Managing your bladder

A guide for people with MS

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MS Trust Information Services

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Introduction

Around 75 in every 100 people with MS experience bladder problems and these symptoms can have a big impact on your everyday life. However, this is an area where successful treatments are available and straightforward lifestyle changes can make a real difference. These treatments and lifestyle changes can stop bladder problems impacting, or having as much impact, on your daily life.

This book aims to provide practical ideas and suggestions that will help you manage your bladder problems.

It explores:

- why bladder problems can happen in MS
- how to monitor symptoms and recognise factors that might make them worse
- simple strategies that can improve your bladder problems
- treatment options that might be relevant to you
- how working in partnership with the right health professionals can be the key to finding the approach that works best for you.

The book includes comments from people with MS who know first-hand what it's like to live with bladder problems and draws on the experience of health professionals, including MS specialist nurses, and community bladder and bowel services.

1. Talking about bladder problems

Many people feel a sense of shame and embarrassment about bladder problems. You may feel awkward raising these issues with a health professional. The reality is that bladder problems are very common for people with MS. Talking to a health professional is an important first step in getting the right treatment.

Your health professional will have lots of experience talking about these kinds of symptoms – it's likely they've heard it all before! Your MS nurse, GP or bladder and bowel specialist will be aware that MS can have an impact on how the bladder works. Try not to feel embarrassed about bringing up the topic. Be honest about the problems you've been experiencing and remember, we're all human and we all go to the toilet – there's absolutely no shame in it.

"Fear of other people's reactions is what can stop you talking about bladder problems, but for me being honest and open really helped."

It's OK to talk about this aspect of life and many people are grateful to be able to share their stories.

"While out with very close friends, I was talking about my bladder problems when a couple close by asked if they could join us. They were so relieved that someone was talking about this openly and wanted to share their experiences."

Community bladder and bowel services deal specifically with bladder and bowel problems. In some areas you can refer yourself directly to them. If not, your MS specialist nurse or GP can make a referral. These services offer appointments in clinic and home visits for people who can't attend a clinic.

When talking to your health professional about bladder problems, use the language you are most comfortable with. We use the word urine throughout the book, but using wee or pee is fine – your health professional will understand what you mean.

2. When should I contact a health professional?

If you're experiencing any of the bladder problems listed below, it might be time to contact a health professional for some help and support.

- You're having bladder accidents, and you avoid important activities because of this.
- You often feel an urgent need to urinate, but sometimes don't make it to the toilet in time.
- You go to the toilet much more often than you used to, during the day and/or at night.
- Going to the toilet is painful or your urine has an unusual smell.
- You feel the need to urinate, but you're unable to.
- You notice your urine stream is getting weaker, or you feel as if you haven't fully emptied your bladder.
- You notice a red or brown tinge to your urine, or on toilet paper after wiping.

What will happen at my appointment?

When you talk to your health professional it's important to be clear about your symptoms and how long they've been affecting you. You could tell them how your bladder problems affect your life. For example, if it's making things difficult at work or stopping you going out with friends. Keeping a diary of your bladder symptoms can be helpful to share during your appointment (see page 27 for more on keeping a bladder diary).

When you see your health professional, they'll take a full history of your symptoms. They might ask you to keep a detailed bladder diary for a short period of time. They might also carry out the following investigations.

Urine test

Your health professional may ask for a sample of your urine so they can test it for any infection – this is sometimes called a dipstick test. A small, chemically treated stick is dipped into your sample. If bacteria are present, it will change colour, indicating you may have a urinary tract infection (UTI).

Bladder ultrasound

The amount of urine left in your bladder after passing urine will be measured. This is carried out with an ultrasound scanner which is applied to your lower abdomen and gently moved over the skin. This creates an image of your bladder and shows how much urine is left behind.

If there is less than 100ml left after your bladder has been emptied, then your symptoms are more likely to be due to problems storing urine. If there is more than 100ml left, then the symptoms are likely to be due to problems emptying your bladder.

The results will help your health professional find the most appropriate approach to treatment. Treatment options will be discussed with you and information provided to help you make informed decisions about your options. You can change your mind about the treatment/s you choose at any point and alternatives can be discussed.

It's important to recognise that not all bladder problems are caused by MS. Your health professional will try to rule out other possible causes of your symptoms. Some common things that can cause bladder issues are:

- enlarged prostate in men
- pregnancy and childbirth (which can weaken pelvic floor muscles)
- fibroids (non-cancerous growths) in the womb
- a vaginal prolapse (where pelvic organs drop because of weakened pelvic floor muscles)
- infection in the urinary tract (the kidneys, ureters, bladder and/or urethra)
- abdominal surgery
- caffeine and alcohol consumption.

