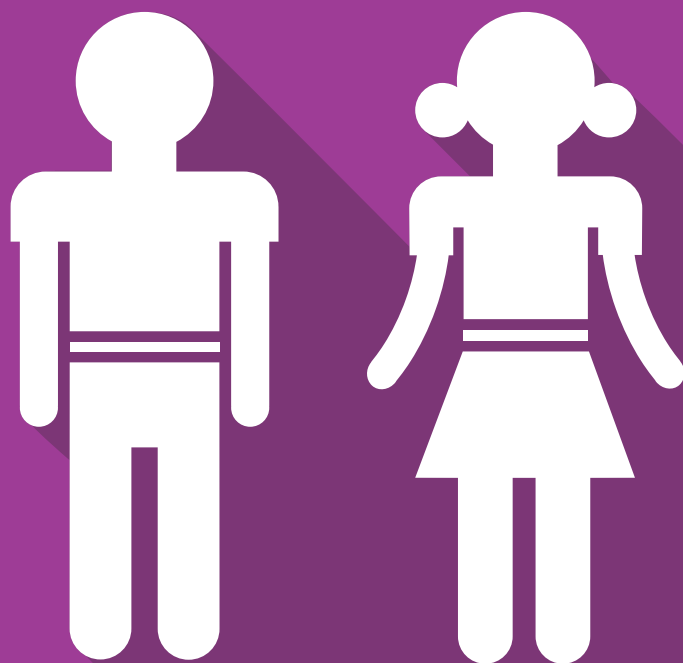


Bladder and bowel



Editorial Board

Multiple Sclerosis International Federation (MSIF)

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Our objectives are to:

- Stimulate and facilitate international cooperation and collaboration in research into the understanding, treatment and cure of MS
- Support the development of effective national MS societies
- Communicate knowledge, experience and information about MS
- Advocate globally for the international MS community

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Letter from the Editor



This issue of *MS in focus* is dedicated to elimination dysfunction; that is, bladder and bowel problems. Often these two topics are discussed together because the same MS lesions in the spinal cord can impair the transmission of messages that control both these functions.

Not everyone with MS will experience bladder or bowel problems, but they are fairly common. These symptoms can occur anytime during the disease course and are not clearly related to the length of time a person has had MS.

Bladder and bowel problems can be extremely upsetting for people with MS. As well as sometimes being physically uncomfortable, these symptoms can disrupt daily life, interfere with work and diminish participation in a person's social life. Because of an intense fear of experiencing involuntary loss of bladder or bowel control, these symptoms can affect the choices people make about how to interact with others.

Unfortunately, some people with MS do not talk to their neurologist or other MS specialist when they are experiencing these problems. They may feel too uncomfortable or embarrassed to raise these topics. Or they may lack information and not realise that these problems are fairly common and that they can often be successfully managed by the person themselves, or with help from health care professionals. In some countries, a lack of access to an MS specialist can, unfortunately, also be a significant obstacle for being evaluated and treated for bladder and bowel problems.

Our hope is that this issue of *MS in focus* will provide useful information to both health care professionals and people with MS, will help to answer questions about bladder and bowel problems, and will serve to encourage an open discussion about these symptoms.

I look forward to receiving your comments.

Michele Messmer Uccelli, Editor

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The next issue of *MS in focus* will be on ageing with MS. Please send questions and letters to michele@aism.it or marked for the attention of Michele Messmer Uccelli at the Italian MS Society, Via Operai 40, Genoa, Italy 16149.

Editorial statement

The content of *MS in focus* is based on professional knowledge and experience. The Editor and authors endeavour to provide relevant and up-to-date information at the time of publication. The views and opinions expressed may not be the views of MSIF. Information provided through *MS in focus* is not intended as a substitute for advice, prescription or recommendation from a physician or other health care professional. For specific, personalised information, consult your health care provider. MSIF does not approve, endorse or recommend specific products or services, but provides information to assist people in making their own decisions.

Introduction

Sangeeta Mahajan, Urogynecologist, University Hospitals Case Medical Center, Cleveland, Ohio, USA, and Francois Bethoux, Physiatrist, Mellen Center for MS Treatment and Research, Cleveland, Ohio, USA

Bladder and bowel symptoms, which may occur at the onset of MS or at any time throughout the course of the disease, can interfere with vital life activities such as a person's ability to socialise, work, take part in sports or hobbies, and engage in satisfying sexual activities. However, recent improvements in the diagnosis, management and treatment of these symptoms means their impact can be reduced or mitigated.

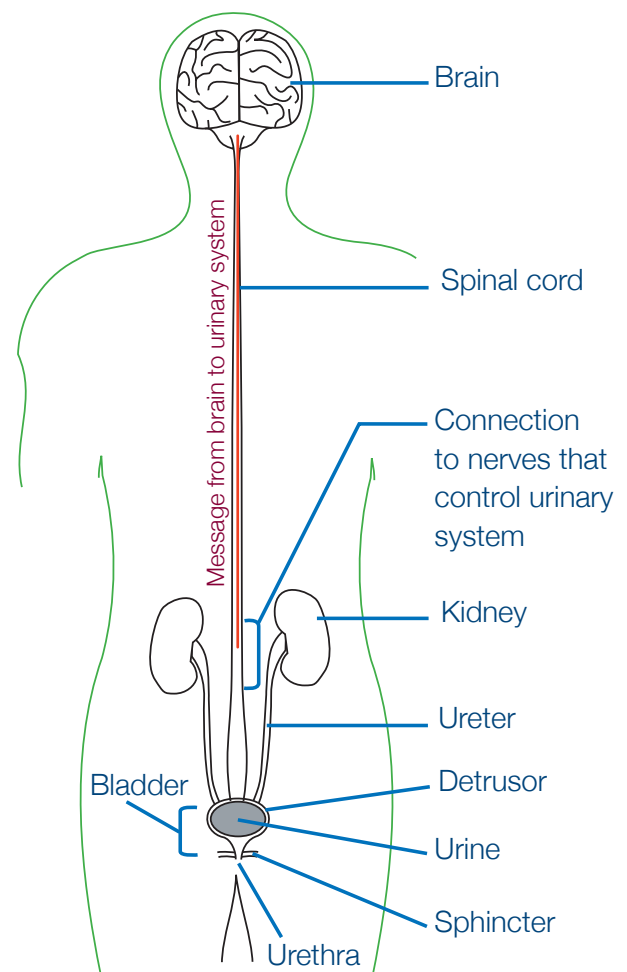
Normal bladder function

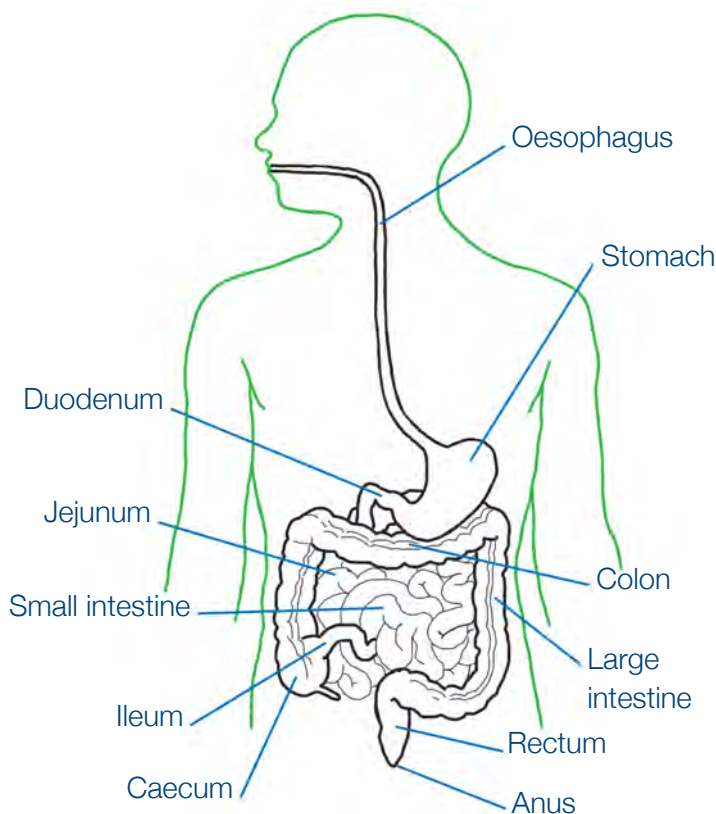
The urinary tract is divided into the upper urinary tract (kidneys and ureters) and the lower urinary tract (bladder and urethra). The bladder is a hollow muscular organ situated in the pelvic cavity. In general, MS mostly affects the function of the lower urinary tract.

Normal bladder function is controlled by the brain, using the spinal cord to communicate with the bladder and urethra. During urine storage, pressure receptors in the walls of the bladder sense the degree of bladder filling based on bladder stretch. This information is relayed to the brain via the spinal cord and stimulates the firing of the nerves in charge of bladder storage, resulting in the "guarding reflex" which causes relaxation of the bladder. At the same time, closure of the urethra is maintained by contracting sphincter muscles, thereby preventing leakage of urine while the bladder fills. When the bladder is filling with urine, the detrusor muscle remains relaxed and stretches to hold the urine. When it is time to urinate, the detrusor muscle contracts to allow the urine to come out.

