

Managing your bladder

A guide for people with MS



We hope you find the information in this book helpful. If you would like to speak with someone about any aspect of MS, contact the MS Trust information team and they will help find answers to your questions.

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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 successfully 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 appropriate 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 is like to live with bladder problems and draws on the experience of health professionals including MS specialist nurses and continence advisors.

1. Talking about bladder problems

Toilet talk is common if you have young children but we don't expect to have to think about it again in later life. Research has shown that six out of ten people aged 40 or over with bladder problems have never discussed these with a doctor or nurse. Many people feel a sense of shame and embarrassment about bladder problems and feel awkward raising them with health professionals.

It's important to remember that 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 continence advisor will be aware that MS can have an impact on how the bladder works, so 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 have to 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 pleased to be able to share their stories.

“Out with very close friends I was talking about my bladder problems when the 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.”

Many hospitals and local primary care services have a continence advisor, or continence nursing service, that deals specifically with bladder and bowel problems. In some areas you may be able to refer yourself directly to continence services, or else your MS specialist nurse or GP can make a referral.

“I’ve got problems with water works.”

“I just tell it like it is – I feel it’s best to be honest.”

“I tend to just say ‘I can’t pee’.”

“Say whatever comes to mind! Depends who it is!”

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

2. When should I contact a health professional?

If you are worried about how your bladder problems are affecting your life, if things have changed or you have any questions about medication you are taking, don't hesitate to contact your health professional. Specifically this might be if:

- you experience bladder accidents, and you avoid important activities because of it
- you often feel an urgent need to urinate and rush to a bathroom, but sometimes don't make it in time
- you go to the toilet much more often than you used to, during the day and 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 that your urine stream is getting weaker, or you feel as if you haven't fully emptied your bladder.

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 and sharing this with your health professional can help you to describe this during your appointment (see page 24 for more on keeping a bladder diary).

When you see your health professional they will take a full history of your symptoms, and 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’. Your urine will be tested for bacteria using a small, chemically treated stick (known as a dipstick) that is dipped into your urine sample. If bacteria are present it will change colour, indicating you may have a urinary tract infection (UTI).

Bladder ultrasound

If there is no sign of a urinary tract infection, the amount of urine left in your bladder after urinating will be measured. This is carried out with a simple ultrasound scanner which is gently applied to your lower abdomen and moved over the skin. This creates an image of your bladder and shows how much fluid is left inside.

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

The results will enable your health professional to understand the cause of the problem and to work with you to find the most appropriate approach to treatment.

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

- enlarged prostate in men
- pregnancy and childbirth can weaken pelvic floor muscles in women
- infection in the urinary tract (water infection)
- abdominal surgery
- caffeine and alcohol consumption.

