



Managing bladder and bowel care needs for a person who is suffering with dementia

Introduction

This leaflet gives you information about how to manage or support bladder and bowel care needs of a person with dementia.

Dementia is a term used to describe a range of increasing neurological disorders (conditions affecting the brain). This could be a problem or difficulty with the person's memory, thinking, concentration and other functions of the brain which may affect their daily functions such as toileting.

About continence and incontinence

The way we gain control of our bladder and bowel (known as continence) is a complex skill which we learn as a young child. It allows us to voluntarily put off (for a short time) the passing of urine or faeces until an appropriate time and place are found.

Incontinence, losing control of this skill can be humiliating and distressing for those around them. For some individuals an episode of incontinence or losing control of emptying their bladder and/or bowel may happen occasionally. For others, as the condition progresses, the episodes of incontinence may happen all or most of the time which will affect a person's sense of dignity and quality of life.

In this leaflet we describe issues about bladder and bowel incontinence. Both types of incontinence may be treatable, so always discuss the problem with a healthcare professional.

It is important to understand that problems with bladder and bowel control can be due to a treatable (medical) cause of the incontinence. These problems can co-exist with advancing neurological disorders such as dementia and Parkinson's.

Reference No.

GHPI1582_05_24

Department

**Gloucestershire
 Continence**

Review due

May 2027

**Patient
Information****Incontinence caused by a treatable medical cause**

Urinary Tract Infection (UTI) – the person may complain of pain or burning when passing urine. If they have difficulty talking, they may show a pained expression on their face. You may notice that the person is making more frequent trips to the toilet or that their urine looks cloudy or smells offensive. They may also become confused or experience increased confusion. Sometimes an infection can be present without specific symptoms, so it is always worthwhile asking a nurse or doctor to test the person's urine. Urinary Tract Infections (UTI's) usually respond well to medication such as antibiotics.

UTI's can increase more in the warmer weather as it is easier to become dehydrated, so the person then produces less urine in the bladder allowing the germs to grow before they are passed. You should make sure that more fluids are drunk during hot weather to avoid this happening.

Prostate gland enlargement (in men 50 years and over) – the person may find they are making more frequent trips to the toilet and may be having difficulty starting their flow of urine.

They may appear to strain as the urine is passed; the flow may be slower or stop and start. Dribbling of urine may also be noticed. The person's healthcare professional or GP will be able to assess if the prostate gland could be causing this problem. Advice about medication treatment (alpha blockers) or an operation will be given, either of which may resolve the problem.

Bladder urgency and Over Active Bladder (OAB) – bladder urgency is having the sudden urge to hurry to pass urine, often with the fear of not getting to the toilet in time. People with bladder urgency often find they have to pass urine very often during the daytime and at night. Sometimes bladder control can be lost and an embarrassing leak of urine might happen. Studies have shown that bladder urgency is a common problem but, with the right assessment, treatment can work well.

Patient Information

The bladder can also become overactive (OAB). This means that instead of the bladder being relaxed as it fills up, it starts squeezing (contracting) without any warning during filling, causing the sudden urge to pass urine. This is called urinary urgency. The need to pass urine can be so strong that it can lead to a urine leakage called urgency urinary incontinence.

What you can do to help?

Whatever the cause, there are certain steps to follow to help control and improve symptoms:

- Do not reduce the amount that the person drinks as this will cause their urine to become more concentrated, making the bladder irritable. It may also cause constipation and make the problem much worse.
- Try to avoid drinks containing caffeine, which is found in tea, coffee, chocolate and cola. Caffeine can make the bladder more sensitive.
- Fizzy (carbonated) drinks containing aspartame (artificial sweetener) can irritate the bladder, so try to avoid.
- Alcohol causes dehydration which may make the bladder symptoms worse.

For more information about this, please ask the person's healthcare professional or GP for a copy of leaflet GHPI0531 'Bladder urgency and Overactive Bladder syndrome (OAB)'.

Constipation – this may cause urinary incontinence because the full bowel (rectum) will be putting pressure on the bladder. It can also cause bowel incontinence or overflow leakage, which will be a loose and strong stale smelling leakage. This liquid leaks around the hard stool lodged in the bowel and is often mistaken as diarrhoea. It is important to discuss this problem with your healthcare professional or GP who will advise you about medication treatment (laxatives) and/or management with suppositories or enemas. They will also offer advice about diet (particularly fibre) and fluid intake. For more information about this, please ask the person's healthcare professional or GP for a copy of leaflet GHPI1412 'Improving bowel function and control'.

