



# The NTG FAQ: Some Basic Questions about Adults with Intellectual/Developmental Disabilities Affected by Alzheimer's Disease or Other Dementias

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## Alzheimer’s and related dementias

**Q1.** *What is cognition?*

**A1.** “Cognition” is a term used to describe our mental processes and activities, such as attention, memory, language understanding and expression, solving problems.

**Q2.** *What is dementia?*

**A2.** “Dementia” is a term used to describe cognitive decline from any cause (e.g., brain disease, head injury, stroke, or loss of oxygen to the brain) that results in impaired personal, social, or occupational adaptation. It is persistent and progressive and is associated with a chronic generalized brain disorder, such as Alzheimer’s disease, or a multifocal neurological condition, such as multiple strokes involving several discrete areas of the brain.

Dementia resulting from Alzheimer's disease is the most common type of dementia. There are other causes of dementia, such as vascular dementia, which results from a stroke or embolism, and fronto-temporal dementia and Lewy-body dementia, which result from other neuropathologies of the brain.

Dementia generally occurs at a later age but can also occur in middle-age (known as early-onset dementia). Behavior due to brain changes before the end of childhood and before the person is cognitively mature is not considered dementia.

**Q3.** *What is Alzheimer's disease?*

**A3.** Alzheimer's disease is a progressive brain disease, characterized by loss of function and death of nerve cells in several areas of the brain leading to loss of cognitive functions, particularly memory, language, orientation, and attention. The behavioral change resulting from these losses is termed "dementia."

## Dementia and persons with intellectual disability

**Q4.** *Do people with intellectual disability develop dementia?*

**A4.** Yes, adults with intellectual disability can develop dementia as they get older. The types of dementia that affect people with intellectual disability are similar to those that affect people without such disability. Alzheimer's dementia is the most prominent type of dementia among adults with Down syndrome.

**Q5.** *What is the prevalence of, in other words how common is, Alzheimer's disease in adults with intellectual disability?*

**A5.** Studies in the United States have found the prevalence of dementia in persons with intellectual disability to be about the same as in the general population. Dementia appears in about 6% of the population of adults with intellectual disability over the age of 60 years, and 12% of the population over the age of 80 years.

Adults with Down syndrome show a much higher prevalence: about 60% among adults aged 60 and older. There is also a higher rate among younger age adults with Down syndrome – about 20% among adults aged 40 and older.

**Q6.** *When does Alzheimer's disease generally appear in persons with*

**A6.** Onset of Alzheimer's disease generally occurs in adults with intellectual disability in their late 60s. However, for adults with Down syndrome onset can be much earlier – generally in their early 50s. Most studies show the average age of onset as about 52. Other types of dementia may have more variable ages of onset.

*intellectual disability?*

“Onset” is generally defined as the point at which the changes in the person’s memory, behavior, and function are sufficiently pronounced to begin to be noticed by others.

**Q7.** *How long are adults with intellectual disability affected by dementia?*

**A7.** Adults with intellectual disability affected by dementia live for a varying number of years. Some adults will survive for many years after onset – sometimes up to 15 to 20 years. Others may have shorter post-onset lifespans.

Some people with Down syndrome will survive up to 10 years after onset. However, most will survive for a fewer number of years. A small percentage of persons with Down syndrome will experience a rapid decline and survive for only 1 to 2 years after noticeable onset.

**Q8.** *What are the causes of dementia in adults with intellectual disability?*

**A8.** Multiple strokes, brain hemorrhage, multiple head injuries, brain tumors, and chronic kidney disease are some other causes of dementia in adults with and without intellectual disability. These are referred to as secondary dementias because their cause or causes are attributed to other physical conditions or diseases.

In contrast, fronto-temporal dementia and dementias related to conditions such as Alzheimer’s disease or Pick’s disease are called primary dementias because the actual cause(s) of the progressive cognitive decline is not fully understood or known.

**Q9.** *Does dementia affect adults with varying intellectual or developmental disabilities differently?*

**A9.** Most research information on dementia in adults with intellectual disability has been focused on adults with Down syndrome. Among this group, Alzheimer’s disease is the primary cause of dementia. Among persons with other intellectual disabilities, the types of dementia vary and are generally similar in prevalence to the general population.

There is very little research on the prevalence of dementia among adults with other neurodevelopmental disabilities, such as autism, cerebral palsy, and epilepsy. Therefore, no definitive trends have been reported. Besides Down syndrome, the other condition that shows a high risk for Alzheimer’s related dementia is brain trauma or injury.

For more information, it is recommended accessing the NTG’s report, *Examining Adults with Neuroatypical Conditions for MCI/Dementia During Cognitive Impairment Assessments – Report of the Neuroatypical Conditions Expert Consultative Panel*, which is available from [www.the-ntg.org](http://www.the-ntg.org)

**Q10.** *Do people with intellectual disability*

**A10.** Like other persons affected by Alzheimer’s disease, people with an intellectual disability who have Alzheimer’s disease experience memory loss, disorganization and loss of skills, and changes in personality and

*experience  
Alzheimer's  
disease in the  
same ways as  
other people?*

behavior. Because people with an intellectual disability have limited cognition, the early manifestations of dementia in such a population may not be easily detected. Changes may involve more behavioral problems as opposed to cognitive decline.

