

Learning disabilities and dementia

Advances in medical and social care have led to a significant increase in the life expectancy of people with learning disabilities. Understanding the effects of ageing among this group – including the increased risk of developing dementia – has therefore become increasingly important. This factsheet explains how dementia may be experienced by someone with a learning disability and gives some suggestions for how the person can be supported.

A person with a learning disability has a lifelong condition that impacts on their learning, communication and understanding. They may require support with some tasks including planning, learning new skills and socialising.

The causes of different learning disabilities vary and are not always known. Some learning disabilities occur before birth and are due to genetic disorders, such as Down's syndrome and fragile X syndrome. Others occur after birth but before adulthood; they may be due to infection (eg bacterial meningitis), brain injury, lack of oxygen at birth or prematurity. The effects of a learning disability on the individual range from mild to severe to profound (very severe).

The term 'dementia' describes a set of symptoms that typically include loss of memory, behavioural or mood changes, and problems with communication, reasoning and daily activities. These symptoms occur when the brain is damaged by certain diseases, including

Alzheimer's disease and vascular dementia. Dementia is a progressive condition which means that the symptoms will get worse. For more information, see factsheet 400, What is dementia?

This factsheet looks at Down's syndrome in more detail than other learning disabilities. This is because Down's syndrome is the most common known cause of learning disability and because people with Down's are at particular risk of dementia.

What is different about dementia in someone with a learning disability?

Dementia generally affects people with learning disabilities in similar ways to people without a learning disability, but there are some important differences. People with a learning disability are at greater risk of developing dementia at a younger age – particularly those with Down's syndrome:

- often show different symptoms in the early stages of dementia
- are less likely to receive a correct or early diagnosis of dementia and may not be able to understand the diagnosis
- may experience a more rapid progression of dementia
- may already be in a supported living environment, where they are given help to allow them to live independently
- may have already learned different ways to communicate (eg more non-verbal communication if their disability affects speech)
- will require specific support to understand the changes they are experiencing, and to access appropriate services after diagnosis and as dementia progresses.

What are the risks?

People with learning disabilities have an increased risk of developing dementia as they age than others. People with learning disabilities

also generally develop dementia at a younger age. This is particularly the case for people with Down's syndrome: one in three develop dementia in their 50s.

Down's syndrome and dementia

When people with Down's syndrome develop dementia, this is usually due to Alzheimer's disease. However there is a growing awareness that people with Down's syndrome can develop other forms of dementia.

Studies have shown that the numbers of people with Down's syndrome who have Alzheimer's disease are approximately:

- 1 in 50 of those aged 30 to 39 years
- 1 in 10 of those aged 40 to 49 years
- 1 in 3 of those aged 50 to 59 years
- more than half of those who live to 60 or over.

These numbers indicate a greatly increased risk for dementia compared with the general population. Studies have also shown that in later life almost all people with Down's syndrome develop the changes in the brain associated with Alzheimer's disease, although not all develop the symptoms of Alzheimer's. The reason for this has not been fully identified. However, it is known that the protein that causes brain cell damage in Alzheimer's disease is produced from a gene on chromosome 21. People with Down's syndrome have an extra copy of this chromosome, which may largely explain their increased risk of developing Alzheimer's disease.

Other learning disabilities and dementia

Studies suggest the numbers of people with learning disabilities other than Down's syndrome who have dementia are approximately:

- 1 in 10 of those aged 50 to 65

- 1 in 7 of those aged 65 to 75
- 1 in 4 of those aged 75 to 85
- nearly three-quarters of those aged 85 or over.

These numbers indicate a risk about three to four times higher than in the general population. At present we do not know why this is the case and further research is needed. Genetic factors may be involved, or a particular type of brain damage associated with a learning disability could be a cause.

How do the symptoms of dementia differ for people with a learning disability?

Down's syndrome and dementia

The symptoms of dementia in people with Down's syndrome are broadly similar to those in the general population, although there are some differences. Changes in behaviour or personality (eg becoming more stubborn, irritable or withdrawn) are more often reported as an early symptom of Alzheimer's than memory loss.

