

Continence



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People with dementia may experience problems with using the toilet, leading to them wetting or soiling themselves – known as incontinence. Incontinence may be:

- urinary: an involuntary leakage of urine (pee)
- faecal: an involuntary leakage of faeces (poo)

Some people may have both types of incontinence, known as ‘double incontinence’.

Incontinence can be distressing for the person with dementia and those around them, but there are ways to manage it and ensure that they are helped to maintain their dignity and privacy.

What causes incontinence?

There are many reasons for incontinence – some simple, and some complex. In some cases, it is caused by a physical condition, such as:

- prostate problems
- urinary tract infections (UTIs), such as infections of the bladder or kidneys
- constipation
- diarrhoea
- diabetes
- strokes
- muscular or neurological problems, for example Parkinson’s
- menopause



Other causes include:

- mobility problems caused by illness, injury or age that mean a person might be slow to reach the toilet
- medication that impacts a person's bladder or bowel control (eg diuretics for relieving water retention) or their ability to get to the toilet (eg sedatives)
- childbirth, which can lead to some women having weaker bladder control causing leakage of urine if they exercise, sneeze, cough or laugh – but incontinence after childbirth should not be considered inevitable and can often be treated
- age – as people age, their bladder and bowel muscles might weaken, but incontinence should not be seen as a natural or unavoidable part of ageing

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A person with dementia may also experience incontinence due to :

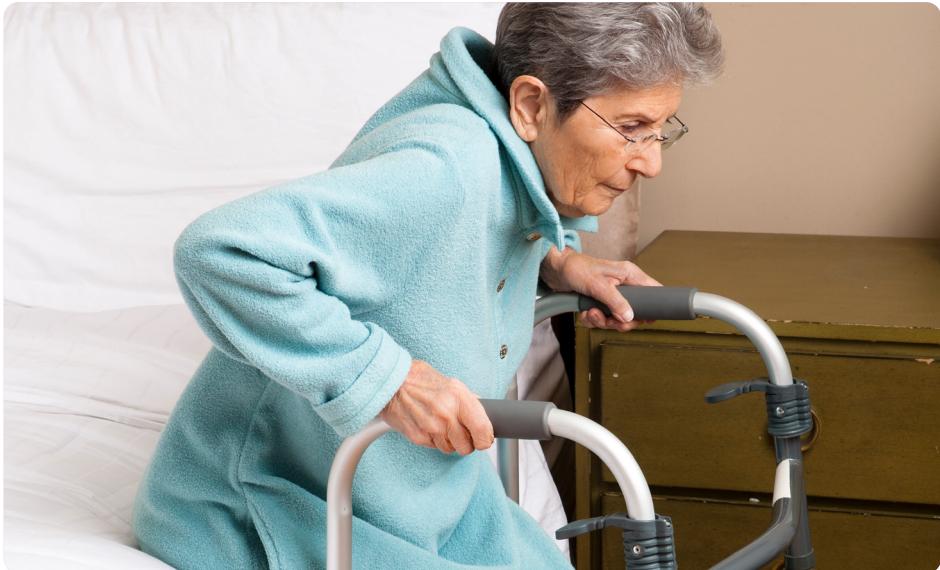
- not recognising the signs of needing the toilet
- difficulty finding the toilet or reaching it in time
- problems with movement and coordination
- damage to the area of the brain that controls the bladder – this may occur in some types of vascular dementia
- struggling to undo clothes quickly enough
- being confused about their environment and urinating in inappropriate places, such as a bin or cupboard

If a person with dementia is experiencing incontinence, it is important for them to see their GP. Some causes of incontinence can be treated, such as urine infections, constipation and prostate problems. The GP can also refer the person to a district nurse or continence nurse for further assessment and support.

Managing incontinence

While incontinence can be upsetting and uncomfortable for the person with dementia and often frustrating and distressing for their carers, it is important that they feel well supported. The right support can:

- reduce the risk of the person getting UTIs and constipation
- reduce agitation and pacing
- help the person sleep better
- prevent skin damage
- help preserve the person's privacy and dignity



Communication techniques for managing incontinence

If a person with dementia has been incontinent, it is important to be supportive, patient and reassuring. They may feel ashamed or uncomfortable; or they might not realise they have lost control and feel embarrassed or upset when they notice or it is pointed out to them.

If possible, ask the person how you can help them manage their continence – bear in mind they may find it difficult to recognise or express what they need. Find out about their previous routines or habits, eg the frequency of bowel movements – if there are particular times of day that they used to go to the toilet, for example after a meal, you could gently prompt them to use the toilet at these times.

Sometimes, there are non-verbal signs that the person might need the toilet, such as fidgeting, pacing, holding their crotch or their stomach, or going to the corner of the room. Look out for these signals and discreetly encourage them towards the bathroom.