Studies indicate that the initial symptoms of dementia among adults with Down syndrome are more related to the loss of ability to perform familiar tasks and personality changes. These changes are often seen earlier in the lifespan.

**Q11.** *Are there any possible causes of confusion and memory loss in an aging adult with intellectual disability other than dementia?*

**A11.** Sensory deprivation, including hearing impairment or vision loss, can cause changes that can look like dementia. Pain or infection may also cause confusion and appear like dementia.

Other conditions that can mimic dementia include medication side effects, mood problems, hormonal and chemical imbalances such as thyroid disease or high blood levels of ammonia. Liver or kidney disease can also cause cognitive and memory changes that look like dementia. Such conditions are generally reversible with appropriate medication or treatment.

**Q12.** *Among some people with Down syndrome, can other conditions confound impressions of what might look like dementia?*

**A12.** Yes, sudden onset of any change in behavior can be related to other causes. It will be important for the health care provider to understand other conditions that might be present. People with Down syndrome have a high incidence of sleep apnea, celiac disease, and osteoarthritis. In addition, they sometimes have instability in the 1<sup>st</sup> and 2<sup>nd</sup> vertebrae that may lead to walking abnormalities and weakness in their arms. All of these may present as dementia-like symptoms.

Psychiatric issues related to depression, anxiety, and grief may be contributing factors to behavior changes.

Individuals with Down syndrome also experience a phenomenon known as "accelerated aging," which can begin when they are in their 40s. Accelerated aging results in the emergence of conditions associated with other aging individuals who are 5, 10, or even 20 years older. Some adults with Down syndrome may show dementia-like symptoms while in their 20s or 30s, but the underlying cause is currently unclear.

A good resource is the National Down Syndrome Society's publication, *Aging with Down Syndrome: A Health and Well-Being Guidebook*, available from: <https://ndss.org/resources/aging-and-down-syndrome-health-well-being-guidebook>. A free print version of this publication can be obtained by contacting NDSS at [www.ndss.org](http://www.ndss.org). See also *Alzheimer's Disease & Down Syndrome*, available from: <https://ndss.org/resources/alzheimers>

**Q13.** *Can Alzheimer's disease be cured?*

**A13.** No, Alzheimer's disease cannot be cured, nor its eventual progression abated. However, exercise, diet, and environmental stimulation may have a positive impact on the function, attention, and cognition of the person with dementia and thus may delay onset and the nature of progression. Controlling high blood pressure, treating depression, and avoiding sedating medications, when possible, can also help.

There are several medications that can mitigate the symptoms of Alzheimer's disease by improving memory, attention, and focus on the short term. However, none of the available medications has clearly been shown to slow the eventual progression of the disease.

**Q14.** *Are the senses of adults with intellectual disability affected by Alzheimer's disease?*

**A14.** A person with an intellectual disability affected by Alzheimer's disease often has difficulty processing sensory stimuli. Cues in the environment that could help the person function are no longer understood, often resulting in behavior that appears as confusion or inappropriate responses.

The proprioceptor and vestibular systems, the two primary senses used for "location in space" and way-finding, are particularly challenged. The lack of understanding of the sensory cues that ordinarily help the individual know where she or he is "located in space" results in the person being "lost in space." This can appear as aimless wandering, anxiety, or inability to perform functions of daily living, such as using utensils to eat.

If the person does not know where he or she is in reference to utensils and food, it becomes difficult to be able to bring the utensils to the mouth. Difficulty in functioning may be attributed to the disability and ignored rather than related to disease progression and addressed.

**Q15.** *Is there anything one can do about a sense of being "lost in space" for adults with intellectual disability and Alzheimer's disease?*

**A15.** Yes, the environment should be simplified to reduce sensory input. Keep the environment structured and consistent. For example, have the individual sit in the same chair, at the same place at the table, and at the same times every day. Using contrasting colors for the table, dishes, and utensils will help the individual identify the space to be used. Serving food one item at a time in a dish that is a contrasting color may be helpful. Busy patterns or designs should be avoided. Family or staff may need to assist the individual locate the utensils, begin the arm movement, or place the utensil in the mouth with the food. Such problems usually occur in the latter stages of dementia.

**Q16.** *What happens when dementia*

**A16.** How dementia progresses and the length of time involved depends on the nature of the dementia, its underlying cause, the constitution of

*progresses in an adult with intellectual disability?*

the person affected, the nature of the environment, and the services that the person receives.

In Alzheimer's disease, adults with intellectual disability will generally progress from minimally to severely impaired over a long period of time. This progression is generally seen in stages, with notable, but minor impairment in the early stage, more significant impairment and dysfunction in the mid-stage, and almost total incapacity in the late stage. In adults with Down syndrome these stages may be compressed, meaning the individual will progress through the stages at a quicker rate and with more notable changes.

With other dementias, the progression may be similar, but with some variations in duration depending upon what brain functions are initially affected.

**Q17.** *What concerns should be anticipated as dementia progresses in an adult with an intellectual disability?*

**A17.** The progression of dementia increases the risks of various life-threatening outcomes. Caregivers should be vigilant concerning gait dysfunction and falls, choking and swallowing dysfunction, and lung and bladder infections.

Monitoring of the individual for possible inadvertent abuse and/or neglect by caregivers will be necessary as communication skills diminish.

