



Spina Bifida Hydrocephalus
Queensland

INFORMATION SHEET

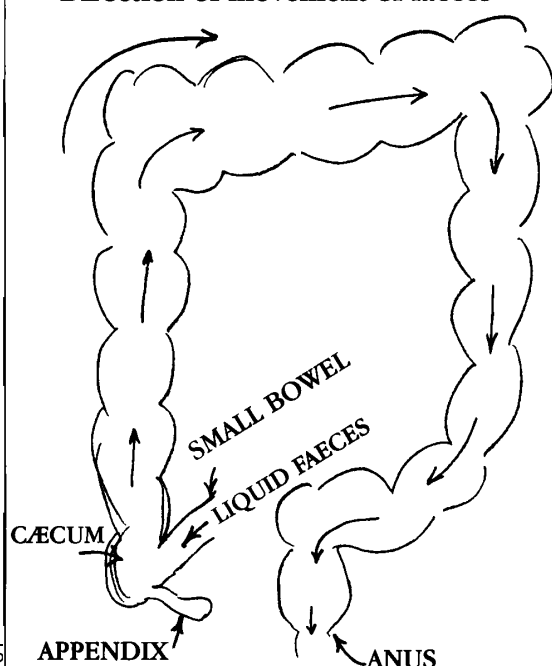
Living life with dignity The MACE Procedure

The urologist has two important goals in the management of a child with the spina bifida anomaly; ensuring the child's good health; and allowing the child to live with the same dignity as its fellow human being. While many things contribute to human dignity none of us would argue that being clean, dry and independent are all exceedingly important factors. The subject of this paper is the contribution that the MACE procedure makes to the maintenance of human dignity.

MACE is an acronym for Mitrofanoff for Antegrade Colonic Enema. Mitrofanoff is a French urologist who popularised an operation whereby the appendix was implanted into the bowel or bladder to create a one-way valve. Sometimes the "M" is used to represent Malone, who was the first surgeon to report this surgical approach to the management of constipation and faecal incontinence.

anatomy of large bowel

Direction of movement of faeces



The Problem

The small bowel delivers liquid stool (faeces) to the large bowel one of whose functions is to absorb much of the water out of the liquid faeces and return it to the body. By doing this, the stool becomes firmer and takes on the consistency with which we are all familiar.

People with spina bifida or similar anomaly usually have an abnormal nerve supply to the bowel and bladder. Because of this the bowel can only move the faeces fairly slowly and this permits the colon to absorb more than the usual amount of water. The faeces therefore can become very hard making evacuation difficult and causing constipation. Despite what is now a long

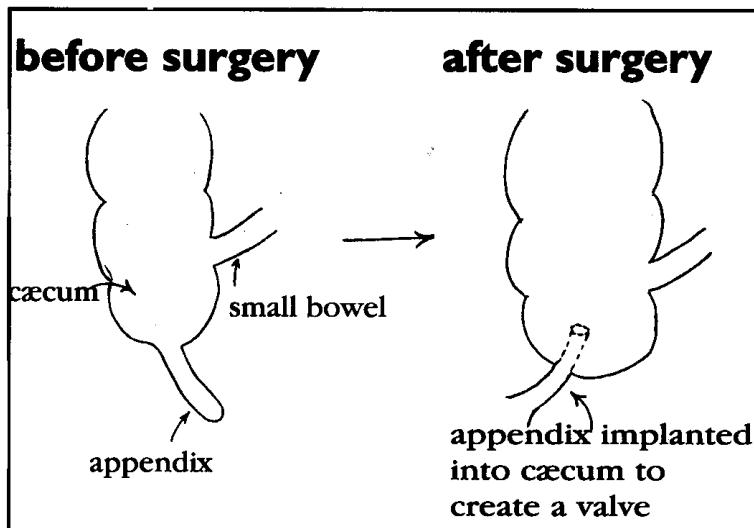
column of hard constipated stool, liquid faeces continues to be delivered to the "top" end of the colon. It runs around the column of stool and out of the anus giving the impression that the person has diarrhoea and often causing faecal incontinence.

