

Standalone Document 1

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# MS Essentials For people living with MS

This publication is available in large print Call 020 8438 0999 or email shop@mssociety.org.uk

## Managing the bowel in MS

Bowel problems are a common symptom of MS, so if you are experiencing problems you are not alone.

There are two main bowel problems that can occur with MS. Constipation is the more common one, but some people also experience bowel incontinence.

This booklet looks at how the bowel works and how it is affected by MS. It also explains how you can manage MS-related bowel problems. Finding a way to manage bowel problems is not always straightforward, and you may need help from a health care professional. For just about everyone, it is likely that something can be done to help.

*i* Where you see this symbol, turn to 'Useful organisations' on page 21 for contact details.

## Contents

- 02 MS and the bowel
- **05** How the bowel works
- 07 Constipation
- 14 Bowel incontinence
- 18 Managing day-to-day
- **20** Further information

## MS and the bowel

The first time I mentioned it to my MS nurse I was afraid that she would say that she had never heard anything like that. However I was surprised to find out that this can be a symptom and it was a relief to know that I was not crazy. - Shirlee "

Having MS can make you more likely to develop bowel problems than the rest of population. Around half of people with MS experience constipation, compared to approximately five per cent in the general Western population. Around 30 to 50 per cent of people with MS experience bowel incontinence at some stage, compared to approximately two per cent of the general Western population. So, if you have MS and are experiencing bowel problems, you are not on your own.

MS bowel problems can happen at any stage, although they are more common in people who are more severely affected by their MS.

Some people who have constipation will also experience bowel incontinence – the two problems are often linked in MS. For example, a common cause of bowel incontinence in MS is constipation: when a stool becomes impacted in the bowel there can be leakage around it. However, people who have constipation will not necessarily go on to develop a problem with incontinence, or vice versa.

Causes of bowel We know guite a bit about how MS affects the bladder, but less about how MS affects the bowel. It may be that in MS, the colon problems muscles can become weak and sluggish and the gut slows down, so that processing waste takes longer and stools become harder and more difficult to pass, causing constipation.

> Nerve damage in MS could mean that your body is unable to interpret sensations in the rectum and upper anal canal. MS might affect reflexes and voluntary control of muscles, where anal sphincter muscles may not relax properly or squeeze tightly enough when you need them to.

Things that are secondary to MS can also cause bowel problems. Some medications can cause constipation. Medication taken to ease constipation may cause loose stools which, in turn, could lead to bowel incontinence. If you reduce your fluid intake, perhaps because of MS-related bladder problems, this can also add to constipation. If fatigue or mobility issues limit your exercise and activity levels, this can have a similar effect. Straining to open your bowels can lead to muscle problems.

	Emotional and psychological factors can also affect your bowel habits. If going to the loo seems like too much of a struggle, you might put it off even if you feel the need to go. If you lose motivation or become depressed, you may become more inactive, which can make your bowels sluggish and lead to constipation. If you have had an episode of incontinence, your anxiety about it happening again could contribute to another episode. If you depend on others for your care or if your toilet is not properly accessible, this can also affect your bowel habits.
	Because bowel problems in MS are often caused by a number of factors, you may find you need to try a range of different approaches in order to tackle them. The strategies you use may also need to change over time, as your condition changes.
Getting help with bowel problems	In many cases, there is usually something that can be done to manage your bowel problems. While some of these approaches are things you can try on your own – for example, adjusting your diet – for others you will need to get help from a health care professional.
	Not everyone finds it easy to talk about bowel problems with their doctor or nurse. But health care professionals are used to talking about them and are likely to be able to offer help, so it's worth overcoming any embarrassment. You can use whatever words you feel comfortable using – so, for example, while your health care professional might talk about 'stools', it's OK for you to refer to it as 'poo'.
	Your GP or MS nurse can give you general advice on managing bowel problems, and your GP can also prescribe medications such as laxatives. While some of these medications are available from a pharmacist without a prescription, it's best to speak to your GP or other health care professional before taking anything. They will be aware of your individual medical history and will be able to advise you on the best treatment options for you. They can also refer you to a continence adviser, who will carry out further tests to investigate how your bowels are working, and give you individual advice on how to tackle your bowel problems.
	You can also speak to a continence adviser by calling the Bladder and Bowel Foundation Helpline. $\boxed{i}$
The emotional impact of bowel problems	Bowel problems – particularly incontinence – can have a huge emotional and psychological impact. Having a bowel accident, especially if it happens in a public place, can be extremely embarrassing and distressing. For some people, the fear of this happening can affect how often they go out and where they go.

