Choices



Bladder and bowel



Multiple sclerosis information

Welcome to this Choices booklet about bladder and bowel...

MS-UK believe we must listen to the voices of people affected by multiple sclerosis (MS) to shape the information and support we provide. It is these people that bring us perspectives that no one else can give.

For every Choices booklet we produce, MS-UK consults the wider MS community to gather feedback and uses this to inform our content. All of our Choices booklets are then reviewed by the MS-UK Virtual Insight Panel before they are published.

This Choices booklet has been designed with you in mind. We hope it will answer some of your questions and also provide some first-hand experience from those who have been in your position people who can truly understand and empathise with your current thoughts and feelings.

Every time you find bold text with quotation marks like this, it is a quote directly from someone affected by multiple sclerosis

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Bladder and bowel

Bladder and bowel problems are common symptoms among people with MS. In fact, three quarters of people with MS are likely to experience continence problems at some point in their lives. These problems do not necessarily occur in isolation either. Prior to revising this booklet, we asked the MS community to let us know how they are impacted by bladder and bowel problems. Just over half of those who responded confirmed that they were affected by both.

To date, there has been a lot of research into bladder and bowel problems, which has helped identify the best ways of dealing with them (1) (2).

With expert medical and nursing advice, most bladder and bowel problems can be brought under control, and this booklet explains more about the methods that can be used to do this.



Don't be embarrassed. This is an issue that many people have to put up with, not just MSers



Bladder

The bladder is a muscular organ that acts as a reservoir for storing urine and emptying it when appropriate.

Most adult bladders can hold up to 500mls of urine, which equates to almost one pint, and voiding generally occurs every three to four hours in a day and once at night. However, this can vary from person to person.

With MS the nerve signals between the brain and the bladder can be impaired or damaged which changes how the bladder works. Sensations felt in the bladder can become altered so you don't always feel the need to pass urine, or you may feel the need to urinate more frequently and/or urgently.

There are solutions out there so talk to your MS nurse or GP about how you are affected by bladder problems

Bladder problems and MS

Research shows that approximately 10 per cent of people with MS have experienced problems with bladder function at the point of diagnosis, with almost all being affected around the 10-year post-diagnosis mark (3).

The most common problems are urgency and frequency during both day and night, difficulty in emptying the bladder, a feeling of incomplete bladder emptying or a combination of all of these.

The bladder has complex nerves which are easily disrupted. This can lead to an overactive or 'unstable' bladder that needs emptying

very often (frequency) and in a hurry (urgency). If a toilet is not reached in time urge incontinence can result. Alternatively, nerve damage can mean that the bladder does not empty properly, leading to overflow incontinence and other possible problems such as urinary tract infections (UTIs).

It is important to emphasise that bladder problems are extremely common in the general population, not only in those who have MS. While there is no centrally collected data on the number of people in the UK who experience issues with bladder continence, NHS England recently estimated that approximately 14 million people were affected to some degree (4).

There are many possible causes for this, MS being just one of them. Do not simply assume that MS is the cause – symptoms should always be properly investigated, and an accurate diagnosis made. Despite being so common, bladder difficulties are a hidden symptom and people don't like to talk about them.

In the following pages we take a look at ways in which bladder problems can be managed, focusing on lifestyle, medication and other commonly used techniques.

Lifestyle and the bladder

There are certain lifestyle changes that can be made which are known to help support good bladder health.

Exercise

Generally, keeping as fit as possible will have a beneficial effect on your bladder. If you experience bladder problems, part of your exercise regime should include pelvic floor exercises, also known as Kegel exercises, which can be used by both men and women. They work by isolating certain muscles situated in your pelvic floor and holding them in a contracted position for a very short period, a matter of seconds.

Kegel exercises are similar to Pilates in that they are lowimpact and involve breathing naturally whilst maintaining a static position. There are male and female-specific Kegel exercises which are designed to target the most appropriate areas of the pelvic floor muscle group for each (5).

More information

To find out more about the benefits of accessible exercise in managing the impact of MS, including bladder problems, please read our dedicated 'Exercise' Choices booklet. www.ms-uk.org/choices-exercise-content



Try to relax and have patience when emptying the bladder. Don't be embarrassed needing to pop to the toilet frequently or using your 'MS card'

Diet

What you eat and drink can play a significant role in good bladder health. Water-based drinks offer the best way to stay hydrated and in turn promote healthy bladder function. Try to drink plenty of water, squash, diluted fruit juice, and teas which are naturally caffeine free. Aim for between six to eight glasses of these bladder-friendly fluids per day (6).

On the subject of caffeine, drinks that contain this substance should be avoided or at least consumed in moderation as they can affect bladder activity, such as by increasing the urgency and frequency of the need to urinate. Other fluids to be aware of are soft carbonated and alcoholic drinks as they are both known to irritate the bladder, particularly by making it overactive.