People with Down's syndrome are more prone to fits than others. However, epilepsy that appears in someone with Down's syndrome later in life is almost always a sign of dementia and should be investigated thoroughly.

The middle and later stages of dementia in people with Down's syndrome are similar to these stages in the general population (see factsheet 458, The progression of Alzheimer's disease and other dementias). However, there is some evidence that dementia in people with Down's syndrome progresses more rapidly.

Other learning disabilities and dementia

Dementia in people with a learning disability other than Down's syndrome is less well studied and symptoms can vary widely. For those

with mild learning disabilities, dementia seems to appear and progress similarly to dementia in the general population. For those with more severe learning disabilities, the initial symptoms of dementia are often less typical, possibly involving changes in personality or behaviour. This can make diagnosis of dementia harder.

How can you tell if someone might be developing dementia?

It is not possible to diagnose dementia from a simple assessment. Carers, friends and family play an important part in helping to identify dementia in people with learning disabilities, by recognising changes in behaviour or personality. Dementia is often diagnosed by excluding other possible causes and assessing a person's performance over time. People with Down's syndrome should have regular assessments from age 30 as this will help doctors to identify changes in their behaviour or personality over time that could be due to dementia.

It is important not to assume that a person with a learning disability has dementia simply because they fall into a high-risk group.

The process of making a diagnosis will include:

- A detailed personal history – this is vital to establish the nature of any changes that have taken place. It will usually include a discussion with the main carer and any care service staff who understand the person and their methods of communication. This history should take account of significant changes in the person's life, such as a recent bereavement.
- A full health assessment – it is important to exclude any physical causes that could explain changes in the person. There are a number of conditions that have similar symptoms to dementia but are treatable – for example, underactive thyroid (hypothyroidism) and depression, both of which are common in people with Down's syndrome. Any medication that the person is taking will be reviewed. Problems with vision and hearing are more common in people with learning disabilities so these should also be looked at.

- Psychological and mental state assessment – it is important to rule out any other psychological or psychiatric causes of memory loss. Standard tests that measure mental ability (such as the Mini Mental State Examination) are not usually appropriate for people with learning disabilities, who already have some mental impairment and may not have the language or memory skills that the tests require. A range of assessment tools have now been developed specifically for people with Down's syndrome or other learning disabilities.
- Special investigations – it can be difficult to interpret a brain scan from someone with a learning disability and the person may find having a scan distressing. However, a brain scan may be useful in excluding other conditions when an assessment of suspected dementia has not been conclusive.

What support should be offered after a diagnosis?

Someone with a learning disability may not understand the consequences of a diagnosis of dementia. Careful thought and planning should make sure that terms familiar to the person are used by all family and care staff to explain changes. The person may be living with other residents or a partner with a learning disability when they receive their diagnosis. It is important to consider the impact of dementia on these people, as well as on the person receiving the diagnosis.

Although dementia is a progressive condition, the person may be able to continue with many activities for some time if they are given the right support. They should be encouraged to maintain their independence for as long as possible, if this is what they want. It is vital that the person is given the opportunity to fulfil their potential as an individual. However, the experience of failure can be frustrating and upsetting, so it is important to find a balance between encouraging independence and ensuring that a person's self-esteem and dignity are not undermined.

At present, there is no cure for dementia. People progress from mild to moderate and, eventually, to more advanced dementia over a period

of years. The available anti-dementia medications seek to temporarily slow down or delay the progression of symptoms (see factsheet 407, Drug treatments for Alzheimer's disease). The latest (2011) guidelines from the National Institute for Health and Clinical Excellence on the use of these drugs acknowledge the difficulties with assessing dementia in people with learning disabilities and give the doctor greater flexibility in drug use.

