

Lewy body disease

This help sheet explains Lewy body disease, including signs and symptoms, diagnostic process, seeking a diagnosis, and where to find further information.

About Lewy body disease

Lewy body disease is a term that incorporates both Parkinson's disease and dementia with Lewy bodies, which share similarities in the ways by which they both damage the brain at the cellular level and in the symptoms a person may experience.

Lewy bodies are microscopic structures that can be seen inside some of the brain cells of people diagnosed with both Parkinson's disease and dementia with Lewy bodies. The Lewy body is composed of a protein called alpha-synuclein that, for reasons that are not understood, becomes disrupted and tangled. It is not known whether Lewy bodies represent the primary cause of the disease, but the gradual loss of brain cells results in changes in movement, thinking and behaviour.

Forms of Lewy body disease

Lewy body disease includes three overlapping disorders:

- Parkinson's disease, which is diagnosed by the presence of significant movement symptoms including slowness, muscle stiffness and tremor.
- Parkinson's disease dementia, which is diagnosed when a person develops dementia symptoms after having at least 12 months of established Parkinson's disease. The progression from Parkinson's disease to Parkinson's disease dementia can be slow.

- dementia with Lewy bodies, a prominent feature of which is the presence of dementia symptoms at least 12 months before the development of the significant movement symptoms that are prominent in Parkinson's disease. These movement symptoms are known as 'Parkinsonism symptoms' but not everyone who has dementia with Lewy bodies will develop them and not everyone will be diagnosed as having Parkinson's disease.

Signs and symptoms of Lewy body disease

Along with the symptoms described above, other health conditions may indicate the presence of Lewy body disease. These include:

- apathy
- anxiety
- depression
- fainting
- constipation
- urinary incontinence
- excessive sleepiness
- poor sense of smell
- delusions.

Symptoms will depend on which the area of the brain is affected and disease progression.

Diagnosing Lewy body disease

Lewy body disease and its accompanying conditions can be challenging to diagnose, partly because there can be a variety of symptoms in the early stages.

A full assessment may include:

- a medical history from the person
- an interview with a family member
- blood tests
- tests of cognitive abilities
- brain imaging
- other medical tests as requested by a doctor or medical specialist.

Even with these tests, a definitive diagnosis may not be possible at the first assessment.

Getting a diagnosis can be more challenging when the physical signs are not as evident. Often the person with symptoms:

- may not agree with the concerns of others
- may present as being unaffected at a doctor consultation
- can perform well on initial cognitive screening tests, such as the Mini Mental State Examination (MMSE).

A ‘watch and review’ plan is sometimes suggested, or medication is offered for the most pressing health issue.

Family and friends can be advocates. They may express their concerns to the individual or perhaps consider talking to their doctor in person, or by telephone or letter. Together, the individual and family member or friend may visit the doctor and, if still concerned, ask for a referral to a specialist (for example, geriatrician or neurologist).

To assist the specialist, consider writing a diary of behaviours and actions of the person one week before the appointment, noting changes in behaviour, thinking and abilities that may be regarded as out of character for the person or troubling to the person or you. Reference days and times to indicate how often changes are present or not, for how long when present, and how frequently they change.

Additional reading and resources

- Dementia Australia has developed a suite of help sheets about Lewy body disease
Visit: dementia.org.au/help-sheets
- Dementia Australia library service
Visit: dementia.org.au/library
- Dementia Australia support
Visit: dementia.org.au/support
- Parkinson's Australia
Visit: parkinsons.org.au

Further information

Dementia Australia offers support, information, education and counselling.

National Dementia Helpline: 1800 100 500

For language assistance: 131 450

Visit our website: dementia.org.au