Similarly with foods, moderate your intake of those which are spicy and acidic in nature. Some foods that are linked to bladder irritation include vinegar, chili, tomato-based products and foods with significant sugar content (7).

For a more bladder-friendly diet try to concentrate on consuming foods that are fibre-rich, such as beans, lentils, whole grains and non-citrus fruits which include kiwi, bananas and pears. Also, vegetables are great at supporting bladder health, particularly kale and cauliflower as they contain high amounts of vitamin C and calcium which are needed for good kidney health, with potatoes being a great source of magnesium, which can support better bladder control (8).

More information

Our Diet and Supplements Choices booklet provides further reading on the link between diet and MS, including more information about gut health, its link to living healthily and the specific diets that have been developed and used by people with MS, with positive results.

www.ms-uk.org/choices-diet-and-supplements-content

Bladder training programmes

These are available via the NHS in the UK and provide advice and support to help people gain more control over their bladder problems. Bladder training programmes usually take a multidisciplinary approach, using a combination of exercise, diet and other lifestyle changes to provide you with a bespoke programme that is designed to promote better bladder health.

Drug treatments and medical intervention

Bladder urgency, frequency and urge incontinence may be controlled by drugs and certain medical procedures.

Antimuscarinics

There are a number of drug treatments available to help with bladder issues, these are known as antimuscarinics and are used to calm the bladder (9). Example antimuscarinic medications include oxybutynin, darifenacin and tolterodine. They work by blocking the involuntary nerve messages that cause the bladder wall to contract, relaxing the bladder's squeezing muscles while tightening those of the sphincter, therefore reducing how often you need to empty it. Antimuscarinics are usually prescribed as oral tablets, occasionally as a skin patch and sometimes as a liquid for people who find it difficult to swallow tablets.

Mirabegron

In cases where antimuscarinic drugs are either contraindicated, are shown to be clinically ineffective, or are intolerable due their side effects, National Institute for Health and Care Excellence (NICE) recommends another drug called mirabegron, also known as Betmiga (10). This is a selective beta-3 adrenoceptor agonist drug designed specifically for the treatment of an overactive bladder and works in a different way to antimuscarinics. The detrusor muscle in the wall of the bladder is relaxed when the beta-3 adrenergic receptors found on the surface of the muscle cells are stimulated. Once relaxed the capacity of the bladder is increased and reduces the need to pass urine as a result (11).

I take mirabegron for bladder urgency which helps enormously

Botulinum toxin type A

Botulinum toxin, more commonly known as Botox, is another form of treatment that can help to reduce bladder problems (9). It acts by binding to a muscle's nerve endings, which blocks the release of the chemical that causes the muscle to contract. When injected into the bladder wall muscle it prevents it from being overactive and as a result relieves the feeling of urgency. Botox treatment has been found to be extremely effective for people with MS who experience overactive bladder problems, it reduces incontinence and makes a significant impact on quality of life.

Botox is carried out as an outpatient procedure using local anaesthetic. Approximately 40 injections are given in one procedure and the benefits of this should last between six and 12 months.

I would really consider pushing for annual Botox injections into your bladder, which means you will have to self-catheterise, but once you get used to it, it is completely liberating and enables you to get back control over your bladder. I can't recommend it enough - it helped me get my life back

It is important to note that Botox is generally only considered when oral drug therapies have not been beneficial.

Posterior tibial nerve stimulation (PTNS)

PTNS is a therapy that is used to counteract the symptoms of an overactive bladder. The procedure involves inserting a needle close to a nerve which is situated just above the ankle, with an electrode being placed on the foot. Once these are in place a mild electric current is passed through the needle and is then directed to the nerves that are responsible for controlling bladder function. These nerves are situated in the lower back. This treatment is administered

via a series of outpatient sessions, held once per week, with each session lasting approximately thirty minutes.

The NICE patient guide for PTNS confirms that it is a reasonably safe and effective way to treat an overactive bladder, particularly if first line treatments such as medication, bladder training and pelvic muscle training have not had the desired effect (12). Moreover, studies have shown that PTNS treatment is effective in treating people with MS who experience problems with an overactive bladder (13).

Sacral Nerve Stimulation (SNS)

This is a type of neuromodulation therapy that can be used to treat people experiencing persistent problems with an overactive bladder, usually in cases where first-line management techniques, such as lifestyle and drug treatments, have been ineffective. Studies have shown that it can be an effective tool in managing bladder urgency and frequency, with positive results persisting well into the medium to long-term (14).