Patient Information

Medication – unfortunately some medications can affect how the bladder and bowel work. Please ask the person's GP or healthcare professional to review their medication as it could be changed to help improve the problems.

Incontinence caused by a non-medical reason directly related to an illness or condition

Immobility (unable to move without the help of another person) – it is important to get into a regular toileting routine to help with maintaining continence, particularly with bowel function. Bowels like routine and establishing a daily toileting regime helps to maintain continence. If the person is unable to get to the toilet without assistance it will increase their risk of incontinence.

Cognitive impairment (lack of recall, confusion, forgetfulness) – many conditions or illnesses cause changes in the way a person thinks and behaves. Some people may forget to go to the toilet, forget where the toilet is or what to do in the toilet. Some changes may mean that an individual does not recognise the need to go to the toilet. These changes can often affect the ability to carry out basic toileting functions leading to problems with bladder and bowel control. In these situations, it is important to try to help the person keep their own skills for as long as possible. When you think about it, using the toilet is a complicated activity to do involving lots of different steps to be successful.

Try to keep the process to a few regular, simple steps. Always use the same language to ask or describe what is happening. Try to keep a composed and calm approach.

Disorders of the brain (spatial disorientation, dyspraxia, change in behaviour) – many conditions or illnesses cause changes in the way a person thinks and behaves about toileting. Some people can get spatial disorientation. This is where they are unable to find their way around the house, care home or ward; this will include finding the room with the toilet and spatial problems when at the toilet.

Patient Information

Some changes may mean that an individual is unable to perform complex movements such as using zips, buckles, ties and sometimes layers of clothing. Some people can lose the ability to understand simple instructions or are unable to express themselves. Some individual's behaviour may become socially inappropriate or aggressive towards carers; not taking advice or accepting help. These changes in behaviour can make maintaining continence more difficult.

How you can help to promote continence

Useful methods to consider are:

Regular toileting – get to know the person's toileting habits, you may find it helpful to keep a diary. This may seem a strange and personal thing to suggest but usually our bladder and bowel have some pattern to them.

Encourage the person to use the toilet at regular times throughout the day, as this can cure or reduce incontinence. This method may not work well at night. Try to identify a time when the person is most likely to need the toilet. You will be able to help by prompting them at these times.

Decide on a toilet routine; try to keep this as a regular routine and tell others who care for the person. This is important so that if the person spends time apart from you the toileting routine can remain the same. You should also always use the same language when prompting the person.

Diet and fluids – having enough water and fibre in the diet is essential and may help the person maintain continence; 8 cups of fluid a day is recommended. Breaking it down to 4 hot drinks and 4 cold drinks a day can make it more achievable. Disguise fluids in soups, jellies, foods high in water content such as melons, pineapples, blueberries, cucumbers and lettuce. Dehydration can make confusion worse.

You should make sure that the person drinks enough during the day. If the person is incontinent at night, advise them to drink decaffeinated drinks and avoid drinking for 2 hours before going to bed.

Patient Information

Some people can forget or be reluctant to drink. Other people may have difficulty in recognising food and drinks or may be unable to drink without assistance. Provide regular prompts and encouragement to drink. Use a coloured beaker/cup rather than a glass as this is more visible and might remind the person to use it. It may be necessary to place the cup in the person's hand.

Fibre is an extremely important part of a balanced, healthy diet. Its main role is to keep the digestive system healthy and avoid constipation, which can cause bladder symptoms. For more information, please ask the healthcare professional or GP for a copy of leaflet GHPI0533 'Fluid and caffeine intake for bladder and bowel health'.

Try to keep mealtimes relaxed and unhurried.

Communication/behaviour – it may be that the person finds it difficult to tell you when they need to use the toilet. It can help to read the body language of the person. You will need to become aware of other signs such as fidgeting, standing up and down frequently, wandering in a restless way, pulling or taking clothes off, urinating in buckets or a bin. Try to think about what the behaviour means – what might they be trying to say?

As much as 90% of communication can be non-verbal and equally, they will be able to read your body language and recognise the tone of your voice. Where possible, approach the person from the front and adjust to their level as it will help to maintain their eye contact. A tense facial expression may upset them. Speak clearly and calmly, making sentences short and simple and only making one point at a time. Be patient, try not to hurry them; taking in information can take longer than it used to. Listen carefully for clues and read their body language.

