Intellectual Disability and Dementia:

A Caregiver's Resource Guide for Alabamians

Central Alabama Aging Consortium
Connecting You to Services

PANDA PROJECT
Providing Alzheimer's 'n Dementia Assistance

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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. We hope that this resource guide will provide you with the foundation you need to begin the conversation in planning supports for the individuals you support.

CITATION

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Contents

HOW TO USE THIS RESOURCE GUIDE

This guide, while written for families of adults with intellectual disabilities, 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 disabilities.

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 them.

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 Alabama.

A note about Alzheimer's disease and dementia - Alzheimer's is a disease of the brain that causes a person to lose their 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.

INTRODUCTION

The fact that you are reading this guide means there is someone with an intellectual disability whom you care about and for whom you are concerned. You may be seeing changes in the individual's health or behaviors that are unusual. A healthcare provider may have mentioned the possibility of this person 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 people with intellectual and developmental disabilities and the aging process.

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 the individual's medical history, the one person who knows what brings that person joy or what causes pain. Learning about the health issues your person may face as he/she ages can have a very positive impact on that person's 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 to help. We know that, as people with an intellectual disability age, changes will occur. The best thing you can do is learn as much as you can and advocate whenever it's needed, so that they can live thrive in their communities and have the best quality of life possible.

Let this guide be a tool you can use as you work with family members or clients with intellectual disabilities and dementia.

BECOMING A HEALTHCARE ADVOCATE

Healthcare advocates 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 disabilities. You are the expert on your family member. 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 become 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 an 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 goal is to ensure that a thorough examination is conducted to make an accurate diagnosis and provide you with suggestions for the care of your family member.

Preparing for a medical appointment

Keep a list of questions you have and make notes of concerns you have. 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. 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 them in a safe place so you can refer to them later if needed. Contact other family members and those who provide care for your loved one to give them information they may need to know. If changes need to be made to support the services your loved one receives, contact the appropriate person. Make sure your loved one, when capable, is included in the discussions and decisions that are made.

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

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 issue for individuals who are showing no signs or symptoms. 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, screening for dementia may involve asking some basic questions that can help identify someone who may be experiencing some changes in cognitive ability and behavior. However, please note that, depending on the type and severity of the intellectual disability, this type of dementia screening may not be appropriate.

Most screenings can be completed by a family member or agency staff. The screening should be done at a time that is best for your loved one. A dementia screening will look for changes in:

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

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 an 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 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 is not 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 to share.

You can complete an initial screening at home using the form developed by The National Task Group (NTG) on Intellectual Disabilities and Dementia Practices. 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 allows you 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 a 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 online.

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. 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 needed to complete that task. The more you can document, the more you or others will have to draw from later. Even minor suggestions, like the order that your loved one puts on his clothes, are 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 *personal bests.*

One way to gather information is to use your smart phone's video function to record some of the things your loved one can typically do. You can share it with your healthcare provider should you have suspicions about changing behavior.

The NTG recommends recording several things a loved one can do to create a baseline file. 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 that 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 your information 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 a year. However, if you notice changes during that time, be sure to record them on video or on the *NTG-EDSD*. Keeping good records is very important.

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

- Your loved one's and your family's medical history, which includes medication use, 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.

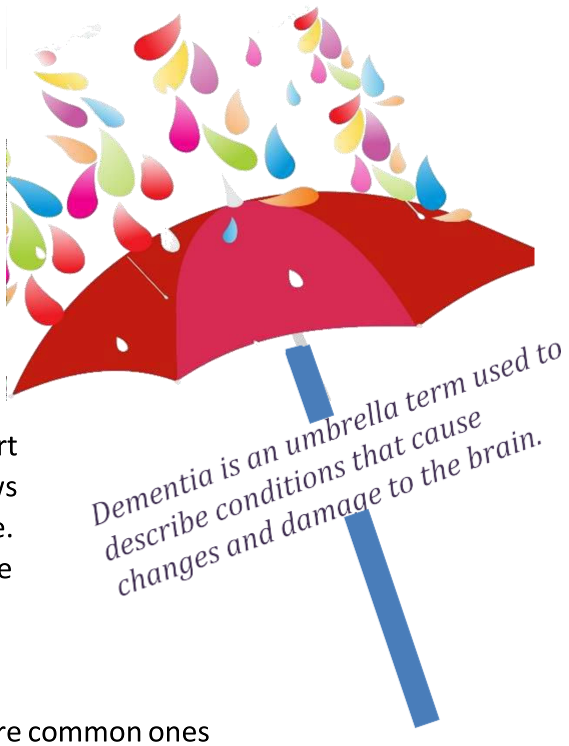
The healthcare provider may refer your loved one for a diagnostic visit with a clinic or a memory center. There, specialists will further assess loved ones and determine if there is a disease of the brain that is causing dementia. You may be asked to provide more information to help the clinic make this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

