

A photograph of a man with short dark hair, wearing a grey zip-up hoodie, sitting at a wooden table. He is looking slightly to his left with a neutral expression. A clear glass of water is on the table in front of him. The background is blurred, suggesting an indoor setting.

MS and your bladder

We're the MS Society. Our community is here for you through the highs, lows and everything in between. We understand what life's like with MS.

Together, we are strong enough to stop MS.

We rely on the generosity of people like you to fund our vital work. If you would like to make a donation, you can do so by:

- Calling us on: **0300 500 8084**.
Lines are open Monday to Friday, 9am – 5pm
- Visiting us at: **mssociety.org.uk/donate**
- Posting your donation to: MS Society, National Centre, 372 Edgware Road, London NW2 6ND. Please make cheques payable to the 'MS Society.'

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A word from Caroline, who has MS

My bladder problems were yet another MS issue to deal with. Something else to feel embarrassed about.

When I started weeing myself, I remember thinking 'I'm too young for this'. Who can't control their bladder, and needs pads in their 30s? Me, that's who!

Looking back, sometimes I got really bloated and couldn't wee. Other times I'd dribble. I'd wee myself if I couldn't get to the toilet quickly. Or it'd happen if I laughed, sneezed, or fell. Sometimes it happened for no reason at all.

I was so pleased to find that there are people able to help. My continence nurse specialist was - and is - a star.

She deals with everything in a matter of fact way. She provides ideas and solutions. My first appointment felt like a weight had been lifted off my shoulders.

Don't be afraid to talk about bladder and bowel issues. You're not alone, and you can get help. Your GP, neurologist or MS nurse can help - but only if you tell them.

Information like this booklet is so helpful and can point you in the right direction.

So don't suffer in silence.

A handwritten signature in black ink that reads "Caroline". The script is cursive and elegant, with a large initial 'C'.

Five things to know

- 1 You're not alone with your bladder problem. As many as 9 in 10 people with MS will get one at some point
- 2 Your bladder can have a big impact on your sleep and energy levels, your social life, sex and relationships, your mood and how you feel about yourself
- 3 A bladder that's not working properly can also lead to urinary tract infections. These can make MS symptoms worse
- 4 For all these reasons it pays to get a bladder problem looked at. Most can be managed
- 5 Don't let a bladder problem control your life. There's specialist help and different treatments that you can try



About this booklet

As many as 9 in 10 people with multiple sclerosis (MS) may get a problem with their bladder at some point.

This booklet tells you why and how this happens. It also looks at who can help, and the treatments they can offer you. It has lots of tips for bladder problems, too.

You can contact the MS Helpline to talk to someone about your bladder. Call them on **0800 800 8000** (closed weekends and bank holidays). Or email them at helpline@mssociety.org.uk

You can also send them a private message by visiting our Facebook page [facebook.com/MSSociety](https://www.facebook.com/MSSociety). Use the 'send message' tab under the main picture.

You can also ask questions and get support on our online forum. There you'll find other people with bladder problems who know what you're going through. It's at [mssociety.org.uk/forum](https://www.mssociety.org.uk/forum)

This booklet uses everyday words, like 'to pee' instead of 'urinate'. The Heath Service now uses these words too, but your doctor, MS nurse or continence service might use more formal ones.

When you talk to them you can use the words you normally use - they'll understand you.

One last thing. If you see a word in bold, it means you'll find it explained at the back of the booklet.

“Sometimes I just can't get to the loo in time. It's not helped by the fact I can't get anywhere in a hurry. I also have to get up between three and six times each night. This does nothing to help my energy levels.”
Yvonne

How MS can affect your bladder

On average people start to have bladder problems six to eight years after they're diagnosed with MS. But about one in ten have them from the start.

To better understand your bladder problem, it helps to know how nerves make your bladder work – and how MS affects these.

In MS your immune system attacks nerves in your brain and spinal cord by mistake. It damages the fatty covering around the nerves called myelin. Myelin protects your nerves and helps messages travel quickly along them.

Nerves and your bladder

Your bladder is made of muscle. Nerves in the muscle make it tighten or squeeze ('contract'). This pushes pee out when you go to the toilet. Your bladder also has two sphincters. They act like valves, letting pee out. Nerves in

