Managing your bowels

A guide for people with MS

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Introduction

Around half of all people with MS experience bowel problems at some time. Many people find these symptoms difficult and embarrassing to talk about. However, with the right information and support, most bowel problems can be managed so they have much less impact on your daily life.

"I can actually live life now instead of being a prisoner in my own home and unable to have a social life, now I am back to loving my life."

This book provides practical ideas and suggestions to help you manage your bowel problems.

It explores:

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

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

1. Talking about bowel problems

Many people feel embarrassed or uncomfortable talking about bowel problems. You may feel awkward raising these issues with a health professional. The reality is that bowel problems are common for people with MS. Talking to a health professional is an important first step in getting the right treatment. They can provide a safe and shame-free environment to discuss bowel issues.

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

"If only I had discussed this with someone sooner. It would have saved years of uncertainty, worry, loss of dignity and freedom."

Many hospitals and community healthcare settings have a continence service that deals specifically with bladder and bowel problems. In some areas you can refer yourself directly to them. If not, your MS specialist nurse or GP can make a referral. These services offer appointments in clinic and home visits for people who can't attend a clinic.

"There's no need to struggle – health professionals don't have a problem talking about bowel issues – it's the rest of the population that does!"

When talking to your health professional about bowel problems, use the language you're most comfortable with. Your health professional will understand what you mean. We use the words poo, stool and faeces throughout the book.

"Talking about bowel symptoms might not be as traumatic as you may imagine, and the solution may be straightforward."
– MS specialist nurse

2. When should I contact a health professional?

If any of the bowel problems listed below are affecting your life, it might be time to contact a health professional for help and support.

- You've noticed changes in your bowel habits, such as going to the toilet more or less often.
- You spend a long time trying to empty your bowels, but without success.
- If your stools have changed – they might be harder, softer or have changed colour.
- You're having to rush to the toilet.
- You have no control over when your bowels open.
- You leak faeces or pass wind without being aware of it.

If you have blood in your poo, prolonged diarrhoea, constipation, or unexplained weight loss, speak to your GP straightaway for an assessment. It's important not to ignore these symptoms as they can be a sign of bowel cancer.

What will happen at my appointment?

When you talk to your health professional, it's important to be clear about your symptoms and how long they've been affecting you. You could tell them how your bowel problems affect your life. For example, if the symptoms are making things difficult at work or stopping you going out with friends.

When you see your health professional, they'll take a full history of your symptoms. They may ask you some of the following questions.

- How often do you usually empty your bowels?
- Do you ever have problems with constipation or loose bowel movements?
- How much fluid do you drink each day?

- What type of fluids do you drink? (eg, water, squash, coffee)
- What are your stools like? (eg, hard, soft, liquid)

In addition to taking a history of your symptoms, they may ask you to complete a bowel diary for a week. This will give them an insight into your diet, any medications you take, how often you use the toilet, and the consistency of your poo (see page 25 for more on keeping a bowel diary).

Your health professional may also ask to carry out an examination of your back passage (rectum) and bowel opening (anus). This is known as a rectal examination. This is to assess your muscle tone and sensation, and to see if there are any other problems that might affect your bowels, such as haemorrhoids (piles). It should only take a few minutes and isn't usually painful.

It's important to recognise that not all bowel problems are caused by MS. Your health professional will try to rule out other possible causes of your bowel symptoms.

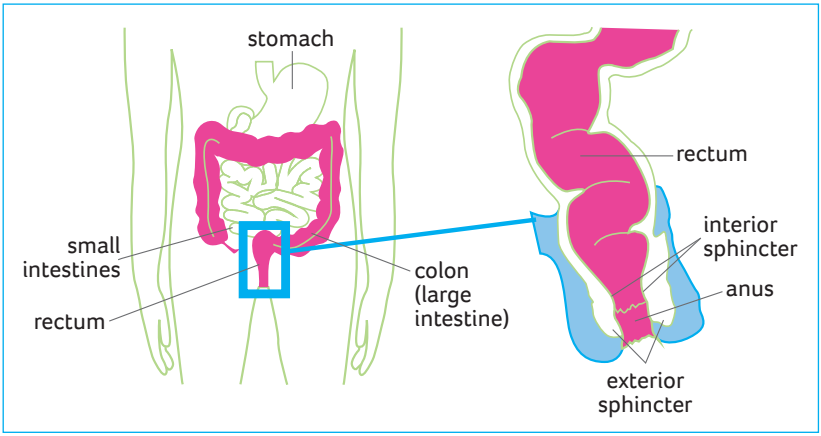
Bowel issues can also be caused by:

