

Dementia and Down's Syndrome - *Factsheet*

Dementia web 
Information resource for carers, professionals and you

www.dementiaweb.org.uk



Dementia and Down's Syndrome

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Dementia is not an illness in itself. It is an umbrella term for a collection of conditions and diseases which cause disorders of the brain. These diseases cause a person to have difficulty with 'cognitive functioning', that is, thinking, remembering and reasoning.

This fact sheet is about people with learning disabilities (formerly known as mental handicap) and their risk of developing dementia as they grow older.

There is evidence that people with learning disabilities have a much greater chance of developing dementia than those in the general population. This risk is particularly high for people with Down's syndrome, the most common form of learning disability.

What is the risk?

Life expectancy has risen hugely for people with Down's syndrome over the last eighty years. In 1929 someone with Down's syndrome could only expect to live for an average of nine years. Now, people usually live into their fifties and some survive into their seventies. With this increase in life expectancy has come an increased risk of developing dementia.

Estimates vary, but it is thought that around 10% of people with Down's syndrome may be found to have dementia between the ages of 40 and 49, rising to around 54% between the ages of 60 and 69. People with learning disabilities other than Down's syndrome also have a much higher likelihood of developing dementia than the general population.

What is the cause?

At present, the reason why people with learning disabilities are more prone to developing dementia is not fully understood. There could be genetic factors, or a particular type of brain damage associated with learning disability may be implicated.

It has been discovered that almost all people with Down's syndrome have the plaques and tangles in their brains which are associated with Alzheimer's disease. However, not all of these people will develop the symptoms of Alzheimer's disease. Research has, however, shown that amyloid protein found in the plaques and tangles is linked to a gene on chromosome 21. As Down's syndrome is caused by an extra copy or copies of chromosome 21, this could explain the increased risk. Raised levels of cholesterol have also been implicated by some researchers.

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Diagnosis

Because people with Down's syndrome may normally experience difficulties with memory, concentration and problem solving and with expressing themselves, it can be difficult to establish that they have developed a dementia. Often, the early stages of dementia are not noticed, because the symptoms are assumed to be part of the learning disability. The person may not be able to explain how they are feeling, and communication problems may make it hard for other people to assess the situation accurately. In addition, standard tests which measure cognitive ability are not generally useful for people with learning disabilities because they may not have the necessary language skills, and they already have some cognitive disability.

Those who know the person well are likely to be in the best position to recognise and identify changes in personality or behaviour. As with anyone else, it is important that a full health assessment is carried out when possible signs of dementia are seen. Although people with Down's syndrome are much more likely to develop dementia, it should not be automatically assumed that they have it before considering all possibilities.

It could be that the symptoms are an indication of something else altogether, such as depression, thyroid imbalance or even something as simple as constipation. The process of diagnosing dementia in a person with Down's syndrome should therefore be careful and thorough and should include a consideration of every aspect of the person's mental and physical health.

Professor Tony Holland, of Cambridge University, has developed a diagnostic tool to help try and pick up dementia in people with Down's syndrome. Early diagnosis is important, in order that people may access to the treatments and services available to others with dementia.

What can be done?

Although research is ongoing, there is at present no cure for dementia. In Alzheimer's disease damage is caused to brain cells, causing them to die off gradually. The disease is progressive and irreversible, so the person will gradually become more affected by the death of brain tissue, and the symptoms will worsen.

The most recent guidance from NICE (the National Institute for Health and Clinical Excellence) recommends that people in the moderate stages of Alzheimer's disease may be given treatment with the "anti-dementia" drugs donepezil (Aricept), galantamine (Reminyl) or arnivastigmine (Exelon), and this includes individuals with dementia and learning disabilities. These drugs are not currently licensed for use in the early stages of the disease.

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These drugs do not cure dementia, but they may slow down its progression for a while or help with some of the symptoms giving the appearance of improvement. Each person responds differently to drug therapy, so the benefits can vary considerably from person to person.

Due to the progressive nature of the disease people will still be able to enjoy a reasonable quality of life for some time. It is important to maintain a positive attitude and to encourage and enable people to maintain their skills and abilities, their interests and their enthusiasms. At the same time, it is important to be aware that needs will gradually increase, and to be ready to provide additional support as it is required.

Where to get help

As the person with learning disabilities is likely to have been monitored throughout their life by various services and support networks, concerns that they might be developing dementia should first be referred to those who already know them well. These agencies are likely to be able to offer ongoing advice, support, and possibly even tailored services to meet the different needs of a person who is learning disabled and who is now experiencing the onset of dementia.

It may be that the person's dementia reaches a stage where their family can no longer cope with their care. If moving into a care home is seen to be the best way to meet the person's needs, independent reports and quality ratings on all homes in your local area can be found on the website of the Care Quality Commission which regulates them www.cqc.org.uk (use its webform)

Or telephone them, (8.30 am to 5.30 pm Monday to Friday) on **03000 616161**

It should be remembered that a person with learning disability who develops dementia is likely to be in their forties or fifties whereas most people will be aged seventy and upwards. A home specifically for younger people with dementia will therefore be more appropriate.

Guideposts Trust provides specialist information and care services for people with dementia and their carers. www.dementiaweb.org.uk

Contact the Helpline number: **0845 1204048** available Monday to Friday office hours, answer service at other times or by email at info@dementiaweb.org.uk

The Down's Syndrome Association www.downs-syndrome.org.uk is a charity offering advice and support. A helpline is available from 10.00 to 4.00 Monday to Friday – **0845 230 0372** and a welfare benefits advice line is available on the same number from Monday to Thursday from 10.00 to 4.00. Email info@downs-syndrome.org.uk

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The Alzheimer's Society is a care and research charity for people with Alzheimer's disease (and other forms of dementia) and their families. As well as a national helpline, there are over 250 local branches.

Helpline: **020 7423 3500**

Email: enquiries@alzheimers.org.uk

Website: www.alzheimers.org.uk

Carers UK provides advice and information to carers and the professions who support carers.

Carers UK Adviceline: **0808 808 7777** (Wednesday and Thursday 10am to 12pm and 2pm to 4pm)

Email: adviceline@carersuk.org

Website: www.carersuk.org

The British Psychological Society (2009): 'Dementia and people with learning disabilities'

Dementia Information Service for Carers

Helpline Number **0845 1204048**

Call in normal office hours. Answer phone at other times.

Email: info@dementiawebgloucestershire.org.uk

Web: www.dementiawebgloucestershire.org.uk

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