3. How your bladder works

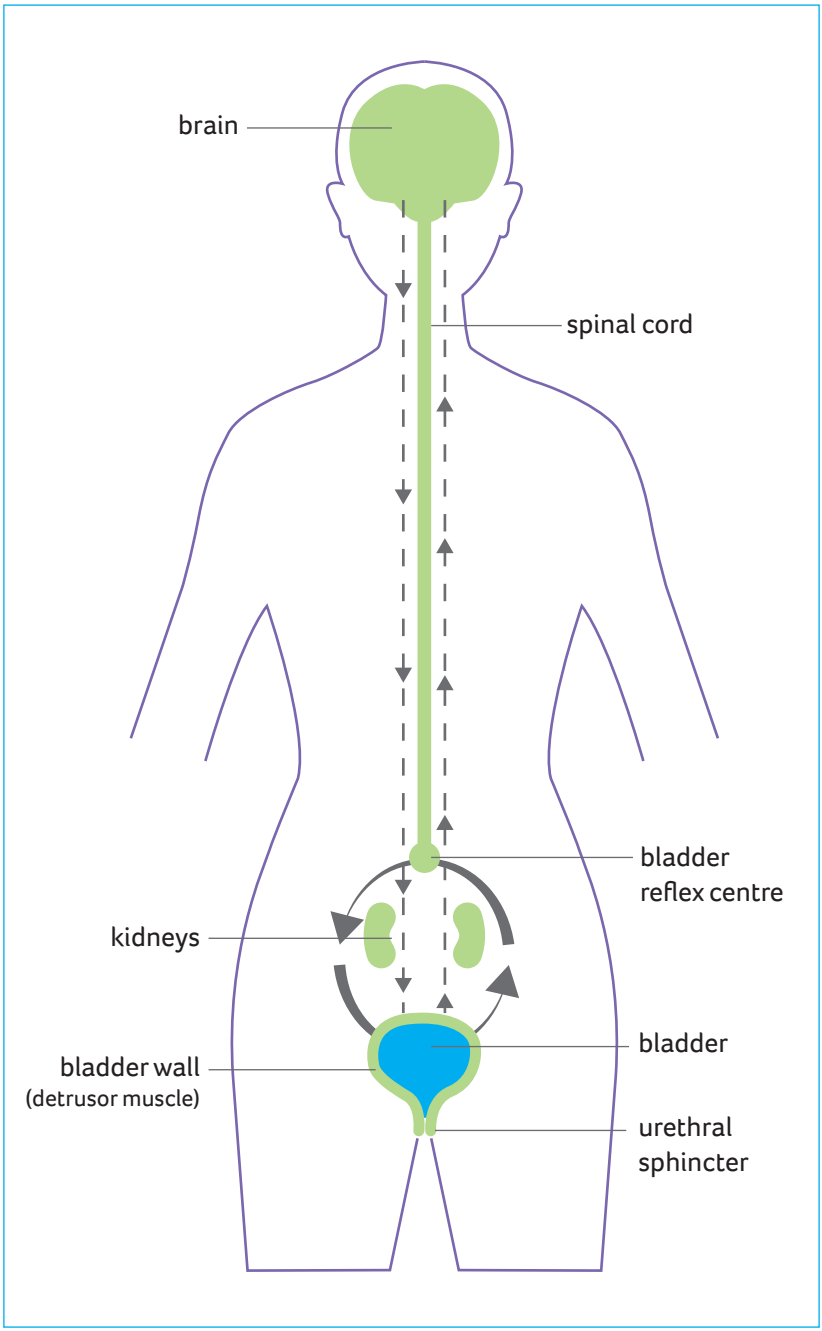
The bladder has two main functions: storing urine and emptying urine at an appropriate time.

The kidneys make urine by removing waste products and excess water from your blood. Urine drains from the kidneys – via two tubes called the ureters – to the bladder, where it is stored. The bladder wall is a bag-like muscle (called the detrusor muscle) that expands as it fills with urine and contracts (tightens) when it's time to empty.

Nerve endings in the bladder wall are triggered when urine reaches a certain level in your bladder. They send a message to the part of the spinal cord that controls your bladder emptying reflex. A message is then sent to your brain, letting you know that you need to go to the toilet. These messages can be suppressed by your brain so you can hold on until you're able to get to a toilet.

When it's appropriate, your brain sends messages back through the spinal cord to your bladder, telling it to contract. At the same time, the valve-like muscle at the bottom of the bladder (the urethral sphincter) relaxes, allowing you to urinate.

Most people will usually go to the toilet between six and eight times a day, depending on how much they've had to drink. A healthy bladder can hold between 300–500ml of fluid (somewhere between half a pint and a pint). You usually feel the urge to urinate when your bladder is around two thirds full. The bladder only contracts, or tightens, when emptying. It's rarely completely empty, with about 10% of urine left after a visit to the toilet.


brain
spinal cord
bladder
reflex centre
kidneys
bladder
bladder wall
(detrusor muscle)
urethral
sphincter

What can happen in MS?

MS can damage the areas of your spinal cord or brain that play a part in controlling your bladder function. The symptoms you experience will depend on which areas are affected. Bladder problems can be divided into two types: those relating to the storage of urine and those relating to the emptying of urine. Some people experience a combination of these symptoms.

Problems storing your urine

Storage problems can cause you to need the toilet immediately (urgency) and more often (frequency). This can happen during the day and at night (nocturia). Bladder accidents (urinary incontinence) may also happen where bladder control is lost and urine leaks out.

Problems emptying your bladder

Emptying problems can result in symptoms such as difficulty passing urine (hesitancy and intermittency) and feeling like your bladder has not completely emptied (retention).

4. Problems storing your urine

Urgency and frequency

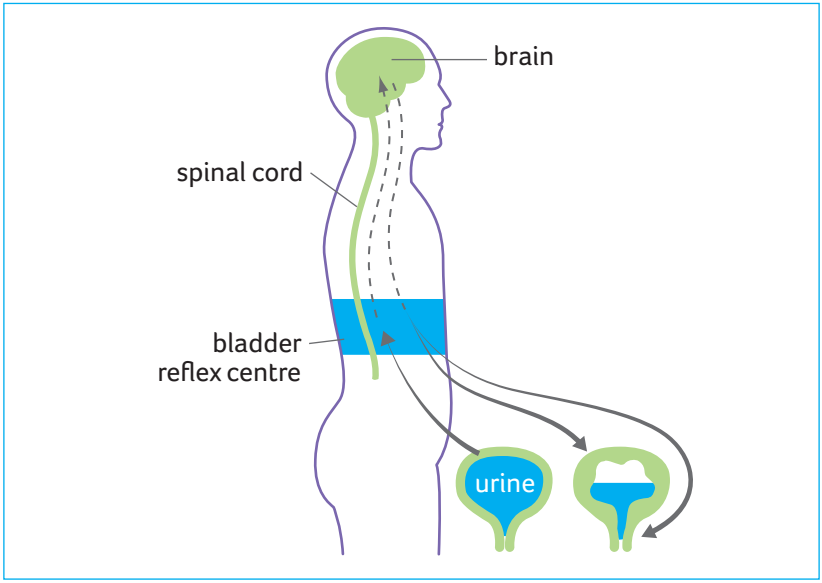
You have a sudden urge to go to the toilet or you're unable to hold on and reach the toilet in time – this is known as urgency.

You need to use the toilet more than eight times a day, sometimes as soon as half an hour after already going – this is called frequency.

"I feel as though my bladder has a life of its own."

These symptoms result from problems with your bladder storing urine. The bladder becomes overactive and spasms or tightens unpredictably, and sometimes uncontrollably. This results in an immediate or frequent urge to go, also known as overactive bladder (OAB).

In MS this happens because the messages that control when you empty your bladder are interrupted. This can result in the reflexes telling the bladder muscle to contract as soon as it starts filling.



Treatment options

Antimuscarinic drugs

Antimuscarinic drugs block the messages that start bladder contractions. This reduces how frequently you need to empty your bladder. They can also reduce sensations of needing to reach a toilet urgently. These drugs are taken orally as tablets or through skin patches. It can take up to four weeks before you see the full benefits of treatment.

Some examples of antimuscarinic drugs include:

- oxybutynin (Ditropan, Cystrin and Kentera)
- tolterodine (Detrusitol, Detrusitol XL)
- solifenacin (Vesicare)
- fesoterodine (Toviaz)
- trospium chloride (Regurin, Flotros)
- darifenacin (Emselex).

