

**Factsheet 534 Understanding sleep problems,
night-time disturbance and dementia**

January 2021

Understanding sleep problems, night-time disturbance and dementia



**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia



This factsheet is written for anyone caring for or supporting a person with dementia. It explains how dementia can affect sleep. It also suggests practical tips you can use to help the person you care for if they are struggling to sleep.

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1 Sleep, health and wellbeing

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A person with dementia needs regular sleep to stay well. Most adults need between seven and nine hours of sleep a night. Sleeping well helps a person to be in a better mood, think more clearly and maintain a healthy immune system. It can also help to prevent falls and accidents, and puts the body under less stress.

The body clock and sleep pressure

The two systems in the body that work together to control sleep are a person's body clock and sleep pressure.

Body clock

Our bodies sense natural light to know roughly what time of day or night it is. We also get a sense of time from routine daily activities, such as mealtimes, to create a sleep and wake cycle over 24 hours. This tells our brains when it's time to go to sleep (usually late in the evening) and when to wake up again (usually in the morning). The body clock of a person with dementia may become damaged, making it harder for them to feel awake and alert during the day, and sleepy during the evening.

Sleep pressure

Sleep pressure is the increasing need to sleep after being awake for a long time. The longer a person has been awake for, the more likely that they will feel sleepy, and the more deeply they are likely to sleep. As a person sleeps, the pressure to sleep gradually wears off and they become more likely to wake up. Some stimulants, such as caffeine, work by blocking the chemicals that make a person feel sleepy.

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How do the body clock and sleep pressure work together?

It's much easier for a person to get to sleep when they have built up lots of sleep pressure during the day, and their body clock senses that it's evening. This turns on both sleep systems at the same time, and should make the person feel sleepy at the right time. If the person doesn't feel sleepy at night, their body clock may not be working well. They may also not have been awake for long enough to make the body need to sleep (for example, if they have taken a nap in the day).

Another factor that can affect a person's sleep is patterns in their sleep during their lives. Some people will never have slept for long periods, and others may have had unusual sleeping patterns, such as working night shifts. It may be very difficult for a person to change their lifelong sleeping patterns to suit other people, such as the daily schedule of a care home.

A person who doesn't get enough good-quality sleep is likely to be tired, irritable, have a low mood and be less able to think clearly. It can also make them more likely to fall or have an accident. This can make caring for them more difficult.

Talking about the impact of caring for a person who has sleep problems can help. Talk to a friend or family member, or a professional such as a counsellor or dementia adviser. Call our Dementia Support Line on **0333 150 3456**. To talk to other carers, visit our Dementia Support Forum – go to **forum.alzheimers.org.uk**

If the stress of caring is making you unwell, talk to your GP. You should try to get as much good-quality sleep as possible. For more information see factsheet 523, **Carers – looking after yourself**, or for general information on all aspects of caring, including looking after yourself, see booklet 600, **Caring for a person with dementia: A practical guide**.

2 Sleep problems in dementia

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For a person with dementia, getting enough sleep can be a challenge. Sleeping well can be difficult for a person aged over 55, as the parts of the brain that control sleep may not work as well. An older person is likely to go to sleep earlier and may have difficulty sleeping through the night as much as they used to.

They may:

- have difficulty getting to sleep
- wake up several times during the night
- sleep less deeply
- sleep for less time overall.

As well as disruption to their body clock, a person with dementia may sleep more in the day and have difficulty sleeping at night. This process can start to happen even before a person has dementia, or if they have mild cognitive impairment (MCI). Some common reasons why the person may not have a good night's sleep are:

● Medication

It is common for a person with dementia to have other long-term health conditions, such as high blood pressure, diabetes or depression. Sometimes, the medicines used to manage these conditions can also make a person's sleep worse. They may also have health conditions that regularly wake them up in the night, such as being in pain or having urinary problems that require going to the toilet often.

● Melatonin

Dementia can affect the production of a sleep hormone in the brain called melatonin. This helps the person to feel sleepy when it gets darker in the evening. As a person's dementia progresses, their brain may make less melatonin, which makes it harder to fall asleep in the evening. This can be made worse by damage to the person's body clock, which means melatonin levels don't rise at the right time. Being in a bright environment during the day (particularly the morning), and a darker environment in the evening, can help to keep the sleep and wake cycle working as well as it can.

