

Associations

The British Colostomy Association has information regarding children with Colostomies.

British Colostomy Association

15 Station Road, Reading,
Berkshire, RG 11G.
Tel: 0800 3284257

The Ileostomy Association and the Urostomy Association have information regarding children with stomas. They may also hold local meetings in your area.

Ileostomy & Internal Pouch

Support Group

National Secretary, Bruce McKenzie
PO Box 132, Scunthorpe,
DN15 9YW
Tel: 01724 720150

Urostomy Association

National Secretary, Mrs Angela Cooke,
Buckland, Beaumont Park, Danbury,
Essex, CM3 4DE
Tel: 01245 224294

There is also an association specifically for parents who have children with stomas.

National Advisory Service For Parents Of Children With A Stoma

Mr John Malcolm
51 Anderson Drive, Valley View Park,
Darvel, Ayrshire, KA17 0DE.
Tel: 01560 22024

Local Groups

Some local and regional support groups may have been set up in your area.

Ask your stoma care nurse for details.

Children with a stoma



Written by
Joanne Haines R.G.N.
&
Elizabeth Sharples R.G.N.

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Stoma surgery in children may occur from the baby to the adolescent. In the case of the very young the psychological effects and emotional responses to the stoma are felt more by the parents and the family.



Helpful Hints

- Answer questions, which are asked by your child. Communicate directly and clearly. Be honest. If you can't answer them ask your Stoma Nurse.
- Share your thoughts with your family – they may be thinking the same things.
- Learn as much as is possible. To help you literature is available from your Stoma Nurse.
- There are many different appliances specifically designed for children which can be sampled, so do ask your Stoma Nurse.
- Inform teachers – your Stoma Nurse can always visit to educate the teachers.
- Teach your child to give detailed instructions on how to change a pouch. You can do this by playing and pretend you know nothing

Possible Reasons for Surgery

Spina Bifida is a condition in which the child is born with a spinal defect and nerve damage to the bladder and rectum may occur. Urinary diversion used to be the main surgical intervention and the child or carer would be taught to carry out intermittent catheterisation. However the trend is now away from surgery.

Imperforate Anus is a congenital condition in which the child is born with no external exit for faeces. A temporary colostomy may be formed as an emergency whilst corrective surgery is carried out to the anus.

Hirschsprungs Disease is a condition in which the lower bowel is devoid wholly or partially of the specialised nerve cells which stimulate muscular contraction in the bowel. Movement of faeces along the bowel is compromised and obstruction can occur. A temporary ileostomy may be formed and the affected part of the bowel removed. Reconstruction of the bowel will be performed later.

Necrotising Enterocolitis is seen frequently in very small pre-term babies who now survive, thanks to the sophisticated support systems and intensive care facilities. The diseased part of the bowel is removed and a temporary colostomy or ileostomy is created while the remaining bowel heals.

Ulcerative Colitis and Crohn's Disease are occasionally found in children. The debilitating nature of the disease causes growth retardation in some children. Surgery with ileostomy formation may be necessary.

- Always take a notebook when seeing a surgeon or Stoma Nurse – never be afraid to ask if you do not understand.
- No one needs to be told i.e. neighbours if you don't want them to know.
- Let your child tell their friends if they want to.
- If your child has a colostomy a drainable pouch can be used on long journeys or at times of diarrhoea ask your Stoma Nurse for details.
- Some accessories i.e. wet wipes, creams, flanges and deodorants are available on prescription – ask your Stoma Nurse.

