

Understanding restlessness



Many people with dementia experience restlessness, including fidgeting, pacing and trying to leave the place where they live. This can be upsetting for the person with dementia – especially if they are prevented from moving around – and for family members, who may worry about the person's wellbeing and safety.

Restlessness can occur for many reasons. Here, you can read about some of the possible causes and ideas to help you manage it.

Hunger or thirst

People with dementia may forget to eat or drink, or not recognise the signs of hunger or thirst. These tips might help:

- Offer smaller portions or snacks like 'finger food' if the person does not want to eat full meals or sit at the table
- Eat a snack or meal together as encouragement
- Make sure there is always a drink close at hand, and encourage them to take sips
- If the person does not like drinking water, provide squash or juice instead
- Keep caffeinated drinks to a minimum as these may increase restlessness
- In the later stages of dementia, when chewing and swallowing may be affected, use ice chips or artificial saliva to stop the person's mouth becoming dry and uncomfortable

Please see Sources of support on p14 for details of our leaflet on eating and drinking with dementia.



Being too hot or cold

- Set the heating to a comfortable temperature – 18-21 °C is ideal
- Leave a blanket within reach that the person can use if they are cold
- Help them choose appropriate clothing for the weather – giving an ‘either/or’ choice can help. People with dementia sometimes get confused about what they should wear and when
- Ensure they have the right bedding to keep comfortable at night
- Consider offering a hot water bottle, heated blanket or microwaveable heat pack, but ensure the person is supported to use these safely – if they use them to warm their bed, remove or switch them off before they get in

- In hot weather, offer drinks regularly and open windows. If you are concerned that the person may try to get out through a window, you could use window locks that stop them being opened fully or use an electric fan or air conditioning unit
- In sunny weather encourage the person to sit in the shade and wear a sun hat

Pain

Pain is a common reason for restlessness, so think about what might be causing the person discomfort – especially as many people with dementia also have other conditions alongside like arthritis, joint pain, heart conditions, stomach or bowel problems, or dental issues.

- Ensure the person takes any medication as prescribed
- Keep up with regular health checks with their GP and other healthcare professionals, including sight and hearing tests to detect any vision problems, eye strain or hearing difficulties that may be causing discomfort or distress
- Support the person with a mouth care routine to prevent oral pain. For details of our leaflet on mouth care, please see Sources of support on p15
- Make sure the person's chair and bed are comfortable. You could use pillows or pressure-relieving cushions to position them, especially if they spend long periods sitting or lying down; or consider adaptive furniture that helps them sit or stand
- Encourage movement – even if just walking around the room – to prevent discomfort or pressure sores
- Help them to stand every hour or so to relieve the pressure on

their sacrum (the bony area at the base of the spine)

- Make an appointment with the GP if you believe the person maybe in pain to discuss treatments and/or pain medication
- A pharmacist can also advise on over-the-counter pain relief

For our leaflet on pain and dementia, please see Sources of support on p15.

Bladder and bowel problems

- Encourage the person to eat a balanced diet with plenty of fruit and vegetables and regular drinks, and to move around, if possible, to prevent constipation
- Look for signs of problems like a urinary tract infection (UTI) or constipation – for example, needing the toilet more often, or pain while passing urine or opening their bowels. Make a GP appointment if you have concerns
- Ask the person regularly if they need the toilet and support them if necessary – they might need help locating the bathroom, for example, especially in an unfamiliar environment, or if all the doors in their home look similar
- Leave the toilet door open and the light on at night
- Look for non-verbal signs of needing the toilet, such as holding their crotch or stomach or fidgeting in their seat
- If the person experiences incontinence, make sure they are wearing the right protection to keep comfortable, and help them change as necessary to prevent leaks or discomfort

For details of our information on continence, please see Sources of support on p14.

Boredom

- Support the person with dementia to have a change of scene. You could go out for a walk, sit in the garden, play some familiar music as you walk around the home together, or just move to a different room
- Find meaningful activities to engage in. This could be anything from voluntary work in the early stages of dementia, to helping in the garden or kitchen, to doing jigsaws or simple crafts
- Encourage visits from friends and family, but do be aware that some people with dementia may be unsettled by unexpected visitors – it may be best if people do not drop in without advance notice
- Look for new opportunities for social contact and mental and physical stimulation, like support groups for people with dementia and their carers, day centres, memory cafés and singing groups

Anxiety and distress

It is often thought that people with dementia do not experience anxiety or depression, but this is not the case – they may just not be able to express how they are feeling.

