

# Lewy body disease information for acute care workers

This sheet is designed to give you some basic information about Lewy body disease and its associated disorders. It also gives you some tips so that you can assist both the patient and their carer during the stress of an acute admission.

## What is Lewy body disease?

It is a common neurodegenerative disease of ageing. This means that the disease causes gradual brain damage. It occurs when a protein (called alpha synuclein) collects in brain cells preventing them from functioning properly. It is not known why this happens and there is currently no cure.

Lewy body disease includes three overlapping disorders:

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

This overlap results in the disease being called a spectrum disease.

## Parkinson's disease

Most people understand that Parkinson's disease is a movement disorder affecting a person's physical or motor ability. It has been accepted for years that many people with Parkinson's disease develop cognitive impairment or dementia as it progresses. This is called Parkinson's disease dementia.

## Dementia with Lewy bodies

We now understand that sometimes the cognitive impairment begins before the motor problems and this is classified as dementia with Lewy bodies. The term 'dementia with Lewy bodies' is relatively new. It was first discussed in the medical literature in 1995, which explains why few people have heard about it, or understand what it means for the person diagnosed with this condition.

Your patient may have been given a diagnosis of dementia or Parkinson's disease or they may be presenting for the first time because of an acute episode. There may be some confusion with

the diagnosis of dementia because the cognitive impairment with Lewy body disease is different from that seen in Alzheimer's disease dementia. It is not uncommon for people with Lewy body disease to score well on the Mini Mental State Examination.

## What are the signs?

The dementia associated with Lewy body disease can affect a person's ability to multi-task and to plan and carry out sequences of activities. They can be apathetic, find it hard to cope in noisy or crowded places and have trouble with visuospatial tasks.

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. They may appear lucid on first contact but then lose the ability to keep track of conversations and interact appropriately.

Other signs that their carers may report include fluctuations, where a person has 'good' days and 'bad' days or hours and signs of parkinsonism (changes in gait or increased stiffness). Vivid visual hallucinations are a feature of the disease in most patients. Hallucinations in other modalities, delusions and depression are supporting diagnostic criteria for dementia with Lewy bodies.

As the disease progresses difficulty swallowing and absence of the gag reflex can exacerbate aspiration pneumonias.

**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 absolutely unavoidable. If medication is unavoidable, consult a specialist, preferably a psychogeriatrician.*

National Dementia Helpline 1800 100 500

[dementia.org.au](http://dementia.org.au)

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

## Managing acute admissions

### Understand the illness

Talk to any accompanying person and find out how the illness is affecting both the person and their carer. Carers find it difficult to talk about their problems in front of the patient. They will often advocate strongly for active intervention describing a connected, active and 'well' person prior to the onset of the presenting condition.

Do not rely on the patient being able to provide a complete or accurate history.

Not everyone is affected in the same way but it is important to recognise that, depending on their presenting state, your patient:

- may have insight into their condition – they know what is happening to them
- may not have memory loss – they are in the "here and now" and can follow their grandchildren's achievements or their favourite sporting events
- may know their family and friends for a long time – even until the end of their life
- may be slow in thinking about what you say and coming out with a response
- may fluctuate – on a bad day they may not know who you are, where they are or be able to hold a conversation. They may be agitated or aggressive. These states are common reasons for admission. The fluctuations occur even when the patient is 'well'.

### Providing acute care

If the patient has a family member with them encourage that person to be actively involved in presenting the information and remaining with the patient, even if the patient appears to be lucid and cognitively capable. If they present unaccompanied, establish contact with family as soon as possible.

## Resources

Parkinson's Australia is the peak body for advocacy and support of people with Parkinson's disease. Visit [parkinsons.org.au](http://parkinsons.org.au) or call **1800 644 189**.

US Lewy Body Dementia Association visit [lbda.org](http://lbda.org)

UK Lewy Body Society visit [lewybody.co.uk](http://lewybody.co.uk)

## Be prepared

Manual handling and falls assessments can vary from day to day.

- A patient assessed as requiring a hoist transfer may independently get up and walk.
- A patient who is capable of walking around may 'collapse at the knees' on standing due to orthostatic hypotension.

Neuropsychiatric symptoms and fluctuations are common

- The 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.

## Course of the illness

In contrast to the 'slow dwindling' 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. Frequently, the end stage is heralded by increasing falls, inability to swallow with a loss of the gag reflex and loss of axial control. Encourage families to accept referral to appropriate services.

## FURTHER INFORMATION

Dementia Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at [dementia.org.au](http://dementia.org.au)



Interpreter

For language assistance phone the Translating and Interpreting Service on **131 450**