an adult with intellectual disability who is experiencing changes in health or behavior may be done to determine if those changes are due to aging, a reversible or treatable condition, or some type of dementia. The assessment process may take some time so that continuing observation can occur. The healthcare provider will be looking for a gradual, progressive decline and change from your loved one's baseline level of functioning.

Diagnosis is the identification of a condition or illness. It may be reached quickly (like the diagnosis of a flu or strep throat) or may take time as other conditions are identified or ruled out. The determination of dementia is considered a differential, or “ruling-out” diagnosis and will take time as the medical provider determines what is happening in the brain that is causing the changes – and whether it is or isn't dementia.

Also, dementia in adults with an intellectual disability may be more difficult to diagnose, depending upon the severity of the intellectual disability. It has been reported that the more skills the person has, the more noticeable changes will be. For those with less adaptive and language skills, it may be more difficult to assess changes.

Screening an individual with an intellectual disability

Screening is a fairly easy process and anyone who is very familiar with the person can help in this activity. Because your loved one may not be able to complete the same type of screening as the general population due to limited language skills or other reasons, know that you can help the medical professional by having information available for her.

You can complete an initial screening at home using the form developed by The National Task Group on Intellectual Disabilities and Dementia Practices (the NTG). It is called the **NTG-EDSD** (Early Detection and Screening for Dementia). Any family member can fill out the form, although it is helpful when the whole family is involved.

The **NTG-EDSD** looks at many areas of your loved one's life including memory, behavior, self-care and general functioning, as well as important medical issues. It gives you the opportunity to note if there are changes, and whether they are relatively new within the past year or if there have been significant changes. Other areas on the form let you note out-of-the ordinary events that have happened, such as a change in providers, death in the family, or other events that may have upset your loved one. The **NTG-EDSD** also provides a place to list the medications loved one is taking.

Because you know your loved one best, you will probably be one of the first to notice when something is different. Using the **NTG-EDSD** will give you a place to record your impressions and make note of any concerns you have. What you note on the screening form can help start a discussion about your suspicions with your healthcare provider or another staff person.

Your healthcare provider may not be familiar with the **NTG-EDSD**. However, it has been reported by users that it has been well received by healthcare providers, and often becomes part of the medical record. As in building any partnership, information shared in a constructive, organized manner will usually result in a positive response and experience for all involved. If your loved one's healthcare provider does not show interest in the

information obtained in the *NTG-EDSD*, don't get discouraged. You can still keep track of changes using the form and provide that information to your loved one's healthcare provider in other ways. You can get a copy of the *NTG-EDSD* from your caseworker or agency representative or on the Internet at <http://www.aadmd.org/ntg/screening>. In addition,

- i** Seven Hills Rhode Island may be able to assist you at <http://www.sevenhills.org/programs/idd-adrd>.

Collecting personal best information about your loved one

Creating your loved one's life story will be extremely helpful when you begin seeing changes that are of concern. Those old photos that may be in a shoe box in the closet will help you put together a story of who your loved one is and has been. Through a life story, others will know about the skills and interests your family member has had throughout her life. Sort through your photos and put them in a scrap book. Make notes next to each photo to identify when it was taken and explain what the person is doing. For example, if there is a picture of your loved one doing the dishes, write a little note about any help she may have needed to complete that task; if she could wash dishes independently, make note of that, as well. The more you can document, the more you or others will have to draw from later. Even little nuances like the order that your loved one puts on his clothes is important. Silly family stories can make a loved one special in other people's eyes. In addition to being a great source of all the skills and interests your loved one has had, this can serve as a baseline of her *personal best*. Others who work with her, who may not know her as well, can use the scrapbook to learn more about her.



If you have a smart phone, an easy way to gather information is to use the phone's video function to record some of the things loved one can typically do. If you save this video, and keep it in a safe place, then you can share it with your healthcare provider should you have suspicions about changing behavior.

To create a baseline file, the NTG recommends recording several things loved one can do. These would include:

- Walking back and forth
- Carrying on a conversation, and answering some easy questions (such as *what is today, what is your address, what did you do yesterday...*)
- Completing simple tasks (such as *unlocking and locking a small padlock, and picking up some coins and putting them in a small jar*)



Sharing a thorough history of changes, especially those which show a gradual yet progressive decline in function or behavior with the healthcare provider could be an important key to a diagnosis.

Preparing for an assessment

If the medical professional suspects that your loved one may have dementia, gather the information you have collected that demonstrates the skills and interests of your loved one. Be prepared to share the information you have on the *NTG-EDSD*, your loved one's life story and any video recordings you have. Recordings that can show the decline in your loved one's skills or interests, or changes in her behavior will be especially helpful.

If the healthcare provider suspects that your loved one may have a mild cognitive impairment, he may suggest that you continue gathering information about her abilities every six months or year. However, if you notice changes during that time, be sure to record them in video or on the *NTG-EDSD*.

During the assessment, you may also be asked questions about:

- Your loved one's and your family's medical history, which includes medication use and surgeries and other medical interventions
- Your home (or your loved one's home if he or she lives away from you)
- Significant life events such as:
 - illnesses
 - transitions and moves in work or residence
 - meaningful losses for the person

The healthcare provider needs this information to help determine if there may be some other cause for changes in your loved one.

The healthcare provider may refer your loved one for a diagnostic visit with a clinic or a memory center. There, specialists will further assess loved one and determine if there is a disease of the brain that is causing dementia. You may be asked to provide more information to help the clinic make this diagnosis. Be advised that traditional memory tests used with the general public have been found to be inappropriate for many people with intellectual disability. Be sure to ask the healthcare provider what the benefit of this referral would be.

Finding diagnostic help in Rhode Island



If you aren't sure where you can get help with screening, assessment and diagnosis check first with your loved one's healthcare provider or your local senior center. In addition, you may find additional resources to access these services in the *Getting Assistance in Rhode Island Section* beginning on page 32.

LEARNING ABOUT DEMENTIA

Discovering various types of dementia

Dementia is not a specific disease, but is a set of symptoms that cause changes in the brain. These symptoms are severe enough to interfere with daily life. It may include memory issues, changes in personality, and impaired reasoning.

It is important to know that dementia is not a normal part of aging, and some changes that occur as a person grows older may be due to conditions that may be correctable. The diagnosis of any type of dementia should only come after a thorough look at all other possibilities for the changes that are occurring.

There are numerous types of dementias. Some of the more common ones include:

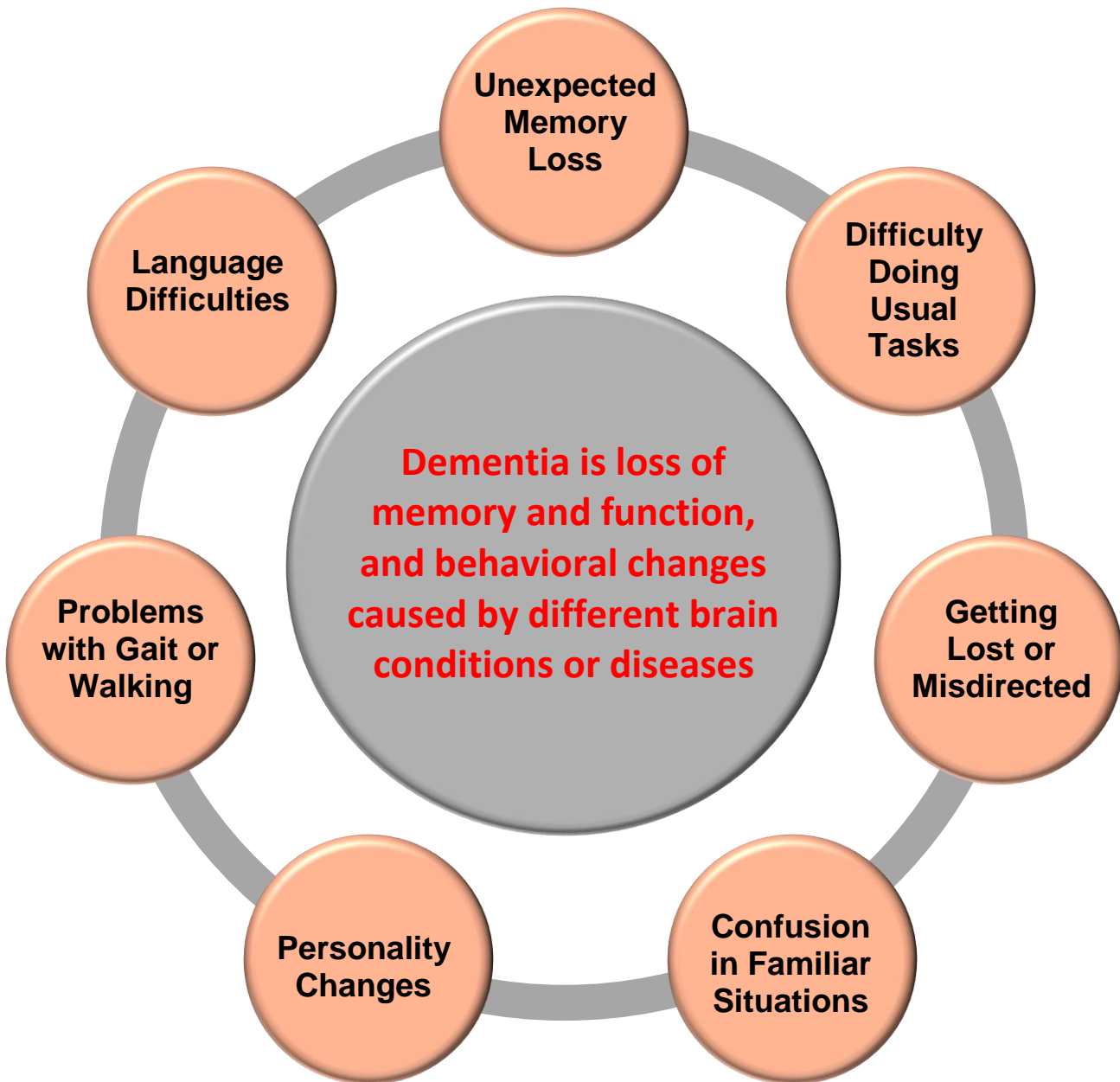
- **Alzheimer's disease** – the most common disease of the brain that is identified as a dementia, affecting more than 60% of people who have been diagnosed with dementia. It may start 20 years or more before symptoms are noticed; it is progressive and degenerative, attacking brain nerve cells or neurons. It includes symptoms of memory loss, confusion, communication difficulties, anxiousness and sometimes paranoia.
- **Vascular Dementia** – the second most common type of dementia and is identified as a “post-stroke” dementia. Symptoms include memory loss, impaired judgment, loss of motivation, and a decreased ability to plan.
- **Lewy Body Dementia** – a less common type of dementia. It includes sleep problems, memory loss, hallucinations and frequent changes in alertness.
- **Frontotemporal Dementia** – also a less common type of dementia that is identified by behavioral and emotional changes more than memory or cognitive declines. There is an increase in inappropriate behaviors, apathy, decreased empathy, compulsive behaviors, as well as anxiety and depression.

