



# MS and your bowels

The MS Society is here to make life better for people with MS, through research, campaigning and support.

We can see a future where nobody needs to worry about MS getting worse.

We believe that, together, we can stop MS.

**[mssociety.org.uk/stop-ms](https://mssociety.org.uk/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](https://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 Elizabeth, who has MS

I was diagnosed with MS over 20 years ago. It was probably around three years after that when I began to have bowel trouble.

I've had such a variety of symptoms. At times it's been difficult to pick the worst one. My MS was very aggressive for the first few years. I was in and out of the acute ward in the hospital regularly as there were no disease modifying therapies (DMTs) at that time.

Nobody mentioned bowel problems in those days, so I had to ask. I was told it was yet another symptom of MS. Just great! As usual with this disease, not everyone had this symptom, and not everyone wanted to talk about it.

I volunteer with the MS Society's Research Network, and I've found plenty of challenges to keep me busy and my mind working. Having a very unreliable

bowel has proved difficult when attending meetings or functions.

It's not something you can announce as you rush for the nearest toilet for the second time in fifteen minutes! At other times, when your bowel stops for over a week, you're scared to leave the house.

My GP has been very sympathetic. I've tried all sorts of remedies for all sorts of situations, from linseeds to diarrhoea preparations. But it's very much hit or miss.

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

So, I'm pleased that this booklet exists, with its sensible advice. I hope you'll find it a great help.

A handwritten signature in black ink that reads "Elizabeth". The script is cursive and fluid, with a large initial 'E' and a long, sweeping tail on the 'h'.

# Five things to know

- 1 It can be hard to talk about bowel problems, but they're very common in MS. You're not the only one
- 2 People say this is among the most difficult of MS symptoms to live with – for partners and family carers, too
- 3 Don't accept that you must 'just learn to live with it' or 'nothing can be done.' There are usually things you can do so that your bowels have less impact on your life
- 4 Through trial and error you should find things that work for you. But this might take some time
- 5 Don't suffer in silence or let your bowels control your life. There's specialist help out there and plenty of treatments to try



# About this booklet

For up to 7 in 10 people with multiple sclerosis (MS) it can cause a problem with how their bowels work.

This booklet explains why and how this happens, and who can help. It looks at treatments that might make a difference, and offers some useful tips.

We use everyday words in this booklet, like 'poo' instead of 'stools'. The Health Service now uses these words too.

But some medical staff use more formal words to describe bowels and how they work. We explain these at the back of the booklet.

When you talk to them, you can use the words you normally use. They'll understand you. Any words in this booklet in bold are also explained at the back.

You can contact our MS Helpline to talk to someone about your MS, including your bowels. Call

us on **0800 800 8000** (closed weekends and bank holidays). Or email [helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk)

You can also send us 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.

On our online forum you can ask other people with MS questions and get support with bowel problems. They'll know what you're going through. Find it at [mssociety.org.uk/forum](https://www.mssociety.org.uk/forum)

**“This is an embarrassing subject that lots of us don't discuss. Many of us have been treating ourselves for a long time. Admitting there's a problem is probably the most difficult thing to overcome.”**

**Christine**



# How MS can affect your bowels

For some people a bowel problem – often constipation – was an early sign that they had MS. For others bowel problems begin later, especially when MS starts to affect their walking.

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

## Bowels and how they work

Your bowels are made up of your large and small bowel (also called the large and small intestines).

Once food reaches your stomach, it's broken down into a thick liquid. This moves into your small bowel – a tube made of muscle about six metres (20 feet) long. Here your body takes out of it the goodness that it needs.

Next this liquid moves into the first part of your large bowel called your **colon**. This is another

muscular tube, one that's about 1.5 metres (five feet) long. At the end of it are your **rectum** and **anus**.

In your colon water gets taken out of the liquid. This turns it into solid poo. Your bowel squeezes ('contracts') to push poo forward towards your rectum. That happens in waves of **contractions** called peristalsis.

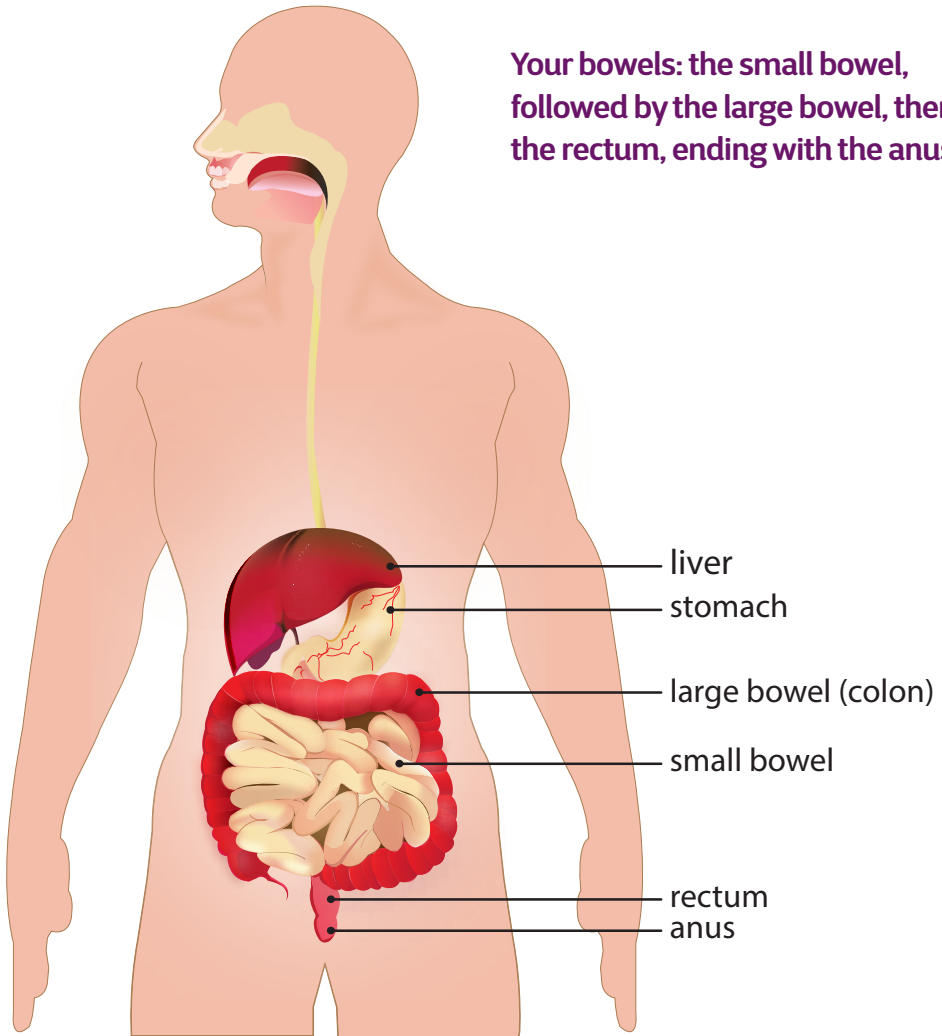
Your rectum (back passage) is the last 20 cm (about 8 inches) of your large bowel. It's usually empty until just before you go to the toilet. Then its walls relax to fill with poo.

As your rectum fills, its walls stretch. This triggers the feeling that you need the toilet. A ring of muscle (your internal sphincter) relaxes and opens to let poo into the last 2 to 5 cm (1 to 2 inches) of your rectum.

If you're ready to poo now, a second sphincter (your external sphincter) relaxes and opens to let



Your bowels: the small bowel, followed by the large bowel, then the rectum, ending with the anus.



poo leave your body through your anus. You can control this second sphincter and decide when you're ready to poo. Muscles in your belly and rectum then help squeeze the poo out.