Once significant bladder filling is achieved, receptors in the wall of the bladder relay increased pressure sensations to the brain, where the pontine micturition centre (PMC) processes this information. Once a critical amount of tension in the bladder

is achieved, the PMC becomes activated and stimulates contraction of the detrusor muscle and relaxation (opening) of the urethra, shifting control of the bladder from the nerves in charge of urine storage to the nerves in charge of bladder emptying. With these events, urine is pushed out of the bladder by the contracting detrusor muscle via the open urethra, resulting in urination. Much of the mechanics of voiding urine occur without conscious control, but there is some ability by individuals to regulate voiding consciously, including controlling bladder sensations and switching from bladder storage to voiding.





Normal bowel function

The human gastrointestinal (GI) tract (or digestive system) is made up of several components, including: oesophagus, stomach, small intestine, large intestine, rectum and anus. The GI tract is further divided into the upper and lower tracts. Overall, the human GI tract is nine metres (29.5 ft) long.

The upper GI tract consists of the oesophagus, stomach and duodenum. The lower GI tract includes the majority of the small intestine, the large intestine, the rectum and anus. Anatomically, the small intestine is made up of the duodenum, jejunum and ileum and the large intestine is divided into the caecum and the colon.

The digestion of food is regulated by the constant release of hormones including gastrin, secretin, cholecystokinin and ghrelin. The main function of the small intestine is to absorb proteins, lipids and vitamins. The main function of the large intestine is to absorb water.

The breakdown of food begins with chewing in the mouth. Food then travels via the oesophagus to the stomach. In the stomach, digestion continues

with stomach acids. Then on to the duodenum where pancreatic juices and bile are added, further digesting proteins and fats. Digested food then travels to the jejunum and ileum where the absorption of sugars, amino acids, fats, vitamin B12 and other nutrients occurs.

Ingested foods then travel to the caecum, (which contains the appendix), and from there to the colon. The colon is divided into the ascending, transverse and descending colon that function to absorb fluid from bowel contents, eventually forming stool which passes into the rectum until it is ready to be expelled via the anus. The smooth wall muscle of the rectum and striated muscles of the circular anal sphincter are essential to the maintenance of faecal continence.

Impact of MS on bladder and bowel

MS can impact bowel and bladder function directly – by MS lesions damaging the areas of the central nervous system that control reflexes, disrupting function – or indirectly, for example decreased mobility due to MS can increase the risk of constipation. Surveys show that bladder symptoms are reported by 80 percent or more of people with MS, and bowel symptoms by more than 50 percent. Problems with bladder or bowel control can occur at any stage of the disease. It is important to remember that other factors, such as pregnancy and the normal ageing process, can also influence bladder functioning.

People with MS are sometimes reluctant to talk about issues related to bladder and bowel control during a medical visit, due to the sensitive and private nature of these topics. However, bladder and bowel dysfunction have been shown to affect the quality of life of those living with MS. In addition, medical complications can occur, such as urinary tract infections, skin breakdown and blockage of the GI tract. These complications require specific treatment, sometimes a hospitalization, and may in turn lead to a worsening of MS symptoms.

This issue of *MS in focus* discusses specific symptoms, evaluations and treatments of bladder and bowel dysfunction.

Bladder function in MS

Agustín Franco de Castro, Urologist, Hospital Clínic of Barcelona, University of Barcelona, Spain

The lower urinary tract, which consists of the bladder, the sphincter system and the urethra, normally functions in two phases: in the bladder storage phase the bladder is relaxed and the sphincter system is activated and closed. But when a person urinates, the opposite occurs: the bladder contracts and the sphincter relaxes and opens.

In MS there can be several dysfunctions of the lower urinary tract due to the alteration of nerves and of brain and spinal cord pathways. The main urinary problems in MS are the storage of urine, voiding issues or a combination of both. As with many MS symptoms, it is not unusual for bladder function symptoms to vary greatly from one person to another.

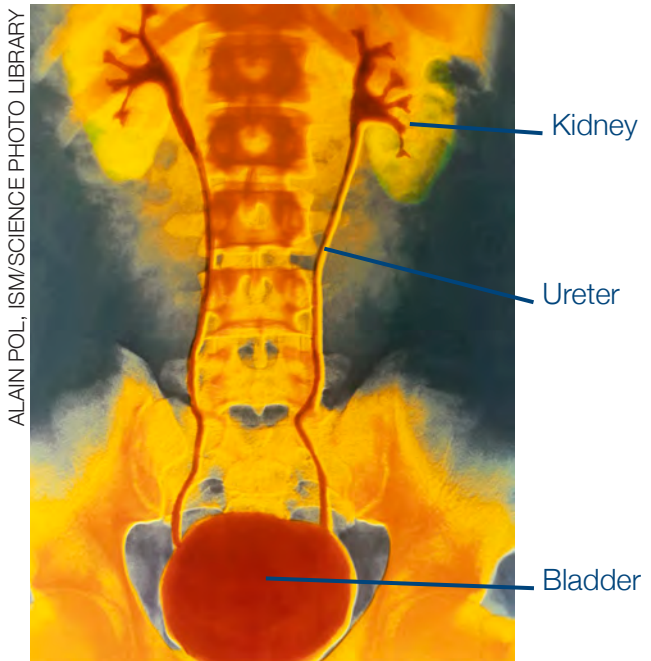
Storage issues

The most frequently reported problem is when a person experiences involuntary contractions of the bladder in the storage phase. This causes the person to feel a sudden urge to urinate, which he or she cannot delay. This is called urinary urgency, which can be so intense that it causes urinary incontinence. In addition, it can also be associated with increased urinary frequency (day and night). This medical condition is called a hyperactive (or overactive) bladder.

Less frequently, people with MS may have a decrease or a loss of sensitivity to the storage in their bladder and do not notice the urge to urinate.

Voiding issues

Some people with MS may experience problems during urination if the bladder contracts at the same time as the sphincter (which should relax in this phase). This can cause a difficulty starting urination, a weak and intermittent trickle of urine, or a situation where the bladder does not empty



completely, leaving post-voiding residue. This residue of urine is a leading cause of urinary tract infections.

In some cases it can be impossible for a person with MS to urinate (known as an acute retention of urine). On rare occasions, the bladder reaches high interior pressures, which can cause the kidneys to dilate, affecting their function and causing kidney failure.

Some people have a symptom where the bladder contracts very little or not at all during urination. This is known as having a hypoactive detrusor during urination and can also be the cause of post-urination residue.

Description, prevalence and impact of symptoms

People with MS can present various problems of the lower urinary tract as a consequence of lesions to the nervous system – this is usually known in medicine as a “neurogenic bladder”. A significant number of people with MS report urinary symptoms at the time of diagnosis of MS and 75-90 percent of

people with MS have urination problems, although for some the symptoms are mild and treatment is not always necessary. It is important to determine if post-voiding residue exists, particularly when urinary infections occur. Urinary infections affect approximately 25 percent of people with MS.

Seeking treatment to help gain bladder control is important for people with MS because in the majority of cases, an improvement in symptoms such as urgency and incontinence can be obtained. Guidance and help from a health care professional can also result in better and earlier control of any urinary tract infections which may arise. In the unlikely situation that there are alterations in the upper urinary tract (approximately 16% of cases), their early detection can help prevent an eventual deterioration of kidney function.

Communicating with urologists, urology nurses and MS professionals may also help men who experience erectile dysfunction as part of their MS.

Diagnosing urinary problems

The symptoms experienced by a person with MS do not always indicate what causes them. For example, the symptom of increased urinary