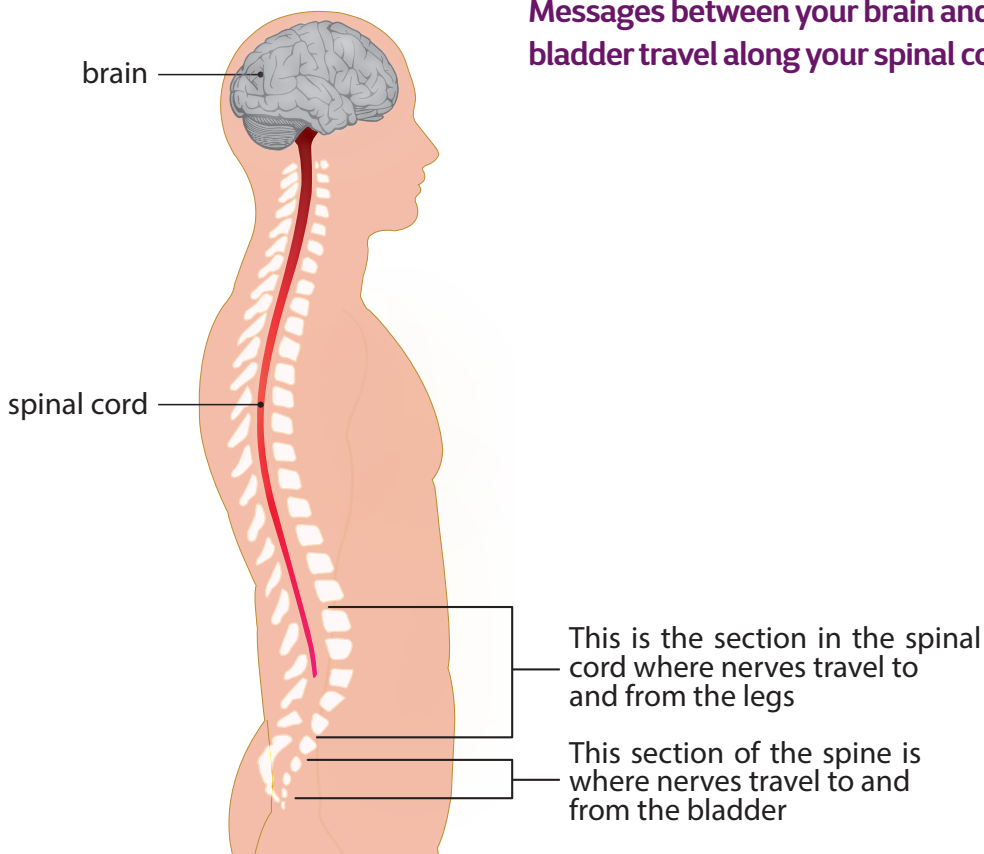
these sphincters relax to open, and they contract to close.

Nerves in your bladder are linked to others in your lower back. These take messages from your bladder, up your spinal cord, then to your brain – and back again. Specific parts of the brain also play an important role in how your bladder works.

So, for example: as your bladder fills up, your pelvic nerves send messages along your spinal cord to your brain. This lets you know it's time to go to the toilet. Your brain then sends messages down to your bladder telling it to squeeze out your pee – but to hold on until it's safe for it to empty.

If MS has caused areas of damage to nerves ('lesions') in your spine, you're more likely to get bladder problems. If you have difficulty walking, your bladder is more likely to be affected too.

This picture shows the part of your spine where you find nerves that control your bladder:



Messages between your brain and bladder travel along your spinal cord.

How damage to nerves affects your bladder

Damage to your nerves stops or slows down messages between your brain and your bladder. This can affect your bladder in two main ways:

- it doesn't hold pee like it should
- it doesn't empty properly

Later in this booklet you can find out more about these two problems.

Understanding words that doctors and nurses use

Overactive bladder	The muscle in your bladder squeezes ('contracts') when it shouldn't. It tries to empty when it's not full. An overactive bladder might not be able to hold a normal amount of pee because it's become used to emptying often. So you suffer from urgency and frequency, with or without leaking.
(Urinary) frequency	For most people, if their bladder works normally, they'll pee about 6 to 8 times over 24 hours. 'Urinary frequency' means you feel the need to go more often than this.
(Urinary) urgency	This is a strong feeling that you can't 'hold on' and need the toilet right away
(Urinary) hesitancy	You go to the toilet but can't start peeing - or it comes out in a weak or interrupted stream.
Nocturia	You get up in the night to use the toilet
Incontinence	<p>You can't hold your pee in. This leads to a bladder 'accident' (you wet yourself or there's some leakage).</p> <p>'Stress incontinence' is leakage when you cough, sneeze, laugh or strain (such as run, jump, walk or lift things).</p> <p>'Urge incontinence' is when you feel a sudden, intense urge to pee. Your bladder squeezes when it shouldn't, causing a bladder accident before you reach the toilet</p>
A voiding problem	You find it hard to empty your bladder

Who can help with your bladder?

People with MS often wait a very long time after their bladder problems start before they ask for help.

Not knowing how to talk about it, or who to turn to can all play their part, as does embarrassment. But there are lots of treatments that work well. And health care staff can help you find one.

Your GP



This can be your first step towards getting help. Your doctor won't be a bladder expert but he or she can give you a referral to a specialist like a urologist or local continence service.

Get referrals through your GP if you don't have an MS nurse, or if you don't regularly see a neurologist.

Your MS nurse



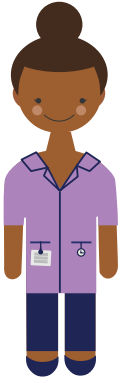
If you have one, an MS nurse can give you advice, information and support with bladder problems. They can refer you to a local continence service.

You can talk to your MS nurse about how your bladder affects your quality of life, mood, your fatigue levels, your self-esteem, and sexual relationships.

If you don't have an MS nurse, find where your nearest one is at [mstrust.org.uk/about-ms/ms-services-near-me](https://www.mstrust.org.uk/about-ms/ms-services-near-me)

You might be able to contact one yourself. Or you may need your GP to arrange a referral.

Your local continence service



These NHS services are based in a hospital, clinic or health centre. They have specialist continence nurses (sometimes called advisors) who can assess your problem and do tests. You can tell them all the ways your bladder is affecting you.

They can give you information, support and treatments. They can carry out some medical procedures, like fitting or changing catheters. They can help you get equipment and products you might need, like incontinence pads, catheters, **penile sheaths**, special clothing or bedding.