The small and large bowels get their names, not from how long they are, but from their width.

## Nerves and your bowels

Nerves do many things to make your bowels work properly.

Your bowel is a long tube made of muscle. Nerves in it make it squeeze to push poo forward. They also let you feel when your rectum is full.

Nerves in your two anal sphincters make them open and close to let poo out.

Muscles around your bowels, like your **pelvic floor muscles**, help you push poo out, and nerves make that happen, as well.

All these nerves send signals from your bowel, up your spinal cord and onto parts of your brain that control pooing (and back again).

## How damage to nerves affects your bowels

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

These messages can't come through like they should (or at all) when myelin in your spinal cord is damaged – or if it's damaged in parts of your brain that control your bowels.

Nerves linked to your bowels, rectum and anus are at the bottom end of your spinal cord. This is just below nerves that control your legs (see the picture opposite).

So you're more likely to get bowel problems if MS has caused areas of damage (lesions) to nerves on the lower part of your spinal cord.

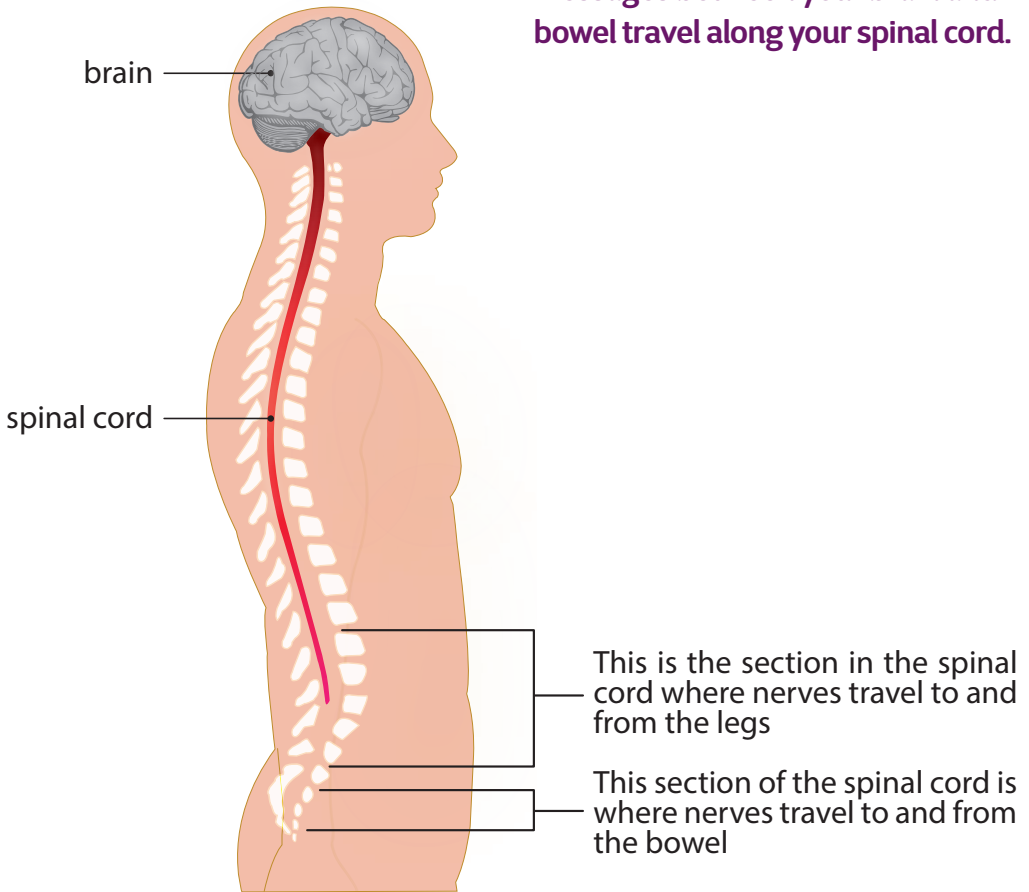
This is why in MS bowel problems often go hand in hand with problems with walking.

Nerve damage can affect any of the ways mentioned above that muscles make your bowels work. On top of that:

- MS can stop you being physically active. This will make your bowels slower

This shows the part of your spine where you find nerves that control your bowel.

### Messages between your brain and bowel travel along your spinal cord.



- MS can slow you down, stopping you reaching the toilet fast enough
- Medicines for other MS symptoms can cause a

bowel problem, mostly constipation.

- Taking several drugs at the same time can also cause this (see pages 31 and 42).

## What bowel problems are caused by MS?

When damage to your nerves stops or slows down messages between your brain and your bowels, the two main results are:

- **constipation** and/or
- **faecal incontinence** (leakage of poo that you can't control)

We'll look at these in more detail in the coming pages.

**“My enjoyment of meeting friends and going to interesting venues, has been all but lost. I'm either counting the days of constipation, or running backwards and forwards too many times to risk leaving the house.”**

**Sue**

### What are the signs of bowel trouble in MS?

Talk to your doctor, neurologist or MS nurse if you:

- aren't going to the toilet as often
- struggle to poo
- feel bloated or in pain
- keep getting diarrhoea
- keep needing the toilet urgently
- or if there's been a time when you couldn't control your bowels and had an 'accident' when you leaked poo.

But a bowel problem might have nothing to do with your MS. So tell your doctor or nurse if you see blood or mucus in your poo. Let them know if there's a change in your bowels that you can't explain.

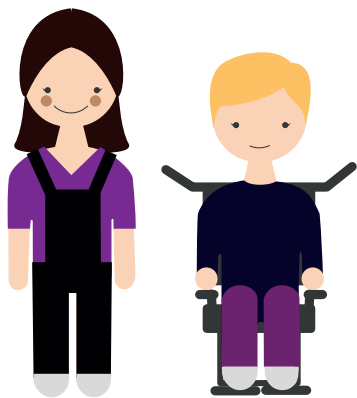
# Who can help?

It's not easy to talk about bowels and poo, especially if you have bowel 'accidents'. Some people wait a long time before asking for help.

Embarrassment can stop you getting the help you need. And you might not know how to talk about it, or who to turn to.

Some health care staff find it easier to talk about bladder problems, and might avoid your bowels. So if they don't bring bowels up, you'll need to.

## Family and carers



You might get help with your bowels from your partner, someone else in your family, or maybe a carer who gets paid.

If your partner or family carer need to help you take care of your bowels, they can be taught what they need to know by medical staff.

Some people have paid carers, often a Personal Assistant (PA). They hire one using Direct Payments from their local council (or, in Northern Ireland, their local Health and Social Care Trust).

When you hire a PA, check they've had training to help with bowel problems. If your PA doesn't have these skills, it's your responsibility – as the person who hires them – to make sure they get them. Or find a PA with the right training.

In the next two pages we'll look at the medical staff who can help with your bowel problems.

**“GPs and other healthcare professionals can become a bit flustered”.**

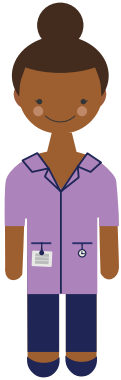
**Christine**

## Your GP



Your GP can be the first step in getting help. They won't be a bowel expert, but they can refer you to a specialist **continence service**.

## Your local continence service



In many places these are now called bladder and bowel services. They're based in a hospital, clinic or health centre. They have specialist continence nurses or 'advisors' (some have physio-therapists too).

The nurses assess your problem and perhaps do tests. You can tell them how your bowels affect you.

They can give you information, support and treatments. They can help you get any equipment and

products you need, like incontinence pads, or special clothing or bedding.

These nurses might visit you where you live. Or you visit them in their hospital or clinic. They usually deal with bladder problems too.

