

# An ACE way to independence

Some people with spina bifida suffer from constipation which does not respond to a regime of high fibre diet, suppositories, medication and exercises to promote daily emptying of the bowels.

The bowel has the ability to stretch and accommodate large quantities of faeces. The more it stretches, the more difficult it is to empty. This causes the faeces to remain in the large bowel for long periods, during which time water is removed from the faeces, giving hard, dry stools. This makes it even more difficult to empty the bowels. When every effort has been made to restrain the bowel, without success, high bowel washouts may offer a solution.

The rectal washout involves running a specified amount of normal saline into the rectum via a special catheter. There are several options to be considered when choosing a catheter.

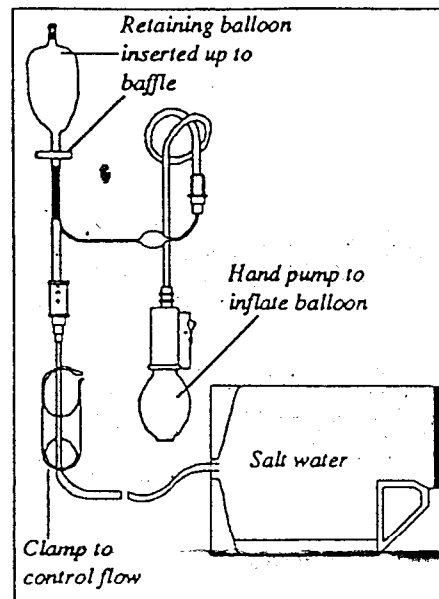
The Canadian, Toronto or Cardiomed catheter which was specifically designed for this task, is not available on prescription and costs about £100. Some hospitals will purchase the catheter for patients, but this is not always possible.

Stoma washout kits are perfectly adequate for some people and these kits are available on prescription.

Large Foley catheters may also be used and are readily available.

The Canadian and Foley catheters have retaining balloons. The bag of saline (20ml per kilo of body weight), which is warm tap water with salt added at one teaspoon per pint, is positioned four feet

*Jane Williams, ASBAH continence adviser, explains how Bowel Washouts can be used to achieve independence in continence management.*

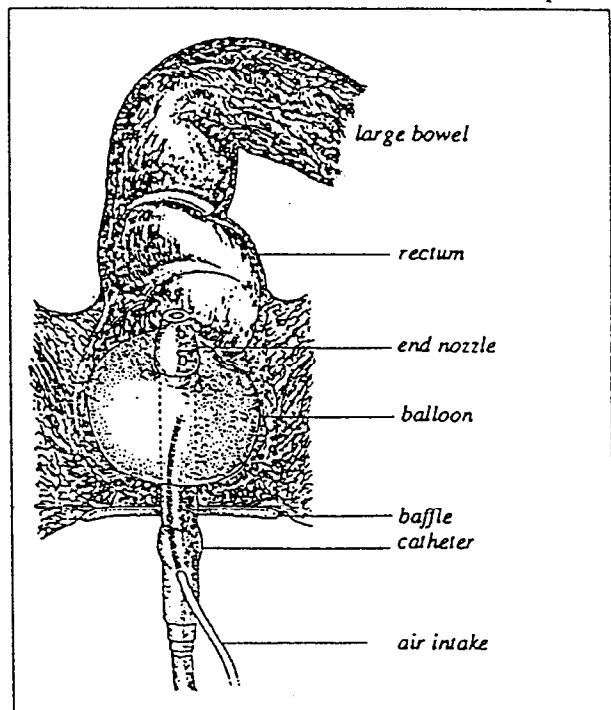


above: The Cardiomed Enema Containment catheter

above the toilet, giving force to the water flow. Once the solution is put in, the catheter is removed and the contents of the bowel, plus the saline, empty into the toilet. The procedure requires a certain amount of agility, good balance and several pairs of hands! Once accustomed to the procedure, some people can manage independently.

If the washout system works well for you, but does not give you full

independence, you may be interested in the ACE surgical procedure which was developed to aid independence. The appendix is removed from the large bowel, with its own blood supply, and inserted into the first part of the large bowel, so as to form a flap valve. The other end is brought out onto the front of the abdomen to form a stoma which looks rather like a belly button. It is not like a conventional stoma. (NB different surgeons use different techniques and, therefore, the appearance of the stoma varies). This gives a catheterisable channel through which a soft catheter is passed and either saline, at a rate of 20ml per



above: Cross section of lower bowel showing Cardiomed inserted

kilo of body weight, or a phosphate enema, or a combination of both, is passed. Again, the fluid is put in under pressure (ie from a height of four feet) whilst sitting on the toilet. The contents of the bowel is evacuated into the toilet. The stoma is a continent stoma, so when the catheter is removed there is no leakage.

