

Continence and using the toilet

People with dementia can experience difficulties with using the toilet. Accidents and incontinence can also cause problems, particularly as their condition progresses. This can be upsetting for the person and for those around them. However, incontinence is not an inevitable consequence of dementia and support is available. This can be a sensitive topic for many people, but talking about it can help to deal with the problem.

This factsheet looks at what causes problems with using the toilet and incontinence, and how they might affect a person with dementia. It gives practical tips to help prevent or manage incontinence, and looks at the professional support available.

What is incontinence?

Incontinence is the involuntary (not on purpose) leakage of urine or faeces, or both, known as 'double incontinence'.

Urinary incontinence

Urinary incontinence may be a small occasional leak, a trickling after passing urine, or total loss of bladder control.

There are several different types of urinary incontinence. Probably the most common form in people with dementia is an overactive

bladder. This gives the feeling of a sudden and intense need to go, and frequent urination.

Women are also at particular risk of a different type of urinary incontinence called stress incontinence. This is when a cough, sneeze or laugh causes a small leak of urine.

Faecal incontinence

Faecal incontinence may range from passing a small amount of faeces 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.

Why might a person become incontinent?

Incontinence in older people

Older people in general have a higher risk of incontinence. In some cases this is because of a medical condition, which may be treatable. Medical causes of incontinence, in older people with or without dementia, include:

- urinary tract infection (UTI) – this is where bacteria get into the urethra (the tube that allows the passage of urine from the bladder to outside the body) and infect the bladder or kidneys. Symptoms can include a sudden urge to urinate, pain or a ‘burning’ feeling when passing urine, a fever and urinary incontinence. A urinary tract infection can usually be treated with a course of antibiotics
- constipation – this is uncomfortable and makes both emptying the bladder and ‘holding on’ more difficult. Constipation is also a very common cause of faecal incontinence, for example when liquid faeces flow around a hard, impacted stool
- prostate gland trouble – this condition affects men, and may be treatable

- side effects of medication – the GP may be able to address this by changing the person’s prescription or altering the dose
- other gut conditions such as irritable bowel syndrome.

Many people feel embarrassed about these problems and this stops them seeking help from health professionals. However, it is important to talk about them with the GP or specialists, as 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, problems with the toilet or incontinence than a person of the same age who doesn’t have dementia.

The reasons for this can include:

- not being able to react quickly enough to the sensation of needing to use the toilet
- failing to get to the toilet in time – for example, because of mobility problems
- not being able to tell someone that they need to go to the toilet because of problems communicating
- not being able to find, recognise, or use the toilet. If someone becomes confused about their surroundings, they may urinate in an inappropriate place (such as a wastepaper basket) because they have mistaken it for a toilet
- not understanding a prompt from someone to use the toilet
- not being able to, or forgetting how to, perform the activities of using the toilet, such as undoing clothing and personal hygiene

- not letting others help with going to the toilet, perhaps 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 lack of motivation, or because the person is distracted
- embarrassment after an accident, which the person unsuccessfully tries to deal with. This may lead to wet or soiled clothes or faeces being put out of sight. For example, they may be wrapped up and put at the back of a drawer to be dealt with later, only to be forgotten about.

For some people, incontinence develops because messages between the brain and the bladder or bowel don't work properly. This may mean people don't recognise that they have a full bladder or bowel, or have the control needed to empty them. However, this is not a common cause of toilet problems and incontinence in people with dementia. It usually only occurs when the person's dementia is more advanced.

Tips for carers: the importance of maintaining a healthy bladder and bowels

Keeping the urinary tract and bowels healthy is a good first step to preventing toilet problems and incontinence. You can help to make sure the person with dementia is following these tips:

- Drink six to eight glasses of fluids each day – more if the person has hard stools. Not drinking enough fluids, or not drinking them for long periods of time (for example, to avoid the need to go to the toilet during the night), can cause constipation.
- Eat a balanced diet with at least five daily portions of fruit and vegetables, and enough fibre to ensure regular bowel movement.

Fibre can be found in cereals, brown rice and potatoes, for example.

- 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 daily routine, and allow enough time for the person to empty their bowels. Trying to go a few minutes after a meal often works – many people favour going after breakfast.

If a health professional has suggested the person with dementia might have an overactive bladder, they will also advise avoiding drinks which may irritate the bladder. This could include replacing tea, coffee, cola or alcohol with water, herbal teas, squash and diluted fruit juices.