If this affects you, you may find it helpful to talk about it with someone. You can call the freephone MS Society Helpline on 0808 800 8000 from 9am to 9pm, Monday to Friday. You can also get support from other people with MS who have experienced the same issues via the message boards on the MS Society website: www.mssociety.org.uk/forums

You may also be interested in the MS Society's credit-card sized 'Can't Wait' card. It says, in English, German, French and Spanish: 'Please help me. Because of an illness which is not infectious, I need to go to the toilet urgently. Thank you.'

#### Don't put everything down to MS

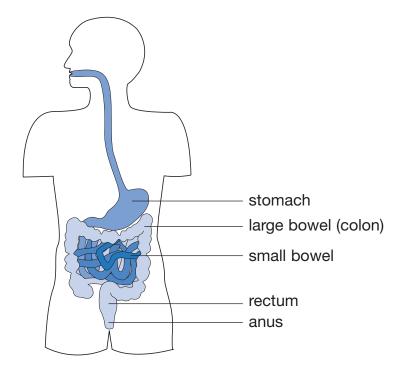
Sometimes, everything gets put down to MS. But people with MS can be affected by diseases that affect the general population too. For example, bowel cancer is common in the UK, and while most symptoms do not turn out to be bowel cancer, do talk to your GP if you have any of the following (particularly if you have a family history of bowel cancer):

- Persistent change of bowel habit over four to six weeks with unexplained constipation or diarrhoea
- Persistent bleeding from your bottom with no soreness, pain, swelling or itching around the back passage
- Unexplained severe pain and/or lump in your belly
- Extreme tiredness without an obvious cause

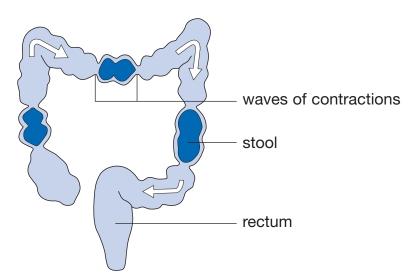
More information about the symptoms of bowel cancer is available from Bowel Cancer UK. i

## How the bowel works

Knowing how the bowel is supposed to work can help you to understand how MS might affect it. This can also help you to recognise ways to deal with any problems you might have.



The bowel is part of the digestive system. Put simply, the digestive system absorbs the goodness from food that you eat, and gets rid of the waste products from the food that the body cannot use. The small bowel (or small intestines) is the part of the bowel where the useful parts of food are absorbed. The large bowel or colon is the waste processing part of the system.



The small bowel delivers three pints (1,500 ml) of waste to the colon per day. Waste is the consistency of thick pea soup when it enters the colon. It is the job of the colon to absorb fluid from the waste and gradually form it into stools (also called faeces).

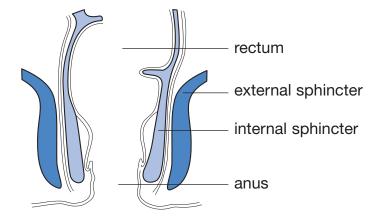
**The colon** (large bowel)

The digestive system

Whether stools are soft or hard will depend on how much water has been absorbed from them: the longer the time spent in the colon, the harder the stools will be. Food usually takes one to three days for the body to process, and 90 per cent of that processing time is spent in the colon.

You can think of the left side of the colon and the rectum as a storage tank at the end of the large bowel. Stools do not enter the rectum from the colon on a continuous basis. Instead, waves of contractions or mass movements happen from time to time along the colon to send waste to the rectum. Waves are often set off by the so-called 'gastro-colic reflex': this is an automatic response, triggered by food or drink entering the stomach, which increases movement along the colon. The gastro-colic reflex is the reason why many people feel the need to go to the loo shortly after eating a meal, particularly first thing in the morning.

Stool entering the rectum will lead to a feeling that you need to empty the bowel, which doctors describe as 'the call to stool'. Whenever possible, do not put this off. Doing so may lead to reduced motivation, abdominal pain, cramps, and in some cases a reduced appetite.

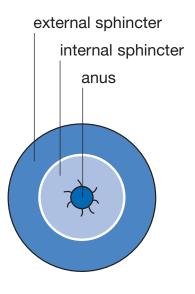


The anal sphincter muscles are two rings of muscle around the anus – the exit from the bowel. They form part of the 'pelvic floor muscles'.

When stools move into the rectum, the internal anal sphincter relaxes automatically (a reflex or involuntary action) and allows the stool into the top of the upper anal canal. Nerve endings in the anal canal can tell between wind (also called gas or flatus), loose or runny stools that need urgent attention, and a normal stool.

Using the external anal sphincter to open the bowel is a voluntary action – you can decide when to do it. If it is not convenient, squeezing the external sphincter can push the stool back to the rectum. If it is convenient to pass the stool, you can relax the muscle.