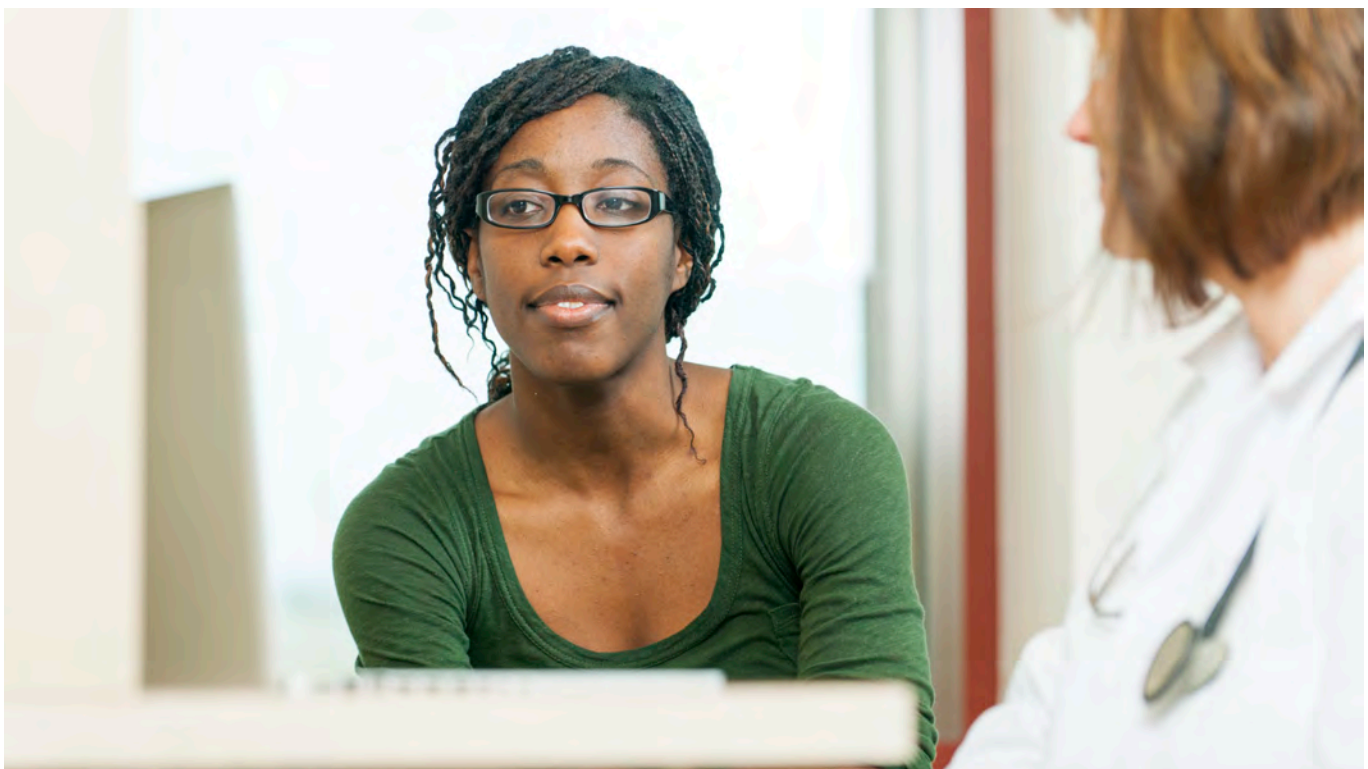
frequency could have its origin in the presence of involuntary contractions of the bladder or in post-urination residue. These causes would require very different treatments.

Diagnosing a urinary tract infection

A analysis of a person's urine can detect an infection. Analysing the sediment of the urine (by centrifuging and microscopic analysis) can detect leucocytes when there is a urinary infection. The urine is usually cloudy with a strong smell. Reactive urine strips can also be used which indicate the presence of leucocytes and nitrates. This is referred to as the urine dipstick test, which serves to exclude the presence of infection and the results are immediate. A urine culture (the urine is placed on a plastic slide on which a medium such as gelatine has been deposited) helps to confirm the infection and indicate which bacteria have caused the infection, and an antibiogram can be used to indicate which antibiotic is the most active against that germ. The results of the complete urine culture usually take two or three days to process.

Diagnosing other urinary problems

An echography of the kidneys and the bladder is a non-invasive method that allows health care



Symptoms, signs and diagnosis of a urinary tract infection

A urinary tract infection (UTI) can be one of the most serious urological problems for people with MS and, if not detected and treated in a timely way, can worsen other MS symptoms, particularly spasticity and weakness. A UTI can cause a pseudo-relapse, or a temporary worsening of symptoms that may seem like a relapse but is due to the infection. It is important that individuals and their caregivers are alert to the symptoms and signs, and that they see a health care professional for a diagnosis and treatment.

Urinary tract infection symptoms:

Acute cystitis (female):

- Burning sensation when urinating
- Increased frequency and urgency of urination
- Cloudy urine
- Unexplained worsening of MS symptoms, particularly fatigue, weakness and spasticity
- Incontinence

Prostatitis (male):

- Fever
- Burning sensation when urinating
- Increased frequency and urgency of urination
- Cloudy urine
- Unexplained worsening of MS symptoms, particularly fatigue, weakness and spasticity
- Incontinence

Kidney infection (male and female):

- Fever
- Lumbar pain
- Burning sensation when urinating

Diagnosing a urinary tract infection:

- Perception that the urine is cloudy with a strong smell.
- Urine strip: leucocytes
- Urine sediment: leucocytes
- Culture: germ that causes the infection.
- Antibigram: most adequate antibiotic for the germ.

The first two methods can be performed by the person with MS or a caregiver and can help in the early detection of a urinary infection. The urine should be collected directly while urinating or from a catheter (indwelling or intermittent). Urine taken from urine bags is not valid.

professionals to assess:

- The amount of urine in the bladder before and after urination. This is a less invasive method than the use of a catheter for measuring the residual volume.
- If there is dilatation of one or both kidneys.

A flowmetry test consists of urinating in a funnel (normally placed under a chair) in order to know the urinary flow rate and the volume urinated. It is necessary for the person to urinate at least 150ml of urine.

When the urinary symptoms of a person with MS appear to be worsening, such as a deterioration of kidney function, an increase in the number of symptoms or severe urinary incontinence, urodynamic testing is used. This consists of determining how the lower urinary tract functions by measuring physical parameters such as volumes and pressures.

Urodynamic testing is performed by using a fine catheter to fill the bladder through the urethra. It is then possible to measure:

- the bladder's sensitivity to storage
- the bladder capacity
- the elasticity of the walls of the bladder to storage (accommodation)
- if the detrusor muscle is relaxed or not during storage, and
- if the sphincter system functions well.

Then, as the person urinates, a urologist can check:

- if there is suspicion of an obstruction in the lower urinary tract
- the contractibility of the detrusor during urination
- the behaviour of the sphincters during urination
- if there is post-urination residue.

Conclusion

Bladder problems are common for people with MS. Fortunately there are reliable ways to assess and treat them. It is important that people with MS have a good understanding of bladder functioning, particularly the signs of complications that may occur.

Bowel function in MS

Evelyne Castel-Lacanal, Physical Medicine and Rehabilitation Specialist, Service de Médecine Physique et Réadaptation, CHU Rangueil, Toulouse, France

Normal bowel functioning

Bowels normally function in two main and distinct ways under neurological control. In the first step, stools are moved through the colon, the intermediate part of the intestines, pushed gradually by rhythmical contractions of the walls of the colon. In the second step, the stools pile up in the rectum, the terminal part of the intestine. When the rectum is full, it sends a message to inform the brain that it is time to be emptied. During voluntary defecation, the rectum contracts and the anal sphincter opens to expel the stools (called the recto-anal reflex). The autonomic nervous system (which regulates the functions of our internal organs such as heart, stomach or intestines) controls the colonic contractions, the sensation of the bowel being full and the contractions of the rectum. The anal sphincter is controlled by the voluntary nervous system.

Bowel issues in MS

The main bowel dysfunctions associated with MS are constipation and faecal incontinence. These symptoms are often underestimated. People with MS may not feel comfortable speaking about these problems, or may not realise they can be related to MS. Doctors may fail to address the problems through a lack of knowledge about treatment and therapy options.

Constipation has been reported to be present in up to 90 percent of people with MS, with faecal incontinence reported in as high as 70 percent and approximately half of people with MS experiencing both symptoms. It is important to note that other studies have found these problems to be much less frequent. Thus, the real prevalence of bowel problems in MS is unclear. One third of people with MS spend more than 30 minutes a day managing their bowel problems.

Risk factors for bowel problems are age, level of disability, the stage and disease duration of MS and whether there are associated urinary disorders.

Constipation

Changes caused by MS lesions in the autonomic nervous system may cause stools to progress more slowly in the colon and arrive later in the rectum. Stools may pack into the colon and become dehydrated and hard, which makes them more difficult to expel from the rectum, causing constipation. Constipation is defined as having fewer than three bowel movements a week or bowel movements with stools that are hard, dry and small, making them painful or difficult to pass. People may feel bloated or have pain in their abdomen. People with MS may also be constipated if they have limited mobility, increased muscle tone of the anal sphincter, impaired voluntary defecation or as a side effect of medications such as anticholinergics, antidepressants and analgesics.



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Faecal incontinence

Faecal incontinence is defined as the inability to control the release of a stool. This can be due to a weak capacity of the rectum, a loss of sensitivity in the rectum or a loss of voluntary control of the anal sphincter. Constipation and faecal incontinence may be associated, and faecal incontinence should not be considered as a case of diarrhoea. Anti-diarrhoeal treatment for faecal incontinence could aggravate constipation.

Other related problems

Other problems can include faecal urgency which is caused by an alteration of sensitivity in the rectum. Reduced sensation means that the rectum does not send information to the brain when it is full, so feeling the need to defecate is delayed and therefore felt more urgently than normal. A smaller capacity of the rectum (because it contains a smaller volume of stools) may be responsible for a more frequent urge to defecate or for anal leakage. Some people with MS find it difficult to completely empty the rectum due to impaired voluntary defecation or if there is difficulty opening the anal sphincter during defecation.

Impact on daily life

Bowel dysfunction can have a considerable impact on daily life. Bladder and bowel dysfunctions were rated by people with MS as the third most important symptoms (after spasticity and incoordination) that limited their ability to work. Bowel disorders also have a psychosocial impact, involving disturbed sleep, acute discomfort and

anxiety, and the avoidance of social situations. Bowel problems may also exacerbate lower limb spasticity and urinary disorders.

How are problems diagnosed?