As with any drug, there's a chance you may experience side effects, although not everybody does. Antimuscarinics can cause dry mouth, constipation and blurred vision. They can also affect cognition, cause confusion and increase the risk of falls, particularly in older people. These side effects are known as the anticholinergic burden. Studies have shown that newer antimuscarinic drugs, such as solifenacin, tolterodine and fesoterodine, are associated with a lower risk of experiencing these side effects. They, therefore, tend to be preferred over the older drugs, like oxybutynin.

For people with advanced MS, or where cognition is more of a concern, darifenacin and trospium chloride may be more suitable.

Mirabegron (Betmiga)

Mirabegron (Betmiga) may be tried if antimuscarinics haven't been effective for you or if the side effects were too difficult to tolerate. The drug is taken orally as a tablet and works by relaxing your bladder muscle, allowing your bladder to fill and store urine more effectively.

Mirabegron can be used in combination with an antimuscarinic drug, or as an alternative.

Desmopressin

Desmopressin is a synthetic hormone that works by reducing the amount of urine the body produces. It's used to treat daytime and nighttime frequency. It may be offered to you if other drugs don't work well. Desmopressin may be given as a nasal spray or tablets. It can only be taken once in 24 hours, otherwise there is a risk of your body retaining too much water. It is not licensed for use in people over 65. Your sodium levels, weight and blood pressure will need to be monitored when taking this drug.

Botox injections

Botulinum toxin type A injections (Botox) are sometimes used if antimuscarinic treatments have not been effective. They work by stopping nerve messages to your bladder muscle and freezing its contraction. This can improve urinary continence and significantly reduce symptoms of an overactive bladder.

Following treatment with Botox injections, your bladder may no longer be able to empty itself. You may, therefore, need to be prepared for the possibility of using a catheter (see page 16 for more on catheters). You may wish to discuss this further with your bladder and bowel team, GP or urologist, before you decide to go ahead with treatment.

Botulinum toxin is injected into your bladder wall from the inside. The procedure is usually carried out under local anaesthetic. A fine tube, containing a very small telescope, is inserted into your bladder via the urethra. Then, around 20–30 injections are administered. The benefits generally last between 6 and 12 months, after which the procedure can be repeated.

"This was the best thing for me – it means I'm in control of my bladder at last."

Tibial nerve stimulation

If antimuscarinic medications haven't been effective and you don't want to try botulinum toxin, percutaneous tibial nerve stimulation (PTNS) may be offered. PTNS can also be used in combination with antimuscarinic medication.

The procedure involves having a small needle inserted near a nerve just above your ankle. A mild electric current is then passed through

the needle. This relaxes the nerves in your lower back that control bladder function.

You'll need at least 12 weekly sessions, lasting 30 minutes each. Effects may not last long after the sessions have stopped, so more sessions may be needed. But it's still a safe and effective treatment for some people.

Sacral nerve stimulation

This is a procedure used to treat overactive bladder. A device is implanted over your sacral nerve in the spine under anaesthetic. A wire in the implant sends mild electrical impulses to stimulate the nerves at the base of the spine. These nerves affect the bladder, pelvic floor muscles and urethral sphincter.

The implant works by reducing how often the nerves send signals to your bladder to empty.

It's not offered by all hospitals and may not be suitable or effective for everyone.

5. Problems emptying your bladder

Retention, hesitancy and intermittency

You feel as though your bladder hasn't emptied fully when you've been to the toilet – this is known as retention.

The flow of urine is interrupted or slow, or starting to pass urine takes longer than normal – this is called hesitancy and intermittency.

"I can be absolutely desperate to go to the loo and once I get there – I can't go!"

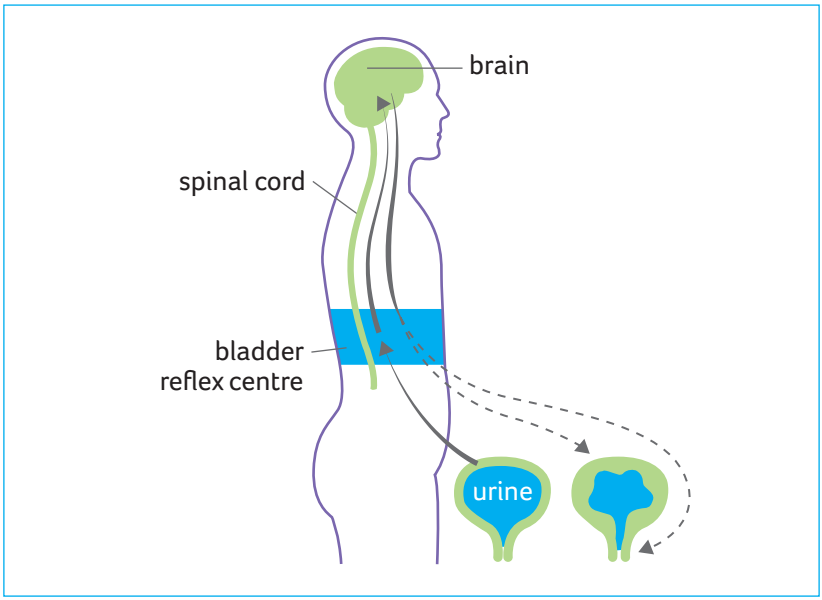
These symptoms occur because there may be problems with your bladder emptying properly. You might experience a reduced flow or an interrupted stream of urine. This is often accompanied by a feeling of your bladder not being completely empty.

For some people, these symptoms may be combined with feelings of needing to find a toilet quickly and often. This can lead to bladder accidents despite earlier efforts to empty the bladder.

There are several possible causes for difficulties emptying your bladder.

- The area of your spinal cord that controls the bladder emptying reflex may be damaged by your MS. As there is no signal to urinate, your bladder becomes very full, but you are unaware of how full it is, so leakage of urine may occur.
- Messages from the brain are confused, so when your bladder muscle contracts to start emptying, the valve which allows urine out of the bladder (the urethral sphincter) closes at the same time. This can block or interrupt the bladder's attempts to empty.

For some people, although urine may be easy to pass and flow normally, the bladder does not empty properly (retention). This happens when the area of the spinal cord which controls the emptying reflex becomes damaged. This can cause the bladder muscle to stop contracting before the bladder is empty.

