Welcome to this Choices booklet about bladder and bowel

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

This Choices leaflet 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
Bladder and bowel problems are common symptoms amongst people with MS. In fact, three quarters of people with MS are likely to experience continence problems at some point in their lives. There has been a lot of research into both problems and the best way of dealing with them (1) (2).

With expert medical and nursing advice, most problems can be brought under control.

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 (almost a pint) and normal voiding generally occurs every three to four hours in a day and once at night. However, this can vary between different people and yet still be classified as ‘normal’.

In 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 more frequently and/or urgently.

**Bladder problems**

The most common problems are urgency and frequency during both day and night, difficulty in emptying the bladder, 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 which 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 bladder problems which fluctuate between the two patterns.

It is important to realise that bladder problems are extremely common in the general population, not only in those who have MS. It is thought that up to six million people in the UK have bladder problems (3). 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.

**Helping yourself**

Generally, keeping as fit as possible will have a beneficial effect on your bladder. It is important to try to avoid constipation as this can also disrupt the bladder. Do not get into the habit of emptying the bladder more and more often ‘just in case’. You may find that the habit becomes very hard to break and you end up with a bladder that is very sensitive.

Many people are sensitive to caffeine and if you pass urine too
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’, and get a disabled toilet key. There are also a number of Toilet finder apps

often it is worth trying decaffeinated drinks to see if this reduces the frequency.

**Drug treatments**

Urgency, frequency and urge incontinence may be controlled by drugs, which help to calm down unstable bladder muscle contractions.

There are a number of drug treatments available to help with bladder issues, two of the main ones used are tolterodine (detrusitol) and oxybutinin (ditropan). These are known as antimuscarinic drugs which are used to calm the bladder (4). They do this by blocking the involuntary nerve messages that cause the bladder wall to contract, therefore reducing how often you need to empty it. They relax the bladder’s squeezing muscle while tightening those of the sphincter. They are usually prescribed as oral tablets and sometimes as a skin patch. They can also be given via a catheter directly into the bladder.

All drug treatments come with possible side effects. The most common for antimuscarinics is a dry mouth, other possible side effects are disrupted vision and constipation. Preventative measures should be taken against constipation, as this can make bladder problems worse. When the bowel does not empty it swells up and pushes on the bladder.
In cases where antimuscarinic drugs are either contraindicated, are shown to be clinically ineffective, or are intolerable due to their side effects, NICE recommends another drug called mirabegron (betmiga) (5). This is specifically for the treatment of an overactive bladder and works in a different way to standard 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 (6).

I take Mirabegron for bladder urgency which helps enormously

Sometimes a drug therapy will be used in combination with a bladder retraining programme. Depending on the main cause of the incontinence this programme may be recommended. The aim of bladder retraining is to slowly stretch the bladder muscle and as it gradually becomes used to holding more urine, the problems of overactive bladder and urgency are reduced. Pelvic floor exercises may also be suggested as they can increase the muscle strength needed to control the bladder and therefore increase its capacity.

Urinary hesitancy is a term used when it is difficult to actually empty the bladder. This can include a reduced flow rate, which can often be accompanied by the feeling of incomplete emptying (retention). Damage to the nerve supply to the bladder is the main cause of the problem. Hesitancy is managed in the same way as urinary retention.
Botulinum toxin (Botox) is another form of treatment that can help to reduce bladder problems (4). 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 specific muscles, the muscle becomes paralysed or weakened, but it leaves surrounding muscles unaffected, allowing for normal muscle function. It is injected into the bladder wall and has been found to be extremely effective for people with MS who experience 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. It can become less effective over the years but it is still helpful in managing your incontinence. I can’t recommend it enough - it helped me get my life back.

It is important to note that Botox is generally only used when oral drug therapies have not been beneficial. Learning how to self-catheterise is also important in case you develop problems emptying your bladder.
**Incontinence**

When despite every effort bladder control remains unreliable, finding a way to manage the problem will help to improve your quality of life. Not being able to reach the toilet in time can result in occasional incontinence.

There is a great range of absorbent products available, both washable and disposable. You can get pads to wear and sheets for bed protection. Different sizes and designs can be tried to find the one that suits you best. It may be possible to get these free from your local health authority - if not there are many varieties available for sale in shops and by mail order.

You can find out more about these products by contacting your local continence nurse.

---

**Catheters**

**Intermittent self-catheterisation (ISC)**

This will ensure the bladder is completely empty. It involves learning how to insert a thin tube (catheter) up the urethra into the bladder to drain the urine. An MS nurse or continence nurse can teach you how to do this. The main aim is to drain away any urine that may be left in the bladder. This retained urine is what can irritate the bladder causing the urgency even though the bladder is not full. It can also cause urinary tract infections (UTIs). Self-catheterisation is usually done twice or three times a day and maybe before bed too. Although this can seem quite alarming at first most people find learning to catheterise very easy.