Often you can contact a continence service yourself. Or your GP, MS nurse or neurologist will refer you to them. Find your nearest service at <http://search.bladderandbowel.org/> Just enter your nearest town or city (not postcode).

## Your MS nurse



An MS nurse can give you information, advice and support with bowel problems, and refer you to a local continence service.

You can tell them how your bowel problem affects your quality of life, relationships and how you feel about yourself.

Don't have an MS nurse? Find where the nearest one is at [mstrust.org.uk/about-ms/ms-services-near-me](http://mstrust.org.uk/about-ms/ms-services-near-me)

You might be able to contact an MS nurse yourself. Or ask your GP or neurologist for a referral.

### Your neurologist



He or she might treat your bowels themselves. They can also send you to a bowel specialist like a gastroenterologist or continence service.

You don't need to wait until you're next due to see your neurologist to get help. It can be quicker to get a referral to a continence service through your GP or MS nurse.

### Your gastroenterologist



This is a hospital-based specialist whose work includes MS-related bowel problems. They work with continence nurses and offer treatments and advice.

For more difficult to treat problems, like with advanced MS, they can talk to you about surgery. Your GP or neurologist can refer you to a gastroenterologist.

### Your district (or community) nurse



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

They can provide care to do with your bowel issues. This could be things like help using equipment (such as for **anal irrigation**) or having a **mini-enema** if you can't do this yourself.

### Your first appointment

Before you see a continence service or bowel specialist, they might want you to keep a diary for a week. In it you record your symptoms, how often you poo (or try to), what the poo's like, and what you eat and how much you drink.



At your appointment they'll ask questions about:

- your bowel symptoms and when they started
- how often you poo and what it looks like (see opposite)
- the food you eat and how much fluid you drink
- your medical history and what medication you take (including laxatives)
- how physically active you are
- what support you have at home
- how easy it is for you to move around (and get to a toilet in time)
- whether your bowels affect your work or sex life
- if you also have problems with your bladder

**“Have a plan in place before you go. Take this booklet. Think about what treatment best fits your lifestyle. Then ask for it.”**  
**Christine**

## Examination

With your permission, the doctor or nurse might look at your bottom and belly.

They might put a gloved, lubricated finger inside your bottom to check how well your **sphincter** works.

You might need tests and scans to check how your insides are working.

You'll also get help and advice with:

- looking after your skin (see page 46)
- products that might help, like pads
- dealing with laundry and problems with the smell of poo

You'll get a treatment plan. You or your partner/family carer will be taught anything you or they need to do as part of your treatment.

## Describing your poo

When they talk about poo, medical staff use the Bristol Stool Chart (opposite). If you know this, it'll help you tell them what yours are like.

This chart shows you the seven types of poo people can have.

## Bristol stool chart



**Type 1** Separate hard lumps, like nuts (hard to pass)



**Type 2** Sausage-shape but lumpy



**Type 3** Sausage-shape but with cracks on the surface



**Type 4** Like a sausage or snake, smooth and soft



**Type 5** Soft blobs with clear-cut edges (easy to pass)



**Type 6** Fluffy pieces with ragged edges, mushy



**Type 7** Watery, no solid pieces (just liquid)



# Treatments

Whatever your bowel problem is, you'll probably need to try a range of things, often at the same time. It might take while to find the right treatment for you.

The problem might not totally go away. But, through trial and error, you should find treatments that make things better.

Some treatments are tricky to carry out. And some are used even though there's little strong evidence they work.

## Step one: bowel routine

The first step is to try and get a regular bowel routine, one where you go to the toilet more often and it's easier to 'go'.

The goal is that your poo becomes softer (to prevent constipation) and, if you have bowel 'accidents', that these stop.

Numbers 3 or 4 on the Bristol Stool Scale is the type of poo to aim for (see page 17).

Other goals may be spending less time on the toilet, and using laxatives less often.

At night your bowel slows down. It then 'wakes up' when you do in the morning. Your body's urge to poo is often strongest within half an hour of waking up.

Moving around, drinking and eating all help get your bowel moving. And half an hour after a meal is the best time to empty it.

All this makes breakfast time a very good time to try and go. So don't skip breakfast.

Stick to a fixed daily toilet schedule even if you don't feel the need to go. Sit on the toilet about half an hour after breakfast.

If you can't poo, try again at the same time the next day.

If you're constipated and feel you need the toilet between your scheduled times, try to go. But don't be tempted to keep trying through the day. Wait until you're due to poo the next day.

You might use these (on their own or together) to help you poo at a set time:

- laxatives or **suppositories** (see pages 27-30)
- **abdominal massage, digital stimulation** or **manual evacuation** (see pages 31-32)
- **transanal irrigation** (see page 33-34)

## Where to begin

You start with gentler treatments. If these don't work, the next treatments are ones you'll need help with.

The table on the next page shows how bowel problems are treated.

At the top are the gentlest options. These are the ones that are used

most, and that work for many people.

At the bottom is surgery, but only a few people have that.

For the best results, you might use several treatments from different levels of the table at the same time.

## The two bowel problems that MS causes

In the next two chapters we'll look at how to treat the two main bowel problems you get with MS: constipation and faecal incontinence (leakage).

It might seem strange, but you can have constipation and incontinence at the same time. Watery poo builds up behind a mass of hard poo, then it leaks from around it.

Also, treating constipation may trigger incontinence (and the other way round). So you need to use these treatments with care.

## Possible treatment options (most common listed first)

⌵	Physical activity, or changing what you eat or drink
⌵	Laxatives, anti-diarrhoea drugs, <b>stool softeners</b> or other drugs
⌵	Putting things into your bottom (like <b>suppositories, mini-enemas</b> or <b>anal plugs</b> )
⌵	Using your finger or hand to help you poo ( <b>digital stimulation, manual evacuation</b> or <b>abdominal massage</b> )
⌵	<b>Biofeedback</b> (retraining your bowels)
⌵	Washing your bottom out to make you poo ( <b>anal irrigation</b> )
⌵	Electrical stimulation of nerves linked to your bowels
⌵	Surgery

“I’m going to look at options like irrigation. I’d really like to be able to go out and do things on the spur of the moment, and have a bit more of a normal life. I’m sure my husband would like this too.”

**Louisa**







# When your bowels don't empty often enough

Constipation is the most common of the two bowel problems that MS causes. Up to 7 in 10 people with MS can get this.

## What is constipation?

This is when it's hard to poo – or you don't do it often enough. Between three times a day to three times a week is normal.

Had some of these symptoms for three months? Then you're probably constipated:

- pooing less than three times in a week
- spending a long time trying to poo, but nothing happens
- hard, dry, lumpy poo (types 1-2 on page 17). When it won't move along your **colon** and **rectum**, it's called 'impaction'
- straining on the toilet
- feeling sick or bloated (or it hurts to poo)

- feeling you've not fully emptied your bowels
- not feeling hungry (and you're losing weight)
- watery diarrhoea-like fluid (this leaks from behind hard, impacted poo)
- you can't tell if your rectum is full (while you have the symptoms above)

## How does MS cause constipation?

MS slows down your bowels. Poo doesn't move fast enough along them. Because it spends too long in your colon, too much water is taken from it. That makes your poo hard and difficult to pass.

There are two ways that MS makes your bowels slower:

- it stops nerves working like they should in the muscles in and around your bowels

- MS fatigue or problems moving about can make you less active. Walking stimulates muscles in your bowels to move poo along. The less you move, the more sluggish your bowels get

Damage that MS causes to nerves in your bowels can also mean you lose feeling in your back passage (rectum). You don't realise it's filling up and that you should go to the toilet. So poo builds up, causing constipation.

If your MS means it's not easy to move about, going to the toilet can involve a lot of effort. So you might wait as long as you can. Your rectum stretches and gets used to being full. The urge to poo gets less, ending in constipation.

