

Managing your bowels

A guide for people with MS



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

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For a full list of MS Trust publications, to sign up for [Open Door](#) and much more visit our website at mstrust.org.uk or phone 01462 476700.

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Introduction

Around half of all people with MS experience bowel problems at some time. Many people find these symptoms difficult to talk about as they can cause embarrassment, but with the right information and support, the majority of bowel problems can be managed successfully so they no longer impact, or have as much 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 aims to provide practical ideas and suggestions that will help you successfully 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 problems
- treatment options that might be relevant to you
- how working in partnership with the appropriate health professionals can be the key to finding the approach that works best for you.

The book includes comments from people with MS who know first-hand what it is like to live with bowel problems and draws on the experience of health professionals including MS specialist nurses and continence advisors.

1. Talking about bowel problems

“It is a difficult area to talk about. People can just about accept bladder problems, but bowels seem to be a real no no.”

Toilet talk is common if you have young children but we don't expect to have to think about it again in later life. Many people feel embarrassed or uncomfortable talking about bowel problems. It's important to remember that your health professional will have lots of experience talking about these kinds of symptoms – it's likely they've heard it all before! Your MS nurse, GP or continence advisor will be aware that MS can have an impact on how the bowel works, so try not to feel embarrassed about bringing up the topic. Be honest about the problems you've been experiencing and remember, we're all human and we all have to go to the toilet – there's absolutely no shame in it.

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

“Talking about bowel symptoms might not be as traumatic as you may imagine, and the solution may be straightforward.”

MS specialist nurse

“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!”

“I tend to just say ‘I can’t poo’.”

Although health professionals might tend to use more medical language such as faeces or stool, using poo or number two is fine. We use the words stool and faeces throughout the book, but try to use the language you feel the most comfortable with when you see your health professional – they’ll understand what you mean.

2. When should I contact a health professional?

If your bowel problems are affecting your life, if things have changed or you are worried, don't hesitate to contact your health professional. Specifically this might be if:

- you've noticed any changes in bowel habits, for instance if you're going to the toilet more or less often
- you spend a long time trying to empty your bowels but without success
- if your stools (poo) have changed – it might be harder or softer or have changed colour
- if there is blood in your faeces, prolonged diarrhoea or constipation, or unexplained weight loss
- if you have to rush to the toilet
- if you have no control over when your bowels open
- if you leak faeces without being aware of it.

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 it's making it difficult to go out to see friends or if it's causing any problems at work.

When you see your health professional they will take a full history of your symptoms and 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 and what type of fluid do you drink each day?
- What type of stool do you pass? Eg hard, soft, liquid.

In addition to taking a history of your symptoms they may also ask you to complete a bowel diary for a week to get a good understanding of your diet, medications and when you go to the toilet (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 anus to find out more about the muscle tone, sensation and any other problems such as haemorrhoids that might affect your bowels. A rectal examination only takes a few minutes and is not usually painful.

It's important to remember that not all bowel problems are caused by MS. During your appointment, your health professional will try to rule out other causes of your bowel symptoms.

Here are some of the common things that can cause bowel issues:

- medications – particularly for pain, bladder problems and antidepressants
- what you eat and drink
- how much you exercise and how mobile you are
- in pregnancy and after childbirth the gut often slows down due to the hormones present in pregnancy
- fear of pain when going to the toilet – for example haemorrhoids (piles)
- abdominal surgery
- other health conditions such as irritable bowel syndrome.

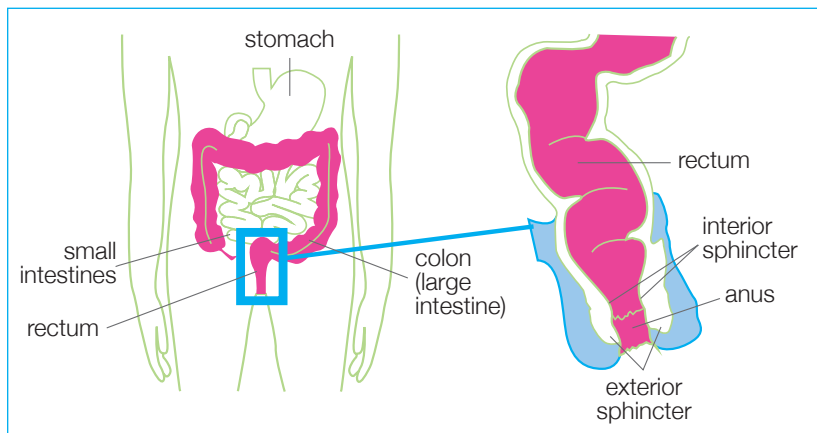
For women, hormonal changes related to the menstrual cycle can affect bowel movements. For some people being away from home – with different foods and toilet environments – can also make a difference.