Finding diagnostic help in Alabama

If you aren't sure where you can get help with screening, assessment, and diagnosis, check first with your loved one's healthcare provider, your local Area Agency on Aging, or the Alabama Department of Mental Health.

LEARNING ABOUT DEMENTIA

Discovering various types of dementia


Dementia is an umbrella term used to describe conditions that cause changes and damage to the brain.

Dementia is a not a specific disease, rather it 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.

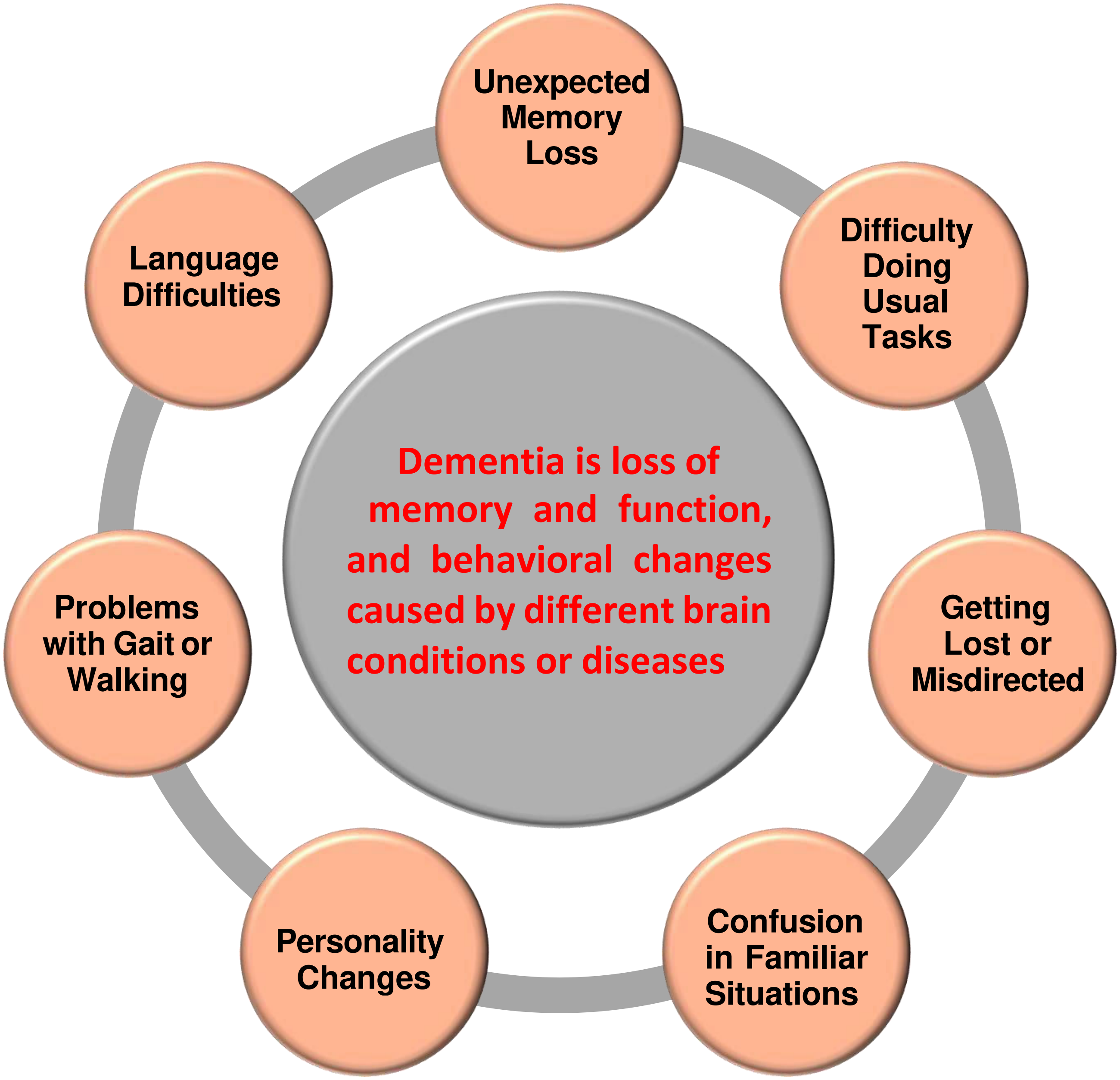
There are numerous types of dementia. Some of the more common ones include:

