Headway
the brain injury association

# Continence problems

## after brain injury

This publication explains what may happen to the bladder and bowel following a brain injury, and outlines what treatment, professional support and services are available to help. It also provides practical tips for living with ongoing continence problems.

www.headway.org.uk
0808 800 2244

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# Introduction

Continence, or the ability to control when you urinate or empty your bowels, is a vital component of a person's health and wellbeing. Unfortunately, problems with continence are common following a brain injury, particularly in the first several weeks. For many people, this loss of toilet control is a very sensitive issue, and people may feel embarrassed, distressed or less independent.

Urinary and bowel continence problems can occur alone or at the same time, and can range in severity from just a small leak to a complete loss of function. Some people may experience continence problems on a daily basis, whereas for others it may only happen from time to time. This can be physically and emotionally

difficult for not only the brain injury survivor, but also those around them, and can have a major impact on daily life.

Fortunately, with time and practice, many people regain control of their bladder and bowel functions. However, for others, continence problems can be an issue that they will need to manage in the long-term.

This publication explains what may happen to the bladder and bowel following a brain injury, and outlines what treatment, professional support and services are available to help. It also provides practical tips for living with ongoing continence problems.

**The information in this publication does not replace clinical guidance from medical professionals. You should always get advice from your GP or other suitably qualified professional for help with managing the effects of brain injury.**

## Types of continence problems

There are different types of continence problems that can occur, sometimes in combination, as a result of brain injury:

- **Neurogenic** - damage caused by a brain injury preventing messages from being transmitted between the brain, bladder and bowel.

- **Functional** - physical disabilities or problems with cognition and communication preventing a person from getting to the toilet on time.

- **Frequency** - the need to pass urine or faeces more often than normal.

- **Urgency** - a sudden and uncontrollable need to pass urine or faeces at unexpected times.

- **Nocturnal enuresis -** wetting the bed while asleep.
- **Nocturia** - the need to go to the toilet several times during the night.
- **Stress** - leaking urine or faeces during physical movement or activity, such as coughing, sneezing, laughing, lifting or passing wind.
- **Reflex** - no sensation that the bladder or bowel are full, therefore passing urine or faeces without realising it.
- **Retention** - straining or difficulty emptying the bladder or bowels (i.e. constipation).
- **Overflow** - the bladder or bowels over-fill and leak due to loss of feeling.

If someone is constipated, this can also press on the bladder, worsening any bladder problems that may be present. This is called faecal impaction.

## Continence problems and brain injury

There are a number of reasons why someone may have problems with their bladder and bowel function following brain injury. These may include:

- Damage to the part of the brain that controls bladder and bowel functions;
- Being unconscious and unaware of the surrounding environment;

- Peripheral nerve damage preventing messages from being transmitted between the brain, bladder and bowel;
- Being less mobile than usual;
- Eating and drinking less than usual;
- Physical difficulties affecting one's ability to remove clothing and/or reach a toilet in time;
- Weakness in the muscles controlling the outflow of urine or faeces;
- Communication difficulties affecting one's ability to indicate the need for the toilet;
- Memory problems affecting one's ability to recall when they last went to the toilet or remember the location of toilet facilities;
- As a side effect of commonly prescribed medication (e.g. diuretics).

For the majority of people, these problems will resolve over time. However, if problems do persist in the longer term, there is help available.

## Initial care of continence problems after brain injury

If someone is in hospital following a brain injury, there are a number of ways in which continence problems can be managed by the medical staff until the patient is ready to start actively

regaining control of their bladder and bowel function. The staff may use the following:

- High-absorbency pads and pants;
- Catheters - a fine tube inserted into the bladder to drain urine;
- Other urine collection devices such as handheld urinals or sheaths
  (a condom-like catheter for men);
- Faecal collection devices (most often used in intensive care);
- Anal plugs.

Those who do have good bladder and bowel functions, but are unable to indicate the need for the toilet, will be offered the toilet or commode (a chair with a removable potty under the seat) throughout the day. If the patient is bed bound, they may be transferred using a hoist, or given a portable urinal or bed pan to use.

When appropriate, the medical team will undertake a full assessment to establish the underlying cause of the patient's continence problems. The physical, cognitive and emotional function of the patient will also be taken into account.

For more information on the hospital stage, see our publication *Hospital treatment and early recovery after brain injury*.

## Continence assessment

The continence assessment may include:

- Completing a questionnaire, and a bladder and bowel chart prior to the appointment;
- Providing the patient's medical history;
- Reviewing any medication that is being taken;
- Gathering information about the patient's fluid and diet intake;
- A urine sample analysis to check for possible infection;
- A physical examination;
- A bladder ultrasound scan;
- An abdominal x-ray;
- Any other specialist investigations.

