

## Continence Issues for Adults with Spina Bifida



As the Spina Bifida population ages, there will be many people who have never had their continence issues addressed. This leaflet is intended to help this group to look at their bowel and bladder management.

### Bowel

Most people with Spina Bifida will have bowel problems. These may include constipation, diarrhoea, and faecal overflow or be a combination of all three. You need to know what your faeces should look like – you need to aim for it to be firm but not hard, well formed but not knobbly.

If you have never been given appropriate advice about bowel management you will probably be wearing pads with all the accompanying difficulties (leakage, odour control, sore skin etc).

You may like to try a different way of dealing with your bowels:

- Establish a bowel routine. Start a new regime on an empty bowel. Get your GP to check for high up blockages. You may need to have a good “clear-out” before you start a new way of doing things. Regular emptying of the bowels should be encouraged. The best time is after breakfast or other meal times when natural bowel movement is most active.
- Eat a well-balanced healthy diet with plenty of fluid and fibre to help keep your motions soft and easy to pass. If you are unsure what constitutes a “healthy diet” speak to a dietician.
- It is important to exercise daily to the best of your ability as it helps to keep your bowels moving. If you are unsure what exercises you are able to do, ask your physiotherapist, or talk to someone at your local gym.
- Sometimes you will need to use a combination of diet and regular medication - do not worry about your bowel becoming “lazy”. If you need to take medicine then you need to take it. The medication prescribed will depend on what your bowel problem is. Medicines are used to soften your stool, to help your motions pass easily, to clear the bowel out, to stop diarrhoea and to make your stools more bulky.
- You may have always used manual evacuation (using your fingers to remove faeces from the lower bowel). This method is no longer widely taught; it is difficult with this method to remove enough faeces, so can lead to an overloaded bowel. It can also be difficult to get carers or community nurses to carry out manuals if you or your usual carer cannot do it (holidays, illness etc). For that reason it is worth considering another method.



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- Gently stroking your anus (bum hole) with your finger can sometimes produce a bowel movement.
- Coughing or blowing your nose or laughing whilst sitting on the toilet may also produce a bowel movement.
- If you cannot manage to regulate your bowels, and still have episodes of soiling, enemas may be the next step. Again, there are various types of enemas available depending on your needs.
- Some people use a system, to completely clear the bowels out every 2-3 days. This is called a high bowel washout. A tube is inserted into your bottom and fluid is washed around the bowel. The tube is removed and the fluid and any faecal matter will exit the bowel.
- When all these methods have been tried without success, surgery may be the only option. Discuss this with your GP and ask him to refer you to a specialist. (See SBHI's information sheets 'ACE Procedure' and 'Colostomy')

Keeping yourself constipated may seem like an easy option, but used over a long period can result in complications, including a condition called mega colon. It can also cause faecal overflow; you need to be aware of the difference between diarrhoea and faecal overflow – many people think that they have diarrhoea when in fact it is overflow. If this leads to incorrect treatment ie giving anti diarrhoea medication, your bowel management will worsen. Also be aware that faecal overflow can be misdiagnosed as Irritable Bowel Syndrome and will need investigating.

**It is never too late to change!**

### Bladder

You may not be able to achieve bladder continence until you have achieved bowel continence.

Hopefully you may have been seen by a urologist at some point in your life and will therefore understand the importance of achieving urinary continence. The priority when managing your bladder is to preserve kidney function. If regular assessments are not carried out, irreversible kidney damage may result. A bladder which does not work normally might:

- cause urine to flow back to the kidneys;
- not empty completely. This could lead to urinary tract infections.

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Good bladder management should include:

- Referral to a urologist with an interest in the neuropathic bladder (a bladder whose nerve supply may be interrupted eg as in Spina Bifida).
- Access to a continence adviser with knowledge of the neuropathic bladder.
- An explanation of how good bladder management will protect your kidneys.
- Regular (preferably yearly) Urodynamics to check bladder and kidney function (see SBHI's information sheet "Bowel and Bladder investigations").
- Ability to recognise urinary tract infections and know how to deal with them.

There are several ways of managing urinary incontinence. Adults do not need to be sitting in wet pads.

Talk to your urologist or continence advisor about:

- CIC or ISC (Clean Intermittent Catheterisation or Intermittent Self Catheterisation – see SBHI's information sheet on catheterisation).
- Medication to "calm" the bladder (where appropriate).
- Urinary sheaths (for men only) – a device similar to a condom with a hole in the end which is attached to a bag.
- Long term catheters into your bladder via the urethra (tube that urine comes out of) or through a small incision in the abdomen (belly) called a supra-pubic catheter. Both types of catheter will need frequent changing either by the district nurse or at the hospital.
- Various surgical options, some of which are not suitable for everyone. Ask your GP to refer you to a urologist to discuss your options. (It may be helpful for you to read SBHI's information on Mitrofanoff and Urostomy).

Remember to drink at least one cup of fluid each hour during the day. Avoid "brown" drinks (tea, coffee, cola etc), anything with caffeine, fizzy drinks. Clear fluids are best – there is nothing wrong with tap water!

To help avoid urinary tract infections drink a glass of cranberry juice each day, 2 glasses a day if you have a current urinary infection. Cranberry tablets and capsules are available, but are less effective than the juice. NB Do not drink cranberry juice or take tablets/capsules if you are taking a blood thinning drug such as warfarin or aspirin.

Taking control of bladder and bowel continence is a big step towards achieving the independence that you hope for, expect and deserve.