

Things to Know about Health and Adults with Dementia:

A Guide for Families, Caregivers
and Adults with Intellectual Disability



A Supplemental Module to

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



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THE NATURAL AGING PROCESS



Aging is an inescapable part of life. The natural aging process begins when we are born and continues throughout our life until we pass on. The typical and expected transformations that we all may expect to see and feel when we get older include changes in our vision, hearing, and sense of smell, as well as weakening of our bones, loss of hair, skin thinning and wrinkles. We may experience a reduction in our stamina and endurance. There are expected changes in our brains as well. Short term

memory and the ability to recall information also begins to slow down. This usually starts in the 40s for most of us and continues slowly as we become subtly less sharp with advanced age.

Health Promotion and Aging

As we age we are at risk of developing numerous health conditions including osteoporosis, heart and lung disease, falls related to problems with balance, and cancers, as well as dementia. There is growing research that shows if we take care of ourselves throughout our lives we can help to reduce the chances of developing some of these difficulties, or to at least minimize their impact upon our lives as we age.

Health promotion includes healthy eating, limiting alcohol use, avoiding tobacco products, learning stress reduction techniques, and maintaining regular visits to our healthcare provider. Proactive care can minimize the effects of any problems that may come up, such as high blood pressure, high cholesterol, or diabetes. Finding balance in our lives that promotes happiness, good relationships, and a sense of purpose has been shown to reduce some the effects of these illnesses, including the impact of dementia caused by Alzheimer's disease.



AGING IN PEOPLE WITH INTELLECTUAL DISABILITY AND DOWN SYNDROME

Individuals with intellectual disability, including those with Down syndrome, are living longer than ever before. Medical advances have contributed to increased longevity; social policies have led to special services and have begun to open doors for respect and value for this segment of our society. The typical aging processes affect adults with intellectual disability just as much as everyone else.

However, when someone has had a lifelong disability, the impact of normal aging may have greater consequences upon their health, as well as upon their personal and social connections. The ability to compensate for a change and decline in function with aging may not be as successful and the need for supports may possibly arise sooner. Adults, in general, may have a sense of what to expect with age, but for many adults with intellectual disability (including

Down syndrome), anticipated age related changes, (even those things that may be a sign of abnormal aging such as an underlying disease) may not be as evident. Additionally, many healthcare providers may not be familiar with the particular healthcare needs of adults who have an intellectual disability.

Health Concerns in Adults with Down Syndrome

Individuals with Down syndrome are prone to very particular health changes as they age, such as obesity, hearing loss, thyroid disease, sleep apnea, cataracts, osteoarthritis, as well as *early onset* Alzheimer's disease. It's important to be aware that these conditions can happen, and as a family member or caregiver to be on the lookout for signs of changes in an adult who may not be able to speak about or describe difficulties that they are having.



WHEN CHANGES HAPPEN

If changes in an individual occur, at what point does it become concerning that these differences are a sign of an underlying condition or illness? When an abrupt change occurs within moments or dramatically within a short time, this should be a signal to seek immediate help and even consider going to an emergency room. The more uncertain situation is when the change is slower in onset and evolves over weeks and months. In those circumstances, it is important to document the changes and keep the healthcare provider informed.

When changes occur, who can best appreciate that the person is not who they used to be? Who will know that they are having more challenges with their abilities, communication skills, and general function in their life? Who will know the person has less interest in favored activities, and difficulty with memories?

Having a clear sense of one's *life story* is the best way to gauge whether the changes that have occurred are substantially different. Such an assessment is only possible if there is a clear appreciation of what the person used to be like when they were at their best.

There are many ways to document the best times of a person's life. Some people make scrapbooks with stories that accompany photos. In this digital age, it has become easier to capture videos of folks in their every day lives. Even a journal with written notes about what the person has done each day or week is helpful (activities of daily living).