Lastly, constipation can also be a side effect of drugs you might take to treat other MS symptoms (see page 31).

## First line treatments

These are treatments you try first. They're the easiest ones to have and they work for many people.

They make your poo less hard, and speed up how fast it moves through your bowel. That means less water is taken out of it, so it stays soft enough.

After you get into a regular toilet routine, the next step is to:

- eat more fibre
- drink more

It might help if you become more physically active.

There's no hard evidence that these work with constipation caused by MS, but it's worth trying them.

In an MS Society survey in 2010, people told us laxatives helped the most. Next came **suppositories**, diet changes, then **digital stimulation** and **manual evacuation**. These were followed by enemas and **abdominal massage**.

This survey happened before **transanal irrigation** became popular, so only a few people said they used that.

Some people try things like reflexology, aromatherapy and homeopathy. But in our survey fewer people said these had any effect.

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.

Let's look at treatments in more detail.

## A regular routine

Constipation is less likely if your bowels are used to emptying at certain times. Learn how to do this on page 19.

## Exercise and diet

Cut your risk of constipation by changing what you eat and drink, and by getting more exercise.

### Drink more fluid

This is often the key to managing constipation. Drink 6 to 8 glasses or cups of fluid a day (more if the weather's hot or you're exercising).

Apart from your first pee of the day (which is often darker), wee should be pale yellow. Darker wee means 'drink more'.

You may be tempted to drink less if you have a bladder problem, or your MS makes getting to the toilet difficult.

But this can make constipation worse. Talk to your MS nurse, GP or continence nurse about how to manage this.

## Be more active

Moving more stops your bowels getting sluggish. Exercise that uses your stomach muscles will strengthen the muscle in your bowel and help it push poo along.

Check out our exercises at [mssociety.org.uk/care-and-support/everyday-living/staying-active](https://mssociety.org.uk/care-and-support/everyday-living/staying-active) If you use a wheelchair, you'll find exercises there that you can do too.

### Eat more fibre

Fibre makes your poo have more bulk. That makes it easier for it to move along your bowel.

Have at least five pieces of fruit or vegetables a day – ideally more. It can be tinned, dried, frozen or come as a juice. Eat a mix, not just one type of fruit or veg.

Ditch white rice, regular pasta and white bread. Instead eat brown rice, whole-wheat pasta and wholemeal bread.

For breakfast choose whole-grain cereals. These include porridge, Shredded Wheat, bran flakes, Weetabix or muesli (but without added sugar in it).

Snack on nuts, seeds and dried fruit. Or add them to meals, along with lentils or any kind of peas or beans. Baked beans are good too.

Some people add a tablespoon of linseeds (also called flaxseeds) to food or a yoghurt.

When you add fibre to your diet, go slowly. If you suddenly eat more fibre, you'll get bloated and full of wind.

Because fibre soaks up water in your bowel, you'll need to drink more. Without enough fluids,



your poo will be hard and your constipation won't get better.

Fibre doesn't make things better for everyone. Some people find fibre, bran in particular, makes their constipation worse, especially if they don't drink more.

For these people, fibre can slow their gut down, or cause diarrhoea. It might make Irritable Bowel Syndrome (IBS) worse, too. Get advice from a doctor, dietician or MS or continence nurse.

**“I try to manage my constipation by eating as near to my five a day as I can in fruit. And by drinking plenty of water. It doesn't always work. Certain combinations of fruit work better than others to keep me regular. It's taken a bit of trial and error.”**

**Louisa**

## Drugs

It's hard to control constipation with medication alone.

Constipation drugs, like laxatives, can also tip you from being constipated into leaking poo. To avoid this, a health worker can tell you how to tailor your use of them.

## Laxatives

Laxatives use different ways of getting poo to move through your bowels. They come as tablets or capsules that you swallow. Or they might come as a powder that you add water to.

You can also put a capsule up your bottom where it dissolves (called a suppository). Or you put a gel or liquid into your bottom (known as a mini- or micro-enema).

On average laxatives take about 8 hours to work. You take them at night so the effect is strongest by morning.

Over the next couple of pages we look at the different types of laxatives.

## Bulk-forming laxatives

These are also called bulking agents. Fibre in these laxatives soaks up water in your bowel. This makes your poo bigger and heavier. A bulkier poo stimulates your bowels to squeeze more, so it moves along quicker.

These laxatives may take two to three days to work. Examples are ispaghula husk (also called psyllium). Brand names are Isogel or Fybogel, sachets of high fibre, fruit-flavoured powder.

There's also methylcellulose (brand name Celevac) and sterculia (Nomacol).

Bulk-forming laxatives are the gentlest on your body and the safest to use long term.

## Osmotic laxatives

These draw water into your bowels from the rest of your body, and keep it there. This softens your poo.

They may take two or three days to work. Examples are lactulose

(its brand names are Duphalac and Lactugal) and polyethylene glycol (also known as PEG or macrogol). Brand names are Laxido and Movicol.

Too much causes diarrhoea, so follow medical advice. It can take a few weeks to get the dose right. Some people need two sachets a day, others manage with one every two days.

## Stimulant laxatives

These make muscles in your gut squeeze more, moving poo along faster.

These take 6 to 12 hours to work. Examples include bisacodyl (brand name Dulcolax), sodium picosulfate (brand name Dulcolax Pico) and senna (brand name Senokot).

Some doctors think senna shouldn't be used for longer than a week. But for some people with MS senna can be a good long term solution. Some people using it will find it works less and less over time. Senna should only be used long term on medical advice.

## Stool softeners

These laxatives also let water into your poo to make it less hard. Often stool softeners aren't enough on their own, so you use them with a stimulant laxative.

Stool softeners include arachis oil and docusate sodium. Brand names are DulcoEase and Dioctyl.

You can also get stool softening gels to use as micro-enemas called Docusol or Norgalax.

**“My GP was excellent. She ordered an ultrasound scan and X-ray, and referred me back to the continence nurse. We agreed to manage my symptoms by using laxatives and stool softeners, and by improving my diet and exercise regimes.”**  
**Lindsey**

## What kind of laxative to take?

People usually try a bulk-forming laxative first. If that doesn't work, they might try an osmotic laxative (or take one with the bulk-forming laxative).

If this fails, they might try a stimulant laxative together with the osmotic laxative.

A bulking agent on its own may make constipation worse. So you might use one together with another type such as the prescription-only laxative prucalopride (Resolor).

### Using laxatives long term

It's not a good idea to treat yourself over a long time with over-the-counter laxatives.

The longer you use them, the less they tend to work. And overdoing laxatives can cause bowel accidents.

Let your GP, MS nurse or continence nurse advise you on what to use, and how to tailor your use of them.



MS might mean you can't get to a toilet fast enough. Or it stops you knowing when the laxative is about to work and that you need to empty your bowels. So people often feel they need to stay close to a toilet to avoid bowel accidents.

## Suppositories

Some laxatives you can take as a suppository.

These let you decide when to empty your bowels, and they work faster. For example, bisacodyl (Dulcolax) tablets take 6 to 12 hours to work. The suppository version takes 10–45 minutes.

A suppository is made of a firm jelly-like substance shaped like a bullet. Some are simple glycerin without any medication; others include a laxative. You cover it in lubricant, then push it into your bottom where it melts.

Some come with an applicator to help you get it inside. Or it might come as a liquid that's inside an applicator. You put that inside your bottom and squeeze the liquid out.

Put a suppository inside your bottom about half an hour before you want to go to the toilet.

## Mini or micro-enemas

These use a small amount of stool softener which comes in a little tube. You put it inside your bottom, then squeeze out the softener. It works in 5 to 20 minutes, so stay near a toilet.