Women with mild dementia and urinary stress incontinence sometimes learn pelvic floor exercises, with the support of a specialist continence nurse or physiotherapist. These exercises can cure stress incontinence caused by weakness of the pelvic floor muscles due to childbirth or ageing.

Constipation

If the person with dementia has constipation, laxatives might be able to help. Laxatives are a type of medication designed to relieve constipation and are widely available over the counter. However, they should not be used for more than a week without seeking advice from a GP or pharmacist, as the symptoms may be masking another condition.

If constipation is the cause of faecal incontinence, it is possible to massage the person's abdomen to relieve the blockage. Specialist continence nurses can train you to use this technique, although being successful will depend on how the person with dementia reacts. It requires the person with dementia to co-operate, and they may not like this sensation.

Tips for carers: reducing accidents

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 vision 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 location 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 awkwardly placed furniture and open any doors the person may find hard to open themselves. The room and the route to the toilet should be well lit, especially at night. Movement sensor lights in the bedroom and bathroom can also help at night time. These are available from shops selling independent living aids and equipment, or through an occupational therapist – ask the GP or social services.
- Make it easier for people with mobility problems to use the toilet. Handrails and a raised toilet seat may help. An occupational therapist can give free advice on these, or you can ask someone at a local independent living shop.
- Help the person to identify and use the toilet. A contrasting colour (for example, a black seat on a white base) can make it easier to see. Some men who have poor mobility or balance, or who can no longer direct their penis when urinating, may find it easier to sit rather than stand.

- Choose clothing with fastenings 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 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. PromoCon (see ‘Other useful organisations’) and independent living shops provide information on commodes and other aids. Alternatively, you can ask the occupational therapist, community nurse or social services.
- Ensure 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).

Some of these products are available from Alzheimer’s Society’s online shop. Go to **shop.alzheimers.org.uk**

Help when out and about

Toilet problems and incontinence can make it harder to be out and about. Being more confident and able to cope with accidents is important, because toilet problems can lead to giving up activities or becoming socially isolated. There are several ways to 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 light 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 – including people with dementia – independent access to thousands of locked public toilets around the country (see ‘Other useful organisations’).

Remembering to go to the toilet

Giving the person with dementia regular reminders about using the toilet is a common way to help reduce accidents. For someone with urinary incontinence, the carer should ask regularly (every two to four hours) whether the person needs the toilet. The person should also be given encouragement and assistance if they ask for help. It is important to check that they have used the toilet, and not forgotten or become distracted. There is evidence that, over time, this can help some people reduce the number of accidents they have.

You should be sensitive when prompting the person to use the toilet, to avoid patronising, annoying or upsetting them. Watch discreetly for signs that the person wants to go to the toilet, especially if they cannot communicate this clearly. These signs may include fidgeting, pacing, getting up and down, or pulling at their clothes.

Developing a routine

For someone who regularly wets themselves, it may be helpful to develop a timetable that offers a reminder for going to the toilet. For example, the timetable could list when the person wakes up, before each meal, at coffee or tea times, and before bed. An automatic reminder – for example, on a smart phone – 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 often possible to make the person continent again by going to the toilet at a set time each day, and helping them to stay long enough to have a bowel movement.

At night-time

Many older people wake during the night to urinate. A person with dementia may wake disorientated and be unable to act quickly enough to find (or get to) the toilet. Ideas that might help include:

- motion sensors for lights or night lights in the bedroom, hallways and bathroom
- a urinal bottle (designed for men and women) or commode next to the bed at night
- not drinking anything for two hours before going to bed – but ensuring that the person drinks enough during the day to avoid becoming dehydrated.

Tips for carers: dealing with an accident

Hygiene and going to the toilet are very personal and private issues, and having difficulties or being incontinent can make someone feel like they are losing control. 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 an intimate area of their life. It can be particularly difficult if the help is from someone very close to them.

Every individual will react differently to the experience of incontinence. Some people find it very upsetting, while others find it easier to accept. Approaching the problem with understanding, a matter-of-fact attitude and humour, if it feels appropriate, can help to improve the situation for everyone concerned.

If someone has an accident, it is 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. If you find feelings about incontinence difficult to handle, it is a good idea to talk things through with a health professional. This could be the GP, a community nurse or a continence adviser (a nurse with specialist training in management of incontinence). It is important to try not to let dealing with incontinence get in the way of your relationship with the person you are caring for.