## Anal sphincter muscles



View across – 'rings of muscle'

## Bowel movements – what is normal?

What you think of as a healthy bowel movement tends to be based on your own personal experience and what you have been brought up to believe. In reality, there is a big range of what is considered 'normal'.

Some people will pass stools every day, but a bowel movement every second day may be your routine, as can opening your bowels every few days, or having up to three bowel movements in a day. Going to the loo fewer than three times a week will cause most people discomfort.

## Constipation

People can mean different things when they talk about constipation. For some people, it can mean not going to the loo very often. For other people it can mean not emptying their bowels completely when they go, or passing hard, pellet-like stools. Other symptoms include straining, bloating, abdominal pain and excessive wind. While most people will not have all of these, a combination is possible.

Providing it is not causing problems, not going for a few days is not a cause for concern. Yet for many people with MS, intervals between bowel movements can be a lot longer than three days, and they may also feel the need to strain.

## Managing constipation

I do suffer with constipation which I try to manage by eating as near to my five a day as I can in fruit and drinking plenty of water, but this doesn't always work. I find certain combinations of fruit work better than others to keep me regular, but this has taken a bit of trial and error. – Louisa

If you are constipated, there are some general measures you can try to help you achieve regular bowel movements. These are:

- good fluid intake
- a balanced diet
- activity and exercise
- regular and comfortable routine
- medication review

#### Good fluid intake

The generally recommended fluid intake is approximately 10 cups (1.5 to 2 litres) per day. Maintaining a good fluid intake can help to treat and prevent constipation.

Increasing your fluid intake will also affect your bladder. If you have been limiting your fluid intake because of MS-related bladder problems, you will need to have them treated as well. There's more information in our booklet *Managing bladder problems*.

For some people, coffee may stimulate bowel movements. However, as caffeinated drinks can irritate the bladder and increase the flow of urine, it's not a good idea to rely on them as your main source of fluids. In addition, coffee can sometimes cause loose stools so if this happens you may want to switch to tea.

#### • A balanced diet

Eating a balanced diet, which includes at least five portions of fruit and vegetables every day and plenty of fibre, can help you to achieve regular bowel movements. There's more information on eating a balanced diet on the NHS Choices website. *i* 

Fibre helps to keep stools bulky, and this can stimulate the bowel. If you have mild constipation, it may respond to high-fibre cereals, perhaps taken with other high-fibre foods like dried fruit, nuts or seeds, for example. However, if your constipation is more severe, fibre in unprocessed bran, for example, may not help waste move through the colon any faster and could lead to bloating. In this case, you might prefer to get your fibre from fresh fruit and vegetables, and include high-fibre foods like prunes (or prune juice), figs, other dried fruit, linseeds and nuts in your diet. It can be trial and error to find foods that make your control better or worse.

For more on diet and MS, see our booklet *Diet and nutrition*.

#### Activity and exercise

If MS symptoms, such as fatigue or reduced mobility, mean that you are less active than you used to be, this can add to problems with constipation.

Being active doesn't have to mean going out and playing a sport – it's about finding the right activity to suit you and your abilities. If you haven't exercised for a while and you're unsure where to start, you can get advice from a neurophysiotherapist or an occupational therapist. Ask your GP or MS nurse for a referral.

There's more information about exercising with MS in our booklet *Exercise and physiotherapy*.

## • Regular and comfortable routine

Scheduling a regular time to go to the toilet can help to establish a routine. You may find the best time is after a meal, so that you can make use of the gastro-colic reflex (see page 6) that can stimulate a wave of contractions in the bowel. Around 20 to 30 minutes after breakfast is often the best time, or you might schedule a regular time after coffee or a hot meal. It can take time to develop your own routine.

A toilet also needs to be fitted out so you can feel comfortable and stable. As it is most natural for humans to squat to pass a stool, you may find it helps to find something to rest your feet on, so your knees are above hip level, and to keep your feet apart.

When going to the loo, try to relax and breathe normally. If you hold your breath and strain, you'll tense up your anus – whereas you should be aiming to relax your anus, to allow the stools to pass. Give yourself plenty of time (and privacy), but try not to spend endless time in the toilet straining. If your bowels do not open, try again at the same time the next day.

## Medication review

I started having bowel problems after a relapse which affected my walking and so I was sedentary for a period of time. I started taking pregabalin daily and I am also on Rebif. These medications can have the side effect of constipation, so alongside being more sedentary and comfort eating I was in a vicious circle that led to chronic constipation. – *Lyndsey* 

Some types of drugs commonly taken in MS can cause constipation, including:

- Drugs used to treat over-active bladder in MS, known as anticholinergic drugs, of which there are many such as oxybutynin (brand name Ditropan) and tolterodine (Detrusitol, Detrol).
- Anti-spasticity drugs used to treat muscle stiffness and spasms, including baclofen (Lioresal).
- Anti-convulsant drugs used to treat neuropathic pain, including gabapentin and pregabalin.
- Anti-depressants, which are used frequently to treat a number of MS symptoms, as well as depression. These can include tricyclic antidepressants, such as amitriptyline, as well as selective serotonin reuptake inhibitors (SSRI), such as fluoxetine and citalopram.