If intermittent self-catheterisation is difficult to manage, or you just don’t get on well with doing it, there are other options available.
Don’t be afraid to try self-catheterisation

If intermittent self-catheterisation is difficult to manage, or you just don’t get on well with doing it, 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.

Urine is drained from the bladder by either using a valve or by having it attached to a bag. If a valve is used then urine will be stored in the bladder and can then be released at regular intervals into a toilet, a bottle or a bag. It is important not to let the bladder become over-full. Urine can free flow into a catheter bag or the valve can still be used to help prevent the bladder from shrinking as it gets used to not storing as much urine.

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

The catheter needs to be changed regularly, usually at least every three months (7).

**Supra pubic catheters**

This type of catheter involves a minor operation to insert it through a small incision into the abdomen (a few inches below the tummy...
button) directly into the bladder. This is usually done by a urologist under local or general anesthetic.

As with the indwelling catheters, either a valve or bag can be attached. This type of catheter is a permanent solution to bladder problems. They are sometimes preferred as they are easier to change and it bypasses the genital area by going directly in the abdominal wall, which can be much easier to manage.

Although people are often put off by surgery, those who have had the procedure often find that the improvement to quality of life is worthwhile.

This type of catheter is usually changed every four to 12 weeks (7).

**Other suggestions**

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

**Complementary therapies**

Some complementary therapies may help to reduce bladder and bowel symptoms.

Some hospitals around the country may offer acupuncture for an overactive bladder. It is worth finding out if this is an option by discussing with your MS nurse or continence nurse.
The relaxation that can be gained from these therapies may help to calm the bladder. However, they are not a cure and should not be a replacement for any medical therapies that are offered.

Please see our Complementary and Other Therapies Choices booklet to read more about them.

**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 (8). Cranberry juice does contain a lot of sugar and therefore some people prefer to take it in tablet form.

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 tablet or powder form. Studies have shown that it can be taken to help reduce and even prevent the occurrence of urinary tract infections (9). It does this by sticking to the e-coli bacteria (which is often the main cause of the UTI), so it can be effectively ‘rinsed’ out during urination.
Bowel

Problems with the bowel are common among people with MS, but are often not spoken about as some people find it too embarrassing. Around half of people diagnosed with MS will experience bowel problems at some point (10).

The main problems tend to be with constipation and emptying of the bowel, or a lack of control over the bowel opening. It is also not uncommon for people to experience both of these at the same time. People with mobility issues may find they are more likely to have problems with their bowel (11).

This may be because of coordination issues between many different nerves and muscles. Also those with limited mobility may find reaching a toilet in time difficult.

This is something that you should not have to deal with on your own. There are a number of healthcare professionals who are available to speak to about such problems and can help to find the best solutions. Bowel issues can lead to higher levels of anxiety and distress which can have a negative impact on the quality of life of the person who experiences them. Psychological and emotional support through access to counselling can really help to improve

Visit www.ms-uk.org to find out more
many aspects of a person’s life (2).

Although bowel problems are common among people with MS. It is also important to remember that a number of medications can cause these problems too. An assessment with a continence nurse or an MS nurse will help determine the best course of action.

It is also important to remember that MS may not always be the cause of a bowel issue.

**Why do some people with MS have bowel problems?**

For some people with MS the messages from the rectum to the brain may get interrupted and this can stop you being able to tell when you need to empty your bowels. Messages from the brain to other parts of the digestive system can also be interrupted. It takes the coordination of many different nerves and muscles to control the bowel correctly.

Most areas have access to a continence nurse or MS nurse who can provide specific information and advice and find the best ways of dealing with the individual’s situation.

The rectum has many highly sensitive nerve endings. Most people become aware of the need to evacuate their bowels through messages sent via these nerve endings to the brain, where the brain can tell the difference between solid or liquid stools or the need to pass wind. MS can affect these messages causing changes to bowel movements. This is just one way that MS can cause bowel problems. Messages between the brain and various parts of the digestive system can be a cause too. This is a complex procedure that the body completes and when nerve damage
occurs the process can be easily disrupted.

Changes to your normal habit may not only be a symptom of MS but could be due to dietary changes, fluid intake, changes to your emotional state or a side effect of a new drug. These are things that shouldn’t be overlooked when finding out what is causing the problem.