3. How your bowel works

The bowel is part of your digestive system and it has two major functions.

- Digesting food and absorbing the nutrients into the blood stream.
- Eliminating waste products at an appropriate time.

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

the majority of its time as water is removed, before moving into your back passage to be passed.

As the waste builds up in your back passage, it stretches and this triggers messages to your brain, making you aware that you need to go to the toilet. Your back passage is filled with sensitive nerve endings which can tell the difference between solid, liquid or wind. When you have normal sensation in your back passage it is easy to tell the difference between wind, runny faeces that need urgent access to a toilet and normal stool. Once an individual experiences the urge to go to the toilet, they are usually able to choose whether to go immediately or hold on until later because they 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 only every three or four days.

What can happen in MS?

Bowel problems in MS occur as a result of the disruption of messages between the brain and various parts of the digestive system. This causes problems with sensation in the back passage and control of the muscles at the bottom of the anus, and two main problems result:

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

Less often MS might cause diarrhoea or loose bowel movements. Bowel problems can also be made worse by other MS symptoms such as spasticity and fatigue. For instance, fatigue might lead you to become less active which may slow the movement of waste through your colon. Similarly, spasticity may affect muscle control and tone which may make going to the toilet more difficult. Conversely bowel problems can also make other MS symptoms worse, such as spasms and bladder problems.

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.

It's not fully understood how and why constipation happens in MS but research has identified a number of contributing factors, which may be experienced together.

- In some people with MS, waste travels through the colon more slowly (known as a sluggish bowel). As one of the functions of the colon is to reabsorb water, the longer it takes for waste to travel through the colon (health professionals call this transit time), the harder and smaller your stools become. Normal transit time is less than 36 hours.
- Reduced sensation in the back passage. This can lead to a loss in awareness of the need to empty the bowel, so that stools remain in the back passage for longer, making constipation worse and potentially resulting in overflow incontinence. This is where loose, diarrhoea-like fluid passes around a hard plug of impacted stool.
- Weakness or lack of coordination of the anal muscles, weakness of the pelvic floor muscles (the muscles that form the 'floor' of the pelvis and support the bladder and bowel) and problems in the back passage, which might have been caused by excessive straining on the toilet, during childbirth or because of heavy lifting, can also cause difficulties.

Tips to improve constipation

The aim of managing constipation is to produce faeces that are not too hard or soft, and allow you to empty your bowels more easily (and effectively) on a regular basis. 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, and 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 and 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. This means 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 which is found in fruit, nuts and vegetables, and insoluble in the form of wheat or grains (eg bran-based breakfast cereals). Soluble fibre dissolves in water and becomes a gel-like substance when it reaches your stomach. Insoluble fibre on the other hand doesn't dissolve and remains largely the same as it goes through your digestive system.

Fibre from the recommended five portions of fruit and vegetables per day, with 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.

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

You can use a bowel diary to record any changes as you gradually alter your diet and monitor the effects these changes have (see page 25 for more on keeping a bowel diary).

Insoluble fibre

Food	Amount required for 2g of fibre
Bread	Wholegrain – 1 small slice White – 2 small slices
Breakfast	Bran based – 1 tablespoon Cornflakes – 8 tablespoons
Rice and pastas	Brown rice – 3 tablespoons White rice – 5 tablespoons White pasta – 4 tablespoons Wholewheat pasta – 2 tablespoons

Soluble fibre

Food	Amount required for 2g of fibre
Vegetables	Cauliflower, cabbage, carrots – a few large florets/slices/chunks
Fresh fruit	Apple, orange, pear – one medium Banana – one small
Dried fruits	Grapes – a handful, approx. 110g Raisins, sultanas – 1 tablespoon Prunes – a handful, approx. 4

“Lots of people I see swear that porridge has a really big impact on constipation.”

