



Dementia with Lewy bodies

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Introduction

This information sheet is for partners, family members and friends of people with dementia with Lewy bodies (DLB). Some people with early DLB may also find it useful.

DLB may also be known as Lewy body dementia, diffuse Lewy body disease,

dementia of Lewy body type or Lewy body variant of Alzheimer's disease.

Key points

Although DLB is common, it can be difficult to diagnose because the symptoms don't necessarily suggest some form of dementia. Short term memory may be unaffected to begin with.

The person's abilities may fluctuate from day to day so it can be hard to pin down the problem.

The doctor should take a detailed history of the symptoms and problems the person is having. Key features to look out for are:

- Hallucinations
- Fluctuating cognition
- Parkinson's-like symptoms

Early accurate diagnosis is important because of the serious and potentially dangerous reaction of many people with DLB to anti-psychotic drugs (strong tranquillisers).

What is dementia with Lewy bodies?

Dementia with Lewy bodies is caused by small, round clumps of protein that build up inside nerve cells in the brain. These are named Lewy bodies after Dr Frederick Lewy, who first identified them in 1912.

The protein clumps damage the way brain cells work and communicate with each other. The nerve cells affected by Lewy bodies

control thinking and movement. Researchers do not yet know what causes the protein to build up, but work is underway to try and find out why it happens and ways to stop it.

How many people are affected by DLB?

Depending on the source of the statistics, the percentage of the total number of people with dementia who have DLB varies considerably, from as few as 4%¹, or 10%² or even as high as 15%³.

In Scotland, this means that between 3,200 and 12,000 people may be affected by DLB.

Some say it is the second most common type of dementia, after Alzheimer's disease.

What is the cause?

The cause of DLB is uncertain. It may be related to Alzheimer's disease and Parkinson's disease as there are certain similarities with those two conditions. People who have Lewy bodies in their brains also have the plaques and tangles associated with Alzheimer's disease. Some scientists say that there is a Lewy Body variant of Alzheimer's disease; others suggest that people may have both DLB and Alzheimer's disease.

DLB usually occurs sporadically, in people with no known family history of the disease.

Genetic studies are trying to discover which genes may contribute to the development of DLB, but these are still at an early stage.

Symptoms

People with DLB will have many of the same symptoms as people with other forms of dementia - a gradual loss of mental abilities,

including orientation and memory, reasoning and intelligence, and a progressive decline in the ability to carry out daily tasks.

But there are certain symptoms which are much more likely in DLB, including:

Patchy mental impairment

As with other forms of dementia, someone with DLB will experience memory problems but this is likely to be patchy, with some quite normal memory function.

He or she may communicate clearly, but may have difficulties with things like problem solving and planning.

There may be frequent episodes of drowsiness, long periods of staring into space, lethargy or disorganised speech.

However, the mental decline in some people with DLB may be just like it is in someone with Alzheimer's disease.

Hallucinations and delusions

Seeing or hearing things which are not there is very common in this type of dementia, with 90% of people being affected.

Usually these are visual hallucinations - seeing colours, shapes, animals, people, or objects that aren't there. This can be an early symptom of DLB.

Occasionally the hallucinations are auditory – hearing music or voices – or involve the other senses of taste, smell and touch.

Most people with DLB find their hallucinations puzzling, rather than upsetting or frightening. Unlike hallucinations in many mental illnesses, the person may have quite a lot of insight.

Some people may experience delusions - false ideas about another person or situation.

¹ Alzheimer Scotland. The dementia epidemic, 2007

² Alzheimer's Society. What is dementia with Lewy bodies (DLB) (factsheet) 2010

³ National Institute for Health and Clinical Excellence & Social Care Institute for Excellence, 2006. Dementia: supporting people with dementia and their carers in health and social care.