Brand names include Enemeez, Norgalax and Micralax.

**“My bowel problems started after a relapse that affected my walking. I started taking pregabalin. And I'm on a disease modifying therapy. These medications can have the side effect of constipation. So alongside more time spent sitting and comfort eating, I was in a vicious circle that led to chronic constipation.”**

**Louisa**

## Drugs that cause constipation

Some medicines used in MS cause constipation. These include drugs for:

- **muscle spasms and stiffness** such as baclofen (Lioresal) and gabapentin (Neurontin)
- **pain** such as pregabalin (brand names are Lyrica, Alzain, Lecaent and Rewisca) and gabapentin (Neurontin). Also any painkiller with codeine in it (including Co-codamol, Nurofen Plus and Solpadeine Max or Plus), or any with morphine in it (like Oramorph)
- **bladder problems** such as oxybutynin (Ditropan) and tolterodine (Detrusitol or Detrol)
- **depression** such as amitriptyline (Lentizol, Tryptizol, Domical and Elavil), fluoxetine (Prozac) and citalopram (Cipramil)

Always speak to your doctor before you stop taking a drug.

## Abdominal massage

You press firmly on your stomach to encourage a poo. For ten minutes you make a movement in a circle with the palm of your hand or fist, moving from right to left.

It's thought this stimulates your bowel to squeeze poo faster through it. It may make it softer too.

In studies it made people poo more often. Some felt their bowels were more likely to empty better. Others said they were less bloated, had a better appetite and going to the toilet was easier.

Abdominal massage doesn't work for everyone. And the difference it makes for others might not be very big. But it costs nothing, has no side effects, and it can be done by yourself (or your carer).

You could use it along with other treatments like laxatives, **anal irrigation** or **biofeedback**.

See someone doing the massage at: <https://www.gcu.ac.uk/amber/resources/videosforstudyparticipants/>

Abdominal massage isn't right for all types of constipation. Before you try this, a doctor or nurse needs to check why you're constipated. If it's right for you, a trained person must teach you the massage.

## Using a finger

### Digital stimulation (or 'digitation')

You use your finger to make the muscle in your rectum squeeze so that it pushes poo out.

You put a gloved finger (lubricated with water-based gel) into your bottom, then slowly turn it around making a circle. You keep your finger touching the lining of your **rectum**. A carer can also do this for you.

Do this for up to 20 seconds, then pull your finger out to let a poo happen. You do this a few times every five to ten minutes until you've passed all your poo.

Stop if nothing happens after three tries. Carry out a 'manual evacuation' instead.

It's best to do digital stimulation –

or manual evacuation – sitting over the toilet (or a **commode** or showerchair with a built-in toilet seat). Being upright helps poo move down into your rectum.

### Manual evacuation

You can do this over a toilet or commode – or lying on a bed. You'll need to cover the bed with a disposable protective sheet while you do this (a nurse can prescribe these for you).

You stick a gloved, lubricated finger into your bottom. You use this hooked finger to break up or to take out the poo, flushing it down the toilet. If you're on a bed, you collect the solid poo in a container, then flush it away.

If the poo isn't solid enough to be flushed, or the sheet gets poo on it, double bag it (put one plastic bag inside another to stop it leaking). You can then put this with the normal household rubbish.

For more advice on getting rid of this kind of waste, speak to your continence service.

If your finger or hand control isn't good, someone else can do this for you. This could be a district nurse or your family carer (once they've had training to do this).

**Important: Don't try manual evacuation until a specially trained nurse has taught you how to do it.**

Digital stimulation or manual evacuation is easiest if your poo is around 3 to 4 on the Bristol Stool Chart (see page 17).

## Second line treatments

You try these if first line treatments don't make your constipation any better. They're often more of a challenge.

### Other drugs

If two different types of laxatives haven't worked, there are two prescription-only alternatives:

- Prucalopride (brand name Resolor). This type of laxative stimulates nerves in the muscles that line your bowel. This makes poo move along

it quicker. This drug isn't recommended on the NHS in Scotland

- Lubiprostone (brand name Amitiza). It's not a laxative, but makes your bowel keep more water in it to soften your poo.

### Transanal irrigation (TAI)

This is also called rectal or anal irrigation.

You wash your bottom out with water to make you poo. It can be used for constipation and **faecal incontinence**.

TAI lets you decide when and where you poo. You only use it if gentler treatments don't work.

You use a pump system, or one that works using gravity, to push warm tap water into your bowel.

You use enough water to reach past your rectum. This encourages muscles there to squeeze out poo.

You sit on the toilet (or on a commode), then put a tube (catheter) up your bottom to get the water up there - or you use a cone instead.

The catheter has a small balloon on it that blows up when it's inside you. This stops it falling out and seals the water in. If you're using the system with a cone, you hold the cone in place.

When you take the tube or cone out, muscles in your bowel squeeze, your bowel opens and water flushes poo out.

TAI usually stops you getting constipated (or being incontinent) for two days. Ideally you use it every other day. You can do it yourself or someone can help you.

You can only get a TAI system on prescription from your GP or a specialist nurse (from a continence service, for example).

Before trying it, a doctor or nurse must examine you and teach you how to use it. An MS nurse, or a nurse from the company who makes it, visits you. They make sure you can use it. But they don't need to be in the room when you use it for the first time.

To make TAI work you need to be motivated. It can take up to two months before you feel confident using it.

You may need to use TAI along with abdominal massage, digital stimulation and laxatives, at least for the first few months.

TAI won't work for everyone. Some people give up because it takes quite a bit of time (20 minutes to an hour).

But TAI has changed lots of people's lives. It lets them stay in work, go on holiday, and so on. It's safe and works long-term.

The TAI systems with a catheter are called Peristeen© and Navina©. The ones that use a cone are Qufora©, Iryump© and Aquaflush©.

## Biofeedback

This is retraining your bowels. You use tools to improve how muscles work together when you poo. This includes your sphincter and muscles in your belly and around

your bowels. Biofeedback might also help you get better at feeling when your rectum is full.

Here's one example of biofeedback:

You sit on a **commode** with a sensor inside you that measures how your muscles work as you push.

The sensor turns this into patterns on a screen (or into sounds). So you can see how your muscles are working on a screen.

By following what you see, you learn to change how the muscles work.

How many training sessions you have, and how long they last, is different from centre to centre. Some have follow-up sessions to keep you on track.

Only a few centres offer biofeedback. But it might help some people with MS-related constipation (and incontinence), especially if their MS isn't too advanced.

## Functional Electrical Stimulation (FES)

With this you stick pads on to your abdomen (belly) with electrodes in them. These are connected to a small battery pack.

The electrodes send mild electrical signals into the muscles of your abdomen, making them squeeze. Poo then travels through your bowels faster, preventing constipation.

This treatment can last for half an hour twice a day for six weeks. You do it to yourself at home, or a carer helps you.

There have been a few small studies of FES. It helped with constipation, improved people's quality of life, and they used fewer laxatives. It has no side effects. But it's a fairly new treatment, so we need more studies. Not many places offer FES.

Don't try this unless an FES specialist has assessed you and taught you how to do it.

# When you can't control leakage from your bowels

MS might mean you can't control when your bowels empty. This leakage of poo causes bowel 'accidents' and is called faecal incontinence.

This isn't as common as constipation (about half of people with MS might get this sort of leakage). But a bowel accident in public can be very upsetting.

When you're out, you can get anxious about where the nearest toilet is. You might avoid leaving the house in case you have another accident.

These are symptoms of faecal incontinence:

- you leak poo. Maybe you can't control when you pass wind, too
- but you might not even notice the leakage until afterwards
- you notice stains or poo on things you're wearing
- or you have a sudden need for the toilet, then have an accident because you can't get to it fast enough

## Why does this happen in MS?

You're more likely to get leakage if MS has caused nerve damage (lesions) on your spinal cord.