3. How your bladder works

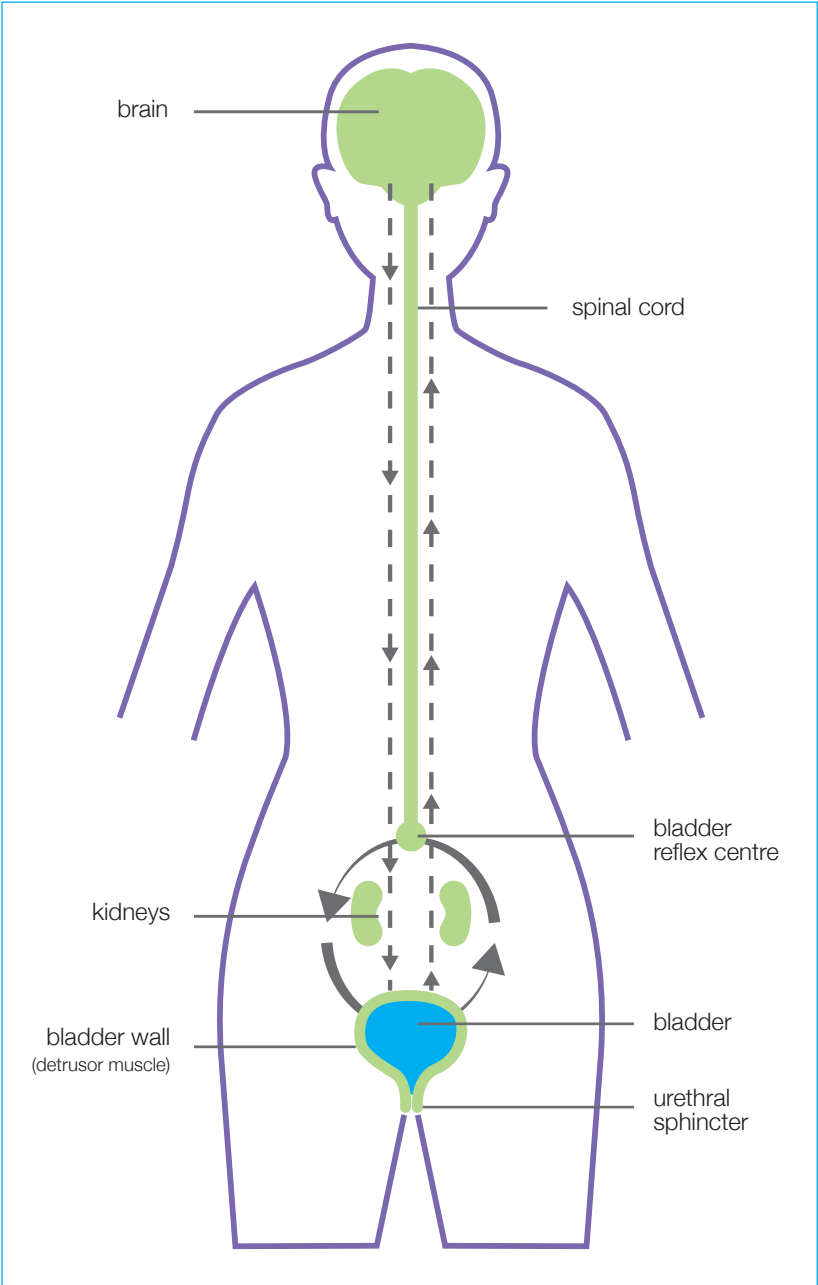
The bladder has two main functions.

- Storing urine.
- Emptying urine at an appropriate time.

The kidneys filter your blood to collect waste products and create urine which is stored in your bladder. The bladder wall is a bag-like muscle (called the detrusor muscle) that can expand and contract. When urine reaches a certain level, nerve endings in the bladder wall send a message to the part of the spinal cord that controls your bladder emptying reflex.

This area of the spinal cord then sends messages to your brain, letting you know that you need to go to the toilet. These messages can be controlled by your brain until there is an opportunity for you to get to a toilet. When you've found an opportunity to go, your brain sends messages back through the spinal cord and onto your bladder, telling it to contract and the muscle at the bottom of the bladder that acts like a tap or valve (the urethral sphincter) to relax. This allows 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, equivalent to 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 and it's rarely completely empty, with about 10% of urine left after a visit to the toilet.



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 and the symptoms you experience will depend on which areas have been 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 lead to symptoms such as needing to go to the toilet immediately (urgency) and needing to go to the toilet often (frequency) during the day and night (nocturia). Occasional bladder accidents may also occur 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 a feeling of the bladder not emptying properly (retention).

4. Problems storing your urine

Urgency and frequency

You have a sudden urge to go to the toilet or are 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 has a tendency to spasm or tighten unpredictably and sometimes uncontrollably, resulting in an immediate or frequent urge to go. This is also known as overactive bladder.

In MS this happens because messages are interrupted between the bladder emptying reflex in your spinal cord and the part of your brain that has control over when you empty your bladder. This can result in the reflexes telling the bladder muscle to contract as soon as it starts filling.