Neurological symptoms

People with DLB quite often have vague neurological problems which can include symptoms that are like those of Parkinson's disease, but which may not respond well to the usual treatments given to people with Parkinson's disease. These symptoms are often in just one part of the body, and may include:

- rigidity and stiffness
- difficulty starting movements (known as 'bradykinesia')
- slowness of movement
- a shuffling walk
- tremor
- loss of facial expression
- changes in the strength and tone of the voice.

This pattern is different from other kinds of dementia. Neurological problems are rare in the early stages of Alzheimer's disease, although people in the very late stages develop problems with mobility and other neurological problems. People with vascular dementia may have some of the neurological problems associated with having small strokes.

Other symptoms which people with DLB may get include vague weaknesses of arms or legs and clumsiness. They may also fall for no apparent reason, because they have problems judging distances or making accurate movements. These symptoms may come and go.

Fluctuating abilities

The person's abilities can vary from moment to moment or day to day. One day, he or she might be able to carry out a particular task, but be completely unable to do it the next day. He or she may have episodes of quite sudden severe confusion, which then pass. The person's insight is also likely to vary: at times he or she may realise that things are not right, that the hallucinations are imaginary, etc, but at other times may have

no apparent understanding of his or her illness.

Sleep disturbance

People with DLB may fall asleep very easily by day but be wakeful at night, sometimes not sleeping at all, night after night. The person may not realise this; but it can be very distressing for those they live with. Lack of adequate rest can in turn make the person's cognitive problems worse.

Some people with DLB seem to experience an unusual condition where they lose the normal paralysis that we normally have when we sleep. This means that they may be physically active, talk in their sleep, or act out dreams in the night.

Depression

Depressive symptoms are common in DLB with around 40% of people having a major depressive episode at some point.⁴

Diagnosis and tests

One problem with DLB is getting a correct early diagnosis, as this dementia can often be mistaken for Parkinson's disease, depression or another dementia. Often relatives and the person with DLB do not expect a connection between hallucinations and dementia and will therefore not mention this to the GP. So it is a good idea to write down the changes you have noticed and any other symptoms the person is experiencing, even if you don't think there is a connection.

Many GPs will not recognise early signs of DLB and will therefore not pick up on the diagnosis quickly. Ask to be referred to a specialist in order to obtain an accurate diagnosis.

There is no specific test for DLB. A specialist (usually an old age psychiatrist) will take a precise history of the pattern of the person's

⁴ McKeith, I G. Dementia with Lewy bodies. British journal of psychiatry 180 2002 144-7.

symptoms. This is so that the doctor can be sure first of all that the person has dementia, as there are other reasons why a person may experience symptoms such as visual hallucinations (for example, people who are in delirium, the confusion that is caused by a physical illness). The specialist will then exclude other possible diagnoses, including vascular dementia and Alzheimer's disease.

A brain scan may show shrinkage of the brain. A SPECT scan, which looks at the pattern of blood flow in the brain, may be able to show up some of the changes that are happening. However the Lewy bodies themselves can only be seen by looking at brain tissue after death.

The specialist may need to see the person more than once over a period of time before a diagnosis becomes clearer.

Course of the illness

Unlike Alzheimer's disease, which usually begins very gradually, DLB often starts quite rapidly or acutely, with quite a fast decline in the first few months, although later there may be some levelling off. DLB tends to progress faster than Alzheimer's disease and can last from 5–7 years, although this will vary from person to person.

Caring for someone with DLB

Information and support

If you need help with a particular problem, specific information or access to a service it is vital that you ask for it. Speak to your GP or social worker or Alzheimer Scotland for information and advice. Contact a local carers' group to find out about other people who are caring or have cared for someone with DLB, as they will often be a vital source of information and support.

Very few people know what DLB is, and partners and family members often find that there is little support from other people, as they do not understand what they are going through. As a result carers can feel very

isolated. Being able to talk to someone who understands is very important. Alzheimer Scotland's **Dementia Helpline**, on freephone **0808 808 3000** is open 24 hours a day for information and emotional support, and can provide a free information pack and help you find services and support near you; or see the website at www.alzscot.org.