Other commonly used drugs, including over-the-counter supplements, can also add to constipation. For example, some medicines to treat heartburn, high blood pressure and heart problems, painkillers containing codeine, and iron tablets, or multivitamin tablets including iron, can all be constipating.

If you think some of the medications you're on might be contributing to your constipation, you may want to discuss it with your doctor. It may be possible to switch to a different drug that you find more agreeable, or vary the dosage. Or you may be able to do something to compensate, such as varying your diet.

Severe constipation The general measures already outlined above can help many people, but if they don't, you'll need to speak to your GP or a continence adviser who will be able to prescribe further treatments.

There are several treatments to try, not all of which are laxatives. You may need to test things in a systematic way by trying or adding one thing at a time to see what works. It is likely that, over time, you will need further professional advice to reassess how you manage.

A general aim of a number of treatments is to try to reduce 'transit time' (the time waste spends in the gut) and keep stool soft. Other treatments are focused more towards stimulating the bowel to act. Note that nearly all laxatives become less effective over time, so keep to the minimum that works for you. If you can find two or three that work, you can rotate them. It's best to do this with advice from a health professional.

#### Bulking agents

If you stretch the bowel wall, it stimulates pressure and waves of contraction in the colon. Bulking agents help to start this process by increasing the mass of the stools. Bulky, softer stools can also be easier and more comfortable to pass. A number of bulking agents are the undigestible parts of plants, like husks or stalks. Bulking agents include natural bran, sterculia (for example, Normacol), ispaghula husk (for example, Fybogel or Manevac) and methylcellulose (for example, Celevac).

If your gut is slow, however, bulking agents might not be suitable. If that's the case for you, a stool softener might be the right treatment to try instead.

#### Stool softeners

As the name says, these try to keep the waste soft by adding a softener such as an oily substance to the stools. Like bulking agents, the aim of stool softeners is to increase the bulk of the stools. However, the way they do this is different. Stool softeners help stools to retain moisture and stay soft and bulky as they pass through the colon. You may not get as much bloating as with a bulking agent. Stool softeners include castor oil and sodium docusate (for example, Dioctyl).

My GP was excellent, she ordered an ultrasound scan and then an x-ray and referred me back to the continence nurse. We agreed to manage my symptoms by the use of laxatives (Movicol) and stool softeners (Docusulfate) and improving my diet and exercise regimes. – *Lyndsey* 

#### Osmotic laxatives

As waste passes through the digestive system, fluid is drawn out of it through the walls of the colon. This is known as osmosis. Osmotic laxatives try to stop the bowel from drawing out so much liquid from the stools, so they stay soft and bulky.

Osmotic laxatives include lactulose, and polyethylene glycol (including the branded medicine Movicol). If you take too much, however, they can lead to diarrhoea. Always follow your GP, MS nurse or continence adviser's guidance to avoid this. It may take a few weeks to get the right dose for you – some people find they need to take two sachets a day while others manage their constipation with one sachet every two days.

#### Stimulant laxatives

These contain medications to stimulate the pressure waves in the colon to get the gut going. They can be reliable and effective, providing you take the right dose. A professional can help you vary the dose so the stools do not become liquid and cause excessive urgency. They can also cause cramping and urgency if, for example, you have a build-up of hard stools. Stimulant laxatives include senna, and bisacodyl (including the branded medicine Dulcolax).

A newer drug, prucalopride (brand name Resolor), is available for women with chronic constipation who have tried at least two laxatives and they haven't helped. However, it is not yet known if it is effective in MS.

#### • Suppositories and enemas

If treatment with laxatives hasn't helped, you may be offered suppositories or enemas. These stimulate the wall of the rectum to push stools out, or distend the rectum to get a reflex action. They can be useful to empty the contents of the rectum. They are given either as a firm jelly-like preparation that is inserted into the rectum (a suppository) or as a fluid inserted into the rectum (an enema). One advantage they have is that you can predict your bowel movements. They may also help stimulate movement further up in the bowel.

Glycerine suppositories have a mildly irritating action that promotes emptying of the bowels. Other types of suppository, such as bisacodyl, contain a stimulant medication. Similarly, an enema might be medication-free, such as a water enema, or contain stimulant. You may find it best to begin with a glycerine suppository and only progress if necessary to other treatments such as a stimulant suppository or enemas. Again, seek professional advice.