Nurses might visit you where you live. Or you go to them in the hospital or clinic. They also deal with bowel problems. These services often have physiotherapists too.

You can be referred by any health care professional like your GP, MS nurse or neurologist. You can often contact them yourself. Find your nearest one at [bladderandbowel.org/news/continence-clinic-healthcare-search-tool/](https://www.bladderandbowel.org/news/continence-clinic-healthcare-search-tool/)

Just enter your nearest town or city (not postcode).

Your neurologist



He or she might treat your bladder themselves. They can also send you to a bladder specialist such as a urologist, or continence service.

Don't feel you need to wait until you're next due to see your neurologist to get help. It'll be quicker to get a referral to specialist bladder services through your GP or, if you have one, your MS nurse.

Your urologist



This is a hospital-based specialist whose work includes MS-related bladder problems. They work with continence nurses.

Urologists can give you Botox injections for your bladder and

other treatments, plus advice on different types of catheters. You need to be referred to one through your GP or neurologist.

Your district (or community) nurse



These nurses tend to work away from hospitals and are often linked to GPs. They can visit clinics, care homes or where you live.

They can provide care to do with things like catheters and bladder issues.

Your first appointment

When you're seen by a urologist or at a continence service, you'll be asked questions, examined and have tests.

When you get the letter about your appointment, you'll probably get a bladder and bowel diary or chart. Over three days or so you record how often and how much you pee, how often you urgently need the toilet and any times when you have a bladder accident. You fill this in and take it to your appointment.

Questions

You can be asked about:

- your bladder symptoms and when they started
- your medical history and what medication you take
- your lifestyle and what support you have at home
- how easy it is for you to move around
- how well can you do things with your fingers and hands
- if you have problems with your memory and thinking

- whether your bladder is affecting your sex life
- if you also have problems with your bowels

Examination

With your permission, you may have your bottom and belly examined (and, for women, your vagina too). They might also check:

- a sample of your pee
- how much is left in your bladder after you pee (using a hand-held scanner placed on your belly)
- the pressure inside your bladder when it fills up and empties (called a ‘urodynamics’ test)
- how your pelvic floor muscles are working
- your reflexes

Tests

Dipstick test

A ‘dipstick’ test will check your pee for infections. If the dipstick changes colour, it means you have a bacterial infection that needs antibiotics.

When people test their own pee, they often don’t interpret their results correctly. So ask your doctor or nurse for advice if you’re thinking of using home dipstick tests.

Ultrasound

An ultrasound scan shows if your bladder empties like it should. A handheld scanner is passed over your belly to see how much pee is left in your bladder after you’ve emptied it. You might hear this called your PVR (postvoid residual volume) measurement.

If your PVR is under about 100ml, then your bladder symptoms are more likely to do with how it holds your pee. Over that level and the problem is more likely to do with how your bladder empties. 100ml is just over one third of a can of fizzy drink.

You might need to come for this test with a full bladder. This means drinking a litre (or four glasses) of water an hour before your visit. But only do this if the hospital tells you to when they give you your appointment.



Retro
1885
New Jersey

When your bladder doesn't hold pee like it should

MS can stop your bladder holding your pee properly. This happens when your bladder becomes overactive.

Symptoms of this are:

- you feel you can't 'hold on' and need to go right away ('urgency')
- you need to go to the toilet more often through the day and night ('frequency'). That's more than 6 to 8 times over 24 hours
- you can't hold your pee, making you leak ('incontinence')

Tests

For details on what tests you'll have, turn to page 14.

First line treatments

These are the treatments you'll be offered first. They're the ones

most likely to work for most people. If your bladder's not holding pee as it should, you can be offered:

- training for your bladder to make it behave differently
- drug treatments
- electrical stimulation

You'll also get advice on how much liquid you drink and what you eat.

“I usually wake up two to three times per night, needing to urinate. I go to the loo, and manage a very weak flow of water. I end up retaining water in my bladder which makes me want to go again a few minutes later.”

Dom

Training your bladder

With the help of your continence nurse, MS nurse or a bladder expert, you can try this on your own or at the same time as you have drug treatments or electrical stimulation.

Learning to change how your bladder behaves can include:

Bladder retraining

You put off peeing for longer and longer periods. You start by waiting an extra five minutes, then gradually add more time. Over months this stretches your bladder so that it holds more.

Training can include timed voiding (see below). Find out more about this and training in general at [bladderandbowel.org/conservative-treatment/bladder-diary/](https://www.bladderandbowel.org/conservative-treatment/bladder-diary/)

Timed voiding

You learn to empty your bladder at set times during the day, such as every two hours. It eases the sudden, strong need to pee, and makes you less likely to leak. You won't be asked to fight the urge to go to the toilet.

Pelvic floor muscle training (PFMT)

Pelvic floor muscles support your bladder and bowel. They help stop your bladder leaking. These muscles stay tightened all of the time, except when they relax to let you go to the toilet.

If you have mild symptoms of stress incontinence or an overactive bladder, pelvic floor exercises can make you hold your pee better. Men and women can do them.

You can do the exercises on their own. Or you can do them with **biofeedback** and/or electrical stimulation such as **neuromuscular electrical stimulation (NMES)**.

A physiotherapist or continence nurse can teach you pelvic floor exercises and bladder training. Your GP or MS nurse can refer you to one.

