

Information for home care and community respite workers

This help sheet provides information about Lewy body disease. It will help you understand how the condition impacts someone living with Lewy body disease and how you can assist in their care.

Lewy body disease is a form of dementia that can affect someone's ability to multi-task, plan and carry out sequences of activities. They may not have memory loss like other types of dementia, such as Alzheimer's disease.

Lewy body disease is an umbrella term signifying there are underlying protein deposits in the brain. It includes three overlapping disorders:

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

Lewy body disease is a neurodegenerative disease of ageing that causes gradual brain damage.

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.

Someone with Lewy body disease may:

- show or feel no interest, enthusiasm nor concern
- find it hard to cope in noisy or crowded places
- may lack awareness of people, places or objects that surround them.

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
- cooking
- looking after their personal hygiene
- gardening
- enjoying hobbies
- being engaged in the lives of members of their family.

People with Lewy body disease can usually participate in rational conversation, but they may need extra time to process any directions or information and formulate their answers.

Other signs may be:

- changes in abilities throughout the day
- signs of parkinsonism (a change in their walking pattern or increased stiffness)
- having visual hallucinations (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.

How you can help

Get familiar with your client's individual needs

Not everyone is affected in the same way, but it is important to recognise that the person:

- 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 need time to think about what you say and respond, so slow down and take your time communicating
- may cope better having one on one time with you rather than being with a group of people
- may say hurtful or embarrassing things
- may vary in their abilities over a day or even hours; one moment they may engage as they always have and another moment they may not know who you are, where they are or be able to hold a conversation
- may be agitated or aggressive.

Be flexible

Ask for information about the client's symptoms that will help you deliver the best support. Provide reassurance that you understand the client's needs.

Consider that someone's main carer may find it difficult to:

- ask for help
- receive support
- discuss the symptoms of the person they are caring for.

Sometimes the carer needs to take time out for a coffee and a chat.
Some days that is more important than the client's shower.

Depending on your role, if plans need to change:

- Consult with the carer and client about how you can best assist them in the allocated time.
- If an outing was proposed, arrange in-home respite.
- Stay with your client at home so their carer can have some free time.
- If you are at a centre, allow your client to stay there with a carer.
- Record and report variations and the reasons for them to your supervisor.
- Discuss the information on this sheet with your colleagues and clients.

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.

Report changes

Notify your supervisor of any significant changes in your client's health and complete any incident and accident reports as needed.

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