- **Alzheimer’s disease** – is the most common disease of the brain that is identified as a form of 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.

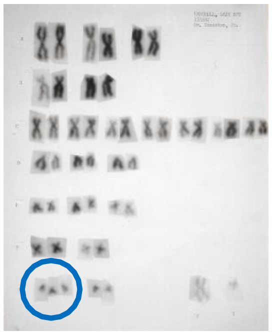
Recognizing signs & symptoms of dementia

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 are will vary with the 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 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 over how 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.

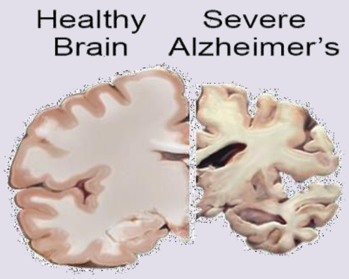
More information about Alzheimer's disease and how it affects adults with Down syndrome can be found in this excellent publication from the National Down Syndrome Society. You can find it on their website at http://www.ndss.org.

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 into 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.



Cross sections of the brain show atrophy, or shrinking, of brain tissue caused by Alzheimer's disease.

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			
Duration varies, but generally, in adults with intellectual disability (5 + years) ***Adults with Down syndrome (1-2 years)***			
Memory/Thinking	Language	Behavior/Mood	Self-Care
• Difficulty with short-term memory • Loses things • Poor attention • Difficulty with calculations and organizational skills	• Trouble finding words and names • Repeats statements or questions	• May become depressed, • Withdrawn and irritable • Loss of interest in previous activities of interest	• 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			
Duration varies, but generally, in adults with intellectual disability (5-10 years) ***Adults with Downs syndrome (2-3) years***			
Memory/Thinking	Language	Behavior/Mood	Self-Care
• Difficulty with short/ long term memory • Forgets parts of one's history • Has trouble solving simple problems • Easy disoriented	• Trouble tracking a conversation • Difficulty forming complete sentences	• More easily upset or withdrawn	• 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			
Duration varies, but generally, in adults with intellectual disability (2-3 years) ***Adults with Downs syndrome (1-2 years)***			
Memory/Thinking	Language	Behavior/Mood	Self-Care
• Mixes up recent and past events • Forgets friends and relatives • Cannot follow a 2-step command • No apparent awareness of past and future	• Unable to have meaningful conversations • Disconnected sentences • Cannot speak or uses only a few words	• May express unmet needs by yelling and calling • Difficult to engage • Severe decline in ability to show emotion	• 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.

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 your 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 you understand. 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

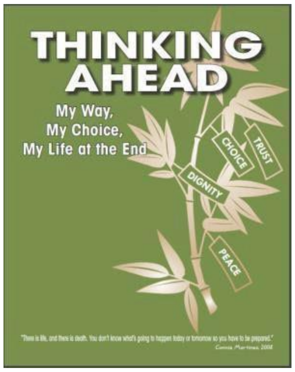
Some families have struggled with how much they tell their loved ones or whether they should say anything about the diagnosis. It is a very personal decision and one that only you and your family can make.

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 on their website.

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

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.

In support of your loved one, as a healthcare advocate, you may find these steps to decision making helpful:

- Gather the facts and possible options.

- Determine what the goal is or what you are 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.

Advance Planning for People Living with Dementia

Advance planning empowers people to make their own decisions about important topics like finances, health care, and living arrangements before the need arises. Despite this, most older adults have not created advance directives.

The advance planning guides were created to support people living with dementia and their family members or other care partners in knowing what to plan for and how to get started. The guides cover four topics: 1) health care planning; 2) financial planning; 3) care planning; and 4) supporting someone living with dementia in making decisions.

Note: There is a way to co-brand these guides with your agency logo.

