

Tackling bladder problems

This leaflet was produced by Ataxia UK and reviewed by consultant urologist Mark Harrison, M.A., F.R.C.S. in March 2006

Bladder problems are extremely common, and do not just affect people with ataxia. Essentially the problems relate to an inability to retain a reasonable volume of urine in the bladder or an inability to empty the bladder completely. The former is much more common. Women are particularly affected – around one in three experiences some kind of incontinence problem. At its mildest, this amounts to urgency when needing to pass urine, which can lead to periodic leaking of urine. Although inconvenient, this is easily managed. At the other end of the spectrum, it is such an extreme loss of bladder control that it causes embarrassment, physical and emotional distress and social unease. Any involuntary loss of urine is termed 'urinary incontinence'.

People with ataxia experience incontinence problems either because of decreased mobility (not being able to reach the toilet in time), or because of damage to the nerves concerned with bladder function. However, if you experience incontinence, it is important to get a correct diagnosis because your incontinence may be nothing to do with your ataxia.

HOW THE BLADDER WORKS

Urine is produced in the kidney. After it leaves the kidney it is propelled along tubes into the bladder, a flexible, hollow muscular organ held in place by attachments to pelvic floor muscles and, in men, to the prostate gland. It enters the bladder in spurts at 10 second intervals, rather than as a constant trickle.

A ring of muscle called a sphincter is usually squeezed close (or 'contracted') around the outlet of the bladder to prevent urine escaping. As the bladder expands and fills with urine, it triggers off a series of nervous impulses, or messages, to allow urination. The sphincter muscles relax or loosen; the bladder contracts pushing the urine out of the body along a tube called the urethra. When the bladder has emptied, the sphincter muscles contract or tighten up again. This emptying process (which is relatively quick compared to the speed at which the bladder fills) is extremely complex and not fully understood. It is controlled both by an area in the brain called the cerebral cortex and also by local reflexes running in the nerves along your backbone.

WHEN THINGS GO WRONG

STRESS INCONTINENCE: Although this is the most common form of incontinence in the general population (usually affecting women), it is not usually directly caused by ataxia. It happens to people whose urethral sphincter and pelvic floor muscles have been weakened (often as a result of childbirth) and have allowed the bladder to slip out of position. Its symptoms are leaking (frequently only small drops, but in more severe cases floods) on coughing, laughing, or sneezing. In people without stress incontinence, this kind of sudden rise in outside pressure will act evenly on the bladder and the sphincter and no urine will escape. However, if the sphincter and muscles have been weakened, with sudden pressure from a sneeze the sphincter will not tighten automatically, and urine will be squirted out.

URGE INCONTINENCE: Urge incontinence is the most common type of incontinence associated with ataxia. It is caused by instability or overactivity of the muscle of the bladder wall and develops because of neurological damage to the nerves linked to the bladder. Someone with urge incontinence will have the sudden and desperate feeling of needing to dash to the toilet, be unable to prevent the bladder contracting and, once urination starts, will not stop until the bladder is empty.

Ataxia UK, Lincoln House, Kennington Park, 1-3 Brixton Road, London SW9 6DE

www.ataxia.org.uk
Tel: 020 7582 1444

helpline@ataxia.org.uk
Helpline: 0845 644 0606

PROBLEMS WITH EMPTYING THE BLADDER: If the weakened bladder wall muscles cannot contract strongly enough to expel urine and/or the sphincter muscles are so damaged that they cannot relax sufficiently to allow urine out, this loss of co-ordination can cause problems with urine retention and/or emptying the bladder. The bladder never empties completely, reducing the space available for new urine coming from the kidneys, and this leads to increased frequency and urgency to pass urine. Some bladders will always be full and result in an overflow or constant dribble of urine ('overflow incontinence'), or 'hesitancy' (a delay between the desire to pass urine and trying to start emptying the bladder).

MANAGING BLADDER PROBLEMS

Even if urinary incontinence cannot be cured it can almost always be managed. Visit your GP who can refer you to a specialist such as a continence adviser or a physiotherapist. Continence advisers are specially trained NHS nurses. There are about 450 in the UK. You can also contact the The Bladder and Bowel Foundation Helpline for details of your nearest advisor. Occasionally you may need to be referred to a gynaecologist or urologist for special assessment or tests.

Do not cut down the amount you drink in the belief that this will reduce incontinence. On the contrary, lowering your fluid intake will result in more concentrated urine, which will only make matters worse and may even add to them with urinary infections. Like anyone else, you should drink plenty of plain water, ideally 1.5 litres a day.

Stress incontinence can often be corrected with physiotherapy to strengthen the pelvic floor muscles. This is a very successful treatment, entirely free from side effects, but the exercises should be taught properly by a physiotherapist or a continence adviser and done regularly. (You must be well motivated!) Do not expect instant results - any noticeable improvement can take three to six months. Therapy for urge incontinence can involve re-training the bladder to 'hang on' through learning and establishing a regular pattern of visiting the toilet. This needs an even higher degree of commitment than pelvic floor exercises! Diet and lifestyle can make this condition worse: smoking, alcohol and caffeine-containing drinks (including fizzy drinks) can all act as irritants on the bladder and should be avoided.