#### Digitation

Some people with MS are taught a method of using their finger (a 'digit') to help the stool out. 'Digital stimulation' massages the anal sphincter muscles to get the rectum and anus to respond and expel stool. 'Manual evacuation' is like hooking the stool from within the rectum. Get advice from a health professional before you try either of these techniques.

The stubborn side of me thinks that I have control over very few other things in my life due to the MS that I should be able to sort this myself. But my sensible head is starting to win over and I'm going to look at options such as self administered irrigation 'cos 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 and I'm sure my husband would like this too. – *Louisa* 

You may be referred to a gastroenterologist (a doctor who specialises in digestive disorders) as part of your treatment. They can carry out different tests that can help establish which aspects of your bowel function may be causing problems, and where there is good function, too. They can measure transit time through the gut, use x-rays to help analyse the way the rectum and anus are working (defaecography), measure the 'squeezing pressures' of sphincter muscles (anorectal manometry) or use a very small telescope to inspect the lining of the bowel (endoscopy).

## Further tests and treatments

Following these tests, they may suggest further treatments, including:

#### Abdominal massage

You can be taught how to apply firm massage to your abdomen in the direction of the flow of the colon for several minutes.

## Biofeedback

This is a way of trying to 'retrain' the bowel. A course of biofeedback sessions may help people become more aware when their rectum is full, for example. There is limited research in MS, but what there is suggests that biofeedback may benefit people with MS who are more mobile. Continence advisers are likely to know where biofeedback sessions might be held locally.

## Irrigation

A technique known as transanal irrigation (TAI) involves washing out the bowel with special equipment. You would be given training in the technique by a healthcare professional, after which – if appropriate – you can carry it out at home. The advantage of this procedure is that it completely empties the bowel and reduces the risk having an accident later in the day. A disadvantage of it is that some people can become reliant on it, so they are unable to open their bowels without it.

There have not been many studies into the effectiveness of TAI in people with MS, but what evidence there is suggests that it may be useful for some people, particularly those who are less mobile.

## • Surgery

This is a rare last resort for constipation when doctors identify a problem that can be corrected by surgery. Surgery requires careful evaluation, as it can sometimes make matters worse.

Colostomy (diversion of the large bowel to an artificial opening in the abdominal wall), or ileostomy (diversion of the small bowel to an artificial opening in the abdominal wall) may improve the quality of life for people with severe disability. An antegrade continence enema (ACE, also known as the 'Malone operation') allows irrigation of the bowel and has been successful in some people with MS.

In rare instances, it is possible that chronic straining can result in a blockage of the bowel, when it turns in on itself. So-called 'intussusception' or rectal prolapse might be the problem in people who have severe difficulty passing stools and a continuous sensation that they haven't fully emptied their bowels. Surgery can correct this and straighten out the bowel.

#### What about complementary therapies?

Some people report benefits from therapies such as reflexology, acupuncture and hypnotherapy, although there is no research evidence to support their use. Be wary of anything that makes miracle claims. There's more on complementary therapies in our booklet *Complementary and alternative medicine*.

## Bowel incontinence

I'd got in the habit of taking a container of linseeds on holiday with me – this time I'd forgotten. The result of that was uncomfortable constipation towards the end of the week. Then something worse happened, because travelling home in the car I felt the urgent need to go all of a sudden and developed the opposite – diarrhoea, needing to stop at each motorway services from Eurotunnel to South Wales. – *Eiona* 

Bowel incontinence can be very distressing. You may have an involuntary leakage from the bowel only very occasionally, once in perhaps three months, or more frequently. Whatever the frequency, it can lead to huge uncertainty and worry. Along with this, you may also find you're unable to control wind.

With careful management there is usually something that can be done to help control these embarrassing and distressing symptoms.

There are a number of different possible causes of bowel incontinence in MS.

Most studies show that bowel incontinence in MS is often associated with constipation, when stools (faeces) become impacted in the bowel and there is leakage around them. Impacted stools become very hard and this can irritate the wall of the bowel, causing it to produce more fluid and mucus that then leaks out through the anus (back passage). As this fluid is stained brown by stools, it can be mistaken for diarrhoea.

Because of this link between bowel incontinence and constipation in MS, if you have bowel incontinence but not constipation you should be investigated for other lower bowel problems.

Another cause may be to do with the anal sphincter muscles and the nerves in the anus. Passing stools from the anus is a delicate and complex process. If MS interferes with the reflex action that is needed, the ability of nerves to sense stools or your voluntary

Causes

ability to control muscles, or there has been previous damage to the muscles themselves, this process will be impaired. For example, some people with MS are less able to squeeze their anal sphincter muscles, and diarrhoea or loose stool is harder to hold if your muscles are weak or your nerves are less able to sense stools.

