

Alzheimer's Dementia in Persons with Intellectual Disability

Some Common Questions and Concerns



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namhi is a national voluntary organisation working to promote the rights of people with intellectual disability in Ireland to ensure their full and equal participation in society. **namhi** was founded in 1961 and has become the co-ordinating body for over 160 organisations providing supports and services to almost 27,000 people with intellectual disability in Ireland.

namhi provides a central forum for its members to identify priorities and formulate nationally agreed policies to present to Government and statutory bodies, other relevant groups as well as the general public. **namhi** campaigns for changes in services and legislation that will improve the quality of life and participation for people with intellectual disability in Irish life.

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Acknowledgements

This booklet was developed for **namhi** by Dr. Mary McCarron, Lecturer at the Department of Nursing and Midwifery Studies, Trinity College Dublin & also Policy Advisor on Dementia for the Daughters of Charity Services.

Dr. McCarron has worked in the area of Intellectual Disability for twenty years and has found that many people who have relatives with Intellectual Disability who develop Alzheimer's Dementia have the same concerns and questions.

This booklet was written to try to help you to understand the changes that are taking place in your life and that of your family member with intellectual disability, and to give you practical advice on how to cope with those changes.

We hope you will find it useful and will let us know if you have other issues that you would like dealt with.

namhi would like to acknowledge the great work that Dr McCarron has put into researching & writing this booklet and to thank her for sharing her invaluable expertise and experience with us. We hope the information will be of use to families, carers and support workers.

Further copies of this booklet may be obtained from

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What is Dementia?

Dementia is a name given to a collection of diseases of the brain that slowly affect the mind and lead 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 or accompanied by changes in the person's personality, mood, social behaviour or motivation. The most common type of Dementia is Alzheimer's Dementia and other types of Dementias include for example, multi-infarct Dementia (or vascular Dementia), Creutzfeldt-Jakob disease (CJD), Picks disease, Huntington's disease, Lewy-body disease, AIDS-related Dementia and Alcoholic Dementia.

What is Alzheimer's Dementia?

Alzheimer's Dementia (AD) is a term used to describe a dementing disorder, which is marked by certain brain changes that result in abnormal brain function. The cells in the brain of a person with AD are slowly and progressively destroyed. Over time the person will become completely dependent for even the simplest activities.

Alzheimer's

The cells in the brain of a person with Alzheimer's Dementia are slowly and progressively destroyed. Over time the person will become completely dependent for even the simplest activities.

Are People with an Intellectual Disability at greater risk?

Persons with Intellectual Disability without Down Syndrome appear to have the same risk as other adults in the general population for Alzheimer's Dementia.

Large population studies show that generally, adults are at greater risk of developing the disease if they:

- Are more than 60 years old

- Have had some form of severe or multiple head injury
- Have a history of Alzheimer's Dementia in their family
- Persons with Down Syndrome are at increased risk of developing Alzheimer's Dementia as they age, with the age of onset at around 50 years

RATE OF DOWN SYNDROME AND ALZHEIMER'S IN IRELAND

Age	%
40-50	6
50-60	30
60-70	42
> 70	50

If a person with Down Syndrome is over 35 years old and has loss of memory/skills and personality changes, do they have Dementia?

No, not necessarily. Whilst rates of Alzheimer's Dementia particularly in persons with Down Syndrome do increase with age, it does not mean that all persons with Down Syndrome will develop Dementia. It is necessary to rule out the possibility that the experienced symptoms and changes observed have a different and perhaps more easily treatable cause.

It is important that the person has a comprehensive assessment to determine the cause of the changes.

Some common causes of decline in later life for persons with Down Syndrome include:

Depression:

Depression may present with similar symptoms as Alzheimer's Dementia and is common in ageing persons with Down Syndrome. Very often this population may not be able to say how they are feeling. The person may appear sad and/or agitated. They may have loss of interest in previously enjoyed activities and events. They may find it difficult to concentrate, have sleep disturbance and changes in appetite. It is important to determine if depression is present, as this can be treated with therapy and/or medication. It is important to understand that the person with Alzheimer's Dementia can also be depressed and treating their depression will also help them feel better.