The procedure involves the insertion of a neurostimulator implant that is placed under the skin and connects to one of the sacral nerves by a series of electrode leads. The implant then stimulates the sacral nerve that is associated with the lower urinary tract, the aim of which is to correct poor or inappropriate messages that are sent from the brain to this particular nerve, with the result usually being more regular bladder function.

SNS is not appropriate for everyone, and you will be evaluated by a specialist doctor prior to the procedure going ahead. This evaluation will ensure that the procedure is right for you, both in terms of its potential to resolve your bladder problems and any wider medical considerations.

Bladder augmentation

This is a major surgical procedure also known as augmentation cystoplasty or enterocystoplasty which can be used to treat people whose chronic overactive bladder issues cannot be sufficiently managed by less invasive treatments. The procedure involves making the bladder larger by using a piece of your bowel which is patched onto it, enabling the bladder to hold more urine.

The procedure is effective in that approximately two thirds of people who undergo bladder augmentation find their overactive bladder problems have been cured, however it does come with significant considerations. For example, you are more prone to being affected by bladder and urinary tract infections and develop bladder stones, plus many will find that they need to use catheters to ensure the bladder is completely voided (15).

Additionally, there is a slightly higher than usual risk of developing bladder tumours post-procedure. Therefore, NICE guidelines suggest that patients who have undergone bladder augmentation should be monitored periodically to ensure any potential complications are found and managed appropriately (1).

Catheters

Urinary catheters are devices that help to empty the bladder and are used by people who have difficulty urinating and voiding the bladder

completely. They work by directing the urine through a flexible tube which is then collected in a drainage bag or drained into a toilet. This can help prevent complications, such as urinary tract infections that occur when the bladder cannot be emptied completely.

By using catheters, I have substantially reduced the number of urine infections, which can only be a good thing

Intermittent self-catheterisation

This is a self-catheterisation method which involves temporarily inserting a pre-lubricated soft hollow tube up the urethra and into the bladder to drain the urine. The main aim is to drain away any urine that may be left in the bladder into a toilet or other capture vessel such as a jug or drainage bag, which can then be emptied. An MS nurse or continence nurse can teach you how to do this.

Self-catheterisation is usually done two or three times per day and maybe before bed too. Although this can seem quite alarming at first, with the right support, learning to self-catheterise can be a relatively simple process.

If intermittent self-catheterisation is difficult to manage, or you just don't get on well with doing it, don't worry, there are other options available.



Indwelling catheters

Once other methods of bladder management have been exhausted, an indwelling catheter may be recommended. This is a long-term solution whereby the catheter is inserted into the urethra in the same way as an intermittent catheter, only it is left in place. Indwelling catheters can pose an increased risk of contracting catheter associated UTIs (16).

Urine is drained from the bladder via a tube which connects either to a catheter valve or drainage bag. If a valve is used, urine will be stored in the bladder and can then be released at regular intervals into a toilet as opposed to using a drainage bag only, which allows the urine to flow freely into it.

Using a catheter valve offers you more control over bladder voiding and can help to keep it in good working order. However, it does require some degree of dexterity in the hands, which should be considered when opting for this type of drainage option.

Drainage bags can be very discreet and are available in different sizes and types. They can be strapped to the leg under clothing or held in specially designed underwear.

An indwelling catheter needs to be changed regularly, usually at least every three months (17).

Suprapubic catheters

A suprapubic catheter differs from intermittent and indwelling types as it does not involve inserting a tube through the urethra, meaning it is a viable alternative for people whose urethra has been damaged. It is fitted by way of a minor surgical procedure whereby a small incision in the abdomen is made and the catheter is inserted directly into the bladder.

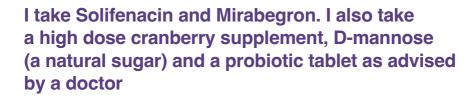
As with indwelling catheters, it is a long-term solution and either a valve or drainage bag can be attached to collect the urine. Some people prefer suprapubic catheters as they bypass the genital area by going directly into the bladder via the abdominal wall. They can also be easier to change than indwelling catheters.

Although people are often put off by surgery, fitting a suprapubic catheter is usually a relatively simple process and can be administered under general and local anesthetic. Those who have had the procedure often find that the improvement to quality of life is worthwhile.

A suprapubic catheter is usually changed every four to twelve weeks (17).

Other suggestions

Aside from the lifestyle, drug and medical interventions which we have explored so far, the following are additional suggestions that you may wish to consider as part of your overall bladder management strategy.



Complementary therapies

Some complementary therapies may help with promoting good bladder health. For example, acupuncture may be recommended to help you manage problems with an overactive bladder. It is worth finding out if this is an option by speaking with your MS nurse or continence nurse.

Studies have also shown that yoga may be helpful in the management of urinary incontinence, particularly in relation to urgency related incontinence in women (18).

