Welcome to this Choices leaflet 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 see a box with an icon like this, it is a quote directly from someone affected by multiple sclerosis.
Bladder and bowel

Bladder and bowel problems are common symptoms amongst people with multiple sclerosis (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 a little forward planning and use of expert medical and nursing advice, most problems can be brought under control.

Remember that these people are health professionals and there is no reason to be embarrassed. They are there to help and support you.

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 3-4 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 around three to six million people in Britain 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 often hidden 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 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 dampen 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 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).

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. Bladder
retraining slowly stretches 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 the bladder 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 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. Therefore reducing incontinence and making a significant impact on their quality of life.

The procedure 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 6 and 12 months.

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 are great ranges 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. This 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 ‘left behind’ 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.

**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.

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A continence advisor ‘nurse’ has been very helpful when bladder issues first arose and since. She gently guided and encouraged me to use ISC which has made a difference to everything. She spent a lot of time helping me get it right.
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 whereby it is inserted 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 anaesthetic.

As with the indwelling catheters either a valve or bag can be attached, whichever is more convenient for the individual. 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 and 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 six to eight weeks (7).

**Other suggestions**

**Complementary therapies**

Some complementary therapies may help to reduce bladder and bowel symptoms. To find out what therapies are offered at your nearest MS Therapy Centre see our ‘Therapy Centre’ leaflet and our ‘Complementary and other therapies’ leaflet to read more about them.

Some hospitals around the country may well 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.

**Cranberry juice**

Cranberry juice or cranberry tablets are also reported to be a helpful supplement for those with bladder problems (8). Studies have shown that cranberries can help to prevent urinary tract infections. It has also been stated by researchers that there is no ‘best’ amount of juice or tablets to take each day, or if one works more effectively than another. It is personal preference.

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 that of glucose, 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 if 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).

This is a bit of a taboo subject however there are solutions out there. Talk to your MS nurse or specialist who can refer you to someone who a specialist in this area.

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 at hand to speak to about such problems and 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 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 people with MS can be affected by other diseases of the bowel too.

**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 it is not always known when you may have the need to evacuate. 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.

A team of dedicated professionals who provide information and support and know the best ways to manage problems satisfactorily can help you manage any problem. Most areas have access to a continence nurse or MS nurse who can provide specific advice and find the best ways of dealing with the individual’s situation.

Most people become aware of the need to evacuate their bowels through messages which are sent from the rectum to the brain; where the brain can tell the difference between solid or liquid stools or the need to pass wind. The rectum has many highly sensitive nerve endings; 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 stools are in the colon, the more water it will absorb, therefore the harder the stools 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. The longer this is ignored, constipation can result. 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, 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 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, 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.

There are 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).

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. Depending on the person this can happen occasionally or more 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

Email info@allanda.co.uk

www.allaboutincontinence.co.uk

Bladder and Bowel UK (formerly PromoCon)

Helping to improve the life of all people with bladder and/or bowel problems by offering impartial advice and product information, and practical solutions to both professionals and the general public. They offer the National Confidential Bladder and Bowel UK helpline for individuals and healthcare professionals.

Call 0161 607 8219

Email bladderandboweluk@disabledliving.co.uk

www.bladderandboweluk.co.uk

The Bladder and Bowel Community

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

Call 01926 357220

Email help@bladderandbowelcommunity.org

www.bladderandbowelfoundation.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.

Website includes a map of all locations of these changing places toilets.

Call 020 7696 6019
Email ChangingPlaces@mencap.org.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 Association

Provide information, advice and support to people who have undergone, or considering colostomy surgery.

Call 0800 328 4257
www.colostomyassociation.org.uk
Disability Rights UK

The ‘National Key Scheme’ guide gives disabled people access to disabled toilets around the country. A free app is available for Smartphones.

Call 020 7250 8191

Email enquiries@disabilityrightsuk.org

www.crm.disabilityrightsuk.org/radar-nks-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 01702 579859

Freephone 0800 018 4724

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.
Sources


Last reviewed: July 2017
Use me for your notes

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