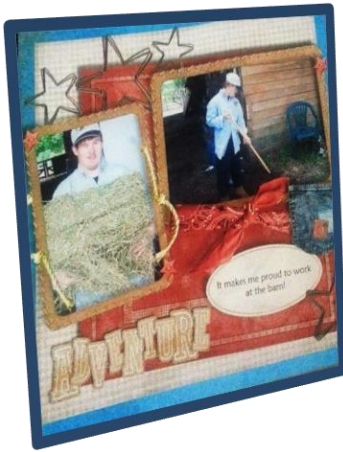


It is important to know that individuals with intellectual disability maybe very sensitive to personal, social, and environmental changes. Those changes may turn out to be the direct cause of why the person is acting a certain way or behaving differently. Collecting current information about one's recent life is

extremely important. The following questions may help you to determine why changes are occurring.

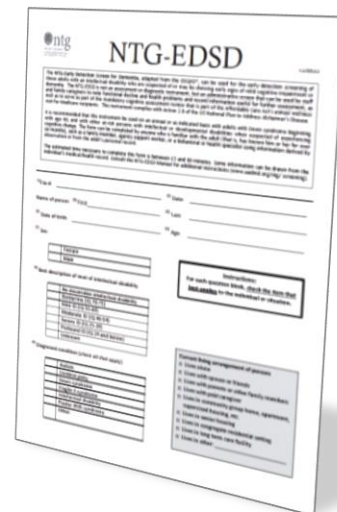
- Has there been a recent illness or death of a friend, family member, or close associate?
- Has there been a disruption in any personal, family, social, or workplace situation?
- Has there been an addition of a new medication or change in dosage of a medication?
- Has there been a change in sleeping habits?
- Has there been a change in interests in previously desired activities?

Finding the Reason for Changes in Behavior



Keeping a journal to record the persons *life story* is important because it will document how the adult functioned earlier in life and what they were capable of doing. A life story is an account of an individual's life.

Also, the use of a screening tool, like the NTG-Early Detection Screen for Dementia (EDSD), can be used as an additional way to document that change has occurred. Such a tool, usable by both families and staff, can help you record the types of behaviors you are seeing now – as well as



indicating whether these should be of concern to you.

Both types of documentation can help you convey to the healthcare providers information that can be useful for them to understand your concerns. The best person to seek initial help from is someone who has known you and the adult with an intellectual disability for some time.

However, if this is not possible, then find a healthcare provider who is patient, willing to listen, appreciates your concerns, and is able to develop a positive relationship with the adult. Such a provider will see the individual as a person who has value, and will treat them with dignity and respect.

Talking to a Healthcare Provider about Your Concerns

The healthcare provider should be open to all possibilities as to why the changes have occurred and not jump to premature conclusions. A healthcare provider should consider each of the following as a cause of the change:

- Depression and anxiety – emotional problems, such as sadness and nervousness
- Medication effects – potential adverse reactions to the medication(s) being taken (even those the person may have been taking for some time)

changes occur (page 2). Any significant changes in health, function, or cognitive abilities should be brought to the attention of a knowledgeable healthcare provider.

Normal slowing and memory problems do occur when people get older. One concern may be whether the person is developing dementia. When other causes have been ruled out, the healthcare professional may consider *Mild Cognitive Impairment* (MCI) or dementia to be the reason for the changes.

Mild Cognitive Impairment (MCI)

MCI refers to a slower progressive change in cognitive abilities, but one that has not had any major impact upon the person’s abilities to function. MCI presents a more dramatic change than what would be expected of normal memory loss due to aging. At times, having MCI may eventually lead to dementia. Your healthcare provider may refer to this as *conversion to dementia*.

Dementia

Dementia is a term that describes a progressive loss of function in what is known as cognitive skills. These may include loss of memory, thinking, perception, language, and attention. These skills all have an impact, to some degree on the person’s abilities to perform previous activities and actions. An illness resulting in dementia would be the most concerning condition to be considered, but many other reasons and causes must also be taken into account.

Dementia is a constellation of difficulties and not a true medical diagnosis. The underlying reason why dementia is occurring is very important to figure out. Healthcare providers identify many brain illnesses leading to loss of memory and function under the label of *dementia*. Such causes include Alzheimer’s disease, among others.



Knowing the specific cause of memory loss and other changes is important. There may be many reasons why changes occur, and it is good to know if they can be reversed or slowed down. At the very least, the healthcare provider may be able to offer some indication about what to expect in the future. Identifying the cause can also help with planning and preparing for the type of progression and what to anticipate with further behavioral change or physical decline.

