

# Managing sleep disturbance in Lewy body dementia



**The Lewy Body Society**

Shining a light on Lewy body dementia



**DementiaUK**

Helping families face dementia

# Managing sleep disturbance in Lewy body dementia

## Introduction

Problems with sleep are common in dementia. They affect approximately 40% of people with Alzheimer's disease and up to 90% of people with Lewy body dementia.

**Sleep disturbance can include:** difficulty falling asleep; difficulty staying asleep at night; restlessness during the night e.g. walking around, acting out dreams, movement disorders, being woken by dreams, hallucinations, needing to go to the toilet; and excessive daytime sleepiness.

Reduced activity and sleeping during the day can also lead to difficulties with sleeping at night.

Being disturbed at night on a regular basis can be very distressing and have a significant impact on the well-being of both the person with dementia and those caring for them.

In Lewy body dementia, sleep-related changes often occur months or even years prior to the onset of other symptoms.

## What does sleep involve?

Sleep is a natural state of rest occurring each night. It is essential in helping our mind and body to recharge.

Two main factors influence whether we feel tired and ready for sleep or awake and alert.

1. Our internal 'body clock', located deep within our brains, creates a 24-hour circadian rhythm that makes us feel tired or alert at regular times.
2. A chemical substance builds up in our brain when we are awake, creating 'sleep pressure' to fall asleep. The longer you are awake the more that chemical accumulates and the sleepier you feel.

### Melatonin

is a natural hormone that is released when it gets dark, to tell the body to prepare for sleep. Once sleep is underway, melatonin slowly decreases in concentration and production usually stops once the body notices it is light. As we age, the body secretes less melatonin which can affect sleep quality.

## A good night's sleep?

When we fall asleep our bodies follow a 90-minute sleep cycle that is broken down into 4 stages. During this cycle we experience two different types of sleep - Non-Rapid Eye Movement (non-REM) and Rapid Eye Movement (REM) sleep.

Stages 1 to 3 are non-REM sleep and the final stage is known as REM sleep.

<b>Stages</b>	<b>What happens?</b>
<b>Stage 1 (3-5% of sleep)</b>	Falling asleep - a very short light stage of sleep. You can be easily woken and may experience muscle twitching or jerks.
<b>Stage 2 (45-50%)</b>	A light sleep as your body is preparing for the deep sleep that is about to come. Your heart rate decreases, body temperature drops, and brain activity slows.
<b>Stage 3 (20-25%)</b>	A deeper stage of sleep when it is more difficult to wake. You may feel disorientated if woken from this stage of sleep. This is the most restorative sleep of all the sleep stages.
<b>Stage 4 (20-25%)</b>	Known as rapid eye movement (REM) sleep. During this stage of sleep our brain activity increases and it is when we are mostly likely to dream.

After going through all four stages, we move back to being more alert, and either wake up or move back into another sleep cycle.

A good night's sleep usually consists of four or five 90-minute cycles, whereas disturbed sleep consists of far fewer. The amount of REM and non-REM sleep we have can also change during each cycle. We need to experience all four stages in order to wake up feeling refreshed and rested.

**Stage 3** plays an important part in making us feel rested and restored. Sometimes you can appear to have had a good night's sleep, but don't wake up feeling refreshed. This could be a sign that you're not getting enough deep sleep.

### How sleep changes with age

As we get older some people can start to experience a change in the quality and duration of sleep and can experience the following:

- More frequent waking in the night.
- Needing to empty the bladder more often.
- Loss of non-REM Stage 3 sleep (which means sleep is less refreshing).
- Increase in daytime napping.
- Reduced drop in body temperature during sleep.
- Change in circadian rhythms and sleep pressure leading to earlier bedtimes and earlier wake-up times.
- Lifestyle changes – spending less time outside and reduced activity.
- Physical health problems such as pain, restless legs, incontinence.

## What causes sleep disturbance?

It is unusual for disturbed sleep to just have one cause; there are often several factors.

