

Factsheet

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Bowel Management in MSA

How the digestive system works

The digestive system runs from your mouth to your rectum (back passage). It serves two main functions:

- 1. The breakdown of food into small parts that the body can use
- 2. The disposal of unusable food.

The muscles in the digestive system walls rhythmically contract and squeeze the food through the system (a process called peristalsis). The stomach acts as a reservoir for the food, mixing it with acids and enzymes to start its breakdown.

The food then moves into the bowel which has two distinct parts, the small intestine and the large intestine. The small intestine absorbs the useful parts of the food into the blood



stream. The remaining food waste then passes through into the large intestine where water is reabsorbed and the faeces are stored until they pass out of the body through the rectum.

What do the autonomic nerves do?

The movement of food through the digestive system is controlled mainly by the autonomic nervous system. The autonomic nerves act to keep food moving steadily through the bowel to the rectum. Normally you are unaware of this process. These nerves also send messages to the bowel to enable us to eliminate faeces on a regular basis.

In conditions where the autonomic nerves are impaired, such as in MSA, the movement of food through the digestive system becomes disrupted.

The whole process becomes slower and can be uncomfortable and unpredictable. This slowing down results in more water than usual being reabsorbed by the colon.







This makes faeces hard and difficult to pass.

The slowing down can also cause bloating or cramp like pain. There may also be an urgent sensation of the need to go to the toilet or the sensation of needing to open the bowels can be reduced. Muscle weakness means pushing stool out can also be difficult.

Bowel problems and MSA

Constipation is the most common bowel problem experienced by people with MSA. However, a number of people with MSA will experience diarrhoea and some people have fluctuation between constipation and diarrhoea. These are discussed under the headings below:

Why does constipation occur?

There are a number of reasons why people with MSA are susceptible to developing constipation:

- 1. Often people with MSA have reduced mobility which limits being in a standing position and moving around. Moving around helps stimulate the bowel and encourages normal function.
- Resisting the feeling of needing to go to the toilet to open your bowels because it is difficult to get there at that time. Repeatedly doing this teaches the bowel to ignore the feeling of needing to go.
- 3. Poor positioning on the toilet; if the trunk muscles are working extra hard to help keep your balance on the toilet they can't work as well to help empty your bowel. An Occupational Therapist or Physiotherapist may be able to provide a raised toilet seat with back and arm support to help with this. If the toilet seat is raised, you may need a small step to rest your feet on whilst sitting on the toilet to maintain your balance.
- 4. Not allowing enough time to completely open your bowels; the muscles that are used may be weaker, so it takes longer to complete the process. Feeling rushed because you know a partner or carer are waiting to assist you after using the toilet may result in only partial clearance of the lower bowel/rectum, so you may still feel you need to go, even if you have passed some stool.
- 5. Not emptying the lower bowel on a regular basis can result in an increasing backlog of stool and chronic constipation occurring. If stool that is left behind fills the large bowel it becomes increasingly dried out. The bowel contents coming along behind this thencan't get into the part of the bowel that removes fluid from the contents, so it stays liquid and seeps down past the hard stool appearing as diarrhoea this is what is termed 'overflow' due to chronic constipation.
- 6. Presence of firm stool in the rectum stretches the bowel wall and this triggers the feeling of needing to go to the toilet. We need enough bulk in our stool for this trigger; but if there is a constant build-up of stool in the bowel it will lose its elasticity and feeling the need to go will only occur when the bowel is stretched even further.
- 7. The bowel needs plenty of liquid (aim for two litres a day) to keep the bowel movement soft and easy to pass people with MSA often struggle to drink adequately.
- 8. The sort of foods that can help stimulate the bowel and assist passing stool (e.g. fresh fruit and vegetables that provide natural fibre) are often difficult for people with MSA to eat enough of due to reduced appetite, fatigue, difficulty feeding yourself and swallowing difficulties. Puréed fruits, smoothies and porridge oats are all soft moist foods that may be more manageable and will help the bowel.
- **9.** The digestive tract is constantly moving from mouth to anus and carrying the food contents along.







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The autonomic nervous system is important in controlling this movement, increasing the speed of it and reducing the speed of it.

10. If the bowel is moving slower than normal, too much fluid is removed from the large bowel and you will be constipated. If it is moving faster than normal, not enough fluid is removed and you will experience episodes of diarrhoea. The autonomic system is also responsible for stimulating/suppressing the release of hormones and enzymes that affect how well our food is digested and how guickly it moves through our gut.

Other problems that can occur due to bowel problems

Straining on the toilet can cause a drop in blood pressure (postural hypotension) which is a problem that some people with MSA are prone to; particularly when they move from lying to sitting and from sitting to standing positions. So, getting up off the toilet can result in feeling dizzy, light-headed or even passing out. If this is a problem speak to your GP. Drinking plenty of fluids not only helps reduce constipation but assists with keeping a good blood pressure.

Some medications can increase the risk of constipation, particularly pain killers, so ensure your GP and Specialist are aware of your bowel problems when they prescribe new medications. There may be some forms of a specific type of medication that are less likely to cause constipation or it may be necessary to consider whether the benefit of the new medication outweighs the problems it causes for your bowel.