- what you eat and drink
- being away from home, with different foods and toilet environments
- lack of exercise and reduced mobility
- medications – particularly antidepressants and those used to treat pain and bladder problems
- hormonal changes related to the menstrual cycle
- pregnancy and childbirth – the gut often slows down due to the hormones present in pregnancy, and childbirth can weaken pelvic floor muscles
- fear of pain when going to the toilet – for example, because of haemorrhoids
- other health conditions, such as irritable bowel syndrome
- abdominal or pelvic surgery
- bowel cancer.

3. How your bowel works

The bowel is part of your digestive system. It digests food and absorbs the nutrients into your blood stream. The bowel also expels the leftover waste products (faeces) that our body can't use.

The main parts of the digestive system include your mouth, stomach, small intestine and large intestine (colon). Together, the small and large intestines are called the bowel. The last sections of the bowel are your back passage (rectum) and bowel opening (anus). Muscles at the bottom of the anus (anal sphincters) act like a valve which allow the anus to open and close.



Bowel control is an extremely complex process and involves the coordination of many different nerves and muscles.

Digested food passes from your stomach into your small intestine, where the essential nutrients are absorbed into your body. The waste left after this process passes into your colon, where it spends most of its time as water is removed. It then moves into your rectum to be passed.

As waste builds up in your rectum, its muscular walls stretch. This triggers messages to your brain, making you aware that you need to go to the toilet. Your rectum is filled with sensitive nerve endings which can tell the difference between solid, liquid or wind. When you have normal sensation, it's easy to tell the difference between wind, runny faeces and a normal stool. Once you feel the urge to go to the toilet, you're usually able to choose whether to go immediately or hold on until later because you have control of the anal muscles.

Bowel habits vary from person to person. For example, some people normally go to the toilet more than once a day, whereas others may go once every three days.

What can happen in MS?

Bowel problems in MS occur when messages are disrupted between the brain and the digestive system. This can cause problems with sensation in the rectum and control of the anal sphincters. As a result, people with MS may experience:

- constipation – difficulties emptying the bowel
- incontinence – lack of control over bowel opening, leading to accidents.

Less often, MS might cause diarrhoea or loose bowel movements (see page 18).

Other MS symptoms can make bowel problems worse. For instance, fatigue might lead you to become less active, slowing the movement of waste through your colon. Similarly, spasticity may affect muscle control and tone which may make going to the toilet more difficult.

On the other hand, bowel problems can cause other MS symptoms to worsen. For example, constipation can trigger spasticity and spasms. It can also make bladder problems worse.

4. Constipation

Constipation is defined as passing hard faeces with excessive effort, usually less than three times a week. It can be accompanied by abdominal bloating and discomfort, tiredness and fatigue, and a loss of appetite.

Why it happens

It's not fully understood how and why constipation happens in MS. Research has identified several contributing factors, which may be experienced together.

- In some people with MS, waste travels through the colon more slowly. This is known as a sluggish bowel. One of the functions of the colon is to reabsorb water. This means the longer it takes for waste to travel through the colon (known as transit time), the harder and smaller your poo becomes. Normal transit time is less than 36 hours.
- Reduced sensation in the back passage can make you less aware that you need to empty your bowel. Poo that remains in the back passage for longer can make constipation worse and result in overflow incontinence. This is where loose, diarrhoea-like fluid passes around a hard plug of impacted poo.
- Weakness or lack of coordination of the anal muscles can make passing stools more difficult.
- If your pelvic floor muscles are weakened or you have any problems in the back passage, this can make emptying the bowel more difficult. Problems like this can occur because of pregnancy and childbirth, long-term constipation, being overweight, excessive straining on the toilet, and heavy lifting.

How to improve constipation

The aim of managing constipation is to make your stools softer so they're easier to pass. What you eat and drink, how much you exercise and adopting regular bowel habits can make a real difference.

Eating regularly

Eating regularly is good stimulation for your bowels. The most active time for the reflex that helps to empty the bowel is around half an hour after a meal. The response is strongest after breakfast. Skipping meals, especially breakfast, can lead to a sluggish or irregular bowel.

