

Sleep and dementia

Sleep

Sleep plays an important part in keeping our brain healthy and performing to the best of its ability. During sleep, our brain cleanses itself of waste toxins built up during the day and forms new long-term memories and networks. Without enough sleep, we all find it harder to remember, concentrate and function well.

How much sleep we need varies from person to person, but the average is 7 hours each night.

There is a wide range of issues that can lead to sleep deprivation. The most common are listed below:

Nocturia

One of the most common causes of disturbed sleep is increased nighttime urination, also known as nocturia. This is very common, with about half of over 60s experiencing it at some point. There are many causes, such as drinking too much in the last two or three hours before bed and drinking caffeine or alcohol in the afternoons and evening. However, nocturia can also be symptomatic of other diseases/illnesses, and requires proper medical investigation

Chronic Obstructive Pulmonary Disease (COPD)

COPD can cause people to wake during the night feeling breathless. COPD is also very common, particularly for smokers and ex-smokers.

Sleep apnoea

If a person experiences sleep apnoea, their breathing can stop and start throughout the night, causing them to wake. This can happen many times per hour/ per night and the person may not be aware of it – but it can lead to tiredness the following day. Signs include loud snoring or snorts as the person gasps for air, morning headaches or fatigue.

Insomnia

Finding it hard to go to sleep or waking up during the night and struggling to get back to sleep is called insomnia. This is a common disorder that can be caused by worry, stress or environmental factors like noise, feeling too hot/cold, feeling uncomfortable, or the effect of substances on our bodies like caffeine, alcohol or nicotine. Treatments for insomnia include cognitive behavioural therapy and acupuncture.

Restless legs syndrome

This causes strange sensations in the legs including tingling, crawling, cramping or burning which can be relieved a little by rubbing or moving them. The episodes usually start in the evenings and can be very disruptive to normal sleep.

Long term pain, constipation and dehydration

- **Pain** – This can be a common and sometimes overlooked problem particularly for people who are living with dementia. As dementia progresses, a person's ability to recognise and communicate pain can be affected. They may attribute pain to a different part of their body or may tell you they don't feel pain. However, this is not always the case, and some people can be significantly affected. Signs may include difficulties getting to sleep and frequent awakenings, avoiding some movements, rubbing, hot or swollen areas, shouting out, pushing carers away, increased confusion and distress.
- **Constipation** – is described as moving bowels fewer than 3 times a week. Constipation can affect mood, increase inflammation and cause pain and discomfort. Going backwards and forwards to the toilet, being unsettled, stomach pain, and a faecal smell to the breath are all signs to look out for. Keeping a bowel movement record might be helpful too. Sometimes people who are constipated will pass watery stools referred to as bypass so if you notice this, or any other signs, contact their GP for treatment. Constipation can be linked to delirium and should be treated quickly. It can be particularly common in people who have dementia with Lewy bodies.
- **Dehydration** – can be more common as dementia progresses. People may need more support, prompts and encouragement to drink. A telltale sign of dehydration is dark urine, with other symptoms such as a dry mouth, increased confusion, dizziness, fatigue and a headache also common. Leaving drinks directly in front of the person in a brightly coloured beaker can act as a prompt but be aware that tastes can change due to dementia and people may now prefer different drinks to those chosen in the past. It can also be helpful to have fruits available if swallowing is not an issue, as well as jellies and jelly sweets.

Dementia

Dementia can affect all aspects of daily living and issues with sleep can be very common.

Long term memory loss and time slipping

As dementia progresses, some people may no longer remember the later parts of their life and may believe they are living in much earlier times. For example, they may believe they live at home with their parents, they have jobs to go to or have a young family. This can make it difficult for someone to settle, particularly if they feel they are in the wrong house and that other family members are waiting elsewhere for them. If this is the case, it is important to try to stay calm and to reassure the person. Your own distress at being woken in the night can very quickly be picked up by the person and the situation can escalate. If you feel frustrated, annoyed and worn out, it can be very hard to cope but if you can, take a moment and a deep breath. Try to present a calm exterior – it may help to get the situation resolved quicker. Shouting or telling the person off will almost always make things worse.

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Listen carefully to the person and try to understand what it is they really want. Are they feeling frightened or do they want the safety of somewhere or someone familiar? If this is the case, being with them, talking to them and reassuring them may work. Can they be reorientated? If you tell them they are at home with you, you are their husband/wife, partner etc, do they accept and understand this and calm down?