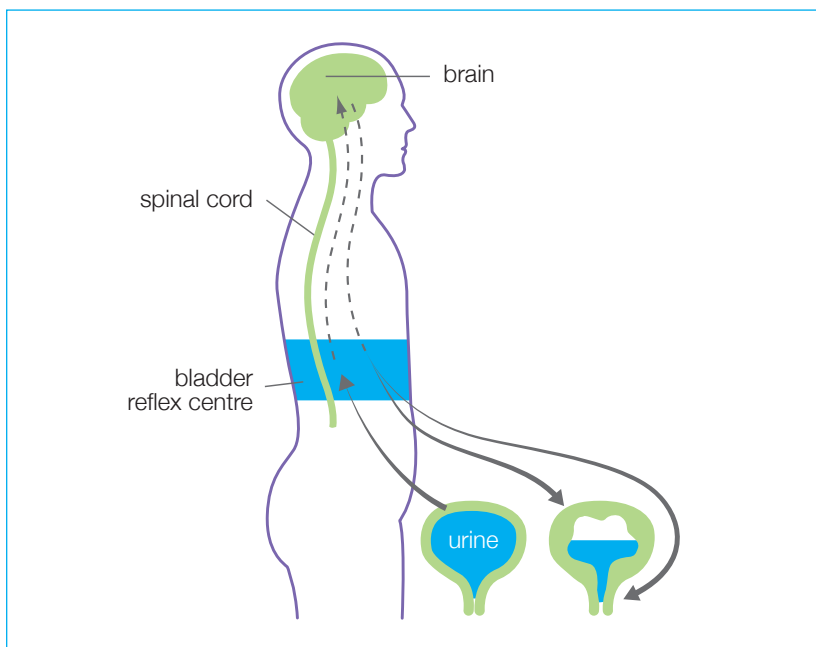
When you see your health professional about urgency or frequency problems, they may carry out the following investigations.

Urine test

As symptoms from urinary tract infections can be similar to those of other bladder problems, your health professional may ask for a urine sample so they can test for any infection.

Bladder ultrasound

You may also need to have an ultrasound of your bladder to check the volume of urine left in your bladder after going to the toilet. If this is less than 100ml, your symptoms are most likely to be due to problems storing your urine.



Treatment options

Antimuscarinic drugs

Antimuscarinic drugs block the messages that start bladder contractions, reducing how frequently you need to empty your bladder. They can also reduce sensations of urgently needing to reach the toilet. These drugs are taken orally as tablets or through skin patches. Some examples of antimuscarinic drugs include oxybutynin (Ditropan, Lyrinel XL, Cystrin and Kentera), tolterodine (Detrusitol, Detrusitol XL), solifenacin (Vesicare), fesoterodine (Toviaz) and trospium (Regurin, Flotros). It can take up to four weeks before you see the full benefits of treatment. As with any drug, there's a chance you may experience side effects although not everybody does – these can include constipation, dry mouth, and dry eyes in some people. Studies have shown that solifenacin and trospium produce fewer side effects.

Mirabegron (Betmiga)

Mirabegron (Betmiga) is another option if antimuscarinics haven't been effective for you or if the side effects were too difficult to tolerate. The drug is taken orally as tablets and works by relaxing your bladder muscle, allowing your bladder to fill and store urine correctly.

Desmopressin

Desmopressin is a synthetic hormone that works by reducing the amount of urine the body produces. It's used to treat day and night time frequency and it may be offered to you if other drugs don't work well. Desmopressin is available as tablets or a nasal spray. It can only be taken once in 24 hours and it is not licensed for use in people over 65.

Bladder 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 muscles and freezing their contraction, improving urinary continence.

Following treatment with Botox injections, your bladder may no longer be able to empty itself so you may need to use a catheter (see page 18 for more on catheters). You may wish to discuss this further with your continence team before you decide to go ahead with treatment.

