

Where to go for help.

Being diagnosed with DLB may be a shock but it can also give a name to something that people already knew was going wrong. It is generally useful for people with DLB and their families to get support around the time of the diagnosis, and to learn about the condition and where to find the right help. Parkinson's New Zealand is a good source of information and advice, as is Alzheimers New Zealand (which also helps people with other types of dementia). Staff from both these organisations can help point you in the right direction depending on what you need.

Further resources on the Internet.

www.ninds.nih.gov/disorders/dementiawithlewybodies/dementiawithlewybodies.htm

www.nottingham.ac.uk/~mpzjlw/lewy/lewyhome.html

www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=570

www.lewybodydementia.org/

Thank you to Dr Matthew Croucher, Old Age Psychiatrist, Canterbury District Health Board and Dr Colin Peebles, Consultant in Old Age Psychiatry, Psychiatric Service for the Elderly, The Princess Margaret Hospital, Canterbury for writing this pamphlet.



The Parkinsonism Society of New Zealand (Inc)

Parkinson's New Zealand is a not for profit organisation that offers support, education and information to people living with Parkinsonism conditions, their families, carers and health professionals. Parkinson's New Zealand has divisions and support groups nationwide.

We can offer:

- Information on Parkinson's and Parkinsonism conditions including MSA and PSP
- Regular up-to-date information through our national magazine, website and local newsletters
- Responsible reporting of recent research
- Books and audio-visual material
- Local meetings and education programmes
- Advice on health and welfare assistance available
- Support from a professional Field Officer in your area
- Fellowship and support



Parkinson's New Zealand is reliant on funding from grants, bequests and donations. Your support is welcome!

Contact:

Parkinson's New Zealand
PO Box 11 067
Manners Street
Wellington 6142

Phone: 04 472 2796

Fax: 04 472 2162

Freephone: 0800 473 4636 (0800 4 PD INFO)

Email: info@parkinsons.org.nz

www.parkinsons.org.nz

Or:

Alzheimers New Zealand

Freephone: 0800 004 001

Email: nationaloffice@alzheimers.org.nz

www.alzheimers.org.nz

Your local Parkinson's New Zealand contact is:

An introduction to Dementia with Lewy Bodies

March 2008 - Designed by Gibson Rusden



www.parkinsons.org.nz



Dementia with Lewy Bodies

DLB is a cause of dementia.

Dementia is a condition typified by a decline in thinking or cognitive processes such as memory, language and judgement. There are many different causes of dementia, with Alzheimer's disease being the best known and the most common cause. Until recently not a lot was known about Dementia with Lewy Bodies (DLB). It is a relatively common cause of dementia in people over the age of 65 years, although it is rarer in younger people. Lewy Bodies are found in Parkinson's disease. Some researchers have suggested as many as one in five people with a dementia over the age of 65 years have DLB. It may also co-exist with other causes of dementia.

What causes DLB?

The problems that arise with DLB are associated with abnormal accumulations of proteins within the brain. The illness takes its name from the presence of "Lewy bodies" containing these proteins, named after Friedrich Lewy, the German neurologist who first described them in the early part of the twentieth century.

Lewy bodies are microscopic complexes of proteins found inside the brain cells of people with DLB. It is not known what causes them to form but their presence indicates abnormal functioning of the brain.

DLB and Parkinson's

They are also found in Parkinson's and most researchers now believe there is a close link between DLB and Parkinson's. In DLB there are early symptoms of dementia whilst in Parkinson's the first symptoms are usually problems with movement (although some people with Parkinson's later develop a dementia). DLB and Parkinson's also differ in the parts of the brain where Lewy bodies first appear.

Who gets DLB?

DLB is uncommon before the age of 65 years. Different overseas studies have estimated rates of DLB ranging from 1 in 1000 people over 65 years, to 5 in 100 people over 75 years.