The relaxation that can be gained from these therapies may help to calm the bladder and help with muscle strength and functions. However, they are not a cure and should not be a replacement for any medical therapies that are offered.

More information

Our Complementary and other therapies Choices booklet provides more information about the many different therapies that can be used to manage the impact of MS, including ways to access them. www.ms-uk.org/choices-complementary-and-other-therapies-content

Cranberry juice

Cranberry juice or cranberry tablets are reported to be a helpful supplement for those with bladder problems. Studies have shown that cranberries can help to prevent urinary tract infections (19). Cranberry juice does contain a lot of sugar and therefore some people prefer to take it in tablet form, where the sugar content can be minimised.

It is worth noting that cranberries can interact with certain medications, so it is always best to check with a medical professional beforehand.

D-Mannose

D-mannose is a naturally occurring sugar similar to glucose. It's available in foods such as blackcurrants, redcurrants, gooseberries, cranberries, blueberries and tomatoes, also as a supplement in tablet or powder form.

Studies have shown that it can be taken to help reduce and even prevent the occurrence of urinary tract infections (20). It does this by sticking to e-coli bacteria that is living in the urethra, a common cause of UTIs, so it can be effectively rinsed out during urination, lowering the bacterial load in the urinary tract (21).

CBD oil helps with bladder symptoms and a Kegel machine also helps

It is best practice to check with a medical professional beforehand if you decide to use D-mannose supplementation, particularly if you are pregnant or breastfeeding.

Vitamin D

Vitamin D is important to help maintain a healthy immune system, for brain development and function and the wellbeing of the cardiovascular system. It also helps our bodies regulate the amount of calcium and phosphorus in the body. These are the building blocks for strong bones, teeth and muscles. It is also commonly accepted that vitamin D deficiency plays a role in the onset of MS.

Studies have shown that there is also a link between low levels of vitamin D and an overactive bladder. Very recently a systematic review of over a dozen studies that were charged with investigating this link concluded that vitamin D deficiency increases the risk of overactive bladder and urinary incontinence, with supplementation reducing this risk (22).

The human body creates vitamin D when the skin receives direct sunlight when outdoors. Exposure to the sun can produce up to

90 per cent of the body's daily vitamin D. However, it can also be found in several foods, including oily fish such as salmon, mackerel, herring, and sardines, red meat, and egg yolks. Vitamin D is also added to some breakfast cereals, spreadable fats, and non-dairy milk alternatives.

More information

Our vitamin D Choices booklet provides more details about vitamin D and its link to MS. www.ms-uk.org/choices-vitamin-d-content

Bowel

The bowel forms a major part of our digestive system as it helps us not only to pass food and fluid waste but absorb the nutrients from our food. It is made up of two parts, the small and large bowel (also known as the colon) and each performs vital roles in the digestion and processing of what we consume.

The small bowel's main role is to absorb nutrients from food and fluids, with the large bowel mainly being responsible for the storage



I would encourage anyone affected by bowel problems to talk to their MS nurse or GP who can refer them to the help and support they need

and excretion of waste. However, the large bowel is also tasked with absorbing nutrients and retaining water and is also home to thousands of different good and bad bacteria which are influential in our body's general wellbeing (23).

MS can impair the neural connections between the brain, the bowel, and the digestive system as a whole. This can lead to issues with bowel control and function, which we will now look at in more detail.

Bowel problems and MS

A considerable proportion of people with MS will experience bowel problems at some point during their post-diagnosis lives. A study in Australia showed that almost half reported problems with constipation and approximately one third were affected by faecal incontinence (24). While bowel problems in people with MS may be common, they are not often spoken about, as some people find the subject taboo and embarrassing to disclose.

Constipation and faecal incontinence do not necessarily occur in isolation, so it is not uncommon for both to be experienced at the same time. For example, constipation can cause overflow incontinence, which is where watery stools flow around the impacted stool then leak out of the bottom. This is common when the muscles around the rectum are weakened, which is made worse in severe cases of constipation as the impacted stool can stretch them.

Problems with bowel functions can occur as a direct result of the damage MS causes to the neural pathways that connect the brain and digestive system. An example of this is when pathways

I swing between chronic constipation and diarrhoea

connecting the muscles around the rectum and the brain get interrupted, which can make you unable to tell when you need to empty your bowels. The whole digestive process is incredibly complex, and it takes the coordination of many different nerves and muscles to ensure effective bowel control.

Mobility also plays a part in good bowel health. People who experience mobility issues may find they are more likely to have problems with their bowel functions (25). This is particularly so regarding faecal incontinence, which is also known to be impacted by fatigue. It has also been found that fatigue plays a significant role in the onset of constipation in people with MS (24).