Botulinum toxin is injected into your bladder wall from the inside. The doctor will use a fine tube, also containing a very small telescope, inserted through your urethra into your bladder to give the injections (approximately 30). This is usually carried out under local anaesthetic. 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.”

Nerve stimulation

If antimuscarinic medications have not been effective and you don't want to try botulinum toxin, percutaneous tibial nerve stimulation (PTNS) may be offered.

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

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

5. Problems emptying your bladder

Hesitancy and retention

You don't feel as though your bladder has 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.

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

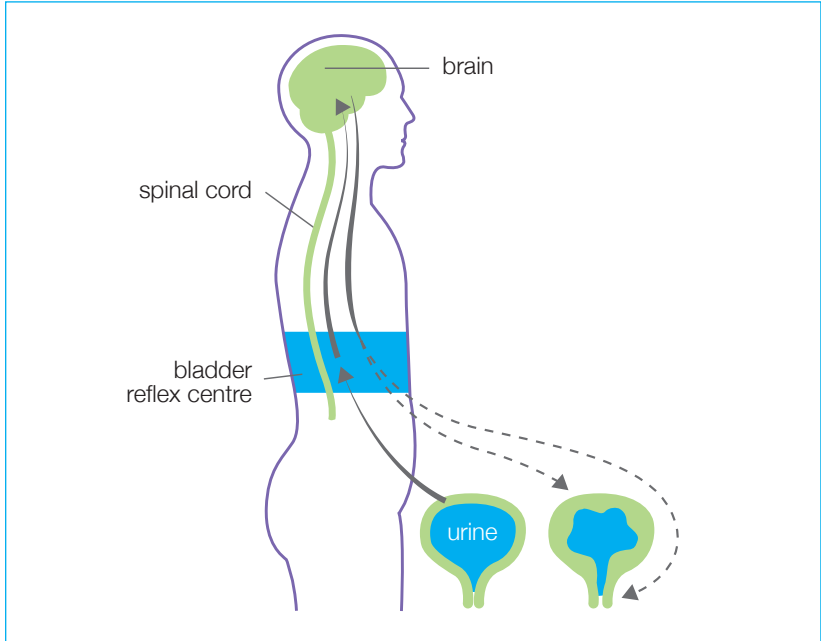
These symptoms occur because there are problems with your bladder emptying. You might experience a reduced flow or an interrupted stream of urine, often accompanied by a feeling of your bladder not being completely empty.

For some people, these symptoms may also be combined with feelings of needing to find a toilet quickly and often. This can lead to bladder accidents in spite of 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 that 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, blocking or interrupting the bladder's attempts to empty.

For some people while urine may be easy to pass and may 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, causing the bladder muscle to stop contracting, or tightening, before the bladder is empty.



When you see your health professional about hesitancy or retention problems, they may carry out the following investigations.

Urine test

As symptoms from urinary tract infections can be similar to those of other bladder problems, your health professional may ask for a urine sample so they can test for any infection.

Bladder ultrasound

You may also need to have an ultrasound of your bladder to check the amount of urine left in your bladder after going to the toilet. If this is greater than 100ml, your symptoms are most likely to be due to your bladder not fully emptying.

Treatment options

Catheters

If you have problems emptying your bladder, your health professional may suggest using a catheter. A catheter is a thin, 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 are all inserted and used in slightly different ways.

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, 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'll usually need to carry out this process several times a day – this 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 nurse or continence advisor will go through the process with you and fully support and reassure you until you feel confident using a catheter independently.

Catheters can be a really positive and life-changing step for some people. They can give you better control over your bladder, reducing the impact your symptoms have been having on your daily life and improving your confidence. Using an intermittent catheter can also reduce the number 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 and for this reason, they are 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 rather than being removed after each use, an indwelling catheter is kept in place by a small, inflatable balloon attached to the bladder end that stops it falling out. Your urine drains out the other end of the tube and into a bag which is usually attached to your leg using Velcro straps. The bag can easily be 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.