Getting enough fibre

Making sure you have enough fibre in your diet can make a positive difference to constipation. It can even reduce the need for bowel medications, such as laxatives. Most adults in the general population don't eat enough fibre – the recommended daily amount is 30g.

"The thing that helped me personally was adding more fibre to my diet. I started eating bran flakes or muesli for breakfast."

Adequate amounts of fibre in your diet are necessary to maintain the bulk and softness of stools. There are two types of fibre: soluble and insoluble.

- Soluble fibre dissolves in water. It becomes a gel-like substance when it reaches your stomach. Soluble fibre is found in fruit, nuts and vegetables.
- Insoluble fibre doesn't dissolve and remains largely the same as it goes through your digestive system. It's found in wheat and grains (eg, bran-based breakfast cereals).

Eating five portions of fruit and vegetables per day, and one or two portions of wholegrain foods, can help ease constipation. The fruit and vegetables may be fresh, frozen, tinned or dried.

You can also increase the fibre in your diet by adding a tablespoon of linseeds or flaxseeds to your food. These form a gel coating when they come into contact with fluid in your gut. This helps soften your poo, making it easier to pass. You should drink 150ml of fluid per tablespoon of linseeds or flaxseeds. Adding them to yoghurt or cereal

can help ensure this. Speak to a health professional before introducing linseeds or flaxseeds to your diet as they're not suitable for everyone.

For people experiencing constipation, too much insoluble fibre (wheat and grains) can slow down the gut even further. When increasing your fibre intake, it can be useful to increase soluble fibre first (fruit and vegetables). Then, increase insoluble fibre more slowly. Any fibre should be increased gradually to avoid abdominal bloating or wind. Fluids should be increased alongside this.

You can use a bowel diary to record any changes you notice from altering your diet (see page 25 for more on keeping a bowel diary).

Insoluble fibre

Food	**Amount of fibre (approx.)**
40g (1 slice) wholemeal bread	2.5g
40g (1 slice) white bread	1.2g
30g bran flakes	4.6g
30g cornflakes	0.8g
75g (uncooked) brown rice	4.3g
75g (uncooked) white rice	3.5g
75g (uncooked) pasta	3.7g
75g (uncooked) wholewheat pasta	6.5g

Soluble fibre

Food	**Amount of fibre (approx.)**
100g cauliflower	1.8g
100g carrots	2.4g
100g cabbage	2.4g
100g potatoes	2.6g
1 apple	2.4g
1 orange	1.7g
1 pear	3.6g
1 banana	2.1g
30g raisins	1.3g
30g sultanas	1.7g
30g prunes	2.8g

"Lots of people I see swear that porridge has a really big impact on constipation."
– *MS specialist nurse*

Drinking enough fluids

Some people try to manage bladder problems by reducing the fluid they drink. However, when you're not drinking enough, your body tries to reabsorb as much water as possible from food waste. This leads to harder stools.

Current recommendations are to drink at least 1.5 litres of fluid a day (about six to eight glasses). Ideally, this should be water rather than tea or coffee which can have a dehydrating effect. Your urine should be pale or straw-coloured. If it's a darker yellow than this, it's a sign you're dehydrated.

"I found drinking much more water than I used to and cutting out tea and coffee had a really beneficial effect."

"Not drinking tea, coffee or fizzy drinks really helps me."

Exercising regularly

Exercise increases the muscle contractions within your gut. This encourages movement of waste along the bowel and improves your ability to empty.

Reduced mobility and lack of exercise can lead to weaker muscles, difficulty getting to the toilet and constipation. Staying as active as possible through regular exercise can improve constipation. If you have limited mobility or maintaining a regular exercise regime is difficult for you, even standing for short periods (including assisted standing) can help to get your bowels moving.

Speak to a physiotherapist if you're considering a new exercise regime. They can advise on exercises that will best suit you and your ability.

"It doesn't have to be a specific type of exercise – you'd be surprised what a difference just walking around can make to the bowel."

Getting your posture right when sitting on the toilet

The human body's natural posture for bowel opening is to squat. The nearest thing is the brace and bulge technique shown below.

- Knees higher than hips.
- Lean forward.
- Elbows on knees.
- Bulge out abdomen.
- Straighten spine.

