

Urological Care



The urological care of children and adults with Spina Bifida has undergone several important changes in the last decade. The emphasis is now on early catheterisation of the child's bladder function and preventative infection treatment to preserve both kidney and bladder function.

Newborn Assessment

As soon as the neurosurgical condition is stable, an assessment should be made of the baby's kidney and bladder function. A renal ultra sound may be used if there is evidence of deterioration or abnormality with either the kidneys or bladder, followed by blood urea nitrogen (BUN) and creatinine testing.

Continence Management

INFANCY

Bladder: Assessment of kidney and bladder function is essential. The specialist may be a paediatrician, urologist or clinical nurse specialist. Your child's bladder function will be tested to ascertain if urine flowing back to the kidneys or if the bladder is not empty completely. This could lead to urinary tract infections and deterioration of the kidneys. Many parents are now taught to do clean intermittent catheterisation (CIC) as a precaution when their child is very young. This ensures regular bladder emptying.

A Vesicostomy is sometimes preferred where the child is thought to be at risk of developing kidney damage. A Vesicostomy is a small opening below the child's belly button from which the bladder will drain continuously into a nappy. This is usually a temporary measure used only if CIC is not possible.

Bowel: Babies with Spina Bifida can have altered nerve supply to their bowel which will alter their 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 drinks of cooled, boiled tap water between milk feeds, once or twice daily, (especially in formula fed babies) and to maintain a good level of hydration. When mixed feeding begins, encourage foods with high fibre content, like cereals, prunes and other puréed fruits and vegetables like peas, beans and lentils. It is important to continue to encourage the taking of extra clear fluids. See *Dietary Advice*

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PRE SCHOOL CHILDREN

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

Bladder: Renal tract check-ups should be carried out at least once a year. Remember the importance of fluids such as water and juice (NOT fizzy drinks or caffeine based drinks such as tea). Encourage your child to drink at least 8 glasses of water a day (the aim is to increase fluid intake to 2 litres) and take a water bottle everywhere this will help to reduce the risk of urinary tract infections. Water or juice should be drunk at regular intervals throughout the day – NOT all at once. The last drink at night should be taken two hours before the last CIC, unless otherwise advised by your medical team. Cranberry juice is recognised as being useful in preventing urinary tract infections, in some children. One to two glasses a day is recommended.

Bowels: Encourage a well balanced healthy diet (see *Dietary Advice*). A high fibre diet will help to keep the motions soft and easier to pass. Avoid eating too much food 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 dynamics may change, it is important to maintain monitoring of the renal tract by your paediatrician, urologist or clinical nurse specialist. 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 need to be written into an educational statement. 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 and information of the condition should be made available to the appropriate school personnel.

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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 (See Dietary Advice). For example, if beans induce a bowel movement, only eat them for this purpose. Otherwise, "accidents" may occur. Other foods may cause constipation - which can interfere with bladder emptying and make urinary continence problems seem worse. Remember those extra fluids!!

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 SBHI Family Support Worker. 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 contact your Family Support worker who can put you in touch with SBHI's Continence Advisor if necessary.

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 SBHI Family Support Worker.