MS specialist nurse

Drinking enough fluids

Some people with MS try to manage bladder problems by reducing the amount of fluids they drink, however to compensate the body will try to reabsorb as much water as possible from food waste which leads to harder stools.

Current recommendations are to drink at least 1.5 litres of fluid a day or about six to eight glasses – ideally 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 can be an indication that you're dehydrated.

There are some foods and drinks that can overstimulate bowel activity or draw excess fluid into the colon. These include:

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

“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 is thought to be important as it helps to increase the muscle contractions within your gut, promoting transit of waste along the bowel and improving your ability to empty your bowels.

Reduced mobility and a lack of exercise can lead to weaker muscles and difficulty getting to the toilet which can also lead to constipation. Staying as active as possible and finding and maintaining an exercise regime that works for you is really important. If you have limited mobility and maintaining a regular exercise regime is difficult for you, even standing for short periods during the week can help with constipation.

It's best to speak to a physiotherapist if you're considering a new exercise regime as they can advise on exercises that will best suit you and your ability.

“It doesn't have to be specific 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.
- Put elbows on knees.
- Bulge 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 and your back straight; lean forward, resting your elbows on knees, if possible. Movement of faeces can then be helped by bracing your abdominal muscles and bulging the abdominal wall outwards.

Giving it time

It's important to give yourself time when trying to open your bowels. Try to find a time when you're not rushing to do other things and use a toilet where you feel comfortable and relaxed. Try not to force it 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. Establishing a routine for emptying your bowels at a regular time that suits you is really valuable in managing constipation. Health professionals often call this a bowel management routine.

Trying abdominal massage

Abdominal massage before or whilst opening your bowels can help to encourage movement of stool through the gut ready to be pushed out. 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 gently but firmly up the right side of your abdomen, across at the level of your belly button and down the left hand side of the 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 medicines you're taking can cause or contribute to constipation as a side effect. Drugs for bladder symptoms (including oxybutynin and tolterodine), spasticity (baclofen) and depression (including paroxetine and amitriptyline) as well as iron supplements and antacids (used to relieve indigestion and heartburn) can have this effect. It is 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 to monitor this.

Treatment options

Laxatives

Many common over the counter laxatives are licensed for short-term use only and they can become less effective if taken in the long-term. They're usually taken orally either as a tablet or a sachet of powder that you mix with water and drink. It's important to work together with your MS specialist nurse or continence advisor to find the approach that works best for you. This might involve a little bit of trial and error to begin with.

- *Bulk forming laxatives* work in the same way as dietary fibre, increasing the bulk of stools. They may be useful if dietary fibre can't be increased and are used daily at regular times. A good fluid intake is essential. Overuse can result in sluggish stool transit. Examples of bulk forming laxatives include ispaghula (Fybogel, Isogel), methylcellulose (Celevac) and sterculia (Normacol).
- *Osmotic laxatives* make the faeces softer by drawing water from the lining of the gut to smooth out the faeces and make it easier to pass. Macrogol (Movicol, Laxido) or lactulose (Duphalac, Lactugal) are examples of osmotic laxatives.
- *Stool softeners* soften the stools by increasing their fluid content, making them easier to pass. Docusate (Docusol, Norgalax) is one example of a stool softener. A stool softener used on its own may not always be sufficient and a stimulant laxative may also be needed, especially in the case of a sluggish bowel.
- *Stimulant laxatives* cause the muscles of the colon to contract more often, and with greater force. When the colon contracts, it moves the gut contents along more effectively. Stimulant laxatives take between eight and 12 hours to work. If you need help getting to the toilet it is important to plan the right time to use stimulant laxatives, so that you know you can get to the toilet at the right time. Senna and bisacodyl are both stimulant laxatives.

Rectal stimulants

Rectal suppositories and enemas can be used to lubricate the stool to make it easier to pass, or to stimulate the bowel to empty. They come in the form of capsules, liquid or gel which you insert into your rectum (back passage). They 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 to help lubricate the faeces and to stimulate the rectum to expel the faeces. Several different types are available.
- *Enemas* are fluids inserted into the rectum to stimulate emptying. Mini enemas can be inserted by an individual on a regular basis to help the bowel to empty. Larger volume enemas are usually given by a health professional and are used on an occasional basis only.

