

# Our Special Children

A practical guide to stoma care  
in babies and young children



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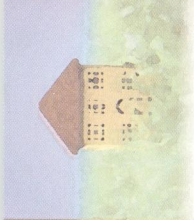
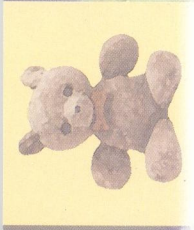
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508/1200

**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





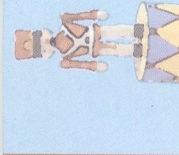
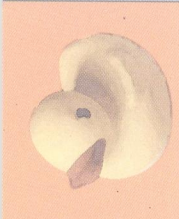
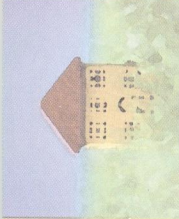
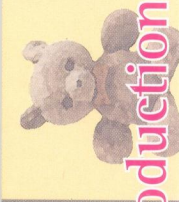
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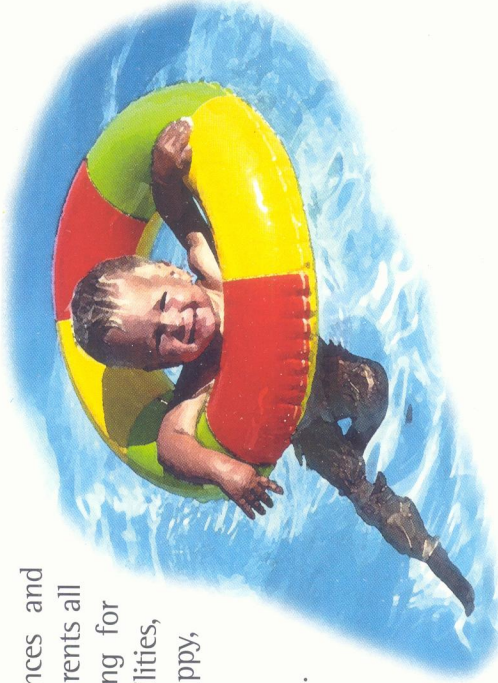
It is a traumatic time when you are first told your child needs a stoma. Surgery may need to be carried out urgently, often within hours of your baby's birth, and there may be little time for consultation and discussion. You will find that hospital staff are caring and supportive, but you may not have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

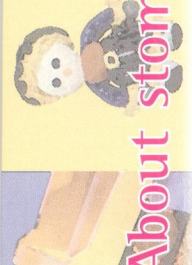
Share your experiences and worries. There are parents all over the world caring for children with disabilities, leading fulfilled, happy, normal lives.

### REMEMBER ...

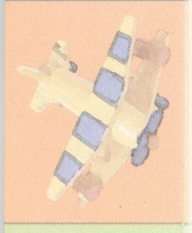
all children have special needs at some time in their lives – our special children have normal needs at most times.







## 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

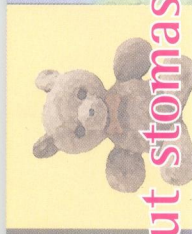
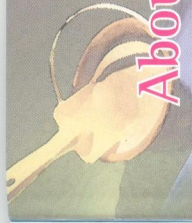
An opening made into the small intestine (ileum)

#### Urostomy

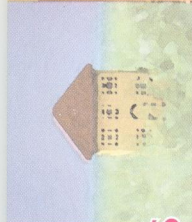
An opening made to divert urine from the bladder

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

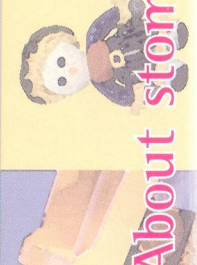
The large bowel, bladder and penis have not formed properly

#### Eagle-Barrett syndrome

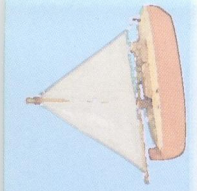
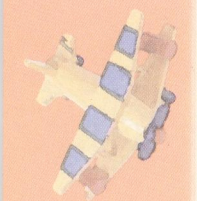
Urinary problems and absence of stomach muscles

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.