A person may also have more than one type of dementia. Other causes of dementia can be due to anything that damages the brain or nerve cells. HIV-Aids, Parkinson's disease, Huntington's disease, and alcoholism can all contribute to the symptoms of dementia.



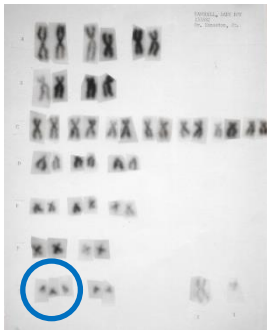
Recognizing signs & symptoms of dementia

The diagram below illustrates many of the symptoms that people with dementia will show throughout the progression of the condition. In addition, some individuals will exhibit an onset of new seizures. How and when they occur, as well as how intense they may be will vary with each individual's changes in functioning, such as language or behavioral changes, problems in memory and with gait.



Understanding the risk of Alzheimer's in people with an intellectual disability

Your loved one may be identified as having an **intellectual disability** that began before his or her 18th birthday. It is a disability that creates limitations in intellectual functioning (intelligence) and in adaptive behavior (everyday social and practical skills). Or, he may have a **developmental disability** that began before his 22nd birthday. Typically, a developmental disability interferes with a child's normal development. It could be intellectual, physical or both. Examples of a developmental disability include autism, cerebral palsy, developmental delay, Down syndrome, epilepsy, intellectual disability, Prader-Willi syndrome, spina bifida and other genetic conditions that impair growth and development.



As the aging population grows, the number of people with Alzheimer's has more than doubled since 1980. With advances in healthcare, people with intellectual disability are also living longer. For example, people with **Down syndrome**, a chromosomal condition that may be associated with intellectual disability and some health complications, are often living well into their 60s and beyond. They are a special population at higher risk for developing Alzheimer's because of the extra copy of the 21st chromosome. People with other types of intellectual and developmental disability have only a slightly higher risk.

Dementia in adults with intellectual disability will generally be the result of Alzheimer's disease, but they may also have dementia due to other causes. Early signs may include changes in health, in some cases, the development of later-age seizures. Other changes may include the loss of skills for dressing, self-care, and completing multiple-step tasks. Loss of language skills and memory are other signs that changes may be connected to a dementia such as Alzheimer's. However, in a person with an intellectual disability, these are typically seen later in the progression of the disease.

Learning about the different characteristics of dementia, including diagnosis and care, along with the stages of the disease, is a good way to prepare and plan for your loved one's care as he or she ages. Although the information can be overwhelming at times, it can also give you more control to handle the challenges you will face. It is helpful to understand the importance of preparing, reaching out to community resources, and putting a plan in place.

Observing dementia in adults with intellectual disability

Generally, memory and behavioral changes for most adults with intellectual disability are like those in the general population. However, for adults with Down syndrome the first signs may come earlier and the course of the disease may be shorter and more intense.

For persons with Down syndrome, the average onset of dementia, or the time when losses become noticeable, occurs by the early 50s. Changes in personality, skills, behavior, and communication are more noticeable in the middle stage, while the most significant health changes are seen in the advanced stage. As the disease advances, there are progressively more physical changes, such as difficulty swallowing and problems with walking. Although seizures are typically seen in the advanced stage of dementia in the general population, adults with Down syndrome often develop them early in the disease process. The onset of seizures may require increased daily supports.

i More information about Alzheimer's disease and how it affects adults with Down syndrome can be found in this excellent publication from the National Down Syndrome Society. You can find it on their web site at <http://www.ndss.org>.

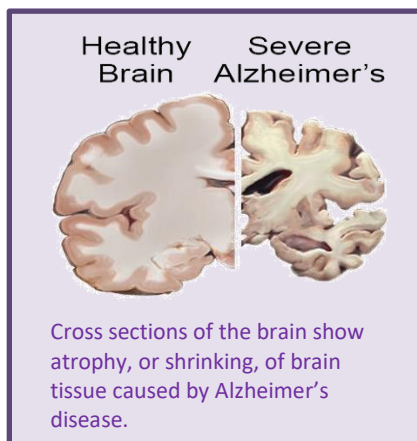


Staging Alzheimer’s

The rate of progression seen in dementia varies from person to person. Some people decline to the point of needing full-time care within a few years, whereas others may be mildly impaired and only need partial assistance for five years or more.

Every person with dementia is unique, but it is helpful to know the typical course of the disease so you are better prepared to face the challenges ahead. For the sake of simplicity, the course of dementia can be divided among three stages: early, middle, and late.

The chart on the next page shows the expected changes in behavior in each of the stages of dementia from the perspective of the person affected. Symptoms fluctuate and stages often overlap so the chart should be considered a rough “road map.” You know your loved one



best. Individuals with intellectual/developmental disabilities may normally exhibit some of these behaviors or require support in these areas. The important thing is to pay attention to any *declines* in these areas, or notice that your loved one is requiring more help engaging in activities or completing tasks.

Declines in function occur at a different rate as each person experiences the disease process differently. As depicted in the brain images to the left, you can see how Alzheimer’s disease causes massive cell loss in the brain.

Photo credit: <https://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-fact-sheet>

Dementia Stages and Symptoms

| Early Stage Changes | | | |
|--|--|--|---|
| <i>Duration varies, but generally, in adults with intellectual disability (5 + years)</i> | | | |
| <i>Adults with Down syndrome (1-2 years)</i> | | | |
| Memory/Thinking | Language | Behavior/Mood | Self-Care |
| <ul style="list-style-type: none"> • Difficulty with short-term memory • Loses things • Poor attention • Difficulty with calculations and organizational skills | <ul style="list-style-type: none"> • Trouble finding words and names • Repeats statements or questions | <ul style="list-style-type: none"> • May become depressed, • Withdrawn and irritable • Loss of interest in previous activities of interest | <ul style="list-style-type: none"> • Needs help with household affairs, such as cooking • Trouble managing money and conducting personal affairs • May get lost or confused when using public transport or walking |
| Middle Stage Changes | | | |
| <i>Duration varies, but generally, in adults with intellectual disability (5-10 years)</i> | | | |
| <i>Adults with Downs syndrome (2-3) years</i> | | | |
| Memory/Thinking | Language | Behavior/Mood | Self-Care |
| <ul style="list-style-type: none"> • Difficulty with short/long term memory • Forgets parts of one’s history • Has trouble solving simple problems • Easy disoriented | <ul style="list-style-type: none"> • Trouble tracking a conversation • Difficulty forming complete sentences | <ul style="list-style-type: none"> • More easily upset or withdrawn | <ul style="list-style-type: none"> • Needs reminders or practical help with personal care (ADL) • Slowed walking and reaction time • No longer safe to go off own • Fatigues easily |
| Advanced Stage Changes | | | |
| <i>Duration varies, but generally, in adults with intellectual disability (2-3 years)</i> | | | |
| <i>Adults with Downs syndrome (1-2 years)</i> | | | |
| Memory/Thinking | Language | Behavior/Mood | Self-Care |
| <ul style="list-style-type: none"> • Mixes up recent and past events • Forgets friends and relatives • Cannot follow a 2-step command • No apparent awareness of past and future | <ul style="list-style-type: none"> • Unable to have meaningful conversations • Disconnected sentences • Cannot speak or uses only a few words | <ul style="list-style-type: none"> • May express unmet needs by yelling and calling • Difficult to engage • Severe decline in ability to show emotion | <ul style="list-style-type: none"> • Needs constant reminders or practical help with personal care • Loss of control to bowel and bladder • Trouble with balance and coordination • Needs total assistance with personal care • Unable to walk and shows little movement • Poor appetite and has swallowing problems • Sleeps much of the time |

WORKING WITH THE HEALTHCARE PROVIDER

Communicating with healthcare providers, caregivers, and the support team



It may sometimes feel like you are lost in a maze as you attempt to uncover the answers to changes that are happening with your loved one. One way to find your way is to gather as much information as you can by talking to others who spend time with your loved one.