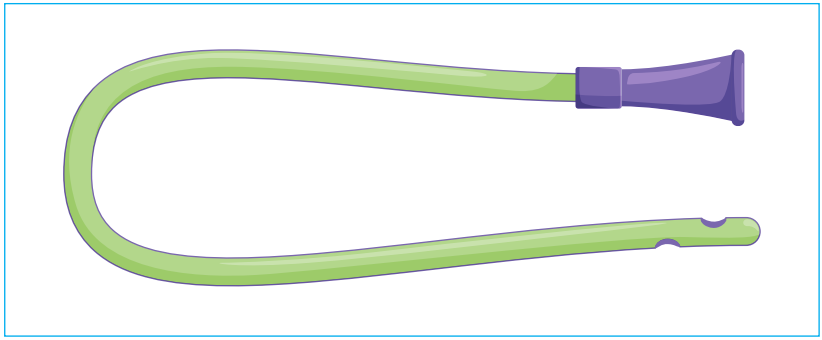


Treatment options

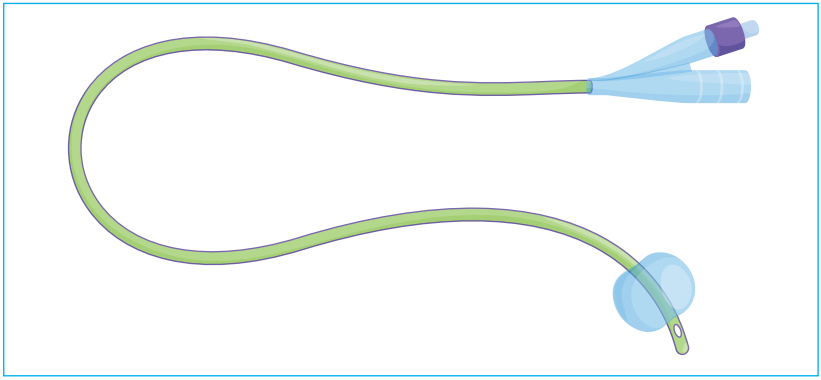
Catheters

If your bladder isn't emptying properly, your health professional may suggest using a catheter. A catheter is a thin, smooth, hollow tube that's used to drain urine from your bladder. There are a few different types of catheter available – intermittent, indwelling and suprapubic. They're all inserted and used in slightly different ways.

Intermittent catheter



Indwelling / suprapubic catheter



Intermittent catheters

Intermittent catheters are inserted into your bladder through the urethra – the tube that allows urine to pass out of your body. You carry out this process yourself by guiding a thin, smooth, hollow tube through your urethra and into your bladder until urine starts flowing out of the tube. The other end of the tube is left open so your urine can either be drained into a toilet or collected in a bag. Once the urine stops coming out of the tube, the catheter can be removed and disposed of. You may need to carry out this process several times a day, depending on how much urine you retain. This process is known as clean intermittent self-catheterisation (CISC).

Using a catheter can seem daunting at first. It's completely normal for it to take a little bit of getting used to – expect it to take some time and lots of practise before you feel fully confident. Your MS nurse or bladder and bowel specialist will go through the process with you. They'll support and reassure you until you feel confident using an intermittent catheter independently.

Using intermittent catheters can be a positive and life-changing step for some people. They can give you better control over your bladder. They can reduce the impact your symptoms have on your daily life and improve your confidence. Using CISC can also reduce the likelihood of urinary tract infections as they ensure the bladder is fully emptied.

“Using catheters means my bladder empties properly, and I get less of those awful water infections.”

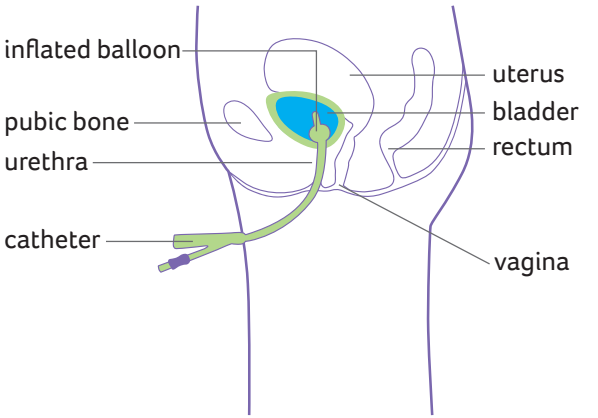
“The best thing I have used. I can empty my bladder before I go to bed and have a good night’s sleep.”

The process of inserting an intermittent catheter requires you to have good manual dexterity. For this reason, they’re not suitable for everyone. If this process would be difficult for you, your health professional may suggest an indwelling catheter instead.

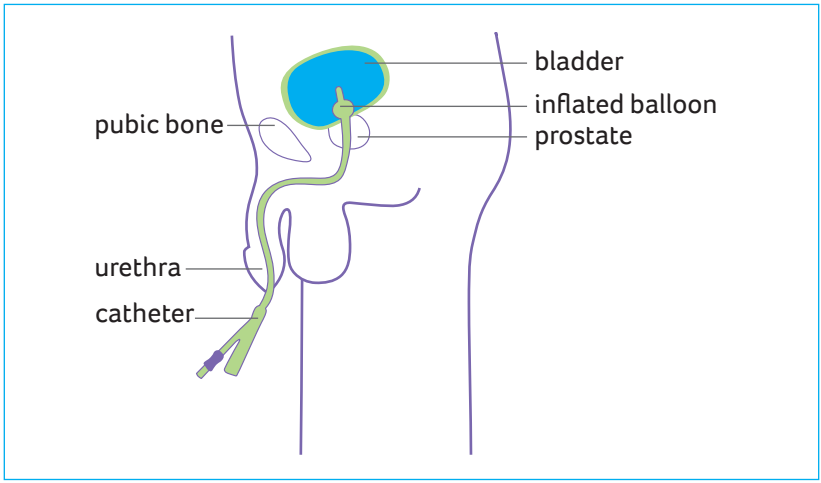
Indwelling catheters

Indwelling catheters are similar to intermittent catheters. They consist of a tube that’s guided through the urethra and into the bladder. However, they’re not removed after each use. Instead, an indwelling catheter is kept in place by a small, inflatable balloon that stops it falling out. Your urine drains out the other end of the tube and into a bag, which is discreetly attached to your leg using straps or a sleeve. The bag is then emptied into a toilet when it’s full. At night, the catheter may be attached to a night drainage bag that hangs by the side of your bed.

