Bowel Changes in Multiple Sclerosis

The Normal Bowel
**Bristol Stool Chart**

<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Separated hard lumps, like nuts (hard to pass)</td>
</tr>
<tr>
<td>2</td>
<td>Sausage-shaped but lumpy</td>
</tr>
<tr>
<td>3</td>
<td>Like a sausage but with cracks on its surface</td>
</tr>
<tr>
<td>4</td>
<td>Like a sausage or snake, smooth and soft</td>
</tr>
<tr>
<td>5</td>
<td>Soft blobs with clear-cut edges (passed rarely)</td>
</tr>
<tr>
<td>6</td>
<td>Fluffy pieces with ragged edges, a mushy stool</td>
</tr>
<tr>
<td>7</td>
<td>Watery, no solid pieces, Entirely Liquid</td>
</tr>
</tbody>
</table>

**Where to get help**

Assessment by:
- a MS Nurse
- continence advisor
- local doctor
- Gastro-enterologist
What Happens in a Bowel Assessment?

Bowel Problems Associated with Multiple Sclerosis
Bowel Dysfunction

Bowel dysfunction is another common symptom associated with Multiple Sclerosis.

Surveys have indicated that 75% of people with Multiple Sclerosis have bowel dysfunction at some stage.

Bowel Symptoms

- Constipation
- Diarrhoea
- Bowel incontinence (solid or wind)
- Pain
Bowel problems associated with MS

1. Loss of, or very reduced, peristalsis
2. Loss of the gastro-colic reflex
3. Spasticity of the anal sphincter
4. Loss of sensation in the anus and rectum
5. Spasticity of the colon

Loss of Peristalsis: Treatment

- Regular aperients, either daily or second daily
- No added fibre
  - fibre in the diet is alright but, as the bowel has lost most of its movement, any excess bulk cannot be pushed through the bowel
  - this may increase constipation or cause impaction
- If constipation continues, then a regular enema (Microlax or Bisalax) may be necessary
Loss of the Gastro-colic Reflex: Treatment

• Try to empty bowels every day, even though the urge to empty the bowel may not be present

• If necessary, a regular aperient may be used

Spasticity of the Anal Sphincter: Treatment

• If the sphincter does not relax, use a gloved finger to stimulate the bowel to open
  • alternatively, a glycerine suppository can be used

• If the sphincter does not close properly, constant soiling will occur
  • if this happens, you may then need to see a colo-rectal surgeon
Loss of Sensation in the Anus or Rectum: Treatment

A glycerine suppository before exercise will reduce the risk of faecal incontinence.

Most people do not have a problem with this when they are at home.

Spasticity of the Colon: Treatment

Regular enemas + regular aperients = reduced faecal accidents.
The Medication Maze

**Stool softeners**
- Docusate (Dulcolax, Coloxy), Metamucil (Psyllium), Lactulose
- Osmotic laxatives
- Movicol

**Stimulant laxatives**
- Senna
- Bisacodyl
- Castor Oil

**Suppositories**

**Enemas**

**Anal irrigation**

**Antidiarrheal medications** - Imodium, Lomotil
Basic First Aid for Bowel Problems

- Knees higher than hips
- Lean forward and put elbows on knees
- Bulge abdomen
- Straighten spine

Basic First Aid for Bladder and Bowel Problems

- Review caffeine intake
- Review fluid intake
- Elevate feet
- Avoid constipation
- One change at a time
- Diet and exercise
- Talk to a doctor, a MS Nurse or a continence nurse
Other Helpful Titbits

- Helpful internet sites:
  - [www.continence.org.au](http://www.continence.org.au)
- Useful apps for smart phones:
  - Wheelmate - tells you where the nearest accessible toilet is to your current location
  - Cathnow - an alarm reminds you to catheterise
  - National Public Toilet Map

How to source advice for all continence issues

- MS Connect 1800 042 138
- National Continence Helpline 1800 330 066
- General Practitioner
Summary

• Bowel- How does it work
• How MS affects bowel
• First aid
• Where to get help

Questions
Bowel

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.