If the person often seems anxious, distressed or depressed, it is worth making an appointment with their GP to discuss what might help. For more information, please see Sources of support on p14.

These tips may also help:

- If the person is in unfamiliar surroundings and this is making them anxious, try to return to a familiar environment
- If this is not possible, providing a safe, quiet space – for example,



a spare room in the house they are visiting – with something familiar like their own blanket or cushion may help them feel safe

- Ask the person how they are feeling and listen carefully to their answer. Even if they cannot fully express their emotions, being asked may validate their feelings and ease any anxiety
- Try to establish if something in their environment is causing anxiety, like loud noises (eg someone doing DIY), strong cooking smells or bright light, and remove the source of distress if possible
- Check the person's clothing for sources of irritation like a scratchy label or tight waistband
- Sit close to the person, hold their hand, stroke their arm or give them a gentle hand massage to provide reassurance

- Play music, read to the person, watch a film together or look at photos
- Give them something comforting to hold, like a cuddly toy or soft blanket
- If there are children or young people in the home who are becoming too noisy, encourage them to do something quiet in another room, or use headphones when listening to music or playing videogames

What to do when someone wants to move around

Pacing is common in people with dementia. This is a self-soothing behaviour, but it can be upsetting for both of you. However, there is always a reason for it, even if the person cannot identify or communicate it.

Spending a lot of time inside, sitting down, can cause frustration – especially if the person is younger and used to being active – so it is okay to let them walk around as long as they are not in any danger and it is not causing distress. You may need to walk together to ensure they are safe.

Make the person's home environment as safe as possible to prevent falls, for example by tucking trailing wires out of the way, removing rugs or using grippers to secure them, and fitting handrails on steps. Also check that the person's shoes and slippers are sturdy and well-fitting to prevent falls. Our information on making the home safe and comfortable has more ideas: see Sources of support on p14.

Try to establish whether the person has an unmet need that you could help with. For instance, they may have stood up to go to the toilet but forgotten what they were doing or need help to get there.



They may have been sitting down for too long and need to stretch their legs, or simply feel more at ease moving about.

If the person is in hospital or a care home, tell the staff looking after them that they like to walk around so they can be supported to do so safely.

Coping with wanting to leave the home

A particular worry for many families is the person with dementia wanting – or trying – to leave their home. This may happen if they are unaware of the risks of going out alone, or if they are confused about the time or place. For example:

- They may be retired but still think they need to go to work; or that they need to pick their children up from school, even if they are now adults

- They may have become disorientated and not recognise that where they are is ‘home’
- They may be thinking about somewhere they lived in the past and want to return there

This confusion often becomes worse at dusk – known as ‘sundowning’. Please see Sources of support on p15 for details of our leaflet on sundowning.

The following tips may reduce the person’s desire to leave the house.

- Put coats and bags away in cupboards, rather than keeping them near the front door. For some people, seeing these items makes them think they were about to go out
- Hang a curtain rail above the person’s front door and pull the curtain in the evening or at other times when they often try to leave their home. Hiding the door may stop them wanting to open it
- Involve the person in an activity like gardening, watching sport on TV or preparing a meal. This can make them feel included and purposeful and distract them from wanting to leave the home
- Ask the person about the place they want to go to and listen carefully to what they say. Speaking about their memories of important places may help them feel reassured and less restless, and also reground them in the correct time and place
- If possible, give the person opportunities to leave the house safely, with you or another family member or friend for support

While keeping windows and doors locked may give you peace of mind, do consider the person’s needs, as trying to open locked doors and windows may cause distress. It is also important to think about how



they would get out if there was a fire and exits were locked – you could contact their local fire station and request a ‘Safe and well’ home check for advice (do not call 999 for this).

Keeping the person safe if they leave the home

It is important to have a plan in case the person with dementia does leave their home alone when it is unsafe to do so. You could talk to their neighbours about the situation and exchange phone numbers so they can contact you if they see the person leaving home alone and are worried about their welfare.