If the person has communication difficulties, they may not be able to find the right words to express that they need the toilet, so pay attention to the language they use – phrases like, “I need to go out” might indicate that they want to go to the toilet.

Some people find it helpful to be reminded to go to the toilet regularly, so you could try prompting them every two hours, but do not be too forceful or insistent. You could also suggest using the toilet before going out.

If the person has been incontinent, deal with it quietly and discreetly in a private place. Some people find it helpful to be reassured – for instance, you could say, “Don’t worry – let’s get cleaned up and we can carry on.” Others might prefer you to talk about normal things and mention what has happened as little as possible. Be informed by what you know about the person and what they would find most comforting.

Some people may hide wet or soiled clothing or cover a wet bed because they are embarrassed. Instead of pointing this out, quietly remove soiled linen and replace it.

Eating and drinking advice

Do not stop the person with dementia from drinking, as this can cause dehydration and constipation which may make incontinence worse. Encourage them to drink at least six to eight glasses of fluid per day – water is ideal, but other drinks, including tea, fruit juice and squash, all count.

It is a good idea to switch to decaffeinated drinks, as caffeine can stimulate the brain and irritate the bladder. Caffeine is found in coffee and tea as well as many other products such as cola and energy drinks, but decaf versions of most drinks are available.



Also, try to discourage the person from drinking alcohol, as alcoholic drinks stimulate the body to produce more urine, and can make it harder for them to recognise that they need the toilet. Switch to low- or zero-alcohol versions of wine, beer or spirits.

While it is important that the person drinks regularly throughout the day, discourage drinking lots of fluid just before bedtime.

Encourage a healthy, balanced diet with plenty of fibre to encourage regular bowel movements. Maintaining a healthy weight can also reduce the risk of incontinence.

Please see Sources of support on p14-15 for information on healthy eating, drinking and hydration.

Helping the person use the toilet

The person with dementia may need help to use the toilet. These tips may be useful:

- Guide the person into the bathroom if necessary
- Offer encouragement with undoing their clothes in small steps, for instance: “Can you undo your buttons/zip?”; “Now can you pull down your trousers?”
- Help the person with their clothes if necessary, and if they are happy for you to do so – tell them what you are going to do and ask for their consent, if they are able to give it
- Loose clothes such as tracksuit bottoms, trousers with Velcro instead of buttons, and socks instead of tights might be easier for some people to manage
- Help the person sit down on the toilet if needed
- For men who stand to urinate, remind them to sit on the toilet at least once a day to open their bowels
- If possible, leave the person to have some privacy – stay out of sight but close by, for example outside the bathroom door
- Give the person plenty of time to empty their bowels and bladder
- Check the toilet to see if the person has used it and make a note for the GP if there are any irregularities in the contents such as blood in the toilet bowl
- Report anything unusual to the person’s GP or nurse
- Assist the person to ensure they are clean and dry, and to wash their hands

Practical tips for the home

- Keep access to the toilet clutter-free and remove any trip hazards – please see Sources of support on p15 for information on making the home safe and comfortable for a person with dementia
- Put a sign on the toilet door with a symbol or picture of a toilet. You could take a picture of the person's own toilet and stick it to the door to aid recognition
- Keep the toilet door ajar between uses, and leave a light on at night
- For men who stand to urinate, ensure the toilet seat is left up
- Install a toilet seat in a strong or primary colour that contrasts with the colour of the toilet, and fix brightly coloured grab rails to make them easy to see. Blue is often easier for a person with dementia to see than red
- Use nightlights in the bedroom and landing/hall leading to the bathroom so the person can find their way in the dark
- Think about getting a commode or urinal for night-time use
- A toilet step to elevate the feet whilst using the toilet can help to position the bowel and avoid straining and constipation
- A toilet frame or raised toilet seat may help people with mobility problems to sit more easily
- Keep wet wipes or sanitiser handy for cleaning hands after going to the toilet
- Keep supplies of incontinence products if the person uses them, clean clothing and disposable gloves in the bathroom

- If the person tends to urinate in inappropriate places, try to remove objects that may confuse them, like wastepaper bins

You can also ask your GP to refer the person for an occupational therapy (OT) assessment to look at what equipment and adaptations might help them when using the toilet.

Incontinence products and care

Incontinence products can help the person with dementia feel more comfortable and preserve their dignity, as well as preventing clothes and furnishings being soiled. The person's GP can refer them for a continence assessment with a district nurse or continence nurse. The nurse can advise you on what products may be useful, and the person may be eligible for free incontinence pads, although these may be more basic and less comfortable than those you can buy.

There are many incontinence products on the market, ranging from leakproof underwear and pads to disposable pants/pull-ups. You may need to try a few to find the ones that work best for the person with dementia. Avoid using sanitary pads as these are less absorbent and stay damp, which may make the skin sore.