Whilst sitting on the toilet, raise your knees so they're higher than your hips. You can use a footstool, or something similar, to help. Keep your feet flat on the footstool. Lean forward, keeping your back straight. Rest your elbows on your knees, if possible. Movement of faeces can then be helped by bracing your abdominal muscles and expanding your waist.

Sometimes rocking backwards, forwards and side to side can increase abdominal pressure and encourage a bowel movement without straining.

Giving it time

Give yourself time when trying to open your bowels. Find a time when you're not rushing to do other things. Use a toilet where you feel comfortable and relaxed. Breathe gently and make sure you're not straining while you're on the toilet.

"I like to have great things to read in the toilet – everyone comments and giggles when they've been in there."

If, after ten minutes, nothing has happened, stop and try again after your next meal or the next day. Try to establish a routine for emptying your bowels at a regular time. Health professionals call this a bowel management routine.

Trying abdominal massage

Abdominal massage can help to encourage movement of faeces through the gut. Your MS specialist nurse or continence advisor can teach you how to do this.

Abdominal massage involves rubbing your stomach in a clockwise motion using the heel of your hand or a fist. Your hand should gently, but firmly, massage up the right side of your abdomen, across at the level of your belly button, and then down the left side of your abdomen. The massage is best done in a semi-reclined position for approximately ten minutes. Regular use of an abdominal massage technique whilst lying on your back can also be beneficial.

Reviewing your medicines

It's possible that constipation may be a side effect of the medication you're taking. Drugs for bladder symptoms, spasticity and depression can have this effect. This includes medications such as solifenacin, tolterodine, baclofen, paroxetine and amitriptyline. Iron supplements and antacids (used to relieve indigestion and heartburn) can also contribute to constipation.

It's therefore important to identify any of these and work with your health professionals to find alternatives if possible. Your bowel diary (see page 25) can help you monitor this.

Treatment options

Laxatives

Laxatives are medicines used to treat constipation. They're often used if lifestyle changes haven't been effective. They're usually taken orally, either as a tablet or a powder you mix with water.

Many over-the-counter laxatives are licensed for short-term use only. They can become less effective if you take them long term.

There are different types of laxatives which work in different ways. Speak with your MS specialist nurse or continence advisor to find the approach that works best for you. This might involve a bit of trial and error to begin with.

- *Bulk-forming laxatives* increase the bulk (or weight) of your poo. This makes them bigger and softer, which helps to stimulate your bowel. This type of laxative works in the same way as soluble fibre. They may be useful if dietary fibre can't be increased. Bulk-forming laxatives are used daily at regular times. A good fluid intake is essential. Overuse can result in sluggish stool transit. An example of a bulk-forming laxative is ispaghula husk (Fybogel).
- *Osmotic laxatives* make faeces softer by drawing water from the lining of the gut. This smooths out your stools, making them easier to pass. Macrogol (Movicol, Laxido, CosmoCol) and lactulose are examples of osmotic laxatives. Some osmotic laxatives can increase gas and stomach bloating (eg, lactulose).
- *Stool-softener laxatives* increase the amount of water in your poo. This softens them and makes them easier to pass. Docusate (DulcoEase, Dioctyl, Norgalax) is one example of a stool softener. A stool softener used on its own may not always be sufficient. A stimulant laxative may also be needed, especially if you have a sluggish bowel.
- *Stimulant laxatives* make the muscles of the colon contract more often and with more force. This helps to move the contents of your gut along more effectively. Stimulant laxatives take 8–12 hours to work. If you need help getting to the toilet, it's important to plan when you're going to use stimulant laxatives. Use them when you know you'll be able to get to the toilet in time. Senna and bisacodyl are both stimulant laxatives.

Rectal stimulants

Rectal suppositories and enemas can be used to lubricate your poo and make it easier to pass. They can also stimulate your bowel to empty. They come in the form of capsules, liquid or gel which you insert into your rectum.

Rectal stimulants are an important part of a bowel management routine as they allow you to choose when to open your bowels.

- *Suppositories* are solid, bullet-shaped medications inserted into the rectum. They lubricate the faeces and stimulate the rectum to push out the faeces.
- *Enemas* are fluids inserted into the rectum to stimulate emptying. Mini enemas can be inserted on a regular basis to help the bowel to empty. Large-volume enemas are usually given by a health professional. They can be used on an occasional basis.