Check out our video about pelvic floor exercises at [mssociety.org.uk/about-ms/signs-and-symptoms/bladder/managing-bladder-problems](https://www.mssociety.org.uk/about-ms/signs-and-symptoms/bladder/managing-bladder-problems)

Drugs

Antimuscarinic drugs

These include:

- oxybutynin (brand names: **Ditropan**, **Lyrinel XL**, **Cystrin** and **Kentera** patches)
- trospium chloride (**Regurin**)
- darifenacin (**Emselex**)
- propiverine (**Detrunorm**)
- tolterodine (**Detrusitol**, **Neditol**)
- solifenacin (**Vesicare**)
- fesoterodine (**Toviaz**)

These drugs all block the messages telling your bladder to squeeze or tighten. This relaxes it so that it's less irritable and overactive. You'll no longer feel you need the toilet all the time.

Many people notice a difference within a week, but it might take about a month before you get the full benefit, or even longer for some drugs.

These drugs come as tablets that you take one to three times a day. Oxybutynin also comes as a patch you wear on your skin.

The most common side effect with them all is a dry mouth. More than 1 in 10 people get this.

Up to 1 in 10 might get:

- constipation
- dry eyes, skin, nose or throat
- blurred vision
- headache
- stomach ache
- indigestion/heartburn
- feeling sick
- feeling dizzy, tired or sleepy

Side effects are less likely with the newer drugs. Oxybutynin can affect your memory and thinking. So it's better to take one of the newer drugs as they don't do this

Desmopressin

You take desmopressin for an overactive bladder, including if you pee a lot (day or night). You spray it up your nose. It causes your body to make less pee. It can cut down on bladder accidents, too.

Its brand names are **Desmotabs**, **DDVAP** or **DesmoMelt**. You might be given it as a tablet, or as a tab

that melts under your tongue, or a nose spray.

Desmopressin has been shown to give people with MS on average an extra two hours of uninterrupted sleep a night. You shouldn't use it if you're over 65.

Its side effects can be:

- headache
- stomach ache or feeling sick
- your bladder not emptying fully
- low levels of sodium in your blood

Symptoms of low sodium include feeling or being sick, tiredness, confusion, headache, restlessness, weak muscles, spasms, cramp, seizures or passing out. You may need blood tests to check your sodium levels.

If for any reason you get vomiting or diarrhoea, stop taking this drug until you're well again.

Mirabegron (**Betmiga**)

Mirabegron is a beta 3-receptor drug. It's the first drug of this kind to be used for overactive bladder.

Its brand name is Betmiga. It relaxes the muscle in your bladder. There aren't many studies on people with MS, but it seems to help a lot with **urgency, frequency** and **incontinence**.

This drug comes as a tablet. You might be offered it if antimuscarinic drugs don't work, or you find their side effects too much. You might be given it to take it with desmopressin or an antimuscarinic drug.

For up to 1 in 10 people mirabegron can cause:

- fast, strong, or irregular heartbeat
- **urinary tract infections**
- feeling sick
- constipation
- headache
- diarrhoea
- dizziness
- dry mouth (but less likely than with antimuscarinic drugs)

High blood pressure, cold-like symptoms and your bladder not emptying fully can be other side effects.

Electrical nerve stimulation

With this treatment mild electrical signals are sent to the nerves in some of your muscles.

One type of this is neuromuscular electrical stimulation (NMES).

For a set period you use a small battery-powered device to send electrical pulses or signals to nerves in your pelvic floor muscles that control your bladder.

This stimulates them to squeeze and tighten. You're taught to control muscles that you use when you pee. You learn this by using feedback that you can see on a screen or from a sound the feedback makes.

Lifestyle changes

Changing things about your day-to-day life might help with your bladder problem.

Find lots of suggestions on pages 32 to 34.



Second line treatments

What if first line treatments don't work, or you get side effects that you can't live with?

Then these second line treatments might work:

- botulinum toxin (Botox)
- electrical stimulation of your tibial nerve

Botulinum toxin (Botox)

Botulinum toxin is injected into muscle in the wall of your bladder.

It stops nerve messages reaching your bladder, so that it doesn't squeeze or tighten as much. This lets your bladder hold more. You won't feel the need to keep going to the toilet.

Most people know this toxin by the brand name Botox. Another brand name is Dysport.

Under a local anaesthetic, a urologist will put a thin tube with a camera in it (a cystoscope) through your urethra into your bladder. Your bladder wall is then injected 20 to 30 times. About six

weeks later you should notice it working.

Eventually the effect wears off. You usually need more injections every six to 12 months. Botox doesn't work for everyone, but most people find it makes a big difference.

We don't know for sure if Botox will work lifelong. Sooner or later about half of people with MS stop using Botox. Often they switch to another treatment like **neuromodulation**. Or their problem gets worse and Botox no longer helps.

An important side effect

Botox is good for treating an overactive bladder and problems with holding pee or **incontinence**. But for many people Botox creates a new problem: it stops their bladder emptying properly.

So, before you have Botox, you must agree that you'll use **intermittent self-catheterisation (ISC)** if you need to. This means using a catheter each time you need to pee.

Some people can still empty their bladder normally after Botox treatment. But they'll need tests to measure how much pee is in their bladder after they've emptied it.

“It’s changed my life completely. I’m able to forget about finding loos wherever I go. I can easily have three hours or more before needing to go.

