



National
Intellectual Disability
Memory Service



**Answers to your questions
about intellectual disability
and dementia**

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Introduction

Ageing in people with intellectual disability (ID) is a success story, with people now living into their 60s, 70s and beyond. Many people with an ID will live a very fulfilled life transitioning from childhood, to teenage years, adulthood and into old age. People with an ID are contributing in many ways to their communities, through employment, volunteering and enhanced social roles.

People with Down syndrome are susceptible to accelerated ageing and are at a higher risk of developing dementia. A new National Intellectual Disability Memory Service has been established at Tallaght University Hospital in partnership with the Daughters of Charity Disability Support Service and Trinity College Dublin. The aim of this service is to provide access to specialist memory assessment, comprehensive diagnostic work-up and post-diagnostic support for persons presenting with memory concerns.

The intent of this publication is to address some of the questions and concerns related to dementia and to provide guidance on:

- Alzheimer's Dementia and why people with Down syndrome are at increased risk
- Understanding the signs and symptoms of dementia
- Understand the key components of making a diagnosis
- Practical advice on attending the National Memory Service and how to be prepared for your initial visit.

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What is Dementia?

Dementia is a general term for loss of memory, language, problem-solving and other thinking abilities that are severe enough to interfere with daily life. It contributes to a deterioration in the person's ability to remember, learn, concentrate, understand, reason and care for him or herself independently. The loss of these abilities may be preceded by or accompanied by changes in the person's personality, mood, social behaviour or motivation. Whilst the person may have difficulty in remembering recent events, they will often continue to retain long term memories well into their illness and will benefit from and continue to enjoy valued life pursuits. Maintaining connections with family and friends will be very important and impact greatly on the person's quality of life.

There are many different types of dementia as shown in Figure 1. Alzheimer's disease is the most common cause of dementia.

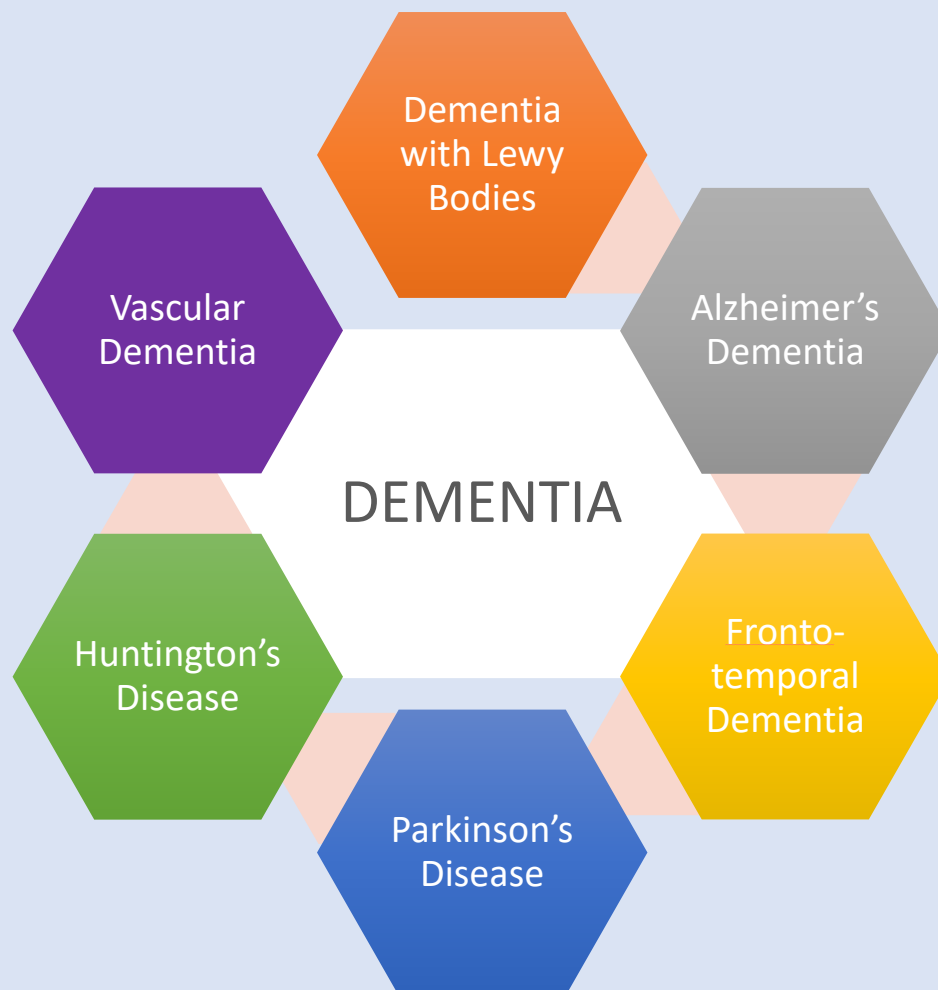


Figure 1: Types of dementia

What is Alzheimer's Dementia?