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● Not being active and engaged enough

A person with dementia can end up sleeping for long periods during the day if they don't have enough meaningful physical, mental or social activity to keep them active and engaged. You may find that they don't feel tired enough to want to sleep at night and probably won't sleep for very long if they do. Shorter sleeps tend to be lighter, so the person doesn't get the benefit of a sustained, deep sleep lasting several hours.

● Being confused in the night

When a person with dementia wakes up during the night, they may feel anxious or confused, and not know what time it is. Instead of going back to sleep, they may believe it is time to start the day, or that they need to be somewhere to do something important. For example, they may get dressed in the middle of the night in the belief that they need to get ready for work, or take their children to school. The person may try to go about an old routine, making breakfast and trying to leave the house for work. It can be stressful for you if the person is often awake and active during the night – particularly if you are worried that they might be doing something that isn't safe. For more information see factsheet 527, **Changes in perception**.

Support and care for a person with dementia and sleep disturbance

Sleep problems tend to become more common and more severe as dementia progresses. They can happen daily, and last for a long time. The growing exhaustion can affect the person with dementia and you, their carer. Over time the person may need more support, especially if your own sleep is often disturbed. If the person you care for is frequently up in the night, it may be possible to have a night sitter. This is a carer who will look after the person with dementia at night, to help you to have a good night's sleep. A person with dementia with severe sleep problems may need to be cared for by a live-in or visiting carer, or in residential care. For more information see booklet 689, **Care homes and other options: Making the decision**.

It is also very important to look after yourself and talk to other people about how you are feeling, as well as the impact on you. You could talk to a friend or family member you trust, or to a professional such as a counsellor or dementia adviser. You can call our Dementia Support Line on **0333 150 3456**. To talk to other carers, visit our Dementia Support Forum – go to **forum.alzheimers.org.uk**

3 Tips for healthy sleep

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A healthy sleep routine can help the person to feel better, be less confused, be more co-ordinated and have more energy in the daytime. They may also sleep longer with less disturbance at night. The following suggestions may help:

- **Treat any underlying conditions**

Many health conditions can make it harder to sleep. Reduce any pain or discomfort with painkillers, gentle heat or massage before bed. Ask your pharmacist if you are worried about medicines causing sleep problems.

- **Keep a routine**

Having a routine during the day and at bedtime can help when a person's body clock doesn't work as well as it should. Doing regular activities at the same time each day will provide a familiar routine that helps the person make sense of the time. Keeping a routine before bed should also encourage feelings of sleepiness. For example, have a warm caffeine-free drink, use the toilet, change for bed, wash and brush teeth, get into bed, and listen to something calming.

- **Spend time in natural daylight**

Going outside in the daytime, ideally in the morning, can help to set the person's body clock. They are more likely to feel sleepy during the evening. During the late evening, you can dim lighting to encourage sleep at bedtime (unless they are getting sleepy too early). If the person can't go outside in the daytime, you could use a lamp or lightbox that creates a bright indoor light. These devices have a similar effect to natural light on the person's body clock.

- **Engage in fun and interesting activities**

Activities during the day can help reduce daytime sleepiness. Being active can produce a satisfying feeling of tiredness that makes sleep easier at bedtime, and may also reduce feelings of anxiety and restlessness. Physical activities, such as walking and gardening, are particularly good for improving the quality of sleep. If the person can do these activities for at least 20–30 minutes a day, several times each week, this can help. Too much activity in the evening can keep a person feeling awake. For more on staying active and involved, see booklet 77AC, **The activities handbook**.

- **Avoid caffeine**

Caffeine is a stimulant that reduces feelings of sleepiness. It also makes a person need to go to the toilet more. As the effects last for several hours, it's best to switch to caffeine-free drinks from lunchtime onwards. This could be water, milk, natural juice, or caffeine-free tea or coffee.

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● **Avoid cigarettes and alcohol**

Smoking and drinking alcohol during the evening can make it harder to sleep properly. Nicotine increases a person's heart rate and reduces feelings of sleepiness. Although alcohol might make it easier to fall asleep, the quality of sleep is worse and the person is more likely to wake up in the night. Alcohol makes a person need the toilet more often, which can disturb sleep.