I must have had Botox seven or eight times over the years. It lasts around 16 months for me, longer than usual. I couldn’t do my voluntary work without this amazing procedure.”
Sue

Electrical stimulation of your tibial nerve

What if drugs, including Botox, don't work for your overactive bladder? Or they have too many side effects?

Another option might be available, depending on where you live. A nerve in your leg is stimulated by a mild electric current. This relaxes nerves in your lower back that control your bladder.

Two types are offered as second line treatments. Both involve stimulating the tibial nerve which runs down your leg.

Percutaneous tibial nerve stimulation (PTNS)

A needle is put into the skin above your ankle, near the tibial nerve. An electrode is placed on your foot. The needle and electrode are connected to a stimulator device.

This sends electrical signals along the nerve. This helps retrain an overactive bladder.

Transcutaneous tibial nerve stimulation (TTNS)

A patch with an electrode in it is placed on the skin near your tibial nerve. There's no need to pierce the skin with a needle (like there is with PTNS).

With PTNS and TTNS your nerve is stimulated once a week for

half an hour. This lasts for three months. Some people need extra treatments to keep it working, say, once every three weeks.

Tibial nerve stimulation is a safe treatment that can help with incontinence (leaking), **frequency**, **urgency** and an **overactive bladder**.

If second line treatments fail

If you don't get success with the treatments we've covered so far, you can have surgery on your bladder. But as other treatments have got better, there's less and less need for this these days.

There's also sacral nerve stimulation.

Sacral nerve stimulation

This is a kind of **neuromodulation**. It's called sacral nerve stimulation or sacral neuromodulation (SNM). It's not offered by all hospitals and **continence services**.

Under a general anaesthetic an implant is put under the skin over your sacral nerve. This nerve is in the bottom part of your spine, at the top of your buttocks.

A wire in the implant – powered by a battery – sends mild electrical impulses to your sacral nerve, which controls your bladder, sphincter and pelvic floor muscles.

These impulses cut down how often the nerve sends signals to your bladder to empty.

It's quite a new treatment that doesn't work for everyone. But it's had good results in people with nerve-related bladder problems.

There are no official guidelines about using this treatment with people with MS, but some have had it. It's not seen as the best kind of treatment for people with MS. For example, bladder problems in MS tend to get worse over time, so this treatment might not work in the long term.

Also, until recently you couldn't have an MRI scan of your spine if you had an implant in your back (scans of your head have never been a problem).

But there are now implants that are safe with MRI scans. Your neurologist can tell you more.



When your bladder doesn't empty like it should

MS can affect your bladder by stopping it from emptying ('voiding') fully.

The muscle in your bladder doesn't squeeze your pee out like it should. Or the **sphincter** in your bladder doesn't relax and open when the muscle in your bladder wall squeezes.

We normally feel the need to empty our bladder when it's two thirds full.

In a healthy bladder, after you've been to the toilet, about 10% of the pee is left in it. More than this and bacteria get the chance to grow, causing an infection.

A common problem with MS is that too much pee gets left in the bladder. This makes **urinary tract infections** more likely.

These infections can make your MS symptoms worse. If you get

relapses, it's possible that an infection might even trigger one.

On page 35 you'll find what the symptoms of these infections are.

When a bladder isn't emptying properly, you might notice any of these:

- you want to pee but nothing happens. Or the stream of pee isn't as strong and steady as it should be ('urinary hesitancy')
- you strain when you pee
- half a minute or so after you've had a pee, you go again
- you don't feel your bladder is really empty after you've been to the toilet
- you keep getting urinary tract infections

Tests

The main test measures how much pee is left in your bladder after you've been to the toilet.

This is called your 'post residual volume' (PVR). If this is more than about 100ml, then your symptoms are most likely to be happening because your bladder isn't emptying completely.

Page 14 has details of this test and others you might have.

Treatment

Using a catheter

When your bladder doesn't empty properly, the treatment is usually to use a catheter (catheterisation).

A catheter is a small, flexible thin tube. They can be made from soft plastic, silicone rubber or latex.

You put it into your **urethra** until it goes into your bladder. To make this more comfortable, the catheter might already be covered in lubricant gel – if not, you put lubricant on it.

When the catheter is in your bladder, it takes pee out of it, down the tube and into either a bag on the end of it or into a toilet.

You then take the catheter out. You usually throw it away, and use a fresh one each time.

A continence nurse or district nurse will teach you how to use a catheter. An MS nurse might do this in the few parts of the UK with no continence services.

Intermittent self-catheterisation

People with MS and their doctors usually prefer this way of using catheters.

You might see this called 'clean intermittent self-catheterisation'. This refers to the need to use good hygiene when you handle the catheter and put it in.

This stops bacteria getting on the catheter and/or into your urethra and bladder (where it would cause an infection).

'Intermittent' means you use a catheter at regular times when you need to pee – but it's not

always inside you. You use one about four to seven times a day, depending on how much you drink. You use a fresh catheter each time.

Using catheters solves the problem of pee being left in your bladder. This means bacteria can't grow in it and cause an infection.

Your nurse will support until you're confident enough to put a catheter in on your own.

