

Dementia with Lewy Bodies - *Factsheet*

Dementia web 
Information resource for carers, professionals and you

www.dementiaweb.org.uk



Dementia with Lewy Bodies

Dementia with Lewy Bodies

This is a very common form of age-related illness. According to the latest updated figures, it is experienced by some 4% of the 750,000 people with dementia in the UK. However, it is difficult to know exactly how many people are living with this disease, as the symptoms are similar to those of Alzheimer's and Parkinson's disease, and some people may have been misdiagnosed. The Lewy Body Society believes that about 100,000 people in the UK have this disease.

How Lewy body disease affects the brain

An area of the brain stem called the substantia nigra degenerates, as it does in Parkinson's disease. Nerve cells die, and the remaining nerve cells are found to contain the structures known as Lewy bodies. These are tiny, spherical deposits of abnormal proteins. In addition, there is degeneration of the cortical areas of the brain, with many features seen in Alzheimer's disease. Abnormal structures known as cortical Lewy bodies are found here. The cause of these changes in the brain is presently unknown. However, it seems clear that Lewy body disease is not caused by exposure to anything in the environment or lifestyle factors, such as diet. It can affect anyone, and although it becomes more common as people age, it can affect people in middle age. Cases of inherited Lewy body disease are extremely rare.

The symptoms of Lewy body disease

The features of Lewy body disease overlap with those of Alzheimer's disease in that there are likely to be difficulties with memory, reasoning and language. There are also physical symptoms of stiffness and slow actions, which can mistakenly be assumed to be caused by Parkinson's disease. As well as these symptoms, people with Lewy body disease will experience difficulties with judging distances and carrying out simple actions. They might fall for no obvious reason, because of this inability to judge distance and make accurate movements. People may experience problems with bladder, bowel and blood pressure control.

Hallucinations are common in people with Lewy body dementia and those of people and animals are the most typical. They may see faces in the pattern on a curtain or people in the house, or a pet on a chair when there is nothing there. These visions are very clear, but often puzzling rather than alarming.

Also typical of dementia with Lewy bodies are dramatic swings in the level of alertness. People can fluctuate from clarity to confusion, often in a short period of time. They may, or may not experience the tremor associated with Parkinson's disease.

Sleep disturbance is also common, and some people may not sleep at all and may be up and about all night.

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There is a suggestion that those with Lewy body disease can form new memories better than those with Alzheimer's disease, and that alertness, speed of thinking and concentration might be worse affected than memory and language. Some people may be able to communicate quite clearly, but have problems with problem solving, for example. Maybe because of increased awareness, depression is common.

The symptoms of Lewy body disease often fluctuate, from day to day and even hour to hour. Sometimes someone can carry out a task without difficulty one day, and be totally unable to do it the next. This, added to the presence of stiffness and slowness of movement can sometimes cause carers to be convinced that the person is being deliberately uncooperative.

The development of the disease is variable, and some people might show little progression for some time, while others will deteriorate more quickly. Whereas the average duration of the disease is about seven years, there are considerable individual variations. As dementia with Lewy bodies is most often seen in elderly people, it is quite possible that another illness, such as a stroke or pneumonia, will cause the person's death.

What treatment can be given?

Much ongoing research is being carried out, but at present there is no cure for Lewy body dementia. However, drugs are available which can slow the progress of the disease while alleviating the symptoms to some extent.

Drugs such as Aricept can sometimes improve or delay progression of the symptoms, but there may well be a difficulty in getting them prescribed as they are currently only licensed for use in mild to moderate Alzheimer's disease. Although a variety of drugs are available which may alleviate tremor, hallucinations or sleep disturbances, there are problems, because whilst some symptoms may be improved, there might be a concurrent worsening of others.

In particular, neuroleptic tranquillisers, and especially chlorpromazine, haloperidol or thioridazine should be used with great caution for people with Lewy body disease. They should be started in very low doses and monitored very closely because in some cases they may have severe, non-reversible effects and could even be fatal.

What to do

It is important to consult a doctor as soon as worrying symptoms appear. There are a number of reasons for this:

- If Lewy body disease is diagnosed, the doctor will immediately be aware of the safeguards which need to be observed in regard to neuroleptic medication.
- Other possible causes for the symptoms can be investigated.

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- An early diagnosis will allow the person and their family to learn about the disease, to come to terms with the situation and to plan for the future.
- The person will be able to state their preferences about future treatment, financial arrangements, care choices etc.
- An early diagnosis will allow access to drugs which might slow the progress of the disease.
- Carers will be able to seek help and advice for themselves, as well as for the person with Lewy body disease.

Where to get help

Contact your GP for support, advice and information. The GP will rule out reversible or temporary causes for symptoms, carry out first line tests, refer to a specialist if necessary and assume ongoing responsibility for the person's general health. The GP can be seen as a "gatekeeper" who can provide access to a range of specialist services. The person may be referred to any one of a variety of consultants. In some areas there are memory clinics, home support, day services and 'talking therapies'.

Many other people may also be able to help, such as social workers, community psychiatric nurses, district nurses, speech therapists, occupational therapists, counsellors, advocates and carers who may come into the home to assist with personal care.

It may be that the person's illness 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 solution, 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 the webform)

Or telephone 8.30 am to 5.30 pm Monday to Friday on **03000 616161**

You can also refer to our factsheet: "Moving to a Care Home and Funding Your Care" - coming soon.

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.

The Lewy Body Society was founded in 2006 in order to support research into dementia with Lewy bodies and to raise awareness and educate the public, the medical profession and those in health-care decision-making positions about the disease.

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You can visit the website at www.lewybody.org

Or you can telephone on **0131 473 2385** or Email: info@lewybody.org

Or you can write to

Hudson House,
8, Albany Street,
Edinburgh
EH1 3QB

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

Dementia Information Service for Carers

Helpline Number **0845 1204048**

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

Email: info@dementiaweb.org.uk

Web: www.dementiaweb.org.uk

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