**Bowel problems**

**Constipation**

People who have bowel movements less than three times per week are described as having constipation. Stools can become hard when inside the bowel, leading to difficulties and straining when trying to evacuate. The longer the stool is in the colon, the more water it will absorb, therefore the harder the stool will be, and the more uncomfortable to pass. It can cause discomfort, embarrassment and sometimes pain. It is often not spoken about and people suffer in silence.

Constipation can have many causes - a sluggish bowel, not enough fluid intake, possible medication side effects, reduced mobility and also reduced sensation in the rectal area.

Reduced sensation can lead to reduced awareness of the need to empty the bowel. A continence nurse can help advise of a management strategy of how to deal with this.

There are many strategies used to deal with constipation. These include abdominal massage, specific posture positions, and assessment of diet to encourage a regular bowel habit. Reflexes that empty the bowel are most active around half an hour after breakfast.

Do not rush! It is important to allow yourself time when trying to
open your bowel. If nothing has happened after 20 minutes stop and try again after the next meal or the next day.

Evacuation difficulties can be caused by lack of coordination of the muscles that control the bowel emptying. Sometimes stools can travel normally through the colon but can be problematic passing them out of the rectum. It can feel like constipation even though the stool is softly formed. Specific exercises can be taught to help with this. As mentioned above, these can include posture changes and abdominal massage.

Reduced fluid intake can cause problems for those with MS. As it is also common to have bladder problems, some people often 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. It really is important to drink enough - 1.5 litres per day is recommended (this is around eight glasses) (2).

This will vary according to a person’s weight and height. If extra fluid intake aggravates bladder problems this should be discussed with a continence nurse or MS nurse.

Medication can have a huge impact on constipation. Commonly prescribed drugs, such as detrusitol, oxybutinin, tegretol and amitriptyline all list constipation as a potential side effect. Dietary supplements such as iron tablets can also cause bowel problems. It is important to rule out drug side effects as it may be that another drug may be more suitable for you.

Medications taken for other conditions can also cause constipation and may not be something you first think of. It is worthwhile checking the information leaflets for these drugs if constipation becomes an issue.

Reduced mobility can lead to lack of exercise and often weaker muscles.
Both of these factors are thought to be important as muscle strength is required for the muscle contractions that happen in the gut. 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 also 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.

**Management of constipation**

One of the main things to look at to help manage this symptom is your diet. Assess daily what you are eating and drinking. As previously stated, fluid is so important. Look closely at your fibre and fluid intake. Fibre is required to help soften stools but it needs to be the right sort of fibre. Too much bran can slow down the gut and make a sluggish bowel worse. Fibre from fruit and vegetables should help but introduce them gradually so you do not get bloated.

Studies have found that abdominal massage can be helpful in reducing constipation (12). One study found that even one educational contact with a nurse can be really beneficial to the patient.

There are medications and supplements that are commonly used when additional help is required. These range from stool softeners and enemas to different types of laxatives.

Stool softeners are usually a short-term solution to help relieve constipation, they are to help make it easier to pass stools.

Enemas are used to help clear out the bowel by introducing liquids into the rectum and colon via the anus. This stimulates the wall of the rectum to help push the stool out. Similarly a suppository may be used which is a capsule that is inserted into the back passage. Glycerol suppositories are medication-free, whereas others contain a stimulant medication.
Eating lots of fruit and vegetables, and including Linseeds helps with constipation

There are two different types of laxative, osmotic and stimulant. An example of an osmotic is Movicol. They work by increasing the amount of water that stays in your faeces as they pass through your large bowel. This makes them softer and easier to pass. Examples of stimulant laxatives are senna and bisacodyl. They work by speeding up the movements of your intestines. It is important to get the right dose on both of these. Advice can be given by your GP, MS nurse, continence nurse or you can ask a pharmacist.

Another method to help relieve constipation is transanal irrigation. It can be used for both constipation and bowel incontinence, and comes as a complete system that can be transported. It works by inserting lukewarm water into the rectum using a catheter. When sitting on the toilet whilst 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 bowel symptoms (13).

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.
An assessment is required by a healthcare professional that will then teach the procedure to the person or care giver.

**Bowel incontinence**

Involuntary leakage can cause huge distress and embarrassment, but once assessed it is normally treatable.

It is commonly linked to constipation. If stools become ‘impacted’ there can be leakage around it. The stool can become very hard which in effect acts like a plug inside the bowel. This can irritate the bowel wall causing more fluid and mucus to be produced which can leak out through the anus. It is important to help clear the impaction first using some of the options listed above. If this is not successful a consultation with a healthcare professional is needed to seek an alternative treatment.

Other causes can be due to overuse of laxatives. Too much osmotic laxative can have the opposite effect.

It is also important to remember that gastrointestinal viruses can still occur for people with MS, as can infections, a stomach upset from bad foods, antibiotics and other medications.