Female indwelling catheter



Male indwelling catheter



Some indwelling catheters can be used with a valve, rather than a bag, so you can empty your bladder directly into a toilet. When the valve is closed, your urine will collect in your bladder until you're ready to open the valve and empty your bladder. Valves are not always a suitable option and need to be discussed with a health professional.

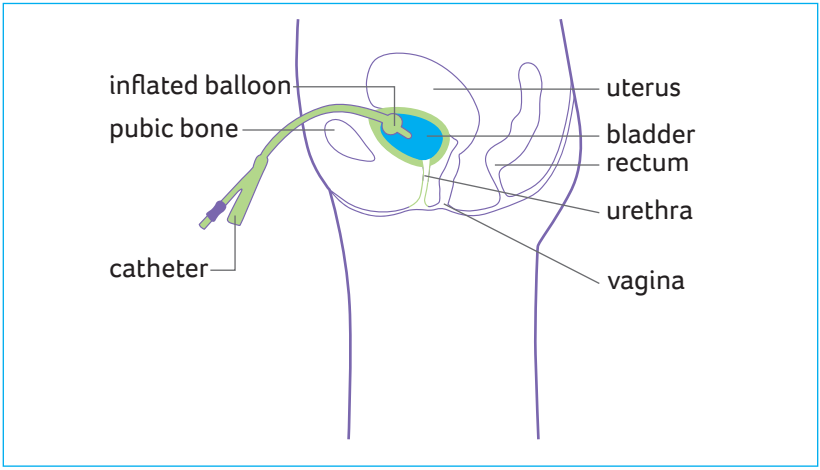
Your nurse will insert the catheter for you and teach you how to manage and empty it. Indwelling catheters usually need to be replaced at least every three months.

An indwelling catheter shouldn't stop you from having sex. Women can tape the catheter tube up onto their abdomen to keep it out of the way during sex. Men can fold the tube along the shaft of the penis and hold it in place with tape or a condom. A valve is a useful option during sex, so you don't have to worry about a drainage bag getting in the way.

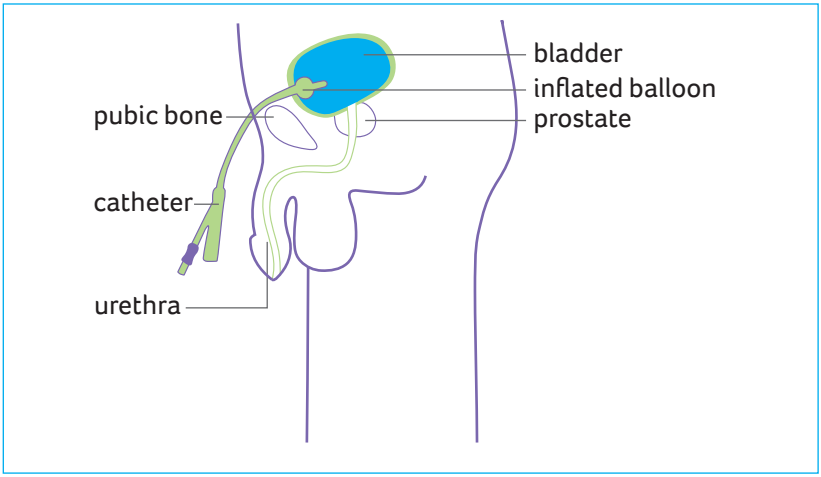
Suprapubic catheters

A suprapubic catheter is a long-term approach to bladder problems. It's inserted directly into your bladder through a hole in your abdominal wall and is left in place. This is a surgical procedure.

Female suprapubic catheter



Male suprapubic catheter



Once inserted, your urine drains through the tube and is collected in a drainage bag. It can be easily emptied when full. Drainage bags can be discreetly attached to your abdomen (belly bags) or your leg (eg, on your thigh or calf). Alternatively, you can use a valve which allows you to empty your bladder directly into the toilet. Your urine will be stored in your bladder until you open the valve. A drainage bag can be temporarily replaced with a valve during sex to avoid it getting in the way.

Some people prefer suprapubic catheters as they're less intrusive and usually easy to manage. They're also associated with less bladder infections and allow full sexual activity. Suprapubic catheters are usually changed every 4 to 12 weeks.

"My suprapubic catheter is fantastic for the waterworks – and saves energy by me not having to get to the loo in time, 10 times a day."

Your health professional may give you a catheter passport. This contains information about how to care for your catheter at home. It ensures anyone involved in your care (such as a carer or nurse) has the right information about your catheter and its management. You should take it with you to all healthcare appointments, hospital stays and when you travel.

Suprapubic vibration

There is some limited evidence to suggest that a vibration device or buzzer, such as the Queen Square bladder stimulator, placed over the pubic area can help with bladder emptying. It's thought to work by helping the muscle at the bottom of the bladder (the urethral sphincter) relax. This can improve emptying if hesitancy is a problem.

6. Bladder accidents

Some people with MS experience bladder accidents, also known as urinary incontinence. Fear of having an accident can be one of the most worrying things.

There are different types of urinary incontinence.

- Urge incontinence – where you feel a sudden urge to go and you can't reach the toilet in time.
- Stress incontinence – where you experience leaks when you cough, laugh or sneeze.
- Mixed incontinence – a combination of urge and stress incontinence.
- Overflow incontinence – where your bladder doesn't fully empty, resulting in leaks.

There are many different types of products available to help you manage bladder accidents. They can be valuable as a backup whilst you're undergoing treatment. For some people, they may also be useful in the long term.

These include continence pants and pads, which come in a variety of sizes and shapes. Some pads are disposable, other pads can be washed and reused. Products such as penile sheaths for men (also known as external or condom catheters) can help contain urinary leakage. These are fitted over the penis like a condom. A tube drains off any urine into a bag attached to your leg. For men and women, handheld urinals are available that you can use when you're out and about. These are non-invasive and discreet. Some are disposable, others can be washed and reused. Bed urinals for men and women are available on prescription to avoid the need for getting out of bed at night. Finally, if you need to get to the toilet in a hurry, clothing that's easy to undo may also help prevent accidents.