The genetics of DLB are not well understood. People with close, biologically related family members with DLB may have a slightly higher chance of developing a similar illness themselves. However, this risk is still low. Whilst there have been reports of families where DLB occurs commonly these are probably very rare.

What are the symptoms of DLB?

As with Alzheimer's disease, people with DLB will develop problems with memory and other thinking processes which gradually become more severe and increasingly affect day-to-day living. In DLB fluctuations in alertness and attention are particularly characteristic. People with DLB may vary strikingly within the day from being quite confused to being quite clear.

Most people with DLB experience some form of abnormal visual experiences or visual hallucinations, for example, seeing little children or animals that others cannot see. Whilst some people find these experiences distressing, many do not and recognise that these experiences are not real. People with DLB may also have particularly vivid dreams and sometimes move about in bed and call out whilst they are dreaming.

People with DLB will also usually develop some movement symptoms similar to those that occur in Parkinson's disease. In particular their movements may become slower, they may develop stiffness in their muscles, their faces may become more expressionless, and they may have problems or instability with their walking. A tremor may also occur.

Other symptoms which sometimes occur include; repeated falls or blackouts, dizziness on standing, urinary accidents and abnormal beliefs or delusions.

People with DLB may also become depressed or anxious. This may make their dementia seem worse than it actually is and with appropriate treatment, marked improvements may be experienced.

How is DLB diagnosed?

There are no specific tests for DLB. DLB is diagnosed on the basis of a history and an examination by an experienced clinician. The clinician will enquire about the pattern and duration of symptoms and obtain a detailed medical history. In most cases some form of cognitive testing will be helpful to assess the severity of memory and other related problems. A physical examination with particular emphasis on the neurological system will be performed.

Blood tests will usually be taken to identify and rule out other causes of dementia. Commonly a CT or MRI scan of the head will be arranged. These show details of the structures within the brain. As with blood tests the main reason for doing a scan is to identify other abnormalities such as a stroke which might be an alternative cause for the symptoms and require a different form of treatment. In the future there may be a greater role for other tests such as SPECT scans which can show patterns of activity within the brain.

What is the prognosis in DLB?

Everyone with a dementia follows their own individual course. However, the disease will gradually lead to ongoing damage to brain cells which may result in worsening symptoms and a decreased ability to manage daily tasks. The support and treatment that a person with DLB receives can make a big difference.

It is not possible to accurately predict the life expectancy of an individual with DLB because there is so much variation. However, in some studies of people with DLB the average life expectancy after the onset of symptoms was about 5-7 years. The cause of death is frequently something other than the dementia itself, such as pneumonia.

What treatments are available?

Medical treatments depend upon the particular symptoms of concern. Most importantly, doctors need to be careful with medicines and their side effects – a solution to a new symptom in DLB may be to reduce or stop an existing medicine rather than start a new one. In addition, people with DLB can also be very sensitive to some medications – particularly the older types of antipsychotic medication that are sometimes prescribed to people with other forms of dementia or for other medical and psychiatric conditions.

Medications used in DLB include:

- Cholinesterase inhibitors such as "Exelon", "Donepezil" and "Remyntal" can be particularly helpful for memory problems and confusion, and may reduce hallucinations.
- Hallucinations and delusions may be helped by low doses of modern antipsychotic drugs.
- Dopamine-related drugs such as "Madopar" and "Sinemet" may help with movement symptoms such as stiffness, slowing and tremor, or with nerve symptoms such as pains in the legs.
- Some blood pressure and bladder medicines may help with dizziness on standing and continence troubles.
- Low doses of sleeping medicines can help with sleep problems.

Non-medical treatments are also very important including:

- Dietary advice from a Dietician.
- A Physiotherapist can help with movement and balance problems.
- Occupational Therapists can advise on ways to manage daily tasks, help people stay busy and motivated, and can also assist people to manage any changes in memory and brain power.
- Psychologists and counsellors can help and support those with psychological or mental health symptoms.

Some people also find it helpful to seek advice from complementary medicine practitioners.