Continence Management for Children with Spina Bifida

Spina Bifida, meaning ‘split or divided spine’, is one of the most common birth defects in the western world, affecting one in every 500 pregnancies. The term refers to a neural tube defect that happens in the first month of a pregnancy when the spinal column of the baby doesn’t close completely. This results in the baby being born with exposed nerves or damaged vertebrae, neither of which can be repaired.

People with Spina Bifida experience reduced mobility due to paralysis and impaired sensation to lower limbs, and often Hydrocephalus, an abnormal accumulation of cerebrospinal fluid in the brain that often requires sufferers to have surgically implanted shunts to drain the excess fluid into another area of the body. Another effect of the condition is Neurogenic bladder and bowel, a urinary problem in which the bladder does not empty properly, with resulting incontinence.

**Bladder Management**

The key to a healthy urinary system for Spina Bifida patients is regular and complete bladder emptying, managed by clean intermittent catheterisation (CIC) four to five times per day and often supported by medication such as Oxybutynin which facilitates storage of urine between catheterisations.

As no two children with Spina Bifida are the same, a personalised management strategy needs to fit in with the family situation, activities and lifestyle, as well as the age and development level of the individual. Teaching self-CIC depends on cognitive ability, level of disability and whether or not hydrocephalus is a factor, as children with hydrocephalus tend to have increased learning difficulties. For example, it can take twice as long for someone with Spina Bifida and Hydrocephalus to learn how to complete a procedure or routine than an average person. These patients often lack motivation and may have difficulty with spatial awareness, organisation and planning and this means tasks and self-care procedures need to be taught with great patience, reinforcement and repetition. Breaking down tasks into small steps and using checklists can be very helpful. It is also important to remember that once a sequence or procedure is learned, it is very difficult, if not impossible, to change.

Some key educational aides for paediatric care can include the use of videos, flash cards, colouring books and dolls. Most children with Spina Bifida will also require continence pads of varying size and absorbencies, while adolescent males may sometimes use a penile appliance. Regular renal tests and urodynamic testing as required are also important elements of bladder management and a renal scan can be useful if there is any concern about renal scarring.

**Bowel Management**

Instituting a regular bowel management program as soon as possible is also important. A “Toilet timing” program emphasising a regular, consistent routine, commences around two years of age. Here, avoiding constipation through the regulation of diet, exercise and fluid intake is vital, along with regular evacuation of the bowel (usually daily after breakfast or after dinner) with a suppository or Microlax enema as required. Stimulant laxatives should be avoided. Youngsters need to be taught to know their own bodies, be observant and to anticipate higher risk times for accidents.

**The Long Haul**

People with Spina Bifida will often require multiple hospital admissions throughout their youth and so will often avoid coming to hospital as an adult. This means home-visits and building a strong relationship with youngsters is crucial in maintaining consistent care. Promoting independence at different ages and stages of life where appropriate can also help develop lasting self-care strategies.

Spina Bifida is a lifelong condition so working with those affected can involve years of support and advice, even assisting families with the transition to adult health care services. As such, working in the early years with families and schools, not just individuals, is the best way to create a holistic network of support and education for children with Spina Bifida to ensure their continence concerns are managed in a sustainable way, allowing them to live as normal a life as possible.

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