People with MSA often experience bladder problems which can be made worse by constipation. Due to the positioning of structures in the pelvis if you are constipated it can cause pressure on the bladder and urethra (the tube that allows urine to drain from the bladder). Therefore, constipation can cause feelings of urgency to pass urine; difficulty passing urine and increased need to pass urine. Drinking plenty not only helps reduce constipation but helps keep urine diluted thus reducing irritability within the bladder and alleviating the symptoms.

NB: You may experience headache, poor appetite, nausea, bloating, feeling of fullness, wind, lethargy and restlessness if your bowel is not functioning well. You should ask your GP for advice.





Managing bowel problems

Summary of good habits to develop:	
Develop good drinking habits	Aim for an intake of two litres each day. Try not to drink too many fizzy drinks, alcohol, tea and coffee in a day. Water, diluted fruit juices, herbal teas are all helpful. Taking prune juice and fruit or vegetable smoothies can be
	helpful.
Establish a regular toilet routine	Try to time your toileting to work with when your bowels are naturally activated (the gastrocolic reflex), which is usually when we take our first meal of the day.
	Allow plenty of time to use the toilet
Develop good eating habits	Always eat breakfast - This intake of food after the bowel has 'rested' overnight triggers the gastrocolic reflex.
	Eat regular smaller meals rather than infrequent large meals.
	Where possible, reduce the amount of pre-cooked processed foods, and avoid bran/wholemeal grains but try to increase intake of soluble fibre e.g. oats.
	Discussion with a Dietician can be helpful for this.
Use whatever aids and equipment are necessary to achieve a good position on the toilet that gives you maximum comfort.	This will relax you and all effort can then be focussed on the lower bowel and abdominal muscles to enable good emptying of the rectum.

There are a number of over the counter preparations such as *liquid paraffin*, Senna and Bisacodyl that some people find helpful and if you have found something that works for you keep with this – but do discuss with your GP if you are having difficulties with your bowels.

If you are susceptible to episodes of low blood pressure then straining to open your bowels could bring on an episode. It may, therefore, be helpful to wear a pendant or watch alarm to alert someone if you fall. Your Social Worker, Parkinson's nurse or nearest Age UK branch can advise you how to get these or there may be details of local schemes on your local authority website

Medications for bowel problems

There are a number of medications that can be helpful for the three most common bowel complaints: constipation, abdominal cramps and diarrhoea. Below are some commonly used examples; however, there are many others available. They all work in a similar way so do not worry if you have a medication for your bowel of a different name to those mentioned.





Constipation

Туре	Names	How they help
Softeners	Liquid Paraffin; Movicol, Laxido, Lactulose or Docusate	These are medicines that help keep fluid in the stool, thus keeping it soft. It is important to drink plenty to help these work effectively and reduce the risk of getting dehydrated, as more fluid is lost through the bowel when using these medications. If you experience bloating and increased wind then Docusate may be the best choice of softener. Some of these medications come as a powder to mix in water. If taking the full volume is a problem for you then discuss this with your GP as some are now available as a suspension medicine, so the same dose in in a much smaller quantity.
Stimulants	Senna, Bisacodyl or Dulcolax (common brands include Ex-Lax)	These medications increase the bowel muscle contractions and speed of movement through the bowel. They are sometimes used together with softeners. All can cause cramping discomfort, especially Senna. Dulcolax works as a combined softener and stimulant, so for people who need both actions regularly this may be a good option.
Bulk- forming	Fybogel, Normacol or Psyllium	These increase the bulk of the stool stimulating the stretch fibres of the bowel wall to assist bowel movement. Again, they need to be taken with plenty of fluid. They are most effective if a person tends to pass very small hard stools. Commonly used in people with diverticulitis or irritable bowel syndrome.

Abdominal cramps

The drugs listed below slow the bowel which may be helpful; if stools are loose but can increase the risk of constipation so fluid intake is important. Common medication examples include:

- Dicycloverine Hydrochloride also known as Merbentyl
- Hyoscine Hydrobromide also known as Buscopan
- Mebeverine Hydrochloride also known as Colofac.

Diarrhoea

Anti-diarrhoeal medicines slow the speed of gut movement allowing more fluid to be absorbed from the gut and firming up the stool. Common medications include:

 Loperamide – also known as Immodium, which is probably the most commonly used and approved for diarrhoea.





• Codeine Phosphate which is also a good pain killer is very effective at slowing the gut – if taken regularly, it can cause constipation.

The aim of bowel management is to achieve a regular, soft and well-formed stool, see type 4 on the Bristol Stool Chart (right). You can find more on the Bristol stool scale here: Bristol stool scale - Wikipedia

For those who have had chronic constipation the bowel may well have become overstretched and you will need to take laxatives to keep things moving for some time. It can take months for the bowel to shrink back down and regain its sensitivity to the presence of normal volume of stool.

