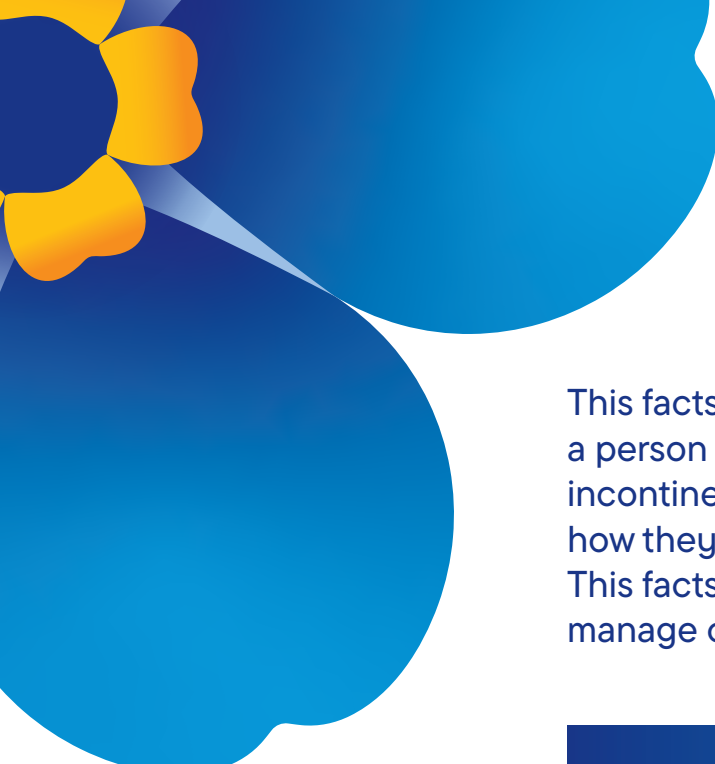


Continence and using the toilet



**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia



This factsheet is for anyone caring for or supporting a person with dementia. It explains the causes of incontinence and problems using the toilet, and how they might affect someone with dementia. This factsheet also offers practical tips to help manage or prevent incontinence.

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1 What is incontinence?

Incontinence is unintentional leakage of pee (urine) or poo (faeces), or both – known as ‘double incontinence’.

Urinary incontinence

Urinary incontinence may be a small occasional leak of pee, a continued leak after peeing, or total loss of bladder control.

There are several types of urinary incontinence. One of these – especially common in people with dementia – is an overactive bladder. This causes the feeling of a sudden and intense need to pee, and frequent peeing.

Women are also at particular risk of a type of urinary incontinence called stress incontinence, often caused by pregnancy and childbirth. This is when a cough, sneeze or laugh causes a small leak of pee.

Faecal incontinence

Faecal incontinence can range from accidentally leaking a small amount of poo when breaking wind, to having no bowel control at all. Faecal incontinence is less common than urinary incontinence. It affects men and women about equally.

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2 Why does a person become incontinent?

There are lots of possible reasons why someone loses continence. A person is more at risk of incontinence if they are older, or if they have dementia.

Incontinence in older people

In some cases, older people have a higher risk of incontinence because of a medical condition, which may be treatable. Medical causes of incontinence in older people include:

- **urinary tract infection (UTI)** – this is where bacteria get into the tube (the urethra) that empties pee from the bladder out of the body. This can lead to infection of the bladder or kidneys. Symptoms can include a sudden urge to pee, pain or a ‘burning’ feeling when peeing, a fever and urinary incontinence. A urinary tract infection can usually be treated with antibiotics
- **constipation** – this is uncomfortable and makes both emptying and controlling the bladder more difficult. Constipation is also a very common cause of faecal incontinence. When the bowel gets full of very hard poo which cannot be passed, liquid poo can leak out from around the edges of the blockage. It is easy to confuse this with diarrhoea
- **prostate gland problems** – these affect men, and may be treatable
- **side effects of medication** – the GP may be able to address these by changing the person’s prescription or altering the dose
- **other gut conditions** – such as irritable bowel syndrome.

Many people find it embarrassing to talk about these problems, and this can stop them from seeking help from health professionals. GPs and specialists deal with issues like these frequently and it’s important to get advice and support from them. Medical causes can often be treated or managed.

