

Learning disabilities and dementia

Factsheet 430
March 2015

People with learning disabilities, particularly those with Down's syndrome, are at increased risk of developing dementia. If a person with a learning disability develops dementia, they will face different and additional challenges to people who do not have a learning disability.

This factsheet is an introduction to dementia in people with learning disabilities, which are increasingly known as intellectual disabilities. It explains what dementia and learning disabilities are, and how someone with a learning disability is more likely to develop dementia. It covers how dementia in a person with a learning disability is diagnosed and treated, and gives some suggestions for how a person with a learning disability and dementia can be supported to live well.

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Learning disabilities and dementia

The word dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. A person with dementia may also experience changes in their mood or behaviour. These symptoms occur when the brain is damaged by diseases, including Alzheimer's disease, or a series of strokes. Dementia is a progressive condition, which means that the symptoms will get worse. For more information see factsheet 400, **What is dementia?**

A learning disability is a lifelong condition that affects someone's learning, communication and understanding. The person may require support with some aspects of their life, including planning, learning new skills and socialising. There are estimated to be about 700,000 people living with a learning disability in the UK, although this may be an underestimate.

There are different learning disabilities with various causes. Not all of them are well understood. Some learning disabilities, such as Down's syndrome or fragile X syndrome, occur before birth and are due to genetic disorders. Others occur after birth but before adulthood. These may be due to infection (such as bacterial meningitis), brain injury, lack of oxygen at birth or premature birth. The effects of a learning disability on the individual range from mild to severe to profound (very severe).

Life expectancy for people with Down's syndrome and other learning disabilities has improved significantly in the past 30 years, thanks to advances in medical care. For example, the life expectancy of someone with Down's syndrome has risen from 25 years in 1983 to over 60 years in 2015. One consequence of this improvement is that more people with learning disabilities, such as Down's syndrome, are living to an age where they are likely to develop dementia.

This factsheet looks at Down's syndrome in more detail than other learning disabilities. This is because Down's syndrome is relatively common, with more than 40,000 people living with the condition in the UK, and because people with Down's syndrome are at particular risk of developing 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 learning disabilities. However, 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 more likely to have other physical health conditions which are not always well managed
- 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, although this can be complicated by difficulty or delay in diagnosis
- may have already learned different ways to communicate (for example, more non-verbal communication if their disability affects speech)
- may already be receiving social care in the family home, or be in a supported living environment, where they are given help to allow them to live independently
- will need specific support to understand the changes they are experiencing, and to access appropriate services after diagnosis and as dementia progresses. These may be specialist services for those with a learning disability or general services for older people.

Risk of developing dementia

People with learning disabilities are at increased risk of developing dementia as they age, compared with others without a learning disability, although the figures vary according to how the diagnosis is made. About 1 in 5 people with a learning disability who are over the age of 65 will develop dementia. People with learning disabilities who develop dementia generally do so at a younger age. This is particularly the case for people with Down's syndrome: a third of people with Down's syndrome develop dementia in their 50s.

1 in 5

People with a learning disability who are over the age of 65 will develop dementia

Down's syndrome and dementia

When people with Down's syndrome develop dementia, it is usually due to Alzheimer's disease.

Studies have estimated that 1 in 50 people with Down's syndrome develop dementia in their 30s, rising sharply to more than half of those who live to 60 or over. By comparison, the number of people among the population without learning disability aged 60–69 years who develop dementia is about 1 in 75. These studies, therefore, show a greatly increased risk of developing dementia among people with Down's syndrome, compared with the general population without a learning disability.

Studies have also shown that by the age of about 40, almost all people with Down's syndrome develop changes in the brain associated with Alzheimer's disease. However, not all go on to develop clinical symptoms of dementia. The reason for this increased risk has not been fully identified, however it is thought to be linked to the extra copy of chromosome 21 which most people with Down's syndrome have. This chromosome carries the amyloid gene thought to play a role in Alzheimer's disease.

Other learning disabilities and dementia

Studies suggest that approximately 1 in 10 people aged 50 to 65 with learning disabilities other than Down's syndrome have dementia. This rises to more than half of those aged 85 or over. This suggests the risk is less than for people with Down's syndrome but still between two and three times greater than for the general population.

At present we do not know why this is the case, and more research is needed. Genetic factors may be involved, or a particular type of brain damage associated with a learning disability could be a cause.

Symptoms of dementia in people with a learning disability

Down's syndrome

The symptoms of dementia in people with Down's syndrome are broadly similar to those seen in the general population, although there are some differences. Changes in behaviour and personality (such as becoming more stubborn, irritable or withdrawn) or loss of daily living abilities are common. Memory loss, the most common early symptom of Alzheimer's disease among older people generally, is seen less often as an early symptom in people with Down's syndrome. This may be because most people with Down's syndrome will already have poor short-term memory.