In health, the bowel is normally not active overnight, but in some people with long-standing MS, the bowel may empty while asleep at night. This may happen occasionally or regularly.

Repeated straining when going to the loo or something unrelated to MS, like a tear during childbirth or surgery to the anus, can also be a cause of leakage as the anal muscles are weakened.

Fatigue, general muscle weakness, spasticity and impaired mobility can contribute to problems with bowel incontinence.

Like anyone else, people with MS may get diarrhoea through infections, having an upset stomach from eating bad food, from antibiotics or medications.

## I think bowel problems are the worst part of MS – it is for me and all of the folk I know who have it. I have suffered with diarrhoea since being diagnosed. After hospital tests – camera up the bottom and also a barium meal x-ray – it was decided that it had to be the MS that was causing it and I had 'rapid transit'. – *Frances*

A first step to managing bowel incontinence will generally be an assessment of the problem by a health care professional, such as your GP, MS nurse or continence adviser. This will help work out if the problem is likely to be caused by your MS or the result of other factors. It can also assess the extent of any nerve or muscle damage and recommend the best treatment for you.

Questions you may be asked include:

- When did it start?
- How often do you open your bowels?
- Do you have to rush to the toilet?
- Do you have to strain to empty your bowels?
- Is it painful to empty your bowels?
- Are your stools hard, soft but formed, or loose (runny)?
- Do you ever see blood when you open your bowels?
- Do you have difficulty wiping clean after opening your bowels?
- Do you ever lose stools when you walk, or in bed at night?

## Managing bowel incontinence

- Do you need to wear a pad?
- If you are losing stools, how often, how much, what is the consistency?
- Are you taking any medications?
- Do any foods or drinks make it better or worse?

You will also be asked general questions about past operations, childbirth, and your diet and fluid intake. You might be asked to keep a diary showing how often your bowels open, and when you have a bowel accident, or when you need to change a pad, if you wear one.

Medical staff will examine the anal sphincter muscles but an accurate evaluation of 'squeeze pressures' is only really obtained from using an anorectal manometry test, where a small tube or balloon measures pressures in the anus. There are other tests to find structural problems, like tears in sphincter muscles. Endosonography uses ultrasound to scan the sphincter muscles. Defaecography uses x-rays to help medical staff assess the workings of the rectum and sphincter.

Once they've assessed the problem, they will suggest some ways to manage it. These may include:

## A balanced diet

All-Bran and bran fibre tablets helped a lot, but All-Bran with milk in the morning is heavy going. Recently I've found that alcohol makes it worse, but drinking plenty of water helps. – *John* 

You may be able to improve things by making changes to your diet. For example, high-fibre foods, caffeine, milk products, chocolate, alcohol, spicy food and artificial sweeteners can have the effect of producing loose stool in some people. Arrowroot biscuits, marshmallow sweets and ripe bananas can help make stools firmer. It's worth experimenting to see if you can identify anything that upsets your control or makes stools firmer.

#### • A regular and comfortable bowel routine

Establishing a regular routine for going to the toilet can often help. You can plan to be in place at a time when your bowels are most likely to open, for example, 20 to 30 minutes after a meal or a hot drink. If you have a set routine and can feel comfortable and relaxed, this can help encourage the bowel to develop a regular pattern.

## Medications

Some medications, particularly any you may be taking for constipation, may be contributing to your incontinence. There can be a fine line between helping constipation with laxatives and causing bowel incontinence.

#### • Steps to control leakage and diarrhoea

An anti-diarrhoea drug like loperamide (including the brand name drug Imodium) may be effective in treating loose stool. Sometimes codeine phosphate is used.

When you are constipated, bowel leakage may stop if you clear the bowel with, for example, a suppository or enema. If not, you may need to combine, with caution and advice, a treatment that empties the bowel and treatment with loperamide.

Some people may be taught to wash out the lower bowel. You can also be taught to stimulate local reflexes using a finger (digital stimulation).

## Sphincter exercises for strength and control

I was given exercises to aid the external sphincter strength and lessen the urge of having to go right there and then. Five times a day I lightly hold the muscle for 10 seconds, relax for five seconds, and repeat 10 times. Don't strain it, just half the full pressure and this builds up the muscle. I keep forgetting to do this (MS memory loss) but this exercise does help. Eight months down the line and things have improved, like if I'm out I don't have to think where I can go if desperate. Before I was always thinking of places I could go like supermarkets or large pubs. – John

Squeezing the muscles around the anus may help strengthen them and may also improve the way you control your muscles. You need to learn to do the exercises the right way and to check from time to time that you are doing them correctly. A specialist physiotherapist can help you to identify the right muscles. Once you know how to do the exercises, they should become easy. It takes time for exercise to make muscle stronger. You may need to exercise regularly over several months before muscles gain strength.