Alzheimer's Dementia (AD) is a term used to describe certain brain changes that result in progressive loss of brain function, leading to dementia. The hallmarks of Alzheimer's type dementia are plaques and tangles that disrupt the working of the neurons in the brain. It is a progressive disorder that causes brain cells to waste away (degenerate) and die, resulting in a continuous decline in thinking, behavioural and social skills that disrupts a person's ability to function independently. Dementia of the Alzheimer's type is more common in people with Down syndrome, due to their genetic predisposition.

What are the main symptoms of Alzheimer's Dementia?

Memory

- Forgetting recent information and events
- Forgetting daily routines and familiar people
- May still remember events in their past
- Difficulty performing routine tasks

Disorientation

- Confused with home layout
- May wander looking for the bathroom, bedroom etc
- Confused sense of time
- Sleep may become disturbed -change to internal clock

Language

- Difficulty finding words or naming things
- More difficulty in holding a conversation
- Speaks more slowly
- Difficulty understanding instructions

Personality

- Mood may change
- May be more easily upset or agitated
- May appear less motivated to do things
- Difficulty coping with times of transition or change

Daily Activities

- Needs more help with usual daily activities
- May lose / misplace personal items frequently
- Needs familiar predictable routines

Physical Changes

- New onset seizures
- Episodes of incontinence
- Unsteady gait and risk of falls

How does Alzheimer's dementia progress?

Dementia is progressive and often we need to change approaches to the support and care somebody receives in response to events. Dementia may progress through three main stages: early, middle and late stage disease. It is important to remember that each individual will experience changes in their own way and some features may appear earlier or later than others. Having adequate services to support the individual across the continuum of dementia including at end of life is important.

For practical caregiving strategies please see our two booklets:

1. Supporting someone with dementia
2. Supporting safe care in the home



If a person with Down syndrome presents with loss of memory / skills, do they have Dementia?

No, not necessarily. While the prevalence of Alzheimer's dementia in people with Down syndrome does increase with age, it does not mean that someone with Down syndrome presenting with changes in memory and skills has dementia. Having a comprehensive diagnostic workup is important to out-rule other common conditions. Table 2 shows common health conditions that can be experienced by older adults that do not necessarily have dementia.

Table 2: Common Health Conditions

Common Conditions	Features	Follow Up
Depression	Person may have: <ul style="list-style-type: none"> - Sadness or agitation - Less motivation - Difficulty in concentrating - Change in appetite - Change in sleep 	Review by doctor Can be treated with supports and medication
Under-active Thyroid Gland	<ul style="list-style-type: none"> - Dry skin - Increased sensitivity to cold - Weight gain - Muscle weakness and fatigue - Constipation 	Review by doctor Blood test taken and treated with medication
Issues with Hearing / Vision	<ul style="list-style-type: none"> - Difficulty in hearing what people are saying - Can't see objects or people 	Annual Hearing and Eye Test Hearing aids, glasses
Physical Illness	<ul style="list-style-type: none"> - Urinary tract and chest infections - Chronic constipation leading to delirium 	Full physical examination and blood test
Vitamin Deficiency	<ul style="list-style-type: none"> - Fatigue/lack of energy - Poor concentration - Pale skin and palpitations 	Blood test taken and treated with improved diet or supplements/B12 injections
Major Life Events	<ul style="list-style-type: none"> - Can include bereavement, moving house, interpersonal difficulties 	Support the person to communicate their stress and help them to cope with it

Is new onset seizure activity associated with Dementia in people with Down syndrome?

As dementia progresses, people with Down syndrome are often at increased risk of developing new onset seizure activity. This condition can be characterised by myoclonic jerks, often occurring upon waking. They may have brief intense jerking movements or whole-body movements, often with no loss of consciousness. Others may present with more severe forms of seizure activity such as tonic-clonic seizures that can include strong body shakes and/or loss of consciousness.