Some indwelling catheters come 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 the catheter is emptied.

Your nurse or continence advisor will fit 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.

Suprapubic catheters

A suprapubic catheter is a more 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. Once inserted, your urine is collected in a bag that is attached either to the side of your body or your leg – it can be easily emptied when full. Some people prefer suprapubic catheters as they are less intrusive, are usually easy to manage and allow full sexual activity. Suprapubic catheters are usually changed every six to eight weeks.

“Suprapubic catheter is fantastic for the waterworks – and saves energy by not having to get to the loo in time, 10 times a day.”

Suprapubic vibration

There is some evidence to suggest that a vibration device or buzzer, such as the Queen Square bladder stimulator, placed over the pubic area can help the muscle at the bottom of the bladder that acts like a tap or valve (the urethral sphincter) to relax and improve emptying if hesitancy is a problem.

6. Bladder accidents

Many people with MS experience continence difficulties, some of which can cause occasional bladder accidents. Fear of having an accident can be one of the most worrying things. There are many different types of products available to help you manage this which can be valuable as a backup whilst you are undergoing treatment and, for some people, these 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. There are also a number of products such as penile sheaths for men (also known as external or condom catheters) that 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 women, handheld urinals are available that you can use when you are out and about. These are non-invasive and discreet. 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 of these products from your local continence service, the Bladder and Bowel Community, the Continence Product Advisor website and Bladder and Bowel UK (see sources of help and support on page 33).

Some incontinence products, such as pads, are available on the NHS. Your local continence service will be able to advise on whether you qualify. This will usually involve an assessment.

7 . Urinary tract infection (UTI)

Urinary tract infections are common in MS. They're often caused by the bladder not emptying properly which provides an opportunity for bacteria to grow. It is important that UTIs are detected early and treated appropriately as 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 symptoms below, although for some people there are no symptoms at all:

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

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 and if bacteria are present it will change colour, suggesting you may have a UTI.

Treatment options

Urinary tract infections 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. Drinking plenty of liquids to flush out your bladder or 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 a day 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, and increasing how often you use a catheter.

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 demonstrate accurately what your bladder patterns are.

Write down what you have to eat and drink, any medication you take, when you go to the loo, any problems with stopping or starting, and if you have any bladder accidents.

If you make any changes, for example the amount of caffeine you drink or starting a new medication, the diary can help you to see how this affects your bladder symptoms.

“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 something more informal like a diary.

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.”

There are also smart phone apps available to help you monitor and keep track of your bladder function.

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 a day, or about six to eight glasses (more if the weather is hot or when exercising). If you don't drink enough fluids and become dehydrated, your urine becomes more concentrated which 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 an indication that you're dehydrated.

On the other hand, drinking too much can make bladder symptoms worse, increasing the number of visits to the toilet and the urgency to urinate, so 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 to see whether any food and drink in particular affects your bladder.

- *Drinks that contain caffeine* – drinks such as coffee, tea, green tea and hot chocolate can cause irritation directly to the bladder lining.
- *Alcohol* – particularly white wine.
- *Fizzy drinks* – carbonated and highly coloured drinks have been shown to worsen some bladder symptoms.

- *Acidic fruit and juices* – 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 as being overweight can increase the pressure on your pelvic floor muscles and can result in stress incontinence – where urine leaks out of your bladder when it’s under pressure, eg when sneezing and coughing.

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

If you’re considering a new exercise regime, it’s best to speak to a physiotherapist beforehand as they can advise on exercises that will best suit you and your ability.

Stopping smoking

Nicotine in cigarettes can irritate your bladder so 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 of muscles that extend 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 give you control when you urinate. They relax at the same time as the bladder contracts (tightens) in order to let your urine out.

