Dementia

With the rise in life expectancy for people with intellectual and developmental disabilities (IDD), the risk of developing age-related conditions also increases. One such condition is dementia. The rates of dementia among people with IDD are higher than in the general population, particularly among individuals with Down syndrome.

What is dementia?

Dementia is a general term for a decline in mental ability that is severe enough to interfere with daily life. Dementia is not a specific disease. It is a term that describes symptoms that are caused by diseases. There are many causes of dementia, but here are the most common:

Alzheimer's	This is the most common cause for dementia. It is caused by plaques and tangles that form in the brain. It causes memory loss, language loss, and eventually affects all abilities. There is a fairly predictable pattern of decline.
Vascular dementia	This is the second most common cause of dementia. It is caused by blood loss to the brain (from strokes, brain bleeds). Symptoms will vary depending on the area of the brain affected.
Frontal temporal	Named for the areas of the brain most affected (the frontal lobe). This controls judgment, mood, level of self-control, and behaviour (among other things). Initial signs will be personality and behaviour changes, then skill or memory loss.
Lewy body dementia	Caused by tiny deposits in the brain (Lewy bodies). Main symptoms are changing mental abilities, visual hallucinations, and spontaneous features of Parkinsonism (tremors, walking and balance changes, rigid muscles, lack of facial expression).

Some people will have more than one cause of dementia (such as Alzheimer's disease + vascular dementia). This is called "mixed dementia". Regardless of the cause of dementia, memory loss will eventually become apparent. Often, people will forget things that occurred most recently (what they ate for breakfast, the name of a new staff member), but over time, longer term memories of information, and how to do familiar tasks will be forgotten too.

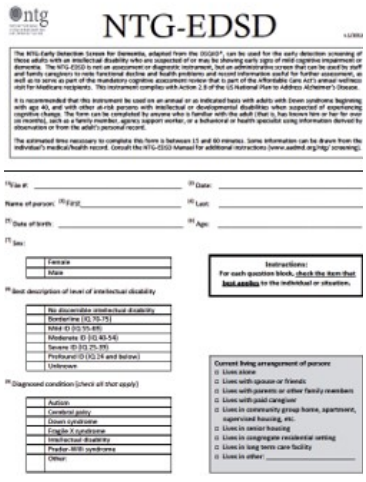
Screening tools for dementia in IDD

The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) was formed (in America) to develop guidelines around screening, treatment and practices for people with IDD and signs of dementia. This is because there is no accepted 'gold standard' quick cognitive screening tool for dementia in IDD. The scores for tools that exist for the general population (like the MoCA, and the Mini-Mental) are not valid for people with IDD, so should not be used. For individuals with IDD, **the first signs of dementia are often behavioural**, and may include:

- ❒ losing interest in hobbies/activities (apathy);
- ❒ losing ability in skills they previously had;
- ❒ changes in speech (trouble finding words, repeating words, speaking softly);
- ❒ becoming disoriented/lost, and confused.

Memory loss may not be obvious at first – this likely occurs later.

The NTG-EDSD (National Task Group Early Detection Screen for Dementia) is freely available at www.aadmd.org/ntg/screening. Caregivers have unique knowledge and information about their family member that helps establish a baseline for measuring change. The NTG-EDSD is a tool that will help you identify changes that can be reviewed with the health care provider.



The NTG-EDSD, a baseline measure. Consider doing annually for people over 40 to capture baseline—and any change.

What to do if you suspect someone might have dementia?

1) Complete the NTG-EDSD tool with others who know your family member well. (It is helpful if you have a previous one to compare with).
2) Accompany your family member to a doctor's appointment. Be prepared to offer your impressions about any changes that have been noticed. Share the findings of the NTG-EDSD.
3) Share as much information as you can about their health and social history.
4) Support your family member through any investigations that the doctor orders. This might include blood work, urine testing, and perhaps imaging of their brain. This will help figure out if there are reversible medical issues that could be causing the changes and can be treated. See below for examples.
5) Specialist involvement may also be sought out—from a neurologist, a psychiatrist, geriatrician or a psychologist. Accompany your family member to these appointments as your knowledge of your loved one's health and social history may be helpful.
6) Continue to offer reassurance and support. Help your loved one to feel important and useful, and connected to things that they enjoy. Remember, having dementia does not change who they are—it is just one aspect.

...Could it be something else?

Because dementia is a progressive condition and there is no cure, it is important to know if the change you are seeing is actually dementia—and not something that can be treated and reversed. The following are common causes for memory/behaviour change that should be addressed before jumping to a diagnosis of dementia.

Sensory changes	Vision or hearing loss. Depth perception challenges.
Metabolic disturbances	Electrolyte abnormalities; hypo/hyperglycemia; B12 or folate deficiencies; thyroid dysfunction; anemia; toxicity from medications.
Mood changes	Depressed/low mood.
Medications	Drug interactions or side effects.
Sleep problems	Sleep apnea or undetected sleep disorders.
Seizures	Undetected or worsening seizures.
Pain	Undiagnosed or worsening pain.
Mobility problems	Mobility disorders causing decreased movement or function, limiting activity.
Psychosocial/ environmental	Changes to routines, death or impairment of family member or friends, new routine at home/work.

Down Syndrome & Alzheimer's Disease

Over half of adults with Down syndrome older than 50 years of age will have symptoms of dementia - things like personality changes, memory loss, and skill loss. This is thought to happen because the extra chromosome characteristic of Down syndrome produces an additional protein—the same protein in the brain that is believed to cause the plaques and tangles of Alzheimer's disease.

On average, people with Down syndrome who develop dementia tend to do so at a younger age than the general population, and the disease will progress more quickly.