Alzheimer’s Disease vs Dementia

Dementia can be caused by many different underlying conditions. Some are reversible; however, many are progressive and irreversible. Scientists are telling us that changes in the

MCI OR DEMENTIA	
MCI	<ul style="list-style-type: none"> • Slower progressive change • May have minor problems with speech, memory or decision making • Symptoms are greater than with normal aging • Symptoms may not worsen
Dementia	<ul style="list-style-type: none"> • Significant progressive change • brain deterioration • Personality changes may occur • Impacts ability to perform previous skills

brain begin some 20 years or more before behavioral changes related to dementia are seen.

The most common cause of dementia is Alzheimer's disease, which is a disease of the brain caused by the abnormal accumulation of a protein called *beta amyloid*. This protein leads to the destruction of brain cells and their connections.

The beta amyloid protein leading to Alzheimer's disease is created in the 21st chromosome. Adults with Down syndrome are particularly prone to Alzheimer's disease because they have an extra copy of this chromosome; therefore, adults with Down syndrome have excessive and early accumulation of these proteins in their brains often beginning in their 20s. Adults with Down syndrome may begin to show the behavioral changes, or signs of Alzheimer's disease, as early as their 40s or early 50s. When these signs occur in mid-life, it is called *early-onset Alzheimer's disease*.

There are several changes that may signal the presence of Alzheimer's disease in adults with intellectual disability, including some of the following:

- Loss of interest in previously preferred activities
- Short-term memory loss
- Decreased communication skills
- Diminished amenability and sociability
- Changes in personal care skills
- Increase in wandering
- Confusion in unfamiliar places
- Seizures
- Loss of understanding what is being said
- General confusion and disorientation

Please keep in mind that not all changes in behavior among older adults with intellectual disability or Down syndrome are due to dementia. Some changes are because of aging and some may be caused by medical conditions or adverse reactions to medications.

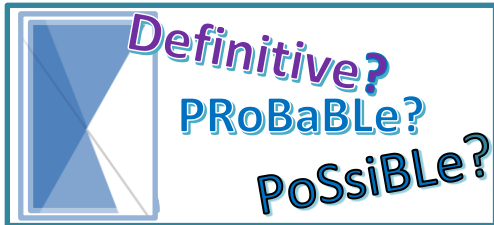
GETTING A DIAGNOSIS AND NEXT STEPS

Unfortunately, at this time, there is no test that proves that Alzheimer's is the correct diagnosis. Therefore, eliminating all other possible causes through tests and a thorough history is vital.

Having a healthcare provider report that your loved one has Alzheimer's disease is typically a serious conversation because of what this illness implies for the rest of their life. Alzheimer's is a progressive disease that eventually will rob the individual of their memories, ability to walk, and generally function. Adults with intellectual disability may have a progressive course that could run up to 20 years. The progressive course among adults with Down syndrome may be shorter and run from 5 to 8 years.



Your healthcare provider should be sensitive when providing this diagnosis and explaining it. In the early phase, it is far from certain how the next stage or changes of progression will occur. Ask questions and try to find out as much as you can about what the examinations showed and what the diagnosis may mean. If your healthcare provider is relatively certain that your loved one has Alzheimer’s disease, he or she may tell you that it is *probable* Alzheimer’s disease. In



other situations, the healthcare provider may need more time to watch for other changes in health or behavior and may tell you it might be *possible* Alzheimer’s disease. This may lead to having your loved one examined periodically (it could take a few years). Usually, a *definitive* diagnosis of Alzheimer’s disease is made after the person dies and the brain is examined through autopsy.

Preparing for the Future

After you leave the healthcare provider with a diagnosis or probability of dementia there are things you can do to provide the best support possible to your loved one. If there are other family members or caregivers to share tasks, talk with them about what is next. If you are the only one available, be sure you find ways to support yourself, as well.

