

Continence Management

June 2007

The Kidneys produce urine, which is collected in the bladder. When the bladder is full, the sphincter opens and the bladder muscle contracts to empty the bladder completely. This is under the control of nerves. Most people with spina bifida have varying degrees of what is known as a neuropathic bladder and bowel – when damage to the nerves interferes with normal bladder and bowel working.

The priority when managing the neuropathic bladder is to preserve kidney¹ function. If regular assessments are not carried out, irreversible kidney damage may result.

Infancy

Bladder

Early referral to a medical specialist for assessment of kidney and bladder function is essential. The specialist would ideally be a urologist or paediatric surgeon with an interest in spina bifida.

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.

Many parents are now taught to do clean intermittent catheterisation² as a precaution when their child is very young. This ensures regular bladder emptying.

Vesicostomy³ is sometimes preferred where the child is thought to be at particular risk of developing kidney damage. This is usually a temporary measure.

Bowels

Most babies with spina bifida have an abnormal nerve supply to their bowel which will alter “normal” bowel function.

The priority is to avoid constipation. In the early days, be aware of your child’s bowel pattern. Aim to ensure regular soft stools which can be achieved by giving extra clear fluids, ie water.

When mixed feeding begins, encourage a wide range of vegetables, fruit and cereals, and continue to encourage the taking of extra clear fluids.

Pre School Children

These are the important years where the aim is to work towards continence.

Bladder

Renal⁴ tract investigations should be carried out at least once a year. Remember the importance of fluids. At least 6 – 8 drinks per day should be encouraged to help reduce the risk of urinary tract infections. Ask about the choices for effective bladder management.

Cranberry juice is recognised as being useful in preventing and treating urinary tract infections, in some individuals. For these, one glass a day is recommended.

Bowels

A varied diet containing vegetables, fruit and cereals will help to keep the motions soft and easier to pass.

Avoid eating too many foods which can cause constipation, like eggs and full cream milk.

Introduce your child to the potty/toilet. Ensure that your child can sit safely and comfortably, supported or unsupported, with his/her feet placed on a firm surface.

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.

Maintain a high intake of clear fluids.

School Years

For the first time, working towards independent continence management becomes a prime objective. It is also a time when parents may have to involve others in the personal care of their child.

Bladder

As the bladder impairment may change, it is important to maintain monitoring of the renal tract by your urologist. This should take place at least once a year.

For many children, the need to catheterise during the school day is essential. Any special requirements to enable this to be carried out should be discussed with the appropriate professionals, and may need to be written into the educational statement. Talk this over with professionals like the specialist urology nurse, school nurse, continence adviser, or ASBAH specialist adviser.

Facilities should be available for children to carry out their continence management. These may include a larger toileting area with a sink and a lockable door to ensure privacy. The child’s needs should be considered when organising residential holidays or day trips.

The school should be informed of the need for extra drinks to be taken throughout the day.

Bowels

Soiling can be particularly distressing for children in school. It is essential to establish and maintain a good bowel regime to avoid this.

Be careful with certain foods. For example, many people find that food and drinks containing caffeine, such as chocolate, cola and coffee, stimulate the bowel and can result in incontinence.

Remember those extra fluids!!

IT IS IMPERATIVE THAT RENAL INVESTIGATIONS CONTINUE TO BE CARRIED OUT ONCE A YEAR. RENAL FUNCTION CAN STILL DETERIORATE.

Transition to Adulthood

Puberty may bring about changes in bladder and bowel function, and some surgery is best left until after this time. Queries relating to sexual activity will need to be answered and issues should be discussed with the consultant, specialist nurse or ASBAH specialist adviser. Regular reviews of bladder and kidney function often stop during the transition to adult services. However it is essential that investigations continue yearly, as renal function can deteriorate during adulthood. Discuss this with your GP, or ASBAH specialist adviser.

Surgical Options

Surgical options for long-term management of the bladder and/or bowel, to achieve continence, may be appropriate at any age. However, they should only be considered when all other choices have been explored. If renal function is deteriorating despite expert medical attention, then surgery is often required to protect the kidneys.

If surgery is indicated, the individuals and their carers should have as full an understanding as possible of the procedure and any implications for future management.

Advances in surgical techniques and on-going research means that the surgical options are changing frequently. Your consultant may mention procedures which you do not understand. Ask for an explanation and seek further information from the specialist nurse at your hospital, or an ASBAH specialist adviser.

Explanation of terms

1. **Kidneys** – organs at the back of your body which make the urine.
2. **Clean Intermittent Catheterisation** – an established technique used to empty urine from the bladder when normal voiding is impossible. A catheter (small plastic tube) is put into the bladder through the urethra and removed when the bladder is empty. This takes only a few minutes.
3. **Vesicostomy** – an opening from the skin into the bladder, below the navel, to allow the bladder to drain freely into a pad or nappy. Usually just temporary.
4. **Renal** – anything to do with the kidneys.

Link magazine

The essential magazine for people with hydrocephalus and spina bifida.

Link is published quarterly (Winter, Spring, Summer and Autumn) and is packed with the latest news, events and issues for individuals, carers and people living with hydrocephalus and spina bifida. To subscribe contact ASBAH's Helpline 0845 450 7755

email: helpline@asbah.org or visit our web site: www.asbah.org and click on the publications page.



Coloplast

Coloplast and ASBAH are working in partnership to campaign for an increased awareness of bladder and bowel health and to support ASBAH's members and families in their efforts to live a full and satisfying life.

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ASBAH relies on people's generosity and support so we can help our clients who depend on us for help and advice - people with hydrocephalus, spina bifida, their families and carers. To donate to ASBAH please visit www.asbah.org or call 01733 421327.