A good resource for learning more about this process is the National Down Syndrome Society's publication, *Alzheimer's Disease & Down Syndrome*, available from: <https://ndss.org/resources/alzheimers>

## Assessment, diagnosis, and treatment

**Q18.** *What should raise suspicion that someone with an intellectual disability is beginning to be affected by dementia?*

**A18.** Generally, changes in memory and behavior may be noticed first. There may be times when the person's personality begins to change; sometimes this is more prominent among adults with Down syndrome. Forgetfulness or confusion may also be noticed. Starting or undertaking a task may become a problem and more prompting may be required even for familiar activities. Walking and balance problems may be noted. In some cases, seizures may be evident for the first time.

In some dementias, significant personality changes, hallucinations or other psychiatric-like symptoms may become more prominent.

**Q19.** *To whom does one turn when there is*

**A19.** If you are a family caregiver, your best resource may be your family physician or the consulting psychologist or physician at the agency that provides services to your family.

*suspicion that the behavioral changes observed may be dementia?*

In some communities, there are memory clinics that perform diagnostic assessments for dementia. There may also be specialty developmental disabilities clinics that can provide a preliminary assessment. Other practitioners who normally perform such diagnostic assessments include licensed neuropsychologists, neurologists, geriatric psychiatrists, and nurse practitioners.

If you are not connected to a disability agency, you may also call your local area agency on aging or aging and disability resource center and request information about who may be able to help you.

**Q20.** *How is the diagnosis of Alzheimer's disease made?*

**A20.** Suspecting this possibility is the first step. Diagnosis is made by exclusion – that is, the need to exclude all other possibilities first. No one clinical test, such as a MRI (magnetic resonance imaging), can establish the diagnosis of Alzheimer's disease at this time. A MRI, however, may indicate if brain shrinkage is evident and support other tests' findings. Usually, multiple sources of information or tests are involved.

Secondly, it is critical that an experienced health care practitioner undertakes a review of the medical history to make sure that other (potentially reversible) causes are ruled out. This should include a review of possible adverse effects of medications.

An experienced health care practitioner will then follow the individual over time, noting progressive changes. Most early diagnoses are labeled "possible" or "probable." ["Possible" is when some behavioral indications point to dementia, "probable" is when tests and other measures strongly indicate that dementia is present.] Recent progress in identifying biomarkers may eventually make a diagnosis more definitive. However, at present, a "definitive" diagnosis of Alzheimer's disease can only be made after death and the completion of a pathology study of brain tissue. New work in the area of biomarkers is showing promise that definitive diagnoses may be made by examining samples of blood or cerebral spinal fluid.

**Q21.** *What tests are used to look for reversible causes?*

**A21.** Depending on the circumstances, there are different tests that a health practitioner can use. These include a MRI of the brain, blood measures (such as thyroid function tests, liver and kidney function tests), and blood levels of vitamins such as B<sub>12</sub>. Vision and hearing assessments should also be considered, as well as any assessments of events that may lead to behavioral change.

**Q22.** *Does the assessment of cognitive decline among persons*

**A22.** Yes, because of differing levels of intellectual development among adults with intellectual disability, assessment instruments used with the general population usually are not useful. Most generic assessment tools presume average intellectual and cognitive functioning as a baseline.

*with intellectual disability differ from assessment of persons in the general adult population?*

Specialized assessments for people with intellectual disability have been developed and usually involve sequential assessments – to look for patterns in decline over periods of time. Such instruments normally look for a decline in memory, communication problems, and decreased executive function skills such as planning, organizing, strategizing, managing time, and attending to details.

However, even tools that have been specially developed to measure functioning among individuals with intellectual disability may have a limited utility for individuals who have a history of severely limited cognitive skills. This is because it is particularly difficult to determine cognitive decline among individuals with severe intellectual disability as verbal and performance measures may not be able to discriminate between the intellectual disability and possible dementia.

Usually, a screening instrument is first used to establish that some changes in health and or function are evident. If the screening instrument shows evidence of notable change, then an assessment is undertaken.

Most groups recommend undertaking an individual screening after age 40 for adults with Down syndrome and after age 50 for adults with other intellectual disability. It is best to use such an initial screening to gather “baseline” information on the person’s optimal functioning before any symptoms of dementia begin to appear.

**Q23.** *What is the difference between screening and assessment?*

**A23.** The difference between “screening” and “assessment” determines what types of instruments are used.

Screening identifies current atypical functioning indicative of decline or cognitive impairment using a standard instrument. Such screening tools are quick, easy to administer, and can be completed by a family member or staff caregiver and can be used at intervals to ascertain changes.

Assessments are a comprehensive evaluation of health and functioning to confirm suspicions. The assessment is conducted by a qualified individual with the appropriate credentials, the focus is on select function areas, and the instrument’s components are appropriate to the innate cognitive capabilities of the adult.

A diagnosis, often using biomedical assessments, assigns a name to the condition found.

**Q24.** *Is there a specific screening*

**A24.** Yes, the National Task Group has issued an administrative screening instrument (termed the “NTG-EDSD”) that can be used as a “first pass” screen that looks for significant changes that warrant a more

*instrument that can be used to identify early onset of dementia?*

comprehensive assessment. The NTG-EDSD is used for early detection and screening and not for diagnosing dementia. The NTG-EDSD helps substantiate suspicions and can provide useful documentation for opening that conversation with a practitioner or diagnostician about the need for a formal evaluation or assessment.