Diagnosis is based on systematic screening: bowel frequency, stool consistency, faecal incontinence, manoeuvres needed to achieve bowel management, complete lists of medication, and diet habits. The Expanded Disability Status Scale score is not sufficient to evaluate these disorders precisely and there is no validated bowel questionnaire in MS. However, health care professionals can use the Neurogenic Bowel Dysfunction Score, the Cleveland Constipation Score, or the St Mark's Incontinence Score to make an assessment of bowel problems in MS.

Clinical examination includes a thorough assessment of the pelvic floor for sensitivity, voluntary movement, anal sphincter and reflexes. Assessment of stool transit time involves abdominal radiography a few days after the ingestion of markers which are visible on a radiograph. If transit time is normal, there will be very few markers visible. A slow transit time is shown by many visible markers, as these have not been defecated. An anorectal manometry assesses continence and defecation by measuring the pressures of the anal sphincter at rest and during straining, and also the sensation in the rectum. When rectal sensation is reduced, stools may leak before the anal sphincter contracts. A reduced capacity may cause symptoms of rectal urgency and frequent defecation. Defecography (or dynamic proctography) is when anus and rectum anatomy and pelvic floor motion is recorded while a person is at rest, coughing, and straining to expel barium from the rectum. A pelvic MRI is the only imaging system that can visualise anorectal anatomy and pelvic floor motion without exposure to radiation.

Conclusion

Bowel dysfunction is frequent in MS, occurring secondary to a change to the autonomic nervous system, reduced mobility and from the side effects of medications. Systematic clinical screening is vital to determine the main problems and therefore find appropriate treatment.



Treating bladder and bowel problems

Noreen Barker, MS Clinical Nurse Specialist, National Hospital for Neurology and Neurosurgery, Queen Square, UK

Bladder and bowel issues are two MS symptoms for which we have a variety of effective interventions and treatments. Lifestyle changes such as altering fluid intake, diet or routine can be very effective. Medications and treatments can also help alleviate symptoms. Individuals may have to try a few options to find the most effective treatment plan for them.

Lifestyle changes

Many people, whether they have MS or not, may try to reduce their fluid intake or diet in order to avoid bladder or bowel problems. Unfortunately this makes the symptoms worse. It is often believed that if fluid intake is reduced, the bladder will empty less frequently. But, in reality, urine becomes more concentrated and the bladder becomes irritated. Over time this causes the bladder to reduce its capacity, causing increased urgency and frequency.

Correct fluid intake varies depending on a person's weight, build and activity, but generally an intake of around eight to ten cups of fluid a



Whole grain foods are a good source of fibre.

day is recommended. It is best to avoid highly caffeinated, coloured, carbonated or acidic drinks. Instead water, flavoured water, fruit teas, less acidic fruit juices (for example, pineapple), and decaffeinated tea or coffee are preferable. A 200ml (6.5oz) glass of cranberry juice a day has been shown by anecdotal evidence to reduce the incidence of urinary tract infections, but larger volumes should be avoided.

A varied, healthy diet, rich in fibre, is essential to avoid constipation, which can exacerbate bladder and bowel symptoms. Fibre can be increased by eating whole grain cereals, bread and pasta, beans, pulses or legumes, nuts and seeds such as flaxseeds or linseeds. Dried fruits, prune juice and aloe vera juice are also known to be effective. Balancing a high-fibre diet with good fluid intake is essential to prevent further complications.

Correct positioning on the toilet and allowing enough time to effectively empty the bladder or bowel is vital. For women, sitting on the toilet rather than hovering over it will help the bladder to empty better. Applying gentle abdominal pressure or double voiding (trying to empty a second time, after finishing voiding) can also help. Correct positioning will also allow easier



Cranberry juice may help reduce the incidence of urinary tract infections.

evacuation of stool. The body's natural posture for opening the bowels is the squat, however this is no longer the position commonly adopted in many countries. It may help to sit with knees higher than the hips, either applying slight pressure to the abdomen with hands, or bearing down gently by making a fist and blowing against it as though blowing up a balloon.

Using the gastro colic reflex (which is when eating and drinking stimulate the gut to move food through the digestive system) can help establish a regular routine for managing the bowel, and reduce the likelihood of faecal incontinence. Simple routine changes such as eating breakfast regularly, and then allowing time to evacuate bowels afterwards (optimum time 20 minutes), can help reduce problems with constipation.

Being aware of how frequently you need to void, and any triggers (such as temperature or "key in the door") is essential. Frequency of urination can be very individual. Avoiding "just in case" voids when the bladder has recently emptied, bladder retraining (encouraging the bladder to fill by holding on for a few extra minutes), and pelvic floor muscle exercises (see page 20) can all be beneficial in reducing frequency and urgency symptoms. Many charities provide "Just Can't Wait" cards which can be used to access toilets speedily when out, and in some countries a universal key which opens all locked public toilets is made available to people with bladder and bowel problems. Check with your MS organisation (find yours at www.msif.org) about what is available in your country.

Pharmacological treatments

Pharmacological treatments can be added to lifestyle changes to improve urinary urgency and frequency. First line treatment is anti-muscarinic medications (see page 14) that work by blocking certain nerve impulses to the bladder, which relax the bladder muscle and increase capacity. These treatments can be effective within a few weeks, but have side effects which some people may find intolerable.

More recently mirabegron (Betmiga, Myrbetriq, Betanis) has been launched in some countries –



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this has a different mode of action and side effects, but similar efficacy. While these medications for overactive bladder may be very effective on frequency and urgency, they may compromise bladder emptying.

There are also medications used to facilitate bladder emptying that are mostly used off-label, although the evidence supporting their efficacy is not strong in MS. It is essential that bladder emptying is assessed prior to starting on these medications, and routinely afterwards, especially if symptoms worsen.

Medications to treat constipation and faecal urgency are often helpful (see page 13) when lifestyle changes alone cannot improve symptoms. These should be used after a thorough assessment however, as constipation with overflow can be mistaken for faecal incontinence, and should be reviewed regularly to avoid unnecessary medication use and to ensure effective dosage.

Non-surgical treatments

Pelvic floor muscle exercises and bio feedback can be used to strengthen pelvic floor muscles to treat urinary stress incontinence, and to improve pelvic floor muscle control to reduce urinary urgency. Pelvic floor muscle exercises and anal sphincter exercises also help improve control during faecal urgency. Percutaneous tibial nerve stimulation can be used for both urinary and faecal incontinence.

Bowel medications

Bisacodyl

Dose: 5-10mg at night.

Mode of action: stimulant laxative, increases intestinal motility.

Adverse effects: abdominal cramps, nausea and vomiting.

Codeine phosphate

Dose: 30mg 3-4 times daily.

Mode of action: prolongs duration of intestinal transit to reduce viscosity of stool.

Adverse effects: abdominal pain, anorexia, seizures, malaise.

Glycerin suppositories

Dose: 1 suppository as required.

Mode of action: rectal stimulant due to mildly irritant action of glycerol.

Isphagula husk

Dose: 3.5mg sachet 1-3 times daily.

Mode of action: bulk forming laxative, increases faecal mass, stimulating peristalsis.

Adverse effects: flatulence, abdominal distension, gastrointestinal obstruction or impaction, hypersensitivity.

Lactulose

Dose: 15ml twice daily.

Mode of action: osmotic laxative, increases the amount of water in the large bowel, drawing water from the body into the bowel.

Adverse effects: nausea, vomiting, flatulence, abdominal cramps, abdominal discomfort.

Loperamide hydrochloride

Dose: 500mcg daily (max of 16mg in divided doses).

Mode of action: prolongs duration of intestinal transit.

Adverse effects: abdominal cramps, dizziness, drowsiness, urticaria, paralytic ileus, abdominal bloating.

Macrogols

Dose: 1-3 sachets daily in divided doses in 125ml water.

Mode of action: osmotic laxative, increases the amount of water in the large bowel, retaining the fluid they were administered with.

Adverse effects: abdominal distension and pain, nausea, flatulence.

Methylcellulose

Dose: 500mg 3-6 tablets twice daily.

Mode of action: bulk forming laxative, increases faecal mass, stimulating peristalsis.

Adverse effects: flatulence, abdominal distension, gastrointestinal obstruction or impaction, hypersensitivity.

Phosphate enema

Dose: 118ml dose, as required.

Mode of action: rectal stimulant.

Side effects: local irritation, electrolyte disturbance.

Senna

Dose: 7.5mg 2-4 tablets at night. Or 1-2 level 5ml spoons of granules with 150ml water.

Mode of action: stimulant laxative, increases intestinal motility.

Adverse effects: abdominal cramps, plus nausea and vomiting.

Sodium picosulphate

Dose: 5-10mg at night.

Mode of action: stimulant laxative, increases intestinal motility.

Adverse effects: abdominal cramps, plus nausea and vomiting.

Sterculia

Dose: 7g sachet, 1-2 washed down with plenty of fluids without chewing.

Mode of action: bulk forming laxative, increases faecal mass, stimulating peristalsis.

Adverse effects: flatulence, abdominal distension, gastrointestinal obstruction or impaction, hypersensitivity.