Here's how MS can make you lose control over your bowels:

- nerves in your **anal sphincters** don't work properly, making these rings of muscle weak. So they can't hold in poo like they should
- damage to nerves in your rectum mean you no longer feel you're full, so poo leaks out
- or you get a sudden need to urgently poo
- nerve damage in muscles in or around your bowels stop them relaxing and squeezing like they should. So you can't hold in as much poo as you once could.



- damaged nerves make your colon spasm, so poo travels through it too fast making it runny. When poo isn't solid, it's harder to feel that your rectum is full

You're likely to need a mix of treatments to get in control of faecal incontinence.

## First line treatments

### A regular routine

Bowel accidents are less likely if you get your bowels used to emptying at regular times. Read more on page 19.

### Drugs

There's not much evidence about which drugs, if any, have a big impact on faecal incontinence. But if your poo is loose or soft, the first step is usually to make it firmer.

The drug loperamide (brand name is Imodium) will slow your gut down, so that runny poo stays in it longer. That means more water gets absorbed by your gut, and the poo becomes more solid. You take this drug as a tablet or a syrup.

Sometimes using laxatives too often, and too much fibre in your diet, can make your poo loose. If that's behind your problem, cut down or avoid these.

Firming up your poo might make it too hard and trigger constipation. So when you start an anti-diarrhoea drug (like loperamide), begin with small doses. Then take bigger ones if you need to.

### Anal plugs

You put one of these up your back passage to stop leakage. It's made of foam and comes in different sizes.

Once it's in place, the wetness inside you makes it open up into a cup or mushroom shape. This stops it slipping out and plugs your bottom so that nothing can leak out.

You can keep a plug in for up to 12 hours (you take it out if you want to poo). Some people find them uncomfortable to wear, especially over many hours. To take it out, pull the string at the end.

You can get plugs on prescription if a health worker has assessed you.

## More things that might help

### Food and drink

Alcohol and caffeine (in cola, coffee and tea) can irritate your guts, making faecal incontinence worse. It might help to avoid them.

Eating more fibre can make your poo firmer (though for some people fibre can cause diarrhoea).

### Continence products

These make a bowel accident less messy:

- special clothing, like swimwear or incontinence pants (which look more like normal underwear than pads). Pads can be useful when you're away from home
- things that protect beds and chairs
- disposable gloves and bags to put poo in
- things that hide the smell of poo (like clothing and pads with a charcoal filter fitted inside)
- products for your skin

You can also get absorbent pads that hold in any leakage. Some are designed to hold poo, others hold wee. People often wear ones made for wee because they're bigger and cover more skin.

Depending on where you live, your GP might prescribe these products, or your local continence service might give you them. You'll need an assessment first.

Before you buy a product or get a prescription, check out [continenceproductadvisor.org](http://continenceproductadvisor.org) for information and reviews.

Bladder & Bowel UK sell these products and can advise you. Check out their website and online shop at [bbuk.org.uk](http://bbuk.org.uk) or call their helpline on **0161 607 8219**.

### Some useful tips

On pages 44–48 are suggestions to help live with faecal incontinence, such as:

- know where toilets are
- look after skin around your bottom
- contact places offering emotional support

- make it easier to get to and use the toilet. Wear clothes you can get out of in a hurry. Make changes at home that let you move around more easily. For more on this check out page 47.

## Second line treatments

If first line treatments don't get results, there are more options. But the evidence for them making a big difference isn't strong.

**NICE** recommend what treatments are available on the Health Service in England. They've said that's it's not clear what - if any - difference **pelvic floor muscle training, biofeedback** and **electrical stimulation** make to faecal incontinence. They only recommend trying them if you don't get results with other treatments.

## Pelvic floor muscle training

Pelvic floor exercises strengthen muscles around your bowels and back passage (including your external **anal sphincter**). Both men and women can do them. Imagine you're clenching the muscles around your back

passage to stop some wind escaping. The muscles you feel tightening are the ones to work on.

You can do the exercises sitting down. Squeeze the muscles 10-15 times in a row without holding your breath. Don't tighten your stomach, buttock or thigh muscles.

Hold each squeeze for a few seconds. Add more squeezes each week (resting between each set of squeezes). Try to do the exercises three times a day. A continence physiotherapist or continence nurse can teach you a good technique.

It takes a few months before you feel it's working. If you start feeling a difference, don't stop. You need to keep exercising those muscles.

You'll find here a leaflet from London's St Mark's Hospital that shows exercises to help with bowel leakage:

<http://www.stmarkshospital.nhs.uk/wp-content/uploads/2014/05/Anal-sphincter-exercises-for-leakage.pdf>

There's more about these exercises at:

[bladderandbowel.org/bladder/bladder-resources/pelvic-floor-muscle-exercises/](http://bladderandbowel.org/bladder/bladder-resources/pelvic-floor-muscle-exercises/)

Evidence that these exercises make much of a difference isn't that strong. You might get better results by combining them with biofeedback.

**“I was given exercises to strengthen my external sphincter.**

**Eight months later and things have improved. If I'm out, I don't have to think where I can go.”**

**John**

### **Transanal irrigation**

This might help with incontinence. After you've used this, new poo won't reach your back passage for two days on average. That way you can stop leakage between irrigations. Find out more on pages 33–34.

### **Biofeedback**

This can teach you to be better at noticing that your rectum's filling

up and needs to empty. It can also work on making a weak sphincter stronger. Read more on pages 34–35.

### **Electrical stimulation**

A low level electric current is sent along nerves that connect with your bowels. This can change how the muscles there behave, helping with incontinence (and constipation). This is called neuromodulation. It can be done in two ways.

#### **Percutaneous Tibial Nerve Stimulation (PTNS)**

A needle is stuck into the skin above your ankle, near the tibial nerve which goes up your leg. An electrode is stuck on your foot. The needle and electrode are connected to a stimulator device. A mild electric current is sent through this into your tibial nerve.

The current goes up your leg to the bottom of your spine. There it works on a nerve that's linked to your bowels to make it behave more normally. You may get this treatment at home or in a clinic. It might take several months before you get the best results.

## Sacral neuromodulation (SNM)

This is another treatment that stimulates nerves. It involves surgery, so read about it in the section that comes next.

### Surgery

For some people surgery is worth thinking about. There are two operations available, sacral neuromodulation and a colostomy.

## Sacral neuromodulation (SNM)

This is also called sacral nerve stimulation. You have an implant fitted under the skin over your sacral nerve. This is at the bottom 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. This nerve is linked to your sphincter, pelvic floor muscles and bowel. The impulses make the nerve behave more normally.

A two week trial will see if this treatment works for you before you have the implant permanently put in.

Until recently people with MS couldn't have sacral nerve stimulation. That's because if you needed an MRI scan of your spine, the implant made this impossible.

But now some implants are safe with scans. Your neurologist or bowel specialist can tell you more.

## Does stimulating nerves with electricity work?

There's not much evidence to show if PTNS and SNM are very useful. That's why there are no official guidelines for using them to treat bowel problems in MS.

You might be offered this if other treatments haven't worked.

Some studies show it can help with faecal incontinence. Using PTNS can cut how many bowel accidents you have.

Other studies have found it made little difference. More studies are needed.

This treatment isn't offered by all hospitals or continence services.

## Colostomy

A colostomy is an operation where a surgeon makes a permanent opening (a stoma) in your belly. The end of your colon is redirected through this opening. Instead of you passing poo in the normal way, it leaves your bowel through the stoma.

You wear a bag over the opening to collect poo. When it's full, you take it off and put a fresh one on. A stoma saves a lot of toilet time, and stops faecal incontinence.