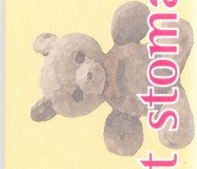




## About stomas



## About stomas

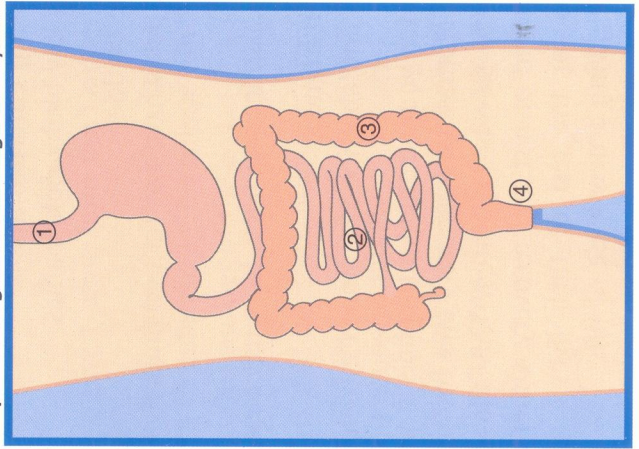


### How the digestive system works

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



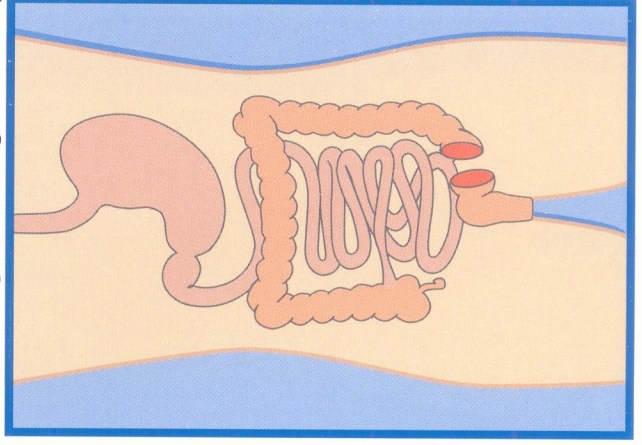
- ① Oesophagus
- ② Small intestine
- ③ Large intestine
- ④ Anus

### 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.

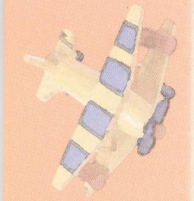
Simplified diagram showing a colostomy



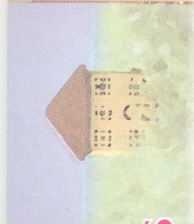
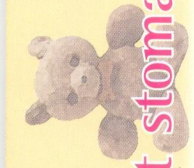




## About stomas



## About stomas

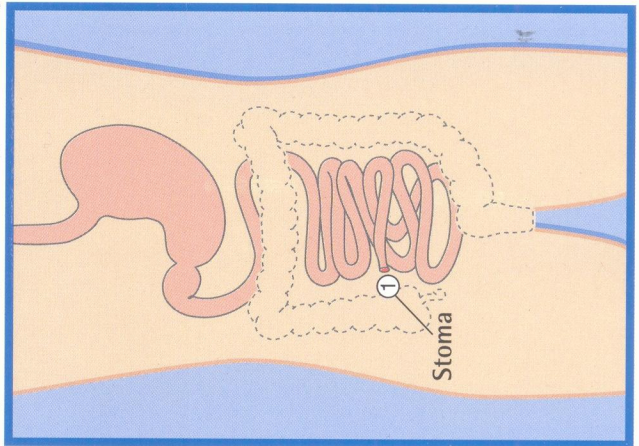


## The ileostomy

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

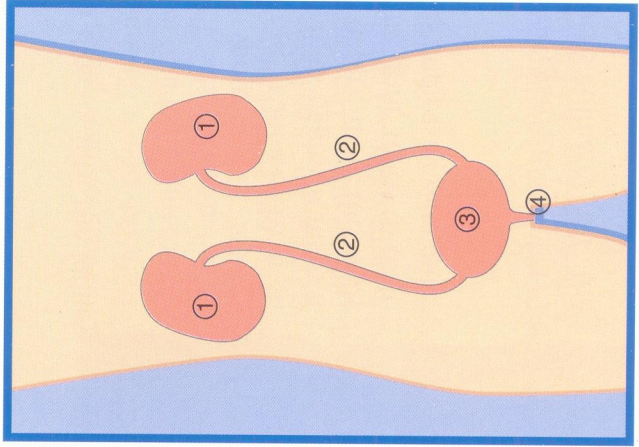


## How the urinary system works

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).