This book has been provided free by the Multiple Sclerosis Trust, a small UK charity which works to improve the lives of people affected by MS. We rely on donations, fundraising and gifts in wills to be able to fund our services and are extremely grateful for every donation received, no matter what size.

**MS Trust information service**

**Helping you find the information you need**

The MS Trust offers a wide range of publications, including a newsletter *Open Door*, which provides an ongoing update on research and developments in MS management. In addition it contains articles from people with MS and health professionals.

For a full list of MS Trust publications, to sign up for *Open Door* and much more visit our website at [www.mstrust.org.uk](http://www.mstrust.org.uk)

**Freephone:** 0800 032 3839
(Lines are open Monday – Friday 9am–5pm)

**Email:** infoteam@mstrust.org.uk

**Write:** MS Trust
Spirella Building
Letchworth Garden City
Hertfordshire
SG6 4ET
Introduction
Around half of all people with MS experience bowel problems at some time. These symptoms can be difficult to talk about and cause embarrassment, but with the right information and support, the majority of bowel problems can be managed successfully.

‘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 give you an insight into why bowel problems can be part of MS, and provides a practical approach to helping you successfully manage bowel problems.
It explores:

- how to recognise any factors that might make 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.

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

Toilet taboo – 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 when we have young children but we don’t expect to have to think about it again in later life. Many people feel awkward talking about bowel problems but all health professionals should understand that MS can have an impact on how the bowel works so don’t be shy in raising this. Your MS nurse, GP or continence advisor are experienced in dealing with these problems and should be able to put you at your ease.

‘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 2’s is fine. Use the language you feel happiest with.
When should I contact a health professional?
If your bowel problems are affecting your life, if things have changed or you are worried do not hesitate to contact your health professional. Specifically this might be if:

- you have 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 stools, prolonged diarrhoea or constipation, or unexplained weight loss
- if you have to rush to the toilet
- if you leak faeces without being aware of it.

What will happen at my appointment?
When you talk to your health professional it is important to be clear about your symptoms and how long they have been affecting you. You could tell them how your bowel problems affect your life, for example making it difficult to go out to see friends.

Not all bowel problems are caused by MS, and it is important to rule out other causes of bowel symptoms.

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

- medications – particularly for pain, bladder problems and anti-depressants
- 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 on 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 habits. For some people being away from home – with different foods and toilet environments – can also make a difference.

Your health professional will take a full history of your symptoms and here are some of the questions you might be asked.

How often do you usually empty your bowels?

Do you ever have problems with constipation or loose stools?

How much and what type of fluid do you drink each day?

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 21 for more on keeping a bowel diary).

Your health professional may also ask to carry out an examination of your 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.
How the bowel works
The bowel is part of the 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 digestive system includes the mouth, oesophagus, stomach, small intestine and large intestine (or colon) – the large and small intestines are called the bowel. The rectum and anus are the final stages of the bowel. The rectum is the last section of the large intestine and the anus is the opening which controls the emptying of stools. The anal sphincters are made up of the muscles at the bottom of the anus that act like a valve and control opening and closing the anus.

Bowel control is an extremely complex process and involves the coordination of many different nerves and muscles.
Digested food passes from the stomach into the small intestine where the essential nutrients are absorbed into the body. The waste left after this process passes into the colon, where water is removed before the waste is passed to the rectum to be eliminated.

As the waste builds up in the rectum, it stretches and this triggers messages to the brain, making you aware that you need to go to the toilet – known by health professionals as the ‘call to stool’. The rectum is filled with sensitive nerve endings which can tell the difference between solid, liquid or wind. When you have normal sensation in the rectum it is easy to tell the difference between wind, runny stools that need urgent access to a toilet and normal stool. Once an individual experiences the ‘call to stool’ they are usually able to choose whether to go and open their bowel immediately or to hold on until later because they have control of the anal sphincters.