The NTG-EDSD can be used by family caregivers or paid staff to record information about changes in behavior signaling potential changes in behavior or function. NTG-EDSD stands for *National Task Group-Early Detection and Screening for Dementia*. Copies are available at [www.the-ntg.org](http://www.the-ntg.org).

**Q25.** *Should a person with an intellectual disability be informed about the diagnosis of dementia? If so, is there a resource to help talk about this?*

**A25.** Yes. People with intellectual disability experiencing dementia know something is happening to them and struggle to understand the changes in their abilities. A discussion of the changes may need to occur more than once. It is also important to talk with the person early during dementia so they can let their wishes be known and have input into future care possibilities.

A booklet produced by Down Syndrome Scotland explains dementia in simple language with graphics. It is a useful resource to begin this discussion as well as explain dementia to others who have an intellectual disability. It can be downloaded from: [www.the-ntg.org](http://www.the-ntg.org). Another resource is the caregivers' guide, *Talking About Dementia: A Guide for Families, Caregivers and Adults with Intellectual Disability*, also available from [www.the-ntg.org](http://www.the-ntg.org).

If the person lives with roommates, it may be useful to share the information with them. This may help to ensure safety for the individual while reducing or validating the frustrations that might be experienced by the roommates.

## Interacting with medical practitioners and health care providers

**Q26.** *Where can I find a local practitioner (medical doctor, clinic) who may be able to help me as a caregiver?*

**A26.** You can start by calling one of the following: the local or regional chapter of the Alzheimer's Association, the area agency on aging (AAA), the state intellectual disabilities services agency, the state unit on aging (the state's aging or elder affairs agency) or the local aging & disability resource center (ADRC). Also, asking other parents or caregivers often may provide information on who to contact.

When locating a local practitioner, it is useful to ask him/her about his/her experience with people with intellectual disability and dementia. It is also important to ask the practitioner about potential referrals to a

**Q27.** *What are the main issues that should be brought up at each office visit with health practitioners?*

specialized clinic or to a more experienced provider for assessment and care planning. Even when a referral to specialized services is made, ongoing communication and dialogue between the primary provider and the specialty service remain paramount to prevent fragmentation of care.

**A27.** Communication among families, support staff, agencies, and the various health care practitioners is a critical element required to ensure quality care and improve outcomes.

Logs of daily activity observations, medication list, observations of potential side effects of medications, and any new medical diagnosis, are all important to gather before making the trip to the health professional's office. During the visit, it will be helpful to engage in a thorough review of treatment options and alternatives possibly along with medication side effects. The visit should include a discussion of the expectations of treatment outcomes, and an understanding of the disease processes and course.

Also, if not already done, advance medical planning and end-of-life care (advance directives) should be discussed with the medical provider. This does not need to be brought up with every visit; however, a Do Not Resuscitate order (DNR) needs to be reviewed regularly.

**Q28.** *Is there useful information that family and staff caregivers can provide to the health care practitioner prior to a diagnostic visit?*

**A28.** Yes, it is helpful to have an extensive medical history for the individual whenever possible. In addition, background information about the individual's accomplishments and prior daily activities may be useful information.

Notes about past activities in written or electronic format may help the health care provider better understand the prior level of functioning and the extent of noted change. One useful tool for this is the NTG-EDSD (see Q24). See also the NTG's *Physician's Quick Guide for Using the NTG-EDSD*, which could be given to the health care practitioner at the time of the visit (obtain a copy from [www.the-ntg.org](http://www.the-ntg.org)).

To prepare for physician, see the NTG's *Guidelines for Dementia-Related Health Advocacy for Adults with ID and Dementia* – which can be found at [www.the-ntg.org](http://www.the-ntg.org).

**Q29.** *Are primary health care providers (medical doctors, clinics) able to support a*

**A29.** While most primary care providers are capable of ongoing care for individuals with dementia and without intellectual disability, the situation of dementia in individuals with intellectual disability is more complex, and often requires more specialized services. These include specialized clinical testing, longer office visits for a diagnosis based on

*person with intellectual disability and dementia?*

**Q30.** *What are some of the special concerns that one should be aware of when an individual with intellectual disability and dementia goes to the hospital?*

**Q31.** *How can technology improve dementia care?*

symptoms (other than memory loss), and recommendations of other specialized support services.

Unfortunately, most general practitioners are not always experienced or trained in such services and may find it challenging to provide optimal care to individuals with intellectual disability and dementia.

**A30.** Emergency department use and extended hospital care are unfortunate but common occurrences due to the health complications that occur as dementia progresses. It is helpful to have a portfolio available that includes information on medication, health care providers, special needs, and useful behavioral strategies which can be shared with the staff at the hospital.

The availability of a familiar person during the hospital stay will help reduce stress and anxiety for the individual while improving communication, addressing health care needs in the care plan, and outcomes. These measures may help to ensure better care, avoid unnecessary sedation and restraints, and decrease the risk of falls.

A transition-of-care plan also needs to be clearly delineated and understood upon discharge. Such a plan or discharge instructions usually describe the follow-up care needed for the individual in the home or caregiving setting, as well as note the follow-up appointments with the primary care or other health practitioner. Sometimes the transition to care may require the coordination and collaboration of several health care practitioners (such as a nurse, dietitian, physical therapist, primary care physician, family, and support staff). The better the care plan the more likely it is that further complications will be avoided.

