CONTINENCE MANAGEMENT IN CHILDREN LIVING WITH SPINA BIFIDA

GOALS OF MANAGEMENT:

- **Preserve Kidney Function** and have a healthy urinary system – regular kidney tests;
- **Effective Regular Bladder Emptying** usually by a program of clean intermittent catheterisation;
- **Avoid Constipation** and regular bowel emptying at a pre-determined time;
- **Social Continence** – to stay clean and dry with a regular routine toileting program and appropriate continence products;
- **Anticipate high risk times** for accidents and to be prepared;

INFANCY (0 – 2 years):

**Bladder -**

- Assessment of kidney and bladder function in neonatal period with baseline kidney tests;
- Parents often taught clean intermittent catheterisation as a precaution and according to kidney test results – this ensures regular bladder emptying and gets the child used to the procedure whilst very young; Catheters are supplied through EnableNSW – see clinic nurse for application;
- A Vesicostomy is sometimes preferred where the baby is thought to be at particular risk of developing kidney damage and clean intermittent catheterisation is not possible. This is usually a temporary measure. (A Vesicostomy is an opening from the skin into the bladder, below the umbilicus (navel), to allow the urine to drain freely into a pad or nappy – usually a temporary measure).

**Bowel -**

- Most babies with Spina Bifida have an abnormal nerve supply to their bowel which will alter “normal” bowel function and the baby will often have a patulous anus (loose opening) that can cause leakage of poo and severe nappy rash – treated with various barrier creams;
- 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 e.g. cool boiled water for bottle fed babies and/or a stool softener e.g. Coloxyl drops as needed;
- When introducing solid food, encourage foods with high fibre content e.g. rice cereal, pureed fruits like prunes, apple and pear. Continue to encourage the taking of extra clear fluids (mainly water).
PRE-SCHOOL CHILDREN (2 – 5 years):
(These are the important years where the aim is to work towards continence – becoming clean and dry).

**Bladder –**
- Kidney Tests at least once per year or as advised by your doctor;
- Remember importance of fluids. At least 6 – 8 drinks (mainly water) per day should be encouraged to help reduce the risk of urinary tract infections;
- Only treat symptomatic urinary tract infections e.g. if child has a fever and very smelly or cloudy urine; Cranberry juice can be helpful in preventing urinary tract infections in some individuals – recommended amount is one glass per day;
- Continue with clean intermittent catheterisation routine as advised by your doctor.
- Ask about the choices for effective bladder management in preparation for starting school at your hospital Spina Bifida Clinic appointments;
- Continence products can be provided by EnableNSW once your child turns 3 years of age – discuss with your clinic nurse.
- Most children attend childcare or pre-school and you will need to discuss your child’s particular toileting requirements prior to them commencing. Special funding of extra support for children with special needs is available to many childcare centres.

**Bowel -**
- Encourage a balanced healthy diet, high in fibre with fresh fruit and vegetables. The consistency of the stool can be controlled by diet, extra clear fluids and constipation avoided. The stool needs to be a sausage like consistency to enable easy evacuation.
- Avoid giving your child too much food like egg, full cream milk and fast take away food that can cause constipation or diarrhoea and decrease their appetite for other healthy foods. If your child is a fussy eater, you may need to be referred to a dietician;
- Introduce your child to the potty/toilet – limit toilet time to no more than 10 minutes. Ensure that your child can sit safely and comfortably, supported or unsupported, with his/her feet placed on a firm surface such as a footstool of correct height – see “Rock and Pop” pamphlet;
- Regular emptying of the bowels should be encouraged. Get to know your child’s likely time to empty their bowel – use a bowel diary if necessary. The best time is after breakfast or other meal times when natural bowel movement is most active. Important to stick to a routine – the same time every day to get the bowel emptying on a regular basis. May need to use a suppository or microlax enema;
- Anal plugs can be used for swimming to prevent bowel accidents in a swimming pool;
- Discuss a bowel program with your doctor or clinic nurse at your hospital Spina Bifida Clinic visits;
- Maintain an adequate intake of clear fluids – mainly water as cordial and fruit juices are high in calories and can cause weight gain.
SCHOOL YEARS (5 – 18 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 –**

