Bladder Management in Spina Bifida
How does the bladder work?

The bladder is a simple organ and is designed to do two things. It needs to be able to store urine normally for three to four hours and then empty completely. The bladder is controlled by a number of nerves which provide sensation to let us know when our bladder is full and emptying nerves that control the bladder muscles. In addition to that there is “social” control to prevent us emptying our bladder in inappropriate surroundings.

How does spina bifida affect bladder function and control?

The bladder in individuals with spina bifida is often called “neuropathic” which means that the nerves supplying the bladder are affected. The reason for this is that the nerves which supply the bladder come from the lower part of the spine, called the sacrum and if there is a fault in the spine, such as spina bifida, the signals from the brain to the bladder are interrupted. There are two main ways the bladder can be affected. Firstly is a “low pressure” bladder which leaks constantly. It is therefore regarded as “safe” and unlikely to damage the kidneys. The second is called a “high pressure” bladder which means that the fault in the nerves may cause the bladder to contract before it has filled with much urine and the urine will be stored at pressures too high to be safe which can damage the kidneys. It results in passing urine frequently and feelings of having to pass urine urgently.

How will I know if I or my child’s bladder is affected?

There are specialised urinary investigations that will be carried out within the first few months of birth. However these can also be carried out in adults if bladder problems develop.

What options are there for management?

The main aims are to protect the kidneys from damage, prevent infections and to achieve dryness.

Continued on the next page
**Clean Intermittent Catheterisation:**

This is a method of completely emptying the bladder at regular times during the day without the need for a catheter to be left in place. A fine plastic tube (catheter) is inserted into the bladder via the opening through which we pass urine (urethra) and removed once the bladder is empty. The reason for this is to prevent urine “refluxing” back up to the kidneys therefore helping to prevent damage. It also helps children and adults to become independent as this can be carried out without any assistance in most people whilst sitting on a normal toilet or even in a wheelchair. You will be taught to use this method by a specialist nurse until you are comfortable carrying it out. The nurse will also discuss the many types of catheters available and help find the most suitable. If a child is using this method it is wise to make their teacher aware in order that they have privacy, adequate time and a place to store catheters and wipes. If the child requires help with this procedure at school then a member of the support staff can be trained by a specialist nurse to carry this out.

**Bladder augmentation:**

This is a surgical procedure in which a piece of bowel, stomach or ureter (the tube which carries urine from the kidney to the bladder) is used to enlarge the bladder. This allows the bladder to hold more urine at lower pressure, however clean intermittent catheterisation is necessary after this procedure.

**Procedures to tighten the urethra:**

The urethra can be tightened by using a piece of the lining of the abdomen. Another method is to place an artificial sphincter around the urethra and pumping a valve which is placed in the scrotum in boys or the labia in girls which activates the sphincter. This causes water to fill up the sphincter and gently compresses the urethra, preventing leakage.

**Continent diversion (Mitrofanoff procedure)**

A channel, using the appendix, ureter, a piece of bowel or Fallopian tube is brought to the surface of the skin on the abdomen. It is a stoma which joins the bladder to the abdominal wall and is visible as a small opening on the skin with no need to attach a bag, although there is the option of covering it, for example when swimming. With this method, urine is drained from the bladder several times during the day using a disposable catheter. It is similar to Clean Intermittent Catheterisation except that the urine is drained through the stoma. This is a major surgical procedure and requires a full understanding and discussion with the Urologist of what is involved before deciding on this method. You may also wish to talk to someone else who has had this carried out and the SBH Scotland Support Team may be able to help with this.

*Continued on the next page*
**Botox**

Botox has been used as a treatment in adults with spinal injuries and paralysis since 1999 and Paediatric Urologists around the UK use it in children with spina bifida.

It is not suitable for every child with spina bifida and works best in bladders which show an overactive bladder muscle. The technique involves injecting Botox into the bladder muscle which stops the muscle contracting and results in a paralysed and relaxed muscle. The surgeon uses a small telescope (cystoscope) under anaesthetic, to look in the bladder and inject in the correct place. After about six to nine months new nerve endings “sprout” from the ends of the nerves and muscle action and tone are restored so further Botox injections will often be required when this happens.

Possible side effects are rare but can include temporary muscle weakness and allergic reactions.

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**Top Tips!**

1) **Drink plenty of fluids to keep your urine clear and your kidneys healthy.**

2) **Don’t have too many drinks which contain caffeine such as coffee, tea or Coke. Caffeine upsets the bladder which may lead to more infections. Drink fresh fruit juices, particularly cranberry juice - they are better for you.**

3) **Drink less beer, wine and other alcoholic drinks. If you drink too many of these, they can play havoc with your bladder management. If you drink too much alcohol, you may forget to catheterise which could cause complications, or, if you have an indwelling catheter you may forget to empty your continence bag and this might leak. When you go drinking with friends, order low alcohol lager or wine. These give the taste without the alcohol.**

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If you have questions or would like further information, please call the **SBH Scotland Helpline** on **03455 211 300** or email **support@sbhscotland.org.uk**

For general enquiries call **03455 211 811** or visit **www.sbhscotland.org.uk**

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