If you have fluctuating constipation and diarrhoea it is important to seek medical advice. You will need to ensure there is no underlying cause to the problem and that the diarrhoea is not 'overflow' - see point 5 above.

Bristol Stool Chart Separate hard lumps, like nuts (hard to pass) Sausage-shaped but lumpy Like a sausage but with Туре 3 cracks on the surface Like a sausage or snake, Type 4 smooth and soft Soft blobs with clear-cut Type 5 edges Fluffy pieces with ragged edges, a mushy stool Watery, no solid pieces. Entirely Liquid

If you have fluctuating bowel motility (spontaneous movement) and it isn't due to a separate underlying cause, the aim is to juggle the medications for constipation and diarrhoea to keep the stool reasonably firm. This may mean for example that 3 days a week you need to take laxatives and 1 or 2 days take Loperamide. For more information about this contact the MSA Health Care Specialists or see your GP.

For those who primarily have diarrhoea it is important to find the right dose of the bowel slowing medicines like Loperamide that give you control without becoming constipated. If you are anxious about issues relating to diarrhoea then you could discuss the matter further with your Continence Advisor.

Other factors

Some people with MSA open their bowels regularly for a good volume of soft formed stool but repeatedly feel the need to keep going back to the toilet. This may occur because of poor messaging to the nerves and muscles involved when the person tries to push to open the bowels. Instead of the muscle that evacuates the stool relaxing and allowing it to pass, it instead contracts and retains the stool or part of it. Practising some relaxation techniques and not being stressed by the feeling to go again will help. Accept that opening your bowels for you will be a two- or three-part process; try to allow half an hour, have a drink and then return to the toilet and try again consciously trying to relax.

A Continence Nurse and Physiotherapist may be able to help you learn and practice a 'biofeedback' mechanism which teaches you to resist the initial urge to open your bowels, allowing stimulation to build up for a more effective urge the next time. This may facilitate better bowel clearance

If this, in time and practice, does not work then it may be worth considering becoming a little constipated so the stool is firm, passing what you can initially then using a glycerine suppository or micro enema to assist passing the residual at the second attempt. The Community Nurse and GP can advise and supply these.





Important to remember

- If you have sudden change to your usual bowel habits inform your GP / Specialist. Although bowel problems are common in MSA do not assume what you are experiencing is down to the MSA over time you will know if it is. New and sudden changes should be discussed with your GP and checked that no other treatable problem is occurring.
- For the general population regular long-term use of laxatives is not recommended. However, due to the effect MSA has on muscle tone and the autonomic nervous system and how this effect impacts on the bowel of people with MSA, it is appropriate and often necessary to use laxatives regularly throughout your journey with MSA.

Useful contacts

The following list guides you to who might offer help and advice about bowel management issues:

GP – they can check that there is no other (non-MSA related) cause for bowel problem. They can prescribe medications, refer you to expert advisors and monitor response to medications.

Local Continence Service – or Bladder and Bowel service they can offer investigations, treatments and support on bladder and bowel issues. You can get a referral to your local service through your GP, Parkinson's Nurse, District Nurse or Consultant.

District Nurses – they can provide you with continence supplies and medications and can also assist with enemas and suppositories etc.

Dietician – they can advise about a balanced diet containing soluble fibre.

Physiotherapist – they can help you with relaxation techniques and abdominal and pelvic muscle exercises.

Occupational Therapist – they can provide aids and equipment such as a raised toilet seat with arm support, bottom wiping aids and grab rails.

Helpful contacts

The Bladder and Bowel Community

The Foundation provides information, advice and expertise to anyone with bladder and bowel problems.

Telephone: 0800 031 5412 (Medical Helpline)

By post: Bladder & Bowel Community, 7 The Court, Holywell Business Park, Northfield Road,

Southam CV47 0FS

Website: www.bladderandbowel.org

Disability Rights UK - National key scheme for locked toilets.

Telephone: 020 7250 8181

By post: Disability Rights UK, Ground Floor, CAN Mezzanine, 49-51 East Road, London, N1 6AH

Website: www.disabilityrightsuk.org





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Disabled Living Foundation - This is a national charity providing equipment advice and information for disabled people.

Telephone: 0300 999 0004 (Helpline)

By post: Disabled Living Foundation, Unit 1, 34 Chatfield Road, Wandsworth, London SW11 3SE

Website: www.dlf.org.uk

WheelMate - This site (also available as a smartphone app) gives you an overview of your nearest wheelchair-friendly toilets and parking spaces throughout the UK

W: www.wheelmate.com

The Trust's contact details:

We have MSA Health Care Specialists that support people affected by MSA in the UK and Ireland. If you would like to find the MSA Health Care Specialist for your area, contact us on the details below or use the interactive map here – https://www.msatrust.org.uk/support-for-you/hcps/.

MSA Trust, 51 St Olav's Court, Lower Road, London SE16 2XB

T: 0333 323 4591 | E: support@msatrust.org.uk | W: www.msatrust.org.uk

Bladder Information - A factsheet on bladder issues is available from the Trust office or to download on our website - www.msatrust.org.uk





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