**Patient
Information**

Reducing the risk of incontinence

There are many methods to consider which can help to reduce the risk of incontinence, here are just a few to try:

- **Signs/tips that encourage toileting** – check whether the person can get to the toilet without any problems. Make sure the person knows where the toilet is, even in their own home. A picture of a toilet on the door can help and may be more effective than words or male and female symbols. Make the image bright and easy to see by positioning it at eye level.

Colour coded doors and markings on the floor to show where toilets are situated are all helpful. Keep the door open when not in use. If the door is closed, the person may not know that the toilet is behind it.

Provide good lighting on the way to and inside the toilet. Make sure that there are no obstacles in the way such as awkwardly placed furniture. Colour contrast the toilet seat (black toilet seat, white toilet) and allow privacy.

- **Mirrors** – remove any mirrors from the room with the toilet as some people get scared of mirrors. They can become confused, thinking the toilet is occupied if they see a person in the mirror, not recognising it as their reflection, which will stop them from using it.
- **Clothing** – simplify clothing. Make sure that any clothing can be quickly removed and unfastened. Some people will find Velcro[®] fastenings easier than zips or buttons. Consider elastic waistbands, making it easier to go to the toilet.
- **Toileting aids** – provide aids around the toilet such as grab-rails, a raised toilet seat and toilet tissue that is easily reached. If it is becoming more difficult for the person to get to the toilet consider an aid such as a urinal (for men) or a commode; these might help to maintain the person's continence.
- **Incontinence aids** – if you have tried everything you can to maintain continence but the person is still becoming incontinent, then you need to help them feel more comfortable and also protect clothing, bedding and furniture.

Patient Information

There are various products available such as incontinence pads and pants. These can be worn day and night or just at night. Your local Continence Service or community nurse can give you further advice. It is important for the person to be assessed properly for the right absorbency product to be prescribed.

Other products to consider, usually available from a chemist, disability shop or mail order are mattress, duvet and pillowcase protectors. Absorbent washable under-sheets are useful and provide protection for beds and chairs.

Tips to help with bladder and bowel care needs

Mobility – encouraging regular exercise, keeping mobile reduces the risk of falls associated with getting to the toilet and reduces the risk of incontinence. Being active can help to keep the bowel moving and regular. Even if mobility is restricted to being chair bound, doing upper body exercises can have a positive effect, together with, strengthening muscles and being more flexible.

Hygiene – being incontinent can cause skin break down and increases the risk of pressure damage. Encourage regular washing with warm water and mild soap. Pat dry, avoid rubbing the skin as this can cause further damage.

You should avoid excessive use of baby wipes as this can cause irritation to the skin. A specialised cream may be prescribed by your healthcare professional or GP to provide a protective film over the area.

Use incontinence pads appropriately and change soiled pads regularly. The pads are designed to keep the skin dry and should be used according to the manufacturer's guidelines. Avoid double padding and make sure that the pads are secured to the body correctly. If the pads are not absorbent enough, talk to your healthcare professional or GP who will be able to organise a reassessment of the person's needs.

Patient Information

Psychological help - Losing control of both bladder and/or bowel is difficult for both the person being incontinent and the carer. Try not to get cross or upset as this can make the problem worse. It can be very emotional and tiring dealing with not just feelings of frustration, guilt, sadness and grief of the progression of the neurological condition(s), but also the physical changing/washing that comes with incontinence. It is important to talk to someone if you feel like this. Healthcare professionals are there to help.

Bladder and bowel incontinence can be managed discreetly as part of everyday life. According to Urinary Incontinence UK, it is estimated that 5 to 10 out of every 100 people suffer with some degree of urinary incontinence. Please visit website www.incontinence.co.uk for more information.

Get support – ask for help at the person’s GP surgery, they will be able to direct you to services available in your area. You can also contact the Adult Continence Service for help and advice.

Contact information

Gloucestershire Bladder and Bowel Health

Cheltenham General Hospital
Sandford Road
Cheltenham GL53 7AN

Tel 0300 422 5305

Monday to Friday, 9:00am to 4:00pm

Email: ghn-tr.gloscontinenceservice@nhs.net

Further information

The GP

While the person with dementia is living at home, their GP will be the main provider for their health care needs, assessments and reviews. The GP can also advise you of relevant services and care professionals for further advice and support.

There is a Dementia Community Nurse attached to each GP practice, please ask the GP of the person living with dementia for more information.