Consider using disposable or reusable waterproof mattress and duvet protectors, sheets and pads to protect beds, sofas and chairs – see Sources of support on p15 for a list of websites where these can be bought.

Skincare

It is very important to care for the person's skin to avoid discomfort and skin damage (which you may hear referred to as 'skin breakdown'). Wet skin is more prone to damage, so people who are incontinent may develop sores and infections.



After an episode of incontinence, the skin should be gently washed with soap-free products as soon as possible and patted dry. This is also important if the person uses the toilet but finds it difficult to wipe themselves afterwards using toilet paper – wet wipes may be helpful.

If the person uses protective incontinence products and you are aware that they are wet or soiled, help them change as soon as possible, and check them every couple of hours throughout the day.

Regularly inspect the skin around the groin and buttocks for signs of redness, broken skin or sores. Ensure you do this discreetly and inform the person what you are doing and why. Make a GP appointment as soon as possible if you see signs of skin damage.

If you are using barrier creams and ointments to protect the person's skin, be aware that they can reduce the absorbency of incontinence products.

Frailty and continence

Issues around incontinence may indicate that the person with dementia is becoming increasingly frail, so it is important to consider this as a possibility. The physical characteristics of frailty include:

- weight loss
- poor nutrition and hydration
- fatigue
- weakness
- reduced physical activity
- general ‘slowing down’

It is important to identify frailty as it can negatively impact the person's health and independence. Typically, their GP will be the first point of contact. If they are identified as frail, the person will usually undergo a thorough assessment (known as a comprehensive geriatric assessment, or CGA) by a team of professionals with expertise in managing frailty. This will help plan their care and treatment around their frailty needs.

Support for you

Incontinence can be one of the hardest things for a family carer to cope with. You may feel that dealing with incontinence is part of your duty of care for the person with dementia but find it very difficult to manage. You may be embarrassed about dealing with intimate personal care, and conscious of the person's embarrassment too. You may find it hard to ask personal questions about their toilet habits.

If you are caring for your partner with dementia, there may be issues around sex and intimacy and how incontinence affects your relationship. If you care for a parent or other relative, you may find it uncomfortable to deal with nakedness and having to touch them in intimate places.

Dealing with soiled clothing, bed linen and furniture can also take a physical and mental toll.

Children and teenagers may find a parent's incontinence particularly embarrassing and avoid being seen with them in public or inviting friends to their home.

It is important that you are well supported when dealing with someone's incontinence. It is a good idea to contact your local Adult Social Care Team through social services and ask for a carer's assessment for yourself and a needs assessment for the person with dementia to identify any support that would make things easier. Please see Sources of support on p14-15 for information on these assessments.

You may also want to look for support groups – online or in person – where you can share experiences and advice with others in the same situation.

Often, this is the point at which the family carer realises they need outside help with caring for the person, either from a professional carer or in a care home. Try not to feel guilty if you have reached this stage – being able to hand over the more difficult aspects of personal care can relieve some of the exhaustion and embarrassment and improve your relationship with the person you look after.

Sources of support

If you are living with dementia or caring for someone with the condition, register for our free online sessions, ‘Dementia: what next?’ at dementiauk.org/dementia-what-next

To speak to a dementia specialist Admiral Nurse, call our free Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email helpline@dementiauk.org

If you prefer, you can book a phone or video call with an Admiral Nurse at a time to suit you: please visit dementiauk.org/book

Dementia UK resources

The carer's assessment

dementiauk.org/the-carers-assessment

Changing relationships and roles

dementiauk.org/changing-relationships-and-roles

Coping with feelings of guilt

dementiauk.org/coping-with-feelings-of-guilt

Eating and drinking with dementia

dementiauk.org/eating-and-drinking

Emotional impact of a dementia diagnosis

dementiauk.org/emotional-impact-of-a-diagnosis

Finding help and support at home

dementiauk.org/finding-help-assistance

Good hydration for a person with dementia

dementiauk.org/hydration

Looking after yourself as a carer

▷ dementiauk.org/looking-after-yourself-when-youre-caring

Making the home safe and comfortable for a person with dementia

▷ dementiauk.org/safe-comfortable-home

Staying healthy after a diagnosis of dementia

▷ dementiauk.org/staying-healthy

Other resources**Age UK incontinence shop**

▷ ageukincontinence.co.uk/incontinence-shop.html

Bladder and Bowel UK

▷ bbuk.org.uk

Complete Care Shop

▷ completecareshop.co.uk/continence-care

Continence Product Advisor

▷ continenceproductadvisor.org

Living Made Easy

▷ livingmadeeasy.org.uk

Needs assessment

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

NHS guide to incontinence products

▷ nhs.uk/conditions/urinary-incontinence/incontinence-products

**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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