If your loved one does not live with you or she has a caregiver that comes into your home to help with her care, they may have some observations that you will want to know about. Others on her support team, such as day program staff, may also have information that could be the key to what is happening with your loved one.

Every bit of information you can get will help the healthcare provider make a diagnosis. To best support your loved one, it is important that you know exactly why the diagnosis was made and what it will mean for you and loved one. Once a diagnosis has been confirmed you should try to learn as much about it as possible. Ask the healthcare provider to explain the diagnosis and loved one's condition in words that that you understand. If you don't understand, ask him or her to go over it again, and perhaps in a different way. Some families have found it helpful to take a second person to the appointment who can help take notes and discuss the conversation afterward. Ask for information in writing so you can review it later and follow up by getting additional material that will help you understand the diagnosis and how you can best support your loved one. Here is a list of tasks you can do that may be helpful as you work with the healthcare provider:

- **Learn all you can about dementia** and its connection to people with intellectual and developmental disabilities. Awareness of the disease process can help you better plan and gather information to best support your loved one.
- **Keep a notebook with your questions.** Ask a lot of questions as this will help you learn.
- **Create a listing of loved one's abilities, activities, likes, dislikes, characteristics,** as well as **medications** used and **medical visits.**
- **Discuss your concerns with the healthcare provider and care team** as you begin to see changes such as difficulty walking, confusion, mood changes, or declines in other areas.
- **Ensure that your loved one is accurately assessed;** this is important as there may be other conditions that mimic symptoms of dementia which may be correctable.
- **Do not be afraid to ask for clarification, additional tests or referrals** to specialists to get the most information possible.



Telling your loved one

Some families have struggled with how much they tell their loved one or whether they should say anything about the diagnosis. It is a very personal decision and one than only you and your family can make.

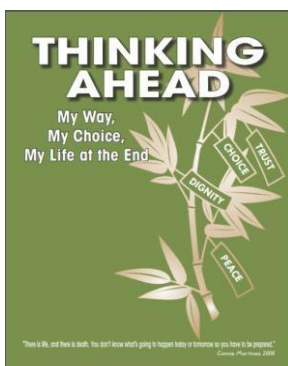
Consider these factors as you make this decision:

- Will my relative understand?
- How will I tell him or her?
- How much information should I share?
- How can I keep the message simple, and not scary?

An excellent source of information on dementia for persons with an Intellectual disability is a booklet from Down Syndrome Scotland. You can find it at this website:



 <https://aadmd.org/sites/default/files/whatisdementiabooklet.pdf>



Talking about planning your life with a diagnosis of dementia is not easy, and you may wish to seek counsel from a trusted and knowledgeable friend, a social worker, or another person. If you choose to share this information with your loved one, there are resources available that can help you do that. The Coalition for Compassionate Care of California created a workbook that addresses end-of-life care, written specifically for people with developmental disabilities. You can find more information at their website.

 <http://coalitionccc.org/tools-resources/people-with-developmental-disabilities/>

Giving consent

In Rhode Island, a parent is the natural guardian of a child up until the age of 18. At this age, a person is presumed competent to make his or her own decisions. In some cases, people with an intellectual disability may have the capacity to make certain decisions.



Guardianship is just one way to support a person with an intellectual disability who needs assistance making decisions, including those related to health care. Every state has different rules for obtaining guardianship so it is important that you understand the laws in Rhode Island. To learn more about guardianship in Rhode Island contact the Rhode Island Disability Law Center at 404.831.3150 or on their website at

 <http://www.ridlc.org/>.

Some situations will require careful thought before a decision can be made. For example, with decisions about medical interventions and long-term care, think about this:

- **What is being asked?** Is the decision related to something temporary (like the use of a medication or a short-term hospitalization)? Is it a more long-term decision such as where the person will live as she receives ongoing care as the dementia progresses?
- **Who will the decision impact?** Some decisions will impact only your loved one and other decisions may affect her family, roommates or caregivers, as well.
- **Can my loved one make an informed choice about this situation?** Is your loved one capable of using the information available to make a decision that is best for her quality of life? You may decide she is and look for ways to give her more information to make the best decision possible.

Making decisions

Dementia symptoms are caused by underlying progressive diseases, so there will be many times that decisions need to be made. In the initial stage, those may include further testing, choices of medications (or whether to continue a medication that has been prescribed). As the disease progresses, you will want to be sure that you have made plans for where care will be provided and how end-of-life care is given.

Our values, past experiences and input from others can help guide us to make important decisions. Even if you have gathered all the facts or information about the situation and are the only one who has the legal responsibility, it can be helpful to talk with someone you trust – another family member, your religious or spiritual counselor, or your healthcare provider. In support of your loved one, as his healthcare advocate, you may find these steps to decision making helpful:

- Gather the facts and possible options.
- Determine what the goal is or what are you trying to do.
- Understand the choices available.
- Talk with someone you trust.

NOTE: Sometimes we make a choice and then get additional information that leads us to another decision. People with an intellectual disability, just like others, have the right to change their minds when more information becomes available or the situation changes.

Some people with intellectual disability may have had personal involvement with another family member or friend who had dementia. Sometimes those experiences can help them make more informed decisions. Keeping notes and pictures about their encounters may help shape later conversations and aid the person to understand the issues.

“My friend with intellectual disabilities knows what dementia is, as he has experienced what it was like with my mother who has a dementia whom he also knew. This experience greatly helps when we talk about dementia and try to document his choices.”

NOTE: With respect to making decisions, it is important to realize that even though parents of an adult son or daughter with a disability may not have been questioned about consent in the past, when permission is necessary in an emergency, it can become very emotional and complicated. One family who took their adult daughter to a new clinic for evaluation found themselves in a “catch-22.” The primary physician had indicated that the woman could make her own decisions, yet the staff at the new clinic didn’t feel she could. And, they wouldn’t give information to the parents because they weren’t legal guardians.

This is a good example why it is recommended that families seek advice about guardianship, power of attorney or healthcare advocacy as early as possible.



Helpful Rhode Island Booklets

The discussion of guardianship and its details is beyond the scope of this guide. For more detailed legal information, these resources may be helpful:

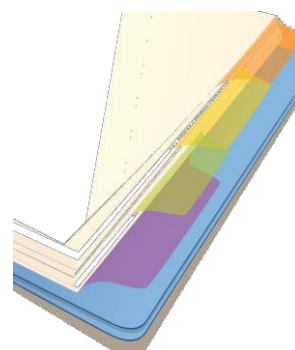
For information on legal guardianship, the **Rhode Island Disability Law Center**, has an informative booklet, *Guardianship and Alternatives to Guardianship* available at <http://www.ridlc.org/media/publications/ridlc-guardianship-booklet.pdf>

This document also reviews examples of alternatives to guardianship, based on the kinds of decision-making supports that a person needs, such as Representative Payee or Fiduciary, Power of Attorney, Trusts, and more. *Rhode Island Durable Power of Attorney for Healthcare* <http://www.health.ri.gov/lifestages/death/about/livingwill/>

PROVIDING CARE

Determining next steps

Once a diagnosis has been confirmed and any medical conditions that are treatable have been dealt with, you may want to create a personal road map that will guide you on the dementia journey. Some families use a three-ring binder with sections that allow them to add information as it is gathered. It will be a good place to keep your loved one's records and other important documents related to your loved one's care. Other ideas include keeping files in one location on your computer or paper files.



You may want to keep the following information where it is easy for you to find:

- **An Emergency Kit with critical information about the person** in case something happens to the caregiver
- **Information about the diagnosis** that you receive from trusted sources
- **A calendar with a To-Do list** that you can change and update as needed
- **A copy of the NTG-EDSD** or other screening tool you can update as your loved one's skills change
- **A copy of your loved one's life story**
- **A list of your loved one's medications** that includes the name of the prescribing healthcare provider, the date first prescribed, purpose, side effects to watch for, and notes
- **A list of your loved one's healthcare providers and other members of her support team** with their role, their address, and contact information for each
- **Copies of legal documents** such as healthcare directives, durable power of attorney for healthcare, living will, and burial plans
- **A list of local resources** that can help with caregiving and other support you may need

Learning about caregiving

If you have been giving care to your loved one his entire life, you already know that it can take a lot of your time. In the early stage of Alzheimer's or other dementia, there will be little change in the level of care that is needed; however, there are some things you should know.



First and foremost, do not spend all your time reading about dementia. Find good sources of information, like the NTG or the Alzheimer's Association to learn about dementia. Then, find others who are providing care to loved ones with intellectual disability and dementia. There may be a support group in

your area that you can attend. Some of the best support you will find may come from others who are on the same journey. As you learn, share with others in your family so they can support you and your loved one. That adage of “it takes a village,” is true when it comes to caregiving. The more people who know what you know, the more support your loved one will have. Even if all the others do is listen when you need to vent, at least they will understand your frustration.