Transanal irrigation

Transanal irrigation – also known as rectal irrigation – involves introducing warm tap water into your bowel. The water is inserted via the anus, using a catheter or cone, whilst you sit on the toilet. The water helps to wash faeces out of the bowel and encourages the bowel muscles to contract. This helps to push the faeces out without straining.

Transanal irrigation can be useful if you've been unable to successfully manage your bowels with lifestyle changes and medication. There are several systems available on prescription, including Aquaflush, Navina, Peristeen and Qufora. Some irrigation devices are small enough to be discreetly carried in your bag.

Assessment and training with a suitable healthcare professional is essential before using transanal irrigation (see sources of help and support on page 30).

"Using transanal irrigation in the morning means that within 20–30 minutes, it's done. You can get on with your day knowing your bowel movements are taken care of – it has changed my life."

"I don't have to worry about accidents or not being able to go out for fear of being too far away from a toilet."

All these treatment options can be used as part of your bowel management routine. This will help you regularly open your bowels to avoid constipation.

5. Loose bowel movements

Some people with MS experience loose bowel movements rather than constipation. Loose faeces are difficult to sense in the rectum and more difficult to control than a formed or constipated stool.

Managing loose bowel movements

Increasing wholegrain fibre

Increasing the amount of wholegrain fibre in your diet can help to bulk up your poo, reduce the frequency of bowel movements and improve your control. Wholegrain fibre includes wholemeal bread, wholewheat pasta and brown rice. Using a bulk-forming laxative (see page 16) may have a similar effect.

Reducing intake of certain foods and drinks

There are some foods and drinks that can overstimulate bowel activity or draw excess fluid into the colon. This can result in soft or very watery poo. These include:

- alcohol
- drinks containing caffeine (eg, tea, coffee, cola and hot chocolate)
- prunes and figs
- food that contains the sweetener, sorbitol.

It might be useful to reduce your intake of these foods and drinks to see if it makes a difference.

Establishing a bowel management routine

This involves emptying your bowels at a regular time that suits you. This could involve the use of laxatives, suppositories or transanal irrigation (see pages 15–17 for more information about these treatments). Emptying your bowels regularly reduces the chances of bowel accidents.

Loperamide

Loperamide (Imodium) is a medicine that slows down the movement of faeces through your intestine. This makes your poo more solid and easier to control. It also means they're passed less frequently. It's important to follow the advice of a continence specialist or MS specialist nurse when using loperamide.

Ondansetron

Ondansetron (Zofran) is a medicine that's used to prevent nausea and vomiting following surgery or cancer treatment. However, one of its side effects is that it slows down the movement of faeces through the intestine. It has been found to help with loose and urgent bowel movements in trials of people with irritable bowel syndrome (IBS). Some continence services may prescribe it for people with MS.

6. Bowel accidents

Some people find they have no control over when their bowels open. This can result in bowel accidents. Your health professional may refer to this as faecal incontinence.

It can happen in MS for a variety of reasons.

- The most common cause of bowel accidents is constipation. When a hard plug of impacted poo builds up in the back passage, a diarrhoea-like fluid can pass around it. This is known as overflow incontinence.
- Bowel accidents can also be caused by reduced sensation in the back passage. This is where you don't recognise the urge to go to the toilet.
- Reduced control of the muscles at the bottom of your anus can lead to accidents.
- Bowel accidents are more likely if you're experiencing loose stools. This is because they're more difficult to feel and control. Faeces may become loose from overuse of laxatives, too much dietary fibre, or gastrointestinal infections (which can cause diarrhoea).

Managing bowel accidents

The aim is to regain control over when you open your bowels. There are several approaches. It may take some time, and a combination of strategies, to find what works for you.

Pelvic floor exercises

Your pelvic floor is a sheet, or hammock, of muscles that extends from your tailbone (coccyx) at the bottom of your spine to your pubic bone at the front. They form the floor to the pelvis and support your bladder and bowel. Pelvic floor exercises may strengthen the muscles around the anus, giving you greater control of your bowel movements.

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

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

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

These exercises are usually taught by a continence advisor or specialist physiotherapist (see sources of help and support on page 30). There are also apps you can use to build an exercise plan and remind you to do your pelvic floor exercises, such as NHS Squeezy (squeezyapp.com).

"Think of it as bowel physio. You change the muscles you use and strengthen them to come to the rescue!"