Bowel habits vary from person to person. For example, some people normally go to the toilet more than once a day, whereas others 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 rectum and control of the anal sphincter, and two main problems result.

- **Constipation** – difficulties in emptying the bowel
- **Incontinence** – lack of control over bowel opening
Less often MS might cause diarrhoea or soft stool. Bowel problems can also be made worse by other MS symptoms such as spasticity and fatigue. Conversely bowel problems can also exacerbate other symptoms of MS such as spasms and bladder problems.

**Constipation**
Constipation is defined as passing hard stools 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 is 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 stools can become. Normal transit time is less than 72 hours.

- Reduced sensation in the rectum. This can lead to a loss in awareness of the need to empty the bowel, so that stool remains in the rectum for longer, making constipation worse and potentially resulting in overflow incontinence.

- Weakness or lack of coordination of the anal sphincters, 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
rectum 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 stools that are not too hard or soft, and allow you to easily and effectively empty your bowels on a regular basis. What you eat and drink, how much you exercise and adopting regular bowel habits can make a real difference.

**Food and drink**

Eating regularly is good stimulation for the 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 habit.

Making sure you have enough fibre in your diet can also 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 18g.

*‘The thing that helped me personally was adding more fibre to my diet. This means eating bran flakes or muesli for breakfast’*

**Fibre**

Adequate amounts of fibre 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. For people with a sluggish bowel, too much insoluble fibre (e.g. bran-based breakfast cereals) can slow down the gut even further.

Fibre from the recommended five portions of fruit and vegetables per day, with one or two portions of wholegrain foods, can help with constipation. You can also increase the fibre in your diet by adding a tablespoon of linseeds or flaxseeds.

Increase fibre gradually to avoid abdominal bloating or wind and increase fluids along with this. The fruit and vegetables may be fresh, frozen, tinned or dried. 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 21 for more on keeping a bowel diary).

Recommended daily amount of fibre 18g

**Insoluble fibre**

<table>
<thead>
<tr>
<th>Food</th>
<th>Amount required for 2g of fibre</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bread</td>
<td>Wholegrain – 1 small slice</td>
</tr>
<tr>
<td></td>
<td>White – 2 small slices</td>
</tr>
<tr>
<td>Breakfast</td>
<td>Bran based – 1 tablespoon</td>
</tr>
<tr>
<td></td>
<td>Cornflakes – 8 tablespoons</td>
</tr>
<tr>
<td>Rice and</td>
<td>Brown rice – 3 tablespoons</td>
</tr>
<tr>
<td>Pastas</td>
<td>White rice – 5 tablespoons</td>
</tr>
<tr>
<td></td>
<td>White pasta – 4 tablespoons</td>
</tr>
<tr>
<td></td>
<td>Wholewheat pasta – 2 tablespoons</td>
</tr>
</tbody>
</table>
Soluble fibre

<table>
<thead>
<tr>
<th>Food</th>
<th>Amount required for 2g of fibre</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vegetables</td>
<td>Cauliflower, cabbage, carrots – large slices</td>
</tr>
<tr>
<td>Fresh fruit</td>
<td>Apple, orange, pear – one medium</td>
</tr>
<tr>
<td></td>
<td>Banana – one small</td>
</tr>
<tr>
<td></td>
<td>Grapes – 4oz (110g)</td>
</tr>
<tr>
<td>Dried fruits</td>
<td>Raisins, sultanas – 1 tablespoon</td>
</tr>
<tr>
<td></td>
<td>Prunes – 4</td>
</tr>
</tbody>
</table>

‘Lots of people I see swear that porridge has a really big impact on constipation’
MS specialist nurse

Fluid

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 and this in turn leads to harder stools.

Current recommendations are 1.5–2.5 litres of fluid a day or about 8 full glasses (ideally water rather than tea or coffee which can have a dehydrating effect). Producing pale, straw coloured urine shows that your intake of fluid is adequate.