**A31.** Technology can be helpful in maintaining communication with the health practitioner, particularly in rural areas. One way is via a hospital or clinic's Internet communication network that serves to provide for communication between practitioners and families. Another is tele-health which involves the delivery of health-related services and information via telecommunications technologies. Tele-health can help with home monitoring, data collection, communication among the care team, and provide specialized consultative services.

Emerging technologies can also aid in enabling home adaptations and applications to use with "smart" products that aid caregivers.

## Medications

**Q32.** *What medications may be useful to reduce the symptoms of memory loss in adults with an intellectual disability who have been diagnosed with Alzheimer's disease?*

**A32.** The two major medications to reduce the symptoms of memory loss are Aricept (donepezil), which increases acetylcholine concentration in the brain, and Namenda (memantine), which reduces inflammation.

These medications may not work with all individuals and their efficacy is reduced over time. Recent research questions the efficacy of both medications when used with adults with Down syndrome.

Several pharmaceutical firms are on working drugs that may affect the continued development of amyloid, a protein suspected of leading to the development of Alzheimer's disease. Any such drugs in clinical trials and showing the decrease of cognitive decline must first be approved by the Food and Drug Administration. For information on which drugs, when approved, might be applicable to adults with early-stage dementia, check with your physician or intellectual disability advocacy organizations.

**Q33.** *Do medications increase the risk of acute dementia in older adults with intellectual disability?*

**A33.** Each medication has its own series of adverse reactions that may mimic or mask underlying diseases or disorders, including dementia. Adults must be observed for any changes when given these medications or if their dosage is increased.

The risk for "acute dementia" (behavior changes that come on suddenly) increases with the number of medications the individual is taking. The challenge is to assess whether the signs of dementia are due to adverse drug reactions, dementia itself, or both. Physicians should be asked to review the medications to determine if any of the medications may be causing these changes.

**Q 34.** *What is "aging into medication"?*

**A34.** Many older adults with intellectual disability have been taking some medications for many years without any serious problems. When a physician reviews the older adult's drug regime, he or she may not include these medications in the review because they have not caused any prior problems.

The normal aging of the body results in an increase in the number of medications found in the blood and if a medication is in the body for an extended period this increases the risk for an adverse drug reaction. Often, if a medication is started when an individual is young there is no problem. However, now that an individual is older, these medications must be considered as a potential part of the problem.

**Q35.** *How can you recognize potential adverse drug reactions in older adults with intellectual disability?*

Medications also may have different effects on younger versus older adults. It is important to have any long-term-use medications reviewed for applicability for continued use by older adults, or whether the dosages prescribed need to be modified.

**A35.** Research has shown that observed changes in a person’s biological activity, his or her behavior, his or her muscular coordination, and in his or her nervous system (such as muscle twitching), are the best indicators of an adverse drug reaction. These changes should be documented and reported.

It is important to being alert to any change whenever the drug regime is modified (e.g., dose, new medications, or medications discontinued).

**Q36.** *What is the effect of ‘Long Covid’ dementia in adults with intellectual disability?*

**A36.** Little research is available on the long-term effects on adults with intellectual disability of having been infected with the SARS-CoV-2 (COVID-19) virus during the pandemic of 2019-2022. Most reports on the general population associate behaviors such as ‘brain fog,’ memory problems, fatigue, mild cognitive issues, and low tolerance to mental activity among adults with severe cases of COVID-19. These effects continue beyond the early infection phase and last for more than three months with recurrence at any time with no warning.

Studies have shown the presence of newly noted cognitive impairment and dementia in some adult survivors following infection by SARS-CoV-2. Only continued surveillance and research over the coming years will reveal the nature and breadth of long-term impact of COVID-19 upon brain health.

Reports have noted that some adults with intellectual disability have shown the signs of Long Covid, and thus any such residual signs should be taken seriously, even if there was no indication of infection (as some symptoms may have been overlooked due to being less obvious and attributed to a person’s intellectual disability).

Research with groups of adults with Down syndrome has shown highly protective effects from serious complications from COVID-19 if the adults have received both the vaccine as well as boosters. Continued vaccination should help mitigate severity and thus the long-term effects of the virus.

A useful resource is *Advisory on Long-COVID and Impact on Cognitive Function in Adults with Intellectual Disability*, available from [www.the-ntg.org](http://www.the-ntg.org).

## Programs, supports, and services

**Q37.** *What kind of training would be helpful to family and staff at the individual's current living environment?*

**A37.** Training of staff and instructions for family caregivers may help ensure optimal care and quality of life for a person with intellectual disability affected by dementia. An awareness of different stages of the disease process is helpful, as is training that highlights safety precautions, positive behavioral interventions, and the features of a calm and consistent living environment. Knowledge of increased risk factors associated with rate of disease progression (i.e., infection, loss of ambulation, nutrition, hydration, aspiration, and pneumonia) should help to avoid complications that might otherwise go undetected.

Depending on the care needs of the person with intellectual disability and dementia, training may be provided by various individuals, such as nurses, physical therapists, nutritionist/dietitians, speech pathologists, behavioral specialists, and staff from a local Alzheimer's Association or other support agencies.