- Define expectations on roles; who does what between visits
- Identify what needs to be done to prepare for the next visit
- Focus on health promotion; keep your loved one physically and mentally active and connected socially
- Watch for *caregiver stress* that may affect not only your well-being, but, indirectly, the person for whom you are providing care
- Get guidance on how to follow and monitor changes in memory and behavior
- Find out about community support options that would be helpful to you and your loved one
- Explore participation in research opportunities
- Get more information on the stages and progression of the disease, and what may occur in advanced dementia, including what you and your loved one may need at the end of their life



LEARNING ABOUT MEDICATIONS THAT CAN HELP WITH DEMENTIA

There are no prescription medications currently available that can cure or prevent dementia, that is caused by Alzheimer’s disease. The only medications that are FDA (Food and Drug Administration) approved are those that have a marginal benefit in slowing down, or minimally and temporarily improving memory in persons with suspected Alzheimer’s disease.



There have been a few studies that have tested these various prescription medications in adults with intellectual disability or Down syndrome, but the results are marginal and their benefit are not fully conclusive. There are several health supplements and vitamins which are advertised as positively affecting brain health and memory, but none of these have been proven to be effective, either. There are medications which are thought to help with memory and cognition and

there are also some medications for behavior, but none have been accepted for use specifically to treat persons with Alzheimer's disease.

Treating memory with medications

If your healthcare provider does recommend prescribing a medication for memory, it is important that they explain the risks, benefits and expectations of this approach. Explore what experiences other caregivers have had with medications and, if appropriate, that information with your healthcare provider. Work with your healthcare provider to learn how you will be able to judge the effectiveness of the medication.

Available prescription medications

There are several medications that healthcare providers may consider prescribing. Each has a specific purpose and only limited effects on behavior and functioning. Raise questions regarding the use of these medications with your healthcare provider and then decide whether their use may help your loved one.

The first three listed below are mostly used with persons in the early stages of dementia. Namenda is usually prescribed in later stages.

- Aricept (Donepezil): Prevents breakdown of acetylcholine (a chemical in nerve cells)
- Exelon (Rivastigmine): Prevents breakdown of acetylcholine
- Razadyne (Galantamine): Prevents breakdown of acetylcholine
- Namenda (Memantine): Blocks glutamate (another nerve cell chemical)

The side effects from these medications may include difficulties with sleep, stomach upset, nausea, dizziness, confusion, and fainting. Your healthcare provider should tell you specifically how these medications may help, and how this benefit can be followed and monitored, as well as to what to expect if side effects occur. If using these medications, carefully monitor your loved one's behavior and function, and report any changes to your healthcare provider.

In the future, there may be prescription medications which will have more of an impact to not only slow down the disease, but to also prevent progression or even possibly reverse the underlying damage that has occurred.



WHEN BEHAVIORAL DIFFICULTIES OCCUR

Changes in behavior are very common in individuals with Alzheimer’s disease and other dementias. Anxiety and depression can often occur early in the disease. Symptoms of disturbed perception, thought content, mood or behavior frequently occur in people who have dementia.

These are called *Behavioral and Psychological Symptoms of Dementia* or *BPSDs*. You may hear this term in your discussions with your healthcare providers or other personnel who may be assigned to help you.

BPSDs

- Depression
- Delusions
- Hallucinations
- Aggression
- Apathy
- Hoarding
- Disinhibition
- Sundowning
- Wandering
- Day/night reversal

These various behaviors can lead to significant amounts of stress to the individual, as well as to you as a caregiver. Caregiver associated health complications, including depression and anxiety are very common. These behaviors may be associated with a worse prognosis, or more rapid decline, and lead to an earlier admission to a long-term care facility.

Treatment of *BPSDs* begins with recognition of the specific type of behavior that is occurring, as well as to recognize the severity, frequency, and what may be causing them (the *trigger*). Treatment is divided into *pharmacologic* (using medications) and *nonpharmacologic* (using behavioral) approaches. It is highly recommended that a nonpharmacologic intervention be considered first before attempts at using medications. It can be very useful to your healthcare provider if you can record when any of these behaviors occur and what may have triggered them. This will give the provider insight into the nature of the behaviors and may help you know how you to redirect them.

Triggers

Think of triggers as tangible events – something that occurs and then the person reacts to what has just happened. For example, there may be a loud noise and the person may react by crying. Other times, something less obvious may be the trigger for behaviors. For example, someone with pain (and the inability to tell you about it) may get overly active because of discomfort. Or, if a caregiver has spoken harshly to the person, they may become agitated when that caregiver comes into the person’s room. Below, are some triggers that may lead to BPSDs. Keep these in mind, as they may not be immediately obvious, but think about whether they may start some

pronounced reaction. As you think more about triggers, and make connections, report them to your healthcare provider.