Emergency Preparedness Toolkit for People Living with Dementia

As the number of emergencies increases, learning how to plan for and respond to these events becomes increasingly critical. Living with Alzheimer's disease and other related dementias can make it harder to cope with these emergencies. The Emergency Preparedness Toolkit is written to help people living with dementia, their family members, and their caregivers understand what to expect in the event of an emergency and how to prepare for one.

The toolkit is made up of seven tip sheets and checklists for persons living with dementia, their families, and others who interact with them. The sections cover the following topics: Planning for a Disaster, My Important Contacts, Emergency Supplies Checklist, My Medical Conditions and Care Needs, Disaster Planning Tips for People Living Alone with Dementia, Planning for after a Disaster, and Tips for Communication and Responding to Dementia Symptoms. An individual can fill in the Important Contacts, Emergency Supplies Checklist, and My Medical Conditions and Care Needs forms by using a computer or printing the form out and writing on it.

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 disabilities 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 in understanding the issues.

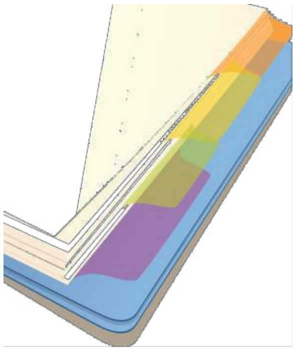
> *"My friend with intellectual disabilities knows what dementia is, as he has experienced what it was like with my mother who has dementia whom he also knew. This experience greatly helps when we talk about dementia and try to document his choices."*

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

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 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

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.

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 the wishes, likes and needs of your loved one to ensure that the 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.

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

Over the course of the disease, it will be important to integrate medical care with non-medical interventions and approaches that work best with your 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

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.

Thinking about legal and financial issues

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, or a living will.

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 heartbreaking 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 a monetary value attached to a burial plan, it is not counted against your loved one in the 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 hard to have a 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.

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Planning for end-of-life care

During this journey, many decisions 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 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 a loved one has advanced dementia and is close to dying. It is important to understand what is happening and how support 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 a complex illness, specializing in comfort and symptom relief. Under palliative care, ongoing treatment including curative care can continue. The focus is on 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 to determine whether 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*.

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 such as dementia. These can be accessed at http://www.aadmd.org/ntg/practiceguidelines.

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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 the brain is changing, your loved one will live, at times, in a new reality which is real to the individual. Meet your loved one in that reality. Always agree, when possible, rather than trying to correct. Trying to teach or give instructions will only be frustrating, because your loved one can no longer 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.

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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 the home. Your loved one 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, some 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.

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.

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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.

ℹ 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 a bedroom or the bathroom
- Appears to be doing a hobby, 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 ensure 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/

Healthy foods boost brain health

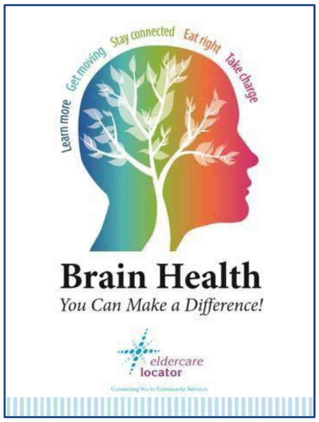
What you eat can affect your composure, help with stress, and help you maintain your mental strength. Know your food groups and be careful with your choices… look for healthy foods that reduce your fat and salt intake, and increase fiber, vitamins and helpful nutrients.

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 is critical for your loved one's well-being. As your loved one moves through the stages of dementia, mealtimes 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 mealtimes. 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

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 wake-up 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 that 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 people 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 the 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 a **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 reassurance,** 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.

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

ℹ 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 one – 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 ALABAMA

Considering guardianships, alternatives to guardianships, and end-of-life planning

On top of caregiving responsibilities, it can be overwhelming to think about legal matters like guardianship and its alternatives and end-of-life planning. But the more you learn about available options – and the earlier you start thinking about them – the easier the task will be. There are a number of free or low-cost legal resources and services in Alabama that can help.

Guardianship and Alternatives

A guardianship is a formal legal procedure in which a court removes from a person the power to make personal decisions about their life and gives that power to another person. In a guardianship, a court grants one person (the guardian) the power to make nearly all personal decisions for another person (the ward). In general, those decisions include where the ward lives, what services and care the ward receives, and what contracts the ward can make.

