



# COMMUNICATION AND SLEEP IN DEMENTIA

**A GUIDE FOR FAMILY AND  
FRIENDS WHO LOOK AFTER  
A PERSON WITH DEMENTIA**

# COMMUNICATION IN DEMENTIA

**Dementia brings changes to the brain that can impact memory, language and comprehension making communication challenging for both people living with dementia and their carers. This can result in misunderstandings about what was meant leading to frustration on both sides.**

When we communicate with family and loved ones, we share many years of relational history that provides a shared context, which gives meaning and purpose to our conversations. This includes the time, season and even places in which our conversations take place.

Initially the person with dementia may find it difficult to comprehend the date and time, but gradually, overtime their ability to communicate will change and they will need more help to navigate a conversation. People with dementia may also experience time shifting, and have difficulties hearing and seeing which can make communication more challenging. This can lead to times of confusion, and frustration for you both that can cause anger, disappointment and embarrassment. But starting each communication as an opportunity to connect, understand and support the person with dementia through observing and entering their world is a skill that can be developed. Combined with the communication tips below this can help prevent potential negative communication cycles.

Remember it's the dementia that makes communication difficult rather than the person living with dementia. So any sudden behaviour changes, such as rudeness, anger, impossible requests and sentences you can't understand - while challenging- are a symptom of dementia not the individual.

If you can learn to name whats happening, and understand why - this will help to reduce your frustration. It will also enable the person with dementia to feel supported in their communication with you. This is vital to reduce any anxiety and frustrations they may feel when communicating with you. Finally when reading and implementing the communication insights in this booklet be patient and kind to yourself. It takes practice to step back, breathe and observe your loved one before responding. We are all imperfect humans being human and have good and bad days.

**“ I try to listen carefully enough to understand what causes the changing behaviour problems and work out how best to diffuse the situation**

**Carer of a person with dementia**



## Communication challenges between carers and people with dementia

<b>Challenge</b>	<b>Possible solution</b>
Difficulties with hearing or seeing clearly.	<p>Check if the person is wearing their hearing aids correctly and batteries are working. Check if their glasses are clean and they are wearing their most recent prescription.</p> <p>Find the best position for them to see your face clearly to lipread and interpret your facial expression and body language cues. Avoid standing directly in front of bright windows or lights that could overshadow you.</p> <p>Don't be afraid to slow down, pause, breathe and relax your body and face before continuing to communicate. This will cue the person to your calming presence and help them to relax too.. It can also help to project your voice, and speak more slowly and simply.</p>
Struggling to find the right word. For example saying <i>fire</i> instead of <i>birthday candle</i> .	<p>Slow down, take a breathe and pause to find the meaning behind the words the person you are listening to is using.</p> <p>Try not to speak over or correct the person you are listening to.</p>
Difficulty storing information about recent events. People may ask questions to help them to rebuild the information that's missing.	<p>Slow down, take a breath and pause. Check your body language and facial expression. Practice a half smile if you are feeling stressed so that the person can receive your message in a non-confrontational way.</p> <p>Remember, the person you are speaking with may be confused and trying to gather information to make sense of their surroundings. It can be helpful to keep notes or a memory book to help empower the person you're caring for to clarify information without having to ask you.</p>
Forgetting who people are.	<p>It can be very upsetting if the person you care for forgets who you are. At first, this is likely to be temporary, but over time the person you care for may be less able than before to put a name to your face or recall the relationship. This is due to changes in the brain that affect how they perceive and experience the world, which can result in hallucinations, misinterpretations, delusions and time-shifting. This is why developing a calm and safe presence for a person with dementia is so important.</p> <p>Giving reminders and cues can be very helpful. It can be helpful to write names by photographs and to introduce people within conversations. For example, you might say my brother Dafydd rather than 'Dafydd'.</p>
Difficulty producing and understanding spoken language.	<p>If this happens, then touch (such as a hug or holding hands) can give mutual comfort. It can also be helpful to have memory books to share or to do something with the person you care for that you both enjoy, such as singing.</p>

## Challenge

Difficulty in understanding

## Possible solutions

To help a person with dementia, you can use the names of people, objects and activities more often, instead of, *she, them, that* and so on.

Try to avoid questions that need context such as *'did you have a nice time this morning'*. Switch it to *'did you have a nice time when you went to the garden centre this morning?'*

Using the context around you may help you recognise what the person with dementia is referring to. If they can't recall information, they may rely more on what they can see and hear, or on memories from long ago that they can recall more easily.

Also, keep in mind that they may not be able to estimate what you already know, so they might assume you already know what they are talking about. Rather than getting frustrated, you could try checking out possibilities, such as saying *'oh, are you talking about Ellen's wedding?'*

Use your knowledge of their personality and life to help you. It will often be easier for you to try to navigate their thought patterns, than for them to make sense of yours. Keep in mind that new contexts are more difficult to process, so keeping to routines can help. This doesn't mean you can't go out to more than one café, but it's worth noticing if the person is more settled and willing to engage in conversation when it's a place they've been to before (even if they don't recall being there).