Some doctors see this as a 'last resort' to try if all other options have failed. But some people choose this earlier than that. They say it's made a big difference to their quality of life and gives them control over their bowel.

**“Looking back,  
I realise just  
how much my life  
has had to be  
ordered by  
the state of my  
bowels.”**

**Sue**

## Drugs that cause runny poo

Meds that cause diarrhoea include:

- **baclofen** (brand name Lioresal), a drug to treat muscle spasms and stiffness. Your dose may need checking
- these disease modifying therapies (DMTs) can cause diarrhoea: **teriflunomide (Aubagio)**, **dimethyl fumarate (Tecfidera)** and **fingolimod (Gilenya)**
- **laxatives**
- **blood pressure drugs** like beta-blockers and calcium channel blockers
- **metformin**, a diabetes drug
- antibiotics like **penicillin** and **erythromycin**
- some **antidepressants** (tricyclics and SSRIs)
- the sedative **benzodiazepine**

Your doctor or MS nurse can advise you if you get diarrhoea from these drugs. Don't stop taking a drug without first talking to your doctor.





# Tips for bowel problems

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

## On the toilet

These tips should help with trips to the toilet:

- The toilet should be private, safe and comfortable. You need to feel you can use it as long as you need to, while sitting safely
- Have something to read in there
- Keep your feet apart and on the floor, or resting on a foot stool (especially if you've fitted a raised toilet seat)
- Knees should be a bit higher up than your hips
- Lean forward a bit with elbows on knees if you can. But keep your back straight when you push
- Brace the muscles in your abdomen (belly), then bulge the abdominal wall outwards
- Don't strain or hold your breath when you push. That makes muscles tense. You need to relax them

- Give up after 10 minutes if nothing happens. Try again the same time the next day



**“It never occurred to me to raise my feet when on the toilet. Then someone pointed out how animals always squat to poo as it’s a more natural position.”**

**Christine**



## 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 such as the Wheelmate app at **coloplast.co.uk**
- 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 local Community Toilets Scheme. It lets you use toilets in shops, restaurants and pubs without paying



## Skin care

- Poo left on your skin makes it sore. It can become infected with bacteria and fungal infections.
- After a bowel accident, don't sit in a damp pad or clothing. Wash your skin as soon as you can. Unscented soap is best, or just water.
- Don't rub skin dry. Gently pat it instead.
- With dry or irritated skin use a gentle skin cleanser, not soap. Use an unperfumed moisturiser twice a day (no talcum powder).
- Avoid skin products with alcohol, disinfectants or perfumes in them. They make skin dry and inflamed.
- A barrier cream like Sudocrem shields skin from wee or poo. It cuts down on friction from bedding and clothing, and soothes irritated skin. Don't put too much on or it'll stop continence pads and pants absorbing wee or poo after an accident. Too much cream also makes clearing up after accidents harder.

## Emotional support

- You can turn to an MS nurse for support and information. Or call our MS Helpline to talk to someone in confidence. They're trained in giving emotional support. The different ways you can contact us are on page 49.
- The MS Society forum is a good place to get useful tips and share your experiences. It's at <https://community.mssociety.org.uk/forum>
- Bladder and Bowel UK have a helpline on **0161 607 8219** run by specialist nurses and continence product information staff. You can also email them on [bbuk@disabledliving.co.uk](mailto:bbuk@disabledliving.co.uk)



## Making changes to your home

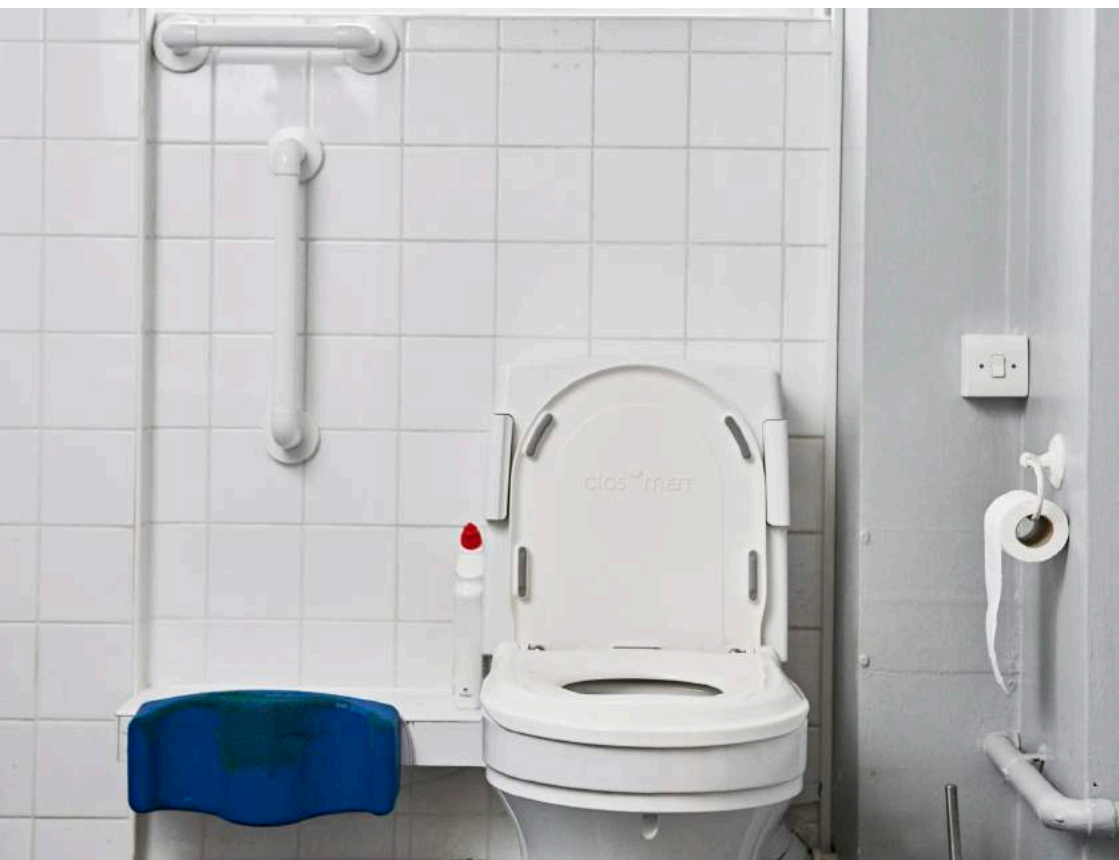
- Alterations to your home ('adaptations') might be helpful. They can be small, like fixing grab rails to the wall by your toilet, or putting something on your toilet seat to raise it up (like in the picture on the next page). Or it could be a bigger change, like moving your toilet downstairs or converting a bathroom into a wet room.
- You might be able to get help with this from your local council (or, in Northern Ireland, from your Health and Social Care Trust). An occupational therapist can come to your home and advise on adaptations.
- Our booklets on social care cover adaptations and financial help available, such as Disabled Facilities Grants. Find more details at [mssociety.org.uk/care-and-support/everyday-living/home-adaptations](https://mssociety.org.uk/care-and-support/everyday-living/home-adaptations)
- Apply before you have any work done. You'll get no money if you apply afterwards. And you shouldn't pay VAT on adaptations. There's more about this at [gov.uk/financial-help-disabled/vat-relief](https://gov.uk/financial-help-disabled/vat-relief)

## Toilets at work

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](https://mssociety.org.uk/reasonable-adjustments)

## Is medication causing your bowel problem or making it worse?

- Constipation or diarrhoea can be a side effect of drugs you take to treat your MS symptoms (see pages 31 and 42 for examples). You can always ask a pharmacist if you have questions about medications you take.
- You could also ask for a Medicines Use Review with the pharmacist who gives you your prescriptions. They'll make sure that you know what what you're taking and why. They'll check if these drugs together might give you side effects, like bowel problems.
- In Scotland you can ask for a Medicines Care Review instead (the pharmacist will have a form for you to fill out). If your pharmacist doesn't offer this service, you can ask for one at a different chemist.