● **Avoid being hungry, thirsty or too full**

Eating a light meal several hours before going to sleep can stop a person being hungry in the night, or feeling too full to fall asleep. They should drink enough so they aren't thirsty, but not so much that they need to use the toilet during the night. Keep a glass of fresh water near the bed. If the person wakes up hungry in the night, milk or a yoghurt may help them feel better, but shouldn't stop them getting back to sleep. Avoid offering the person food in the night as getting used to this might mean they wake up because they are hungry.

● **Make the bedroom sleep-friendly**

The person's bedroom should be as quiet and as dark as possible. If they are afraid of waking up in the dark, or worried about finding the toilet in the night, a nightlight may help. The temperature should be relatively cool (about 18°C), but not cold. Keep a window open when it's not too cold, for fresh air. The bedroom should be uncluttered and the bed comfortable and supportive. Ideally it should be used only for sleeping in, or for sexual and physical intimacy. A dementia-friendly clock that displays 'night or day' can help the person feel less disorientated if they wake up during the night.

For more information on making adjustments around the home, see booklet 819, **Making your home dementia friendly**.

● **Reduce screen time**

The blue light from TVs, computers, smartphones, tablets and other electronic devices can affect the body clock and make it harder to fall asleep. Screen devices can also be overstimulating at a time when the person needs to relax. Reducing the time spent looking at screens towards the end of the day can help. If there is something they want to watch in the late evening, you could offer to record it for them.

● **Relax at bedtime**

During the late evening, try calming and relaxing activities that help the person get ready for sleep, such as a warm bath or massage.

4 Sleep problems and treatments

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GPs, and other healthcare professionals, can find sleep problems in dementia difficult to treat. This is because there may be many different causes, and because medication is not very effective as a treatment. However, you can help the person by supporting them with a healthy sleep routine.

All of the following types of sleep problems may be helped by following the advice in section 3 'Tips for healthy sleep' on page 5. These tips should always be explored thoroughly before trying medication. This is because medication is not very effective at improving sleep in dementia.

Speak to the person's GP or nurse if they have sleep problems that last for several weeks or more, and their sleep problem is causing them to become more unwell. You can also speak to the community mental health nurse. A nurse or GP will try to understand whether the sleep problem is being caused by something that can be treated with medicines or other therapies – for example, by increasing levels of pain medication, relieving anxiety or treating urinary problems. Keeping a diary of when a person is having sleep problems can really help a clinician to see what's happening. Some sleep disorders in dementia may need help from a specialist, such as a consultant geriatrician or old age psychiatrist. The GP can refer the person to a specialist. This may take some time, so try to see the GP as soon as you can.

Sleep medication is not recommended for a person with dementia. However, some doctors may suggest trying it for a short period if the sleep problem is severe, and non-medicine treatments have not worked. If the person does take sleep medication, they may become more confused and more likely to fall over the next day. Take extra care with them.

Sundowning

Sometimes, you might see changes in the person's behaviour in the later afternoon or towards the end of the day. During this time, the person may become intensely distressed, agitated and have hallucinations or delusions. This may continue into the night, making it hard for them to get enough sleep. This is sometimes known as 'sundowning', but it is not necessarily linked to the sun setting or limited to the end of the day.

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Sundowning can happen at any stage of dementia but is more common during the middle and later stages. The reasons why it happens are not well understood, but it is possible that a range of different causes make it more likely. These might include:

- tiredness, hunger, pain or other unmet physical needs
- not enough exposure to sunlight during the day
- overstimulation during the day, such as from a noisy or busy environment
- disturbance to the person's body clock caused by damage to the brain
- disturbed levels of hormones that vary over the course of the day
- sensory impairment, such as hearing or sight loss
- tiredness in other people causing the person with dementia to become upset
- mood disorders, such as anxiety or depression
- fewer carers around to look after the person (in a care home)
- side effects of prescribed medicines.

Some of these are related to the time of day, and others may happen at any time. Try to identify which of these problems might be affecting the person, as each problem may need a different treatment.