Under-active thyroid gland:

Under-active thyroid gland is particularly common in ageing persons with Down Syndrome and those over the age of 35 should have a thyroid test. Some of the symptoms of an under-active thyroid gland include: difficulty in concentration, dry skin, intolerance to cold, weight increase, with general slowing down and lethargy. It can be treated with replacement thyroid hormones.

Hearing and visual impairments:

If the person's eyesight or hearing has deteriorated they will have difficulty with general day-to-day tasks.

Physical illness:

Due to language difficulties the person may not be able to adequately express how he/she is feeling. A variety of different infections are often more common in ageing persons with Down Syndrome. Chest and kidney infections, along with other conditions such as constipation if untreated can produce an acute or sudden state of confusion.

Vitamin deficiency:

A simple blood test by a doctor will determine if the person with Intellectual disability is deficient in Vitamin B12 which if un-addressed may result in Dementia-like symptoms. Vitamin B12 related Dementia symptoms are usually reversible.

Major life events:

Persons with Intellectual Disability and Down Syndrome experience the same range of emotions as everyone else. Major events such as separation, bereavement, moving house etc, are also likely to take their toll.

And Dementia...

Once these other illnesses have been ruled out, other tests and assessments will help diagnose Dementia.

COMMON CAUSES OF DECLINE IN OLDER PERSONS WITH DOWN SYNDROME

Depression:

appearing sad/agitated, loss of interest and concentration, changes in sleep and eating habits.

Under-active thyroid:

loss of concentration, dry skin, feeling cold, weight gain, general slowing down and tiredness.

Senses:

loss of hearing and eyesight.

Physical illness:

constipation causing confusion, infections e.g. chest and kidney.

Lack of vitamins:

e.g. B12 causes Dementia-like symptoms.

Life events:

e.g. separation, bereavement, moving house.

Why is early diagnosis of Alzheimer's Dementia in persons with Intellectual Disability important?

- Traditionally services for people with Intellectual Disability have been focused on giving people new skills and on increasing the person's independence. In Dementia the emphasis is on maintaining skills and providing supports when skills are lost.
- Many other conditions can cause Dementia-like symptoms such as depression or thyroid problems. These may be reversible if detected early.
- Identifying the cause will enable the person to receive the proper care and treatment.
- Needs are different so early diagnosis allows more time to plan appropriate care.

How would you know if someone has Alzheimer's Dementia?

There is not any **one** specific test that the person can have that will diagnose Alzheimer's Dementia. We do not yet know the cause of Alzheimer's Dementia and therefore don't know all of the signs to look for. It is impossible to say for sure that a living person has Dementia.

- Only post mortem examination of brain tissue can identify the changes that are associated with disease and confirm the clinical or provisional diagnosis.
- Diagnosis is complicated for persons with Intellectual Disability because very often they already have difficulties in those areas which are known to deteriorate in Alzheimer's Dementia such as memory, language, ability to attend independently to self care needs etc
- Where there is good and reliable information available across a number of areas on how someone has changed, a diagnosis of Dementia can be made with a high degree of accuracy.

How is Alzheimer's Dementia diagnosed in people with Intellectual disabilities?

The most valuable information to assist with diagnosis is an accurate history of change by family or carers who have known the person for quite a long time.

- Only if there is understanding about the person's past ability by family or staff who have known the person for a long time can a judgement be made about whether there has, or has not been change.
- It is important that the family or carer note specific examples that demonstrate change i.e. things that the person used to be able to do, but now is no longer able to do, or now requires more reminding to carry out tasks that previously they would have been able to do themselves.
- Tests for Dementia can only be considered positive if there is also evidence of a decline in memory and mental ability.

Although cognitive changes and memory are important for the diagnosis of Dementia, changes in other aspects of behaviour are also relevant. For example, for individuals with Down syndrome (especially those who are very low functioning) changes in personality, behaviour and mood, and general loss of interest in day-to-day events are also important. These sometimes are the first changes observed and reported by family or staff.

Having knowledge and some record of the person's previous personality, their interests and their general ability and level of independence and support required in day-to-day activities such as personal hygiene, dressing, eating, orientation, writing, and reading is important.