Once the cause of the patient's continence problems has been determined, an individualised treatment programme will be devised. The medical staff will teach the patient and their loved ones how to manage the continence problems, as well as arrange for a supply of any necessary products before discharge. The patient may also be seen by a specialist continence nurse advisor or consultant (such as a urologist), or be referred to other services and professionals for further support.

If someone is at home following a brain injury and experiencing continence problems, it is important that they visit their GP.

## Treatment for continence problems

Treatment options for bladder and bowel continence problems depend on the underlying cause, as well as the degree of severity. In some cases, more than one treatment may be needed.

Common options include:

- **Bladder training** involves learning new techniques to hold urine for longer periods of time. It is achieved by making regular visits to the toilet, then gradually extending the time between each visit.

- **Bowel training** involves establishing regular times to make a bowel movement, often after mealtimes, and learning to delay these movements once on the toilet.

- **Pelvic floor exercises** can strengthen the muscles that are used to stop leakage of urine from the bladder.

- **Electrical stimulation devices** can also strengthen the pelvic floor muscles by contracting them frequently using electric currents.

- **Enema and/or rectal irrigation** involves instilling warm water into the rectum via the anus, stimulating the bowel to contract and flush out its contents.

- **Medication** can be prescribed to help with managing bladder and bowel movements.

- **Surgery** may be performed if symptoms are severe and other treatments are ineffective.

- **Lifestyle changes,** for example:

- Keeping fit (if someone is able);
- Cutting down on caffeinated drinks and drinking enough water;
- Following a balanced diet, for example, eating plenty of fruits and vegetables containing fibre;
- Losing weight (if someone is overweight);
- Quitting smoking (a “smoker’s cough” can weaken the bladder and bowel muscles).

## Living with ongoing continence problems

For some brain injury survivors, continence problems may be an issue that they will need to learn to manage in the long-term. If this is the case, you are not alone. With the right advice and preparation, continence problems can be managed.

Specialist products available to help manage ongoing continence problems include:

- High-absorbency pads and pants;
- Washable or disposable seat pads to protect furniture;
- Washable or disposable mattress protectors and bed pads;
- Commodes (particularly useful to have in the bedroom at night);
- Alarms to sound at regular intervals throughout the day and night;
- Catheters or other urine collection devices for men and women.

Tips for living with ongoing continence problems include:

- **Follow a daily routine** with regular visits to the toilet, especially around mealtimes. It is also important to empty the bladder and bowels fully on each visit to help avoid infection.

- **Plan access to the toilets in advance.** 'Changing Places' toilets are available to use across the UK. These toilets are different from standard accessible toilets and include features such as a peninsular toilet, a changing table big enough for adults, hoists and a non-slip floor. The Changing Places Consortium provide an online map where you can type in an address, town and postcode to identify the location and opening times of your nearest registered Changing Places toilet.

  Disability Rights UK sell the 'RADAR National Key Scheme', which can give those struggling with continence problems access to locked public toilets across the country, in locations such as shopping centres, cafes, bus and train stations. Local councils may be able to provide a RADAR key free of charge.

  The Bladder and Bowel Community also offer a 'Just Can't Wait' toilet card free of charge for those affected by continence problems. The card explains that the card-holder has a condition which requires urgent access to a toilet and provides a discreet and clear way to communicate with others. For more information, see the Useful organisations section.

  Headway Brain Injury Identity Card holders can also request for continence problems to be added to the front of their card. Find out more on our website at www.headway.org.uk/idcard.

- **Carry a rucksack, holdall or handbag** with a 'survival kit' when out and about. It may include items such as a spare set of clothing, deodorising spray, disposable pads, scented disposal bags (for soiled items), antibacterial wipes and hand gel.

- **Reduce the amount of liquid consumed** before bedtime to avoid accidents throughout the night. Choose drinks that are less likely to irritate the bladder, such as water. It is important to drink enough during the day to avoid becoming dehydrated or at risk of developing a urinary infection.

- **Keep a clear pathway to the toilet at all times.** Ensure there are no obstacles in the way, such as furniture or closed doors. In addition, some people may find it useful to have signs leading to the toilet, or a well-lit route, especially at night.

- **Ensure good personal hygiene** to prevent skin irritation and general discomfort. Avoid using wipes and creams which dry the skin around the affected area.

- **Wear clothes that are quick and easy to remove**, for example, with velcro fasteners and elasticated waistbands.

- **Dispose of soiled items safely.** Ensure that any disposal bags are secure and leak-proof and use a bin with a lid to keep in odour.