Incontinence and toilet problems in people with dementia

A person with dementia is more likely to have accidents, incontinence or difficulties using the toilet than a person of the same age who doesn't have dementia. For some people, incontinence develops because messages between the brain and the bladder or bowel don't work properly. They may not recognise that they have a full bladder or bowel, or be able to control them. Other reasons include:

- not reacting quickly enough to the sensation of needing to use the toilet
- not getting to the toilet in time – for example, because of limited mobility
- not being able to tell someone that they need to go to the toilet because of difficulty communicating
- not understanding a prompt from someone to use the toilet
- not being able to find, recognise or use the toilet. If someone becomes confused about their surroundings, they may pee in an inappropriate place (such as a wastepaper basket) because they have mistaken it for a toilet
- not being able to, or forgetting how to, do things needed to use the toilet, such as undoing clothing
- not letting others help with going to the toilet or refusing to use it – this could be due to embarrassment or not understanding an offer of help
- not making any attempt to find the toilet – this could be due to depression or a lack of motivation, or because the person is distracted
- embarrassment after an accident, which the person unsuccessfully tries to manage. For example, they may try to hide wet or soiled clothes at the back of a drawer to deal with later, and then forget they've put them there.

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Searching for support with incontinence; my husband has Lewy Body Dementia and yesterday double incontinence started.

Partner of a person with dementia



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3 Maintaining a healthy bladder and bowels

Keeping the bladder, urinary tract and bowels healthy is a good first step to preventing toilet problems and staying continent. Help the person to do this by:

- Encourage them to drink throughout the day. The recommended amount is six to eight glasses of liquids each day – more if the person has hard poo. Not drinking enough liquids can cause constipation.
- Help the person to eat a balanced diet with ideally five daily portions of fruit and vegetables, and enough fibre (found in cereals, brown rice and potatoes, for example) to help regular bowel movements. For tips on encouraging the person to eat and drink see factsheet 511, **Eating and drinking**.
- Keep active. Walking every day (if the person is able to) helps with regular bowel movements.
- Try to build going to the toilet into the person's routine, and allow enough time for the person to empty their bowels. See 'Developing a routine' on page 7.

If a health professional thinks the person might have an overactive bladder, they will suggest avoiding drinks that can irritate the bladder. This could include replacing tea, coffee, cola or alcohol with water, herbal teas, squash and diluted fruit juices.

Women in the early stages of dementia with urinary stress incontinence sometimes learn pelvic floor exercises, with the support of a continence adviser (see section 7, Professional support). These exercises aim to reduce stress incontinence, caused by weakness of the pelvic floor muscles.

Constipation

If the person with dementia has constipation, laxatives may help. Laxatives are medication designed to ease constipation and are available without a prescription over the counter. However, they should not be used for more than a week without seeking help from a GP or pharmacist, as the constipation may be caused by something serious that needs professional advice.

If constipation is the cause of faecal incontinence, it is possible to massage the person's stomach to ease the blockage. Continence advisers can train you how to do this. However, it may not be suitable for everyone. The person may not like the sensation, so don't continue if it is making them distressed or uncomfortable. Some people with dementia may indicate how they are feeling through facial expressions, sounds or body language.

4 Reducing accidents

Making it as easy as possible for the person with dementia to use the toilet can help reduce accidents, whether you are at home or out and about.

Help with using the toilet at home

The following ideas may help someone to find, recognise and use the toilet more easily:

- Help the person to identify where the toilet is. A sign on the door, including both words and a picture, may help. It needs to be clearly visible, so place it within the person's line of sight and make sure the sign is bright so it's easy to see. You can also help the person to know when the toilet is vacant by leaving the toilet door open when it's not in use.
- Check the position of mirrors in the bathroom. The person with dementia may confuse their reflection for someone else already in the room, and not go because they think the toilet is occupied.
- Make it easier for the person to find their way to the toilet. Move any furniture that's in the way, and leave open any doors that the person may find hard to open themselves. The room and the route to the toilet should be well lit, especially at night.
- Help the person to identify the toilet. A contrasting colour (for example, a black seat on a white base) can make it easier to see.
- Make sure the person has privacy in the toilet, but check that they don't have difficulty managing locks. Some people with dementia struggle with this. To avoid the person locking themselves in, disable the locks or check that you can open them quickly from the outside (for example with the edge of a coin).
- Choose clothing that will be easier for the person to undo when using the toilet. Trousers with an elasticated waist are often easier than zips. Some people find 'adaptive clothing' with Velcro fastenings easier to use than zips or buttons.
- If the person is less mobile, handrails and a raised toilet seat may make it easier for them to use the toilet. Some men with reduced mobility or balance, or who are not able to direct their pee when standing, may find it easier to sit.

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- If getting to the toilet becomes too difficult because of mobility problems, an aid such as a commode may be useful. This will require the person to recognise the commode, know how to use it and be willing to use it.