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 increases the likelihood of constipation.
‘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’

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

Reduced mobility and 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.

‘It doesn’t have to be specific exercise – you’d be surprised what a difference just walking around can make to the bowel’

Posture during bowel opening
The human body’s natural posture for bowel opening is to squat. The nearest thing is the ‘brace and bulge’ technique shown opposite.

Whilst sitting on the toilet, your knees are raised so they are higher than your hips (you can use a footstool, or something similar to help); back is straight; lean forward, resting your elbows on knees, if possible; movement of stools can then be helped by bracing your abdominal muscles and bulging the abdominal wall outwards.
• Knees higher than hips
• Lean forward
• Put elbows on knees
• Bulge abdomen
• Straighten spine

Give it time
It is important to give yourself time trying to open your bowels. Try to find a time when you are not rushing to do other things and a toilet where you feel comfortable and relaxed.

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

If, after twenty minutes, nothing has happened, stop and try again after the next meal or try 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.

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. It can be used with the ‘brace and bulge’ position, as some people find ‘brace and bulge’ does not work on its own. 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. Regular use of an abdominal massage technique whilst lying on your back can also be beneficial.

Review your medicines
It is possible that medicines you are taking can cause or contribute to constipation as a side effect. Drugs for bladder symptoms (including oxybutinin and tolteridine), spasticity (baclofen) and depression (including paroxetine (Seroxat) and amitriptyline (Triptafen) as well as iron supplements and antacids 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 can help you to monitor this.

Treatment options
Laxatives
Many of the common over the counter laxatives are licensed for short-term use only and can become less effective if taken in the long-term. So it is important to work together with your MS specialist nurse or continence advisor, to find the approach that works best for you.
Bulk forming laxatives include ispaghula (Fybogel, Isogel), methylcellulose (Celevac), sterculia (Normacol). These work in the same way as dietary fibre, increasing the bulk of stools. They may be useful where dietary fibre cannot be increased and are used daily at regular times. A good fluid intake is essential. Overuse can result in sluggish stool transit.

Osmotic laxatives eg macrogol (Movicol, Laxido) or lactulose (Duphalac, Lactugal) make the stools softer by drawing water from the lining of the gut to smooth out the stool and make it easier to pass.

Stool softeners eg docusate (Docusol, Norgalax) soften stool, making it easier to pass.

Stimulant laxatives eg senna and bisacodyl. 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. Senna and bisacodyl 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.

Rectal stimulants
These suppositories and enemas are used to lubricate the stool to make it easier to pass or to stimulate the bowel to empty. 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 stool and to stimulate the rectum to expel the stool. 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
This uses warm tap water introduced into the bowel via the anus using a catheter or cone whilst the person sits on the toilet. The water helps to wash stool out of the bowel and encourages the muscles in the bowel to contract and push the stool out. It can be useful where someone has been unable to successfully manage their bowel with medication and toileting alone. Two systems are currently available on prescription (Peristeen or Qufora) but more are becoming available. Assessment and training with a suitable healthcare professional is essential before using transanal irrigation. (See sources of help and support page 25).

‘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 these options can be used as part of your bowel management routine which helps you to open your bowel regularly to avoid constipation.

**Loose stool**
Some people with MS experience loose stool rather than constipation. Loose stool is difficult to sense in the rectum and more difficult to control than a formed or constipated stool. Some ways you can manage this problem are:

*Increase wholegrain fibre* (eg wholemeal bread) in your diet or use a bulk forming laxative (eg fybogel) as this may help to bulk up your stool, reduce frequency of bowel movements and improve your control.

*Loperamide* (Imodium) is a medicine that slows down the movement of stool 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.

*Bowel management routine* – this involves establishing a routine for emptying your bowels at a regular time that suits you, possibly using laxative medications, suppositories or transanal irrigation. This reduces the chances of the bowel opening at the ‘wrong time’.

