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Bowel Management in MSA

Introduction

Experiencing unpredictable and difficult problems with bowel function can severely affect your quality of life. It may prevent you from going out and socialising, getting on with your daily routine and undermine your self-confidence and self-esteem. So it is important to try to understand and manage the difficulties.

How the digestive system works

The digestive system runs from your mouth to your rectum (back passage). It serves two main functions: the breakdown of food into small parts that the body can use and 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 now 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 automatic nerves do?

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

In conditions where the autonomic nerves are impaired, such as Multiple System Atrophy (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 which makes faeces hard and difficult to pass. The slowing down can also cause bloating or cramp like pain. There may be an urgent sensation of the need to go to the toilet.

What bowel problems can occur when you have 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 (see points 5, 7 and 9 below).

Why does constipation occur?

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

1. Reduced mobility . being in a standing position, and moving around helps stimulate the bowel and encourage normal function.
2. 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 to help keep your balance on the toilet they can't work as well to help empty your bowel (see enclosed sheet for correct positioning on the toilet). An Occupational Therapist or Physiotherapist may be able to provide a raised toilet seat with arm support.
4. Not allowing enough time to complete opening 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 left behind fills the large bowel it becomes increasingly dried out; while the bowel contents coming along behind this can'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 the need 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 2 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 bowel is constantly moving from mouth to anus and carrying the food contents along. The autonomic nervous system is important in controlling this movement, increasing the speed of it and reducing the speed of it. 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 release of hormones and enzymes that affect how well our food is digested and how quickly 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 . a problem that some people with MSA are prone to; particularly when they move from lying to sitting and 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 for you speak to your GP. Drinking plenty 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 Consultant 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

What can you do to manage bowel problems?

- Develop good drinking habits throughout the day, and particularly in the morning, aiming 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.
- Establish a regular toilet routine for opening your bowels . there is a natural mechanism called the gastrocolic reflex which is activated when we take our first meal of the day; utilising this reflex by timing your toileting to work with this will make opening your bowels easier.

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- Have breakfast, as this intake of food after the bowel has rested overnight triggers the gastrocolic reflex.
- Allow yourself plenty of time to use the toilet.
- 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.
- 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; especially if bloated feelings, wind, feeling of fullness and passing of mucus are particular problems for you. Discussion with a Dietician can be helpful.
- Taking prune juice and fruit or vegetable smoothies can be helpful.

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 that is good. 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 attack. It may, therefore, be helpful to wear a pendant or watch alarm to alert someone if you fall. Your social worker or Parkinson's nurse or nearest Age UK branch can advise you how to get these.

Medications for bowel problems

There are a number of medications that can be helpful for the three most common bowel complaints: constipation, 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.

Medications for **constipation** are broadly known as laxatives and are available over the counter. There are three main groups commonly used to manage constipation in everyday circumstances:

Softeners . e.g. Liquid Paraffin; Movicol, Laxido, Lactulose

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 Lactulose may not be the best choice of softener.

Stimulants . e.g. Senna, Bisacodyl, Docusate (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. Docusate works as a combined softener and stimulant, so for people who need both actions regularly this may be a good option.

Bulk-forming . e.g. Fybogel, Normacol

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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. Most effective if a person tends to pass very small hard stools. Commonly used in people with diverticulitis or irritable bowel syndrome.

Anti-spasmodic medications, taken for frequent **abdominal cramps** have a drying effect, so can increase constipation and concentrate urine; so again fluid intake is important. However, they may be useful in episodes of diarrhoea where cramps are often most common when the gut has increased movement; and their action will slow the gut down which helps to alleviate the diarrhoea. Common medication examples include:

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

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 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.

Liquorice contains glycyrrhizin and is commonly thought of as a mild laxative. Glycyrrhizin has a possible side effect of lowering potassium which can actually contribute to constipation. Evidence for liquorice as a laxative is limited but thought to be beneficial, however, prolonged use could have negative effects. Therefore, we cannot recommend its use one way or the other. Like other such remedies, if you get benefit from it then stick with it and if in doubt talk to our specialist nurses or consult your GP.

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:

http://en.wikipedia.org/wiki/Bristol_stool_scale

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 as 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

Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on the surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces. Entirely Liquid

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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 Trust nurse 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.

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 / Consultant. 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.

Helpful 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 . 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. The equipment available does vary from area to area, your local continence service can advise on what is available to you.

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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.

Useful contacts

The Bladder and Bowel Foundation (B&BF)

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

T: 0845 345 0165 (Nurse Helpline) | W: www.bladderandbowelfoundation.org

By post: The Helpline Nurse, The Bladder & Bowel Foundation, SATRA Innovation Park, Rockingham Road, Kettering, Northants, NN16 9JH

Disability Rights UK - National key scheme for locked toilets.

T: 020 7250 8181 | W: www.radar.org.uk

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

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

T: 0845 130 9177 (Helpline) | W: www.dlf.org.uk

By post: DLF, 380-384 Harrow Road, London, W9 2HU

The Trust's contact details:

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

T: 0333 323 4591 |

E: support@msatrust.org.uk |

W: www.msatrust.org.uk

MSA Trust Nurse Specialists:

Samantha Pavey (South East & East England): T: 0203 371 0003 | E: samantha.pavey@msatrust.org.uk

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Jill Lyons (Wales & South West England): T: 01934 316 119 | E: jill.lyons@msatrust.org.uk

Continence Information - A leaflet on urinary continence issues is available from the Trust office.

Bristol Stool Chart image courtesy of Jpb1301 / CC BY-SA 2.5

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