

# Our Special Children

A practical guide to stoma care  
in babies and young children



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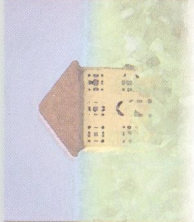
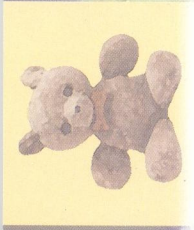
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**N.A.S.P.C.S.**

National Advisory Service for Parents of Children with a Stoma

Charity Reg No 327922. Members of the International Ostomy Associates



## The background to this booklet - from John Malcolm

Chairman/National Organiser NASPCS

In 1984, our twin daughters, Jill and Joanne were born, and Joanne the youngest was born with the congenital defect 'Ectopia Vesicae'

'Ectopia what!' was our reaction back then and as we have come to find out it means 'exposed bladder.'

It was about this time that the charity was conceived, starting as a self-help support group called IMPS and it grew as word spread. By 1988 it became the registered charity NASPCS and since 1990 my wife and I, along with other parents, have been responsible for its operation. Over this period membership has grown steadily, with approximately 650 families as members.

Life is never easy, as we all know, there are good times and bad times and we all hope that the latter pass quickly, such has been Joanne's situation, hospital admissions, time off school and the usual round of urine infections all adding to their toll.

Children will tackle life's problems in their own way. At all times be as honest as possible with your children. In the end it does work out for the best although at the time it leaves you asking 'Have I done the right thing?'

We should give our children more credit than we do, as they are more astute than we realise. At all times be positive even though sometimes it seems there is no light at the end of the tunnel. Progress can be laboriously slow. Persevere, you do get there in the end.

Never hesitate to contact the charity for help as that is what we are here for, to provide you with support and in return gain support from you.

In concluding NASPCS would like to express its deepest gratitude to CliniMed for their support over the years in producing this booklet for us, it has helped many in that time.

*John Malcolm*

John Malcolm

NASPCS



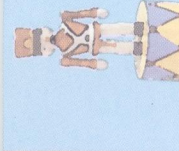
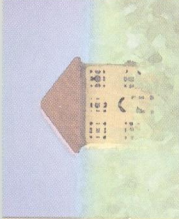
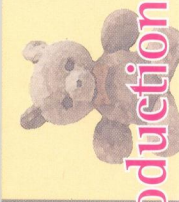
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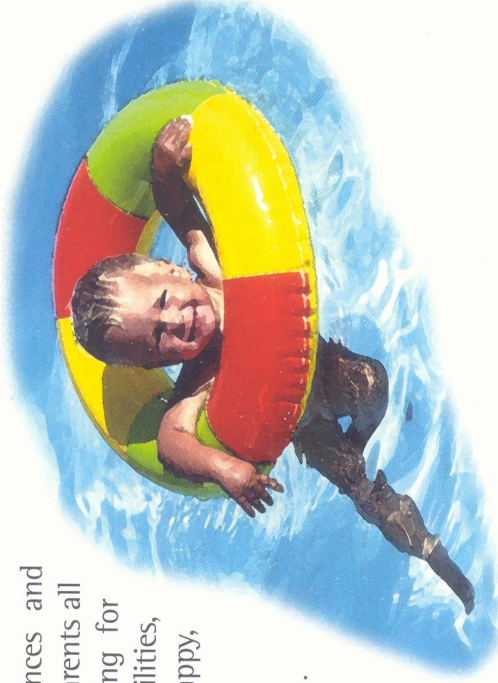
It is a traumatic time when you are first told your child needs a stoma. Surgery may need to be carried out urgently, often within hours of your baby's birth, and there may be little time for consultation and discussion. You will find that hospital staff are caring and supportive, but you may not have been able to take in all the information you need at once.

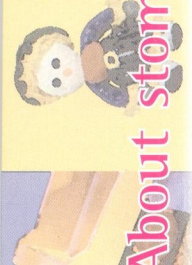
Never be afraid to ask for help, advice and explanations. This booklet aims to give you additional practical advice, reassurance and information about the day-to-day care of a baby or child with a stoma – whether it is created as a temporary or permanent measure – and to answer the many queries that are bound to arise. There is also a list of groups and associations in the back of this leaflet which offer practical advice and emotional support.

Share your experiences and worries. There are parents all over the world caring for children with disabilities, leading fulfilled, happy, normal lives.

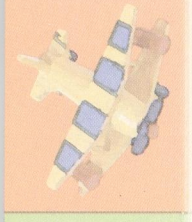
### REMEMBER ...

all children have special needs at some time in their lives – our special children have normal needs at most times.





