

# Lewy body disease information for care facilities

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 resident and their carer to accept and enjoy their new environment.

## 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 resident may have been given a diagnosis of dementia or Parkinson's disease.

Dementia or cognitive impairment in Lewy body disease is different from that seen in Alzheimer's disease dementia.

### **What are the signs?**

Lewy body dementia affects everyone differently, and the symptoms change over time. It 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 problems with spatial perception.

On first impression, it may be difficult to identify any significant deficits in the resident's presentation. However, the stress of an unfamiliar environment with people they do not know may result in anxiety or agitation. They may lose the ability to keep track of conversations and interact appropriately.

Other signs that you may notice include fluctuations, where a person has 'good' days and 'bad' days or hours. There may be signs of parkinsonism (a change in their walking pattern or increased stiffness). A change of routine can result in an increase in their vivid visual hallucinations (they may tell you that their family has visited or that there are spiders on the tablecloths).

Other problems can result in disturbed sleep, falls, bladder and bowel accidents and what can be generally described as socially unacceptable behaviour (such as being rude or having lapses in personal hygiene).

## **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 postural control.

## **Tips for person centred care**

### **Understand the illness**

Talk to your colleagues and the family about the information on this sheet. Find out how the illness is affecting both the resident and their carer. Their carer may find it difficult to talk about their concerns. It is not unusual for patients with Lewy body disease to present with a low care assessment in the first instance.

On respite admissions ensure that you are aware of the resident's current care needs and the aids they need. Both will vary from admission to admission.

Continual assessments, including allied health assessments, are needed because the resident can deteriorate rapidly.

Be aware that your resident:

- 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 favourite sporting events or their grandchildren's achievements
- 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 – so slow down and take your time communicating
- may say things that are hurtful or embarrassing to other residents and staff
- may have fluctuations or good days and bad days

**Be flexible**

It is always difficult to be flexible in service delivery, but it may be necessary to change routines as you become familiar with the resident's fluctuations and preferences.

As an example, on a good day the resident may be independent in walking, find the dining room and interact appropriately, albeit slowly, with other residents. 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, even to family. Alternatively a bad day can involve total apathy and the resident may be unrousable.

**Be prepared**

Here are some of the common issues:

- Spills and dribbles with food and drink because of their visuospatial and motor deficits. Monitor and introduce aids as appropriate. Swallowing is often impaired and a speech pathologist's assessment may be required.
- Falls when moving from sitting to standing and when walking. Complete a risk assessment but also encourage your resident to maintain their mobility. Allow them to fall. In an attempt to catch them you may hurt yourself.
- Continence management is difficult because of the autonomic and physical deficits. However, your resident may be able to reliably indicate the need to urinate or defecate. Assistance is often needed so be alert to your resident's needs particularly if they appear to be independent.
- Group activities may overwhelm your resident. They may precipitate unwanted behaviours.
- Adverse reactions to medications - particularly antipsychotics. Even small changes to established drug regimes can destabilise people with Lewy body disease.

## Finally

Establish a working relationship with the family. Support and encourage their involvement in your resident's care.

### 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)

## 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)



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