**Q38.** *How do I know if activities and interventions are having an effect on the symptoms of Alzheimer's disease?*

**A38.** Diligent observations of the individual's activities of daily living, functional abilities, and any increasing support needed may provide clues to the impact of treatment. Such observations should be documented and presented to health professionals to assist in determining the impact of treatment. A number of intervention assessment tools (question and answer types) have been developed and can be used to monitor the effect of treatment on symptoms of Alzheimer's disease.

**Q39.** *Will my relative have to move from his or her home or will the agency serving him or her continue to provide supports where he or she currently lives?*

**A39.** Some agencies are better prepared than others to provide residential support for people with intellectual disability and dementia. Talk with the agency administrator about his or her staff's abilities to provide supports for persons affected by dementia. If they do provide supports for early-stage dementia, ask about the agency's willingness to continue to provide supports as dementia progresses.

Since dementia prevents an individual from continuing to live alone or unsupervised, some changes in the living arrangement may be necessary. Ask about what options may be available for supervision as well as where the person may move to as dementia progresses.

If there are others in the home, then discuss with the agency what options may be available for continued "aging-in-place" supports. Plan with the agency for future adaptations to the home and living circumstance that will be required over time.

Some agencies have developed special dementia care homes because of requests by family members or staff. These homes provide continued community living and provide staff specially trained in helping people affected by dementia.

**Q40.** *Can families care at home for a person with intellectual disability and dementia?*

**A40.** Yes, it should be possible to care for people with intellectual disability and dementia at home if adequate supports are provided.

Studies have found that families can support people with intellectual disability at all stages of dementia at home. Unfortunately, obtaining formal supports to do so is often a challenge, particularly for late-stage care. One challenge is that in some homes both a person with intellectual disability with dementia and another family member who has become infirm live together. Such situations require inter-agency coordination and more formal supports. Unfortunately, some caregivers in this situation often find themselves unsupported by service systems as they are seen to have coped well as caregivers for many years before dementia developed.

Families should regularly seek the advice of elder care and intellectual disability organizations. These organizations may be able to identify community resources based on changing needs of the aging person and the introduction and availability of new programs.

**Q41.** *What supports are needed to care at home for a person with intellectual disability and dementia?*

**A41.** Supports can include personal care assistance, caregiver respite, support and counseling, linkage with dementia specific services, environmental modifications, assistive technology, and planning for increased support needs and end-of-life care.

It is likely that no one service organization can provide all these services and supports. However, some help can be obtained through the Family Caregiver Support Program, usually administered locally by the area agency on aging. Other help may be obtained from state and local service providers for intellectual and developmental disabilities and the Alzheimer's Association.

**Q42.** *Where can I find helpful information about local programs, supports, and services for older adults with Alzheimer's*

**A42.** A helpful resource is the information and referral line of your local area agency on aging (the AAA). Another resource is the local aging and disability resource center (the ADRC). If the person for whom you are caring is 60 years of age or older, or has a disability, he or she is entitled to receive services and supports from your local AAA /ADRC. As the [National Caregiver Support Program](#) mandates assistance to older caregivers who care for someone with an intellectual disability younger than age 60, this too can be a resource for information. The state agency on aging (or elder affairs, etc.) can provide information about receiving aid from the National Caregiver Support Program. Also, your local

*disease in my community?*

chapter of the Alzheimer’s Association is a useful resource and can be sourced in your local telephone directory or on-line.

Since individuals with Down Syndrome often experience younger-age onset dementia, check for resources available through the local Alzheimer’s Association or local/state chapters of The Arc and the National Down Syndrome Society or national organizations such as National Down Syndrome Congress and the National Down Syndrome Society. In some areas there are specialty clinics for adults with Down syndrome that may be of help (see the Global Down Syndrome Foundation for a listing – [globaldownsyndrome.org](http://globaldownsyndrome.org)).

The national and local contact numbers for these organizations can be found on the Internet or in your local telephone book. In your search look for [www.alz.org](http://www.alz.org), [www.thearc.org](http://www.thearc.org), [www.ndss.org](http://www.ndss.org), [www.ndscenter.org](http://www.ndscenter.org)

**Q43.** *How can I connect with other families for support who also have a relative with intellectual disability experiencing dementia?*

**A43.** Check with your local services provider or the Alzheimer’s Association; they may be able to connect you with other families or offer other practical suggestions to help you. If no resources are available through your local Alzheimer’s Association and your family member has Down syndrome, organizations such as the National Down Syndrome Society or National Down Syndrome Congress may be able to assist you in efforts to find a family that has experienced dementia. Often local caregiver assistance organizations will run caregiver support groups.

It is important that family members have a support network, especially as the disease progresses and the level of care needs become more difficult and a management challenge.

**Q44.** *What are some new models for in-community dementia care for adults with intellectual disability?*

**A44.** Many agencies operate or are developing small-size specialized dementia care group homes. These homes are usually what are termed “dementia-capable” – that is, the staff are specifically trained to care for persons with dementia and the home designs are organized around technologies and structures that help people with dementia function to their utmost abilities. Such neighborhood dementia care group homes are usually small and offer a specialized program designed to maximize the person’s residual skills. Most such homes will provide long-term care and special supports for a small group of adults with various stages of dementia. Such homes are not usually available to the general population as they are operated by many agencies that provide community-based residential supports for adults with intellectual disability.