Offering ongoing care

Your loved one will benefit from a well-developed Dementia Care Plan. This may be a new and separate plan of support or it could be a revision of an existing plan. The foundation of the plan must be **person-centered** and focused on the current and changing needs of your loved one. It should include his wishes, likes and needs to ensure that his journey through the disease is well supported to provide a good quality of life.

Being familiar with changes that may occur can help you and your loved one create a person-centered plan that will support them through the disease process. Declines and changes occur that require more and different types of supports. Work with your healthcare provider and care team to best determine the support loved one needs through each phase. Obtain periodic reviews of the plan to identify changes in health and function and adjust activities and care practices, as needed.

Psychological and medical oversight of dementia-related needs, as well as non-dementia conditions will be important. Even during the disease, people can show acute changes that are not due to the dementia but can be treated. This will make a significant difference in the person’s quality of life. For example, urinary tract infections can present as a worsening of dementia symptoms, yet when they are treated and resolved, the person can return to their former level of functioning.

Over the course of the disease it will be important to integrate medical care with non-medical interventions and approaches that work best with loved one. To ensure that the Dementia Care Plan is supporting your loved one at each stage of the disease, monitor changes in:

- Behavior
- Personality
- Anxiety
- Increased confusion
- Physical changes, such as weight loss, mobility and continence

Person-Centered Care

The key points of person-centered care are to:

- Treat people with dignity and respect
- Know the person’s
 - History
 - Lifestyle
 - Culture
 - Preferences
 - Likes
 - Dislikes
 - Hobbies
 - Interests
- Observe from the person’s point of view
- Provide opportunities for conversations and relationships with others
- Ensure opportunities to try new activities or participate in activities they enjoy

There are many physical issues that occur because of dementia. Individuals may experience problems eating and drinking, loss of bladder and bowel control, lung and urinary tract infections, skin and joint problems (due to an inability to move on his own), pain, and increasing problems with communication. As a family caregiver, you will need to determine how aggressively you want to treat these conditions and what medical treatments you want for your loved one. Monitor your loved one closely to address any dementia-related needs, as well as any potential medical needs. Be mindful of updating and changing support approaches, individual treatment plans, or care plans over the course of the disease.

Talking with other family members

A diagnosis of dementia can be very stressful for families and caregivers. Sometimes, it can be challenging working through family dynamics when deciding on the best care and supports for your loved one.

Understand that each day will be different, and that your role as a caregiver will change over time. You may need to seek help from others in your family with the caregiving demands. Have regular discussions with your family about loved one's changing condition, your changing need for support as his caregiver, and what others can do to assist you in your care role.

Don't forget to make time to take care of *yourself* and be open to getting help. If you are tired or irritated, your loved one will sense and may mirror your feelings, even if your words say something different. Caregiver stress and burnout are real and the risk becomes greater as the care demands increase. Many caregivers have difficulty asking for help for themselves, but you need to take care of yourself as you are the most important medicine your loved one receives. Most family members want to know how they can help. Your honesty and direct requests will be appreciated as they try to support you and your loved one.

Think about what you need. Do you want someone to help you with a healthcare provider's appointment for your loved one? Do you just need someone to come sit and have coffee so you can talk, or would it help to have a relative or friend to stay with your loved one so you can get away for a few hours? This is not a time to be shy about your needs as a caregiver. Remember, relationships with others are very important, for both you and your loved one. They will grow even more valuable as the disease progresses.

Thinking about legal and financial issues

All of us should have a plan for our future that includes how we want our life to end. It is not a topic that is easy to consider, much less to discuss with others. However, advanced

planning allows you and your loved one to think about difficult issues without the pressure of what may be a crisis.

In Rhode Island, you can make advanced directives that will give the healthcare providers information on what you and your loved one want when their life is coming to an end. Know that any decisions that are made are voluntary and can be changed when you request. Some of the decisions you may be asked to make could include:

- Hospitalization
- Artificial nutrition
- Hydration
- Use of artificial breathing equipment
- Use of antibiotics and other medications
- Resuscitation maneuvers
- Initiation of palliative care and/or hospice including other end-of-life wishes

You may want to speak to a healthcare provider to understand what end-of-life procedures may be offered and what can be expected if they are implemented or if they are not used. An attorney can help you understand the legal aspects of any documents you may create or complete, such as a durable power of attorney for healthcare, a living will, or *medical orders for life sustaining treatment* (MOLST).



These forms can be found on the Rhode Island Department of Health website. <http://www.health.ri.gov/lifestages/death/about/endoflifedecisions/>

Future planning includes more than considering medical care for your loved one. You may also want to think about financial issues, including how to pay for care. Some of your loved one's care may be covered by her insurance, such as Medicare or Medicaid. It will be important for you to know what is covered and what other resources may be available. Medicare and RI Medicaid cover health care expenses and RI Medicaid provides caregiving and long-term care supports.

As heart-breaking as it can be to consider, funeral planning can be made a little less painful if it is done before it is needed. Pre-planning is a service all funeral homes offer. By making arrangements ahead of the need, you can be assured that the final acts to honor your loved one are carefully considered and well-thought out. Although there is monetary value attached to a burial plan, it is not counted against your loved one in determination of any government benefits.

These decisions are not easy ones to make. There may be disagreements among family members during these discussions. For some people, these decisions create such stress they may become defensive or argumentative. And some may just refuse to be part of the discussion.

If you find it is hard to have family dialog about the care and final plans for your loved one, consider asking a trusted person to help. Someone like a minister or social worker may be able to facilitate discussion and keep emotions from overwhelming the process. It is important that all family members' opinions are acknowledged in a respectful way. Sometimes, people have difficulty coming to terms with the end of their loved one's life. Allowing an opportunity to talk about their feelings will be important to working together to best support your family member with an intellectual disability and dementia.

Planning for end-of-life care

During this journey, there are many decisions that will need to be made related to complications and natural outcomes of the disease. It can be very difficult to think about end- of-life care. As you give care and support to your loved one daily, it can become exhausting and overwhelming. Sometimes, it just feels easier to put off thinking about the end of this disease. However, thinking about, and discussing end-of-life decisions will benefit everyone when this time comes.

As the disease progresses, people become frailer and are more dependent on others for their care. They will no longer be able to care for themselves, will have lost their mobility and their general health will have deteriorated. You may get guidance from your loved one's healthcare provider or another medical professional when loved one has advanced dementia and is close to dying. It is important to understand what is happening and how supports will need to change.

Your loved one may be eligible for palliative or hospice care. It is important to understand the difference between these two services. **Palliative care** is available for anyone with complex illness, specializing on comfort and symptom relief. Under palliative care ongoing treatment including curative care can continue. The focus is upon comfort and symptom relief; **curative treatments do not have to stop**. There are no time limitations for palliative care. **Hospice care** is available to anyone who has a physician determine the person is predicted to have six months or less to live. This prognosis enables Medicare, Medicaid and private insurers to pay for all hospice services. *Curative treatments are no longer in use when a person receives hospice care.*



In Rhode Island, there are several Hospice Providers and Palliative Care providers; to find them look in the local telephone directory or senior services directory.

 For more general information access these sites:

http://www.alz.org/national/documents/brochure_endoflifedecisions.pdf

<https://www.nia.nih.gov/health/publication/end-life-helping-comfort-and-care/introduction>

Sound Practices



The National Task Group on Intellectual Disabilities and Dementia Practices has produced or has available a variety of useful publications that speak to sound practices when someone with an intellectual disability as dementia. These can be accessed at <http://www.aadmd.org/ntg/practiceguidelines>.

Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia

These guidelines can assist families and organizations in planning for extended care that is needed when there is a diagnosis of dementia. They describe actions that should be taken that reflect the progressive nature of dementias, beginning with the pre-diagnosis stage when early identification of symptoms are first recognized. The guidelines cover all stages of dementia from early to mid, through the advanced stage.

The National Task Group on Intellectual Disabilities and Dementia Practices Consensus Recommendations for the Evaluation and Management of Dementia in Adults with Intellectual Disabilities

These guidelines can aid physicians and other professionals with assessing and diagnosing adults with intellectual disability and dementia.

Guidelines for Dementia-Related Health Advocacy for Adults with Intellectual Disability and Dementia: National Task Group on Intellectual Disabilities and Dementia Practices

Health advocacy guidelines aid family members and staff to prepare for, and advocate during health care visits. Suggestions include taking note of symptoms of cognitive impairment and decline, recognizing and communicating symptoms, as well as finding appropriate practitioners familiar with the medical issues presented by aging adults with lifelong disabilities.

CAREGIVING TIPS

Dealing with confusion and forgetfulness

Memory loss and confusion are symptoms of dementia that your loved one will experience at some point in the progression of the disease. Forcing a person to try to remember will only create anxiety and frustration for your loved one.

Validation and support will give comfort to your loved one. As her brain is changing, she will live, at times, in a new reality which is real to her. Meet your loved one in that reality. Always agree when possible rather than trying to correct her. Trying to teach her or give her instructions will only frustrate her, because she no longer can retain the information you are trying to teach. Rather, redirect with kindness for a better response. Here is an example.

