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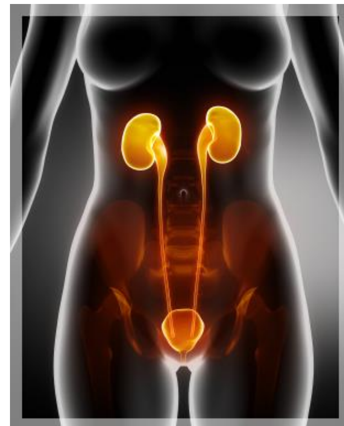
Continence in MSA

It is possible to manage the bladder problems of MSA even if they cannot be cured.

How the bladder works



Urine is produced in the kidneys and passes down tubes called ureters into the bladder.

The bladder, in which urine is stored, is balloon shaped. It is situated low in the abdomen behind the pubic bone. From the bladder the urine leaves the body through another tube, the urethra. The valves or %sphincters+ at the base of the bladder makes it watertight and stop urine leakage.

In health the bladder can hold about 1 pint (500ml) of urine but a reduction in its capacity is a common feature of many bladder disorders. The first sensation of needing to go to the toilet happens when the bladder is about two thirds full.

It used to be thought that the bladder was merely a %waterproof bag+ but in the last 15 years it has been shown that the walls of the bladder are made up of several layers, some of which have the sole function of generating nerve signals to convey information about the bladderqs contents to the spinal cord and the brain. If it is socially appropriate to go to the toilet, the brain sends messages down the spinal cord to relax the sphincter (the valve which opens the bladder) and to contract the bladder wall muscle (the detrusor) so that urine is expelled from the urethra.

It is normal to pass urine between four to seven times during the day and once at night. This may sound straightforward, but it is a very complex process and needs the bladder, the brain and all the nerves between them to be working in co-ordination. Being able to control this process is what is required for continence.

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What goes wrong?

Bladder problems are very common in people with MSA and are often the first symptoms of the illness. However, because bladder problems can occur for other reasons such as prostatic outflow obstruction in men and stress incontinence in women, it is important to think about other possible causes and not put it all down to MSA. This information concentrates on the common problems in MSA.

MSA seems to attack the neurological controlling centres of the bladder in quite a selective way. This is why bladder symptoms occur as an early feature of the disease, and why they may become particularly troublesome over ensuing years. People with MSA get a combination of an overactive bladder, incomplete emptying and sphincter weakness. Some of the potential problems are:

- **Urgency**, needing to go to the toilet suddenly and quickly. This is due to the bladder contracting of its own accord - %bladder overactivity+. If you cannot reach the toilet in time you may suffer urge incontinence. However, urgency incontinence is a common symptom in the general population, not just in people with MSA.
- **Frequency**, going to the toilet a lot (more than eight times in 24 hours) but only passing small amounts of urine. This can either be due to the bladderqs overactivity or because you are not emptying it completely.
- **Double voiding**, needing to pass urine again very soon after just doing so indicating your bladder was not completely empty the first time, sometimes accompanied by a feeling of incomplete emptying.
- **Urine infections**, especially if you have incomplete bladder emptying. Urine infections often make people feel very unwell and can make other symptoms, such as postural hypotension, worse. Although there is a general need to reduce the use of antibiotics in the general public, the early use of antibiotics to treat urine infections is very important for people with MSA.
- **Constipation** adding to problems of poor bladder function.

Other problems with going to the toilet can also be affected by other MSA symptoms:

- Passing lots of urine during the night; this usually happens in people who also have postural hypotension as a symptom.
- Accidental leakage, because of difficulty or slowness getting to the toilet or adjusting clothing in time.

What investigations might be done?

Trying to find out exactly what the problem is, is an important starting point for getting appropriate treatment. When you see a nurse or a doctor they will ask you questions about your general health, how much you drink, the colour or smell of your urine and your bladder problems, including whether you have had any accidental leakage.

You may be asked to produce a sample of urine to test for a number of different things, including signs of infection. The sample can be sent to a laboratory for detailed testing or tested immediately with special urine testing sticks. The sticks give quite a good indication as to whether or not the urine is infected, but a more reliable result comes from the laboratory, although if it is necessary to grow the germs in the urine on a special plate to test for antibiotic sensitivity, it will take longer to get a result (several days).

Measuring the volume and frequency of passing urine can help determine what your exact problem is, so that you may be asked to keep a diary for a few days recording everything you drink and how often you pass urine and even measuring the volumes.

The other investigation that is very useful is checking how much urine is left in your bladder after you have passed urine, using either a small ultrasound machine or a catheter. Any urine left is called %the post-micturition residual urine volume+.

All these tests can be done at your home or the GPœ surgery. If more detailed testing is needed, you may be referred for urodynamics at the hospital. Urodynamics are a range of procedures that tests how well your bladder fills and empties.

Urological treatments for several common bladder problems may involve surgery, but operations in people with MSA are rarely the solution. It is not uncommon for patients with MSA to have had some urological surgery, which may not have helped very much, before the neurological diagnosis is recognised. Further surgery is probably inadvisable.

Who can help?

District nurses and Community Matrons can give advice on continence issues and will refer on to Continence advisors as appropriate

Continence advisors are healthcare professionals who have specialist training and experience in managing bladder and bowel problems. Continence advisors work in hospitals, health centres and in the community. Many accept self-referrals over the telephone, although some may ask that your GP write to them. The Bladder and Bowel Foundation helpline will have details of your nearest advisor (see ±Helpful Contactsq).