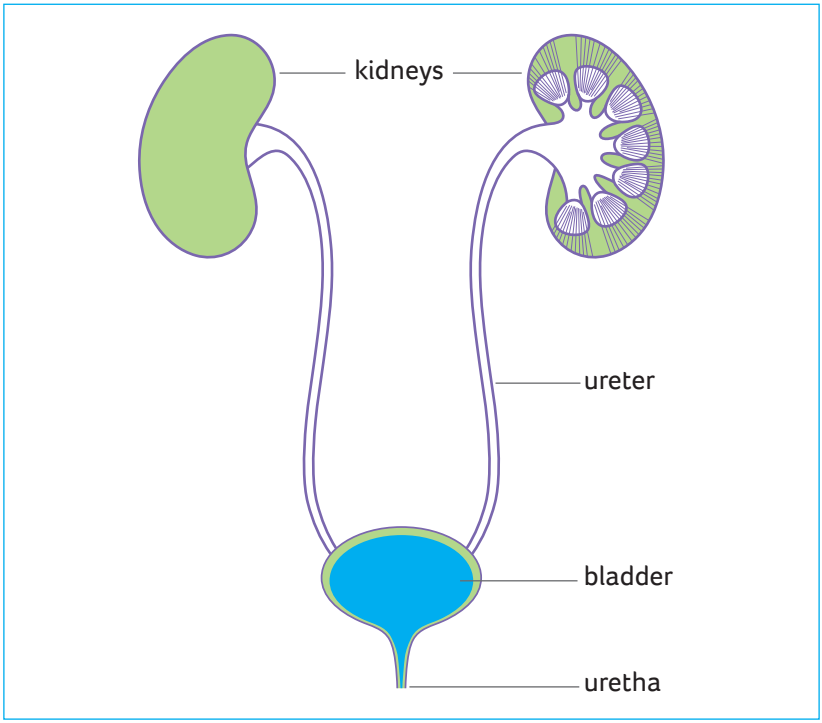
“I’ve found that zips or Velcro instead of buttons on flies are a big help.”

You can find more information about all these products from your local bladder and bowel service. The Bladder and Bowel Community, Continence Product Advisor and Bladder and Bowel UK are also good sources of support (see pages 35–6).

Some incontinence products, such as pads, are available on the NHS. Your local bladder and bowel service will be able to tell you whether you qualify following an assessment.

7. Urinary tract infections (UTIs)

The urinary tract includes the kidneys, ureters, bladder and urethra. Urinary tract infections (UTIs) can affect any area of the urinary tract, although most commonly they occur in the bladder and urethra.



UTIs are common in MS. They're often caused by the bladder not emptying properly which provides an opportunity for bacteria to grow. It's important that UTIs are detected early and treated appropriately. They can worsen other MS symptoms, such as muscle stiffness and spasms, and in some cases trigger a relapse if left untreated.

If you have a UTI, you may experience some or all of the following symptoms, although for some people there are no symptoms at all.

Symptoms can include:

- a frequent urge to urinate
- a painful or burning sensation when urinating
- generally feeling tired or washed out most of the time
- a painful bladder or abdomen, even when not urinating
- passing a small amount of urine, even though there's an urge to pass more
- milky or cloudy urine that smells unusual
- a high temperature
- a pink, red or brown tinge to your urine.

To check for a UTI, your health professional will ask for a sample of your urine. This is tested for bacteria using a small, chemically treated stick (dipstick). The stick is dipped into your urine sample. If bacteria are present, it will change colour, suggesting you may have a UTI.

Symptoms of a UTI can be confused with other MS symptoms, such as fatigue or existing bladder problems. It's important to have your urine checked for infection if you're feeling generally unwell or you experience a worsening of existing symptoms. If there's a flare up of your MS symptoms and you suspect a relapse, your urine is likely to be checked to rule out infection as the cause.

Where MS is very advanced, UTIs may lead to sepsis. This is where the infection spreads to other parts of the body, causing the immune system to go into overdrive. This may be life threatening.

If you're at higher risk of a UTI, you may be offered a urine testing kit to keep at home in case you develop symptoms. This helps to speed up the diagnosis and treatment of a UTI. Home testing kits are only available in some areas. Speak to your MS nurse for more information.

Treatment options

UTIs are treated with a course of antibiotics. If your symptoms continue, let your health professional know as you may need to try a different antibiotic. Drink plenty of liquids to flush out your bladder. Increasing the frequency of self-catheterisation, if you use a catheter, may also help.

Tips for preventing UTIs

There are simple lifestyle changes you can make to reduce the chances of you getting a UTI. These include:

- drinking six to eight glasses of fluid in 24 hours (to avoid dehydration)
- making sure you're not constipated
- wiping from front to back after using the toilet (to stop any bacteria entering the urinary tract)
- regularly emptying your bladder
- maintaining good hygiene generally, and before and after sex.

Anecdotally, some people find complementary options helpful for reducing the frequency of UTIs. This includes food supplements – in particular d-mannose and probiotics – and cranberry juice. But, high quality evidence supporting the effectiveness of these treatments is lacking.

Sometimes a urinary antiseptic can be used, such as methenamine hippurate (Hiprex), to treat and prevent UTIs. This is a tablet that can be prescribed by your GP. It's generally considered safe, although large-scale studies in people with MS are lacking.

8. Getting to know your bladder

Keeping a bladder diary

This can give you an overview of how your bladder problems affect you over time. You can share it with your health professionals to show what your bladder patterns are.

Make a note of what you eat and drink, and any medication you take. You can also keep track of when you go to the loo, any problems with stopping or starting, and if you have any bladder accidents. Some people like to record the effects of exercise too.

If you make any changes, the diary can help you see how this affects your bladder symptoms. This could include starting a new medication or reducing how much caffeine you drink.

"It can be useful to know how much a cup/glass/mug holds as sometimes we believe we are drinking a lot more than we actually are."

You might use quite a formal chart like the one below, or a diary or app.

Time	Food or drinks	Toilet visits	Comments
7am	Cup of tea		
9am		Yes	Needed to rush
11am		Yes	Leaked a small amount of urine
12pm	Glass of water		
1pm	Sandwich	Yes	Didn't feel like bladder emptied properly

"I write briefly what I'm doing differently – eating, drinking or exercising."

9. Tips to improve bladder function

There are simple lifestyle changes that can make a real difference to your bladder problems.

Drinking enough fluids

Make sure you're drinking enough fluids throughout the day. The general guidance is to drink at least 1.5 litres of fluid in 24 hours, or about six to eight glasses. You should drink more if the weather is hot or when exercising. If you don't drink enough fluids and become dehydrated, your urine becomes more concentrated. This can irritate the bladder and create a good environment for infection. Your urine should be pale or straw-coloured; if it's a darker yellow than this, it can be a sign that you're dehydrated.

Drinking too much can make bladder symptoms worse, increasing the number of visits to the toilet and the urgency to urinate. Getting the right balance is important.