Biofeedback retraining

This technique is available in some specialist centres to help people who have difficulty controlling their bowel movements. The aim of biofeedback retraining is to help you understand how to use your bowel muscles more effectively. You're usually given a range of exercises to retrain your bowel muscles to strengthen and relax. This can involve having a small probe inserted into your back passage while you do the exercises. The device provides feedback on how well you're doing them.

Biofeedback therapy can also involve sessions on:

- how the digestive tract works
- positioning techniques
- dietary and lifestyle changes

- behavioural therapy
- psychological support.

A health professional, such as your GP, MS nurse or continence advisor, can refer you for this therapy.

Bowel management routine – (see page 18).

Transanal irrigation – (see page 17).

Colostomy

Surgery may be an option if bowel accidents are affecting your quality of life, and they can't be improved any other way. The surgery offered would usually be a colostomy. This involves bringing the end of the bowel out through the wall of your abdomen. Waste is then collected in a special bag.

This can be a very positive choice for some people. But it needs to be carefully discussed with your continence specialists and MS team.

"I now have a bag stuck to my abdomen – a small price to pay to be totally continent."

Antegrade continence enema (ACE)

Some gastroenterologists may consider an antegrade continence enema for faecal incontinence. This is a surgical procedure. The surgeon will create a small tube that links your bowel to an opening on your abdomen. A narrow tube, called a catheter, can then be inserted into the opening to perform washouts. This involves using a syringe or washout bag to gently push warm water through the catheter into your bowel. This is done while sitting on the toilet and flushes out the contents of your bowel. Your continence specialist will advise on how often you need to perform washouts.

Products that can help

Pads and pants

Pads and pants can help to deal with bowel accidents. They can be useful when you're first exploring treatment options with a continence team and haven't yet been successful in finding a solution that works for you.

There's a wide variety of discreet products available. There are also organisations that can help you choose what's most appropriate for you (see sources of help and support on pages 31–32).

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

Anal inserts

An anal insert is a soft silicone plug that you insert into your rectum. It creates a seal and stops the leakage of faeces. They're inserted using an applicator and removed by gently pulling on the external part of the plug.

It's important that you're assessed by your continence nurse or an appropriate healthcare professional before trying an anal insert. They're not suitable for, or tolerated by, everyone.

"The plug has given me the confidence to go out more often. I know I'm not going to leak. It's been brilliant for me."

Skin care

Caring for the skin around the anus is important when you have incontinence.

Try to remove faeces from soiled areas straightaway, as it can quickly damage the skin. Barrier creams can be useful in preventing discomfort, soreness and damage. Examples include Sudocrem and Cavilon. Be careful not to apply thick layers of barrier cream. This can block pores, clump in orifices, and reduce the absorbency of pads.

It can also help to:

- gently wash and pat dry the area if it's been soiled after a bowel movement
- wear loose cotton underwear that allows skin to breathe
- avoid perfumed soaps, creams, lotions, and talcum powder.

Managing wind

When you have bowel problems you might find it difficult to control passing wind. The smell can often be embarrassing. Some foods can trigger a stronger odour than others. Increased or problematic wind is also common if you're constipated. Dealing with the constipation should help. Using a bowel diary (see page 25) can help you track the effect of different foods. You can then adapt what you eat accordingly.

Chemists stock deodorants designed to control smells. They may also be able to advise on special underwear that can absorb smells. Some people find that peppermint oil, charcoal tablets or herbal teas in the diet can be helpful.

7. Getting to know your bowels

Keeping a bowel diary

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

Write down what you eat and drink, and any medication you take. You can also make a note of when you go to the loo, any problems emptying your bowels, and any leakage or accidents. Some people like to record the effects of exercise too.

If you make any changes, the diary can help you see how this affects your bowel movements. This could include increasing the fibre in your diet or starting a new medication. It can be helpful to make one change at time. Continue with that change for a week before making further changes. This will make it easier to identify what impact the changes are having on your bowel.

You could use a chart like the one below to keep a record of your bowel activity. Or you could use a notebook, diary or app.

Time	Food/Drink	Medication	Exercise	Bowel movement	Accidents
	What did you eat or drink?		Activity	Hard, soft, liquid	Leakage

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

The Bladder and Bowel Community has a bowel diary template you can download from their website (see page 31 for website details). There are also a range of smartphone apps you can use to log your stool quality, such as the Bristol Stool Chart app.

"Your bowel journal can be vital for health professionals. It makes treatment a lot easier to work out."