Rachel keeps saying she wants to go home, yet she is at home. The home she speaks of is her childhood home. The caregiver can ask, "Are you wanting to see the house you grew up in? Tell me about your home." As Rachel responds a caregiver can redirect the conversation from Rachel wanting to go home to talking about childhood memories.

You may also want to use visual cues or reminders to help prompt or remind your loved one when they become forgetful. For example, you can use photos or clip art along with words as a visual reminder of where rooms are located, items are stored, or even a simple schedule for the day. You will find more examples in the following pages as well as in the resource section at the end of this guide.

Here is an example of creating visual cues for hand washing.

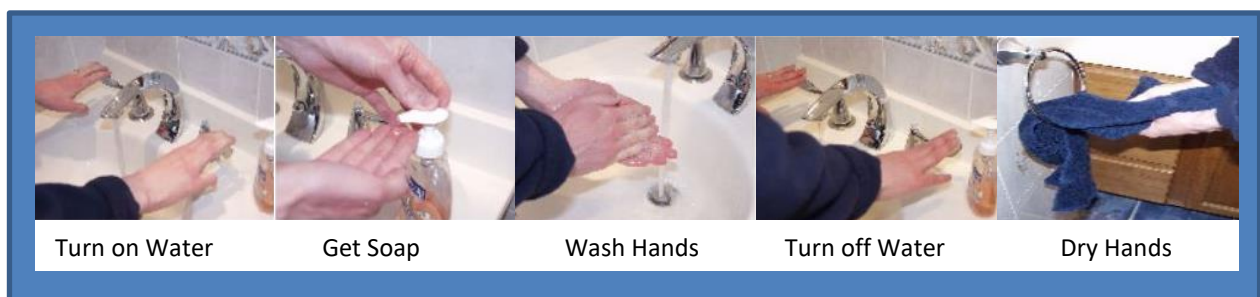


Photo credit: Functional Living Skills and Behavioral Rules, Silver Lining Multimedia, Inc.

Home Safety

Home safety will be an important part of your caregiving, and the needs of your loved one will determine what you should do. As the disease progresses, your loved one's visual perception may change or your loved one may begin to wander inside and outside his home. He may get lost trying to find the bathroom or have difficulty getting out of the tub.

Some changes that you will need to make to your loved one's environment will be no-cost or very low-cost. However, there are some that may entail a monetary outlay. Speak with other members of your loved one's care team to find out if there may be any financial assistance available for changes you might need to make.

i The following list is not exhaustive of everything that can be done to create a safe home environment. The Alzheimer's Association has documents that can help you check every area of your loved one's home. Find them at:

<https://www.nia.nih.gov/alzheimers/publication/home-safety-people-alzheimers-disease/introduction>

Precautions to think about:

- Place emergency telephone numbers and the address near all the phones in the house
- Install smoke alarms and carbon monoxide detectors
- Install secure locks on all doors and windows
- Hide a spare key outside, in case your loved one locks you out
- Avoid using extension cords
- Eliminate clutter like old magazines and newspapers
- Add brightly colored, reflective tape to all stairs
- Remove scatter, throw, and area rugs – anything that can cause tripping
- Keep all medications, both prescription and non-prescription, in a locked cabinet
- Provide adequate lighting, both inside and outside
- Eliminate glare by adding light-filtering sheer curtains to windows
- Add decals at eye level on all sliding doors
- Add decals to the bottom of the tub to provide depth perception
- Install grab bars in the tub and shower area, as well as around the toilet
- Set the water heater to no hotter than 120° to prevent scalding
- Keep the laundry room door locked or laundry supplies in a locked cabinet


For structural modifications, you may want to learn more about universal design principles and aging in place principles to take into consideration when remodeling your space.



Universal Design Principles

Wandering

Wandering is a common occurrence in people with Alzheimer's and other dementias. It is estimated that 60% will wander in their home, neighborhood or community at any time during the disease. It is not unusual for a person with dementia to become disoriented in a place that is very familiar to them, and it can create a very dangerous situation.

 The Alzheimer's Association suggests three things you should be aware of: *know who is at risk* for wandering, *learn how to prevent* wandering, and *create a plan* to implement in an emergency. Additional information can be found at <https://www.nia.nih.gov/alzheimers/publication/home-safety-people-alzheimers-disease/introduction>

Clues your loved one may wander:

- Has difficulty finding his bedroom or the bathroom
- Appears to be doing a hobby she loves but gets nothing done
- Acts restless or paces

Hints to prevent wandering:

- Maintain supervision, a structure, and consistent schedule
- Make sure basic needs, such as food, thirst and toileting, are met
- Reassure him if he seems disoriented or lost, even if it's in his home
- Lock doors and place locks out of your loved one's line of sight
- Install a signal device that sounds when a door or window is opened

Tips for a plan of action:

- Ask neighbors to let you know if they see your loved one alone
- Provide the police with a recent close-up photo and medical information
- Know your home, property, and neighborhood – especially spots that could be dangerous for your loved one
- Know which side is dominant for your loved one - wandering tends to be in the direction of the dominant hand
- Wait no more than 15 minutes to call 911

Maintain an *emergency kit* with your loved one's photo, description, medication list, and information about language skills and peculiarities –to inform the Police or others who may be helping to find him.



Brain Health

Heart health = Brain Health

Healthiness is important for you and your loved one. Heart health is related to brain health - both stem from a healthy diet, exercise, and minimizing stress and are important to well-being in older age.

Overall brain health is dependent on maintaining a healthy balanced diet, engaging in physical activity, social engagement, sleep and rest, and stress reduction.

Focus on activities that can reduce stress and provide meaningful mental stimulation. It is important to assure plenty of rest and sleep. These activities reduce the risk of cognitive decline and maintain alertness and stamina. This is important for you – to maintain your own health – and to your loved one – to maintain the skills that she has.

 [Alzheimer's Association Brain Health](https://www.brainhealth.acl.gov/)

<https://www.brainhealth.acl.gov/>

Healthy foods boost brain health

What you eat can affect your composure, help with stress, and help you maintain your mental strength. Know your food groups and be careful with your choices... look for healthy foods that reduce your fat and salt intake, and increase fiber, vitamins and helpful nutrients.



 <https://www.nia.nih.gov/health/topics/nutrition>

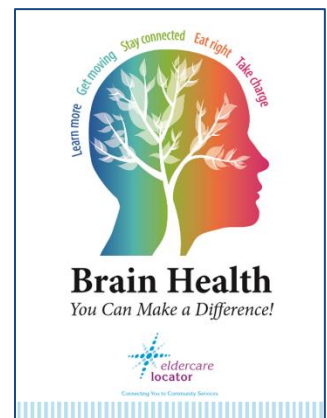
“Brainy Resources”

The Administration for Community Living has partnered with the National Institutes for Health, the Centers for Disease Control and Prevention and leading research groups to offer valuable brain health resources. This information can be a great starting point in becoming brain healthy.

 <https://brainhealth.acl.gov/brainy-resources/?Length=4>

For a copy of the Brain Health brochure:


 <http://www.eldercare.gov/eldercare.net/public/Resources/Brochures/docs/Brain-Health.pdf>



Healthy Aging: Nutrition, Exercise, and Mental Activity

Maintaining healthy eating habits are critical for your loved one's well-being. As your loved one moves through the stages of dementia, mealtime may become stressful. She may no longer realize that she is hungry, may have forgotten that she did not eat or may be overwhelmed by too many food choices. As with other activities in your loved one's daily life, you will want to keep a consistent schedule for meal times. Your encouragement may be all she needs to complete her meal, or, you may need to provide verbal reminders to pick up the fork or take a drink. Sitting with her and smiling as she eats may provide the assurance she needs.

The following ideas may help you support your loved one to continue to enjoy mealtime for as long as possible. Additional information can be found at

 <https://www.alz.org/care/alzheimers-food-eating.asp>
<https://www.alz.org/care/alzheimers-food-eating.asp>

Focus on the environment:

- **Limit distractions** by serving meals in a quiet place (no television or radio) and keeping unnecessary items off the table.
- **Provide a chair** that helps your loved one maintain good posture.
- **Present just the utensils** your loved one will need.
- **Distinguish food from the plate and the plate from the table** by using plain, brightly colored plates and bowls.
- **Allow plenty of time** for your loved one to complete her meal.

Focus on the food:

- **Be flexible.** While it is a good idea to keep favorite foods on the menu, your loved one may forget something was a preferred item, and may like something she would have never eaten.
- **Serve food at the right consistency.** As the disease progresses, it may become necessary to cut food into small bites or even puree it.
- **Serve only one or two foods at a time.** This may mean serving the meal in sequence rather than all at once.
- **Check the food temperature** to be sure that it isn't too hot.
- **Eat together** because mealtime is a social activity and is more pleasurable when shared
- **Remind your loved one to chew, swallow, take a drink and not talk** while eating. These reminders may be what prevents her from choking.
- **Make meals an enjoyable social event** so everyone looks forward to the experience. Research suggests that people eat better when they are in the company of others.

- **Keep in mind the person may not remember when or if he or she ate.**
- It may help to **have simple finger foods** available that she can snack on between meals.
- **Prevent choking** by serving food at a consistency your loved one needs.