Make sure the person always has their name and your contact details on them. You could sew an identity card into their coat, bag, wallet or purse, or encourage them to wear identity jewellery, such as a bracelet or necklace.

If the person has a mobile phone, add yourself and other trusted people as emergency contacts and create a ‘medical ID’ listing their needs – these can usually be set up in ‘Settings’ or a preinstalled Health app. They can be accessed by another person in an emergency without needing a password, face or fingerprint identification.

Assistive technology such as door alarms and monitors can be very useful to help you know where the person is around the house. This means that you do not need to follow them around, which may cause them more anxiety.

A video doorbell that looks out onto the street may be reassuring too. This will record the person going out and can be set up to alert you if this happens. You can then speak to them on your phone via the doorbell and encourage them to go back inside.

You could also consider providing a tracking device, like a GPS-enabled watch, a wristband tracker or a tag in their purse or wallet to help you locate them if they leave home alone.

You can request a needs assessment from social services to establish what assistive technology the person might benefit from, and whether there is any funding for this: see Sources of support on p15 for details.

It is a good idea to also complete a Herbert Protocol form. This is a national scheme to help the police find missing, vulnerable people. As well as personal details, you can include information such as health and communication difficulties; and significant places that they may try to visit, such as a previous home or workplace, or their children’s school. You can hand the form to the police to assist them if the person goes missing. See Sources of support on p15 for details.

If the person is a driver and may be at risk if they drive when restless, or if they have stopped driving but there is still a car at home, keep car keys out of sight.

If the person with dementia becomes agitated and confused when prevented from leaving the home, it may be best not to stop them in case they injure themselves or you in the process. Instead, you could follow at a safe distance or call for help from other family members or friends.

It is also important to learn some strategies to keep you both safe in this situation – please see Sources of support on p14 for details of our leaflet on keeping safe as a carer.



Sources of support

To speak to a dementia specialist Admiral Nurse about coping with restlessness or any other aspect of dementia, please call our Helpline on **0800 888 6678** (Monday to Friday 9am-9pm, Saturday and Sunday 9am-5pm) or email [▶ helpline@dementiauk.org](mailto:helpline@dementiauk.org)

If you prefer, you can book a phone or video appointment at a time to suit you at [▶ dementiauk.org/book](https://dementiauk.org/book)

Dementia UK resources

Anxiety and depression in a person living with dementia

[▶ dementiauk.org/managing-anxiety-and-depression](https://dementiauk.org/managing-anxiety-and-depression)

Continence

[▶ dementiauk.org/continence](https://dementiauk.org/continence)

Coping with distress

[▶ dementiauk.org/coping-with-distress](https://dementiauk.org/coping-with-distress)

Eating and drinking

[▶ dementiauk.org/eating-and-drinking](https://dementiauk.org/eating-and-drinking)

Keeping safe when you care for someone with dementia

[▶ dementiauk.org/keeping-safe](https://dementiauk.org/keeping-safe)

Living aids and assistive technology

[▶ dementiauk.org/living-aids-and-assistive-technology](https://dementiauk.org/living-aids-and-assistive-technology)

Making the home safe and comfortable for a person with dementia

[▶ dementiauk.org/making-the-home-safe-and-comfortable](https://dementiauk.org/making-the-home-safe-and-comfortable)



Mouth care and oral health

➤ dementiauk.org/mouth-care

Pain in dementia

➤ dementiauk.org/pain

Sundowning

➤ dementiauk.org/sundowning

Young onset dementia identity cards

➤ youngdementianetwork.org/young-onset-id

Other resources

The Herbert Protocol

➤ met.police.uk/herbertprotocol

The needs assessment

➤ gov.uk/apply-needs-assessment-social-services

NHS: personal alarms, monitoring systems (telecare) and key safes

➤ nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes/personal-alarms-security-systems-and-keysafes/

**To speak to a dementia specialist Admiral Nurse
about any aspect of dementia:**

Contact our Helpline:
0800 888 6678 or helpline@dementiauk.org

Book a virtual appointment:
dementiauk.org/book

**Our charity relies entirely on donations to fund our
life-changing work. If you would like to donate to help us
support more families:**

- Call **0300 365 5500**
- Visit **dementiauk.org/donate**
- Scan the QR code

Thank you.



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