Learning disabilities and dementia

Information sheet 430

Advances in medical and social care have led to a significant increase in the life expectancy of people with learning disabilities. The effect of ageing on people with learning disabilities – including the increased risk of developing dementia – has become an increasingly important issue. This factsheet outlines some of the issues concerning people with a learning disability who develop dementia.

The causes of learning disability are varied. They include genetic disorders, such as Down's syndrome, pre- or post-natal infections, brain injury, and general individual differences.

What is dementia?

Dementia is a general term used to describe a group of diseases that affect the brain. Alzheimer's disease is the most common form of dementia. The damage caused by all types of dementia leads to a progressive loss of brain tissue. As brain tissue cannot be replaced, symptoms become worse over time. Symptoms may include:

- loss of memory
- difficulty concentrating
- difficulty finding the right words or understanding what other people are saying
- a poor sense of time and place
- difficulty completing self-care and domestic tasks
- difficulty solving minor problems
- mood changes
- changes in behaviour.

What is special about dementia in people with learning disabilities?

There is no evidence that dementia affects people with learning disabilities differently to how it affects other people. However, the early stages are more likely to be missed or misinterpreted - particularly if several professionals are involved in the person's care. The person may find it hard to express how they feel their abilities have deteriorated, and problems with communication may make it more difficult for others to assess change.

It is vital that people who understand the person's usual methods of communication are involved when a diagnosis is being explored - particularly where the person involved does not use words to communicate.

What are the risks?

Down's syndrome and Alzheimer's disease
About 20 per cent of people with a learning disability have Down's syndrome, and people with Down's syndrome are at particular risk of developing dementia. Figures from one study (Prasher 1995) suggest that the following percentages of people with Down's syndrome have dementia:

- 30-39 years 2 per cent
- 40-49 years 9.4 per cent
- 50-59 years 36.1 per cent
- 60-69 years 54.5 per cent.

Studies have also shown that virtually all people with Down's syndrome develop the plaques and tangles in the brain associated with Alzheimer's disease, although not all develop the symptoms of Alzheimer's disease. The reason for this has not been fully explained. However, research has shown that amyloid protein found in these plaques and tangles is linked to a gene on chromosome 21. People with Down's syndrome have an extra copy of chromosome 21, which may explain their increased risk of developing Alzheimer's disease.

Other learning disabilities and dementia

The prevalence of dementia in people with other forms of learning disability is also higher than in the general population. Some studies (Cooper 1997, Lund 1985, Moss and Patel 1993) suggest that the following percentages of people with learning disabilities not due to Down's syndrome have dementia:

- 50 years and over: 13 per cent
- 65 years and over: 22 per cent.

This is about four times higher than in the general population. At present, we do not know why this is the case, and further research is needed. People with learning disabilities are vulnerable to the same risk factors as anyone else. Genetic factors may be involved, or a particular type of brain damage associated with a learning disability may be implicated.

How can you tell if someone is developing dementia?

Carers, friends and family play an important part in helping to identify dementia, by recognising changes in behaviour or personality. It is not possible to diagnose dementia from a simple assessment. A diagnosis is made by excluding other possible causes and assessing a person's performance over time. The process should include:

- **A detailed personal history**? This is vital to establish the nature of any changes that have taken place. It will almost certainly include a discussion with the main carer and any care service staff.
- **A full health assessment**? It is important to exclude any physical causes that could account for changes taking place. There are a number of other conditions that have similar symptoms to dementia but are treatable - for example, hypothyroidism and depression. It is important not to assume that a person has dementia simply because they fall into a high-risk group. A review of medication, vision and hearing should also be included.
- **Psychological and mental state assessment**? It is also important to exclude any other psychological or psychiatric causes of memory loss. Standard tests that measure cognitive ability (see Factsheet 436, MMSE) are not usually applicable for people with learning disabilities, as they already have some cognitive impairment.
and may not have the verbal language skills that the tests require. New tests are being developed for people with learning disabilities.

- **Special investigations**? Brain scans are not essential in the diagnosis of dementia, although they can be useful in excluding other conditions, or in aiding diagnosis when other assessments have been inconclusive.

**What if dementia is diagnosed?**

Although dementia is a progressive condition, the person will be able to continue with many activities for some time. It is important that their skills and abilities are maintained and supported for as long as possible, and that they are given the opportunity to fulfil their potential. However, the experience of failure can be frustrating and upsetting, so it is important to find a balance between encouraging independence and ensuring that the 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 severe dementia over a period of years. New drug treatments seek to temporarily slow down or delay the progression of the disease, and it is hoped that treatments will become more effective in the future. (See Factsheet 407, Drug treatments for Alzheimer's disease.)

**Tips: supporting people with learning disabilities and dementia**

Many practical strategies have been developed to support people with dementia and their carers. Here are some ideas:

- Dementia affects a person's ability to communicate, so they may need to develop alternative ways of expressing their feelings. By understanding something of a person's past and personality we can begin to understand what they might be feeling, and be able to interpret their behaviour.
- Enable the person to have as much control over their life as possible. Use prompts and reassurance during tasks that they now find more difficult.
- Help the person by using visual clues and planners to structure the day.
- Use visual labels on doors to help the person find their way around their home in the early stages.
- 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', comprising photos and mementos from the person's past, may be a useful way to help the person interact and reminisce.
- If speech is a problem, make use of body language. Simplify sentences and instructions, listen carefully, and give plenty of time for the person to respond.
- If someone is agitated, the environment might be too busy or noisy.
- Relaxation techniques such as massage, aromatherapy and music can be effective and enjoyable.
- If the person becomes aggressive, carers and professionals should work together to try to establish reasons for the person's frustration and find ways of preventing the behaviour or coping with the situation should it arise.
- Medication may be used if someone is experiencing high levels of agitation, psychotic symptoms or depression. It is important that any prescribed medicine is monitored closely and that other ways of dealing with the situation are thoroughly explored. (See Factsheet 408, Dementia: drugs used to control behavioural...
symptoms).

For details of Alzheimer's Society services in your area, visit [alzheimers.org.uk/localinfo](http://www.alzheimers.org.uk/localinfo)
For information about a wide range of dementia-related topics, visit [alzheimers.org.uk/factsheets](http://www.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  

Body that works to improve the lives of people with disabilities. Provides a range published and online information.

**The Foundation for People with Learning Disabilities**

7th floor, 83 Victoria Street  
London SW1H 0HW  
T 020 7802 0300  
E fpld@fpld.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 UK charity the Mental Health Foundation.

**Down's Syndrome Association**

Langdon Down Centre  
2a Langdon Park  
Teddington TW11 9PS  
T 0845 230 0372 (England, helpline 10am-4pm weekdays)  
028 9066 5260 (Northern Ireland office)  
029 2052 2511 (Wales office)  
E info@downs-syndrome.org.uk  

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

158-160 Balgreen Road
Edinburgh EH11 3AU
T 0131 313 4225
E info@dsscotland.org.uk
W http://www.dsscotland.org.uk/

Works to improve the quality of life of everyone with Down's syndrome. Offers telephone advice, leaflets and other information, local branches, group support. Publishes a free booklet 'What is dementia' for adults who have a learning disability.

References

Cooper S A (1997) 'High prevalence of dementia amongst people with learning disabilities not attributed to Down's syndrome'. Psychological medicine 27: 609-616


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