Physical Activity

Try to engage your loved one in activities that raises the heart rate such as walking, easy aerobic exercises, or even chair exercises. The point is to maintain conditioning and provide stimulation. Any exercise can be healthy. If wandering is something that occurs, create an inside or outside wandering path that provides for exercise. If functions permit, try an exercise bicycle as a way of promoting movement.

Social Engagement

Developing a network of friends, family, peers, and neighbors to connect your loved one with rich relationships that will be engaging and mental stimulation. As your loved one become more engaged with her social circle, relationships become more meaningful and important to their overall wellbeing.



Behavior Changes

Behavior is communication and it's important to realize that, with dementia, behaviors are going to change. Understanding that the person is not trying to be difficult or create problems will help both you as a caregiver and your loved one with dementia. Most importantly: stop, look, and think before reacting to a behavior change.

Behavior changes are often a way to communicate an unmet emotional or physical need. They tend to show up as distress, anxiety, aggression, or frustration for not being understood – often because of things like pain, boredom, hunger, and confusion. Look for the emotions behind the words and actions. Remember, this is about making every effort to understand what is being communicated. Knowing the person's typical behavior, patterns of their everyday life, and their abilities could help you identify what may be causing behaviors changes.

As dementia progresses, there are changes in perception, causing confusion. Creating an environment that is safe and free of clutter and distractions will often help to reduce anxiety.

SUNDOWNING

Behavior distress often worsens in the late afternoon and evening. You may see increasing confusion, agitation, and anxiety, along with pacing, wandering, and intensification of any behavior problems. It is thought that changes in the lighting and increased shadows make the environment more threatening. Also, by the end of the day fatigue and accumulated stress deplete the person's ability to cope. Some helpful suggestions include:

- Keep the area well lit. Some places keep the light on all day.
- Arrange the person's schedule so that most major activities occur earlier in the day.
- Reduce the hustle-bustle in the evening, such as TV or social activities
- Reduce stimulating large group activities in the late afternoon or evening
- Alternate activity with rest periods if there is a limited ability to cope
- Allow the person to pace in a visible, secure area or take them for a walk
- Offer quiet companionship
- Increase security and comfort by offering "warm, soft- familiar objects", soothing music, or the opportunity for a favorite activity



SLEEP DISTURBANCE

Problems with the sleep-wake cycle, inability to settle down for sleep or disorientation at night can be very problematic . . . especially if the caregivers (and housemates) are not getting their rest. Helpful suggestions include:

- Have a consistent wakeup time, no matter when the person goes to sleep
- Discourage napping during the day
- Keep the house brightly lit both day and night
- Establish a bedtime ritual which is consistent every night
- Do not offer liquids three hours before bedtime and be sure that toileting has occurred
- Offer a “warm, fuzzy” object or soothing music for comfort
- Avoid caffeine, excess sugar, and alcohol. Review medications for side effects
- Offer any prescribed pain medications a half hour before bedtime

MOOD PROBLEMS

Remember, behavioral distresses are the symptoms of the disease and should never be taken personally. There will be good days and bad days, so expect changes and stay flexible and maintain a sense of humor. The most important thing is to give reassurance, affection, and emotional support to your loved one and to be caring to yourself.

Some persons with dementia have extreme **mood changes** or **sadness**, which are rapid swings in emotions, resulting in behavior that is inappropriate. If loved one seems sad or is having mood swings that are not typical, **reassure her** and let her know **you are concerned** and will **always be there for her**.

Reducing depressive behavior:

- **Encourage daily exercise**
- **Acknowledge your loved one's sadness**; express hope she will feel better soon
- **Schedule outings** that include activities and people that your loved one enjoys
- **Celebrate small successes** and occasions

Some persons may experience **anxiety or agitation** as the disease progresses and they do not understand what is happening to them. This behavioral change may be due to medications, medical conditions or changes in the person's environment – a change in residence or caregiver, for example. Changes in your loved one's brain can make it difficult to process new information, resulting in anxiety.



Reducing anxious behavior:

- **Create a calm environment.** You may need to remove your loved one from his current location.
- **Avoid environmental triggers** such a glare from sunlight coming through the windows or the noise of the television.
- **Monitor personal comfort** to rule out pain, hunger, fatigue or infections
- **Simplify tasks and routines.**
- **Provide an opportunity for exercise** as it makes a great outlet for anxiety for your loved one and yourself. Take a walk or dance to your loved one's favorite song.

Some persons with dementia have **delusions** that are firmly held beliefs that are not grounded in reality, or truth, often occurring as a result of changes in the brain. (A delusion is not the same as a hallucination. Hallucinations are the experience of hearing or seeing things that cannot be verified. Both delusions and hallucinations are common in dementing diseases.) Your loved one may be afraid someone is trying to poison him or may believe that something belongs to him that doesn't. If your loved one is exhibiting signs of delusions such as mistaken identity, concern that someone is doing something to hurt or harm him or other false ideas, gently **provide reassurance** and **ask your loved one to tell you more about the delusion.**

Reducing chance of delirium

Delirium is a medical condition that results in confusion and other disruptions in thinking and behavior, including changes in perception, attention, mood and activity level. Adults with dementia are highly susceptible to delirium. Delirium is a more abrupt confusion, emerging over days or weeks, and represents a sudden change from your loved one's previous course of dementia - and due to some medical illness or adverse medication reaction. The confusion of delirium fluctuates over the day, at times dramatically. Alertness may vary from a "hyperalert" or easily startled state to drowsiness and lethargy. A person with delirium cannot focus on one idea or task. Watch for:

- **Urinary tract infections**
- **Influenza**
- A "**brain event,**" such as **stroke** or **bleeding** from an **unrecognized head injury**
- An **adverse reaction to a medication** or **alcohol, mix of medications**

Reducing delusional behavior:

- **Create a calm environment.** You may need to remove your loved one from his current location.
- **Acknowledge your loved one's thoughts and opinions.** *Whatever you do, do not*

argue with her. In her mind, the concern is real.

- **Reassure your loved one.** Let your loved one know you care. Listen, go into your loved one's reality and try to understand.
- **Keep comments simple.** Your loved one is having trouble perceiving his environment accurately. Keep explanations short.
- **Redirect your loved one** with another activity that will take his mind off his thoughts.
- **Replace lost items** as soon as possible. Have duplicates of those items that get lost frequently and pay attention to where he typically places his belongings.

Some persons with dementia also have **paranoia**, which is a false idea, especially of persecution or extreme grandeur, and an irrational distrust of others. It is often connected with delusions, creating suspicions such as thinking that someone is stealing their food or personal items. Understand why they may be suspicious and **use diversion techniques** to help them focus on something else, usually something incompatible with the issues that make them suspicious.

Reducing paranoid behavior:

- **Acknowledge and validate** your loved one's feelings.
- **Provide non-verbal reassurances**, such as a gentle touch or hug.
- **Speak in a gentle, calm tone.**
- **Tell your loved one you will keep him safe.**
- **Redirect** your loved one to a more pleasant activity such as looking at photos.

The Alzheimer's Association has more information on each of these behavior changes that may be seen when people with intellectual disability have dementia.

 Depression:
<http://www.alz.org/care/alzheimers-dementia-depression.asp>

 Anxiety/Agitation:
<http://www.alz.org/care/alzheimers-dementia-agitation-anxiety.asp>

 Delusion:
<http://www.alz.org/care/alzheimers-dementia-suspicion-delusions.asp>

 Hallucinations:
https://www.alz.org/national/documents/topicsheet_hallucinations.pdf

 Paranoia:
<http://www.alz.org/care/alzheimers-dementia-suspicion-delusions.asp>

Meaningful Day

Having a day that is filled with meaning and with a sense of worth and value is vital to all of us. That doesn't change just because someone has dementia. It is important that you are aware of what is of most value to your loved – those people, places and activities that make her feel good about herself. It is equally important that you find ways to ensure she continues to have opportunities for meaningful days.

- **Create a predictable and consistent schedule and opportunities**, based on your loved one's abilities, likes, and interests.
- **Simplify activities** when necessary, but **keep your loved one involved**. If your loved one could do his laundry independently, determine which parts he can still do. Help him do those tasks that are more challenging to him. Perhaps you will need to put his shirts on the hanger, but he can still hang them in the closet.
- **Prepare for changes**, as preferred activities may become a source of anxiety or frustration and engagement may be for short periods.
- **Include a variety of choices** – including physical activities, arts and crafts, music and dance, spiritual and other sensory activities.

Below are some resources you may find helpful.

 ***Developing Meaningful Activities***

<http://www.alzheimers.net/2014-03-06/stimulating-activities-for-alzheimers-patients/>

 ***101 Activities for Individuals with Alzheimer's***

https://www.alz.org/living_with_alzheimers_101_activities.asp





GETTING ASSISTANCE IN RHODE ISLAND

Learning about eligibility

Your loved one may be eligible for services that he is not yet receiving. His primary care provider or other specialist may be able to refer your loved one to services that may be helpful. If he already receives service from the **Rhode Island Department of Behavioral Healthcare Developmental Disabilities and Hospitals (BHDDH)**, his caseworker may know of other services for which he is eligible.

- i** If your loved one has not been receiving services from BHDDH, contact the eligibility caseworker at 1 401 462-3421 or visit their website:

http://www.bhddh.ri.gov/developmentaldisabilities/application_eligibility.php

Accessing and paying for services


If your loved one needs ongoing care, **THE POINT** may be able to assist. THE POINT is Rhode Island's Aging and Disability Resource Center (ADRC), and with community partners can provide you with information, referrals, counseling about your options, and service delivery. THE POINT can be reached at 401.462.4444.