This correlation between mobility, fatigue and bowel problems is due to the impact that lack of physical activity has upon slowing down the digestive process and the weakening of muscles which play a key role in the passing of bowel movements, such as those situated around the anus. Spasticity is also relevant as it affects how these muscles act, making bowel movements difficult to control, which can result in accidental leakages.

A reduction in mobility can also make it difficult to get to a toilet in time, which causes people to hold on to their stools. This can lead to constipation. If a person has a severe reduction in mobility this can cause further problems as they may need assistance in toileting. Carers only arriving at certain times of the day can make it harder to manage toileting issues.

It is also important to remember that problems with constipation and incontinence may not necessarily be caused by MS. For example, infections, gastrointestinal viruses, diet, fluid intake and changes to your emotional state can have a significant impact on bowel health and activity. Commonly prescribed drugs, such as detrusitol, oxybutynin, tegretol and amitriptyline, plus many antibiotics, all list constipation as a potential side effect. Dietary supplements such as iron tablets can also cause bowel problems.

The emotional toll of bowel problems should also be recognised and managed. If not treated it may lead to elevated levels of anxiety and distress, which can have a negative impact on the quality of life of the person affected. Psychological and emotional support including access to counselling can really help to improve many aspects of a person's life (2).

It is important not to try and deal with bowel problems alone. An assessment with a continence nurse or an MS nurse can help determine the underlying cause and identify the best course of action that will provide relief. Solutions may include lifestyle and dietary changes, exercise programmes and medication.

In the following pages we take a look at ways in which bowel problems can be managed, focusing on lifestyle, medication and other commonly used techniques.

Lifestyle and the bowel

There are certain lifestyle changes that can be made which are known to help support good bowel health.

Exercise

Earlier in this booklet we looked at the benefits of exercise for bladder health and control. The same can be applied regarding the bowel, particularly with respect to faecal incontinence, for which exercises may be used to allow you greater control in the passing of stools.

Pelvic floor muscle training can be an option as it can be used to strengthen muscles which, when weak, can cause faecal incontinence. These exercises are usually taught by a specialist continence nurse or physiotherapist, as it is important that they are done correctly to ensure maximum benefits are achieved and avoid any unnecessary injuries. It is also helpful to be mindful that it takes time for muscles to become stronger and to persevere with any regular exercise regime that you may be prescribed, in the absence of injury.

Exercising in general is known to help prevent the onset of constipation (26). Taking regular exercise helps to stimulate the digestive system by speeding up the movement of food within the gastrointestinal tract. This keeps the stool hydrated as the body does not have much time in which to extract water from the food being digested. The more hydrated the stool, the easier it is to pass through the bowel and then out of the body.

More information

To find out more about the benefits of accessible exercise in managing the impact of MS, including bowel problems, please read our dedicated 'Exercise' Choices booklet. www.ms-uk.org/choices-exercise-content

It takes time and dedication to make changes but the rewards for even partial remedy have had a hugely positive effect on my confidence and quality of life

Diet

What we eat and drink plays a significant part in the good health of our digestive systems, with particular importance on fibre and fluid intake.

Fibre is required to help soften stools and also increase their weight, both of which are factors for healthy and regular bowel movements. Good sources of fibre include wheat and branbased cereals, fruit and vegetables, nuts, seeds, peas and beans. If these sources of fibre are not currently part of your daily dietary regime, add them slowly and gradually to prevent side effects such as the feeling of being bloated and flatulence. It is

recommended that adults consume around 30 grams of dietary fibre per day (27).

Recent studies have also shown a link between a healthy gut and constipation (28). As mentioned previously, the bowel is home to thousands of different types of good and bad bacteria which, as part of the wider gastrointestinal tract, play a vital role in ensuring that our bodies stay healthy. It follows that a gut-healthy diet, one that contains a healthy balance of prebiotics and probiotics, may be helpful to maintain regular bowel function.

I swear by at least five portions of fruit and veg and 2 litres of water per day

Consuming fluids regularly, especially water, will help improve bowel health, particularly in relation to constipation as it helps stools to pass through the bowel without impacting. Approximately one and a half litres of water per day is recommended, so approximately eight glasses (2). Try to avoid caffeine and alcoholic drinks as they can irritate the bowel and cause it to act irregularly.

As it is also common to have bladder problems with MS. Some people try managing it by not drinking as much. The knock-on effect this can have is for the body to extract as much fluid as it can from food waste, causing stools to become hard and therefore increasing

constipation. Staying hydrated is an important factor in promoting good bladder and bowel health.

More information

Our Diet and supplements Choices booklet provides further reading on the link between our diet and MS, including more information about gut health and the specific diets that have been developed and used by people with MS, with positive results.

www.ms-uk.org/choices-diet-and-supplements-content

Bowel retraining programmes

These are programmes led by a continence specialist which provide a bespoke approach to resolving bowel problems. The specialist will explore with you a variety of issues that may be causing faecal incontinence and constipation, offering support and education regarding diet, exercise, specific posture positions and overall lifestyle issues which may be contributing to poor bowel health.