People with Down's syndrome are more prone to epilepsy (fits) than others. However, if a person with Down's syndrome starts to develop epilepsy later in life, it is almost always a sign of dementia and should be investigated thoroughly. Up to three-quarters of people with Down's syndrome and dementia develop fits. More severe seizures are linked to a more rapid decline in health.

The middle and later stages of dementia in people with Down's syndrome are similar to these stages in the general population. For more information 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. They may have earlier loss of basic skills such as walking, becoming incontinent and having swallowing difficulties.

Other learning disabilities

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 diagnosing dementia harder.

It is recommended that every adult with Down's syndrome is assessed by the time they are 30 to provide a record or 'baseline' with which future assessments can be compared.

How can you tell if someone might be developing dementia?

A person with a learning disability will already have some differences in their thinking, reasoning, language or behaviour, and their ability to manage daily living. It is a change or deterioration in these – rather than a single assessment – that may suggest dementia. This means carers, friends and family play an important part in helping to identify early signs of dementia, such as changes in behaviour or personality and loss of day-to-day abilities. They should raise any concerns promptly with their GP or learning disability team.

It is recommended that every adult with Down's syndrome is assessed by the time they are 30 to provide a record or 'baseline' with which future assessments can be compared.

As well as this baseline assessment, an adult with Down's syndrome should routinely be offered an annual health check with their GP. This health check will include:

- a physical health check of the person's weight, heart rate and blood pressure, as well as blood and urine tests
- eyesight and hearing tests
- a review of any medicines the person is taking
- an assessment of the person's communication skills
- an assessment of the person's behaviour, including their lifestyle and mental health (such as possible depression)
- an assessment for possible dementia.

The health check should lead to referral to a specialist, if needed, and an agreed health action plan that outlines what the person can do to stay healthy.

The process of assessment and diagnosis for possible dementia in someone with a learning disability other than Down's syndrome is similar to that for the general population. For more information see factsheet 426, **Assessment and diagnosis**.

However, a learning disability does make the diagnosis more complicated. It is important not to assume that a person with a learning disability has dementia simply because they fall into a high risk group or because they are getting older. Equally, it is important that symptoms of dementia are not missed because they are mistakenly seen as part of the learning disability.

Assessment for someone with Down's syndrome is best done by a multidisciplinary team that includes a GP, psychiatrist, community learning disability nurse, occupational therapist and clinical psychologist. Each, with the exception of the GP, should be a specialist in learning disabilities. The learning disability service may work closely with the nearest memory clinic (where people are routinely assessed for suspected dementia) for advice on diagnosis or management.

The process will include:

- **A detailed personal history** – This is vital to establish the details 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 how they communicate. This history should include any significant changes in the person's life, such as moving home, a favourite care worker leaving or a recent bereavement.
- **A full health assessment** – It is important to exclude any physical causes that could explain changes in the person or their behaviour. There are a number of conditions that have similar symptoms to dementia but are treatable, for example underactive thyroid, which is more 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 mental ill health, including depression, as a cause of memory loss. Standard tests that measure mental ability (such as the Mini Mental State Examination) are not appropriate for people with learning disabilities, as they 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. Assessment with one of these tools will be done by a clinical psychologist or other specialist with experience of 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 (such as a tumour or bleed) when an assessment for suspected dementia has not been conclusive.

Even with a thorough assessment, it will not always be possible to reach a clear diagnosis. This may mean waiting, watching carefully to see how the person gets on, and then repeating the assessment several months later.

After a diagnosis

Someone with a learning disability may not fully understand a diagnosis of dementia or what it will mean for them, but it is still their right to know if they wish to. The explanation should be planned and shared with the person carefully, using language familiar to them.

Information about the diagnosis is best broken down into small chunks and tailored to their ability to understand the past, present and future, as well as to their individual communication needs.

Easy-read information about dementia, developed specifically for people with learning disabilities, is widely available and can be used to support the sharing of the diagnosis (see Easy Read factsheet ER1, **What is dementia?**).

The person may be living with a partner, friend or other residents with a learning disability when they are diagnosed. It is important to consider the impact of dementia on these people, as well as on the person receiving the diagnosis.

After the diagnosis, the multidisciplinary team will agree an individual care plan with the person which sets out how they can be supported to live well. The team will discuss this plan with those supporting the person. They will agree when the plan will be reviewed and updated, including checking for and looking into any changes in the person's health, behaviour or living skills.