*Transanal irrigation* – (see page 16).
Bowel accidents – faecal incontinence

Faecal incontinence – having no control over when your bowels open – can happen in MS for a variety of reasons. The most common cause can be constipation. When a hard plug of impacted stool builds up in the rectum, a loose, watery, diarrhoea like fluid can be passed around it.

Incontinence can also be caused by reduced sensation in the rectum of the need to empty the bowel, and reduced control of the anal sphincter. If the stool becomes loose for any reason (over use of laxatives, too much dietary fibre, or gastrointestinal infections causing diarrhoea) faecal incontinence is more likely because it is more difficult to feel and control loose stool.

Managing incontinence

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 as a result of poor transmission of messages to the muscles by damaged nerves, mainly within the spinal cord. 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 page 25).

**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. Your continence advisor can help you with this.

‘*Think of it as bowel physio, you change the muscles you use and strengthen them to come to the rescue!*’

**Bowel management routine**  – (see page 21)

**Transanal irrigation**  – (see page 16)

For a few people with MS surgery may be an option when bowel incontinence is 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 faecal incontinence. There is a very wide variety of discreet products available and organisations and websites that can help you to choose what might be most appropriate for you (see sources of help and support page 25).

Anal plugs – this is like a tampon and is easily inserted into the rectum to help to control leakage of stool. 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 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.
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 had to drink, eat, any medication you take and when you go to the loo, 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 habits. 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.

<table>
<thead>
<tr>
<th>Time</th>
<th>Food /Drink</th>
<th>Medication</th>
<th>Exercise</th>
<th>Bowel movement</th>
<th>Accidents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>what did you eat or drink?</td>
<td></td>
<td>activity</td>
<td>hard, soft, liquid</td>
<td>leakage</td>
</tr>
</tbody>
</table>

‘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’
Wind and smells
When you have bowel problems you might find it difficult to control passing wind and the smell can be offensive and embarrassing. Some foods can have more effect than others such as cabbage. Increased or problematic wind is also common if you are 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 cranberry juice in the diet can be helpful.

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. For example:

- 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’

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 70% of people with incontinence are affected by depression. Depression involves persistent sadness lasting more than two weeks, 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.
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 can prevent some people wanting to be sexually intimate. People fear they will lose control and be incontinent when they are having sex. They 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.
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 – are physiotherapists experienced in the assessment and treatment of neurological conditions. They 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 Foundation
The Bladder and Bowel Foundation 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. They have a confidential helpline staffed by specialist continence nurses and physiotherapists.
Helpline: 0845 345 0165
Website: www.bladderandbowelfoundation.org

Colostomy Association
The Colostomy Association is a charity offering support and care for people who are contemplating or have undergone a colostomy. It provides a helpline and has a network of regional support groups run by volunteers.
Helpline: 0800 328 4257
Website: www.colostomyassociation.org.uk

Disability Rights UK
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.
Website: www.radar-shop.org.uk

Products
Continence Product Advisor
The Continence Products 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.
Website: [www.continenceproductadvisor.org](http://www.continenceproductadvisor.org)

**PromoCon**
PromoCon is a national service, working as part of Disabled Living, which offers product information, advice and practical solutions to both health professionals and people who have continence difficulties.
Helpline: 0161 607 8219
Website: [www.promocon.co.uk](http://www.promocon.co.uk)

**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. Produced by the Bladder and Bowel Foundation.

**Mobile phone apps**
Apps have been developed to help locate the nearest toilet, for example the National Key Scheme app.
Resources from the MS Trust

MS Trust Information Service
The MS Trust Information Team provides a dedicated personal enquiry service offering positive constructive health information for anyone affected by MS.
Information Team: 0800 032 3839
Email: infoteam@mstrust.org.uk

MS Trust Publications
• At work with MS
• Depression – factsheet
• Diet – factsheet
• Managing your bladder: a guide for people with MS
• MS and me: a self management guide to living with MS
• Sex and MS: a guide for men
• Sexuality and MS: a guide for women

All publications are free of charge

Website
All MS Trust publications are available to read, order or download from our website
www.mstrust.org.uk/pubs

It also includes:
• A comprehensive A to Z of MS covering a wide range of information about symptoms, treatments and more www.mstrust.org.uk/atoz
• Exercises and MS – www.mstrust.org.uk/exercises
• Map of local services – including MS specialist nurses www.mstrust.org.uk/map
About the editor

Lynn Fox, Information Officer, MS Trust.