Biofeedback training may also be available, either as a stand-alone option or part of your overall bowel retraining programme. This procedure can be used to help improve bowel control and function. It involves a small electrical probe being placed just inside the bottom, which then feeds back information on how the muscles in the rectum are performing. A continence specialist can then advise of any muscle weaknesses which may be targeted by specific exercises.

Abdominal massage

Abdominal massage may be suggested as part of an overall bespoke bowel training programme, or in isolation, to help the movement of stools through the gut. It can help to relax the muscles in the stomach and aid the digestion process. A metaanalysis of studies in 2023 found that abdominal massage can be helpful in reducing constipation by increasing defecation frequency and provide relief from associated symptoms such as pain, feelings of bloatedness and incomplete evacuation (29).

Drug treatments and medical intervention

Problems with bowel functions may be controlled by drugs and certain medical procedures. These range from stool softeners and enemas to different types of laxatives. Certain medical procedures may also be an option.

Laxatives and enemas

There are different types of laxatives which can be used, usually as a short-term measure, to provide relief from constipation and in some cases, faecal incontinence. NICE suggests that a bulk-forming laxative should be used in the first instance, such as ispaghula (30). These work similarly to dietary fibre as they help the stools retain fluids which increases their bulk and make them easier to pass. It is important to stay hydrated while taking bulk-forming laxatives to ensure they are as effective as possible.

An osmotic laxative, such as macrogol or lactulose, can also be offered if bulk-forming laxatives do not provide sufficient relief. These work by drawing water from your body and into the bowel, with the effect being the softening of stools. This makes them easier to pass through the bowel and out of the body.

Stimulant laxatives can be used when stools are soft, but you still feel the need to empty the bowel. They work by speeding up colonic muscle movements, making them contract and therefore moving the stools out of the bowel and the body. Examples of stimulant laxatives are senna and bisacodyl, also glycerol suppositories, which are medications that, when inserted into the rectum, help to stimulate the emptying of the bowels.

Stool softeners, such as docusate and arachis oil, can also be used to increase the fluid volume of stools which makes them easier to pass. These remedies can be administered in tablet form or as a mini enema (31).

In cases of severe faecal impaction, where stools are stuck inside the rectum and cannot be moved despite treatment being applied, a retention enema containing sodium acid or sodium phosphate may be considered. This is usually conducted by a health professional and may need to be repeated several times to ensure the impaction has been cleared (32).

Advice about the use of laxatives and enemas can be given by your GP, MS nurse, continence nurse or a pharmacist.

Eating lots of fruit and vegetables, and including linseeds, helps with constipation

Transanal irrigation

This is a procedure designed to help manage the impact of constipation and faecal incontinence. It works by inserting water warmed to body temperature into the rectum using a catheter or soft silicone cone. You sit on the toilet while the rectum is filled, the water is then emptied from the bowel along with the stools into the toilet. Studies have shown this to be an effective way of managing constipation and faecal incontinence in people with MS (33).

The procedure can be self-administered, or conducted by a caregiver once training has been provided by a healthcare professional.



I've started the anal irrigation (Peristeen) system. It's worth letting people know it's nowhere near as awful as you think. Yes, it adds time to your daily routine, but stops the worry of having accidents



Sacral nerve stimulation (SNS)

Earlier in this booklet we looked at how SNS can be an effective tool in regulating bladder function, particularly for people experiencing problems with an overactive bladder. This procedure is also suitable for the management of faecal incontinence, the difference being

that the neurostimulator unit is connected to the sacral nerve that is responsible for regulating bowel function (34).

SNS is an option when first-line treatments for faecal incontinence, such as medication and pelvic floor training, have not been successful. As with SNS for bladder management, an initial evaluation process is necessary before the neurostimulator unit is inserted under the skin. This ensures that the procedure is appropriate and effective in helping you to manage faecal incontinence and if so, that the right settings are identified to maximise its efficacy.

Surgery

In more severe cases of faecal incontinence where there is a lot of muscle and/or nerve damage, or where the problem cannot be managed in any other way, stoma surgery may be the only option. A stoma is a surgically created opening situated on the abdomen that allows for faecal matter to be diverted directly into a drainage bag.

There are two types of stoma procedure, known as colostomy and ileostomy, both of which are usually used as a last resort, requiring a lot of thought and discussion with a bowel surgeon, continence nurse, MS nurse and any family or carers involved (2).

A colostomy is where an opening is made from the large bowel and the bag is usually worn on the left side of the abdomen. An ileostomy is from the small bowel and the bag is usually worn on the right side of the abdomen (35).

