

# Growing older with learning disabilities

## Dementia

People with learning disabilities are living longer and experiencing more of the conditions that we normally associate with older age. It's important that we understand the effects of ageing among people with learning disabilities and in particular the risks of developing dementia, signs, symptoms and things that can be done to help.

A person with learning disabilities has a lifelong condition that impacts on their learning, communication and understanding. 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 during or after birth but before adulthood; they may be due to infection (e.g. bacterial meningitis), brain injury and lack of oxygen at birth or prematurity. The effects of a learning disability on the individual range from mild to severe to profound.

Anyone with a learning disability may get a form of dementia, but someone who has Down's syndrome is particularly vulnerable. People with other learning disabilities may have a higher likelihood of developing dementia than the general population, although not at such a young age as those with Down's syndrome. At the age of 60, over 50% of people with Down's syndrome and 10-15% of people with other learning disabilities will have developed dementia compared to 2% of the general population, while at age 90, 70% of people with learning disabilities will have dementia compared to 20-30% of the general population. (*Royal College of Psychiatrists & the British Psychological Society Dementia and people with learning disabilities, September 2009*)

### What is dementia?

The term dementia describes a number of conditions of the brain including Alzheimer's disease, Lewy Body disease, Picks disease and vascular dementia. Dementia is a progressive condition which means that the symptoms will get worse. Each dementia affects the person in a different way but symptoms typically include loss of memory, behavioural or mood changes and problems with communication, reasoning and daily activities.

There is no cure for dementia, although some medications may help in the early stages. As it is a progressive disease, someone affected will lose their ability to do various things over time. The skills needed to carry out certain activities and the ability to understand the world around them will gradually diminish.

### 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 (e.g. becoming more stubborn, irritable or withdrawn) are

more often reported as an early symptom of dementia 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.

### **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.

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 have already learned different ways to communicate (e.g. 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

### **Early signs of dementia in people with a learning disability**

It is helpful to pick up changes that may indicate that someone has dementia as early as possible. The most common changes to look for are:

- deterioration in daily living skills
- increased inactivity
- loss of interest in activities they have previously enjoyed
- reduced communication
- new or increased confusion or disorientation
- changes in sleep patterns
- difficulty in perceiving depth, such as going up or down steps
- increased walking about without a reason

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. Many learning disability health teams (psychologists) carry out a baseline assessment for people

with Down's at age 40 so they can track changes on a regular basis to identify signs of dementia. However it is important not to assume that a person with a learning disability has dementia simply because they fall into a high-risk group.

Misdiagnosis of dementia can occur because the signs are similar to those for other, treatable conditions. For example, people with depression can be withdrawn, less active, have problems with sleep and lose interest in pursuits they previously enjoyed. They may also stop engaging in their usual activities of daily living. All these signs can also indicate dementia. Additionally women with Down's syndrome may experience symptoms linked to the menopause which could be mistaken for dementia, not least because the age of onset may be similar.

### **What support should be offered after a diagnosis?**

It can be difficult for someone with a learning disability to understand the significance of a diagnosis of dementia. The changes they experience need to be explained in terms familiar to the person. It is also important to consider the impact of dementia on the people living with the person and their wider circle of family and friends, 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 they are 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. The latest (2011) guidelines from the National Institute for Health and Clinical Excellence on the use of these drugs acknowledges the difficulties with assessing dementia in people with learning disabilities and give the doctor greater flexibility in drug use.

### **Supporting someone with a learning disability and dementia**

It is important to be able to recognise the early signs of dementia and to know where to go for support and diagnosis. But it is equally important not to jump to conclusions and assume that someone has dementia when it could be something else that is treatable. If you are supporting someone with learning disabilities and dementia, the following may be helpful:

- 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 that the people around them use, will become increasingly important.
- Someone with dementia may have a different sense of reality. Short term memory may gradually fade and disappear, leaving only long term memory. This means that the person may not function well in the present day, but will

believe they are functioning perfectly well in the reality that is their long term memory.

- 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 (e.g. 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.
- If the person's behaviour becomes aggressive, it is important to try 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.

More than anything else, we need to try to understand the reality that each person is experiencing. Because someone with dementia may believe they are in a different time and place, they may live in a different reality altogether. This can cause enormous stress if they are having difficulty making sense of their environment, recognising the people around them or understanding spoken language. It is therefore important that we develop a better understanding of how best to provide support, what causes alarm or upset, what best provides comfort and how to communicate. These will be individual to each person, just as our reality is individual.

Guides which explore the environment for people living dementia and changes that can be made to the family home are available on the Shared Lives Plus website <http://sharedlivesplus.invisionzone.com/index.php?files/download/231-guides-on-developing-a-dementia-friendly-environment/>

The information contained in this guide has been drawn from a number of sources, predominantly the Alzheimer's Society Factsheet 430 'Learning Disabilities and Dementia' and 'Supporting Derek – a practice development guide to support staff working with people who have a learning difficulty and dementia', published by the Joseph Rowntree Foundation.

Disclaimer: This guide has been prepared by Shared Lives Plus and contains general advice only, which we hope will be of use to you. Nothing in this guide should be construed as the giving of specific advice and it should not be relied on as a basis for any decision or action.

Shared Lives Plus does not accept any liability arising from its use. We aim to ensure the information is as up to date and accurate as possible, but please be warned that certain areas are subject to change from time to time. It is always a good idea to seek expert advice on your personal situation. Please note that the inclusion of named agencies, websites, companies, products, services or publications in this guide does not constitute a recommendation or endorsement by Shared Lives Plus.