Common causes include pain, anxiety, low mood, noise, being too warm or too cold, or what we eat or drink prior to sleeping.

### Other causes include:

- Medication - sometimes medications used to manage conditions such as high blood pressure, diabetes or Parkinson's can make your sleep worse. Seek advice from the prescribing clinician if you are concerned about this.
- Inactivity - being inactive can lead to increased daytime sleeping; alternatively, being too active can cause over-stimulation, making it difficult to get to sleep.

## Dementia and sleep

In dementia, physical changes in the brain can affect how much or how well someone sleeps. A part of the brain called the 'supra-chiasmatic nucleus', which helps regulate sleep by responding to light, can be damaged. As a result people may be unable to follow a 24-hour sleep-wake cycle and instead sleep excessively during the day and sleep much less at night.

A syndrome that affects many people with dementia, particularly at dusk, is known as 'sundowning'. This is often caused by tiredness and changes in light which can lead to confusion, restlessness, agitation and distress.



## Lewy body dementia and sleep

In Lewy body dementia reduced levels of dopamine in the brain can disrupt the sleep-wake cycle. The presence of Lewy bodies (abnormal clumps of protein) in certain parts of the brain can result in a number of other symptoms which may affect sleep.

### Sleep-related changes in Lewy body dementia include:

- REM sleep behaviour disorder – known as dream ‘enactment’
  - in which the arms or legs move or thrash around while asleep.
- Parkinson’s related symptoms such as:
  - **Restless legs syndrome** – an overwhelming desire to move the legs when awake or resting, usually in the evening and at night. Symptoms include tingling, burning, itching and throbbing in the legs.
  - **Sleep apnoea** – when breathing momentarily stops during sleep and leads to waking up. Symptoms include loud snoring or choking noises while asleep.
  - **Stiffness and rigidity** – causing discomfort or difficulty with turning over in bed.
  - **Nocturia** – increased urination at night.
- Excessive daytime sleepiness – sleeping two or more hours during the day.
- Difficulty staying alert during the day and fluctuations in functioning.
- Apathy or lack of motivation leading to reduced activity levels.
- Insomnia – difficulty with getting to sleep or staying asleep.
- Not being fully alert when waking from sleep – feeling as though you are still in a dream on waking.
- Hallucinations – seeing or hearing things that are not real, or misidentifying objects in the dark.



## **REM sleep behaviour disorder**

REM sleep behaviour disorder (RBD) is more common in Lewy body dementia. This is one of the core symptoms and may have been present for several years before other symptoms appeared.

RBD takes place during 'rapid eye movement' (REM) sleep.

Normally during REM sleep, the body experiences temporary paralysis of the muscles while the brain is active and dreaming. This allows us to dream quietly and safely throughout the night. In RBD, paralysis does not occur. Instead, the body and voice act out dreams during sleep. Dreams may be very distressing and include fears of being attacked.

This can result in injury due to falling out of bed, banging into things or hitting someone whilst acting out the dream.

## **Parkinson's symptoms and sleep**

Disturbed sleep can be common in Parkinson's due to symptoms of rigidity, stiffness, restless legs, sleep apnoea and increased urination at night. Advice should be sought from a clinician about management of these symptoms.

Parkinson's symptoms can be worse during an 'off' period when the medication level is low. This may lead to stiffness, tremor, pain and difficulty with moving and turning in bed. If medication wears off during the night and causes problems, ask a healthcare professional to review the medication as slow release or longer acting medication may help.

## Apathy

Apathy, loss of motivation or difficulty with initiating activity can be experienced in Lewy body dementia due to changes in the brain.

Feelings of apathy can be overwhelming, making it hard to show interest or emotion in an activity. This may be frustrating for others but it is not deliberate.

### **The following may help:**

- Find tasks and activities that are more likely to be enjoyable, easy to do and feel meaningful.
- Use memories of previous enjoyable activities and talk through how it might feel to do them again.
- Plan the activity on a calendar, weekly planner or whiteboard and leave in a visible place – be realistic and don't try to do too much in one day.