St Mark's Hospital, a specialist hospital for intestinal and colorectal disorders, has produced a leaflet explaining some anal sphincter exercises that can help to improve bowel leakage. *i* 

#### Re-training – using 'biofeedback'

Biofeedback – a series of sessions with a trained health professional, often a specialist physiotherapist - may help you to strengthen your anal muscles and better regulate your bowel. Sessions will vary, depending on the practitioner. Biofeedback can help by showing you on a computer screen what your muscles are doing, so that you can learn to link often vague sensations with rectal and anal activity. NHS continence advisers are likely to know where biofeedback sessions are held locally.

#### Surgery

Surgery may be an option for some people. If there is damage to the sphincter muscles, or if you have prolapse (where the rectum slips out of place and down through the anal sphincter muscles), this can be corrected by surgery.

For a few people with severe bowel leakage that cannot be managed any other way, it may be possible to have a stoma operation, bringing the end of the bowel out onto the wall of your abdomen so you can wear a bag to collect the stools. This may be a positive decision for some people. If a stoma has been suggested for you, a stoma care nurse can provide information and answer questions you may have.

## Managing day-to-day

I have problems both with constipation and loose bowels. I had to keep a diary in the end, as I was spending so much time thinking about it! The diary helped quite a bit. Also have found out that baby wipes are a blessing. – Wendy "

Continence advisers are there to help. You can 'self-refer' to many NHS Continence Advisory Services, though in some cases you may need a referral from your GP. Contact the Bladder and Bowel Foundation for details of your nearest service.

A continence adviser can guide you on preventing soreness and caring for sore skin around the back passage. Gentle wiping of the anus, washing in plain water wherever possible after a bowel action, using plain soaps, avoiding creams and lotions (unless advised to use them), wearing cotton underwear that allows skin to breathe – these things can help. You can also help care for sore skin by wiping with damp cotton wool, using a barrier cream (seek advice), trying not to scratch sore skin, and allowing air to

Skin care

get to the anal area for at least part of every day. Talk to an adviser or your GP if your skin is sore.

- Odour controlA chemist may stock some deodorants and air neutralisers<br/>specially designed to control smells from urine and stools.<br/>Some are available with a doctor's prescription.
- Products to helpMost incontinence pants and pads are designed for bladder<br/>incontinence and are not exactly the right shape for bowel<br/>leakage. A panty-liner can act as a simple pad for minor leakage.<br/>Some people have found that folding it between the buttocks and<br/>holding it in place with a 'G-string' helps to contain soiling and<br/>stops skin getting sore from stool on the skin. If you have a very<br/>occasional leak, especially if it tends to be very liquid, there are<br/>pants with a waterproof gusset that should stop clothes from<br/>staining. More major incontinence will require larger pads, and<br/>many are available free on the NHS.

You can get full details of the range of pants and pads that are available from Promocon, a national resource centre for information on continence products. There's also information available from the Bladder and Bowel Foundation.  $\boxed{i}$ 

PlanningKnowing where to find accessible toilets is a great help when<br/>planning a day out. Disability Rights UK (formerly known as<br/>RADAR) has a National Key Scheme (NKS) that gives disabled<br/>people access to around 9,000 public toilets across the country,<br/>as well as a guide to help you locate the nearest one to you.<br/>Keys cost £4 including postage, or you can buy the key and<br/>guide together for £13.99.

If you are going further afield, the Bladder and Bowel Foundation produces a free booklet called *Travelling with confidence*, with advice on coping with a bladder or bowel problem when going on holiday, or business trip. i

# Further information

#### **Read more**

Our free booklets help explain MS, look at its practical and emotional effects, and help you find your own ways to manage life with MS. Titles are available in large print, audio format and a number of languages. For copies, email shop@mssociety.org.uk or call 020 8438 0999.

We can help you find and borrow other books, research articles and DVDs about living with MS. Search online or call the librarian on 020 8438 0900, email librarian@mssociety.org.uk

#### Find out more online

Get the latest on research, campaigns, and MS news. Chat online with our message boards and Facebook. Follow us on Twitter, see the MS community at Flickr and watch us on YouTube.

#### Join us

Just by being a member you strengthen the voice of all people affected by MS. For just £5 a year you will receive our national magazines – *MS Matters* and *Research Matters* – local newsletters and details of local events, as well as being able to vote on how we are run. Help us continue our vital work and join online at www.mssociety.org.uk/joinus or by calling 020 8438 0759.