- i** Applications for Long Term Services and Supports (LTSS) can be downloaded from the **Department of Human Services (DHS)** Website at <http://www.dhs.ri.gov> or can be requested by calling the DHS LTSS Coverage Line at 1 401 415-8455. Applications can also be completed in person at the central office located at 206 Elmwood Ave. Providence, or at any DHS Office.

You can also get information about applying for LTSS from:

- Hospital Navigators
- Community Action Agencies
- Nursing Care Facilities
- THE POINT
- Senior Centers
- The Rhode Island Department of Behavioral Healthcare, Developmental Disabilities and Hospitals
- The Rhode Island Division of Elderly Affairs


Consider services such as help in the home, day programs, transportation to medical appointments and day programs, and respite care. Information on these and other services can

 be found in the **Rhode Island Division of Elderly Affairs (DEA)** *Pocket Manual of Services for Seniors and Adults with Disabilities* <http://www.dea.ri.gov/Pocket%20Manual/2015-2016%20Pocket%20Manual-pdf.pdf>

Go online at <http://www.uwri.org> or call 2-1-1 RI at 1 401 444-0600 to find out what other financial help for which you might be eligible.

Considering guardianship and other legal options


If you need help determining if guardianship or other legal option is right for your loved one with an intellectual disability, you can contact the **Rhode Island Disability Law Center**. The Disability Law Center is an independent nonprofit law office that is designated as Rhode Island's federal

 Protection and Advocacy System. They are part of a national network created by Congress to help secure and advance the rights of people with disabilities. You can reach them by email at info@ridlc.org or by calling them at 1 401 831-3150.

Thinking about end-of-life planning

When you are ready, there is help for end-of-life planning. Both the **Rhode Island Alzheimer's Association** and the **Rhode Island Department of Health** have information that can help answer your questions. You can reach the Alzheimer's Association at 1 800 272-3900. The Department of Health has information about Rhode Island laws and the forms you can use on their web site

 at <http://www.health.ri.gov/lifestages/death/about/endoflifedecisions/>.

 For more information on these topics please check out the Rhode Island Executive Office of Health and Human Services *Guide for Caregivers* at: http://www.dea.ri.gov/New%20DEA%20Publications/RI%20OHHS%20CaregiverGuide_508_Compilant-pamphlet.pdf

LEARNING MORE: LOCAL, NATIONAL & INTERNATIONAL RESOURCES

| Topic | Resource |
|---|---|
| <i>Advocacy & Self-Advocacy</i> | The Association for Persons with Severe Handicaps (TASH) 2013 H Street NW, Suite 404, Washington, D.C. 20006 202.540.9020 Website: http://www.tash.org |
| | Self-Advocates Becoming Empowered (SABE) P.O. Box 12239, Florence, SC 29504 Email: SABEnation@gmail.com Website: http://www.sabeusa.org/ |
| <i>Aging</i> | AARP 888.687.2277 Website: http://www.aarp.org |
| | US Department of Health and Human Services Administration on Community Living Long Term Care Website: http://www.longtermcare.gov |
| <i>Alzheimer's Disease & Dementia</i> | Alzheimer's Association Rhode Island 245 Waterman Street, Suite 306, Providence, RI 02906 401.421.0008 Website: http://www.alz.org/ri/ |
| | Alzheimer's Association National Office 225 N. Michigan Ave., Fl. 17, Chicago, IL 60601 800.272.3900 Website: http://www.alz.org Webpage: What is Alzheimer's? http://www.alz.org/alzheimers_disease_what_is_alzheimers.asp |
| <i>Caregiving</i> | AARP Prepare to Care Website: http://www.aarp.org/home-family/caregiving/ |
| | Alzheimer's Association on creating a daily routine and personal care Webpage: Daily Care Website: http://www.alz.org/care/alzheimers-dementia-daily-plan.asp |
| | American Association on Health and Disability – Evaluation of Activities of Daily Living 110 N. Washington Street, Suite 328-J, Rockville, MD 20850 301.545.6140 Website: http://www.aahd.us Webpage: Evaluation of Activities of Daily Living http://www.aahd.us/2013/03/evaluation-of-an-activities-of-daily-living-scale-for-adolescents-and-adults-with-developmental-disabilities/ |

| Topic | Resource |
|---|---|
| <i>Caregiving</i> | <p>Paying for Senior Care: The American Elder Care Research Organization 50 West Liberty Street, Suite 880, Reno, NV 86501 641.715.3900 ext. 606151# Website: http://www.payingforseniorcare.com Webpage: Activities of Daily Living http://www.payingforseniorcare.com/longtermcare/activities-of-daily-living.html</p> |
| <i>Communicating with individuals with intellectual disability & dementia</i> | <p>Guidance on how to explain dementia to individuals with intellectual disability and dementia. Webpage: Jenny's Diary: a resource to support conversations about dementia with people who have a learning disability Watchman, K; Tuffrey-Wijne I. & Quinn S (2015) London, Alzheimer's Society http://www.learningdisabilityanddementia.org/jennys-diary.htm</p> <p>Intellectual Disability and Dementia: A Guide for Families Watchman, K (2017) London, Jessica Kingsley Publishers</p> |
| <i>Communication Behavior, & Behavior Management Techniques</i> | <p>Gulf Bend Center 6502 Nursery Drive, Suite 100, Victoria, TX 77904 361.575.0611 Toll Free 800.421.8825 Website: http://www.gulfbend.org Webpage: Alzheimer's Disease and Other Cognitive Disorders Behavior Management for Dementia Caregivers: http://www.gulfbend.org/poc/view_doc.php?type=doc&id=15344&cn=231</p> <p>Indiana Resource Center for Autism Indiana University Bloomington 1905 North Range Rd., Bloomington, IN 47408-9801 Phone: 812-855-6508 Fax: 812-855-9630 Website: https://www.iidc.indiana.edu/pages/irca Webpage: Observing Behavior Using A-B-C- Data http://www.iidc.indiana.edu/pages/Observing-Behavior-Using-A-B-C-Data</p> <p>Michigan Retirement Research Center University of Michigan P.O. Box 1248, Ann Arbor, MI 48104 734.615.0422 Website: http://www.mrrc.isr.umich.edu Working Paper: Communication with Individuals with Intellectual Disabilities and Psychiatric Disabilities: A Summary of the Literature [see section 3.6 Conclusions and Best Practices]</p> <p>National Down Syndrome Society 8 E 41st Street, 8th Floor, New York, NY, 10017 800.221.4602 Website: http://www.ndss.org Webpage: Managing Behavior http://www.ndss.org/Resources/Wellness/Managing-Behavior/</p> |

| Topic | Resource |
|--|---|
| Communication Behavior, & Behavior Management Techniques | <p>Webpage: Common Behavioral Pitfalls and Emphasizing the Positive Approach http://www.ndss.org/Resources/Aging-Matters/Alzheimers-Disease/A-Caregivers-Guide-to-Down-Syndrome-and-Alzheimers-Disease/</p> |
| Communication Behavior, & Behavior Management Techniques | <p>The University of Kansas 1450 Jayhawk Blvd., Lawrence, KS 66405 785.864.0693 Website: http://www.kansas.edu Webpage: Antecedent-Behavior-Consequence (ABC) Chart http://www.specialconnections.ku.edu/?q=behavior_plans/functional_behavior_assessment/teacher_tools/antecedent_behavior_consequence_chart</p> <p>Vanderbilt Kennedy Center for Excellence in Developmental Disabilities 110 Magnolia Circle, Nashville, TN 37203 615.936.8852 Website: http://www.vkc.mc.vanderbilt.edu/vkc/ Webpage: Communicating Effectively http://www.vkc.mc.vanderbilt.edu/etoolkit/general-issues/communicating-effectively/</p> |
| Developmental Disabilities | <p>American Association on Intellectual and Developmental Disabilities (AAIDD) 501 3rd Street, NW Suite 200, Washington, DC 20001 202.387.1968 voice 202.387.2193 fax Website: http://www.aidd.org Webpage: Definition of Intellectual disability http://aidd.org/intellectual-disability/definition#.V1S0iJErKUK</p> <p>Administration for Community Living 330 C St SW, Washington, DC 20201 202.401.4634 Email: aclinfo@acl.hhs.gov Public Law 106-402 An Act Webpage: The Developmental Disabilities Assistance and Bill of Rights Act of 2000 http://www.acl.gov/Programs/AIDD/DDA_BOR_ACT_2000/</p> <p>The Arc of the United States 1825 K Street NW, Suite 1200, Washington, DC 20006 Phone: 202-534-3700 800-433-5255 Website: http://www.thearc.org Webpage: Intellectual disability http://www.thearc.org/learn-about/intellectual-disability</p> |