8. Working with your health professionals

Knowing clearly what you'd like to achieve from your appointments can be helpful. This means you and your health professionals are more likely to be working together towards the same goal.

Be specific about the issues you'd like to discuss at the start of your appointment. Your health professional can then make these the focus, reducing the risk of running out of time.

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

- How long will it take to see any changes?
- When will we review how things are going?
- Do I need to take the medicine regularly or can I take it as and when I need it?
- What if this approach doesn't work?
- How can I get in touch if I have any problems? Is there a direct number or email?

If you're unsure of anything that's discussed in your appointment, don't be afraid to ask for a further explanation.

"Never be afraid to ask questions of your MS nurse. They've heard it all before. They always find an answer for me – whatever the question."

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

Managing your bowels effectively often involves trialling a combination of strategies. It might take some time to find a solution that works for you. If one thing isn't working, ask what's next.

"I was seen by my GP and district nurse. They gave me enemas, suppositories and medicines, all to no avail. My MS nurse suggested transanal irrigation and I can honestly say I haven't looked back."

9. Living well with bowel problems

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

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

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

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

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

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

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

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

Further mental health resources are listed on page 32.

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

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

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

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

There are a range of resources that can help you when out and about, including access to locked public toilets through the National Key Scheme, 'just can't wait' toilet cards, and community toilet schemes. There are also apps to help you find toilets. Read more about these tools on pages 32–33.

"Bowel problems are affecting intimacy with my partner."

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

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

Speaking to your MS nurse or continence specialist about the impact your bowel problems are having on your sex life is important. Many health professionals are used to talking about sex. There's no need to feel uncomfortable or embarrassed about sharing intimate details with them. They can make suggestions that may help, such as going to the toilet before sex or inserting an anal plug. You can then relax knowing that your bowels have been emptied and any accidents are being prevented.

Further resources on sex and MS can be found on page 32.

10. Sources of help and support

People

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

MS specialist nurse

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

Bladder and bowel services

These services are made up of experienced, qualified nurses who have undertaken specialist training to help people with continence problems. Many services accept self-referral. Your GP or MS specialist nurse can also refer you.

Specialist physiotherapist

Physiotherapists who are specially trained and experienced in the assessment and treatment of neurological conditions can devise exercises and pelvic floor training programmes. Your GP or MS specialist nurse can refer you.

Gastroenterologist

Gastroenterologists diagnose and treat conditions of the digestive tract, including the bowel.

Colorectal services

Colorectal services investigate, diagnose and treat people with certain bowel disorders. This includes cancers, inflammatory bowel diseases, prolapse, faecal incontinence and haemorrhoids (piles). A colorectal team is usually made up of colorectal surgeons, specialist nurses, gastroenterologists and oncologists.

Biofeedback services

Some specialist centres offer biofeedback therapy for people who experience bowel accidents or constipation. These services are usually run by nurses, physiologists and physiotherapists. Biofeedback therapy aims to help you understand how to use your bowel muscles more effectively. It involves retraining your bowel muscles to strengthen and relax through a range of exercises, as well as changes to your lifestyle and diet.

Organisations

Bladder and Bowel Community

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

Colostomy UK

Colostomy UK is a charity offering support and care for people who are contemplating or have undergone a colostomy. It provides a 24-hour helpline and has a network of regional support groups run by volunteers.
Helpline: 0800 328 4257
colostomyuk.org

Continence Product Advisor

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

Bladder and Bowel UK

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

MS Trust

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

Mental health and wellbeing mstrust.org.uk/wellbeing
Talking therapies mstrust.org.uk/a-z/psychological-therapies
MS Trust Facebook group mstrust.org.uk/fb-group
Support groups mstrust.org.uk/support
Sexual problems for men with MS mstrust.org.uk/men
Sexual problems for women with MS mstrust.org.uk/women
Relationships and MS mstrust.org.uk/relationships

If you have questions about MS, our helpline can help you find the information you need.
Tel: 0800 032 3839 (Monday to Friday, 9am to 5pm)
Email: ask@mstrust.org.uk

Public toilets

National Key Scheme (NKS)

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

Toilet card

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

Mobile apps

Apps are available to help locate the nearest toilet and to keep track of bowel function.

Changing Places toilets

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

The Great British Toilet Map

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

Community toilet schemes

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

About the authors

Information Team, MS Trust

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

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