There are also anticholinergic drugs (e.g. oxybutynin), although these can cause side effects (not usually severe) such as dry mouth or eyes. Oxybutynin is also available as a skin patch which should reduce its side effects. There are newer drugs which are no more effective but may have less severe side effects: for example, propiverine (Detrunorm), solifenacin (Vesicare) and trospium (Regurin).

If you are having problems emptying your bladder completely, small hollow tubes called catheters can be inserted into it. A specialist can show you how to insert them yourself and many people soon learn how to use this method successfully, although it may not be suitable for anybody with severe **coordination problems. Some people have more permanent catheters, which drain into a bag, put in by a doctor and these can remain in place for several weeks.**

WHAT PRODUCTS ARE AVAILABLE?

The following is a list of the main products available; for more details refer to the PromoCon 2001 booklet 'Choosing products for bladder and bowel control'.

1. Portable urinals provide a practical solution for people who cannot get to the toilet in time. They are available in many designs and can be discreet enough to be carried in a small bag or used in a car.
2. Disposable and washable pads are widely used for dealing with leaks. Many styles are available for men, women and children, offering different degrees of absorbency. Disposable pads are preferable for heavy loss; these generally contain a highly absorbent gel to be less bulky or visible.
3. Mattress, duvet, pillow and chair protectors are available for added security.

HOLIDAYS? – NO PROBLEM!

Incontinence *is* manageable and should never deter you from a holiday. All that is required is extra awareness, specialist products and a degree of planning.

- Take a **good supply of everything** (pads, moist wipes, catheters, etc). If you are flying, split your supplies between bags in case things get lost. Make sure supplies in your hand luggage (including hand towels and toilet rolls) are adequate to cover delays
- A **doctor's letter** might be useful for explaining why you need extra hand luggage on a flight

or are carrying syringes and catheters, or for obtaining a prescription away from home.

- Write in advance to ask if **bed protection** can be supplied (it will save you space and weight in your luggage). If not, pack a 'fits-any-size' protective cover.
- Arrange to have a **seat near the toilet** if you are on a plane or train for a long time. Wear a more absorbent pad than normal to prevent anxiety; take a chair pad. A letter from a doctor sent in advance can be helpful here.
- Enquire about **waste disposal arrangements**. Take a supply of disposal bags or bin liners.
- Check out the **laundry facilities**. Pack a travel washing line and clothes pegs.
- Depending on the volume of items you need, you may find it worthwhile to **courier your supplies ahead**.
- Flying and hot climates can be dehydrating, so **keep your fluid intake up**. In colder climates, you may need to go to the loo more often – so again be prepared.

Incontinence should never cause such overwhelming anxiety that it prevents you leading a normal life. Literally millions of people in the UK experience some degree of incontinence, for all sorts of reasons. There is a powerful network of support services giving advice and encouragement to all concerned. Embarrassment has historically prevented many people from seeking help. It is important to ask and to persist, as there is much help available.

The Bladder and Bowel Foundation (B&BF), SATRA Innovation Park, Rockingham Road, Kettering, Northants, NN16 9JH

- Nurse helpline 0845 345 0165
- Counsellor Helpline 0870 770 3246
- General Enquiries 01536 533255
- Fax: 01536 533240

www.bladderandbowelfoundation.org

Email: info@bladderandbowelfoundation.org

The Cystitis and Overactive Bladder Foundation (COB Foundation) also provides information and support on bladder problems.

946 Bristol Road South, Northfield, Birmingham, B31 2LQ
Tel: 0121 476 1222

www.cobfoundation.org

Email: info@cobfoundation.org

ERIC is a charity that provides information on bowel and bladder problems for children, young people and their parents. www.eric.org.uk 34 Old School House, Britannia Road, Kingswood, Bristol BS15 8DB.

Tel: 0845 370800

PromoCon2001 offers advice and information on products that can help manage bladder and bowel problems. www.promocon.co.uk Disabled Living, Redbank House, St Chad's Street, Cheetham, Manchester M8 8QA. T: 0870 7774714. Helpline 0161-834-2001 (Mon-Fri 10am-3pm)

RADAR has information about keys to toilets for disabled people, as well as information about holiday accommodation that caters for people with continence problems. www.radar.co.uk 12 City Forum, 250 City Road, London EC1V 8AF Tel: 020 7250 3222.

Additional resource for doctors:

In October 2006 the National Institute for Clinical Excellence (NICE) issued guidance on the management of urinary incontinence in women. www.nice.org.uk

Disclaimer

This leaflet is for guidance purposes only and, while every care is taken to ensure its accuracy, no guarantee of accuracy can be given. Individual professional advice should be sought before taking or refraining from taking any action based on the information contained in this leaflet and nothing should be construed as professional advice given by Ataxia UK or any of its officers, trustees or employees. No person shall have any claim of any nature whatsoever arising out of or in connection with the contents of this leaflet against Ataxia UK or any of its officers, Trustees or employees.