Read about using a catheter at:
[bladderandbowel.org/
conservative-treatment/
intermittent-self-catheterisation/](http://bladderandbowel.org/conservative-treatment/intermittent-self-catheterisation/)

**“Intermittent
self-catheterisation
has given me
my life and some
dignity back.”**

Cath

**“When intermittent self-catheterisation
was first mentioned
to me it sounded scary.
Eventually I had to use it.**

**I wish I'd started sooner.
I assumed it would hurt,
but it was painless**

**It's a real blessing,
knowing I won't need the loo
for several hours,
and helping to cut down the risk of infection”**

Dan

Indwelling catheters

These catheters are for people who can't move around easily. Or they won't or can't put a catheter in themselves (perhaps they can't easily use their fingers). It's rare that someone has one if they can still walk.

An indwelling catheter stays inside your bladder. It goes in like a regular catheter but stays there, held in place by a small balloon. This balloon is blown up after the catheter is in your bladder.

The catheter drains into a bag, usually attached to your leg with Velcro straps. When the bag's full, you empty it into the toilet.

When you go to bed you use a night bag to collect the pee. This bag is bigger and hangs by your bed on a stand.

Instead of using a bag, some indwelling catheters have a valve that you can open and close. This lets you empty your pee straight into the toilet.

These catheters can be 'urethral' (going into your bladder through

your **urethra**) or 'suprapubic' (see the next section).

Your doctor puts the catheter in for you using a gel that numbs the area. A healthcare professional who's been trained in this can also put one in.

Indwelling catheters need changing at least every three months. You can be taught to do this yourself, or a district nurse can do it. Leg bags and valves should be changed every seven days.

These catheters come with a bigger risk of infections. There's also a risk of stones growing in your kidney and bladder.

Read more about these catheters at: bladderandbowel.org/conservative-treatment/indwelling-catheters/

Suprapubic catheters

This catheter also stays inside you. But it doesn't go into your bladder through your **urethra**. Instead it goes into it through a small hole made in your belly. A small balloon at the end is blown



up once the catheter is in your bladder. This holds it in place. It's fitted while you're under a local or general anaesthetic.

Your pee either drains into a bag that you empty down the toilet, or the catheter has a valve.

You open and close the valve to empty your pee straight into the toilet, or into a bag strapped to the side of your leg.

These catheters can be more comfortable, have fewer complications (such as infection), and don't get in the way as much during sex.

You need to change it every six to 12 weeks depending on the type. A district nurse usually does this.

A suprapubic catheter can be a good choice if you use a wheel-

chair, or you can't put in a catheter yourself.

Find out more about them at:
bladderandbowel.org/surgical-treatment/suprapubic-catheter/

“The suprapubic catheter has made such a marvellous difference to my life. Before I was needing to wee every hour in the day and three or four times at night.”
Polly

Seven in ten people find catheters OK

A 2014 study of over a thousand people with MS who used catheters found twice as many felt they made their lives better than made it worse. A quarter said it had a negative effect, for one in five it was neutral, and over half said it was positive. Find more information about catheters and support with using them at bladderandbowel.org/bladder/catheter/

A suprapubic vibration device

Some people find a small, hand-held device called the Queen Square bladder stimulator helps. It's often called a 'buzzer'. You place it over your pubic area.

When it vibrates, it stimulates your bladder to relax and start emptying. It helps with **hesitancy** and encourages your bladder to empty properly.

For some people this can be an alternative to **intermittent self-catheterisation**. Others find another method works just as well: they tap over that part of their lower belly with their fingers.

Get advice from a continence nurse on the buzzer or techniques that use your fingers to tap or apply pressure.



Tips for bladder problems

As well as the treatments covered earlier in this booklet, there are other things you can do that might help with your bladder problem. Here are some tips you might find useful.

Eating and drinking

- Giving up caffeine can help
- Caffeine irritates the bladder, making **urgency** and **frequency** worse. Fizzy drinks, smoking and alcohol do the same
- Decaf teas and coffees still have some caffeine in them. For example, instant decaf coffee can have up to 0.3% caffeine in it
- For the least amount of caffeine buy decaf coffee made using the Swiss Water[®] process. This takes out 99.9% of it
- For tea with no caffeine in it try redbush (rooibos) tea
- Avoid spicy foods, citrus fruits and juices (oranges, grapefruit, lemons, also tomatoes). These can irritate the bladder
- Have your last drink no later than two hours (or even longer) before going to bed
- Studies so far show that drinking cranberry juice, or taking cranberry tablets, doesn't seem to prevent **urinary tract infections** in any significant way
- Watch your weight. Being too heavy puts pressure on your bladder and pelvic floor muscles, making leaks more likely

How much to drink

- Flush your bladder through by drinking lots of liquids. It'll cut your risk of urinary tract infections
- But don't drink too much as this could make your bladder issues worse
- 6 to 8 glasses or cups a day is best (1.5 to 2 litres) – more if you're exercising or if the weather's hot
- You might be tempted to drink less so that you don't need the toilet so often. But when pee gets too strong, it can irritate your bladder and cause infections
- And not drinking enough causes constipation, which puts pressure on your bladder
- Through the day your pee should be pale yellow. Any darker means 'drink more'. First thing in the morning it's normal for pee to be darker, especially if you've not been to the toilet in the night.

