# NHS

## Spina Bifida

#### Long-term bowel management

Children born with spina bifida usually have damage to the nerves that control bladder and bowel function (this is referred to as neuropathic or neurogenic bowel).

It can result in

- Slower bowel function which can cause constipation
- Weaker anal muscles making it more difficult to hold the poo in
- Reduced sensation to know that the bowel is full and needs to be emptied.

These problems can be mild to severe.

During the first years of life, the aim of bowel management is to avoid constipation as this will stretch the lower bowel making management in the future more difficult. An over-full bowel can also affect the bladder emptying and may increase the risk of urine infections. It is important to manage the bladder and bowel together from birth.

Usually a baby with spina bifida will pass poo without problems. The poo should be soft and easily passed. If it is small, hard and difficult to pass you should contact your GP or the Nurse Specialist as your baby may require laxatives.

Simple measures such as massaging the buttocks or bending the legs up towards the tummy can help the baby to pass poo.

#### Weaning

As your baby starts to eat solid foods, it is likely that the bowel pattern will change. It is important to introduce fruit and vegetables and plenty fluids e.g. water and apple juice. Your Health Visitor will advise on this.

If the poo is hard or difficult to pass, please contact the Nurse Specialist for advice.

#### **Toilet training**

Toilet training a child with spina bifida can seem like a challenge. However, this stage should not be delayed. It is good to get your child to sit on the potty or toilet after meals as the bowel is most active then. When using the toilet, a child seat and a stool to support the feet should be used. Encourage your child to push by introducing blowing games as this increases the pressure in the tummy. Your child may not pass any poo but should always be praised for sitting on the toilet. This routine will help prepare them for future bowel management.

Some children may require adaptations to the bathroom or toilet to allow them to sit safely e.g toilet seat with handles. An Occupational Therapist will assess what is required.

#### **Bowel management**

During the pre-school years, we will assess your child's bowel pattern.

The goal is to

- Avoid bowel accidents
- Maintain poo consistency (avoiding constipation or diarrhoea)
- Achieve social continence (reduce the need for nappies)

Some children will pass a poo every day at the same time. Others do not have a reliable pattern.

There are several options for long-term management:-

- Dietary adjustments
- Toileting programmes
- Oral laxatives
- Rectal irrigation (see below)
- ACE procedure (see below)

Following assessment and discussion with you, we will advise what may be best for your child. The majority of children with spina bifida will require rectal irrigation.

This is best introduced in the year before school when the child is slightly bigger and likely to be more compliant with sitting for a longer time on the toilet.

### **Rectal Irrigation**

This is a way of emptying the poo from the bowel by inserting a soft tube or catheter into the anus and allowing water to run in from a fluid bag. The poo is loosened and then passed into the toilet.

There are 2 types of equipment. The Nurse Specialist will discuss the options with you and then decide what may suit your child best.

We will provide a DVD and booklets to explain it to you and your child.

### **ACE** (antegrade colonic enema)

Rectal irrigation usually works very well. However for a small number of children it is not fully effective.

The ACE procedure is an operation to form a channel on the tummy, usually using the appendix. A catheter is inserted to allow the washout fluid to flush the poo out into the toilet. The process can take 20-30 minutes but usually keeps the child clean for 1 - 2 days.

This surgery will only be considered at an older age.

Effective bowel management requires time and commitment but this is very worthwhile. Each child is an individual and it is important to work together to achieve the best possible outcome.

#### Contacts

Stoma & bowel management Nurse Specialists

Royal Hospital for Children and Young People

50 Little France Crescent

Edinburgh

**EH16 4TJ** 

Tel: **0131 312 0584**