

Information for acute care workers and staff in care homes

This help sheet provides information about Lewy body disease. It will help you understand how the disease impacts the person living with the condition 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 when someone has cognitive impairment before they develop motor problems (changes in their physical movement).

Someone being admitted to acute care may be presenting for the first time because of an acute episode. A person going into acute care or moving into residential care may have been diagnosed with dementia or Parkinson's disease.

Because the cognitive impairment in Lewy body disease is different from that in Alzheimer's disease, there may be some confusion with the diagnosis of dementia. For example, people with Lewy body disease can score well on the Mini Mental State Examination in the early stages.

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
- lack awareness of people, places or objects that surround them.

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.

As well as cognitive dysfunction, people with Lewy body disease exhibit motor, autonomic and neuropsychiatric dysfunction. Illness and the stress of coming into an unfamiliar environment may result in them becoming anxious or agitated.

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.

Progression of the disease

As the disease progresses, difficulty swallowing and the absence of the gag reflex can exacerbate aspiration pneumonia. As well as an inability to swallow, frequently the end stage is heralded by increasing falls and the loss of postural control.

In contrast to the slow, progressive end stage of Alzheimer's disease, people with Lewy body disease often experience acute episodes of ill health (during which their families advocate for active intervention), followed by recovery.

Medication: Warning

Sensitivity to antipsychotic medications resulting in neuroleptic malignant syndrome is a feature of dementia with Lewy bodies. Antipsychotic medications should not be prescribed unless unavoidable. If medication is unavoidable, consult a specialist, preferably a psychogeriatrician.

Research indicates that a positive response to cholinesterase inhibitors occurs across the spectrum.

Tips for managing admissions

Get familiar with the person's individual needs

To help support the person being admitted:

- Ask the person about their medical history, care needs and aids. Defer to the carer if the information seems incomplete or inaccurate.
- Talk with the person's family or their carer about how the condition is affecting each of them.
- Review the information on this help sheet with your colleagues.
- Discuss relevant topics on this help sheet with the person's family.
- Consider that carers may find it hard to talk about the person's medical condition or episode, particularly in front of their loved one.

- Consider that carers of someone who is coming in for an acute admission will often advocate strongly for active intervention and describe a connected, active and ‘well’ person prior to the onset of the presenting condition.

Consider the person’s health and ability

Someone with Lewy body disease may need extra time to process any directions or information and formulate their answers.

Not everyone is affected in the same way, but consider 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 be slow thinking about and responding to what you say (so slow down and take your time communicating with them).
- may have days where they do not know who you are, where they are or be able to hold a conversation. They may be agitated or aggressive. These are common reasons for admission into acute care and fluctuations can occur even when the patient is ‘well’.
- may need supportive aids and have individual care needs if they are going into respite care.
- may need continual assessments, including allied health assessments, because their health can deteriorate rapidly.

Be flexible

In acute admissions:

- If the patient is with a family member, encourage the person to stay with them and be actively involved in presenting information, even if the patient appears lucid and cognitively capable. If the patient comes in unaccompanied, establish contact with family as soon as possible.

In residential care:

- Try to be flexible. It may be necessary to change routines as you become familiar with fluctuations in a resident's behaviour and their preferences. For example, the resident may be able to walk independently, find the dining room and interact appropriately with other residents. In another moment on the same day, they may not know who you are, where they are, or be able to hold a conversation. They may become agitated or aggressive, even with family.

Be prepared

In acute admissions:

- Manual handling and falls assessments can vary from day to day.
- A patient assessed as requiring a hoist transfer may get up and walk independently.
- A patient capable of walking around may 'collapse at the knees' on standing, due to orthostatic hypotension.
- Neuropsychiatric symptoms and fluctuations are common.
- A compliant, engaged, reasoning patient can change and become disorientated, aggressive or delusional.
- Adverse reactions to neuroleptic medications can be life-threatening.
- Maintain the established medication regime unless the admission is for medication review.

Directives and information provided quickly in a noisy environment may not be understood.

- Monitor fluid balance.
- Monitor food ordering and consumption.
- Monitor the ability to use the call button.

In residential care, common issues include:

- Spills and dribbles while eating and drinking. Offer a straw, spill-proof cup or other aids if appropriate.
- Impaired swallowing. A speech pathologist's assessment may be required.

- 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.
- Bladder and bowel accidents. The person may not be able to reliably indicate the need to urinate or defecate. Assistance is often needed.
- Negative behaviours toward group activities. Group activities may overwhelm your resident. They may precipitate unwanted behaviours.

Supporting families

Establish a working relationship with the person's family. Support and encourage their involvement in their loved one's care. Encourage families to accept referral to appropriate services.

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