Finding a toilet

- Carry our free 'I need some help' card, telling people you urgently need a toilet. Get it by calling **0300 500 8084** or email **supportercare@mssociety.org.uk**
- Find a public toilet at **toiletmap.org.uk** or download one of the public toilet apps
- Join the National (RADAR) Key Scheme. For a few pounds you get a key that lets you into over 9,000 locked accessible toilets in the UK. Get it from **disabilityrightsuk.org/shop/official-and-only-genuine-radar-key**
- If you need a public toilet bigger than standard accessible ones, or you need a hoist, check out Changing Places at **changing-places.org**
- Contact your council to see if there's a Community Toilets Scheme locally. It lets you use toilets in shops, restaurants and pubs without paying

Going to the toilet

- Try to relax. Don't strain
- Run a tap. Running water will encourage your bladder to empty
- After you've had a pee, stay an extra minute and try to pee some more (this is called 'double voiding'). Men need to sit down to pee for this
- If you can do this safely, lean forward on the toilet and rock from side to side
- Tapping over your bladder with two fingers may help it squeeze and empty
- Or stroke your inner thighs, belly or lower back
- A continence nurse can tell you more about double voiding and other tips on using your hands or fingers to help you pee

Record what's going on

- Use a bladder function phone app to record how much you drink and pee. Use it to set goals if you're training your bladder. Examples are the iUFlow app (women) from <http://iuflow.com/> and Bladder Pal (men and women) at <http://myhealthapps.net>
- Some let you send a report to your continence nurse
- Keep a bladder diary. Record what you drink and eat, how often you pee, how many 'accidents' you have, and any problems stopping and starting. This will help you notice what makes things worse or better
- Share what's in your diary or on your app with whoever looks after your bladder

A 'reasonable adjustment'

If you work, would being nearer a toilet help? You can ask for this as a 'reasonable adjustment'. It's a change that the law says your employer has to make. Read more at mssociety.org.uk/reasonable-adjustments

Symptoms of urinary tract infections to look out for

- A burning feeling when you pee
- You can't go even though you feel you need to
- You feel you need to go more than normal
- Just a dribble of pee comes out
- Pee is dark, cloudy or has blood in it, or a bad, 'fishy' smell
- You feel pain or tired, or you have chills or a high temperature

If you notice any of these, get medical help fast.

An untreated infection can make MS symptoms worse. If you get relapses, an infection might even trigger a new one.





Useful organisations

If you need more information or support with a bladder problem, here are places to turn to.

MS Society MS Helpline

Our helpline offers emotional support and information to anyone affected by MS. Talk to them in confidence about your bladder and how it's affecting you.

Call them on **0808 800 8000** (closed weekends and bank holidays) or email them at **helpline@mssociety.org.uk**

You can also send them a private message by visiting our Facebook page **facebook.com/MSSociety**. Use the 'send message' tab under the main picture.

For your free 'I need some help' card that explains you urgently need the toilet, call us on **0300 500 8084** or email **supportercare@mssociety.org.uk**

MS Society forum

The message board on our website lets you connect with other people with MS, including those with bladder problems. They can share what's worked for them. Visit **mssociety.org.uk/forum**

MS Society groups

Around 250 MS Society groups offer support. Through your local group you can meet other people with MS in your area, find out about local services and get support to help you deal with your MS. Find your nearest group at: **mssociety.org.uk/near-me**

Other organisations

Bladder and Bowel UK

Advice and information about problems affecting your bladder (or bowel). Runs an online shop selling continence products.

Helpline: 0161 607 8219 or email **bladderandboweluk@disabledliving.co.uk**
bbuk.org.uk

Bladder Health UK

Support with overactive bladder, continence problems and cystitis (inflammation of the bladder).

Runs an online chat forum, magazine, local groups and a telephone advice line on:

0121702 0820

bladderhealthuk.org

Bladder and Bowel Community

Information and support for those with a bladder or bowel condition.

Has a support and information forum staffed by a nurse, plus an online shop for continence products.

Also has resources you can download, like frequency charts, bladder diaries and pelvic floor exercises. Their website has lots of information on using catheters.

bladderandbowel.org

Continence Product Advisor

General information on bladder issues. Also offers unbiased information and advice on all the continence products available (such as pads, catheters, bags, special clothing, and bed protection).

continenceproductadvisor.org

Disability Rights UK

Runs the National (RADAR) Key Scheme. You buy a key that lets you into over 9,000 locked toilets in shopping centres, pubs, cafés, department stores, bus and train stations.

Shop number: **0203 687 0790**

disabilityrightsuk.org/shop/official-and-only-genuine-radar-key

MS National Therapy Centres

A network of UK centres offering a range of therapies, including physiotherapy and counselling.

mscnt.org.uk

MS Trust

A charity offering information, including about bladder issues, for anyone affected by MS:

Free Phone Information Service:
0800 032 3839

Shift MS

An online community popular with younger people with MS. Users share, support and interact with each other through the shift.ms website.

shift.ms

New words explained

biofeedback – training that gives you better bladder control. For example, you put an electrical sensor inside you, you squeeze your muscles and see on a screen how tense the muscle is. You use this to learn how to squeeze and relax muscles.

catheter – a thin tube made from soft plastic, silicone rubber or latex. You or a medically trained person puts it into your bladder (usually through your urethra) so that you can empty it

continence and **incontinence** – when you can control (continence) or can't control (incontinence) your bladder or bowel

continence service – NHS service in a hospital, clinic or health centre staffed by continence nurses. They can test and treat you for bladder or bowel problems, fit catheters and supply continence products

to **contract/contractions** – when a muscle squeezes or tightens

double voiding – peeing more than once each time that you go to the toilet. This makes sure that the bladder is empty

(urinary) frequency – when you need to go to the toilet often

(urinary) hesitancy – when you can't start peeing, or it comes out in a weak or interrupted stream

incontinence – see **continence**

indwelling catheter – a catheter that's always inside you, not just used when you go to the toilet

intermittent self-catheterisation (ISC) – when you empty your bladder several times a day using a fresh catheter each time

neuromodulation – using mild electrical signals to control muscles involved in how your bladder works. An example is stimulating the tibial nerve in your leg (see **PTNS** or **TTNS**).