## Get in touch

The Freephone 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 (weekdays 9am-9pm) or helpline@mssociety.org.uk** 

## Near you

Our volunteers run over 300 local branches and support groups. They provide information about MS and local services, and a chance to meet others affected by MS and take part in a range of activities.

In many parts of the country, you can pick up our booklets at MS Society Info Points. Larger information centres – including ones in our national offices in London, Belfast, Cardiff and Edinburgh (Newbridge) – can help you with information about MS and services in your area.

Or come along to our local and national events and learn more about MS from expert care professionals, researchers and other people with the condition. Find out more online or call your national office.

## Useful organisations

## Bladder and Bowel Foundation

Support and information, including factsheets and other publications, for people with bladder and bowel problems. Contact their confidential clinical helpline service to speak to a specialist continence nurse. Details of NHS Continence Advisory Services across the UK are available from the helpline and on the website.

Helpline 0845 345 0165 www.bladderandbowelfoundation.org.uk

#### **Bowel Cancer UK**

Information about bowel cancer. Runs the Bowel Cancer Information and Support Service, for anyone concerned about bowel cancer or bowel health.

Information line 0800 840 3540 www.bowelcanceruk.org.uk

#### CORE – fighting gut and liver disease

A range of free information leaflets on common bowel disorders such as Irritable Bowel Syndrome and Ulcerative Colitis, as well as information on Maintaining Bowel Control.

3 St Andrew's Place London NW1 4LB

Telephone 020 7486 0341 www.corecharity.org.uk

## **Disability Rights UK**

Disability Rights UK now manages the RADAR National Key Scheme, which gives disabled people access to around 9,000 locked public toilets around the country.

12 City Forum 250 City Road London EC1V 8AF

Telephone 020 7250 3222 www.disabilityrightsuk.org – click on 'Visit the shop' to order a key

#### **Disabled Living Foundation**

Provides free and impartial advice about all types of products for older and disabled people. Information includes a free factsheet, 'Choosing toilet equipment and accessories'.

Ground Floor, Landmark House Hammersmith Bridge Road London W6 9EJ

Helpline 0300 999 0004 (Monday to Friday, 10am-4pm) www.dlf.org.uk

#### International Foundation For Functional Gastrointestinal Disorders

Has several websites including www.aboutconstipation.org and www.aboutincontinence.org

#### **NHS Choices**

For information about eating well

www.nhs.uk

#### PromoCon

National display of continence products plus product information, advice and practical solutions for people with bladder and bowel problems. Information includes a free booklet called 'Choosing products for bladder and bowel control' (published in conjunction with the charity, Ricability).

Promocon, Disabled Living Burrows House, 10 Priestley Road Wardley Industrial Estate Worsley, Manchester M28 2LY

Helpline 0161 607 8219 www.disabledliving.co.uk/promocon

#### **Spinal Injuries Association**

Has a downloadable factsheet on bowel management for people with spinal cord injury, with much that is relevant to people with MS.

www.spinal.co.uk

#### St Mark's Hospital

This hospital, based in Harrow, is one of the leading hospitals devoted to diseases of the intestine. Their website includes some useful factsheets, including one on sphincter exercises for bowel control. Click on the link for patient information leaflets on the left-hand side of the homepage.

www.stmarkshospital.org.uk

## References

A list of references is available on request, and all cited articles are available to borrow from the MS Society library (there may be a small charge). Contact the librarian on 020 8438 0900, or visit www.mssociety.org.uk/library

## Authors and contributors

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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. The law and government regulations may change. Be sure to seek local advice from the sources listed.

If you have any comments on this information or on the work of the MS Society, please send them to infoteam@mssociety.org.uk

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## **MS Society**

100,000 people live with multiple sclerosis in the UK. Every one of them shares the uncertainty of life with MS.

The MS Society is the UK charity fighting to improve treatment and care to help people with MS take control of their lives.

We're a world-leading funder of MS research. We've already made important breakthroughs, and we're now at the start of a generation of MS research that holds incredible promise.

With your support, we will beat MS.

## **Contact information**

MS National Centre 372 Edgware Road London NW2 6ND Telephone 020 8438 0700 info@mssociety.org.uk

MS Society Scotland National Office, Ratho Park 88 Glasgow Road Ratho Station Newbridge EH28 8PP Telephone 0131 335 4050 msscotland@mssociety.org.uk

MS Society Northern Ireland The Resource Centre 34 Annadale Avenue Belfast BT7 3JJ Telephone 028 9080 2802 information@mssociety.org.uk

MS Society Cymru Temple Court Cathedral Road Cardiff CF11 9HA Telephone 029 2078 6676 mscymru@mssociety.org.uk

National MS Helpline Freephone 0808 800 8000 (weekdays 9am-9pm) www.mssociety.org.uk

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