# Useful organisations

If you need more information or support with a bowel 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 us in confidence about your bowel problems and how they affect you.

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

You can also send the helpline 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 **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 bowel 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

Information and advice, plus an online shop selling continence products. A team of Specialist Nurses and Continence Product Information Staff manage their helpline. Call **0161 607 8219** or email **bbuk@disabledliving.co.uk**  
**bbuk.org.uk/**

## Bladder and Bowel Community

Information and support for those with a bowel or bladder condition. They have support and information forum staffed by a nurse, plus an online shop for continence products.

[bladderandbowel.org](http://bladderandbowel.org)

## Continence Product Advisor

Website with impartial advice for people who use continence products such as pads, skin care, anal plugs, things that deal with smells and protect beds, clothes and chairs.

[continenceproductadvisor.org](http://continenceproductadvisor.org)

## Colostomy UK

Information if you're thinking of getting – or already have – a stoma.

[colostomyuk.org/](http://colostomyuk.org/)

## Disabled Living Foundation

Charity providing advice, information and training on equipment and mobility products for disabled people.

Helpline 0300 999 0004

[dlf.org.uk](http://dlf.org.uk)

They have a free self-help guide

website called AskSARA. Just choose what you need help with. Answer a set of questions and it'll give an instant customised report with suggestions for equipment. Its page on toilets is at:

[https://asksara.dlf.org.uk/choose\\_topic.php?topic\\_id=1044](https://asksara.dlf.org.uk/choose_topic.php?topic_id=1044)

## MS National Therapy Centres

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

[mscnt.org.uk](http://mscnt.org.uk)

## MS Trust

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

Free Phone Information Service:  
**0800 032 3839**

## RADAR National Key Scheme (NKS)

This is run by Disability Rights UK. 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](http://disabilityrightsuk.org/shop/official-and-only-genuine-radar-key)

# New words explained

**abdominal massage** – to get you to poo, you use the palm of your hand or fist to press firmly on your abdomen (belly) and make a circular movement

**anal irrigation** – see **transanal irrigation**

**anus** – the opening to the outside of your body at the end of your bowel. Where poo leaves your body

**anal sphincter** – see **sphincter**

**biofeedback** – training muscles for better bowel control. For example, you put an electrical sensor inside you, squeeze your muscles and see on a screen the effect that has on your bowels. You use this to learn how to squeeze poo out better

**bowel(s)** – the part of your body where food is digested, and what's left is made into poo. It's made up of your small bowel (small intestine). This leads to your large bowel (also called the large intestine or **colon**). Your bowels end with your **rectum** and **anus**

**Bristol stool chart** – a way doctors

and nurses describe different kinds of poo, using a scale from 1 (too hard) to 7 (too runny). See page 17.

**colon** – the part of your bowels where poo is made and passed on to your **rectum**. Also known as the large intestine or large bowel

**colonoscopy** – when a surgeon uses a long, thin, bendy tube with a camera in it to look into your large bowel

**colostomy** – an operation where an opening (**stoma**) is made in your belly so that poo can leave your body from there instead of through your **rectum**

**commode** – a chair, often on wheels, that has a chamber pot built into it that you can use when you need the toilet

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

**constipation** – not being able to poo often enough (usually fewer than three times a week) – or you have difficulty passing poo



**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 and supply continence products

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

to **defaecate** – to have a poo

**digital (rectal) stimulation**, also called **digitation** – you stick a finger inside your bottom and gently turn it round to encourage you to poo. You wear a disposable glove and cover the finger with water-based lubricant

**electrical stimulation** – see **PTNS** and **sacral neuromodulation**

to **evacuate/evacuation** – to empty your bowels (have a poo)

**faecal**, also spelt **fecal** (pronounced ‘fee-kul’) – meaning to do with poo

**faecal impaction** – see **impaction**

**faecal incontinence (or FI)** – when you lose control of your bowels and have an ‘accident’ where poo leaks out of your back passage

**faeces** (pronounced ‘fee-sees’) – poo or stools

**hoist** – you sit in a sling and the hoist, powered by electricity, lifts you up on to a toilet. That way you or your carer don’t get hurt while lifting. Find them in toilets run by Changing Places (see page 45)

**(faecal) impaction** – when a lot of hard poo is stuck in your **colon** or **rectum**. You’ll need medical help. Symptoms are going longer than usual between poos, feeling sick or bloated, or pain. Loose watery poo might leak out from behind solid poo that’s got stuck

**manual evacuation** – when you hook your gloved, lubricated finger to get poo out of your bottom

**megacolon** – when constipation is making your colon stretch too wide

**mini- (or micro) enema** – a small tube of stool softener that you put inside your bottom. You then squeeze out the softener

**neurogenic bowel dysfunction (NBD)** – when your colon isn’t working properly because you have a condition (like MS) that’s causing damage to your brain or



spinal cord. **Incontinence** and **constipation** are symptoms

**NICE (National Institute for Health and Care Excellence)** – part of the Department of Health, NICE makes guidelines for England about which drugs should be available on the National Health Service

**(faecal) overflow incontinence** – if you're constipated, a hard mass of poo builds up. Watery poo gets round it and leaks out of you. Often mistaken for diarrhoea

**pelvic floor muscles** – a group of muscles that lie across the base of your abdomen (belly). They play an important role in controlling how you wee or pass poo

**percutaneous tibial nerve stimulation (PTNS)** – sticking a needle into skin above your ankle to send a mild electrical signal up a nerve in your leg. This can give you more control over your bowel

**peristalsis** – when muscles in your bowels squeeze (contract) in a wave-like movement. This pushes poo along your bowels

**rectum** – lower part of your bowels. It ends with your **anus**. It's the medical word for your back passage

**sacral neuromodulation (SNM)** – a device is put into the upper part of your buttocks. It sends electrical signals to stimulate a nerve that connects with your bowel. This can help with a bowel problem

**sphincter** – a ring of muscle that opens and closes. Your two anal sphincters are at the end of your **rectum**, around your **anus**. They open to let poo leave your body

**stoma** – opening made by a surgeon from your bowel through the wall of your abdomen to let poo out

**stool** – a poo

**stool softener** – you take this to make your poo hold more water, making it softer and easier to pass

**suppository** – a hard, bullet-shaped medicine full of a jelly-like substance. You put it up your bottom where it melts and releases its drug

**transanal irrigation (TAI)** – washing out your **rectum** with warm water to get you to poo

**transit time** – how long it takes for a poo to pass through your colon

# Further information

## Resources

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

To order email:

**[shop@mssociety.org.uk](mailto:shop@mssociety.org.uk)** or visit  
**[mssociety.org.uk/publications](https://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](mailto:helpline@mssociety.org.uk)**

# About this resource

Thanks to all the people affected by MS and professionals who contributed to this booklet, in particular: Professor Christine Norton, King's College London and Noreen Barker, Consultant Nurse, Multiple Sclerosis Team at the National Hospital for Neurology and Neurosurgery.

If you have any comments on this information, please send them to: [resources@mssociety.org.uk](mailto: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: Amit Lennon (cover, pages, 26 and 48), David Dunne (p6), Rebecca Cresta (pages 19 and 22), Paul Moane (p42) and Susannah Fields (p 47). Illustrations: Damion Mulrain (pages 9 and 11) and Emily Midgley (p17).

This resource is also available in large print.

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# Contact us



## MS Helpline

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