Unpredictability and fluctuating abilities

Because someone with DLB's abilities can fluctuate from day to day or even hour to hour, it can make it very hard to plan any event or outing or activity, because you don't know how the person will be at that time.

This can be very frustrating and upsetting and family members may sometimes feel that the person is "putting it on" because at other times he or she manages to do things.

The difficulty starting movements, lethargy and periods when the person spends ages staring into space can also lead family members to suspect the person is just being lazy or awkward. But these symptoms are part of the illness and the person has no control over them.

Dealing with hallucinations and delusions

Hallucinations and delusions are often the most difficult symptoms to deal with. They can cause a great deal of emotional strain for family members.

Some people with DLB will know they are experiencing hallucinations, while others will not be able to distinguish between reality and what is happening in their hallucinations and delusions. A lot will depend on how the person reacts to these hallucinations and what the person "sees" while hallucinating. If he or she is not bothered by them, then family members may be advised to learn to live with them too. Challenging the person or arguing that there's nothing or no-one there may be unhelpful and wearing. In some cases it may help just to reassure the person or distract them in some way.

If he or she is frightened by the hallucinations or reacts badly to them, seek advice the person's specialist or GP, and seek support for yourself, for example through a local dementia carer support group.

Insight

Some of the most distressing times for carers can be when the person they care for understands what is happening to them. One carer found it particularly distressing, when her husband was in a care home, on days when he had insight into his condition. He would ask to come home with her, as he did not want to stay in the home anymore. For this carer this seemed worse than when he was unaware of the changes taking place in their lives. Seek support from family, other carers and professionals to help you cope with the distress the fluctuating insight of DLB can cause.

Sleeping

Some people with DLB are sleepless or physically active in their sleep. (See *Sleep disturbance* on page 3.) This symptom may respond to treatment with low doses of a drug called clonazepam.

If the person has any problems related to sleep, always contact the GP to ensure there are no other problems and for treatment and advice.

Vision

Some people with DLB experience problems with vision, with some suffering from double vision and difficulty with depth perception and judging distances from objects.

This can cause problems with many activities but particularly with driving. Any driver receiving a diagnosis of dementia must tell the Driver and Vehicle Licensing Authority (DVLA) and their insurance company. If the person wants to carry on driving and tells the DVLA that, they will be sent a questionnaire and their doctor will be asked for a report. They

may be required to do a driving assessment but this may take many weeks to arrange.

Eating can also be a problem, as the person may no longer see the food clearly to pick it up. Make sure the food is on a plain plate and that the table or tablecloth is a different colour from the plate, as this helps the person to distinguish between the food, plate and table.

Other strategies to help

There are strategies that can help, especially in the early stages of DLB. These include keeping a set routine, providing written or 'alarm call' reminders and providing reassurance. People with DLB will often have times when they have a lot of insight into their condition and will need a great deal of support.

Closely monitoring the person's condition and the progression of the dementia will help provide vital information for his or her doctors.

Services

There are many services that may help the person with DLB and his or her carer to cope more easily. The person with DLB is entitled to a **community care assessment** from the social work department to work out what services might help. The carer is also entitled to a **carer's assessment**.

Contact your local social work department (listed in the phone book under your local council) to ask for assessments. The Dementia Helpline (0808 808 3000) can explain about assessments and services and can put you in touch with your local Alzheimer Scotland service for support.

Both the person with DLB and his or her carer may benefit from attending local support groups or dementia cafes to meet other people in the same situation. The Dementia Helpline can also send you information about groups and services in your area.

Treatment and drugs

There is no cure yet for DLB and no specific drug treatment. The present form of treatment usually focuses on treating the symptoms.