Such homes provide a needed support in a community setting in compliance with the Olmstead Decision which declared institutional

care as unreasonable in relation to the community-dwelling needs of a person with a disability. In 1999, the United States Supreme Court held in *Olmstead v. L.C.* that unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act.)

Another support program is organizing dedicated dementia care services to an individual living in a group home with others who may not have dementia. This program is provided as part of an ‘individualized dementia care plan’ designed for an adult showing symptoms of or diagnosed with dementia. This enables the person to remain in a familiar setting with people he or she already knows.

The National Task Group has a publication, “*Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia*,” which contains useful information on program and support options. It is available at [www.the-ntg.org](http://www.the-ntg.org)

**Q45.** *Are there complications that impede continuing to attend a day program?*

**A45.** As dementia progresses, it will be important to reassess the person's ability to tolerate participation in a day service. Challenging behaviors and extensive personal care needs that become difficult to manage may impede continued enrollment unless the day service has the capacity to manage people with dementia. Also, the onset of sleep problems may make it more difficult for the person to remain alert during the day and participate in activities.

If the day program is terminated, the person will still need to be in an environment that is calm and predictable while providing suitable stimulation and social interaction. An alternative environment should be identified prior to the termination of a regular day program to ensure that the individual remains engaged.

**Q46.** *Is it possible to maintain a person with intellectual disability and dementia in a regular day program?*

**A46.** Yes. People with intellectual disability and dementia can benefit from being able to continue the routine activities of their lives. For many, this includes continued attendance at a day care or services program. Employment programs and activity settings where there is little supervision may present too many challenges.

It has been demonstrated that day programs that focus upon maintaining activities that were previously enjoyed, organize their space for low noise and small group activity, make “dementia-friendly” environmental modifications, train their staff to be more “dementia-capable”, and organize themselves to be able to support people with incontinence are likely to be more successful in maintaining people with intellectual disability and dementia in programs.

Specific recommendations may be found at [http://ceacw.org/docs/Frontline-winter05-dayprog\\_envmod.pdf](http://ceacw.org/docs/Frontline-winter05-dayprog_envmod.pdf)

**Q47.** *What kinds of difficulties may interfere with a person's living setting?*

**A47.** As dementia progresses, sleep cycles may become reversed or interrupted, which may mean that the adult may be up at night and asleep during the day. Other dementia-related behaviors, such as wandering, hoarding, and shadowing (following someone around), may have an impact on both the individual and his or her housemates. Consideration may have to be given to how this might be remedied in a manner that is beneficial to all. Housemates may not understand the changes that are evident in the individual.

It will be helpful to provide housemates with information that may allow them to better understand the changes and the course of the disease. It may also provide them with an opportunity to support their housemate on an on-going basis and tolerate repetitive behaviors. Safety for all is of critical importance. If the individual is less able to be mobile as dementia progresses, staff will benefit from instruction in safe techniques for lifting and assisting. Augmenting staff to help during periods of the day when such adults may be more active may be necessary.

**Q48.** *What considerations should be factored in if nursing facility admission is required?*

**A48.** A thoughtful approach to what is the best living setting will increase the likelihood that the individual is safe, well cared for, and has access to a setting that will focus on quality of life and quality of care throughout the course of the disease. Before considering a referral to a nursing facility, you may wish to explore what alternative residential settings might be available in your community and assess whether the settings are receptive to or have experience with individuals with intellectual disability and, if possible, have smaller patient-to-staff ratios.

Nursing facility referral should be a consideration of last resort due to advanced dementia and used only when extensive nursing care is necessary due and exceeds the capabilities of the family or staff at the person's residence.

**Q49.** *Do people with intellectual disability and dementia experience "transfer trauma"?*

**A49.** Yes, it is possible. "Transfer trauma" may occur when there is a change in the living environment at any stage of dementia. There is more risk when the adult is still ambulatory, can wander, and has a sense of orientation in place. Anxiety, depression, and behavioral disturbances can also be manifested, so it is advisable to plan to prepare for a safe, smooth transition. Minimizing the dissonance between the original and new environments will aid with adjustment to 'transfer.'

Providing a biography of the individual with pictures introduces the person to the staff and helps recognition of his or her "personhood." Support strategies that value the individual in the new setting,

recognizing the losses that he or she has experienced are important. These measures may reduce crises later caused by illness or further changes caused by the disease. While no situation may be perfect, such efforts will help ensure a quality of life and quality of care throughout the course of the disease. Seek to understand all options to make an informed choice while acknowledging you cannot control all factors.

**Q50.** What is 'advanced dementia'?

**A50.** 'Advanced dementia' is the late stage of cognitive and physical decline where an adult primarily requires personal or nursing care. Heightened behavioral symptoms may present, such as increased agitation, anxiety, wandering (if the person is still mobile), aggression, or sometimes hallucinations. Loss of bodily functions, such as bladder and or bowel incontinence, is common in this stage of dementia, as is loss of appetite and consequent weight loss. This stage may last one to two years (or less) prior to death.