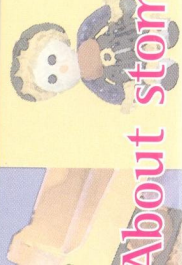
When the bladder is full, nerves signal to the brain and urine passes out of the body through the urethra (4) at a convenient time. The male urethra is about 250mm (10in) long and passes through to the end of the penis. The female urethra is only 25mm (1in) long and surfaces just in front of the vagina.

Simplified diagram showing the urinary system

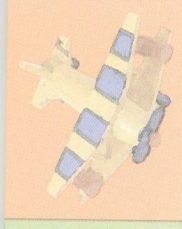


- ① Kidneys
- ② Ureters
- ③ Bladder
- ④ Urethra





## About stomas



### The urostomy

any condition that seriously interrupts the normal flow of urine may lead to a urostomy. A urostomy may be sited in one of several places according to the condition that required it to be formed.

#### Types of urostomy

##### Ileal conduit

The commonest method of diverting urine in children. A stoma is formed, very similar to an ileostomy is formed when the surgeon takes a piece of bowel, usually the ileum and isolates it from the rest of the bowel which is closed again. The small length of bowel is brought through the abdominal wall to form the stoma and the ureters are implanted into the other end which is closed to form a one way conduit for the drainage of the urine.

##### Nephrostomy

A tube is inserted directly into the kidney to bring the urine to the outside.

##### Ureterostomy

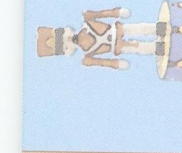
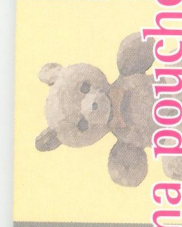
An actual stoma spout is not usually formed and the urine is allowed to drain directly into the babies nappy. It helps if slightly larger nappy than the baby needs is used as the urine tends to drain to and to the sides and easily wets outer clothing.

##### Vesicostomy or cystostomy

The bladder opens directly on the abdominal wall.



## Stoma pouches



Your stoma care nurse will be able to show you a selection of pouches available. There are a variety of types and sizes but the basic requirements are:- a well fitting, comfortable pouch which is non-irritating, odour proof and with sufficient capacity to allow for a reasonable time between emptying or changing.

Pouches are attached to the skin by a special adhesive skin barrier or flange. These flanges also protect the skin from contact with waste matter which can make the skin very sore. The flanges are attached to the stoma pouches in two ways.



### One piece systems

Flanges are made attached to the pouch.

### Two piece systems



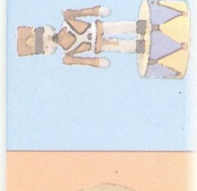
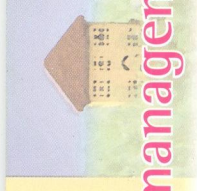
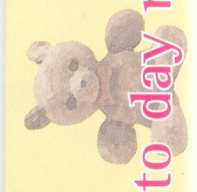
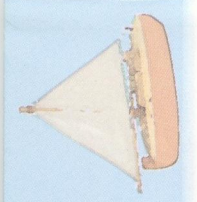
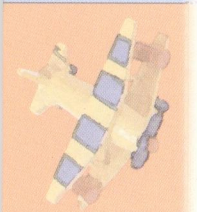
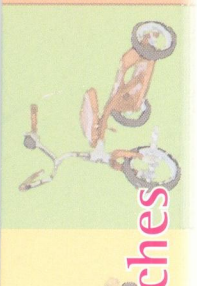
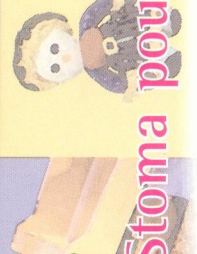
Flanges or base plates are made separate from the pouch. This allows the pouch to be changed whilst leaving the flange attached to the skin.

Two piece systems are generally not suitable for tiny babies. For older babies and children either system can be used. The three types of pouch described below are available in both systems. Your stoma care nurse will help you make your choice.