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Medications for overactive bladder symptoms

Generic name (trade names)	Dose	Mode of action	Side effects
Darifenacin (Emselex, Enablex)	7.5-15mg once daily	Blocks the activity of the muscarinic acetylcholine receptor	Dry mouth, nausea, constipation, blurred vision, dizziness
Duloxetine (Yentreve, Cymbalta)	40mg twice daily (20mg twice daily for two weeks can reduce side effects)	Inhibitor of serotonin and noradrenalin re-uptake	Nausea, vomiting, dyspepsia, constipation, diarrhoea, abdominal pain, abnormal dreams, weight gain, decreased appetite, flatulence, dry mouth, palpitation, hot flush, anorexia, insomnia, paraesthesia, drowsiness, anxiety, headache, dizziness, fatigue, tremor, nervousness, sexual dysfunction, visual disturbances
Fesoterodine Fumarate (Toviaz)	4mg once daily, to maximum of 8mg	Blocks the activity of the muscarinic acetylcholine receptor	Dry mouth, constipation, nausea, abdominal pain, also insomnia, nasal dryness (less common), pharyngolaryngeal pain, cough, vertigo
Mirabegron (Betmiga, Myrbetriq)	50mg once daily	Beta 3 adrenergic agonist on smooth muscle	Cold symptoms, mild headache (common), tachycardia, UTI, palpitations, dyspepsia, cystitis (less common)
Oxybutynin (Ditropan, Cystrin)	5mg 2-3 times daily	Direct relaxant effect on urinary smooth muscle	Dry mouth, GI disturbance, nausea, flatulence, blurred vision, dry eyes, dizziness, difficulty in voiding, palpitations, fatigue
Oxybutynin SR	5-20mg once daily by mouth		
Oxybutynin (Kentera, Oxytrol) (transdermal patch)	36mg 3.9mg/24hrs (one patch twice weekly)	Direct relaxant effect on urinary smooth muscle	As above, with rash or itching beneath patch
Propiverine Hydrochloride (Detrunorm)	15mg 1-3 times daily	Direct relaxant effect on urinary smooth muscle	Dry mouth, blurred vision, drowsiness, tiredness
Solifenacin Succinate (Vesicare)	5-10mg once daily	Reduces smooth muscle tone in the bladder	As oxybutynin, also gastro-oesophageal reflux, oedema
Tolterodine Tartrate (Detrusitol, Detrol)	1-2mg twice daily	Direct relaxant effect on urinary smooth muscle	As above, with chest pain, peripheral oedema, sinusitis, paraesthesia, vertigo, weight gain, flushing, memory impairment (less common)
Tolterodine XL (Detrusitol XL)	4mg once daily		
Trospium Chloride (Regurin, Sanctura)	20mg twice daily	Reduces smooth muscle tone in the bladder	Dry mouth, nausea, constipation, abdominal pain, chest pain, dyspnoea (rarely), myalgia, arthralgia (very rarely)
Trospium Chloride XL	60mg once daily		

Please note: some brand names are listed after each generic name but these vary from country to country. Check with your health care professional about what is available in your country.

This treatment involves inserting a fine needle into the tibial nerve just above the ankle. An electrode is placed on the foot and a mild electric current is passed through to stimulate the tibial nerve. This stimulation sends signals back to the nerves controlling the bladder and pelvic floor muscles. The treatment usually consists of 12 sessions, once a week, lasting 30 minutes.

Trans anal irrigation is a relatively new treatment that facilitates the evacuation of stools from the bowel by introducing water into the colon via the anus. It is thought to result in the emptying of the descending colon, sigmoid colon and rectum and can be conducted over the toilet. Some people find it helps manage both chronic constipation and faecal incontinence.

Invasive treatments

Where lifestyle changes and conservative treatments have been unsuccessful there are now a number of surgical treatments options. Botulinum toxin (Botox, Xeomin, Dysport, Myobloc, Neurobloc) is a neurotoxin which, when injected into sections of the bladder muscle under general or local anaesthetic, relaxes the muscular bladder wall, reducing over-activity. It lasts for about nine months, after which the procedure needs to be repeated.

Sacral nerve stimulation, where a small device is implanted surgically to stimulate the sacral nerve with mild electrical impulses, has been shown to improve urinary urgency, frequency and retention, and both urinary and faecal incontinence. However the evidence for its success in people with MS is limited.

More invasive surgical procedures such as bladder augmentation (where a piece of small intestine is inserted into the bladder, increasing capacity and stability), continent urinary diversions (where a catheterisable channel from the bladder is diverted to the abdomen) and urostomy (surgery to divert urine from the ureters through a detached section of the small intestine and out an opening in the abdomen and into a bag) are not common in MS. If faecal incontinence is due to a damaged or weak anal sphincter, a sphincter repair operation could

be beneficial. Formation of a colostomy (where a portion of the colon is diverted to the surface of the abdomen and out an opening which is covered by a pouch to collect waste products) is now rarely performed due to improvements in less invasive treatments.

Urinary catheterisation

In urinary catheterisation, a catheter (hollow tube) is inserted into the bladder to drain or collect urine. There are two main types of urinary catheterisation: clean intermittent catheterisation (CIC) and indwelling catheterisation. CIC is when the catheter is passed into the bladder and then removed once the bladder is empty. CIC can be performed regularly or at timed intervals to aid complete emptying. Many people with MS learn to self-catheterise using this technique. A caregiver can also perform the technique on a person with MS. CIC is often used in conjunction with anti-muscarinic medications and Botulinum toxin to effectively manage the bladder. There are a wide range of catheters available, each with pros and cons. MS health care professionals can help people with MS better understand the available options.

Indwelling urinary catheters are a more invasive alternative and used in carefully identified individuals. Indwelling catheters are placed either via the urethra (urethral catheter) or via a small incision on the abdomen (supra pubic catheter). Depending on the material, they can remain in place for up to 12 weeks before they need to be changed. They can be connected to leg bags (on free drainage) or catheter valves (which allow the bladder to fill and empty, mimicking normal bladder emptying). They can be an effective form of bladder management and can facilitate independence, but can cause an increased risk of infection, bladder stones, bypassing, spasms and body image concerns.

Conclusion

Today there are many ways that bladder and bowel symptoms can be treated, reduced or managed more effectively. Many are simple changes that anyone can make, or treatments accessed via a doctor, MS nurse or neurologist. These can help stop symptoms being troublesome, reduce anxiety and allow people with MS to live life to the full.

Role of rehabilitation in managing bladder and bowel problems in MS

Michael Whishaw, Consultant Continence Physician, Royal Melbourne Hospital, Victoria, Australia

Bladder and bowel symptoms occur in the majority of people with MS, usually as a consequence of the disease. Symptoms can vary in degree, be very bothersome, and can impact on medical, physical, psychological and social well-being, profoundly affecting quality of life. Sometimes just the fear of leakage or soiling can be disabling.

Fortunately, bladder and bowel symptoms can usually be improved or resolved with appropriate treatment. There are many health care professionals providing individualised care in the area of continence promotion and the management of bladder and bowel symptoms. They include urologists, urogynaecologists, geriatricians, gastroenterologists, colo-rectal surgeons, pelvic floor physiotherapists, continence/urology nurses, specialised clinics and rehabilitation teams.

Rehabilitation aims to maximise the independence of individuals in the home, work and social environment by taking a holistic and person-centred approach, focussing on medical, physical, psychological and social well-being. All health-related issues are addressed, including bladder and bowel problems. Individualised goals are critical to successful outcomes, and all members of the rehabilitation team may be involved in a person's care plan.

It is well known that many people with MS have difficulty discussing bladder and bowel problems with health care professionals, including their rehabilitation team. It is important that all health care professionals initiate a conversation about these symptoms in a sensitive, proactive manner to screen for symptoms, to understand how bothersome they are, and the impact they have. It is possible that some people with MS may have sought treatment

in the past, without satisfactory resolution, so encouragement to revisit a problem is important too. Engaging in the conversation about bladder and bowel function is the most important aspect to achieving long-term benefit following the initiation of treatment. Members of the rehabilitation team are well-placed to provide care as they may have contact with people with MS during hospital stays, outpatient clinics/services or home-based visits.

An assessment comprising history and physical examination by a doctor and/or nurse is paramount, and includes information about diet, fluid intake, previous treatments and their effects, how symptoms have been coped with, as well as degree of bother and impact on quality of life. A focus on both bladder and bowel function is important as one can impact the other. Constipation for example, may make bladder symptoms worse, and effective constipation treatment may even normalise these.

Once the assessment is complete, a full explanation of the issues, and recommended treatment plan, including any potential treatment side-effects should be given. There are a range of treatments available to improve bladder and bowel symptoms. The medical and nursing team are able to monitor the person's response to treatment, modifying it as required.

Where strategies to modify fluid intake and dietary fibre have been unsuccessful to improve bladder and bowel problems, the advice of a dietician may be sought.

Urinary and faecal incontinence or fear of leakage or soiling can have a profound impact on a person with MS. An appropriate continence product can

improve quality of life immensely and for some may mean the difference between leaving the house and maintaining regular employment. Products include disposable or washable undergarments, absorbent products for chairs, beds and floors, all of which are beneficial for home-use, work and travel. Appliances such as bottles to urinate in and urinary sheaths are particularly useful for men. Advice about the best product for individual needs can be provided by a rehabilitation nurse, continence nurse or urology nurse specialist. In some services, this advice may be provided by an occupational therapist (OT). Nurses and OTs will also have information about any national or local funding schemes that help finance access to these products.

