



**PARENTS OF STOMA CHILDREN.**

**What is an stoma or related procedure?**

This is probably the first of many questions parents will ask. An stoma is a surgical opening in the abdomen (tummy) through which waste material is discharged when the normal function of the bowel or bladder is lost. The child may wear an external appliance to collect the wastes, or have a procedure where an internal pouch is created. Children may have permanent or temporary ostomies. Temporary ostomies are reconstructed after a period of time, but there may be long term problems of bladder and / or bowel control that need to be addressed.

Often parents need immediate information and a shoulder to lean on. Children may require stoma surgery either at birth because of a birth defect, or at a later age. In any situation, due to disease or trauma, stoma surgery is usually only part of the health issues faced by the child.

**Why do children have stomas?**

Children may require stoma surgery for various reasons including, but not limited to, the following:

<b>Birth Defects:</b>	<b>Diseases:</b>
<input type="checkbox"/> Imperforate Anus	<input type="checkbox"/> Hirschsprung's
<input type="checkbox"/> Bladder / Cloacal Exstrophy	<input type="checkbox"/> Crohn's Disease
<input type="checkbox"/> Spina Bifida	<input type="checkbox"/> Ulcerative Colitis
	<input type="checkbox"/> Cancer
	<input type="checkbox"/> Familial Polyposis
	<input type="checkbox"/> Motility Disorders

**Some Useful Resources in dealing with these conditions:**

- **The Pull-thru Network (Congenital anorectal malformations)**
- **Spina Bifida Association [www.asbah.demon.co.uk](http://www.asbah.demon.co.uk)**
- **The Guardian Society (Hirschsprung's & motility disorders) [info@theguardiansociety.org](mailto:info@theguardiansociety.org)**
- **Association for Bladder Exstrophy Community (bladder/Cloacal Exstrophy)**
- **Crohn's & Colitis for Children (CICRA) [www.cicra.org](http://www.cicra.org)**

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**Why support for families and children?**

A child's stoma surgery affects everybody in the family. Parents find themselves facing situations for which they are usually unprepared. They must quickly acquire new knowledge and skills to care for their child and at the same time, deal with their own fears and anxieties.

Parents whose child requires a stoma may feel a range of emotions. Parents who have similar health issues are able to respond to some of the anxiety new parents feel, as well as, offer suggestions for clothing, nappies, support groups and socialising.

Parents whose child requires a stoma may feel guilty, wondering what they could have done to prevent the problem. They may question the future:

- How will my child fit in at school?
- Will he/she be able to participate in sports?
- Will our family ever be normal?

Children may sense these parental anxieties and may assume a similar attitude. If parents are able to gain a positive outlook, the child will also remain positive.

### AN INTRODUCTION TO COLOSTOMIES.

It is a frightening thought to have a baby with a colostomy, but as a child, (born 1948), who was born with spina bifida and with an imperforate anus, it is something my family and I had to accept and cope with.

A colostomy is the special name for an operation to make an artificial anus by using the colon (large bowel). To understand this, we need to know the digestive system and how it works.

The digestive system is basically a long tube, which runs from the mouth to the anus. It has several loops and coils. Starting at the mouth, food and liquid passes straight into the stomach which acts like a liquidiser, churning food in the digestive juices and passing it into the small intestines (bowel). Some nutrients from the food are now absorbed to provide energy and materials the body needs to keep healthy.

At the end of the small intestine, digestion is complete but the contents are still in liquid form, so the colon has the job of taking water back into the body leaving behind waste material in a semi-solid form. It is then stored in the rectum before being expelled from the anus at a convenient time or in babies as a reflex action. This process usually takes several hours.

As children with imperforate anus have no anus and often no rectum and some colon missing, it is necessary soon after they are born (within days) to make this artificial anus – colostomy. It is usually only temporary until the surgeon can make an anus and pull the bowel down into the correct place.

During the operation a piece of colon is pulled through a cut in the abdomen, cut through and attached to the skin surfaces. This new end of colon is now called a **stoma** (this is a Greek word for opening or mouth). This has now made an opening for the faeces (motions).

The stoma looks like a small bud or raspberry and is very similar in colour to the lining of the mouth. It has no muscle control and means waste material may be

looser than normal. A bag or pad is used to cover the stoma so that it may catch the motions. There is nothing to be ashamed of in having a colostomy. Many famous people have them and manage to live very full and normal lives.

There are many types of appliances today, which were not about during my early days, which can be used with your child's colostomy. It is often a case of experimenting with different types until you find one that suits the child. The hospital stoma care nurses will probably show you different types, but your health visitor will also arrange an appointment with a stoma care nurse in your area. She will come to your home and will help you to decide which bags etc, are most useful to you. These then are provided on prescription by your family doctor free of charge.

**Problems that may arise.**

1. **Surface bleeding of the stoma:** This can sometimes happen if you are too vigorous in your cleaning routine, or if a knock or fall happens. There is no cause for alarm.
2. **Constipation:** The easiest way of avoiding constipation is to give the child extra fruit purees (if weaned) or fruit juices. Try and give extra fluids between feeds.
3. **Diarrhoea:** With a colostomy, there is no more reason why you should experience diarrhoea than anyone else. Having said that, certain foods do have a tendency to cause it. With a little detective work you can soon discover the culprit and adjust babies/child diet. If diarrhoea persists however let your doctor know.
4. **Skin Soreness:** Try to avoid this in the first place by making sure that the bag fits the stoma well, avoiding leakage. Remember never to remove the appliance too quickly, and to clean where possible. Witch Hazel is a good cleaning agent.