Many older people get up during the night to pee. A person with dementia may wake up disorientated and be unable to find (or get to) the toilet in time.

Ideas that might help include:

- **installing motion sensors for lights or night lights in the bedroom, hallways and bathroom. Set the timer so they won't suddenly leave the person in darkness**
- **keeping a urinal bottle (designed for men and women) or commode next to the person's bed at night**
- **not drinking anything for two hours before going to bed – but making sure that the person drinks enough during the day to avoid getting dehydrated.**

For more information on aids and equipment that can help with continence, speak to an occupational therapist – ask the GP or social services to refer you. Products are also available at shops selling independent living aids and equipment. Many of the products are available from Alzheimer's Society's online shop – go to shop.alzheimers.org.uk

Help when out and about

Staying active and seeing people are hugely important, but toilet problems and incontinence can make it harder for someone with dementia to be out and about. However, there are ways to help increase the person's confidence and manage accidents.

The following tips can make travelling or being out and about easier for the person with dementia:

- Plan in advance – for example, find out where accessible toilets are.
- Be prepared – for example, fit a lightweight pad (the kind that attaches to underwear) and carry spare clothing and pads, as well as a bag for soiled items.
- Buy a Radar Key – this gives disabled people (in this case including those with dementia) independent access to thousands of locked public toilets around the country. Radar Keys are sold by Disability Rights UK (see 'Other useful organisations' on page 12).

Remembering to go to the toilet

Giving the person with dementia regular reminders about using the toilet can help reduce accidents.

The following tips may be useful:

- For someone with urinary incontinence, ask them regularly (every two to four hours) whether they need the toilet.
- Give the person encouragement and assistance if they ask for help.
- It's important to check that the person has used the toilet, and not forgotten or become distracted. Over time, this can help some people reduce the number of accidents they have.
- Be sensitive when prompting the person to use the toilet, to avoid patronising, annoying or upsetting them.
- Watch for signs that the person may want to go to the toilet, especially if they cannot communicate this clearly. These signs may include fidgeting, pacing, getting up and sitting down, or pulling at their clothes.

Developing a routine

Creating a routine can help someone with dementia manage incontinence and other toilet problems.

The following tips may be useful:

- For someone who regularly wets themselves, try making a timetable that includes reminders for going to the toilet. For example, it could include reminders when the person wakes up, before each meal, at coffee or tea times and before bed.
- An automatic reminder – for example, on a smartphone – can also be useful in prompting a person to use the toilet or to check if their pad needs changing.
- For faecal incontinence, it is possible to help the person become continent again by supporting them to go to the toilet at a set time each day, and helping them to stay long enough to have a bowel movement.
- Trying to go to the toilet a few minutes after a meal can help – for example, some people find it helpful to go after breakfast.

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5 Managing an accident

Hygiene and going to the toilet are very personal and private issues. Having difficulties or being incontinent can make someone feel like they are losing control, and this can affect their dignity as well as their self-esteem. Many people find it very hard to accept that they need help from someone else in such a private area of their life. It can be particularly difficult if the help is from someone very close to them.

Everyone will react differently to incontinence. Some people find it very upsetting, while others find it easier to accept. Approaching it with understanding, a matter-of-fact attitude and humour – if this feels appropriate, can help.

If someone has an accident, it's important for carers and friends to:

- remember that it's not the person's fault
- try to overcome any embarrassment or upset they may feel
- avoid appearing angry or upset.

This may not always be easy, particularly if you are very close to the person. Whatever your relationship, this kind of support will be a change for you both.

If you find feelings about incontinence difficult to handle, it's a good idea to talk things through with a health professional. This could be the GP, a community nurse or a continence adviser. It's important to try not to let dealing with incontinence get in the way of your relationship with the person you are caring for.

6 Ensuring good personal hygiene

It's important to make sure that the person cleans themselves properly after using the toilet, or that you help them to do so, if appropriate. You should:

- be mindful that the person may prefer to use a bidet rather than toilet paper, or may use a preferred hand to clean themselves
- wipe from front to back (which helps to prevent infection), rather than back to front
- remind the person to wash their hands after they have used the toilet.