| Topic | Resource |
|-------------------------------------|---|
| <i>Developmental Disabilities</i> | National Task Group on Intellectual Disabilities and Dementia Practices AADMD PO Box 681, Prospect, KY 40059 Webpage: https://aadmd.org/index.php?q=NTG |
| <i>Dementia</i> | Mayo Clinic 13400 E. Shea Blvd., Scottsdale, AZ 85259 800.466.2279 Webpage: Dementia http://www.mayoclinic.org/diseases-conditions/dementia/home/ovc-20198502 |
| <i>Disabilities & Inclusion</i> | Institute for Community Inclusion: Promoting the Inclusion of People with Disabilities Institute for Community Inclusion/UCEDD, UMass Boston, 100 Morrissey Blvd. Boston, Massachusetts 02125 Voice: 617.287.4300 Fax: 617.287.4352 TTY: 617.287.4350 Email: ici@umb.edu Website: http://www.communityinclusion.org Disability Information U.S. Department of Labor Office of Disability Employment Policy 200 Constitution Avenue, N.W., Washington, DC 20210 866.633.7365 TTY: 877.889.5627 Website: http://www.communityinclusion.org |
| <i>Disability Rights</i> | Americans with Disabilities (ADA) The United States Department of Justice 950 Pennsylvania Avenue, NW Washington, DC 20530 202.353.1555 TTY/ASCII/TDD: 800.877.8339 Website: http://www.justice.gov |
| <i>Down Syndrome</i> | Down Syndrome Society of Rhode Island 99 Bald Hill Road, Cranston, RI 02920 401.463.5751 Webpage: What is Down Syndrome? http://www.dssri.org/facts-about-down-syndrome/ National Down Syndrome Society 8 E 41st Street, 8th Floor, New York, NY, 10017 800.221.4602 Website: http://www.ndss.org Webpage: A Caregivers Guide to Down Syndrome and Alzheimer's Disease http://www.ndss.org/Resources/Aging-Matters/Alzheimers-Disease/A-Caregivers-Guide-to-Down-Syndrome-and-Alzheimers-Disease/ |

| Topic | Resource |
|---------------------------------|--|
| <i>Down Syndrome</i> | National Down Syndrome Society 8 E 41st Street, 8th Floor, New York, NY, 10017 800.221.4602 Website: http://www.ndss.org Webpage: A Caregivers Guide to Down Syndrome and Alzheimer's Disease http://www.ndss.org/Resources/Aging-Matters/Alzheimers-Disease/A-Caregivers-Guide-to-Down-Syndrome-and-Alzheimers-Disease/ |
| <i>Education & Research</i> | Association of University Centers on Disabilities (AUCD) 1100 Wayne Avenue, Suite 1000, Silver Spring, MD 20910 301.355.8252 Email: aucdinfo@aucd.org Website: http://www.aucd.org |
| <i>Health Care</i> | Vanderbilt Kennedy Center 110 Magnolia Circle, Nashville, TN 37203 615.322.8240 Email: kc@vanderbilt.edu Webpage: Healthcare for Adults with Intellectual and Developmental Disabilities http://www.vkc.mc.vanderbilt.edu/etoolkit |
| <i>Healthy Eating</i> | Educational Resources Information Center (ERIC) Website: http://www.eric.ed.gov Dietary Guidelines Website: http://www.health.gov/dietaryguidelines/2015/guidelines/appendix-14/ Food Safety Website: http://www.foodsafety.gov/?gclid=CKzWjNyEi9QCFZiEswoddSEogQ Healthy Eating Website: http://www.hhs.gov/fitness/eat-healthy/how-to-eat-healthy/ |
| <i>Meaningful Activities</i> | NTG Practice Guidelines <i>Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia</i> <i>The National Task Group on Intellectual Disabilities and Dementia Practices Consensus Recommendations for the Evaluation and Management of Dementia in Adults with Intellectual Disabilities</i> |

Topic

Resource

*Meaningful
Activities*

*Guidelines for Dementia-Related Health Advocacy for Adults with
Intellectual Disability and Dementia: National Task Group on
Intellectual Disabilities and Dementia Practices*

Website: <https://aadmd.org/ntg/practiceguidelines>

Developing meaningful activities

Website: <http://www.alzheimers.net/2014-03-06/stimulating-activities-for-alzheimers-patients/>

101 Activities for individuals with Alzheimer's

Website: http://www.alz.org/living_with_alzheimers_101_activities.asp

Social Security

Social Security Administration

800.772.1213

Webpage: **Disability Benefits**

<http://www.ssa.gov/disabilityssi>

TERMS & DEFINITIONS

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|--|---|
| Active treatment | A therapeutic approach to supporting individuals with a disability to reach their fullest potential. It includes specific functional and adaptive social skills the person needs to acquire to be the best that he can possibly be in these areas. |
| Activities of daily living (ADLs) | Basic activities that people do every day to care for themselves, such as eating, grooming, bathing, dressing, toileting, and walking. |
| Adult day health program | A program that is in professional care settings in which older adults, including adults with dementia, receive individualized therapeutic, social, and health services for some part of the day. |
| Advanced dementia | Late-stage of dementia, during which an individual is no longer able to communicate, and requires total care for all their needs and care. |
| Alzheimer’s disease (AD) | A type of dementia that results from a disease of the brain. It may begin some 20 years before symptoms are noticed. The disease is a progressive, degenerative disorder that attacks the brain's nerve cells, or neurons, resulting in loss of memory, thinking and language skills, and behavioral changes. It is the most common cause of dementia, or loss of intellectual function, among adults aged 65 and older. People with Down syndrome are at high risk for developing Alzheimer’s disease. |
| Baseline | An individual’s personal best with respect to being able to do things on a day-to-day basis over time. A baseline is what is normal for the person, before changes in behavior and other skills occur. It is used to better understand what an individual can do best and can be used to identify changes in that individual over time or as a disease progresses. |
| Consent | The legal basis for making decisions about or for loved one. |
| Dementia | A decline in mental ability severe enough to interfere with daily life, which includes problems with memory, personality changes, and impaired reasoning. Dementia is not a disease, but describes a set of symptoms that come about from changes in the brain, some are treatable and others are not, such as brain diseases or brain injuries. The most common cause of dementia is Alzheimer's disease. |
| Developmental disability | A general category of childhood conditions that originate prior to birth (such as genetic conditions), at birth, or later during childhood into the late teen years (such as brain injury). A developmental |

| | |
|--|--|
| Developmental disability | disability may combine problems with intellect with problems with sensory or physical abilities. The U.S. Developmental Disabilities Act defines developmental disabilities as a “lifelong condition that impairs normal development and a mental and/or physical impairment occurring before the age of 22 that results in substantial limits to function in three or more major activities including the following: self-care, receptive (such as, understanding) and expressive (such as, speech, writing) language, movement such as walking, self-direction, capacity for independent living and economic self-sufficiency or requires special and individualized services over the lifespan.” <i>Examples of a developmental disability include autism, cerebral palsy, developmental delay, Down syndrome, epilepsy, intellectual disability, Prader-Willi syndrome, spina bifida, and many other genetic conditions that impair typical growth and development. Psychiatric conditions are not included.</i> |
| Down syndrome | A genetic condition that is often associated with intellectual disability and some health complications. Persons with Down syndrome may live normal lives, although some may have needs for supervision and personal assistance. <i>People with Down syndrome are at higher risk for developing Alzheimer’s disease at an earlier age due to the extra copy of the 21st chromosome.</i> |
| Health care provider | A doctor, nurse practitioner, nurse-midwife, or a clinical social worker who is authorized to practice by the State and performing within the scope of their practice as defined by State law. |
| Intellectual disability (ID) | A condition that originated at birth or during childhood. Persons with an intellectual disability typically have below average intellectual functioning (intelligence). Their intellectual impairment can be very mild or may range to very severe. This condition is not a mental illness or psychiatric impairment. As persons with an intellectual disability grow up his abilities may vary; some people may become independent and some may continue to need personal assistance and supervision. <i>Examples of an intellectual disability include genetic conditions such a Down syndrome, Fragile X syndrome, or conditions with roots in environmental factors, such as fetal alcohol syndrome, infection or malnutrition of the mother, environmental toxins (mercury, lead), and social deprivation.</i> |
| Instrumental activities of daily living (IADLs) | Activities that are not considered fundamental, but allow people to live independently, such as meal preparation, housework, maintaining finances, and travelling within the community. |

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| Lifelong Meaningful activities | Birth through to old age. Activities that provide individuals with a sense of purpose, such as engaging in activities that provide stimulation, including physical, mental, social, emotional, and spiritual. |
| Other dementias | Dementias caused by brain conditions other than Alzheimer’s disease. They may include progressive conditions related to brain injury or disease, vascular dementia, frontal-temporal dementia, Lewy-body dementia, or Parkinsonism |
| Person-centered care | A model of care tailored to a person's interests, abilities, history, and decisions made relative to her care. |
| Respite care | Relief from caregiving, either by having some else provide the care in your home, or by using a program in the community that loved one can attend to give some time to yourself. |
| Reversible dementias | Changes in behavior and function that are not the result of diseases or injuries to the brain, but whose symptoms are like those of brain disease based dementias. Reversible dementias are correctable conditions and may be caused by medication interactions, hypothyroidism, depression, Vitamin B ₁₂ deficiencies, normal pressure hydrocephalus, sensory impairments (e.g., hearing or visual losses), and infections. |
| Support team | The professionals and others who work for the agencies in the state that provide a person with services, supports, and other assistance. |
| Treatment | Interventions for dementia which can be both medical (pharmacological) and social (non-pharmacological). |

