

Lewy body disease information for family and friends

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 someone you know and care about. It also provides some tips so that you can assist in their care.

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.

The person whom you know probably went to the doctor because someone in the family thought that ‘something was wrong’, or wondered if they had Parkinson’s disease or Alzheimer’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.

You may have noticed your relative or friend having trouble with things that they had previously done well, such as:

- Driving, particularly around roundabouts and through busy intersections.
- Managing the family finances or fulfilling their role at home, work or in the community.
- Completing hobby activities (e.g. dealing with the knots and tangles in knitting wool or fishing lines, fixing broken furniture, tinkering with cars or sewing).

If you usually see them on a one to one basis you may not think anything is wrong until you are with them at a party or in a crowded place. They may become anxious or 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). They often have vivid visual hallucinations (they may see other people in the room or spiders on the tablecloth).

Some problems can result in disturbed sleep, falls, bladder and bowel accidents and what can be described as socially unacceptable behaviour (such as being rude or having lapses in personal hygiene). Their partner or main carer may find it difficult to talk about some of the problems that they are dealing with. They may seem reluctant to ask for help.

What can you do to help?

Understand the illness

Talk to your relative or friend and their partner or main carer about the information on this sheet. Find out how the illness is affecting them. Show that you want to understand. Ask if they have other information to share.

Their partner or main carer may feel the need to maintain everyone's dignity. It is therefore important to organise a time to have a one on one chat with the carer. It helps if you have some clear questions to ask.

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

- 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 may be necessary to change arrangements at short notice if their partner or main carer tells you it is a 'bad day'. Don't just cancel. Ask if it would be OK to sit with your relative or friend at their home so that the carer can have some free time.

Understand that arriving late and leaving early to a celebration or a relaxed meal in your home is preferable to not coming at all. Accept the carer's judgement without pressuring them.

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 person to take their time. Encourage them to use the support of the chair, table or car door.
- Falls when walking. Allow them to fall. In an attempt to catch them, you may hurt yourself.
- Bladder and bowel accidents. Ask if you should take the 'in case backpack' containing wipes, bags and a change of clothes if you take the person out. Assistance may be required in the toilet so locate disabled toilets at your destination if you go out.

Finally

Continue to enjoy your relative's or friend's company. They will enjoy yours.

Resources:

Parkinson's Australia is the peak body for advocacy and support of people with Parkinson's disease.

Visit parkinsons.org.au or call **1800 644 189**.

US Lewy Body Dementia Association visit lbda.org

UK Lewy Body Society visit 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



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