Both methods should take about half an hour, every other day. Some people have to do it more often, some less. If left too long between washouts there may be problems with constipation.

When changing to either of these methods the bowel needs to be empty before starting the programme. If hard stools remain in the bowel there can be many problems. For people with spina bifida this can take a week of strong laxatives and/or enemas with possible 'accidents' and it can be a difficult period.

The surgery involved for the ACE is not major. There will be a small scar around the stoma and another 4-5 inch one across the lower abdomen, usually in a natural crease. As with any bowel surgery there is nothing to eat before and after the operation. Only clear fluids are given post-operatively until they are sure the intestines are working. The first washout will be approximately a week later, (this varies between hospitals) through a catheter which was inserted at the operation. There may not be a good result with the first washout. This catheter usually remains in place for a few days, until the stoma is healed. Different surgeons have different regimes. It may be necessary to begin to take Lactulose and continue that to keep the stools soft - this may discontinue later.

Depending on the hospital, discharge can be 48 hours after the operation, returning after one week for the first washout. There is a period after this, when the system needs to 'settle down' and changing the amount/type of fluid

is necessary to find the best method for that person. For some, things seem to work out quickly but for others perseverance is necessary. There may be times when things do not go to plan (for example, with tummy upsets and the use of antibiotics) but there may be ways to overcome these problems.

Several ACE operations have now been performed - mainly at the Hospital for Sick Children, Great Ormond Street and at Southampton. At a recent meeting about the procedure at Great Ormond Street, it was generally thought to be a very successful operation. However, as with all surgical procedures, it is not without its problems. Some of the following points were raised.

#### Patient selection

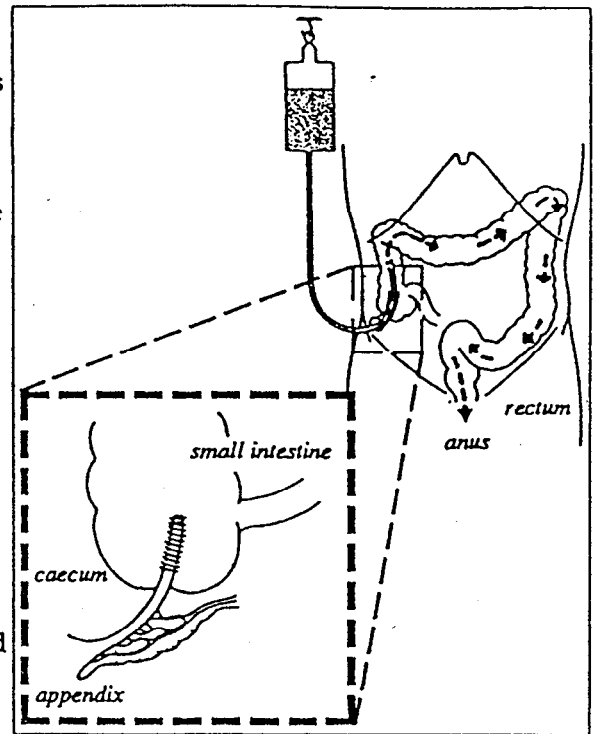
The child or adult themselves must want to use this method of continence management and be prepared to work hard to achieve success. They should have tried all the simpler methods first. Therefore this procedure is not likely to be offered to very young children.

#### Complications

Stenosis - (narrowing) of the stoma has been a problem but techniques are improving. It is thought that catheterising the stoma daily (even if washouts are not done daily) will help to stop this.

Other surgical complications - such as adhesions (tissue 'sticking' to the tissue where it should not) and infections.

Phosphate Toxicity - at the meeting, one case of phosphate toxicity was mentioned. the child had been given a phosphate enema which was not expelled and



above: The antegrade continence enema (ACE)

another was given, which was also retained. This allowed absorption into the blood stream and the child became very ill. The phosphate enema is thought to be safe as long as it is not retained for long periods.

The complication rate is quite low and re-operation has solved the difficulties. There are a couple of people to-date who have decided not to continue doing the washouts.

On the positive side, many of the children gained increased confidence, improved lifestyle and were able to do many activities that had not been possible previously, such as swimming.

Most health authorities have a continence adviser working in the community. Your local continence adviser may be able to advise you on the best method of bowel management for you and may well be able to obtain the necessary equipment and provide, or arrange for instruction.

If you require further advice, please contact Jane Williams or Mary White, ASBAH Continence Advisory Service.