Symptoms caused by bladder emptying problems may be best treated with clean intermittent self catheterisation (CIC). A rehabilitation nurse, continence nurse or urology nurse can teach individuals to use CIC at home. CIC is usually performed by the person with MS, but can also be done by a partner or carer. Although the notion of performing CIC may be daunting at first, the

initiation of CIC can have a profoundly positive effect on symptoms and quality of life. Where CIC is not feasible, an indwelling catheter can be considered (see page 15 for more details).

It is important to assess all aspects of toileting. Rehabilitation physiotherapists (PT) and OTs are able to establish whether problems such as spasticity, mobility, dexterity or bathroom layout contribute to any issues with toileting. These problems, along with bladder or bowel urgency and frequent toileting during the day or night, add to the level of fatigue, a commonly experienced symptom for people with MS. These symptoms also cause significant psychological stress. Rehabilitation PTs and OTs are able to treat or optimise these movement-based symptoms and suggest bathroom modifications to improve the safety and ease of toileting.

Modifications may include the use of hand rails, bath seats, mats, shower chairs and hoses. In the home setting, recommendations may be made for structural modifications, especially for those in wheelchairs or who use wheeled walkers. For



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Rehabilitation specialists may suggest modifications such as hand rails for people with mobility problems.

some, the use of a bedside urinal or commode may be helpful.

An OT can recommend changes to clothing, or clothing adjustments such as the avoidance of multiple clothing layers, excessive buttons and zips to facilitate quick access to a toilet. This is especially helpful for individuals with bladder or bowel urgency.

A social worker and OT are often also able to advocate and make recommendations to facilitate toileting, toilet access and mobility in the workplace. In some countries, relevant organisations have information on where to find accessible public toilets to make socialisation and travel easier.

A psychologist is also an integral part of the rehabilitation team. They can help a person with MS learn strategies to cope with some of the challenges confronted throughout the course of the disease, including some of the social difficulties caused by bladder and bowel symptoms.

In summary, rehabilitation team members can positively impact on an individual's quality of life through bladder and bowel assessment and management. In the event that continence issues cannot be adequately defined and managed, it may be necessary to refer to a continence specialist for further assessment and investigation.

Urinary diary

Name: _____ Date: _____ to _____

Day/time:	Amount voided*:	Amount of urine leaked*:	Urgency present?	Hesitancy present?	Amount and type of fluid consumed
			Yes/No	Yes/No	
			Yes/No	Yes/No	
			Yes/No	Yes/No	
			Yes/No	Yes/No	
			Yes/No	Yes/No	
			Yes/No	Yes/No	
			Yes/No	Yes/No	

* Amounts estimated based on a measurement (for example, teaspoon, drinking glass) agreed between the individual and health care professional.

Self-management of bladder and bowel problems

Marie Namey, Clinical Nurse Specialist, Mellen Center, Cleveland Clinic, Ohio, USA

Often people do not think about bladder or bowel habits, but when patterns change, there is more awareness and focus on these bodily functions. Many things can cause these changes, including MS.

MS-related bladder and bowel symptoms can cause discomfort, incontinence, embarrassment and social isolation, increased expenses for incontinence products, and complications such as skin irritation and bladder infections. Bladder infections can also lead to a worsening of MS symptoms. These symptoms should not just be attributed to normal ageing.

Bladder and bowel dysfunction are common symptoms for people with MS at all stages of the disease, but particularly as mobility becomes impaired. However they are not necessarily limiting to a person's lifestyle. There are many excellent treatment options available, including behavioural and dietary approaches that can help reduce symptoms. It is important to share any

bladder and bowel concerns with a health care professional, and, if they are not able to help, to seek a referral to someone who can.

Self-management of the bladder

In general, urinating every two to three hours – or an average of six to seven times – during the daytime is normal. Most people are able to sleep six to eight hours a night without needing to get up to urinate, although waking up to urinate once during the night is normal for many people, especially if they drink liquids right before going to bed.

People with MS can help take control of their bladder if they:

- Keep well hydrated by drinking 1.4-1.9 litres (48-64oz) of liquid a day.
- Void according to a schedule. Drink 180-240mls (6-8oz) of fluid at regular intervals and then urinate on a regular schedule rather than wait for the urge. It takes about 1½ hours for fluid to get to the bladder.
- Limit the amount of caffeinated beverages and alcohol as these can cause more frequent and urgent voiding.
- Stop smoking – this is a bladder irritant.
- Stop drinking fluids about two hours before bedtime and try to empty the bladder before going to bed.

There are many incontinence products (pads, briefs, adult nappies, underpads) designed to help control mild, moderate and severe symptoms. A bladder diary (see the example on page 18) may also help to identify underlying problems. The diary should detail the frequency and approximate amount of urination, as well as fluid volume and type.

Reduced mobility can lead to bladder and bowel dysfunction.

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Pelvic floor exercises

The pelvic floor is made up of muscles formed like a sling that attach to the front, back and sides of the pelvis. This group of muscles supports the bladder, the uterus, the prostate and the rectum, and coordination of these muscles helps control bladder function.

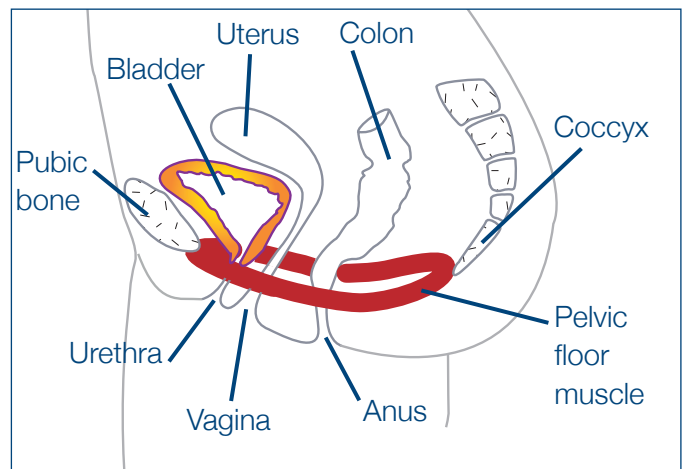
Pelvic floor exercises have been recommended to improve muscle tone and possibly decrease episodes of urinary incontinence. The exercises consist of repeatedly contracting and relaxing the muscles that form part of the pelvic floor.

Simple steps to exercise the pelvic floor:

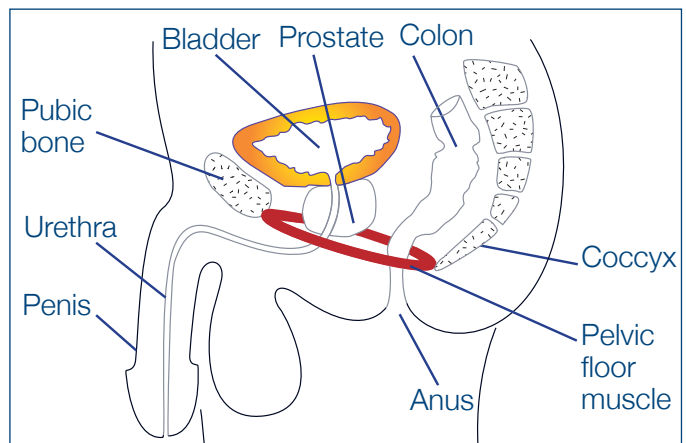
- First you must be able to find the right muscles. To identify your pelvic floor muscles, stop urination in midstream. If you succeed, you've got the right muscles.
- Empty the bladder before exercising.
- Practice tightening the pelvic floor muscles for 5-10 seconds at a time, 3-5 times a day.
- It is important to breathe regularly during the exercise.
- Concentrate on isolating the pelvic floor muscles, trying to avoid flexing the muscles in the buttocks, thighs and abdomen.
- Do not make a habit of using pelvic floor exercises to start and stop your urine stream as this can actually weaken the muscles. It may also lead to incomplete emptying of the bladder, which increases the risk of a urinary tract infection.

Urinary tract infections

It is also important that people with MS are aware of the changes caused by a urinary tract or bladder infection (see page 8 for symptoms). Bladder infections can often cause a change in bladder habits. An infection could cause an increase in stiffness, spasms or fatigue or a person might feel as if they are experiencing an MS attack. A health care professional should be contacted if an infection is suspected.



Female pelvic floor muscles



Male pelvic floor muscles

Self-management of bowel dysfunction

Bowel problems can be a source of embarrassment and discomfort, so it is very important to work with health care professionals to evaluate the cause of the problem and to find solutions.

For predictability of bowel habits, fluid, dietary fibre and regular activity are fundamental. The goal is to have a comfortable bowel movement every day or every other day. A mild laxative can be used if there has not been a bowel movement in 3-4 days.

Here are some simple steps to increase bowel regularity:

- Eat regularly for regular bowel habits.
- Drink at least 6 to 8 glasses of fluids daily. Increasing fluid intake is an important first step in avoiding constipation.
- Increase fibre intake to at least 25-35 grams per day. Natural fibre can be obtained from fresh vegetables and fruits, and cereals and breads made with whole grains. A dietary fibre supplement such as powdered psyllium may also help. Increased fibre intake needs to be accompanied by increased fluid intake; extra fibre without enough fluid can make constipation worse.
- Establish a regular time and schedule for bowel movements, with no more than 2-3 days between movements. Plan for a bowel movement each day about half an hour after eating or drinking something warm (the emptying reflex is strongest at this time). Sit on the toilet for about 10 minutes and try to have a bowel movement. Rocking gently back and forth on the toilet can be helpful for some people. If nothing happens, leave the toilet and try again later.
- Use of stool softeners, enemas, suppositories and laxatives in moderation can help with bowel movements (after consulting a health care professional).