Incontinence can lead to skin irritation and feeling uncomfortable. This can also increase the risk of pressure ulcers (bed sores). After an accident, it's important to act quickly to make sure the person feels comfortable again and maintains a good level of hygiene. The following steps will help:

- If someone has become wet or soiled, they should wash afterwards with mild soap and warm water, and dry carefully before putting on clean clothes and fresh pads, with assistance if needed.
- Soiled clothes, reusable pads or bedding should be washed immediately, or soaked in an airtight container until they are washed.
- Used disposable pads should be stored in a disposal bag or other appropriate container, and thrown away as soon as possible.
- Moist toilet tissues may be suitable for minor accidents, as they clean better than dry toilet paper. However, be aware that they may irritate the person's skin.

When using the toilet, some people with dementia who have constipation may try to remove poo by inserting their fingers. It's important to make sure the person's hands and nails are kept clean at all times.

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7 Professional support

Seeking professional help for incontinence can be hard. Many people do so only as a last resort, as the person with dementia may feel like they are losing their dignity. However, with the right advice and support, accidents and incontinence can be managed or sometimes even cured.

The GP should be the first point of contact. They should review any symptoms or underlying medical conditions (such as urinary tract infection or constipation), diet or medications that might be causing problems. The doctor may do an internal bowel examination.

If the GP's assessment does not resolve the problem, ask for the person to be referred to a continence adviser. NHS continence services vary across the country, and you may have to be persistent to see someone who understands incontinence in people with dementia. There may be service wait times.

The continence adviser will assess the problems and how they are affecting their quality of life, as well as yours. It's common to be asked to keep a chart of toilet habits.

After the assessment, the continence adviser will write up a continence care plan for the person. This should include things the person and you can do to help. It should also include the professional support provided, follow-ups and next steps.

The aim is to cure toilet problems or incontinence if possible. This should be agreed with the person and you. Practical steps such as changing medications or making simple changes to lifestyle may help achieve this.

In some cases, the person may be referred to a further specialist (such as a geriatrician, urologist or gynaecologist). Advice may focus not on curing but on managing incontinence as comfortably as possible using aids (see 'Continence aids' on page 11).

Other health professionals can offer support:

- A community nurse can help access NHS-funded continence products and give advice on managing the problem, hygiene and protecting the skin.
- An occupational therapist can advise on adaptations and equipment.
- A physiotherapist can advise if the person has difficulties with co-ordination or movement.
- A community psychiatric nurse, Admiral Nurse or the community mental health team for older people can help if behavioural changes are affecting how someone uses the toilet.

Speak to the GP about getting a referral to these professionals.

8 Continence aids

Sometimes, you might try everything you can but the toilet problems or incontinence remain. If this happens, using continence aids can help to keep the person comfortable and protect clothing, furniture and bedding. Continence aids include the following:

- Incontinence pads and pull-up pants – these can be worn day and night, or during the night only, to soak up pee. It's important to find the right type and absorbency for the person. They should be comfortable without chafing the skin or leaking. They should be changed as often as necessary.
- Male continence sheath – this is a condom which drains into a bag attached to the leg. It may be especially helpful when worn at night.
- Absorbent bed pad – this is an under-sheet which provides a dry surface on a bed or a chair. These are available as washable or disposable products.
- Waterproof mattress protector – this is often used in combination with an absorbent bed pad. The protector should not come into contact with the skin, as it may cause chafing and soreness. You can also buy special protective duvet covers and pillowcases.

Speak to the continence adviser or community nurse for advice, or to find out how to get NHS-funded supplies. The NHS should supply enough continence products to meet a person's needs. However, this varies across the country, and many people top up supplies or buy different versions of products themselves, with their own money.

You can get further advice and buy products from independent living shops or large branches of high-street chemists. For national organisations that can help, see 'Other useful organisations' on page 12.

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There's not a lot of information out there about incontinence. You have to ask the right people for information. But who do you go to?

Person with young-onset dementia

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Other useful organisations

Bladder & Bowel UK

0161 214 4591 (helpline 9am–4.30pm, Monday–Friday)

bbuk@disabledliving.co.uk

www.bbuk.org.uk

Bladder & Bowel UK is a national service that aims to improve life for all people with bladder or bowel problems by offering product information, advice and practical solutions to professionals and the public.

Continence Product Advisor

www.continenceproductadvisor.org

Continence Product Advisor is a website that gives impartial advice on continence products, written by healthcare professionals.

Disability Rights UK

0330 995 0400 (general enquiries)

enquiries@disabilityrightsuk.org

www.disabilityrightsuk.org

Disability Rights UK sells Radar Keys, which offer disabled people independent access to locked public toilets around the country. Toilets fitted with National Key Scheme locks can be found in shopping centres, pubs, cafes, department stores, bus and train stations and many other locations in most parts of the country.



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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 **Adjusting to caring for someone with dementia**.

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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