For those who have reached this decision it is often a positive one which can offer a better quality of life for the individual. It is important

I don't have bowel problems yet, but I do have a supra-pubic catheter and it was the best thing I did! I will go down the equivalent route if I start with any bowel problems. It saves the worry and embarrassment and means I can go where I want when I want.

that people know this is an option. A stoma nurse will be heavily involved in the before and after process and will be there to answer any questions you may have.

Another possible surgical option to help treat faecal incontinence is what is known as sphincteroplasty. This is a procedure used when the muscles in the anus are damaged with the aim of repairing them so that they function more efficiently, preventing leakages (2). As with stoma surgery, this option can be offered if other treatments have not been effective.

Other suggestions

Complementary therapies

Earlier in this booklet we looked at how complementary therapies may provide relief from the impact of bladder problems and signposted to our Complementary and other therapies Choices booklet for further reading.

Anecdotal evidence also suggests that some people find relief from their bowel problems through complementary therapy. This includes abdominal massage, which we mentioned previously in this booklet. Reflexology has also been found to help people with MS manage constipation (36).

Nutritional therapy or herbal medicines may also be worth exploring, especially if you're sensitive to conventional medications.

It is important to speak to your GP and/or MS nurse if you are looking into these options prior to using them.

Food allergies and intolerance

Food intolerance and allergies can lead to problems with bowel functions. For example, a 2022 review of related studies found a clear connection between lactose intolerance and constipation (37). Gluten is another protein found in some foods which is known to compromise gut health in some people.

Knowing more about how your body tolerates different food types can, at the very least, help you to identify foods that may have the potential to cause problems with your health in general.

More information

The Association of UK Dieticians website hosts a food allergy and intolerance fact sheet which provides trusted information and guidance on the different approaches used.

www.bda.uk.com/resource/food-allergy-intolerance-testing.html

For bladder and bowel

Skin care

Skin care is a factor to bear in mind when a person has bladder or bowel problems. Bladder and/or bowel leakage can lead to skin soreness. Gentle care is needed to stop the soreness from turning into open wounds. This is even more important for those with a limited ability to provide personal care for themselves. Carers should be made aware that the skin can become sensitive. A continence nurse can help with advice on this.

For skin around the anus, perfumed soaps should be avoided, as should perfumed lotions and creams. Allowing sore skin to breathe is important, so wearing loose cotton underwear is helpful. Barrier creams are also useful to help prevent soreness. If sore areas continue it is advisable to make your GP or continence nurse aware.

General everyday care involves ensuring that the skin is cleaned in areas affected by incontinence after episodes have occurred. A point of note for women is to wipe from front to back. This helps to avoid infections of the urinary tract. It is important not to use any abrasives or scrub the skin as this will cause further irritation in what is already a sensitive area of the body.

Continence products

There are a number of useful solutions that can be purchased to help you with managing the impact of bladder and bowel problems. These include continence pads, sheets and bed protection which come in a variety of sizes and styles, disposable and washable. Finding what is right for you is often a case of trial and error.

Some solutions can be handy for when you are out and about, giving you the confidence that any potential incidents can be managed when in public.

The Bladder and Bowel Community is just one organisation that can help give advice on these, as can the Bladder and Bowel UK helpline, or speak to a continence nurse.

More information

The Continence Product Adviser website offers independent information and guidance about the different types of continence products that are available.

www.continenceproductadvisor.org

Help when out and about

Changing Places toilets

These are truly accessible toilets that allow people with profound physical disabilities such as spinal injuries, muscular dystrophy and MS, that often need extra equipment and space, to use toilets safely and comfortably. Changing Places toilets include height-adjustable

Get a disabled toilet key. There are also a number of toilet finder apps

adult-sized changing benches, tracking hoist systems or mobile hoists, adequate space for up to two carers, centrally placed toilets and screens or curtains. Their website includes a map that displays the locations of all of their toilets.

Visit www.changing-places.org

Contact details England, Wales and Northern Ireland Call 0207 803 4814

Email changingplaces@musculardystrophyuk.org

Contact details Scotland

Call 01382 385154

Email changingplaces@pamis.org.uk

Disability Rights UK - Radar Key

The 'National Key Scheme (NKS)' guide gives disabled people independent access to locked public toilets around the country.

Visit <u>www.disabilityrightsuk.org/shop/official-and-only-genuine-radar-key</u>

Call 0330 995 0400

Email enquiries@disabilityrightsuk.org

Toilet Map UK

A very useful online map that allows you to search for toilets near you, which is handy if you go out at any point. You can even filter the search to find RADAR scheme toilets.

Visit www.toiletmap.org.uk

Just can't wait card

The charity Bladder and Bowel Community devised this card, which is available both digitally and as a physical plastic card, to

help people with bladder and bowel issues access local toilets. Many retail outlets are becoming aware of these cards and those that are aware will be happy to provide access to toilets that are not generally available to the public.