- If bowel incontinence or trouble pushing the stool out is experienced, a glycerin suppository can be helpful to stimulate bowel activity. It takes about 20 minutes after inserting the suppository along the rectal wall to activate the bowels.
- The bowels are creatures of habit so once a regular routine is working it should be maintained.
- Complete a bowel diary (based on the urinary diary on page 18). A record of fluid and food intake as well as any changes in bowel habits can point to any dietary or behavioural factors that may be contributing to elimination symptoms. Including the amount of activity or exercise can be helpful too.

Bladder and bowel symptoms are common in MS and can be effectively managed. In general the goals for bladder and bowel management include maximising independence and preventing incontinence, infections and other complications. It is much easier to prevent bladder and bowel problems by establishing good habits, rather than dealing with complications later on.

Like other MS symptoms, bladder and bowel problems vary from person to person. It is important to have an assessment and develop a plan that addresses an individual's particular symptoms.



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Bladder and bowel survey results

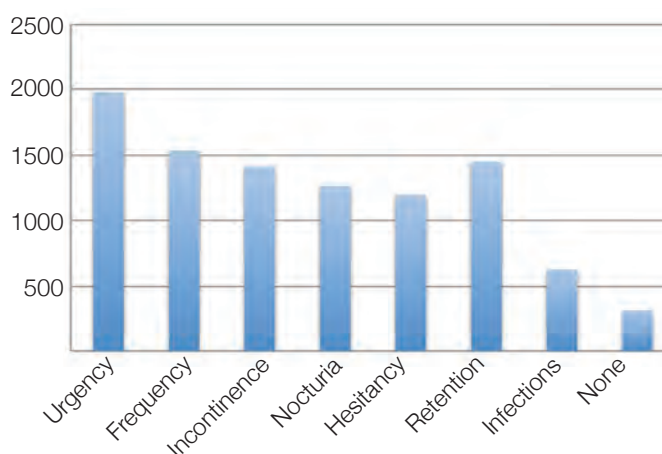
A total of 3,578 people from 73 countries took the online bladder and bowel survey during March 2014 in English, French or Portuguese.

The majority of respondents were aged in their 50s (29%) or 40s (28%), with 19% in their 30s. Three quarters were female, and more than half had relapsing-remitting MS. 20% had secondary progressive MS, 11% had primary progressive MS, 10% were unsure and 6% had progressive relapsing MS.

Urinary issues

Urgency was the most common urinary problem reported, followed by frequent urination and retention. Only 3% of respondents reported no urinary problems.

Common urinary problems



“My bladder function is difficult and can be distressing, but is much easier now I manage it with self catheterisation.”

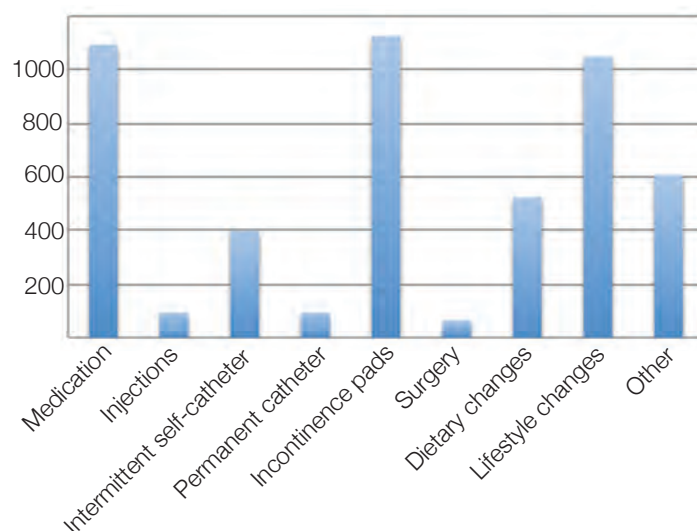
The majority of respondents had been tested for urinary problems (63%). For those who had not been tested, 35% had not talked to their neurologist about their urinary problems. A quarter said their neurologist thought testing was unnecessary and a further quarter preferred to manage their urinary symptoms on their own.

“Sometimes I have to urinate, but cannot immediately. I have to concentrate to be able to urinate.”

“This has become an additional isolating factor. I’ll be fine for weeks and then I have absolutely no control for a couple of days (like today).”

The most common methods for managing urinary problems were incontinence pads (22%), medication (22%) and lifestyle changes (21%).

Management of urinary problems

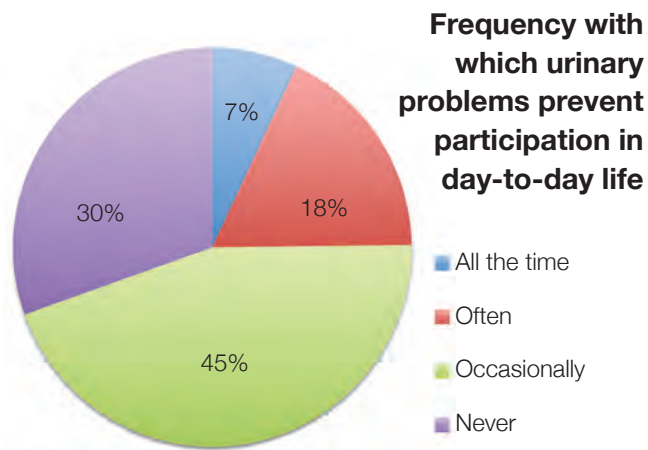


The majority of respondents were partially satisfied (55%) with the management of their urinary problems, 26% were satisfied and 19% unsatisfied.

“I have used Botox the past 10 years; amazing results! Without Botox I would experience many of the problems listed.”

Almost half of respondents (48%) had not seen a urologist about their urinary problems. 29% had been referred to a urologist by their neurologist, and 16% had been referred by another type of doctor. 7% had seen a urologist on their own initiative.

The majority of respondents reported that urinary issues affected daily life “occasionally” (45%).



“Doctors of all specialisms tend to think that because I’ve got MS there is nothing they can do and they quickly discharge me.”

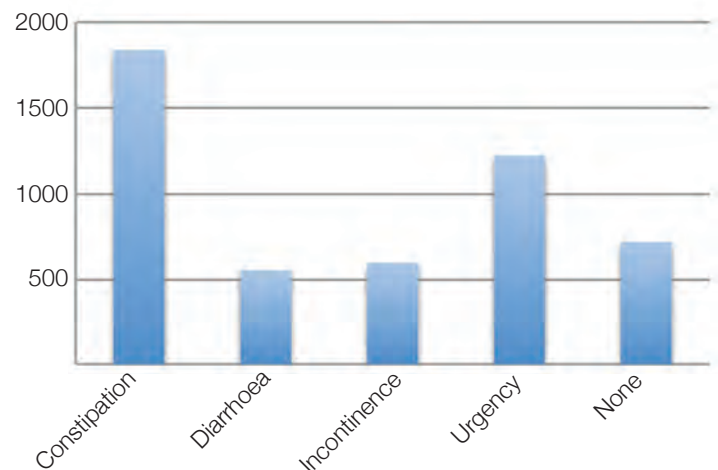
“I can now get through the night without weeing and can manage longish car journeys.”

Most respondents (41%) did not think urinary problems affected their other MS symptoms and 37% were unsure. The remaining 22% said that urinary problems did affect their other symptoms.

Bowel problems

The most common bowel symptoms reported were constipation (37%) and bowel urgency (25%).

Common bowel problems



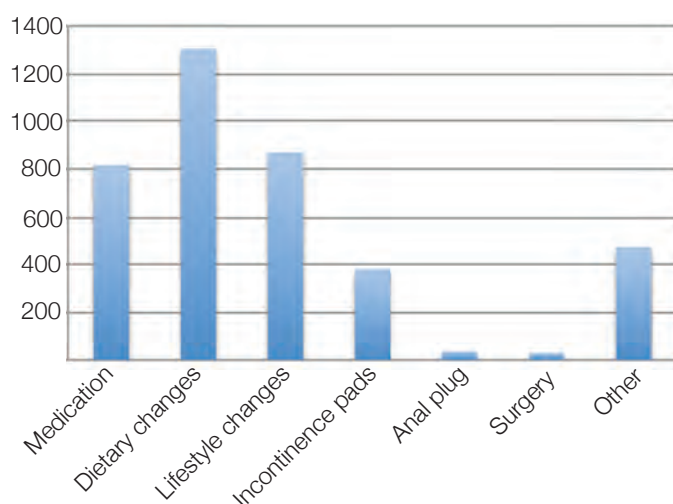
Open communication with health care professionals is the first step to successful management of bladder and bowel problems.

Three quarters of those surveyed had not been tested for bowel problems. The main reasons were not having talked to their neurologist about their bowel issues (41%) and preferring to self-manage the symptom (35%).