Generally speaking, the bowel is not normally active throughout the night. However, in those with longer standing, more advanced MS, the bowel can have movement whilst the person is sleeping. This can happen occasionally or regularly.

**Management of bowel incontinence**

Assessing the problem first and foremost will work out whether it is due to MS or whether it is down to other factors. A continence nurse will be the best person for this. They may ask you to keep a
diary of all bowel movements.

Exercises may be given to help strengthen the muscles to allow greater control. This is of course dependent on a person’s ability and what control they currently have over their sphincter muscles. Exercises are usually taught by a continence nurse. It is important the exercises are done correctly and to be mindful that it takes time for muscles to become stronger.

In some cases loperamide is given, otherwise known as Imodium. This helps to slow down the movement of the intestine. It is best to speak with a continence specialist about taking this for incontinence issues rather than purchasing and self-administering. This will not be effective in treating impaction.

**Surgery**

In more severe cases where there is a lot of muscle and/or nerve damage, or where the bowel problem cannot be managed in any other way, stoma surgery may be the only option. This may be a colostomy or an ileostomy. This is usually a last resort and requires a lot of thought and discussion with a bowel surgeon, continence nurse, MS nurse and the family involved (2).

This operation brings part of the bowel out onto the wall of your
abdomen where a bag is worn to collect the stools. 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.

For those who have reached this decision it is often a positive one and one that can provide a better quality of life for the individual. It is important that people know this is an option. A stoma nurse will be heavily involved and will be there to answer any questions.

**Complementary therapies**

Anecdotal evidence suggests that some people find relief from their bowel problem through a complementary therapy. These mainly help with constipation more than incontinence. The most common are abdominal massage (as previously mentioned) and reflexology. Nutritional therapy or herbal medicines may also be worth exploring, especially if you’re sensitive to medications. It is important to tell your GP and/or MS nurse if you are looking into these options.

**Daily management**

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 nurse aware.

**Useful products**

There are a number of useful continence pads and pants that can be purchased to help contain bladder and/or bowel problems. They 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. The Bladder and Bowel Community are just one organisation that can help give advice on these, as can the Bladder and Bowel UK helpline or a continence nurse.

**Further information**

**All About Incontinence – Allanda**
Information and advice on incontinence issues. Also provide a wide range of incontinence products to meet specific needs.

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

**Bladder & Bowel UK (formerly PromoCon)**
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.

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

Email help@bladderandbowel.org
www.bladderandbowel.org

Changing Places
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 allow them to use the toilets safely and comfortably. These needs are met by Changing Places toilets. These include height adjustable adult-sized changing bench, a tracking hoist system or mobile hoist, adequate space for up to two carers, a centrally placed toilet and a screen/curtain. The website includes a map of all locations of these changing places toilets.

Call 0207 803 2876 (England, Wales and Northern Ireland)
Email changingplaces@musculardystrophyuk.org
www.changing-places.org

Call 01382 385 154 (Scotland)
Email PamisChangingPlaces@dundee.ac.uk
www.changing-places.org

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

Call 0800 220 622
www.coloplast.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.

**Call** 0800 328 4257 (24hr Stoma Helpline)
www.colostomyuk.org

**Disability Rights UK – Radar Key**
The ‘National Key Scheme (NKS)’ guide gives disabled people independent access to locked public toilets around the country. A free app is available for Smartphones.

**Call** 0330 995 0400
**Email** enquiries@disabilityrightsuk.org
www.disabilityrightsuk.org/shop/official-and-only-genuine-radar-key

**The Ileostomy & Internal Pouch Support Group (IA)**
A mutual support group who provide information, advice and support groups to those who have undergone or who are considering ileostomy surgery.

**Call** 0800 018 4724 or 01702 549859
**Email** info@iasupport.org
www.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.

**MS-UK Counselling**

MS-UK Counselling is open to anyone living with MS and is the only service of its kind available in the UK. Whether you want support coming to terms with a diagnosis or to improve your mental wellbeing, our counselling service is focused on helping you.

All of our MS-UK counsellors are BACP registered or accredited with an in depth knowledge of MS.

Visit www.ms-uk.org to find out more
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 www.ms-uk.org/peer-support-service or email peersupport@ms-uk.org.
MS-UK Online

MS-UK’s online service is here to offer a range of activities to stay active and connected for those affected by MS and manage their symptoms to live happier and healthier lives. Activities include exercise sessions, mindfulness courses, chair yoga classes, information sessions and workshops.

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 e-learning course that can help you do this. Visit www.ms-uk.org/ms-awareness-e-learning to find out more.

Visit www.ms-uk.org to find out more
Sources


Reviewed November 2020