### Closed pouches

These may be worn when the pouch needs emptying only once a day and the pouch can be changed daily following the bowel movement. These are suitable for children with a colostomy where the waste tends to be more solid and less frequently passed.



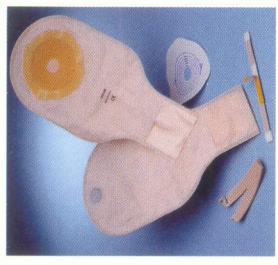


## Stoma pouches

## Day to day management

### Drainable pouches

These should be worn when the pouch needs emptying more than once a day. Clips at the bottom allow for easy emptying. The pouch can be changed daily or up to once every three days. These tend to be used for infants, and children with an ileostomy where waste is more liquid and more frequent.



### Ileostomy pouches



With a urostomy the urine flow is constant and the pouch must be emptied frequently and changed carefully to avoid leakage. Pouches have a non-return valve and a spout or tap for an outlet. These can be connected to a special night drainage system which keeps urine away from the stoma avoiding infection. When connecting leave a small amount of fluid in the pouch so that you do not create a vacuum.

### Stoma hole sizes

The size of a stoma varies and stoma pouches are available with different sized holes. Most pouch manufacturers supply a measuring device. The way to measure the stoma is to find the correct size ring which fits comfortably and snugly round the stoma, without touching or cutting in. This permits the pouch to cover and protect most of the skin surface around the stoma. If your child has two stomas side by side use a template made out of card or paper to help you cut the correct size and shape.

Most stoma pouches have 'starter' holes to allow for changes in stoma size not only post surgery but also as the child grows. Check carefully that each pouch change to ensure a good fit.

Some companies provide a cutting service but it is important not to order too far ahead as the size of the stoma will change with growth.

### Changing pouches

Drainable pouches may be emptied several times before they need changing. Closed pouches need changing more often.

Before changing a pouch, make sure that you have the new one ready and everything you need to hand. With a baby, this is just like changing a nappy, only you seem to need more hands to hold the baby still, stop tiny hands from getting in the way, and to position the pouch making sure it is on properly with no leaks.

### Removing a used pouch

Empty the pouch first if it is drainable, then carefully peel it off with one hand while gently pressing down on the skin with the other. The contents of a closed pouch should now be emptied into the toilet. Seal the used pouch in a plastic bag or nappy sack for disposal in your bin. Many local authorities will provide extra bin bags for the disposal of surgical dressings and pouches.

**NEVER FLUSH USED POUCHES DOWN THE TOILET** unless they are designed to do so and then follow the manufacturer's instructions carefully.

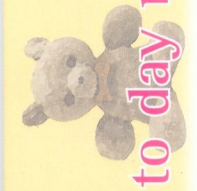
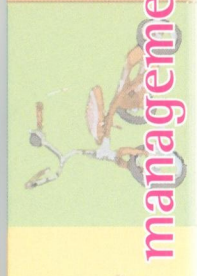
### Cleaning the stoma area

Clean the stoma and surrounding area using warm water and gauze wipes. Cotton wool balls are not recommended because they can leave strands on the skin which can cause leakage. The skin should be washed gently, not rubbed, and if soap is used it must be rinsed off well. Dry the skin thoroughly, patting gently – do not rub.

### Fitting the new pouch

Various skin barrier preparations are available for the area immediately around the stoma. Do ask the stoma care nurse for advice before using them. When applying the pouch do not forget to check it fits snugly around the stoma and that the stoma size has not altered.





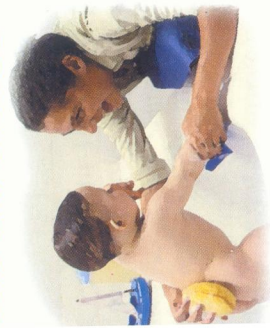
## Day to day management

### Ordering your pouches at home

When you are ready to take your child home, the stoma care nurse or ward sister will give you supplies to last for a few days and a list of items you will need on prescription. Take this list to your family doctor who will write a prescription, which should be taken to your chemist in the normal way. Some of the items may need to be ordered so do not let your supplies get too low – allow at least a week.

