



Considerations for Persons with Intellectual and Developmental Disabilities

Dementia-friendly communities are vital in helping people live well with dementia and remain a part of their community. Most adults living with an intellectual or developmental disability live in a community settings, either independently or with support from families, friends and service providers. There are important considerations to create supportive, dementia-friendly environments for people living with intellectual and developmental disabilities.



What is Dementia?

Dementia is an overall term that describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities. Dementia has many causes. Alzheimer's disease, the most common cause of dementia, is a disease of the brain that leads to changes with memory, thinking, and behavior. Alzheimer's and other dementias are not a normal part of aging.

Key findings of the National Task Group on Intellectual Disabilities and Dementia Practices:

- Studies in the United States have shown that adults with an intellectual disability **with causes other than Down syndrome** have a similar prevalence of dementia, and are affected by the same types of dementia as people in the general population. The average 'onset' of dementia symptoms is first seen in the late 60s and symptoms such as memory loss, disorientation and language difficulties are similar to those seen in the general population.
- It is important to document baseline adult abilities by age 35, including detailed information on the individual's intellectual, social and behavioral function.
- Several cognitive tests have been used to evaluate thinking changes in adults with intellectual disabilities. [The NTG-Early Detection Screen for Dementia \(NTG-EDSD\)](#) is one such tool.
- Cognitive tests should never be the only tool used to diagnose dementia. Rule out other causes of symptoms such as thyroid problems; depression; grief and loss; chronic ear and sinus infections; other infections; pain; effects of medications; and sleep apnea.
- After diagnosis, it is important to build a support network which includes the primary care doctor; memory specialist and other related medical specialists; care partners; day program or workshop staff; state or agency support staff; other family and friends.

Early Signs of Dementia

- Changes in mood and personality
- Withdrawal from work or social activities
- Confusion with time or place
- Challenges in planning or solving problems
- Difficulty completing familiar tasks at home, at work, or at leisure
- New problems with words in speaking or writing
- Misplacing things and losing the ability to retrace steps
- Memory loss that disrupts daily life
- Decreased or poor judgment
- Trouble understanding visual images and spatial relationships

Early Signs for Individuals with Down Syndrome:

- Seizure activity – new onset
- Incontinence – new or increased
- Changes in mobility – new or increased
- Swallowing difficulties – new or increased

Alzheimer's Disease in Individuals with Down Syndrome

- Alzheimer's disease is of more concern for people with Down syndrome than those with other forms of intellectual disability because of the third or "extra" copy of chromosome 21 found in individuals with Down syndrome. Chromosome 21 carries a gene that produces one of the key proteins involved with changes in the brain caused by Alzheimer's disease (APP-amyloid precursor protein)
- There are also several genes on chromosome 21 involved in the aging process which may contribute to the increased risk of Alzheimer's disease.
- Alzheimer's disease is not guaranteed in people with Down syndrome.
- Estimates show that it affects about 30% of people with Down syndrome in their 50s. By their 60s, this number comes closer to 50%. Although risk increases with each decade of life, at no point does it come close to reaching 100%.
- Short-term memory loss is not usually an early sign. Instead, watch for changes in day-to-day functions; reduced enthusiasm for daily activities; loss of interest in social interactions; and changes in personality and behavior. New onset seizure activity is often another hallmark sign.

Dementia-Friendly Communication

- Treat the person with dignity and respect.
- Speak slowly and clearly. Use a gentle and relaxed tone.
- Use shorter simple sentences, and ask one question at a time.
- Avoid arguing with or embarrassing the person.
- Encourage nonverbal communication.
- Patiently wait for a response while the person takes time to process what you said, about 20 seconds.
- Approach the person slowly and from the front, never from behind so they are less likely to be surprised or startled.
- Be aware of your body language: smile and make eye contact at eye-level.
- Seek to understand the person's reality and feelings.
- Apologize and redirect to another environment or topic as needed.

Resources

- Dementia Friendly Iowa - <https://dementiafriendlyiowa.org/>
- Dementia Friendly America - <https://www.dfamerica.org/>
- Alzheimer's Association - <https://www.alz.org/>