If you want to generate a positive conversation, then try visiting a familiar place or a museum. Alternatively, look at books or family photos with them that encourage conversation about their life and experiences. This also reinforces their sense of personal identity. Try to avoid questions, instead make comments, as these are easier to respond to. Instead of saying *'do you remember that?'* and *'what was that called?'* say things like *'ooh, look at that!'*, and *'that looks interesting'*, and *'I wonder how long it took to do the washing in those days'*. This allows the person an opportunity to respond or not and avoids any pressure of forcing them to reply.

## Challenge

Frustration

## Possible solution

To help minimise frustration, it's important to reassure the person with dementia and give them the time they need to express themselves. Try not to dismiss their words even if they don't appear to make sense and consider what might be behind what they are saying.

There may also be times when their reality of events is different to yours. They may not remember a loved one has died or believe they are living at a different time or something has truly been stolen. It is kinder to accept and enter their reality and listen to any hidden meaning in their words.

This is difficult because your relationship is changing and you may no longer be able to share frustrations and disappointments as you once did. So building a support network and finding people that you can trust to share the daily frustrations and challenges of caring as well as exchange communication tips is vital.

Remember to reach out for advice from professionals and peers and give yourself the time to take a breath and get some space.

Don't assume yesterday's challenges will repeat themselves. Dementia symptoms can vary from moment to moment. It's worth trying again.

Some of the information in this chapter draws on a presentation by **Professor Alison Wray**, Cardiff University, that you can watch on Youtube using the link provided in the footnotes in which she introduces her book *The Dynamics of Dementia Communication* (OUP, 2020).



[www.cardiff.ac.uk/people/view/99217-wray-alison](http://www.cardiff.ac.uk/people/view/99217-wray-alison)

[www.youtube.com/watch?v=ZIMsN-\\_KG3k&feature=youtu.be](https://www.youtube.com/watch?v=ZIMsN-_KG3k&feature=youtu.be)

## Sleep

People with dementia can have disrupted sleep patterns. There are many possible causes, from medical issues to being disturbed by bright lighting in a bedroom

### Possible impact of dementia on sleep

- Less sleep overall.
- More sleep in the daytime and more energy at night.
- An inability to differentiate between night and day.

### Possible causes for changes in sleep patterns related to biology

- Damage to the part of brain that manages our natural clock (circadian rhythm).
- Illnesses or pains unrelated to dementia (such as urinary tract infections or depression).

### Possible causes for changes in sleep patterns related to the comfort and suitability of a person's bedroom

- Feeling too hot or cold at night.
- Feeling disorientated in their bedroom.
- Struggling to find the toilet during the night.

There may be some trial and error involved in finding out the causes of sleep disturbances.

As a carer, if your sleep is interrupted regularly, you will struggle to get enough rest and this can affect your mood and well-being during the day.

Speak to a health professional if you are concerned about the sleeping patterns of the person you care for, or how lack of sleep is affecting you.

## Ideas to help manage problems with sleep

- Plan physical activity for earlier in the day.
- Avoid caffeine from late afternoon onwards.
- Make the bedroom a comfortable temperature.
- Have appropriate lighting. Unsuitable lighting and mirrors in the room may dazzle or confuse someone with dementia when they wake up at night. Read more on [www.nhs.uk](http://www.nhs.uk)
- Consider **telecare equipment** that can wake you if needed.
- Ask a family member or friend to occasionally take over your caring role overnight.
- Have a carer's assessment as this can look at how much sleep you get and you may be entitled to financial help to access overnight support from care workers.

### Further information on sleep

[www.dementiauk.org/sleep-deprivation-dementia](http://www.dementiauk.org/sleep-deprivation-dementia)

[www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/sleep](http://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/sleep)

[www.nhs.uk/live-well/sleep-and-tiredness/how-to-get-to-sleep](http://www.nhs.uk/live-well/sleep-and-tiredness/how-to-get-to-sleep)

## Restlessness

Pacing, night-time agitation, anxiety and purposeful wandering are common behaviours in certain types of dementia.

### Possible reasons for restlessness

- A person with dementia may find it difficult to communicate their needs. They may be feeling bored, anxious or in pain.
- Confusion and disorientation can mean a person with dementia may feel they need to be somewhere else. This may be particularly noticeable at dusk and is known as 'sundowning'.
- Trying to find someone or something from the past.

### Ideas on how to manage restlessness

- If you are able to provide a safe space to walk, such as a secure garden, there is no need to ask the person with dementia not to walk around.

- Speak and listen to the person with dementia to reassure them that they are safe.
- Remove items such as coats, handbags and shoes away from the door as these may encourage a person with dementia to attempt to leave. You can also try covering a door with a curtain and installing an automatic locking door for safety at night.
- Speak to a professional about how **assistive technologies** could help you and the person you care for. For example, a tracking device.
- The Herbert Protocol form helps police identify vulnerable adults if they go missing. For further details see the footnotes below.

People with dementia can carry a **helpcard** or wear an **Alzheimer's pin badge**. You can find out more about these on [Alzheimers.org.uk](https://Alzheimers.org.uk)



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<https://safeguardinghub.co.uk/dementia-the-herbert-protocol/>