In MS, neurological damage can result in weakness to the pelvic floor. This is because damaged nerves, mainly within the spinal cord, are not transmitting messages to the pelvic floor muscles as effectively as they used to. However this can also be made worse by other factors such as giving birth, getting older or having surgery in this area of the body.

If your bladder symptoms are mild, pelvic floor exercises can be helpful. Men and women can do them. It may take several weeks of regular exercise before you regain strength in your pelvic floor muscles.

You can feel your pelvic floor muscles if you try to stop the flow of urine when you go to the toilet. To strengthen these muscles, sit comfortably and squeeze the muscles 10–15 times in a row. Do not hold your breath or tighten your stomach, buttock, or thigh muscles. When you get used to doing pelvic floor exercises, you can try holding each squeeze for a few seconds.

'Holding on' – bladder training

The aim of bladder training is to increase the amount of time between going to the toilet. You gradually increase the time between urinating (this can be just by five minutes). It may take weeks or months to be effective but your continence advisor or MS specialist nurse can put together a timetable to support you to achieve this.

“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, similar to 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 sources of help and support on page 33).

10. Working with your health professionals

Before starting any treatment for bladder problems you should have the opportunity to consider all the different treatment options, ask all the questions you need to and discuss any concerns you may have. It is also really valuable to have realistic expectations of what the treatment can offer and what the drawbacks may be. Knowing clearly what you would like the treatment to achieve can be helpful in ensuring that you and your health professionals are working together towards the same goal.

“I want to be able to see a film at the movies without having to go to the toilet half way 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

Self-esteem and depression

Bladder problems can have a major impact on self-esteem, which might already have been affected as a reaction to all that living with MS brings. According to continence nurses, as many as seven out of ten people with incontinence are affected by depression. Depression is a constant feeling of sadness or low mood which lasts for weeks or months. It can be accompanied by other symptoms such as an altered sleep pattern, feelings of hopelessness, reduced energy and the inability to concentrate and to take pleasure in anything. If this is how you are feeling talk to your MS specialist nurse or GP as there are many ways to successfully treat depression, including lifestyle changes, talking therapies and medication.

Work

If you have a diagnosis of MS you are covered by the Equality Act 2010 and your employer is required to make reasonable adjustments to the work place to ensure that you are not put at a disadvantage because of your diagnosis.

It is up to you whether or not to disclose your diagnosis of MS but if you are making frequent or longer toilet breaks that others have noticed, this might be the time to tell your employer. Requesting that you have a desk near to the toilets can be seen as a reasonable adjustment.

Sexuality

Bladder problems can cause great anxiety and prevent some people wanting to be sexually intimate. You might worry you'll lose control and have an accident when you're having sex and feel that it's not worth taking this risk as the embarrassment would be too great. If your bladder problems are affecting your sex life, speak to your MS nurse or continence advisor about it. 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. It's also important to be open with your partner and talk about your concerns with them.

12. Sources of help and support

People

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.

www.mstrust.org.uk/map

Continence advisor

Continence advisors are experienced, qualified nurses who have undertaken specialist training to help people with continence 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.

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.

www.bladderandbowel.org

Bladder Health UK

Bladder Health UK, previously the Cystitis and Overactive Bladder Foundation, 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

www.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 by Centres vary 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.

www.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.

www.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 607 8219

www.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.

www.mstrust.org.uk/bladderandbowel

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

Tel: 0800 032 3839 (Monday to Friday, 9am to 5pm)

Email: infoteam@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.

www.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. The card is produced by the Bladder and Bowel Community and can be ordered on their website.

www.bladderandbowel.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.

www.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.

www.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.

www.gov.uk/find-local-council

About the authors

MS Trust Information Team

The MS Trust is a UK charity for people with MS, their family and friends. We have a personalised enquiry service and provide extensive information through our website, social media and printed publications.

Thank you

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Notes

We hope you found this book useful.

Could you make a difference for even more people living with MS?

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Thank you



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