

# Autonomic (involuntary) changes in Lewy body disease

This help sheet describes how Lewy body disease can cause changes in a person's autonomic abilities (when changes to the nervous system affects regular body functions). It describes common changes and strategies that can help.

- Lewy body disease is a neurodegenerative disease of ageing that causes gradual brain damage.
- It includes three overlapping disorders: dementia with Lewy bodies, Parkinson's disease and Parkinson's disease dementia.
- Lewy body disease can cause autonomic (involuntary) changes to the nervous system, affecting regular body functions.

## Autonomic changes

Lewy body disease can significantly impact a person's autonomic (involuntary) nervous system. This system automatically regulates bodily functions including:

- bladder and bowel function
- temperature regulation
- heart rhythm.

Changes in autonomic function can occur early in the disease and change with time. Some autonomic changes are so common that they are evaluated during a diagnostic process. Not everyone with Lewy body disease will experience all symptoms. Some common symptoms are described below.

## **Bladder function**

Difficulty urinating can occur. In men, this may be mistaken for prostate problems. Nocturnal polyuria is the need to urinate repeatedly at night (20 times is not uncommon). This disturbs the sleep of the person and their partner but is not regarded as incontinence. The combination of poor mobility and bladder overactivity should be monitored by a medical specialist as soon as symptoms start.

## **Bowel function**

Constipation or an urgent need to go to the toilet can occur. This can result in socially distressing situations. Bloating and nausea are other common gastrointestinal symptoms. Constipation is also a leading cause for confusion in those with more advanced disease.

## **Sexual function**

Changes in intimate relationships can occur early in the disease. Impotence appears to be more common than an increase in libido.

## **Temperature dysregulation**

Being unable to automatically regulate body temperature is common. It can result in shivering or perspiring, regardless of the environment temperature.

## **Cardiac symptoms**

Heart rhythm irregularities such as an irregular or rapid heart rate can occur. Cardiac symptoms require specialist assessment. Other symptoms, associated with an inability to control blood pressure, are:

- falls
- dizziness
- drowsiness
- short periods of unconsciousness.

## Recognising autonomic changes

Autonomic changes associated with Lewy body disease can be difficult to assess and treat, particularly if they are viewed in isolation in the early stages of the disease. If there are changes to normal function, it is always important to seek medical advice.

Some changes can be distressing, embarrassing or difficult for the person or their carer to manage. Often the person experiencing changes may not appear to be affected by changes at all.

It can help to have a family member or friend accompany the person to medical appointments. They can provide information to medical specialists, with the person's consent, and support the person during the appointment.

## Tips for managing autonomic changes

Autonomic changes associated with Lewy body disease require medical assessment and treatment. They can add to the impact of the disease and to carer stress.

Some ways to manage autonomic changes are described below.

### Medications

Medications are often prescribed for cardiac or urinary symptoms.

When new medications are prescribed, or doses altered:

- Monitor the person closely and report any changes in their condition to the prescribing doctor.
- Discuss the use of a tablet dispensing system (such as a Webster-pak®) to assist with correct self-medication.
- Support the person with their medication regime if the person is unable to self-manage.
- Limit the number of doctors and pharmacists prescribing and dispensing medications.

## Repeated urination at night

Needing to urinate repeatedly at night can lead to:

- sleep deprivation
- frustration
- carer burnout.

It is complicated by:

- the risk of falls
- low blood pressure
- visuospatial deficits.

It can be distressing for the person and unfortunately, the use of aids is often rejected.

Tips to consider:

- Accept that the person feels the need to urinate frequently.
- Make an appointment with your doctor to discuss possible reasons for repeated urination. It may be related to medication use or an unrelated health condition.
- Discuss the use of continence products with the person (such as pads, washable pants, spill proof bottles, bedside commode, urinary conveyer) to support a good night's sleep.
- Encourage independence by not assisting the person's return to bed.
- Leave a night-light on.
- Consider bathroom modifications early and install non-slip floors and coloured toilet seats.
- Contact the National Continence Hotline for advice.  
Call **1800 33 00 66**.

## Changes in bowel habits

Changes in bowel habits combined with cognitive and physical deficits can be difficult to manage in public and social situations.

Tips to consider:

- Arrange an assessment by a continence nurse and request a management plan.

- Follow a high fibre diet and work to an established bowel routine if possible.
- Accept that assistance with personal hygiene may be needed.
- In case of accidents, carry wipes, spare clothes and plastic bags.
- Plan ahead when travelling, Make a note of accessible public toilets on your trip route. If possible, avoid peak hour traffic and freeways.

## Erectile dysfunction

Whilst often neglected, specialist consideration should be given to the use of medications that can relieve this symptom.

## Additional reading and resources

- Dementia Australia has developed a suite of help sheets about Lewy body disease  
Visit: [dementia.org.au/help-sheets](https://dementia.org.au/help-sheets)
- Dementia Australia library service  
Visit: [dementia.org.au/library](https://dementia.org.au/library)
- Dementia Australia support  
Visit: [dementia.org.au/support](https://dementia.org.au/support)
- Parkinson's Australia  
Visit: [parkinsons.org.au](https://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](https://dementia.org.au)**