## About stomas



### What is a stoma ?

The words stoma and ostomy come from the Greek word meaning 'mouth' or 'opening'. Approximately 1/2 inch of the bowel is brought to the surface of the abdominal wall and turned inside out before being attached with small stitches which usually dissolve on their own. Waste matter, evacuation of which cannot be controlled, is passed out of the stoma into a special stoma bag/pouch.

There are three types of stoma

#### Colostomy

An opening made into the large intestine (colon)

#### Ileostomy

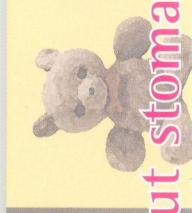
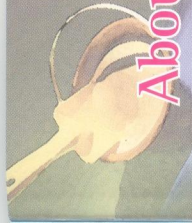
An opening made into the small intestine (ileum)

#### Urostomy

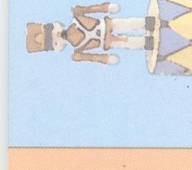
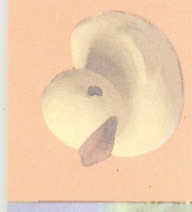
An opening made to divert urine from the bladder

Stomas look like a small bud or raspberry and most resemble the inside of the mouth in colouring. The colour can fluctuate between pale and dark red as the muscles of the bowel contract and relax. This change in colour is normal and should not worry you unless the colour goes very dark and does not fluctuate. Stomas can bleed quite easily but this does not cause pain as there is no feeling in the stoma. The bleeding usually stops as rapidly as it starts.

If you are at all worried about the look of your child's stoma do not hesitate to discuss it with your doctor or stoma care nurse.



## About stomas



### Conditions which require a stoma

Some of the conditions which give rise to a child needing a stoma are listed below. Always ask your child's surgeon or nurse if you want more information.

Keep asking until you get the information you need.

#### Imperforate anus

There is no exit for the bowel or its contents

#### Hirschsprungs disease

Nerves that make the bowel work are missing

#### Inflammatory bowel disease

Includes Crohn's disease and ulcerative colitis

#### Neonatal necrotising enterocolitis

Most common in low birthweight babies

#### Exstrophy of the bladder

The bladder and penis have not formed properly

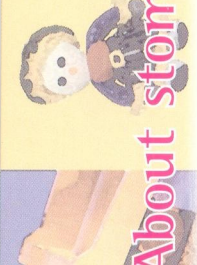
#### Cloacal exstrophy

The large bowel, bladder and penis have not formed properly

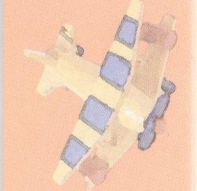
#### Eagle-Barrett syndrome

Urinary problems and absence of stomach muscles

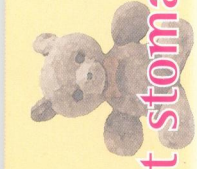
The surgeon will tell you whether your child's stoma is permanent or temporary. Many stomas are temporary and comprise what looks like two stomas side by side or separated. This allows the bowel to be bypassed for a period of rest and recovery. Other children may need to have a stoma for the rest of their lives - often a life-saving measure and one giving a new lease of life.



## About stomas



## About stomas

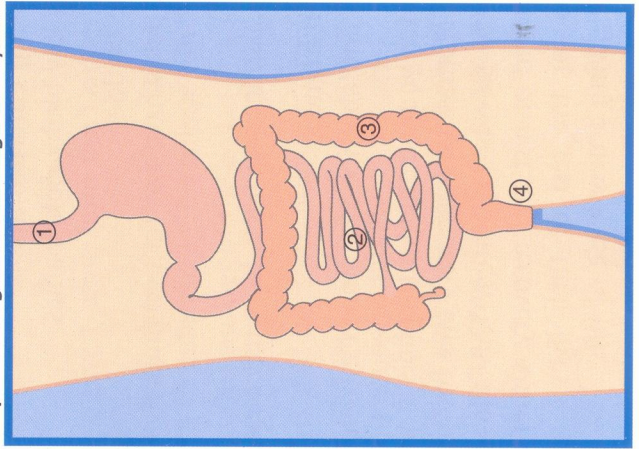


### How the digestive system works

Digestion begins in the mouth. Swallowed food passes down the oesophagus (1) into the stomach where it is mixed with digestive juices and passed into the small intestine (ileum) (2) in a reasonably liquid form.

During its journey through the small intestine most of the nutrients in the food are absorbed into the body, leaving just indigestible matter and water. The large intestine (colon) (3), has the job of taking water back into the body leaving the indigestible or waste matter in a semi-solid form. At the end of the colon, waste matter is stored in the rectum before being expelled through the anus (4) at a convenient time.