- **Avoid becoming socially isolated**. Continence problems can sometimes make it difficult to attend large social gatherings. However, it is important to still interact with people on a face-to-face basis. This could be done by inviting friends and family to a quieter location, or meeting other brain injury survivors at your local Headway who may share similar experiences.

- **Talk to people**, as continence problems can affect mood levels. Remember, the Headway helpline is available to talk,

Monday-Friday (9am-5pm) on 0808 800 2244 or helpline@headway.org.uk.

## Professional help with continence problems

Speak to your GP for professional help with continence problems. Other professionals who can often help with managing continence problems include:

- **Continence advisors** are clinical nurses with specialist training in continence care. They are able to assess a patient's bladder and bowel problems, and advise on treatment and management. Continence advisors may visit the person being cared for at home or at a local continence clinic. The Bladder and Bowel Community can provide details of your local continence clinic using their 'Healthcare Search Tool'. Your GP will also be able to advise on this.

- A **physiotherapist** can provide tips and exercises to improve mobility, which may help the patient access the toilet more easily. They can also assist if pelvic floor exercises have been recommended.

- An **occupational therapist** can assist if the patient needs to make adaptations to their home. For example, the patient may need handrails or a raised toilet seat fitted, or they may need walking aids or a wheelchair.

- A **dietitian** can recommend suitable food and fluids to help the patient with their bladder and bowel problems.

- A **speech and language therapist** can assist with any communication issues that might be present, for example,

if the patient struggles to indicate the need for the toilet. In addition, they can assess any swallowing difficulties that are causing the patient to eat and drink less than usual.

## Caring for someone with continence problems

Continence problems can be one of the most difficult aspects of caring for someone with a brain injury. It is often unpredictable and can be physically and emotionally demanding. Toileting is also a very personal issue and often those who experience continence problems feel as though they are losing control. Many brain injury survivors will find it difficult to accept that they need help, especially if the help is coming from someone close to them.

Tips for carers:

- Watch discreetly for signs that the person needs the toilet, such as fidgeting, pacing, getting up and down, or pulling at their clothing. This is especially important if the person cannot communicate the need to go clearly.

- Make sure to give regular reminders about using the toilet.

- Check the person has finished on the toilet and not become distracted or forgotten what they were doing.

We hope that the information within this publication will also provide a basis for carers to meet the challenges that may lie ahead when caring for someone with continence problems, as well as assist you in finding the support that you may also need.

For more general information on caring for someone with a brain injury, see our publication *Caring for someone with a brain injury*.

## Conclusion

Problems with the bladder and bowel are common following a brain injury, particularly in the first several weeks. Whether it is a small leak or a complete loss of function, it is normal to feel concerned and embarrassed, and while it is a sensitive topic for many people, talking about it can help to deal with the issue.

With the right information and support, and by using specialist products designed to meet your or your loved ones needs, continence problems can be managed to reduce the impact on everyday life. In many cases, they can also be treated with guidance from a licensed healthcare professional.

## Useful organisations

**The organisations listed below are provided for information purposes only. Their inclusion does not imply endorsement, recommendation, or approval by Headway. Users should make their own assessment of any organisation or service before engaging with them.**

**Bladder and Bowel Community**
Web: www.bladderandbowel.org
Email: help@bladderandbowel.org
Tel: 0800 031 5406

**Bladder and Bowel UK (part of Disabled Living Foundation)**
Web: www.bbuk.org.uk
Email: bbuk@disabledliving.co.uk
Tel: 0161 214 4591

**Bladder Health UK**
Web: www.bladderhealthuk.org
Email: info@bladderhealthuk.org
Tel: 0121 702 0820

**Carers UK**
Web: www.carersuk.org
Email: advice@carersuk.org
Tel: 0808 808 7777

**Changing Places Consortium**
Web: www.changing-places.org
Email: changingplaces@pamis.org.uk
Tel: 01382 755389

**Disability Rights UK**
Web: www.disabilityrightsuk.org
Email: enquiries@disabilityrights.org
Tel: 0330 995 0400

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We hope that this has been a helpful resource. Please consider sharing your feedback with us by scanning the QR code or by visiting our publication feedback survey https://uk.surveymonkey.com/r/hwpublications.

Learn more and support our work at www.headway.org.uk/get-involved.

This information was last reviewed in 2019.

# We're here to listen.

**If you need support, or have a question about brain injury, contact our free nurse-led helpline:**

**0808 800 2244**
**helpline@headway.org.uk**

**0115 924 0800 | enquiries@headway.org.uk**
**www.headway.org.uk**

Head office: Bradbury House, 190 Bagnall Road,
Old Basford, Nottingham, NG6 8SF

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