- Acute illness or infection (such as an urinary tract infection), reactions to medications, pain, problems stemming from changes in vision or hearing, poor sleep or constipation
- Cognitive factors, such as the inability to understand, express oneself, lack of insight, misinterpretation of the environment, or difficulties in problem solving
- Emotional distress
- Fear, anxiety, depression, frustration, apathy, boredom, fatigue, poor nutrition
- Environmental factors, such as temperature, noise level, commotions, and lighting
- Changes in a caregiver, confrontational approaches, tasks that exceed abilities, changes in routine, over/under stimulation, lack of visual cues

Nonpharmacologic management of behaviors

The use of medications may not always be the most useful way to address BPSDs. Research has shown that many times careful applications of planning, environmental modifications and adaptations, the application of calming techniques, and lessening frustration can all help in addressing BPSDs. This list notes some common techniques and means of managing behaviors:



- Individualized care planning
- Careful analysis of care interactions
- Meaningful activity, perhaps via use of life stories
- Use of music (listening and singing)
- Physical activity and movement
- Multisensory stimulation programs (such as *Snoezelen*)
- Aromatherapy
- Familiar environment (avoid frequent moves of furniture or other household items)
- Soft tone, yet adequate lighting
- Calming colors
- Places to walk safely, directed wandering for exercise
- Keeping familiar objects, such as photographs, known comforting possessions close by
- Access to outdoor spaces
- Home-like environment
- Low stimuli—minimize background noise
- Quiet room or space
- Controls on early evening stimulation (minimizing *sundowning*)
- Sleep aids in room (use of red bulbs in night lights to help with going back to sleep, if awakened)
- Use of blue lighting to reset circadian rhythm

Using a variety of available nonpharmacological approaches is important. Your healthcare provider may be a resource about how and when to use these approaches, but often this information, and expertise in using these modalities, may best come from a range of experts who work with adults with dementia. Community mental health providers, occupational therapists, and dementia nurses often know about these approaches. In addition, information and resources can be obtained from various online outlets, including the Alzheimer's Association.

Pharmacological management of behaviors

Healthcare providers may recommend prescription medications to help offset various behaviors when nonpharmacologic approaches have not been fully successful. If the behaviors become severe and are thought to be a significant danger to the mental and physical health of the individual and their supporters, a pharmacological approach may be recommended.

Consider speaking with your healthcare provider:

- To determine what the target problem is that needs to be treated
- To determine if nonpharmacologic therapies are available
- When nonpharmacological measures are not successful enough
- To determine if the drug is necessary? To determine if this is the lowest practical dose
- To determine if this drug has adverse effects that are more likely to occur in an older patient
- To identify the criteria for success, and at what time, the effects of therapy will be assessed
- To determine the safety of the medication

Medications for behavior

Medications for behavior management fall into three categories. They include mood stabilizers, antidepressants and antipsychotics.

Mood Stabilizers

These are used to equalize behaviors in those adults who appear to wax and wane from one extreme to another. These medications were first used to treat seizure disorders.

- Depakote (Divalproex)
- Tegretol (Carbamazepine)
- Trileptal (Oxcarbazepine)

Antidepressants

These drugs are used to reduce depression and sometimes anxiety

- Prozac (Fluoxetine)
- Celexa (Citalopram)
- Paxil (Paroxetine)
- Zoloft (Sertraline)

Antipsychotics

- Remeron (Mirtazapine)
- Trazadone

Psychotic symptoms (a severe mental disorder in which thought, and emotions are so impaired that contact is lost with external reality) are treated with these drugs. Psychoses include paranoia, hallucinations, delusions.

- Abilify (Aripiprazole)
- Haldol (Haloperidol)
- Risperdal (Risperidone)
- Seroquel (Quetiapine)
- Zyprexa (Olanzapine)

Antipsychotic medications have a black box warning about their usage in elderly persons who have dementia due to an increased risk of stroke. Ask your healthcare provider to explain in detail the target behavior that is being treated, the goal of treatment, the expected outcome, and length of time the medication may be used.