Patient Information

Leaflets

The following leaflets will give you more information please ask the patient's GP or healthcare professional for copies or visit the Gloucestershire Continence webpage at:

www.gloshospitals.nhs.uk/our-services/services-we-offer/continence-service/

- GHPI1412 'Improving bowel function and control'
- GHPI0531 'Bladder urgency and overactive bladder'
- GHPI0533 'Fluid and caffeine intake for bladder and bowel health'

Carer's information

More information and useful website links for carers can be found on the Gloucestershire Hospitals NHS Foundation Trust 'Information for Carers' webpage:

www.gloshospitals.nhs.uk/your-visit/visitors-and-carers/information-carers/

Gloucestershire Advice ASAP

Website: www.asapglos.nhs.uk

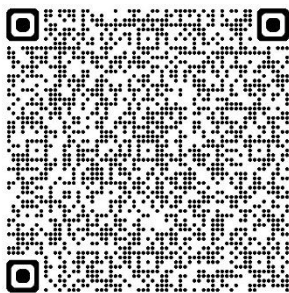
Gloucestershire Adult Social Care Team

Please contact the Adult Social Care helpdesk for further information and guidance.

Tel: 01452 426 868

Email: socialcare.enq@gloucestershire.gov.uk

If you have a smartphone, please follow the QR code below.



Alternatively, you could type the following web address into your internet search box:

www.gloucestershire.gov.uk/health-and-social-care/adults-and-older-people/finding-the-right-information-and-support/information-advice-and-services-to-manage-your-care-and-stay-independent/adult-social-care-helpdesk/

**Patient
Information****Managing Memory 2gether**

Memory assessments and treatment services for people with dementia are available. 2gether also provides carer education and is an information service.

Tel: 0800 694 8800

Email: managingmemory@ghc.nhs.uk

Website: www.ghc.nhs.uk/our-teams-and-services/managing-memory-together/

Alzheimer's Society Gloucestershire

This society provides information, education, advice, support and guidance for people living with dementia and for their family and carers. They also provide Gloucestershire's Dementia Advisor Service, which gives information and advice on how to access services and support for people with a diagnosis of dementia.

Gloucestershire Tel: 01452 525 222

Dementia Support Line: 0333 150 3456

Website: www.alzheimers.org.uk

Gloucestershire Young Carers

Tel: 01452 733 060

Email: mail@glosyoungcarers.org.uk

Website: www.glosyoungcarers.org.uk

The Carers Hospital Liaison Officer

The Carers Hospital Liaison Officer, who works within the hospital, can support carers with advice and information while the patient is in hospital and after discharge. They can be reached via the ward volunteers or Gloucestershire Carers Hub.

Carers may be given or receive in the post an information pack from Gloucestershire Carers Hub giving them details of the free services they provide.

**Patient
Information****Gloucestershire Carers Hub**

This service is provided by People Plus to give support, advice and guidance to unpaid carers and offers carers assessments to those who may need one.

The Hospital Liaison Officer is available in the hospital and works in partnership with hospital staff to ensure carers are best supported.

Gloucestershire Carers Hub
Conway House
31 Worcester Street
Gloucester
GL1 3AJ

Tel: 0300 111 9000

Monday to Friday, 9:00am to 5:00pm

Website: <https://gloucestershirecarershub.co.uk/>

Email: carers@peopleplus.co.uk

Find us on Facebook and Twitter

Dementia UK

Tel: 0800 888 6678

www.dementiauk.org

Age UK Gloucestershire

Tel: 01452 422 660

Website: www.ageuk.org.uk/gloucestershire

Friendship Line: 0800 2980579 - for a friendly chat

Content reviewed: May 2024

Making a choice

Shared Decision Making

If you are asked to make a choice, you may have lots of questions that you want to ask. You may also want to talk over your options with your family or friends. It can help to write a list of the questions you want answered and take it to your appointment.



Ask 3 Questions

To begin with, try to make sure you get the answers to three key questions if you are asked to make a choice about your healthcare.

1. What are my options?
2. What are the pros and cons of each option for me?
3. How do I get support to help me make a decision that is right for me?

These resources have been adapted with kind permission from the MAGIC Programme, supported by the Health Foundation

* Ask 3 Questions is based on Shepherd HL, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial. Patient Education and Counselling, 2011;84: 379-85



<https://aqua.nhs.uk/resources/shared-decision-making-case-studies/>