Avoiding food and drink that can irritate your bladder

Food and drink that can irritate your bladder are listed below. Some people find that reducing or cutting these out completely can help with their bladder symptoms. Keeping a record of any dietary changes you make can help you see whether any particular food or drink affects your bladder.

- *Drinks that contain caffeine* – such as coffee, tea, green tea and hot chocolate can cause irritation directly to the bladder lining.
- *Alcohol* – can cause dehydration and more concentrated urine.
- *Fizzy drinks* – carbonated and highly coloured drinks have been shown to worsen some bladder symptoms.
- *Acidic fruit and juices* – such as citrus fruits including grapefruit, orange, lime, lemon and tomato.

- *Spicy foods* – studies suggest that people who avoid spicy foods, like curry, chilli pepper and cayenne pepper, may reduce their bladder symptoms.

"My MS specialist nurse told me to cut down on caffeine and I just couldn't believe the difference it made."

Maintaining a healthy weight

Maintaining a healthy weight through regular exercise and a healthy, balanced diet is important. Being overweight can increase the pressure on your pelvic floor muscles. This can result in stress incontinence – where urine leaks out of your bladder when it's under pressure. Common examples of this are leaking when sneezing, coughing, exercising or standing up.

Public Health England has a resource called the Eatwell Guide which is available to download on the NHS website **(nhs.uk)**. It provides recommendations on eating healthily and achieving a balanced diet.

If you're considering a new exercise regime, a physiotherapist can advise on exercises that will best suit you and your ability.

Stopping smoking

Nicotine in cigarettes can irritate your bladder. Reducing how often you smoke, or stopping smoking completely, may improve your symptoms.

"Changing little things can make a big difference."

Strengthening your pelvic floor muscles

Your pelvic floor is a sheet, or hammock, of muscles that extends from your tailbone (coccyx) at the bottom of your spine to your pubic bone (at the front). They form the 'floor' to your pelvis and support your bladder and bowel. Pelvic floor muscles relax at the same time as the bladder contracts (tightens) to let your urine out.

In MS, neurological damage can result in weakness to the pelvic floor. Damaged nerves, mainly within the spinal cord, don't send messages to the pelvic floor muscles as well as they used to. This can be made worse by factors such as giving birth, getting older or having surgery in this area of the body.

Pelvic floor exercises can help urinary incontinence. Men and women can do them. It may take several weeks of regular exercise before you start to regain strength in your pelvic floor muscles.

Find your pelvic floor muscles by trying to stop the flow of urine when you go to the toilet. Once you've felt these muscles, you can strengthen them by squeezing the muscles 10–15 times in a row. As your muscles get stronger, you can try holding the squeeze for longer. It can help to do these exercises multiple times a day and build them into your daily routine.

There are apps you can use to build an exercise plan and remind you to do your pelvic floor exercises, such as NHS Squeezy **(squeezyapp.com)**.

'Holding on' – bladder training

The aim of bladder training is to teach your bladder to hold more urine and increase the amount of time between going to the toilet. You gradually increase the time between urinating by waiting when you feel the urge to go – this can be by just five minutes. It may take weeks or months to be effective. Your bladder specialist or MS specialist nurse can put together a timetable to support you to achieve this. They can also teach you techniques to distract you from the urgent sensation, helping delay your need to use the toilet.

"When you go to the toilet, wait for a minute or so and try to go again, you may find a little more comes out and this can reduce the frequency of visits to the toilet."

Other approaches

Hyperbaric oxygen therapy

Hyperbaric oxygen (HBO) therapy involves breathing oxygen through a mask in a pressurised chamber, like a diving bell. Treatment usually consists of an initial course of around 20 sessions, each lasting an hour, spread over one month. Follow-up treatment is then needed at less frequent intervals. Anecdotal evidence suggests that some people find it helpful for fatigue and bladder symptoms. In the UK, hyperbaric oxygen therapy is available through most MS Therapy Centres (see page 35).

10. Working with your health professionals

Before starting any treatment for bladder problems, you should have the opportunity to consider all the options. Make sure you ask all the questions you need to and discuss any concerns you may have. It's also important to have realistic expectations of what the treatment can offer and what the drawbacks may be. Knowing clearly what you'd like the treatment to achieve can be helpful. This means you and your health professionals are more likely to be working towards the same goal.

"I want to be able to see a film at the movies without having to go to the toilet halfway through."

It can be useful to think of questions in advance and take them to your appointment. The following are some examples.

- How long will it take to see any changes?
- When will we review how things are going?
- What if the treatment doesn't work?
- How can I get in touch if I have any problems? Is there a direct number or email?

If you're unsure of anything that's discussed in your appointment, don't be afraid to ask for a further explanation. You can also ask for copies of any letters sent between your GP and other health professionals, including hospital consultants. This keeps you informed and helps you to remember what was said.

You should be able to discuss or review your treatment with your health professionals at regular intervals or when your circumstances change. This can include changing your mind about treatment.

"If at first it doesn't succeed, try, try and try again! Don't be afraid to ask your MS specialist nurse or GP to change your medication if you feel it's not working."

It is important to continue with treatment, but if it's not working ask what's next. It may take some time to find the approach that works best for you.

11. Living well with bladder problems

You may find that bladder problems impact on other areas of your life. This may include feeling more apprehensive about being in certain everyday situations. Or you may notice changes in your mood and feel less confident. This may have a knock-on effect on your working life, social plans and intimate relationships.

Being proactive and seeking treatment for your bladder problems can help ease these anxieties and concerns. This can help you feel more confident in your daily life going forward.

Here we look in more detail at the areas of your life that may be affected by bladder issues and the steps you can take to lessen the impact.

"My bladder problems have left me feeling low and with little confidence."

Living with bladder problems can understandably affect your emotional wellbeing and self-esteem.

Low mood, depression or anxiety can come on suddenly or creep up on you bit by bit without you realising. Talking things through with family, friends or peer support groups can help with low mood. But, if life is becoming a real struggle, don't suffer in silence. Consider seeking professional advice from your MS specialist nurse or GP. There are many treatment options, including lifestyle changes, talking therapies and medication.

If bladder problems, or having MS generally, has changed how you see yourself and reduced your confidence, there are strategies you can try. It can help to look for the positives in your life, keep a sense of normality and continue to do the things you enjoy. Try to be kind to yourself and take care of your physical and mental wellbeing. Eating healthily, exercising and taking the time to do activities that help you relax, and you enjoy, can all have a positive impact.

Remember, MS and the symptoms it brings don't define you. You're a person who happens to have MS – it's not your entire identity.

Further mental health resources are listed on page 36.