GETTING SUPPORTS AS YOU PROVIDE CARE

Family members have a great amount of personal and emotional investment in the care of the their loved one with dementia. Caregivers are at great risk of experiencing high levels of stress. Some caregivers have shared that they experience myriad emotions and a range of reactions while supporting someone with dementia. Parents who have been life-long caregivers for a loved one with intellectual disability may be familiar with these responses.

As a caregiver, you may experience some of the feelings listed above. You will probably not face all of them, however, you should be aware that they may be present and go unrecognized due to the demands of caring for someone with dementia. If you sense that you may be encountering any of these feelings, or if

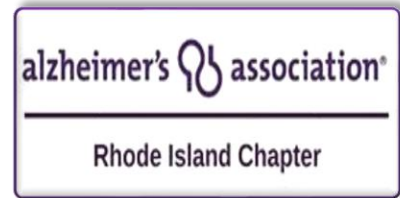
someone like a relative, neighbor, or friend tells you they think you are being challenged by one or more of these conditions, seek help to minimize their impact on your life and that of your family.

Feelings and Reactions

<ul style="list-style-type: none"> ☆ Depressed ☆ Anxious ☆ Worthless ☆ Guilty ☆ Angry ☆ Imbalanced Care Duties 	<ul style="list-style-type: none"> ☆ Trapped ☆ Overwhelmed ☆ Frustrated ☆ Exhausted ☆ Grief 	<ul style="list-style-type: none"> ☆ Lonely ☆ Stressed ☆ Resentful ☆ Irritated ☆ Unfulfilled ☆ Love ☆ Dissatisfied
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These emotions can make caregiving a challenge in some situations. They can differ from one caregiver to another and may even change, day to day and moment to moment. There are resources in Rhode Island that can help you as a caregiver.

Call the Alzheimer's Association or your Area Agency on Aging for help in finding someone who can assist you or connect you with a caregiver support group. You can also go to https://www.alz.org/ri/in_my_community_17562.asp which is the website of the Rhode Island chapter of the Alzheimer's Association.



Warning signs of frustration

The National Center on Caregiving warns about the effects of frustration, which can often be part of providing care for someone with dementia. The Family Caregiver Alliance has some helpful materials on their website: <https://www.caregiver.org/dementia-caregiving-and-controlling-frustration>. If you can recognize the warning signs of frustration, you can pause and adjust your attitude before you lose control. Some of the common warning signs of frustration include:

- Shortness of breath
- Knot in the throat
- Stomach cramps
- Chest pains
- Headache
- Compulsive eating
- Excessive alcohol consumption
- Increased smoking
- Lack of patience
- Desire to strike out



Preventing burn-out

Burn-out is a state of emotional and physical exhaustion caused by a prolonged period of stress and frustration. This often occurs when demands of caregiving become overwhelming and extended.

Being aware that you may be reaching this state is important, so you can seek help and counsel. Getting some relief from constant caregiving can also help lessen the stressors in your life.

Listed below are some things that you can do to relieve stress and prevent burn-out:

- Take care of yourself (keep healthcare provider appointments, see your dentist, exercise, etc.)
- Get away – if only for a few minutes or an hour
- Step back and let someone else take the caregiving lead for a while
- Participate in support groups (online or in person)

- Talk with friends
- Maintain or find hobbies
- Express your spirituality
- Seek respite care
- Use adult day facilities (as respite)
- Seek in-home assistance (such as someone to help with bathing duties, or house care)
- Learn meditation/relaxation techniques
- Ask for help (don't be ashamed to ask for help; you will be able to be better to yourself and the person to whom you provide care)



It is so very important to let your feelings be known whenever you visit the healthcare provider. The way you feel can be sensed by the one you care for and these emotions and reactions towards each other can become quite upsetting and troublesome if not dealt with.