Tips: supporting someone with a learning disability and dementia

Many practical strategies have been developed to support people with dementia and their carers. These should all be based on the principles of person-centred care, which take into account the individual's current and past interests, preferences and needs. Here are some ideas:

- Dementia affects a person's ability to communicate, so they may need to develop alternative ways of expressing their feelings. Non-verbal communication, including body language and the tone of voice of carers, will become increasingly important.
- A person with dementia may have a different sense of reality. By understanding this we can begin to be aware of what they might be feeling, and be able to interpret their behaviour. Long-term memory becomes increasingly important.
- Simplify sentences and instructions so that you are not asking too much in one statement, listen carefully, and give plenty of time for the person to respond.
- Enable the person to have as much control over their life as possible. Use prompts and reassurance during tasks that the person finds more difficult.
- Help the person by using visual or pictorial cues and planners to structure their day. Someone with a learning disability may already be familiar with pictorial cues (eg a sign of a toilet on a bathroom door). Try to structure the day so that activities happen in the same order. Routines should be individual and allow for flexibility.

- A 'life story book' or 'memory box' of photos and mementos from the person's past may be a useful way to help the person interact and reminisce.
- If someone is agitated, the environment might be too busy or noisy. Ordinary levels of background noise from television, radio or conversations can add to the level of confusion a person with dementia experiences.
- The living environment should be calming and familiar. Mirrors and reflections in windows and shiny surfaces are a common cause of confusion to some people with dementia.
- Relaxation techniques such as massage, aromatherapy and familiar music can be effective and enjoyable. Someone with dementia may be able to sing or hum a favourite tune even after they have lost the ability to speak.
- Eating and drinking enough can present challenges for people with dementia. Common sense and creative solutions can help maintain hydration and a healthy balanced diet. For more information see factsheet 511, Eating and drinking.
- If the person's behaviour becomes aggressive, carers and professionals should work together to establish reasons or triggers for the person's frustration and find ways of preventing the behaviour. Changes in behaviour are often caused by the environment, undiagnosed pain or the actions of others. (Antipsychotic medication and sedatives should only be used after all other routes have been exhausted. See factsheet 408, Drugs used to relieve behavioural and psychological symptoms in dementia).

For details of Alzheimer's Society services in your area, visit alzheimers.org.uk/localinfo

For information about a wide range of dementia-related topics, visit alzheimers.org.uk/factsheets

Useful organisations

British Institute of Learning Disabilities

Campion House
Green Street
Kidderminster
Worcestershire DY10 1JL
T 01562 723010
E enquiries@bild.org.uk
W www.bild.org.uk

Body that works to improve the lives of people with disabilities and family carers. Provides a range of published and online information including booklets to help explain dementia to a person with a learning disability.

Foundation for People with Learning Disabilities

9th Floor, Sea Containers House
20 Upper Ground
London SE1 9QB
T 020 7803 1100
W www.learningdisabilities.org.uk

Charity that works with people with learning disabilities, their families and those who support them, providing a range of information and services. Part of the Mental Health Foundation.

Down's Syndrome Association

Langdon Down Centre
2a Langdon Park
Teddington TW11 9PS
T 0845 230 0372 (helpline 10am–4pm weekdays)
E info@downs-syndrome.org.uk
W www.downs-syndrome.org.uk

Charity working to help people with Down's syndrome lead full and rewarding lives. Runs a helpline and local support groups, funds research and champions the rights of people with Down's syndrome.

Mencap

123 Golden Lane

London EC1Y 0RT

T 0808 808 1111 (Learning Disability Helpline)

E information@mencap.org.uk or helpline.wales@mencap.org.uk or
helpline.ni@mencap.org.uk

W www.mencap.org.uk

Charity providing information, advice and support services for people with learning disabilities.

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This factsheet has also been reviewed
by people affected by dementia.
A list of sources is available on
request.



Alzheimer's Society National Dementia Helpline

England, Wales and Northern Ireland:
0300 222 11 22

9am–5pm Monday–Friday
10am–4pm Saturday–Sunday

alzheimers.org.uk

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