Dangers of anti-psychotic drugs in DLB

Anti-psychotic drugs are regularly used for the treatment of restlessness, aggression and psychiatric symptoms common in people with dementia. Because of their potential side effects, these drugs should not be the first choice of treatment but, if other options fail, should be used at as low a dose as possible, for as short a time as necessary, and monitored.

Warning

Anti-psychotic drugs can be extremely dangerous for people with DLB. They can cause a severe reaction that results in severe, irreversible symptoms of Parkinson's disease, unstable temperature and blood pressure control and breakdown of muscle tissue. This can even cause death⁵.

If you are caring for someone with DLB who is admitted to hospital or to a care home, you should tell staff that he or she has DLB and make sure that it is recorded in their notes that anti-psychotics should not be prescribed without consulting a specialist.

Cognitive enhancers

Some of the drugs developed for treating people with Alzheimer's disease can be effective in treating people with DLB. They include **donepezil (Aricept)**, **rivastigmine (Exelon)** and **galantamine (Reminyl)**. These drugs are considered by many psychiatrists as the first line of therapy in DLB.

These drugs prevent the breakdown of acetylcholine, a chemical which carries messages between brain cells. This means that there is more acetylcholine available to transmit messages between nerve cells. This may temporarily improve or stabilise the symptoms of the disease. See Alzheimer Scotland's information sheets on these drugs (Aricept number 11, Reminyl number 17, Exelon number 14).

Guidelines on dementia from the Scottish Intercollegiate Guidelines Network (number 86)⁶ state that rivastigmine can be used to treat cognitive decline in people with DLB and report that it may be useful in reducing apathy, anxiety and hallucinations.

One study showed that people with DLB given donepezil (Aricept) showed an improvement in understanding, behaviour and psychiatric symptoms, although it is important to recognise that they are not suitable for everybody and will not help everyone who tries them.⁷

Drugs for Parkinson's disease

Some people with symptoms of rigidity and stiffness respond to the dopamine replacement drugs (like levodopa) used to treat Parkinson's disease. But they may make other symptoms like hallucinations and confusion worse.

Other treatments

Not all treatments include taking drugs:

- Physiotherapy may help with general fitness and help with flexibility and walking
- Speech therapy may improve low voice volume, poor enunciation, muscular strength, and swallowing difficulties

⁶ <http://www.sign.ac.uk/pdf/sign86.pdf>

⁷ Samuel W et al (2000) Better cognitive and psychopathologic response to donepezil in patients respectively diagnosed as dementia with Lewy bodies: A preliminary study. *International Journal of Geriatric Psychiatry* 15, 794-802

⁵ <http://www.alzheimers.org.uk/factsheet/CSMinfo2>

- Occupational therapy helps maintain skills and promotes functional ability and independence
- Music and aromatherapy may reduce anxiety and improve mood
- Individual and family psychotherapy may be useful for learning strategies to manage emotional and behavioural symptoms

Speak to the person's GP or specialist about referring you to these services.

Useful resources

The Lewy Body Society

Established in June 2006, the Lewy Body Society is the only charity in Europe specifically for people with DLB.
Hudson House
8 Albany Street

Edinburgh
EH1 3QB

Email info@lewybody.co.uk
Website: www.lewybody.co.uk

Pick's disease resource group

This support group includes people with DLB.
www.pdsg.org.uk/

Parkinson's Disease Society

Can offer support, particularly around the symptoms of DLB which are similar to Parkinson's disease.

PDS Helpline 0808 800 0303
Email: enquiries@parkinsons.org.uk
Website: www.parkinsons.org.uk



The logo features a stylized icon of a person's head and shoulders in profile, with a circular arrow around it, symbolizing a cycle or support. Below the icon, the text reads 'Dementia Helpline 24 HOUR' in a large, bold, sans-serif font. To the right of 'Helpline' is a black square with '24 HOUR' in white. Below this, the text 'Freephone 0808 808 3000' and 'Email: helpline@alzscot.org' is displayed in a smaller font. The entire logo is enclosed in a thick black border.

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