Sometimes, what seems like 'sundowning' could be the person trying to communicate a need. This could be needing the toilet, feeling hungry or being in pain. Think about whether something that's happened during the day has affected them. If they seem agitated, try to calm them by distracting them, perhaps talking about a favourite memory or event they enjoy thinking about. If they remain agitated, it could be that they have a need that is not being met. For more information on better understanding and communicating, see factsheet 500, **Communicating**.

Insomnia

Insomnia includes a wide range of sleep problems, such as taking a long time to fall asleep, waking up often during the night, having nightmares and waking up early in the morning. These result in the person not getting enough good-quality sleep.

Insomnia is a common problem for people with dementia, and different causes include the following:

- The person may be struggling with pain or discomfort.
- They may have other health conditions that make sleep more difficult, such as heart or breathing problems, heartburn, constipation, urinary tract infections or incontinence.
- They may be feeling anxious, stressed or depressed.

- They may be taking medications that cause insomnia as a side effect. This is common with medicines prescribed to improve dementia symptoms, such as donepezil, rivastigmine or galantamine. These medicines can also lead to very vivid dreams or nightmares. If this happens, they may find taking their medication in the morning rather than at bedtime helps.

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There are medicines that can help a person get to sleep more easily. However, most have unpleasant or potentially dangerous side effects, such as dizziness and an increased risk of falls. This makes them less safe for a person with dementia to take. They tend to only be prescribed for very short-term use when the person has severe sleep problems.

Excessive daytime sleepiness

Dementia can disrupt the body's normal cycle of day and night and the body clock. This means that many people with dementia feel tired and sleepy during the day. They may take many naps that then make it harder for them to sleep properly at night. The condition is common in people with dementia with Lewy bodies (DLB), Parkinson's disease dementia and the more advanced stages of Alzheimer's disease. It also increases the chances of the person having hallucinations and delusions.

For more information on hallucinations and delusions, see factsheet 527, **Changes in perception**.

The best way to manage excessive daytime sleepiness is through a healthy sleep routine (see page 5). These tips can be very challenging for you to follow if the person with dementia is exhausted from disturbed (or lack of) sleep. If this happens, it is better that they take one or two short naps for less than an hour each, ideally around the middle of the day. This should mean their daytime sleeping will not make it harder to go to sleep at bedtime.

Sleep-disordered breathing

Sleep-disordered breathing is a group of disorders that affect a person's breathing during sleep. The most common is obstructive sleep apnoea (pronounced ap-nee-a). While asleep, the person's airway collapses or narrows, causing loud snoring and preventing them from breathing properly. It's more common in people with Alzheimer's disease and vascular dementia.

Sometimes, a person with sleep apnoea may stop breathing for more than a minute. When this happens their oxygen levels can fall dangerously low, causing them to wake up suddenly and gasp for air. The condition can cause drowsiness, low mood and headaches when the person is awake. It can also contribute to dementia symptoms becoming worse.

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A person with sleep apnoea should see their GP as this can be a serious medical condition. They may find some simple changes help them sleep better. These include:

- sleeping on one side of the body
- not smoking or drinking alcohol before going to sleep
- not taking sleeping pills (unless prescribed by the doctor) as these can make the condition worse.

One treatment for sleep apnoea is continuous positive airway pressure (CPAP). A machine gently pumps air through a mask worn over the mouth or nose when the person is asleep. The CPAP mask can feel very strange and a person with dementia may not be able to tolerate it.

Restless legs syndrome

Restless legs syndrome is a condition where the person has a strong urge to move their limbs while they are awake and at rest. It is much more common at night. It can make falling asleep at night more difficult because the person cannot relax properly. They may have unpleasant sensations, such as aching or tingling, which only feel better if they keep moving. If they have difficulty communicating verbally, they may rub, tap or hit their legs to show you their discomfort. They may often feel the need to get out of bed and walk around at night.

Its cause is still not well understood, but the condition is common in people with dementia with Lewy bodies (DLB) or Parkinson's disease dementia. Other conditions may increase the risk of it, such as arthritis, diabetes, thyroid disorders, kidney problems and iron deficiency. It may be worse for people who take medicines for anxiety and depression.