The traditional method of dealing with constipation in people with a neurological abnormality has been the use of laxatives and *retrograde* enemas. There are unfortunately three problems with this approach:

1. It does not work - because the enema is run in backwards from the anus it can at best only soften and wash out a small quantity of stool
2. It usually does not allow the person to become independent of a carer, and
3. People's image of themselves is not enhanced by having to insert a tube up their own back passage every day.

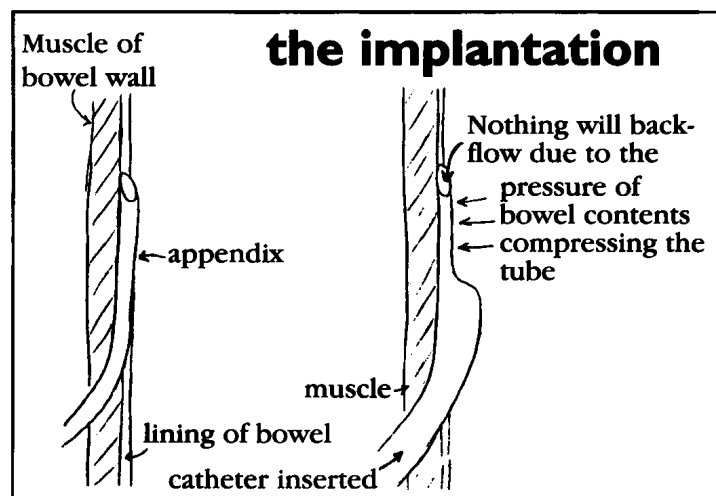
In other words it does nothing for a person's dignity.

The MACE Procedure



The operation uses the appendix, or if it has been removed, a similar sized tube fashioned out of bowel. The appendix or tube is implanted into the caecum, the "top of the colon", to create a valve. *See the diagram on the left.*

The valve allows a catheter to be inserted into the colon, but stops anything coming out in the opposite direction at all other times. *See the diagram on the right.* The outside end of the appendix or tube is attached to the skin, either at the umbilicus (belly button) or somewhere else on the abdomen, creating an opening known as a stoma.



Using the MACE

About three weeks after the operation the colon is thoroughly cleaned of any constipated stool using Golitely (or another colonic lavage preparation) by running it through the MACE stoma. Thereafter the person or their carer inserts a small catheter into the stoma and runs in an enema solution while they are sitting on the toilet. Because this is done regularly there is no hard stool in the colon and the clean out usually takes from 15 to 45 minutes. The enema is generally used every day although some people only need to use it every two or three days.

The Enema Solution

Everyone's colon works a bit differently and so it is frequently necessary to individualise the solution for a person. A phosphate enema (Travad; Fleets) is the solution most commonly used although some people find normal saline (one teaspoon of salt to 500-ml tap water) just as good and occasionally even better. The smallest volume of the solution that gives the desired result, is the most appropriate dose.

Some people find that despite a good result from the enema there is some further loss of liquid for an hour or so after leaving the toilet. Using some Metamucil or a similar product can often prevent this from happening. These agents soak up the excess fluid giving more consistency to the stool but without letting it become hard.

The results

The urologists at the Mater Children's Hospital have been performing the MACE procedure since 1992. They have an accumulated experience of almost 50 patients.

All patients continue to use the procedure and seem pleased that they have had it done. Although some people still experience occasional episodes of soiling, particularly in the hour or so after the enema, most remain reliably clean.

No procedure is without its complications and this one is no exception. The commonest problem has been a narrowing of the opening where the appendix meets the skin, a so-called stomal stenosis. This is easily corrected by a small operation at skin level. There have been a number of other less common problems although all can and have been corrected. Our extensive experience with this operation ensures that the complication rate is now quite low.

Choices

How should you decide whether you (or your child) should have this operation? Firstly you need to be fully informed about the operation and you can only do this by talking to one of the surgeons who performs it regularly. You should know that there is often a tendency for surgeons to genuinely think that their operative results are better than might actually be the case. So you should also get the names of a few people who have had the operation and find out what they think and what they have heard about the results from other children or parents.

If you are still not sure you might want to get another opinion from a different expert. This is the only way you can be fully informed about your choices. In the end however you are the only one who can decide what is best for you or your child.

The goal of the MACE procedure is to provide a good quality of life. It is to permit people with a neurologically abnormal bowel to live life with dignity.

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