Ensuring good personal hygiene

Incontinence can lead to skin irritation and a general feeling of discomfort. After an accident, it is important to act quickly to make sure the person feels comfortable again, and to ensure they maintain a good level of hygiene.

- 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 necessary.
- Soiled clothes, reusable pads or bedding should be washed immediately, or soaked in an airtight container until they are washed.
- Used pads should be stored in an appropriate container and disposed of as soon as possible.
- Moist toilet tissues may be suitable for minor accidents, but be aware that some can irritate the skin.

Professional support

It can be hard to seek professional help for incontinence. Many people do so only at a point of crisis, as it may feel to the person with dementia like they are losing their dignity. Some may see incontinence as inevitable, but for many people with dementia, given the right advice and patience, accidents and incontinence can be managed or sometimes even cured.

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

If this assessment is unable to resolve the problem, ask for the person to be referred to a continence adviser. NHS continence services across the country are quite variable and you may have to be persistent to see someone who understands incontinence in people with dementia. You may have to wait for these services.

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

After a thorough assessment the continence adviser will write up a continence care plan tailored to the individual. This should include things that the person with dementia and any carer can do to help. It should also describe the support that professionals should provide, as well as follow-up and next steps.

The aim should be to cure toilet problems or incontinence wherever possible. This should be agreed with the person with dementia and their carer. In many cases, identifying and addressing practical issues, changing medications or making simple changes to lifestyle (such as diet, drinks and exercise) can help to achieve this.

In a few cases, the person may need to be referred to a further specialist (eg geriatrician, urologist or gynaecologist). For some people, advice will focus not on curing but rather on containing the incontinence as comfortably as possible using aids (see 'Incontinence aids' below).

Other health professionals can visit the person at home and offer support.

- A community nurse can help with access to NHS-funded continence products and give advice on management of the problems, hygiene and how to protect the skin.
- An occupational therapist can give advice on adaptations and equipment.
- A physiotherapist can give advice if the person has problems with coordination or movement.
- A community psychiatric nurse, Admiral Nurse or the community mental health team can help if behavioural changes are affecting how someone uses the toilet.

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

Continence aids

Sometimes, you might try everything you can but the toilet problems or incontinence don't go away. In this case, using continence aids can help to keep the person comfortable and protect clothing, furniture and bedding. The main aids are listed below.

- Incontinence pads and pull-up pants. These can be worn day and night, or during the night only, to draw fluids away from the skin. It is important to find the right type and absorbency for the individual. They should be comfortable without chafing the skin or leaking. They should be changed as often as necessary.
- Male continence sheath. This is a silicone 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. You should talk 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 independently with their own money. You can get 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' below.

Other useful organisations

Continence Product Advisor

W www.continenceproductadvisor.org

Website that gives impartial advice on continence products, written by healthcare professionals.

Disability Rights UK

Disability Rights UK
Ground Floor
CAN Mezzanine
49–51 East Road
London N1 6AH

T 020 7250 8181 (not an advice line)

E enquiries@disabilityrightsuk.org

W www.disabilityrightsuk.org

Disability Rights UK sells the RADAR National Key Scheme, which offers disabled people independent access to locked public toilets around the country. Toilets fitted with National Key Scheme locks can

now be found in shopping centres, pubs, cafés, department stores, bus and train stations and many other locations in most parts of the country.

PromoCon

Disabled Living
Burrows House
10 Priestley Road
Wardley Industrial Estate
Worsley
Manchester M28 2LY

T 0161 607 8219 (Helpline, 9 am to 4 pm
Tuesday to Friday)
E promocon@disabledliving.co.uk
W www.disabledliving.co.uk/promocon/about

Provides a national service to improve life for all people with bladder or bowel problems by offering product information, advice and practical solutions to professionals and the general public.

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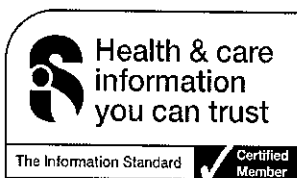
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This factsheet has also been reviewed by people affected by dementia.

A list of sources is available on request.



Alzheimer's Society National
Dementia Helpline

England, Wales and Northern Ireland:
0300 222 11 22

9am–8pm Monday–Wednesday
9am–5pm Thursday–Friday
10am–4pm Saturday–Sunday

alzheimers.org.uk

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