See **sacral neuromodulation** for another example

neuromuscular electrical stimulation (NMES) – a small battery-powered device sends electrical signals to nerves in your pelvic floor muscles that control your bladder. This stimulates them to **contract**

nocturia – when you get up in the night for a pee

overactive bladder (OAB) – when your bladder **contracts** or spasms, making you feel you need to go to the toilet straight away, or go more often. This might cause you to wet yourself

pelvic floor muscle – muscles that support your bladder and bowel and help stop pee leaking from your bladder. They relax to let you pee but stay tight the rest of the time

penile sheath – a covering that fits over a man's penis. It carries pee away through a tube to a small bag attached to his leg

percutaneous tibial nerve stimulation (PTNS) – sticking a needle into the skin above your ankle to send a mild electrical signal up a nerve in your leg. This

gives you more control over your bladder. See also **TTNS**

post residual volume (PVR) – how much pee is left in your bladder after you've been to the toilet

retention – when pee is left in your bladder because it's not emptying properly

sacral neuromodulation (SNM) – a device is implanted in the upper part of your buttocks. It sends electric signals to stimulate a nerve that connects to your bladder. This can help with an overactive bladder

sphincter – a ring of muscle that opens and closes. Your bladder has two, acting like valves to keep pee in your bladder or let it out

stress incontinence – when sneezing, lifting, laughing, exercise, sex or coughing put pressure on your bladder, making you leak pee. This is because your pelvic floor muscle or urethral sphincters have become weak or aren't working as they should

suprapubic catheter – a catheter that doesn't go into your bladder

through your **urethra** but through a cut in your belly made by a surgeon

suprapubic vibration device – a hand-held ‘buzzer’ that you place over your pubic area. Its vibrations stimulate your bladder to start emptying and to empty fully

transcutaneous tibial nerve stimulation (TTNS) – putting an electrode on the skin above your ankle to send a mild electrical signal up a nerve in your leg. This gives you more control over your bladder.

timed voiding – going to the toilet at a fixed time, like every two hours

urethra – the tube that your pee travels down as it leaves your bladder (and eventually your body). In men it’s long and inside their penis. In women it’s inside their body and much shorter

(urinary) urgency – the need to go to the toilet straight away

urge incontinence – when you feel a sudden, intense urge to pee. Your bladder squeezes when it shouldn’t, causing a bladder accident before you reach the toilet

urinary tract infection (UTI) – an infection that can be in your **urethra**, kidneys or your bladder. Often caused when your bladder doesn’t empty properly, allowing bacteria to grow in the pee left in it. UTIs are treated with antibiotics

urinary (tract) antiseptic – a drug sometimes used to treat urinary tract infections. You take it by mouth and it makes your pee less likely to be the cause of an infection. Unlike an antibiotic, it stays in the bladder and doesn’t travel around the rest of the body

urinary frequency – see ‘frequency’

urinary hesitancy – see ‘hesitancy’

urinary urgency – see ‘urgency’

urodynamics – tests that measure how your bladder is working. They can measure things like pressure in the bladder when it’s filling up and emptying

urologist – a hospital-based bladder specialist

to **void** – to empty your bladder

Further information

Resources

Our award winning information resources cover every aspect of living with MS.

To order email:

shop@mssociety.org.uk or visit
mssociety.org.uk/publications

MS Helpline

The free MS Helpline offers confidential emotional support and information for anyone affected by MS, including family, friends and carers.

Information is available in over 150 languages through an interpreter service.

0808 800 8000

(closed weekends and bank holidays)

helpline@mssociety.org.uk

About this resource

Thanks to all the people affected by MS and professionals who contributed to this booklet, in particular: Brian Kinsella, Clinical Nurse Specialist, Ms Mahreen Pakzad BSc Hons MD FRCS(Urol), Consultant Urological Surgeon UCLH and Consultant Neuro-Urologist with specialist interest in MS, Jalesh N. Panicker DM FRCP, Consultant Neurologist and Reader in Uro-Neurology, Angela Patterson, lead clinical nurse specialist in bladder and bowel dysfunction, and the nurses at the Specialist Continence Service of the Belfast HSCT.

If you have any comments on this information, please send them to: resources@mssociety.org.uk

Disclaimer: We have made every effort to ensure that the information in this publication is correct. We do not accept liability for any errors or omissions. Availability and prescribing criteria for drugs in various parts of the UK may change. Seek advice from the sources listed.

References

A list of references is available on request. Call **0300 500 8084**.

Photography

Photography: Rebecca Cresta (cover, pages 6,24,29), David Dunne (p15), Amit Lennon (p31) and Paul Moane (pages 20,34,36)
Illustration: Damion Mulrain

This resource is also available in large print.

Call **0300 500 8084**
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This title will be reviewed within three years of publication.

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