## Cognitive fluctuations

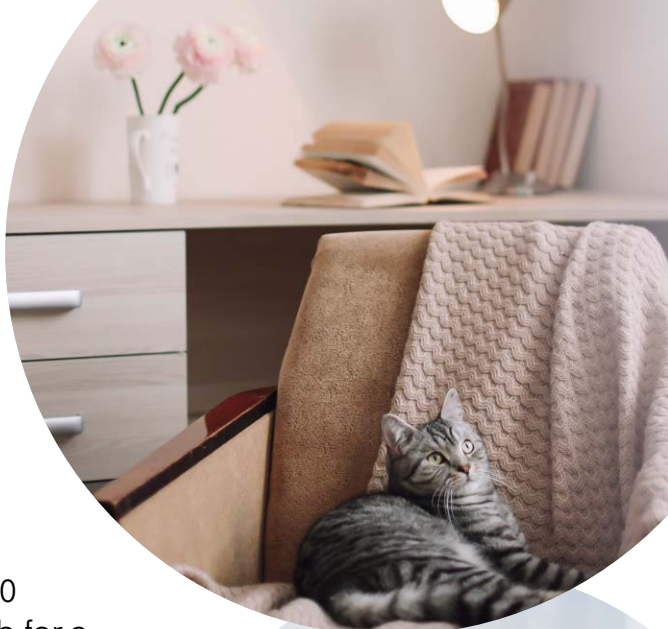
Fluctuating cognition differs from apathy. It involves spontaneous alterations in thinking abilities, attention and alertness. This can range from vacant episodes for a few seconds to being completely unresponsive for a period of time. Someone may look asleep, but it could be a fluctuation in cognition.

### **Is sleeping for short periods during the day i.e. napping, good for you?**

If you haven't slept well or are feeling tired, a planned daytime nap can help improve alertness, memory and relieve stress and fatigue.

## General napping rules

- The best time to nap is between 1pm and 3pm. This is when our sleep pressure has reached a peak and our sleep need starts to increase. Napping too late in the day, after 4pm, can impact on night time sleep.
- A power nap of 20 to 30 minutes can be enough for a recharge, but some people may need longer. If you feel groggy when you wake and it starts to impact on night-time sleep, you've napped for too long.
- If you're feeling tired but can't nap, use the time to just relax.



## Useful resources

The Sleep Charity  
[www.thesleepcharity.org.uk](http://www.thesleepcharity.org.uk)

Trouble sleeping? Every Mind Matters – NHS  
[www.nhs.uk/every-mind-matters/mental-health-issues/sleep](http://www.nhs.uk/every-mind-matters/mental-health-issues/sleep)

Living with Dementia Toolkit  
[www.livingwithdementiatoolkit.org.uk](http://www.livingwithdementiatoolkit.org.uk)

Dementia UK  
[www.dementiauk.org/good-habits-for-bedtime](http://www.dementiauk.org/good-habits-for-bedtime)

## Managing sleep disturbances

As sleep disturbances can have multiple causes, you may need to try a range of solutions.

The following sleep hygiene tips are recommended:

### Routine

- Create a daily routine with activities which are achievable.
- Allow time for rest.
- Create a relaxed night-time routine e.g. less stimulation such as screen time or vigorous activity before going to bed.

### Exercise

- Try incorporating some gentle exercise such as seated yoga or pilates at least 3 times per week, or a daily walk for 20 to 30 minutes.

### Exposure to natural light

- Daily exposure to daylight is beneficial, particularly in the morning. Sitting near the window or use of bright lights may help if getting outside is difficult.

### Environment

- Sleep in a cool, dark, quiet room on a comfortable, supportive mattress.

### Timing

- Try to go to bed at the same time each night and wake up at the same time.