THINGS TO NOTICE

The diagnosis of Dementia in a person with ID therefore requires evidence of a definite change from the person's previous level of functioning and ability. Family and caregivers have an essential role in describing the difference between how the person is now compared with the past (see pages 10 - 11)

- Memory changes - forgetting common day-to-day routines and places
- Increasing dependence, loss of ability to do things they used to do themselves e.g. eating, dressing, personal hygiene
- Changes in personality, behaviour and mood
- General loss of interest in day to day events

What are the main areas that decline/deteriorate in Alzheimer's Dementia?

Memory: One of the most common early signs of Dementia is forgetting recent information. The extent of memory changes will vary depending on the person's level of intellectual disability. There may be some minimum memory loss, particularly of recent events. The person for example, may forget that they have just had their dinner, yet may remember clearly an event that happened years past. Forgetting what they have just done, where they have been or who has just visited are often major symptoms of Alzheimer's Dementia. The person may forget common day-to-day routines and places. They may also have difficulty in remembering names of familiar people that used to be known.

Disorientation to time and place: The individual may appear disorientated and confused. They may wander and have difficulty in locating familiar places for example the toilet or their bedroom. They may be unaware that they are entering or even in another person's room.

There is also a loss of sense of time. The person may have difficulty in understanding the passage of time and that can be a source of stress and anxiety. For example, they may repeatedly ask what time it is and feel they are late for an event. There may also be disturbance to the 'internal clock' and the person's sleeping pattern may become disturbed. The person may wake during the night and feel it is morning, and may become agitated when guided or encouraged to return to bed. They may have difficulty understanding directions or instructions and become disoriented as to where they are or where they were going. As the disease progresses, memory losses become more pronounced.

Misplacing items: Everyone from time to time can temporarily misplace items. The person with Dementia may often misplace and lose items for example their watch, glasses, etc. and may

blame others. They may hoard items, put things in unusual places and may not remember where they have put them.

Language: There may be specific problems with language. The individual may experience difficulty in finding the right words to use during casual conversations. They may have difficulty naming objects or with maintaining a logical conversation. The person may appear to know what they want to say, but just can't say it.

Personality and mood changes: Severe changes in personality may become obvious, and social behaviour may be marked by suspiciousness and delusions.

Problems with day to day living activities: The person may begin to experience loss of self-care skills, for example regarding eating and use of the toilet. For those in a workshop or other job, work performance may begin to deteriorate. Finally, the disease will progress to the point where all abilities to function normally are lost, and affected individuals need total care. Such deterioration may occur over different time periods for different individuals, ranging from 12 months to 8 years approximately.

MAIN SIGNS OF ALZHEIMER'S DEMENTIA

Memory loss/confusion:

especially of recent events and normal every day activities and routines

Language:

difficulty finding the right words or following a conversation.

Personality and mood changes:

e.g. being suspicious or having delusions.

Problems with everyday activities:

e.g. inability to do usual work activities, feed or toilet themselves.

What kinds of tests are there for Alzheimer's Dementia and how long is an assessment likely to take?

The length of time and the type of tests is likely to vary depending upon the preferences of the person doing the assessment, and the quantity and quality of information regarding past history available to the assessor. 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.

Important areas of the assessment should include:

- Full personal and medical history and presenting problems
- Physical examination including neurological examination
- Blood tests
- A nutritional assessment
- Cognitive and memory tests using standardized test instruments. Guidelines issued by the AAMR/IASSID and available on these organisations' websites offer suggested screening and evaluation procedures.

Optional examinations and tests may include: chest X- ray, ECG, and brain scan. In a comprehensive assessment several visits may be necessary.

Is there a cure for Dementia?

Currently, no there is not. However there are medications available which for some people slow the rate of progression. These are not well tested for persons with Intellectual Disability. More work is underway which may result in additional medications in the future.

If a person with ID is aged 60 years and is showing no signs of Dementia should he/she be tested?

Evaluations should be performed at select intervals using the person's previous performance as the comparison measure. It is recommended that all persons with Intellectual Disability over the age of 50 years should have annual assessment of current function. For persons with Down Syndrome this testing should commence at 35 years. In this way there will be systematic records of past functioning available to facilitate assessment when deficits are noted and deficits are more likely to be identified early in a disease process.