The MS Trust is a UK charity for people with MS, their family and friends. The MS Trust Information Service offers a personalised enquiry service; produces a wide range of publications including Open Door, a quarterly newsletter; and provides web based information.

Thank you to:

- All the people with multiple sclerosis who have contributed to this publication, without whose help this book would not have been possible. Particular thanks go to members of the Stone Active MS group.

- Nikki Embrey, Clinical Nurse Specialist MS, North Staffordshire University Hospital, Maureen Coggrave, Clinical Nurse Specialist Neurogenic Bowel Dysfunction, National Spinal Injuries Centre and all the health professionals who reviewed this book and provided invaluable comments.

Please contact the MS Trust information team if you would like any further information about the reference sources used in the production of this publication.

This edition first published in 2013

This publication will be reviewed in three years

Bibliographical information

Lynn Fox, editor.

Managing your bowels: a guide for people with MS
ISBN 1-904 156 29 0
© 2013 Multiple Sclerosis Trust

Registered charity no. 1088353

All rights reserved. No part of this book may be produced, stored in a retrieval system or transmitted in any form by any means, electronic, electrostatic, magnetic tape, mechanical, photocopying, recording or otherwise without written permission of the publisher.
Master Locksmith Access Key (MLAK)

The Master Locksmiths Access Key (MLAK) is an innovative system that enables people with disabilities to gain 24/7 access to a network of public facilities.

The MLAK system has been fitted to elevators at railway stations, accessible toilets in Council municipalities and National Parks and in adaptive playground equipment (Liberty Swing - see below) across Australia.

People with a disability are able to purchase an MLAK master key which will open all toilets, playgrounds and other facilities which are fitted with this specially designed lock.

MLAK keys are available for purchase from Business Members of the Association. To find your nearest Master Locksmith, please make use of our Locksmith Search facility.

Who’s Eligible?

Eligibility is restricted to people who have a disability or have written authority from:

- a doctor
- a disability organisation
- community health centre
- the owner or management of a building with an accessible toilet on site

MLAK Facilities

Spinal Cord Injuries Australia maintains a directory of MLAK-enabled facilities across Australia.

Further Information

For further information, please contact the Master Locksmiths Association (03) 9338 8822 or Spinal Cord Injuries Australia on (02) 9661 8855 or 1800 819 775

National Public Toilet Map

The National Public Toilet Map shows the location of more than 14,000 public and private public toilet facilities across Australia. Details of toilet facilities can also be found along major travel routes and for shorter journeys as well. Useful information is provided about each toilet, such as location, opening hours, availability of baby change rooms, accessibility for people with disabilities and the details of other nearby toilets.

The National Public Toilet Map is also available for Apple’s iPhone. Just go to the App Store on your iPhone or use iTunes to download the National Public Toilet Map App. It’s free!

Liberty Swings

The Liberty Swing is a world-first Australian innovation – a swing that allows children in wheelchairs the opportunity to experience the joy of having a swing in the park.

The Liberty Swing can only be utilised with the use of the MLAK Key. If you require a key, please see your nearest Master Locksmith.

Looking for a Liberty Swing in your State or want further information? Visit the Liberty Swing Website or download the PDF below.

LIKE US ON facebook

Copyright Master Locksmiths Association of Australasia | Terms and Conditions of Use | Advertise with Us | Members | Website by Contact Point