Treatments include more physical activity during the day and a better sleep routine. Some people try massage, acupuncture or wearing a leg compression device. While there isn't enough evidence to show that they help, they might be worth trying if other treatments haven't worked.

The most common medicines for treating this condition are pramipexole, ropinirole or rotigotine. These need to be used carefully. They may make hallucinations or delusions worse in people who have pre-existing psychotic symptoms – particularly those with DLB or Parkinson's disease dementia. Taking a daily iron supplement may help to improve symptoms if the person has iron deficiency (which can be diagnosed by their GP).

Periodic limb movement disorder

Periodic limb movement disorder causes the person to unconsciously move their limbs – most often their legs and feet – while they are asleep. This movement causes the person to wake up often. Their sleep is interrupted, and they may not get enough deep sleep. The condition can occur more often in people with DLB or Parkinson's disease dementia.

Some medicines may cause periodic limb movement disorder, such as antidepressants, allergy medications, anti-sickness medicine and antipsychotics. If any of these are being taken by the person with dementia, then switching to another medicine may help to improve their sleep problems. Most doctors prefer to not treat this condition with medicines unless it is seriously disrupting a person's sleep. When medicines are used, they tend to be similar to those for restless legs syndrome (see page 10).

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REM (rapid eye movement) behavioural sleep disorder (RBD)

REM (rapid eye movement) behavioural sleep disorder (RBD) causes the person to physically act out their dreams when they go through phases of REM sleep.

Usually, muscles are paralysed during this type of sleep. However, for a person with RBD this doesn't happen. They may physically act out their dreams, which can sometimes be violent in nature and so their arms and legs may flail around. They may wake up suddenly and fall out of bed. If they are sleeping next to a partner, these involuntary movements can cause injury. As a result, many couples affected by RBD sleep separately. To help, mattresses can be placed around the bed to cushion the person if they fall out. Some people find sleeping on a mattress on the floor works best for them. Sharp objects should be removed from the bedroom. Some people find that they sleep better in a sleeping bag.

RBD is very common in people with DLB and Parkinson's disease, and is more common in men than women. It often develops several years before the person is diagnosed with dementia. When dreams are vividly unpleasant or violent, it can leave the person feeling drained and exhausted the next day. Usually, the person does not remember that these dreams happened.

The main medicines used to treat RBD are melatonin and clonazepam. Melatonin tends to be prescribed more for people with dementia, as clonazepam may worsen other symptoms of dementia and leave the person feeling drowsy during the day. It may also increase the risk of falling or developing sleep apnoea. Other medicines are sometimes used when neither melatonin or clonazepam improve the symptoms. However, there is not much evidence that they work.

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Other useful organisations

NHS Health Check

www.nhs.uk/conditions/nhs-health-check

The Health Check is a mid-life check-up for those aged 40–74, run by the NHS. At the check-up, a person's blood pressure, cholesterol and body mass index will be measured and results given, along with advice and support. This could reduce the risk of diabetes, heart or kidney disease, stroke and dementia.

The Sleep Apnoea Trust

www.sleep-apnoea-trust.org

The Sleep Apnoea Trust provides information and support for people who experience sleep apnoea, and their partners and families.

The Sleep Charity

01302 751 416

info@thesleepcharity.org.uk

www.thesleepcharity.org.uk

The Sleep Charity, incorporating The Sleep Council, provide advice and support to empower the nation to sleep better. They campaign to improve sleep support and access to high quality information, raise awareness of the value of a good night's sleep and promote understanding around the complexities of sleep.

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This factsheet has also been reviewed by people affected by dementia.

To give feedback on this factsheet, or for a list of sources, please email **publications@alzheimers.org.uk**

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At Alzheimer's Society we're working towards a world where dementia no longer devastates lives. We do this by giving help to everyone who needs it today, and hope for everyone in the future.

We have more information on **Symptoms and treatments**.

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit alzheimers.org.uk

Thanks to your donations, we're able to be a vital source of support and a powerful force for change for everyone living with dementia. Help us do even more, call **0330 333 0804** or visit alzheimers.org.uk/donate



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Together we are help & hope
for everyone living with dementia