Who should a family member or staff in a group home contact to arrange for an assessment for Dementia?

- Contact your general practitioner, psychiatrist, neurologist, geriatrician or specialist nursing personnel in your area.
- Contact your local Health Board for information on memory clinics in your area.

What information should a family member or staff in a group home bring with them when an assessment is scheduled?

- Physical and mental health history
- All previous cognitive, functional and behavioural assessments
- A detailed history from a variety of people who have known the person for a considerable period of time that highlights previous functioning and recent changes to that functioning.
- Someone who has known the person and is familiar with current sources of difficulties should accompany the individual to the assessment.

What do people with Intellectual Disability and Alzheimer's Dementia need?

People with Intellectual Disability and Alzheimer's Dementia need:

1. A safe and secure environment
2. Familiar things and familiar people
3. Programmes that will help them maintain skills and abilities
4. Supports that enable them to continue to participate in activities they value when they are no longer able to manage those activities themselves
5. Programmes that change when their needs change.

Does a person with Intellectual Disability need to move back to an institution or nursing home when they have Dementia?

No. With the right supports many people with AD will continue to be able to live in their community. It is very important that people with Dementia maintain contact with the people and places they have known and enjoyed throughout their lives.

What should a family look for in a group home or other setting when they are no longer able to care at home for a person with Intellectual Disability and Alzheimer's Dementia?

Some important considerations should include:

- An environment that is safe and secure
- Staff who have an understanding of Dementia care issues and who have been trained in Dementia care
- Availability of nursing supports and access to physicians and other multidisciplinary team services
- Opportunities to remain engaged with their community and their favourite activities

- A home that is adequately equipped to support the person through all stages of Dementia care (see page 18).

Are there good books and other materials on Dementia out there that would be helpful to families and staff?

There are several videos and a CD-Rom training package available which may be very helpful to families and staff.

VIDEOTAPES

- *When People with Developmental Disabilities Age*
- *Aging . . . A Shared Experience*
- *Dementia and People with Intellectual Disabilities - What Can We Do?*

For copies of the above e-mail: nrose@ddpc.state.ny.us

Or write to:

Nick Rose
NYS Developmental Disabilities Planning Council
155 Washington Avenue
Albany, NY 12210. USA

- *Face to Face: Respectful coping with Dementia in older people with intellectual disability*

Available from:

Centre for the Study of Developmental Disabilities
National University of Ireland, Dublin
Arts Annexe Building
Belfield, Dublin 4

- **CD ROM training package** - Intellectual Disabilities and Dementia

For copies e-mail: nrose@ddpc.state.ny.us

Or write to:

Nick Rose
NYS Developmental Disabilities Planning Council
155 Washington Avenue
Albany, NY 12210. USA

OTHER RESOURCES

- Information on obtaining a booklet entitled Developmental Disabilities and Alzheimer's Disease is available at the following website: www.uic.edu/orgs/rrtcamr/dementia
- Other information on Dementia and Persons with Intellectual Disabilities is available at the following website: www.albany.edu/ssw/research/mainframe.html
- **Dementia Services Information and Development Centre**
Hospital 4, St. James's Hospital, James Street, Dublin 8
Telephone: 353 (0)1 4162060,
Email: dsidc@stjames.ie
- **Alzheimer Society of Ireland - Information Pack**
Alzheimer House, 43 Northumberland Ave.,
Dún Laoighaire, Co Dublin,
Tel: 01 2846616, National Helpline: 1800 341 341 (10am – 4pm,
Mon-Fri),
Email: info@alzheimer.ie, www.alzheimer.ie
- **Directory of Services for People with Intellectual Disability, 2003**
namhi, 5 Fitzwilliam Place, D2, Tel: 01 6766035 info@namhi.ie,
www.namhi.ie

Are there any materials that are useful for explaining Dementia to persons with ID?

- What is Dementia is a pamphlet created by the Scottish Down's Syndrome Association to use with adults with Intellectual Disabilities. It explains Dementia and its effects on their friends, relatives and parents. Available for download at www.uic.edu/orgs/rrtcamr/dementia

Questions you may be asked at assessment

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. Has the person had 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 house etc.? Have other family members or staff noticed changes?