Simplified diagram of the digestive system



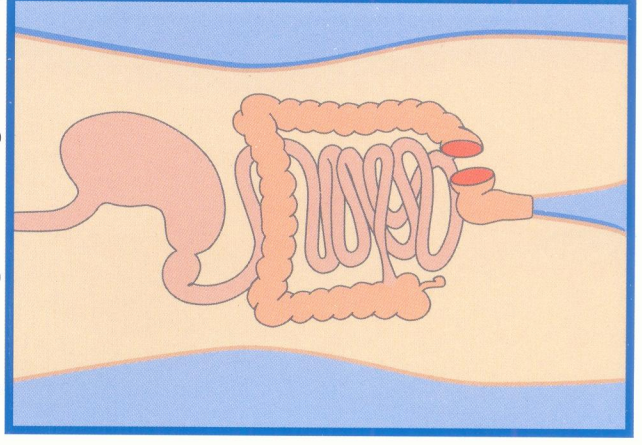
- ① Oesophagus
- ② Small intestine
- ③ Large intestine
- ④ Anus

### The colostomy

A colostomy is formed from the large intestine (colon) and the positioning on the body will depend on how far up the colon the stoma has been formed. Waste products will vary in consistency according to the placement of the colostomy. The further along the colon it is, the more water will have been absorbed and therefore the more solid the waste matter will be.

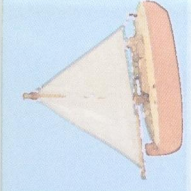
Bowel movements may be fairly regular, with a motion being passed once or twice a day, or sometimes more frequently.

Simplified diagram showing a colostomy

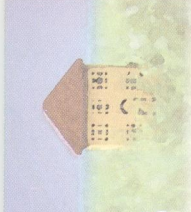
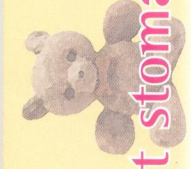




## About stomas



## About stomas

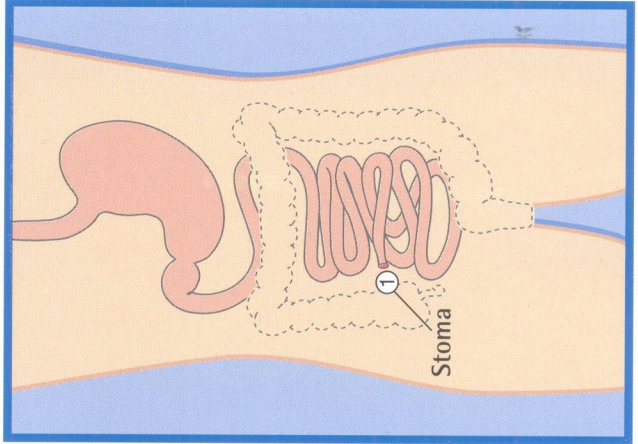


## The ileostomy

An ileostomy is formed from the small intestine (ileum) usually on the right side of the body (1), and the waste from this is always loose. It will also be more likely to cause sore skin if the waste is left in contact with the skin for even a short period of time. Because of this the surgeon will usually make the stoma spout slightly longer to help better drainage into the stoma pouch.

Because the waste matter has not travelled through the large intestine, water, and some minerals will not have been absorbed. The waste materials passed will therefore be very runny and passed frequently.

Simplified diagram showing an ileostomy

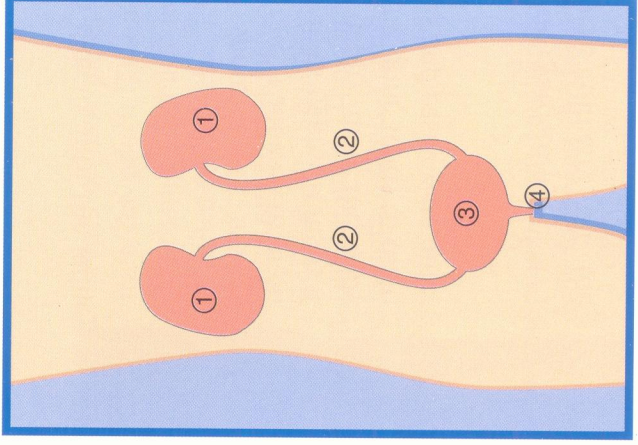


## How the urinary system works

Waste products produced in the body's cells are carried in the bloodstream to the kidneys (1). Waste is filtered out, along with any excess water, in the form of urine. The urine then runs down two pipes, called ureters (2), for storage in the bladder (3).

When the bladder is full, nerves signal to the brain and urine passes out of the body through the urethra (4) at a convenient time. The male urethra is about 250mm (10in) long and passes through to the end of the penis. The female urethra is only 25mm (1in) long and surfaces just in front of the vagina.

Simplified diagram showing the urinary system



- ① Kidneys
- ② Ureters
- ③ Bladder
- ④ Urethra