A court may appoint a guardian to any person whom it determines to be incapacitated. Under Alabama law, an incapacitated person is someone "who is impaired by reason of mental illness, mental deficiency, physical illness or disability, physical or mental infirmities accompanying advanced age, chronic use of drugs, chronic intoxication, or other cause (except minority)" such that they lack "sufficient understanding or capacity to make or communicate responsible decisions." Guardianship is always documented in a court order and letters of guardianship.

Guardianship is an extreme deprivation of a person's rights. The court is stripping the ward of the ward's rights as an adult and giving the ward the legal status of a child. In a guardianship, the court and guardian will control most aspects of the ward's life. Pursuing guardianship can be expensive (typically costing over $1500) and time-consuming. For these and other reasons, a guardianship should be a last resort, undertaken only after careful consideration of other less drastic alternatives like powers of attorney, health care proxies, conservatorships, and, new to Alabama, a supported decision-making (SDM) agreement.

Thinking about end-of-life planning

Advanced Care Planning

End-of-life or advanced care planning refers to the steps a person takes to identify what their end-of-life care should look like and who makes those decisions. This could include drafting a living will or advance directive. It also can involve drafting a will or trust document to dispose of a person's property.

While considering end-of-life care can be difficult, it is important for a person to have their affairs in order to help facilitate a smooth process after their passing.

Resources

If you need help with determining whether a guardianship or a guardianship alternative is right for your loved one, or if you need help with end-of-life planning, here are legal resources in Alabama to which you can turn:

Alabama WINGS

Alabama WINGS is a task force coordinated by the Alabama Administrative Office of Courts. WINGS develops information, resources, and tools to improve guardianship and conservatorship practices in Alabama. Its website has resources for the public, including video resources that explore guardianships and their alternatives.

Alabama Disabilities Advocacy Program (ADAP)

ADAP provides free legal services to support the civil rights and welfare of persons with disabilities. ADAP does not help people obtain guardianship but, instead, focuses its advocacy on alternatives to guardianships, including the use of supported decision-making.

Online Client Intake Form

Legal Services of Alabama (LSA)

LSA provides free civil legal advocacy to low-income Alabamians across a variety of issues, including guardianships, conservatorships, and estate planning.

Aging & Disability Resource Center (ADRC)

Each of Alabama's Area Agencies on Aging (AAAs) has an ADRC for aging, disability, and caregiver help and services. The ADRC can connect you to elder law service providers for help with guardianship and end-of-life planning.

Alabama State Bar Lawyer Referral Service

The Alabama Bar administers a free referral service for persons seeking help with a variety of legal matters.

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 **Alabama Disabilities Advocacy Program** at (205) 348-4928.

LEARNING MORE ABOUT LOCAL & NATIONAL RESOURCES

AARP of Alabama - Caregiving

AARP – Prepare to Care Guide

Administration for Community Living – Development & Disabilities Assistance

Alabama Disabilities Advocacy Program - Resources

Alabama Lifespan Respite Resource Network – Apply for Respite

Alzheimer's Store – See What's New!

American Association on Intellectual and Development Disabilities (AAIDD)

The Arc of the United States – Intellectual Disability

Central Alabama Aging Consortium – Resources

Communicating with Individuals with Intellectual Disability & Dementia – Jenny's Story

Dementia Friendly Alabama – Resources

Get Paid as A Caregiver

HOTLINES for People with Dementia

Intellectual and Developmental Disabilities and Dementia - A Practical Guide for Professionals (2019 National Alzheimer's and Dementia Resource Center)

Institute for Community Inclusion – Promoting the Inclusion of People with Disabilities

Mayo Clinic - Dementia

National Down Syndrome Society - Alzheimer's Disease & Down Syndrome Guidebook

National Down Syndrome Society – Resources

National Task Group on Intellectual Disabilities and Dementia Practices

PANDA Project – Resources

TERMS & DEFINITIONS

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 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." *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.*
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. *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.*
Health care provider	A doctor, nurse practitioner, nurse-midwife, or clinical social worker who is authorized to practice by the State and perform 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 their abilities may vary; some people may become independent, and some may continue to need personal assistance and supervision. *Examples of intellectual disability include genetic conditions such as Down syndrome, and 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.*
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 traveling within the community.

Lifelong	Birth through to old age.
Meaningful activities	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 modelof 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 a 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