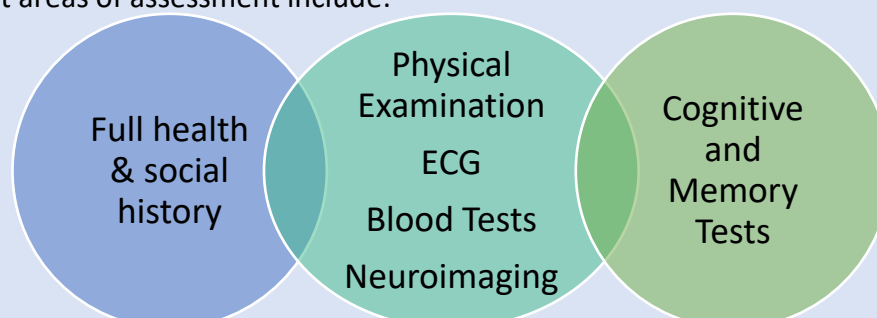
It is important to investigate and treat any late-onset seizures. There are now effective and safe medications available for the treatment and management of seizure activity which will have a positive impact on the person's overall health and quality of life.

How is dementia diagnosed in people with Intellectual Disability?

Diagnosing dementia in people with an intellectual disability is complex because the person may already have difficulties in areas such as memory, language, and ability to attend independently to self-care needs. A diagnosis of dementia can be made with a high degree of accuracy where there is good and reliable information available across a number of areas including social, physical and mental health history. **The most valuable information to assist with diagnosis comes from the history of change described by family or carers who have known the person for quite a long time.** Changes in other aspects of behaviour are also relevant, such as changes in personality, mood, and general loss of interest in day-to-day events. These are sometimes the first changes observed and reported by family or staff.

An annual brain health check is recommended for adults with Down syndrome from 40 years in order to capture the person's optimal function and performance. This baseline can be used as a measure against which future functional and cognitive decline can be assessed.

Important areas of assessment include:



Is there a cure for Alzheimer's Dementia?

There is currently no cure for dementia however people can be supported to maintain good brain and physical health as they age. This will support their brain and memory to function well through their lifespan. There are medications and other treatments that may slow the rate of progression and can help with dementia symptoms. Researchers are working around the world towards developing better treatments to slow the progression of dementia and perhaps eventually even a cure.

Timely diagnosis is so important to enable dementia care to focus on supporting people to live well with the diagnosis and to engage in valued life-enhancing activities. Early diagnosis allows more time to plan for appropriate care and treatment. Person-centred care and futures planning enable the person living with dementia to continue to enjoy life with their family and friends in their community.

If you suspect that a person is presenting with dementia-like symptoms what should you do?

Contact your doctor for a referral to the National Intellectual Disability Memory Service or for further information contact our clinic administrator in Tallaght University Hospital. Tel: (01) 414 2577 or Email: nidms@tcd.ie

What will a visit to the National Intellectual Disability Memory Service involve?

The person and their carer will meet the specialist intellectual disability nurse in the Clinic. The nurse will ask about general mental and physical health, memory concerns and recent life events. They will also conduct a physical health assessment and administer some tests of memory and cognition.

The length of time and the type of tests used is likely to vary depending upon what is required to undertake a comprehensive assessment. The individual's level of intellectual disability and their ability to complete the tests will also influence the length of time the assessment will take. It may take a number of visits to the National ID Memory Service to complete the assessment. The first visit to the Memory Service may take approximately 2 to 3 hours to complete.

The types of questions that might be asked at the assessment may include:

1. When did you first notice changes?
2. Did these changes occur suddenly, or have they happened gradually over time?

3. What are the main changes you have noticed?
4. Is there recent memory loss? Can you give examples?
5. Is it more difficult for the person to do certain things? Can you give examples?
6. Does the person need more help with day-to-day activities such as washing, dressing, feeding etc.?
7. Has the person any difficulty in remembering people that they used to know or in remembering recent events? Can you give examples?
8. Does the person wander or appear lost?
9. Have there been changes noted in the person's work or day placement?
10. Have there been changes in the person's language? Does the person engage in conversation like before?
11. How have these symptoms changed over time?
12. Has there been any change in the person's personality and mood?
13. Does the person need encouragement to take part in activities they previously enjoyed?
14. Have there been changes in the person's sleep pattern?
15. Have there been any changes in appetite?
16. Does the person have any other medical conditions?
17. Is the person taking any medication? (If so, take a prescription with you to the assessment).
18. Did the person have a recent medical examination?
19. Have there been any changes noted in hearing or eyesight?
20. Have there been any recent major changes in the person's life, for example, bereavement, loss, moving to a new house? Have other family members or staff noticed changes?

The National Intellectual Disability Memory Service is committed to improving the early detection of dementia in people with an intellectual disability and offering post-diagnostic supports.

If you have any further questions, please email nidms@tcd.ie





National
Intellectual Disability
Memory Service



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Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin



**Tallaght
University
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An Academic Partner of Trinity College Dublin



Daughters of Charity
Disability Support Services

With the support of



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