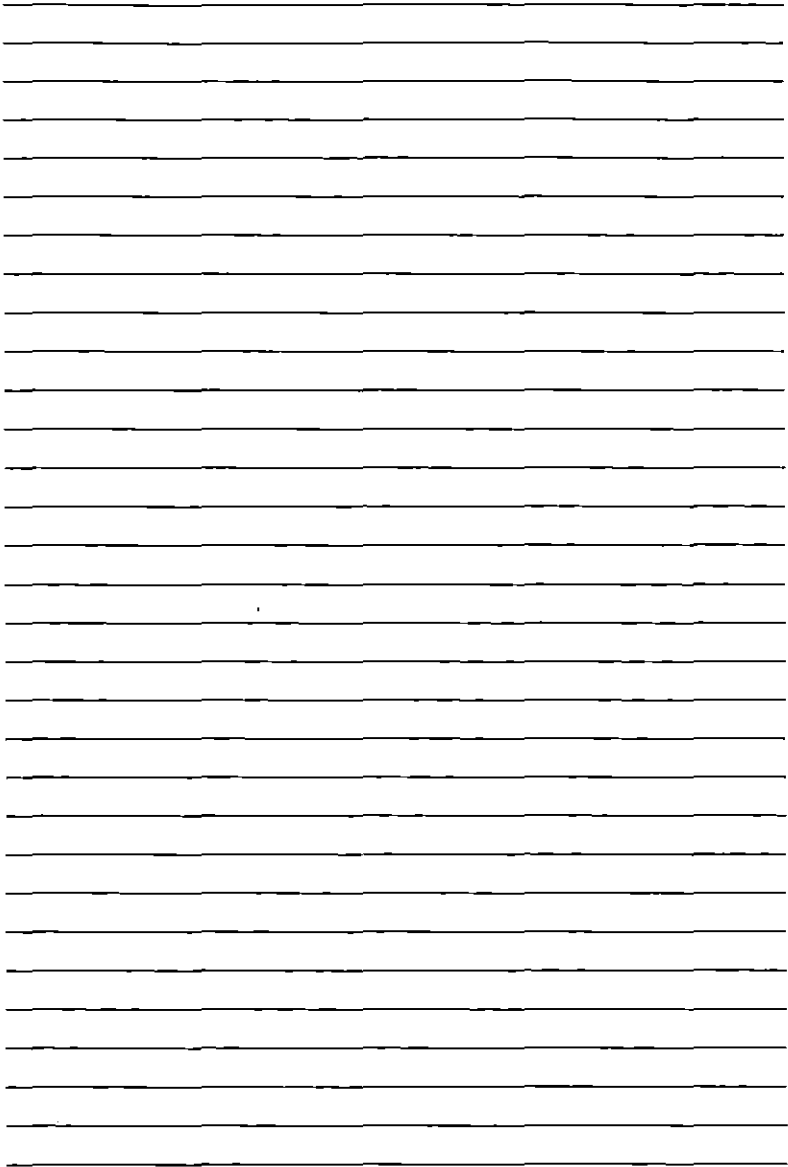
Questions to ask if the diagnosis is probable Alzheimer's Dementia

1. What does the diagnosis mean?
2. What symptoms can be expected next?
3. Over what time period are these changes likely to occur?
4. What level of care will be required now and in the future?
5. What changes can be made to the home to make it safer?
6. Will the person have to move from their current home placement?
7. What resources and supports are available?
8. What medical treatments are available?

Questions to ask about a care setting

1. What is the care setting's mission and philosophy?
2. How many people live in the care setting?
3. Does the setting serve only people with Dementia?
4. Does the care setting serve persons across different stages of Dementia?
5. Will progression of Dementia result in transfer or discharge?
6. If there is a transfer, where will the person transfer to?
7. What type of care is provided for persons with late stage Dementia, including medical and nursing services?
8. Will the person attend a suitable outside day programme?
9. How often are social and leisure activities offered and are they offered in the evenings and weekends?

10. What measures are in place to provide a safe and secure environment for persons with Dementia?
11. Are there safe areas that allow for independent wandering?
12. How does the environment support independence?
13. How many direct staff are on duty days/evenings/nights and weekends?





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