

Information for family and friends

This help sheet provides information about Lewy body disease. It will help you understand how the disease impacts a person living with the condition and how you can support them to live well.

Lewy body disease is a form of dementia that can affect someone's ability to multi-task, plan and carry out sequences of activities. The person may not have memory loss like other types of dementia (for example, Alzheimer's disease), however memory loss can develop with disease progression. Memory loss can also be an early feature in some people.

Lewy body disease is a neurodegenerative disease of ageing that causes gradual brain damage. It includes three overlapping disorders:

- Parkinson's disease
- Parkinson's disease dementia
- dementia with Lewy bodies.

It is associated with the presence of abnormal protein collections in brain cells. It is not known why this happens and there is currently no cure.

Dementia with Lewy bodies

Dementia with Lewy bodies is characterised by significant cognitive decline (changes to thinking) over 12 months that is typically associated with the presence of other symptoms that include periods of confusion/unresponsiveness (cognitive fluctuations), impaired physical movement (parkinsonism), visual hallucinations and dream enactment.

Parkinson's disease and Parkinson's disease dementia

Parkinson's disease is a movement disorder affecting someone's physical or motor ability. As Parkinson's disease progresses, many people develop cognitive impairment (changes in their thinking abilities) or dementia. This is called Parkinson's disease dementia.

Signs of Lewy body disease

Lewy body disease affects everyone differently and the symptoms change over time.

It can affect someone's ability to multi-task, plan and carry out sequences of activities.

Someone with Lewy body disease may:

- be apathetic (show no interest, enthusiasm or concern)
- find it hard to cope in noisy or crowded places
- have problems with spatial perception.

A person with Lewy body disease may have trouble with things they had done well previously, like:

- driving (particularly using roundabouts and busy intersections)
- managing the family finances
- fulfilling their role at home, work or in the community
- cooking
- gardening
- completing hobby activities (such as untangling fishing lines or knitting wool, fixing broken furniture, tinkering with cars or sewing).

If you usually see your relative or friend on their own, you may not notice anything is wrong. But if you see them at a party or in a crowded place, they may become anxious. Or they may be unable to keep track of conversations and socialise appropriately.

Other signs may be:

- changes in ability over days or even hours
- parkinsonism (a change in their walking pattern or increased stiffness)

- having visual hallucinations (for example, seeing other people in the room, or spiders on a tablecloth)
- disturbed sleep
- falls
- bladder and bowel accidents
- socially unacceptable behaviour, such as being rude.

Understand the illness

Talk things over with your relative or friend and their partner or main carer. Let them know you want to understand their situation and be supportive.

You could organise a one-to-one chat with the carer to find out how the illness is affecting your relative or friend. It will help if you prepare some questions to ask.

Everyone is affected differently. It is important to be aware that your relative or friend living with Lewy body dementia:

- may have insight into their condition and know what is happening to them
- may not have memory loss
- may remember their family and friends for a long time, even until the end of their life
- may be slow in considering what you say and responding, so slow down and take your time communicating with them
- may manage better if they have one-to-one time with you, rather than being in a group
- may say things that are hurtful or embarrassing
- may experience times throughout the day when they may engage as they always have in one moment and be agitated or aggressive in another moment.

Be flexible

You may need to change arrangements at short notice.

Rather than cancelling, ask if you can sit with your relative or friend at their home so that their partner or carer can have some free time.

Be understanding when arrangements need to change.

Be prepared

Accidents can happen and probably will. Here are some common ones:

- Spills and dribbles while eating and drinking. Offer a straw, spill-proof cup or other aids if appropriate.
- Falls when moving from sitting to standing. Encourage the person to take their time and use the support of a chair, table or car door.
- Falls when walking. Although it is instinctive to try to stop someone falling, you may hurt yourself if you attempt to catch them. Be prepared to call for assistance.
- Toileting accidents. If you are taking the person out, ask if you should travel with a pack containing wipes, bags and a change of clothes. You could also find out if there are accessible toilets where you are going, so you can provide assistance if required.

Be there for the person

Continue to enjoy your loved one's company. They will enjoy yours.

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