The card does not guarantee that any business will give you access though. You can get a 'Just can't wait card' from their website, the digital version is free, and the plastic card version is available for a small fee.

Visit https://www.bladderandbowel.org/help-information/just-cant-wait-card/

MS Society, MS Card

The MS Society can provide an MS Card which can be handy if you need to use a toilet when out and about.

Visit <u>www.mssociety.org.uk/care-and-support/resources-and-publications/publications-search/i-have-ms-card</u> **Call** 0808 800 8000

Further information and support

All About Incontinence - Allanda

Information and advice on incontinence issues. Also provide a wide range of incontinence products to meet specific needs.

Visit www.allaboutincontinence.co.uk
Call 0800 999 5565

Bladder & Bowel UK

Information and advice for all adults, children and young people with bladder and bowel issues and for their families and carers, as well as the professionals who support them. Offering a free national confidential helpline staffed by specialist nurses and a product information advisor.

Visit www.bbuk.org.uk
Call 0161 214 4591
Email bbuk@disabledliving.co.uk

Bladder and Bowel Community

A UK-wide organisation that provides information on a range of symptoms and conditions related to the bladder and bowel.

Visit <u>www.bladderandbowel.org</u> Email help@bladderandbowel.org

Coloplast

The manufacturer of Peristeen Anal Irrigation system and other bladder and bowel products.

Visit www.coloplast.co.uk
Call 0800 220 622
Email help@coloplastcharter.co.uk

Colostomy UK

A UK charity that supports and empowers people with a stoma. Provides information, advice and support to people who have undergone, or are considering, colostomy surgery.

Visit www.colostomyuk.org
Call 0800 328 4257 (24hr helpline)
Call 0118 939 1537 (general enquiries)
Email hello@colostomyuk.org

The Ileostomy & Internal Pouch Support Group (IA)

A mutual support group that offers information, advice and access to support groups for those who have undergone or who are considering undergoing ileostomy surgery.

Visit www.iasupport.org
Call 0800 018 4724
Email info@iasupport.org

About MS-UK

MS-UK is a national charity formed in 1993 supporting anyone affected by multiple sclerosis. Our hope for the future is a world where people affected by MS live healthier and happier lives.

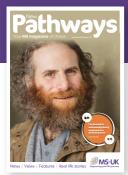
MS-UK has always been at the forefront of promoting choice, of providing people with all the information and support they need to live life as they wish to with multiple sclerosis, whether that be through drugs, complementary therapies, lifestyle changes, a mixture of these or none at all.

We will always respect people's rights to make informed decisions for themselves.

The MS-UK Helpline

We believe that nobody should face multiple sclerosis alone and our helpline staff are here to support you every step of the way.

Our service is informed by the lived experience of real people living with MS, so we can discuss any treatments and lifestyle choices that are of benefit, whether they are clinically evidenced or not.

















New Pathways

Our bi-monthly magazine, New Pathways, is full of the latest MS news regarding trials, drug development and research as well as competitions, special offers and product reviews. The magazine connects you to thousands of other people living with MS across the country.

Available in print, audio version, large print and digitally.

About MS-UK

Peer support service

Our Peer Support Service enables people to connect with others in a safe space and share experiences on topics of interest. Our Peer Pods take place regularly and are all volunteer led. Please visit the website to find out more ms-uk.org/peer-support-service or email peersupport@ms-uk.org.





MS-UK's online activities

MS-UK offers a variety of online activities for those affected by MS to stay active, connected with others and to manage their symptoms to live happier and healthier lives. Activities include exercise sessions, mindfulness courses, chair yoga classes, information sessions and workshops. To get involved, please go to www.ms-uk.org or email register@ms-uk.org.

MS-UK E-learning

Do you work with or support someone living with MS and want to increase your understanding and knowledge of this long-term health condition? Professionals at MS-UK have created an accredited eLearning course that can help you do this. Visit www.ms-uk.org/ms-awareness-e-learning to find out more.

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Check out MS-UK's online activities

Live a happier and healthier life with MS



- Accessible online exercise classes
- Chair yoga classes
- ✓ Mindfulness courses

- ✓ Interactive workshops
- ✓ Information sessions
- ✓ Peer Support Service

Don't miss out – sign up for our new online activities today!

Visit www.ms-uk.org or contact us at register@ms-uk.org





Stay in touch

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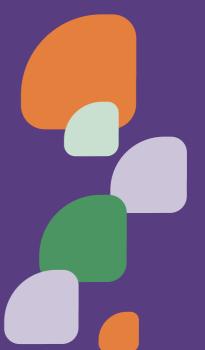
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