Transanal irrigation

Transanal irrigation, also known as rectal irrigation, involves introducing warm tap water into the bowel 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 muscles in the bowel to contract and push the faeces out. It can be useful if you've been unable to successfully manage your bowel with medication and toileting alone. There are a number of systems currently available on prescription, including Peristeen, Qufora, Aquaflush and Irypump. 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 and 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 about not being able to go out for fear of being too far away from a toilet.”

All of these options can be used as part of your bowel management routine which helps you to open your bowel regularly 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 (eg wholemeal bread, wholewheat pasta and brown rice) in your diet or using a bulk forming laxative (see page 18) can help to bulk up your stool, reduce frequency of bowel movements and improve your control.

Reducing caffeinated drinks

Some people find that caffeinated drinks, such as coffee, can result in softer stools so it might be useful to reduce your intake to see if this makes a difference.

Establishing a bowel management routine

This involves establishing a routine for emptying your bowels at a regular time that suits you, possibly using laxatives, suppositories or transanal irrigation (see pages 18–19 for more information about these treatments). This reduces the chances of bowel accidents.

Loperamide

Loperamide (Imodium) is a medicine that slows down the movement of faeces through the intestine. This makes the stool more solid, easier to control and means they are passed less frequently. It is essential to follow the advice of a continence specialist or MS specialist nurse when using loperamide.

6. Bowel accidents

Some people find that they have no control over when their bowels open, causing bowel accidents. Your health professional may refer to this as faecal incontinence and 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 stool builds up in the back passage, a loose, watery, 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, so you don't recognise the urge to go to the toilet, and reduced control of the muscles at the bottom of your anus. If your stool becomes loose for any reason (overuse of laxatives, too much dietary fibre, or gastrointestinal infections causing diarrhoea) bowel accidents are more likely because it is more difficult to feel and control loose stool.

Managing bowel accidents

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

Pelvic floor exercises

The pelvic floor is a sheet of muscles that extend from the tail bone (coccyx) at the bottom of the spine to the pubic bone (at the front). They form the 'floor' to the pelvis and support the bladder and bowel. Pelvic floor exercises may strengthen the muscles around the anus and allow you greater control. In MS, neurological damage can result in weakness to the pelvic floor. This is because damaged nerves, mainly within the spinal cord, are not transmitting messages to the pelvic floor muscles as effectively as they used to. However this can also be made worse by other factors such

as having children, getting older or having surgery in this region of the body. Men and women can do pelvic floor exercises. These exercises are usually taught by a continence advisor or specialist physiotherapist (see sources of help and support on page 30). The NHS website (www.nhs.uk) also has some basic guidance on pelvic floor exercises.

“Think of it as bowel physio, you change the muscles you use and strengthen them to come to the rescue!”

Biofeedback retraining

This is a technique available in some specialist centres. It aims to retrain people’s awareness about bowel opening, diet and fluid intake. It can include sessions on how the digestive tract works, dietary changes, bowel and muscle retraining, behavioural therapy and psychological support. Your continence advisor can help you with this.

[Bowel management routine](#) – (see page 21).

[Transanal irrigation](#) – (see page 19).

Colostomy

For a few people with MS, surgery may be an option when bowel accidents are having an unacceptable effect on quality of life and cannot be improved in any other appropriate way. Surgery offered is usually a colostomy. This involves bringing the end of the bowel out through the wall of the abdomen, so waste is collected in a special bag. This can be a very positive choice for some people but it needs to be carefully discussed with the surgeon and continence advisor or MS specialist nurse.

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

Products that can help

Pads and pants

When all other ways of improving continence have been tried, pads and pants can help to deal with bowel accidents. There's a wide variety of discreet products available and organisations and websites that can help you choose what might be most appropriate for you (see sources of help and support on page 30). 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 plugs

This is like a tampon and is easily inserted into the rectum (like a suppository) to help control leakage of faeces. The plug can be left in place for up to 12 hours after which it is easily removed. It is important that you are assessed by your continence nurse or appropriate healthcare professional before you try it.

“The plug has given me so much more confidence to go out more often. I know I am not going to leak, it has been brilliant for me.”

