

# Lewy body disease information for community respite workers

This sheet is designed to give you some basic information about Lewy body disease and its associated disorders. It will help you understand what is happening to the person being considered for your service. It also gives you some tips so that you can assist both the client and their carer.

## 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 (changes in thinking abilities) 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 client 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.

The person may have trouble with things that they had previously done well, like:

- Driving, particularly around roundabouts and through busy intersections. They may even have stopped driving.
- Managing the family finances, gardening, cooking or their personal hygiene.
- Being engaged in hobbies and their family's lives. Their preference may be to just sit in a chair and watch television.

If you see the person on a one to one basis in their home or your office you may not think anything is wrong. If, however, you place them in a busy activity room they may become anxious and agitated or lose the ability to keep track of conversations and interact appropriately.

Other signs that you may notice may 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).

They often have vivid visual hallucinations (they may see other people in the room or spiders on the tablecloth).

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). Their main carer may find it difficult to talk about the problems that they are dealing with. They may also be reluctant to ask for help.

## **What can you do to help?**

### **Understand the illness**

Talk to your colleagues and clients about the information on this sheet. Find out how the illness is affecting the client and carers. Show that you want to understand. Ask if they have other information that they wish to share with you that will make your job easier.

Not everyone is affected in the same way but it is important to recognise that your client:

- 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 – so slow down and take your time communicating
- may cope better having one on one time with you than being with a group of people
- may say things that are hurtful or embarrassing
- may have good days and bad days – 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.

### **Be flexible**

It is always difficult to be flexible in service delivery, but it may be necessary to change your plans at short notice if their carer tells you it is a ‘bad day’. If an outing is proposed then it may be more appropriate to try and arrange in-home respite for that day or allow the client to remain at your centre with a carer.

## Be prepared

Accidents can and probably will happen – here are some of the common ones:

- Spills and dribbles when eating and especially drinking. Ask if using a straw, spill proof cup or other aids is appropriate.
- Falls, particularly when moving from sitting to standing. Allow the client to take their time and encourage them to use the support of the chair, table or gait aid.
- Falls when walking. Allow them to fall. In an attempt to catch them you may hurt yourself.
- Bladder and bowel accidents. Take an 'in case backpack' containing wipes, bags and a change of clothes if you intend taking the client away from your facilities. Assistance may be required in the toilet.

Discuss the client's medication regime with their carer and supervise medications if they are scheduled whilst the client is in your care.

## Finally

Remember that the client's carer needs respite but will be extremely anxious about using it. Reassure the carer that you understand the client's needs.

People with Lewy body disease can usually hold rational conversations. They may need extra time to process any directions or information and formulate their answers.

### 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**