- Continue yearly kidney tests or as advised by your doctor and continue their bladder emptying program e.g. clean intermittent catheterisation;
- For many children the need to catheterise during the school day is essential. An early meeting (1 year prior to commencement of school) with the prospective school will help to organise funding for a teacher’s aide and for training of school staff about your child’s special needs. Appropriate facilities at school should be available for the children to carry out their continence management – an occupational therapist will usually need to visit the school to make sure it is suitable for your child;
- At the preparation for school meeting – toileting requirements are:
  - private bathroom for catheterisation and changing continence pad;
  - a sink of correct height with hot and cold running water;
  - liquid soap, paper towel and a rubbish bin;
  - a cupboard for storing supplies and change of clothes. Your child may also require a height adjustable change table for the kindergarten year. Maintaining the child’s privacy is essential. The child will probably need one catheter per day at school but two continence pad changes (at catheter time and again after lunch break).
- Once your child starts school, start encouraging your child to take an interest in assisting with catheterisation e.g. washing hands; getting equipment ready; removing catheter. Self-catheterisation usually happens around the age of 8 – 10 years depending on level of disability and cognition. Girls require patience and regular practice to achieve their goal of self-catheterisation – school holidays are a good time to practice when there is no pressure to get ready quickly.
- From 5 years of age, start to encourage your child to change their own continence pad and to clean themselves after bladder or bowel accidents – you may need an occupational therapist for guidance and provision of appropriate equipment;
- The CAPS (Continence Aids Payment Scheme) is available to children once they turn 5 years with permanent severe incontinence – see separate information sheet on Continence Aids Schemes.
- By the time your child starts high school they would usually be independent with their continence management and not require a teacher’s aide but will need a private bathroom and access to help if needed;

**Bowel –**

- Soiling can be particularly distressing for children in school. It is essential to establish and maintain a good bowel regime to avoid this. Discuss with your doctor or clinic nurse at Spina Bifida Clinic visits as there are several options to achieve adequate bowel continence.
• Help your child to be prepared for bowel accidents and encourage them to seek assistance if this happens at school. They need to be aware of what foods or situations are likely to cause bowel accidents. Eating spicy foods or beans can cause flatulence and loose bowel motions and sharing food with other students can change a bowel pattern. Continue to avoid constipation as this can cause overflow diarrhoea and can interfere with bladder function and make any urinary problems seem worse.

• Remember to encourage your child to drink adequate amounts of water during the school day – take a bottle of water to school and mention this to his teacher or teacher’s aide.

• A communication book for your child between home and school can be of great assistance to know if supplies are getting low and if bladder/bowel accidents are becoming a problem. Talk to your clinic nurse if accidents are becoming a problem as there are solutions.

• A variety of surgical and other conservative options are available for bowel management e.g. bowel washouts. These are only considered if the normal bowel regimes have not been suitable for your child.

INTO ADULT LIFE:

• During childhood, annual Spina Bifida Clinic visits should have been carried out as a matter of course. Puberty may bring about changes in bladder and bowel routines, incontinence may get worse and management more difficult. Discuss any health changes with your doctor or Spina Bifida Clinic nurse;

• Yearly kidney tests are to be continued for life to monitor kidney function;

• Transition to adult health services is often a difficult time as partnerships have been closely formed with your paediatric medical team but this needs to be discussed at your Spina Bifida Clinic visits in the teen years.

• It is also helpful if the young person begins to see the doctor alone at Spina Bifida Clinic visits to get them used to managing their own health care. This can depend upon their level of cognition but is to be encouraged from 15 – 16 years of age. The parents or carers can be involved at the end of the consultation.

• It is advised to continue regular consultations with an Adult Spina Bifida Service which is helpful to monitor general health and also to keep up to date with current research and treatment options.

USEFUL WEBSITES:

KIDS REHAB SPINA BIFIDA SERVICE – The Children’s Hospital at Westmead (part of The Sydney Children’s Hospital Network) – Compiled by Julie Dicker – Spina Bifida CNC - March 2013