### Fluids/drinks

- Limit drinking liquids a few hours before bedtime, avoiding caffeine, alcohol and sugary drinks in the evening.



## Medication

Some medications used for sleep disturbance can increase drowsiness and the risk of falls, so should be avoided if possible. Ask for a medication review to reduce any medications that can disturb sleep or increase daytime drowsiness. General sleep hygiene approaches should be tried first and advice sought from a clinician about specific sleep problems.

**For sleep-related disturbances in Lewy body dementia the following can be discussed with a doctor:**

- Cholinesterase inhibitors such as donepezil or rivastigmine can increase alertness so avoid taking them immediately before going to bed.
- For REM sleep behaviour disorder, melatonin or clonazepam in small doses may be tried to reduce night-time waking and disturbance.
- Parkinson's related symptoms such as sleep apnoea, restless legs, stiffness and rigidity and nocturia may be improved through adjustments in medication and/or lifestyle.

## Tips for people with dementia

- Follow the general sleep hygiene tips highlighted in the previous section.
- Try to avoid long daytime naps, i.e. more than one hour.
- Ensure the bedroom is as comfortable as possible:
  - Reduce noise or disturbance from pets.
  - Ensure a comfortable temperature.
  - Make sure it is not too light.
- Have a touch lamp and a visible clock next to the bed in case of waking to help with orientation.
- Use night lights in the hallway or bathroom to help with finding the toilet.
- Ensure you have the correct continence products if required. If necessary seek advice from a continence specialist.
- Try keeping a notebook next to the bed to write down any worries that may be keeping you awake.
- If you wake up and can't get back to sleep – get up for a short period and return when you feel sleepy.

**Remember to keep a sleep diary to monitor sleep, noticing any patterns and what helps. This should be brief and record general observations rather than a detailed account. An example can be found on the Sleep Charity website (see Useful resources on page 11).**

Gadgets or apps to monitor sleep such as watches, may be helpful in monitoring periods of restlessness especially if the person sleeps alone.

## Tips for family carers/friends

- Try to maintain a routine with regular bed and getting up times as well as regular mealtimes – this can help the body recognise when it should be awake or asleep.
- Encourage the person to go to bed when feeling sleepy – signs of sleepiness may include yawning, slowness, tired-looking eyes.
- If someone is thrashing around at night, it is important to protect both yourself and them from injury. Remove any nearby sharp edges and use pillows or padding to reduce harm. It may be necessary to sleep separately for a period of time as being rested yourself will help you to continue to provide care.
- If hallucinations occur, remove any items that may be misperceived, such as clothes on the back of doors.
- Avoid waking someone who is acting out dreams unless you are worried for their safety. This can disrupt sleep continuity and lead to sleep deprivation.
- Encourage daytime activities which are meaningful and achievable.
- Use night lights to help with orientation in using the bathroom and to reduce misperception of objects.
- If someone wakes up during the night and believes it is morning, try getting up. Do something quiet and calm with them, have a warm milky drink, then try repeating a shorter bed routine before going back to bed.

## Summary

Sleep disturbance is common in Lewy body dementia and can significantly affect health and well-being for people with dementia and their caregivers. Sleep-related changes often occur months or even years prior to the onset of other symptoms. In particular REM sleep behaviour disorder (RBD) is one of the core symptoms.

As sleep disturbances can have multiple causes, you may need to try a range of solutions. General sleep hygiene tips are important and keeping a sleep diary can help with identifying possible causes and monitoring different approaches. If sleep problems persist, seek advice from a healthcare professional and request a review of medication.

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If you would like to talk to a specialist dementia nurse about sleep disturbance, you can call the **Admiral Nurse Dementia Helpline on 0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm) or **email [helpline@dementiauk.org](mailto:helpline@dementiauk.org)**

To book a phone or video appointment with a dementia specialist Admiral Nurse in our virtual clinics, please visit **[www.dementiauk.org/book-an-appointment](http://www.dementiauk.org/book-an-appointment)**

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