"I worry about having to use the toilet lots when I'm at work."

If you need to use the toilet more frequently, or suddenly, when you're at work, you might find it helpful to disclose your MS diagnosis to your employer. They must then make reasonable adjustments under the Equality Act to ensure you're not put at a disadvantage because of your diagnosis. Reasonable adjustments may include having a desk nearer to the toilets and being able to take more frequent breaks.

"The logistics of managing my bladder while out with friends is really stressful."

Venturing out when you have bladder problems can bring feelings of anxiety. Many people find that researching where toilets are located beforehand can make you feel more in control and reduce your anxiety.

There are a range of resources that can help you when out and about, including access to locked public toilets through the National Key Scheme, 'just can't wait' toilet cards, and community toilet schemes. There are also apps to help you find toilets. Read more about these tools on pages 36–7.

"Bladder problems are affecting intimacy with my partner."

Bladder problems can cause great anxiety when it comes to sex and wanting to be intimate. You might worry you'll lose control and have an accident when you're having sex, making you want to avoid it altogether.

If this is the case for you, you could start by having a conversation with your partner about your concerns and how you're feeling. This can help clear up any misunderstandings about why you're avoiding intimacy.

Speaking to your MS nurse or bladder and bowel specialist about the impact your bladder problems are having on your sex life is important. Many health professionals are used to talking about sex. There's no need to feel uncomfortable or embarrassed about sharing intimate details with them. They can make suggestions that may help, such as going to the toilet before sex, so you can relax knowing that your bladder has been emptied.

Further resources on sex and MS can be found on page 36.

12. Sources of help and support

People

There may be a range of health professionals involved in the treatment of your bladder problems, depending on your symptoms.

MS specialist nurse

MS specialist nurses provide specialist clinical advice and support to people with multiple sclerosis. They often act to coordinate services for people with MS, referring someone on to a doctor, therapist, or other appropriate services. To find your MS specialist nurse, see the map of MS services on the MS Trust website.
mstrust.org.uk/map

Bladder and bowel services

These services are made up of experienced, qualified nurses who have undertaken specialist training to help people with bladder and bowel problems. Many services accept self-referral or ask your GP or MS specialist nurse to refer you.

Specialist physiotherapist

Physiotherapists who are experienced in the assessment and treatment of neurological conditions can devise and support you with exercise, pelvic floor and bladder training programmes. Your GP or MS specialist nurse can refer you.

Urologist

Urologists specialise in treating conditions affecting the urinary tract, such as bladder and continence problems. Urology also covers conditions affecting the male reproductive system, such as erectile dysfunction.

Urogynaecologist

Urogynaecologists provide a specialist service for women with urinary incontinence and pelvic floor issues.

Organisations

Bladder and Bowel Community

The Bladder and Bowel Community is a charity providing information and support for people with all types of bladder and bowel related problems and their families, carers and health professionals. You can search for your local continence service on their website. They also run a Home Delivery Service for a range of continence products.
bladderandbowel.org

Bladder Health UK

Bladder Health UK supports people with cystitis, overactive bladder and continence issues. They provide information through their website, booklets and fact sheets. They also have an online forum to enable people to support each other online, as well as an advice line.
Helpline: 0121 702 0820
bladderhealthuk.org

Multiple Sclerosis Therapy Centres

MS Therapy Centres are local charities that provide a range of non-drug therapies for symptom management. Therapies offered vary at each centre, but often include hyperbaric oxygen therapy and physiotherapy, as well as support for people with MS and their families. To find your nearest Therapy Centre see the map of MS services on the MS Trust website.
mstrust.org.uk/map

Continence Product Advisor

The Continence Product Advisor website is a not-for-profit collaboration between the International Consultation on Incontinence and the International Continence Society. The website provides evidence-based information on a wide range of continence products.
continenceproductadvisor.org

Bladder and Bowel UK

Bladder and Bowel UK offers advice, support and practical help for people with bladder and bowel problems. They provide information resources and have a confidential helpline which is managed by a team of specialist nurses and continence product information staff. They also provide a wide range of continence products which can be ordered on their website or through their helpline. Bladder and Bowel UK is part of the wider charity, Disabled Living.
Helpline: 0161 214 4591
bbuk.org.uk

MS Trust

The MS Trust website has more on bladder and bowel problems, as well as a range of information on all aspects of living with MS.
mstrust.org.uk/bladderandbowel

Mental health and wellbeing mstrust.org.uk/wellbeing

MS Trust Facebook group mstrust.org.uk/fb-group

Support groups mstrust.org.uk/support

Sexual problems for men with MS mstrust.org.uk/men

Sexual problems for women with MS mstrust.org.uk/women

If you have questions about MS, our helpline can help you find the information you need.

Tel: 0800 032 3839 (Monday to Friday, 9am to 5pm)
Email: ask@mstrust.org.uk

Public toilets

National Key Scheme (NKS)

Disability Rights UK is responsible for the National Key Scheme (NKS) that was previously run by RADAR. For a small charge, a key is provided that gives people with a disability access to many locked public toilets around the country. A guide to the location of toilets in the NKS scheme is available to purchase.
disabilityrightsuk.org

Toilet card

A toilet card, sometimes called a 'no waiting card' or a 'just can't wait card', is a discreet credit card sized card which states that the holder has a medical condition and needs to use the toilet urgently. The card will not guarantee preferential treatment, but most places will usually try to help. These cards are produced by the Bladder and Bowel Community and Bladder Health UK.
bladderandbowel.org
bladderhealthuk.org

Mobile phone apps

Apps have been developed to help locate the nearest toilet and to keep track of bladder function.

Changing Places toilets

Changing Places toilets provide more space and equipment for people who cannot use standard accessible toilets. They have a large changing area, adjustable changing bench and a hoist system. There are hundreds of Changing Places toilets in the UK in major shopping centres, airports, train stations and town centres. You can search for toilets on the Changing Places website.
changing-places.org

The Great British Toilet Map

You can search for your nearest public toilet using this online map. It's the UK's largest database of publicly accessible toilets.
toiletmap.org.uk

Community toilet schemes

Some councils run community toilet schemes which allow members of the public to use toilets in local businesses for free, without having to make a purchase or use their services. Participating businesses usually display a poster or sticker in the window that shows they're part of the scheme. Contact your local council to see whether a scheme is running in your area.
gov.uk/find-local-council

About the authors

Information Team, MS Trust

We are a UK charity that believes nobody should have to manage multiple sclerosis alone. We are here for everyone affected by MS, from the moment of diagnosis and throughout their journey.

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