If you know that this will not work, and that they believe they are in the wrong place and urgently need to go elsewhere, it might be pointless trying to talk them round as it may only cause increased distress and conflict. It's important to calm the situation as quickly as possible, so avoid anything that may lead to escalation. It can help to use a soft and calm tone of voice to reassure the person you are listening to them.

Sometimes, a distraction can help. The person may want to 'go home'; so instead you might suggest that because it is cold and dark outside, it is fine for them to stay where they are for now, perhaps with a warm drink and a biscuit. Try to refocus the person on having a drink and a friendly chat. Once calm, avoid mentioning any aspect of the earlier distress as you could reignite the idea and cause further upset.

The last thing to try is to acknowledge what the person wishes to do but explain that the person they wish to see for example, is busy, and they can see them later. This may feel deceitful – and it is a last resort – but there is nothing to be gained from telling someone who desperately wants to see their mother that she died many years ago. If they have not been able to hold onto this information, telling them of their passing could cause them shock and great distress. It is kinder to acknowledge their feelings but advise it is not possible just now. Some people's ability to recall major life events can vary, so you would only use this technique if the person is unaware the person they are looking for has passed. If someone can be reorientated that should be your first response.

Orientation on waking

Some people who are living with dementia will experience difficulties orientating themselves when they wake, particularly if they are woken up. Waking the person up might be necessary if you have places to go and things to do, but be aware that for some people, this can cause distress and confusion for a few moments. Try to give them time to come round gently before asking anything of them.

Changes in daylight

Disorientation of time can cause people to go to bed very early in the day or get up very early in the mornings. This can be a particular problem when environmental clues change, for example when the clocks change, and around the summer and winter solstice when daylight hours are very short or long.

It is thought that one of the best ways to maintain your normal body clock is to go outdoors in the mornings– getting some early sun, even on cloudy days, is thought to help maintain normal sleep wake cycles. If this is not possible, sitting by a window or using daylight lamps may help. Exercise so that the body and mind tire is also thought to help, for example going walking or joining social groups.

Closing the curtains or investing in black out blinds or linings may be helpful if the home is very bright during the late evenings of the summer months and using additional lighting can help during the winter.

As dementia progresses people tend to sleep more, day and night. They may need to rest after being supported to wash and dress, eat, and take part in social activities. If they are sleeping a lot during the day and all night, you may wish to speak with your GP about supports to prevent pressure sores.

People who have dementia with Lewy bodies may have additional issues with sleep. Vivid dreams, nightmares, and sleep talking or thrashing arms can be associated with this disease.

How to promote good restorative sleep

- If there are any underlying issues, such as those listed in the first section of this information sheet, it's a good idea to have them properly assessed and treated
- Go outside, even on dull days, as this can help regulate a person's body clock, and exercise has a positive effect on sleep. Feeling physically tired helps sleep
- Establishing a routine is helpful, particularly for people who are living with dementia. For example, going through the same bedtime routine at the same time each night can be beneficial
- Get up and go to bed at the same time every day. Some people set an alarm to wake up and another to get ready for bed
- Try to have your main meal in the middle of the day rather than the evening
- Make sure the person's bed is as comfortable as possible, that the mattress supports them well and that they are not too hot or cold during the night
- Keep the bedroom dark at night to aid sleep. Use curtains or black out blinds
- Try relaxation techniques and Cognitive Behavioural Therapy (CBT). If you, or the person with dementia, struggles to unwind and relax at night, try some simple breathing techniques, CBT or mindfulness. Breathing techniques are very simple but effective. Try breathing in slowly through the nose for the count of four, holding your breath for a count of four, breathing slowing out through the mouth for a count of four, then resting for four, repeat. Slowing your breath helps to calm you quickly and counting refocuses your thoughts. Another suggestion is to write down anything that is worrying you on a notepad and set it aside to be dealt with later. Set a time in your day when you are usually able to take a few minutes out and think about the issues then. You may not be able to solve them immediately but set aside time to add anything new to the notepad, training yourself to only think about the issues then. Over time, this should help you switch off and sleep better.
- Avoid watching TV or looking at a phone or tablet immediately before going to bed as the light from these devices can keep you awake.