Dementia is a progressive condition. People progress from mild to moderate dementia and, eventually, to more severe dementia over a period of years. Soon after diagnosis is the time to make or review any advance plans which have been made about what the person wishes for their future. Plans may cover the immediate future but also care options as the person's dementia progresses. By law, the person with dementia should be supported to be involved in this advance care planning as much as they are able. For more see factsheet 460, **Mental Capacity Act 2005**.

Treatment and support

Living well with dementia requires a range of treatment, support and activities. For a person with a learning disability and dementia, getting the best outcome may mean seeing a psychiatrist who specialises in learning disabilities, as well as staff from the learning disability services. Treatments may include drug and non-drug approaches.

At present, there is no cure for dementia. Anti-dementia medications aim to temporarily improve symptoms (see factsheet 407, **Drug treatments for Alzheimer's disease**).

It is not clear whether the drugs that are routinely offered to people with Alzheimer's disease (for example donepezil) are of more or less benefit to people with Down's syndrome and Alzheimer's. Few studies have been done and the results are not consistent. Feedback from day-to-day use of these drugs is that they benefit many people. Drugs like donepezil can cause side effects, but may still be offered to a person with Down's syndrome and dementia, unless they have medical conditions (such as heart problems) that rule this out.

The other anti-dementia drug that is increasingly used in the general population is called memantine. A recent trial of memantine given to people with dementia and Down's syndrome showed no benefit.

A person with a learning disability may already behave in ways that others find difficult or challenging (for example, agitation or aggression) and this can worsen if they develop dementia. The person may have a different sense of reality because of the dementia. By understanding this, carers can begin to be aware of what they might be feeling, and be able to interpret their behaviour. Carers and professionals should work together to understand the reasons or triggers for the person's behaviour and find ways of preventing it.

Changes in behaviour are often caused by the environment, undiagnosed pain or the actions of others. If the living environment is too busy or too noisy (because of television or conversations, for example), this can trigger agitation or increased confusion. Mirrors and reflections in windows and shiny surfaces can cause confusion or lead to misperceptions. The environment should be calming and familiar. See 'Tips for carers' below for further information about how to adapt communication and activities for someone with learning disability and dementia. Antipsychotic medication and sedatives should only be used after everything else has been tried. For more information see factsheet 408, **Drugs for behavioural and psychological symptoms in dementia**.

A person with a learning disability and dementia 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. 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. For more about this see 'Tips for carers' below.

Treatment and support for other conditions more common in people with Down's syndrome (such as hearing loss, depression, seizures, underactive thyroid) may be made more complicated by the person's dementia. It is usually best to start with their GP or community learning disability nurse if there are any concerns.

Tips for carers

There are many practical strategies that can be put in place to support people with a learning disability and dementia and their carers. These should all be based on the principles of person-centred care, taking 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 individuals may need to develop alternative ways of expressing themselves. For anyone communicating with the person, non-verbal communication, including body language and tone of voice, will become 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.
- Maintain and nurture the person's friendships and social relationships. This may require the active involvement of staff or family. 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 (for example, 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. Long-term memory becomes increasingly important.
- Relaxation techniques such as massage and aromatherapy, as well as 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.

Living well with dementia requires a range of treatment, support and activities. For a person with a learning disability and dementia, getting the best outcome may mean seeing a psychiatrist who specialises in learning disabilities, as well as staff from the learning disability services. Treatments may include drug and non-drug approaches.

Other useful organisations

British Institute of Learning Disabilities

Birmingham Research Park
97 Vincent Drive
Edgbaston
Birmingham B15 2SQ

0121 415 6960
enquiries@bild.org.uk
www.bild.org.uk

Works to improve the lives of people with disabilities and family carers. Provides a range of published and online information including 'easy read' booklets to help explain dementia to a person with a learning disability

Foundation for People with Learning Disabilities

1st Floor, Colechurch House
1 London Bridge Walk
London SE1 2SX

020 7803 1100
www.learningdisabilities.org.uk

Charity working to influence government and local authority policies and services so that they better meet the needs of people with learning disabilities, their families and carers.

Down's Syndrome Association

Langdon Down Centre
2a Langdon Park
Teddington TW11 9PS

0333 12 12 300 (helpline 10am–4pm weekdays)
info@downs-syndrome.org.uk
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

0808 808 1111 (Mencap Direct helpline)
help@mencap.org.uk (England)
helpline.wales@mencap.org.uk (Wales)
helpline.ni@mencap.org.uk (Northern Ireland)
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 1122

9am–8pm Monday–Wednesday

9am–5pm Thursday–Friday

10am–4pm Saturday–Sunday

alzheimers.org.uk

Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

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