Your GP or specialist will also be able to help.

The Trustœ MSA specialist nurses are available to discuss bladder problems and treatment (see ±Helpful Contactsq).

Advice

Sensible advice about fluid, toilet habits or diet is often very useful in preventing problems and managing symptoms.

Maintaining a healthy bladder means drinking plenty of fluid (about eight large cups/ glasses each day). Drinking too little fluid can irritate your bladder and cause problems. There is some evidence that drinking cranberry juice may reduce urinary tract infections a bit, and continence advisors recommend reducing your intake of caffeine and fizzy drinks.

Be comfortable on the toilet, especially in public lavatories. Ladies should sit rather than hover (carry some wipes with you to do this) and men should use cubicles which provide privacy.

Some people find bending forward, gently pressing or slow firm tapping over the bladder at the end of the flow helps to squeeze out any urine left in the bladder.

Advice or help in choosing clothes that are easy to get to the toilet for your particular situation, for example Velcro fastenings rather than a zip, can provide valuable time which may prevent accidental leakage.

Medication

Medication, called anti-muscarinic drugs (also known as %anti-cholinergics), allows the bladder to relax and fill better to capacity before needing to empty. These can reduce the symptoms of urgency and frequency.

DDAVP (desmopressin) is a hormone that prevents urine production for several hours after it has been taken. It can be useful if taken at night as it can stop the need to get up to go to the toilet, which improves sleep.

It comes in a tablet and nasal spray but it must only be used once a day and is not recommended in those over 65 years as it can cause water intoxication. It may be useful for people who have postural hypotension as a symptom.

There is some research being carried out to see if injecting botulinum toxin A into the bladder muscle, a treatment that has been found to be very effective in other neurological conditions causing an overactive bladder, might benefit patients with MSA. It is known, however, to make bladder emptying worse and intermittent catheterisation is usually necessary after the treatment.

Regular or daily laxatives may be required if constipation is contributing to bladder problems.

Equipment

An occupational therapist can help to make it easier to use the toilet at home. Adjusting the height of the toilet, adding grab rails or even creating a downstairs toilet are all worth thinking about.

Community nurses can help provide urinals or commodes to make toileting easier.

There is a wide range of continence pads now available with varying absorbency suitable for day or night use by men and women and which can be either disposable or washable. Some are available on prescription and the continence nurse or community nurse can arrange to supply them to you.

Although not strictly a catheter, some men find urinary sheaths useful. They fit over the penis like a condom and attach to a urine collection bag via a tube. These are not usually used for the whole day, as they can cause skin irritation, but they can be useful when out and about or overnight.

Catheters are thin plastic tubes that can be passed into the bladder to drain it and can either be %intermittent+or %indwelling+(i.e., left in for some days or weeks).

Intermittent catheters are inserted into the urethra to reach the bladder, the urine is drained (which only takes a few minutes) and then the catheter is removed. A continence advisor will teach you how to do this for yourself or possibly show your carer how to do it for you. Intermittent catheterisation is a very useful means of improving bladder control if not emptying is a significant part of what has gone wrong.

Indwelling catheters are also inserted via the urethra or through the abdomen (a supra pubic catheter). The catheter drains urine either into a drainage bag or has an attached valve that allows the bladder to be drained at regular intervals.

Although no one likes the idea of using a catheter many people are surprised at how easy they are to use and how they can relieve bladder problems.

Both types of catheter can be discreet and can give people more freedom from needing to use the toilet. However, for many people the decision to use any kind of catheter needs to be given plenty of thought and discussion.

Other help

‘Can’t wait’ card: This credit card sized card can be shown discreetly to gain easy access to toilets when you are away from home. It is free and copies are available from the Trust office.

The National Key Scheme: Initiated by RADAR, this offers independent access for disabled people into over 4,000 locked public toilets around Britain. Ideally all accessible toilets should be kept unlocked, but the scheme is used where it is necessary to lock the toilets to maintain

their cleanliness and to protect them from vandalism and misuse. Keys can be purchased - see ±Helpful Contactsq

Social Services: In some cases financial assistance towards laundry equipment, e.g., a washing machine or to have clothes and bedding laundered, may be available. A social worker or benefit advisor can provide more details.

Sexual activity and continence: Bladder problems donq mean the end of intimate or sexual relationships. Some continence advisors are experienced in offering advice or treatment to enable sexual activity to be maintained. They recognise that for some people this is a very important part of life so will not be surprised or embarrassed if you want to talk about this with them. During a visit, they may even ask you directly if you are experiencing any problems with sexual function so you may want to prepare your reply. The MSA Trust also has a leaflet about sex and relationships which is available by contacting the office.

Useful contacts:

The Bladder and Bowel Foundation (B&BF)

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

Telephone: 0845 345 0165 (Nurse Helpline)

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

Website: www.bladderandbowelfoundation.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.radar.org.uk

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

Telephone: 0845 130 9177 (Helpline)

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

Website: www.dlf.org.uk

The Trust's contact details:

MSA Trust, 51 St Olavq Court, City Business Centre, Lower Road, London SE16 2XB
T: 0333 323 4591 | **E**: support@msatrust.org.uk | **W**: www.msatrust.org.uk

The MSA Trust Nurse Specialists:

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

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Constipation Information - A leaflet bowel management is available from the Trust office.

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References for this information sheet are available by contacting support@msatrust.org.uk.

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