## Nutrition and dietary issues

**Q51.** *Is there a specific diet that can help prevent dementia or delay its progression in individuals with intellectual disability?*

**A51.** Although there has been increasing interest in the role of omega-3 fatty acids (healthy fats from fat fish such as salmon, sardines, mackerel, and tuna) and antioxidant nutrients, such as vitamins C and E, as protective factors for dementia, there is no conclusive evidence that a diet rich in these nutrients can prevent dementia or delay its progression.

In combination with regular physical activity, a healthy diet that provides proper level of calories and nutrients to meet individual needs can help maintain good nutritional status and quality of life. A balanced diet that includes plenty of whole grains, fruits, and vegetables, lean meats and other high-protein foods, dairy, and moderate amounts of healthy oils – plus fluid for sufficient hydration – should be tailored to each person's needs and preferences.

**Q52.** *How can individuals with intellectual disability and dementia who are losing weight increase their food and nutrient intake?*

**A52.** Poor food intake and weight loss are consequences of certain root problems. A comprehensive assessment of the factors that impair or promote food intake is a crucial step in creating an intervention plan. A dietitian/nutritionist should be consulted to assess and make recommendations for a plan of care to meet the person's nutritional needs.

Food intake is affected by many factors including illness and medications, cognition, physical ability, psychological and social well-being, environment, and culture. For example, if the poor food intake is due to poor oral health (mouth sores or ill-fitting dentures), or difficulty in chewing and swallowing, or constipation, then dietary and other

strategies can be used to relieve these problems. A soft or non-irritating diet can help with mouth sores and a high-fiber diet (rich in whole grains, fruits, and vegetables) and liberal amounts of fluid, unless fluid is restricted, can help relieve constipation.

**Q53.** *What are some of the challenges for weight control for overweight or obese individuals with mild cognitive impairment or dementia?*

**A53.** Challenges include certain medications that induce weight gain, limited physical activity, age-related changes in body composition, decrease in basal metabolic rate, difficulty in understanding diet-related information, and the family members' or caregivers' insufficient ability to serve as role models themselves for health-promoting behaviors. Some individuals with dementia may start eating more than they normally do due to real hunger, increased physical activity, boredom or isolation, or new liking for sweets and high-calorie foods and drinks. They may also eat as they have forgotten that they may have just had a meal. In addition, some caregivers may misuse unhealthy foods (those with high sugar or fat content or no nutritional value) as a reward for "good behavior."

**Q54.** *What are some dietary complications when someone with an intellectual disability has later stage dementia?*

**A54.** Swallowing may become a problem. In consultation with a speech-language pathologist, difficulty in swallowing must be assessed and managed properly. Management includes a diet modified for texture and different levels of consistency to promote safe swallowing. In the later stages of dementia, the individual may not be able to swallow at all.

An alternate way of providing nutrition (i.e., tube feeding) may be considered as an option. However, there are potential complications with this alternative and caregivers need to be informed about what might be included in these complications.

Aspiration, the inhalation of what has been eaten or gastric contents, can lead to pneumonia. Pneumonia is a common cause of death for individuals in later (advanced) stage of dementia.

## Palliative and end-of-life care

**Q55.** *What about palliative care?*

**A55.** Since individuals with intellectual disability, including Down syndrome, may not be able to communicate their discomforts, such as level of pain, it may be helpful to investigate options for palliative care. It is likely that they will have the same discomforts associated with aging (e.g., fatigue, constipation) and related disorders (e.g., osteoarthritis) as that experienced by the general population. Discomforts, either physical or psychological, may be expressed as agitation or other behavioral disturbances. Palliative care can be helpful to incorporate within the person's plan of care.

As per the 2013 Clinical Practice Guidelines for Palliative Care by the National Consensus Project for Quality of Palliative Care, palliative care is for those persons from early diagnosis to end of life care. Palliative care is person and family/caregivers-centered care to optimize the quality of life by anticipating, preventing, and treating suffering that may be caused by physical, intellectual, emotional, social, and spiritual needs. Care is coordinated through team collaboration of the person, family, caregivers, and health care providers. The goal is for peace and dignity for the person through the course of illness, the dying process, and after death.

**Q56.** *As end-of-life approaches, what supports may be utilized?*

**A56.** Access to hospice care may be an appropriate alternative to hospitalization. If care is transferred to a hospice provider, it will be important for the caregivers and staff to have a good understanding of how the hospice services will be provided. Many hospice providers will offer hospice or palliative care in the person's home.

**A57.** *What other activities may be helpful to the individual's family and community at the end-of-life?*

**A57.** Cultural or religious rituals that mark the end of life for the general population are equally important to people with intellectual disability. Caregivers, staff, and peers consistently express the need for an opportunity to celebrate the life of an individual with intellectual disability who dies from complications of dementia or from any other terminal illness.

Families who have been lifetime caregivers experience a significant loss and may benefit from access to support services as they work through their grief. Staff and peers who have enjoyed a long-term relationship with the individual may also benefit from this kind of support.

NTG: [www.the-ntg.org](http://www.the-ntg.org)

The NTG is indebted to the NTG members who aided in creating this FAQ, and to Mary Hogan, Elizabeth Bodien, and Kathleen Srsic-Stoehr for their help with fact-checking and wordsmithing.

Comments, corrections, and additions may be sent to Dr. Matthew Janicki at [Janicki @ gmail.com](mailto:Janicki@gmail.com)

V.10-Nov.2022b