WHEN DEMENTIA PROGRESSES

Unfortunately, dementia caused by Alzheimer's disease eventually worsens. It is very important to appreciate that, as the disease progresses into the later stages, there will be several factors that need to be realized:

- Cognitive skills will continue to decline
- Support needs will increase, especially more hands-on physical care
- Risks of falls, injuries will increase
- Swallowing problems will develop and increase
- Occurrences of blood clots, pneumonia, and bladder infections will increase
- Seizures may develop
- There may be incidences of abuse and neglect
- Palliative care and Hospice care will be needed with advanced dementia

Being aware that your loved one is aging, in addition to having dementia, is helpful. He or she may have some health conditions that are unrelated to dementia and these may cause further impairment. Most will be treatable and if they occur, should be discussed with your healthcare provider. Conditions that the person had before dementia do not disappear and must be monitored and treated, if needed. Watch for occurrences of seizures when they never occurred before. Watch out for increases in impaired hearing or vision and unsteadiness in walking (what healthcare providers call *gait*).

The National Task Group on Intellectual Disabilities and Dementia Practices has useful materials on this topic on its website which can help you. You can find them at www.aadmd.org/ntg

KEEPING A HEALTHY HOUSEHOLD

Environmental health is also part of the process of making things easier for you, as a caregiver. Be sure your house is adapted to prevent problems for you and for your loved one. If you have decided to continue to provide care at home, then you might consider steps to *dementia-proof* your home – at least those parts where your loved one will be. This may include safety features, care-ease features, and movement features.



Safety features may include eliminating things that could cause injury to your loved one, such as not having trip hazards (like loose rugs or cords on the floor), exposed electrical outlets, heating equipment that can cause burns, access to cleaning fluids that may be confused with favored drinks – and other toxic items in cupboards or closets.

Care-ease features may include installing grab bars in toilet and bathing areas, raised toilet seats, eliminating barriers for the use of walkers or wheelchairs (such as floor sills in doorways between rooms), use of shower chairs and other bathing aids. Even the use of contrast in colors can facilitate how a person interprets the surroundings.

Movement features may include keeping the configuration of furniture in common rooms constant, elimination of barriers to walking about or the use of walkers, including ramps for entry to the home if a wheelchair is used.

ONGOING RESEARCH THAT MAY OFFER SOME HOPE

Research is presently being conducted related to a test that involves special brain imaging of beta amyloid and may one day be useful. Researchers are also looking at biomarkers which may help identify the presence of Alzheimer's disease at its earliest stages. These biomarkers may also prove useful in substantiating the diagnosis in older adults. A biomarker is a biologic feature that can be used to measure the presence or progress of disease or the effects of treatment.



The National Institute of Health (NIH) has underwritten a new initiative to identify biomarkers and track the progression of Alzheimer's in people with Down syndrome. The NIH Biomarkers of Alzheimer's Disease in Adults with Down Syndrome Initiative supports two major teams of researchers using brain imaging, as well as fluid and tissue biomarkers in research that may one day lead to effective interventions for all people with dementia. The NIH is providing some \$37 million over five years for the following collaborative projects:

Alzheimer's Biomarkers Consortium of Down Syndrome (ABC-DS)

The ABC-DS study is a joint study conducted by two groups of research collaborators — Neurodegeneration in Aging Down Syndrome (NiAD) and Alzheimer's Disease in Down Syndrome (ADDS). Early diagnosis of Alzheimer's disease is critically important so that early intervention, prevention and treatment can be provided. What these groups will do is noted below.

Neurodegeneration in Aging Down Syndrome (NiAD)

- This study focuses on identifying biomarkers and tracking the progression of Alzheimer's in people with Down syndrome.
- The study involves adults with Down syndrome age 25 years and older.

Alzheimer's Disease in Down Syndrome (ADDS)

- This study focuses on a longitudinal and multidisciplinary determination of key biomarkers that are likely to define the progression, including levels and rates of change in blood-based biomarkers.
- The study involves adults with Down syndrome age 40 years and older.

These two research teams will pool data and standardize procedures, increase sample size, and collectively analyze data that will be made widely available to the research community. There are many uncertainties about aging, risks, occurrence, identification and treatment of Alzheimer's disease in adults with Down syndrome. These studies will help to answer many of these questions.

More information can be found at these websites:

<https://www.nia.nih.gov/research/abc-ds>

<https://www.nih.gov/news-events/news-releases/nih-supports-new-studies-find-alzheimers-biomarkers-down-syndrome>

www.aadmd.org/ntg.

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