Skin care

Caring for the skin around the anus is important. Barrier creams, such as Sudocrem and Cavilon, can be useful in preventing discomfort, soreness and damage if incontinence is a problem. Carefully washing and patting dry the area if the skin is soiled after a bowel movement, wearing loose cotton underwear that allows skin to breathe and avoiding perfumed soaps, creams and lotions, can all help.

7 . Getting to know your bowels

Keeping a bowel diary

Keeping a diary can give you an overview of how your bowel problems affect you over time. You can share it with your health professionals to demonstrate your bowel patterns.

Write down what you have to drink, eat, any medication you take and when you go to the loo, including any problems with emptying your bowels or episodes of leakage or incontinence.

If you make any changes, for example the amount of fibre in your diet, the diary can help you to see how this affects your bowel movements. To identify what affects your bowel it can be helpful to make only one change at a time and continue with that change for a week before making further changes.

You could use a template like the one below if you need to keep a detailed record, or there are less formal approaches such as keeping notes in a notebook. 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.

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.”

“Your bowel journal can be vital for health professionals, because it makes treatment a lot easier to work out.”

Managing wind

When you have bowel problems you might find it difficult to control passing wind and the smell can often be offensive and embarrassing. Some foods can have more effect than others such as cabbage. Increased or problematic wind is also common if you're constipated so dealing with the constipation will help. Using your bowel diary can help you to keep track of the effect of different foods and you can then tailor what you eat accordingly. Chemists stock deodorants designed to control smells and some people find that peppermint oil, charcoal tablets or herbal teas in the diet can be helpful.

8. Working with your health professionals

Really knowing what you would like to achieve can be helpful in ensuring that you and your health professionals are working together towards the same goal.

It can also 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?

“Never be afraid to ask questions of your MS nurse – they have heard it all before and they always find an answer for me – whatever the question.”

Managing your bowels effectively often involves tailoring a combination of different strategies to suit you. It might take some time to get right but the solution may be straightforward. If one thing isn't working, ask what's next.

“You just need to persist in getting appropriate help.”

“I was seen by my GP and district nurse, given 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

Self-esteem and depression

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

Work

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

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

Sexuality

Bowel disturbances can understandably cause great anxiety and prevent some people wanting to be sexually intimate. You might worry you'll lose control and have an accident when you're having sex and feel that it is not worth taking this risk as the embarrassment would be too great. If you are worried about your bowel incontinence or feel it is affecting your sex life, speak to your continence advisor about it. They can make suggestions that may help, such as emptying your bowels before you have sex or using products such as anal plugs that are inserted into the rectum to prevent any accidents happening.

10. Sources of help and support

People

MS specialist nurse

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

www.mstrust.org.uk/map

Continence advisor

Continence advisors are experienced, qualified nurses who have undertaken specialist training to help people with continence problems. Many services accept self-referral or ask your GP or MS specialist nurse to refer you.

Specialist physiotherapist

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

Gastroenterologist

Doctors who diagnose and treat conditions of the gastrointestinal tract including the bowel.

Organisations

Bladder and Bowel Community

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

www.bladderandbowel.org

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

www.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.

www.continenceproductadvisor.org

Bladder and Bowel UK

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

Helpline: 0161 607 8219

www.bbuk.org.uk

MS Trust

The MS Trust website has more on bladder and bowel problems as well as a range of information on all aspects of living with MS.

www.mstrust.org.uk/bladderandbowel

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

Tel: [0800 032 3839](tel:08000323839) (Monday-Friday, 9am-5pm)

Email: infoteam@mstrust.org.uk

Public toilets

National Key Scheme (NKS)

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

www.disabilityrightsuk.org

Toilet card

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

www.bladderandbowel.org

Mobile phone apps

Apps have been developed to help locate the nearest toilet.

Changing Places toilets

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

www.changing-places.org

The Great British Toilet Map

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

www.toiletmap.org.uk

Community Toilet Schemes

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

www.gov.uk/find-local-council

About the authors

MS Trust Information Team

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

Thank you

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- Noreen Barker, MS Specialist Nurse, Royal Free London NHS Foundation Trust
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We hope you found this book useful.

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

It's only thanks to donations from people like you that the MS Trust can continue to provide free, reliable, practical MS information.

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mstrust.org.uk/don-info

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Thank you



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