“I find this is a very tricky symptom to bring up with the neurologist.”

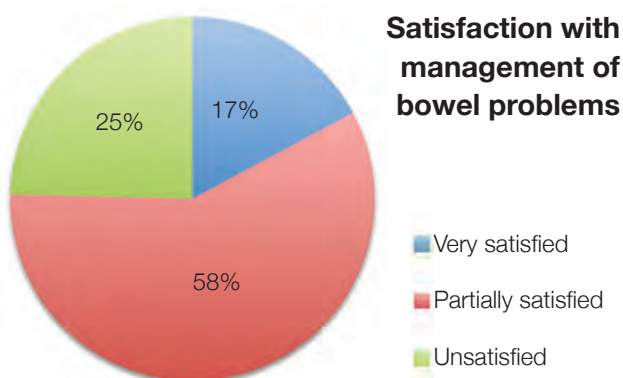
A third of respondents used dietary changes to manage bowel symptoms, 22% made lifestyle changes and 21% used medication.

Management of bowel problems



Most respondents (73%) had not been referred to a gastroenterologist for their bowel problems. Only 6% had been referred by their neurologist, 14% by another doctor, and 7% had seen an gastroenterologist on their own initiative.

The majority of respondents reported that they were “partially” satisfied with the management of their bowel problems.



“Dietary change to whole fruit and grains, with the addition of a probiotic supplement, seems to have alleviated what had been a lifetime problem. I have had no problems for the last year.”

18% of respondents reported that bowel problems impacted on day-to-day life (work, study, socialising, family, hobbies and interests) “often” or “all the time”, 48% said “occasionally” and 34% said “never”.

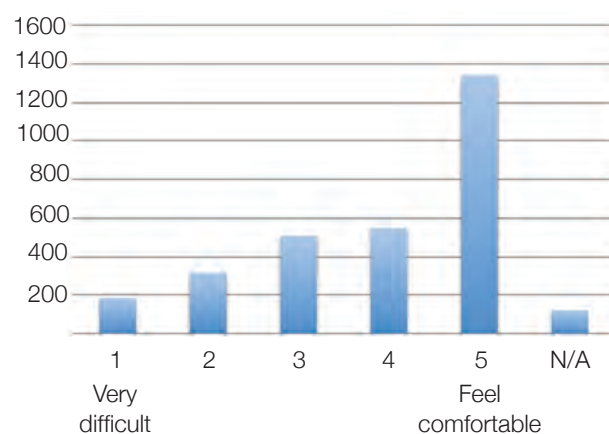
A large number of respondents were unsure whether bowel problems impacted on their other MS symptoms (40%) and 20% felt that there was a negative impact on other MS-related problems.

Information and support

While a large number of respondents did not use many sources of information on this topic, neurologists, MS nurses and MS organisations were found to be the most helpful.

The majority of respondents felt relatively comfortable discussing bladder and bowel problems with health care professionals, although a significant number found it difficult and embarrassing.

Comfort level when talking about bladder and bowel problems with health care professionals



Your questions answered

Q. Is there any chance of getting the use of my bladder back without having to use a catheter every time?

A. For many people with MS, self-catheterisation is a rehabilitation technique for bladder retraining, with the objective being to improve bladder symptoms so that the need to self-catheterise can be reduced or even eliminated in some cases. It really depends on your specific situation, including how long you've been doing self-catheterisation. If possible, it would be helpful to talk to your MS nurse, neurologist or rehabilitation professional to ask more about this.

Q. I have had MS for 5 years. In the past year, I have had difficulty controlling my bladder. Sometimes I cannot make it to the bathroom in time. Other times, I feel that I cannot fully empty my bladder, and I feel the need to void again ten minutes later. I have to get up three times at night to go to the bathroom. I am sometimes reluctant to go to social events because of this. I have found that these problems improve when I don't drink as much water. Is there medication to fix this?

A. These problems may be caused by a mix of over activity of the bladder muscle and abnormal sphincter control (sometimes opens too early, sometimes does not open enough). Restricting fluid intake is not a good idea because it increases the risk of urinary tract infections and may lead to dehydration. Medication that relaxes the bladder muscle could make the retention worse and also cause infections. It is advised that you seek further testing to better understand the mechanisms at the root of your symptoms in order to determine the best treatment approach.

Q. Besides fatigue, bladder control is my longest-lasting, consistently irritating and most life-limiting problem. I have tried many bladder control medications – the last one lead to memory loss. I exercise but find that my stomach muscles are resistant to strengthening. Is there any recent research about e-stim or tens units that successfully help strengthen the pelvic muscles, and therefore, lead to bladder control?

A. The research regarding TENs machines and bladder management remains inconclusive. Existing trials include few subjects and while some feel it helps, it is certainly not a common bladder management strategy for people with MS. However, it is generally well tolerated and largely without side-effects compared to the anti-cholinergic medications. Alternatives include pelvic floor exercises (see page 20) and Botulinum toxin which reduces an overactive bladder. Many people with MS say it has given them their life back. You do need to be able to self-catheterise to have this treatment, and it needs to be repeated every 8-12 months.

Q. I am 63 year old man with PPMS. I have had bladder issues for a long time now which are complicated by my restricted mobility. The problem seems to be getting worse although physically I am fairly stable. Is this a sign my MS is progressing?

A. While the symptoms of MS can change over time it is important not to always think any change is due to the MS. It is suggested that you see your doctor and have tests done to check for non-MS related problems like an infection or prostate problem.

Interview with Helga from Iceland

About Helga

I am a 42-year-old housewife and I live in Akranes, near Reykjavík, the capital city of Iceland. I live with my husband and daughter. I was a cashier in a bank but have not worked since my first MS attack in February 2009 when I became very sick. I have relapsing-remitting MS and my main symptoms are bladder dysfunction, slight bowel problems, blurred vision, neuropathic pain and fatigue.

I try to eat healthy food and keep as fit as I can because I seem to recover better from relapses if I do. I love cycling and mountain climbing in the summer. I also love metabolic training when my symptoms are not flaring up. I do a lot of knitting and crochet and I love music. My husband and I are in a local church choir and this has always kept me going mentally and done wonders for my sanity when times have been rough. I studied singing in the local music school, but have had to take the last two years off. I am aiming to start again next autumn. Before I got ill I trained in karate, which I loved and miss dearly, and I hope that one day I will be able to return to that sport.

When did you first notice bladder problems?

I've had problems with bladder infections from a young age. During my first MS episode I was hospitalised for five days. At first the doctor thought I was having an embolism, but it was soon ruled out. For those five days I could hardly sleep because I felt that I had to go to the toilet every 15-30 minutes. The doctors thought that it was peculiar since I didn't have a bladder infection. I had a balloon endoscopy which revealed that something was seriously wrong, so I was referred to a urologist. After an initial interview and some tests he said that I had MS. I was not surprised because a year before this, I'd seen a neurologist because of numbness in my face and a strange toothache.

How do you manage your bladder problems?

When it became clear that my bladder was not recovering, I started to self-catheterise twice a day to empty my bladder completely. I also



had two drugs to help me with cramps and the overactive feeling I had all the time. Fesoterodine (Toviaz) really helped and after 18 months of self-catheterising I was finally able to wean myself off the drug. I also use tamsulosin (Omnic) to help with the muscle tension, and a natural remedy called SagaPro™. I really believe that it is doing wonders for my bladder, which was confirmed at my last endoscopy. I still get flare-ups and have to use the catheter once in a while but the urge to go to the toilet during the night has reduced a lot. I also take SagaPro™ during the day if I am going hiking and it helps to ease the tension.

Do bladder issues affect your day-to-day life?

At the beginning it was difficult – I felt I couldn't go anywhere. But as time went by I got the hang of it and it didn't bother me as much. I do not panic now about finding a bathroom as soon as I go to a new place. Because I cannot feel when my bladder is full, I make sure I go to the bathroom every 3-4 hours and if I do this, I seem to be okay. My husband is very understanding and helpful and this has not had any negative effect on our love life. I try hard not to let my bladder problems stand in my way – I am an optimist and I am sure that helps.

MSIF member organisations

Argentina: Esclerosis Múltiple Argentina
info@ema.org.ar www.ema.org.ar

Australia: MS Australia
info@msaustralia.org.au
www.msaustralia.org.au

Austria: Multiple Sklerose Gesellschaft Österreich
msgoe@gmx.net www.msgoe.at

Belgium: Ligue Nationale Belge de la Sclérose en Plaques/Nationale Belgische Multiple Sclerose Liga
ms.sep@ms-sep.be www.ms-sep.be

Brazil: Associação Brasileira de Esclerose Múltipla
abem@abem.org.br www.abem.org.br

Canada: MS Society of Canada/Société canadienne de la sclérose en plaques
info@mssociety.ca www.mssociety.ca
www.scleroseenplaques.ca

Cyprus: Cyprus Multiple Sclerosis Association
multipscy@cytanet.com.cy
www.msccyprus.org

Czech Republic: Unie Roska česká MS společnost
roska@roska.eu www.roska.eu

Denmark: Scleroseforeningen
info@scleroseforeningen.dk
www.scleroseforeningen.dk

Estonia: Eesti Sclerosis Multiplex'i Ühingute Liit
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