You can also obtain your supplies by post. Many of the manufacturers run a postal service and there are often local suppliers who will post items to you. Pouches should not be exposed to strong sunlight, airing cupboards or other hot places as they tend to deteriorate.

### Baths and showers



Stoma pouches can be left in place or removed whilst bathing depending on personal choice. Many parents decide to bath their child when the pouch needs changing. With urostomies this should be discussed with your doctor or stoma care nurse first.

### Diet

A normal balanced diet is recommended. Some foods produce more wind than others, so perhaps it is best to avoid these where possible. Wind and odour are the main problems and trial and error will soon enable you to discover which foods are best avoided.

**Urostomy**  
Some foods which are hard to digest such as tomato skins and celery may be best avoided. Children with ileostomies will demand more to drink than normal. This is only their way of replacing lost fluid.

## Day to day management

Drinking more will not make the waste any more fluid, but helps the kidneys to work properly. Babies with ileostomies should be offered cooled boiled water between feeds.

### Urostomy

Children with urostomies should be given plenty of clear liquids to keep the urine dilute. This helps to protect the kidneys from infection.

### Clothing

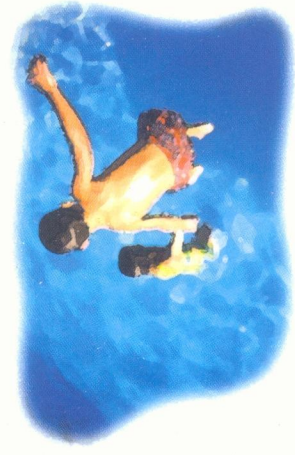
Young babies are easy to dress with stretch one piece suits, dungarees and little dresses. As your child gets older try to avoid stiff waistbands, belts or tight and clinging fabrics. Jogging suits are popular and practical, providing the elastic waist is not too tight. Bold patterns and baggy T-shirts are recommended. However modern pouches are carefully designed to be flat, odour-free and rustle-free and are quite unnoticeable under ordinary clothes.

### Swimming and sport

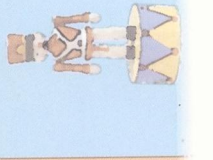
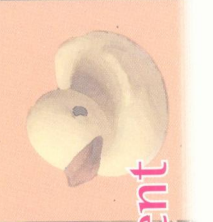
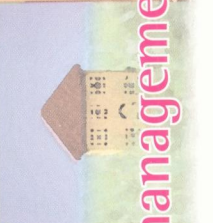
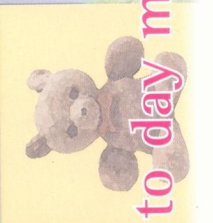
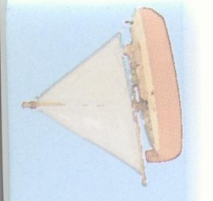
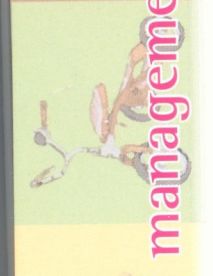
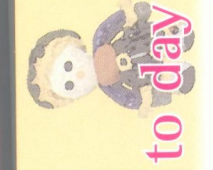
Unless your doctor has told you otherwise there is no reason why your child cannot swim or take part in most sports although, as your child grows up, contact sports such as rugby are best avoided.

If your child swims a lot he or she may require more frequent pouch changes, but this should not prove a deterrent to fun and good exercise. Although their usual pouch can be used for sport, smaller activity pouches are available. Stoma caps can sometimes be used.

Shorts and matching T-shirts can often be worn on the beach. Girls who like swimming can wear patterned swimsuits and boys can wear swimming shorts that go up to their waists. Boots, Mothercare and Next sell all-in-one swimsuits for girls and boys.







## Day to day management

### Travelling

Travelling can be managed quite easily. It is advisable to pack double the amount of pouches than you would normally use. Always carry a travelling kit. A large waterproof toiletry bag is very useful for this and should contain:

- The pouch plus a spare
- A small amount of water for cleaning
- Gauze wipes
- A small plastic bowl
- Any skin preparation, barrier wipes etc. that you use
- A pair of scissors
- Plastic disposal bags
- Hand freshen-up wipes

After a time you will get to know how often the pouch will need changing, and you can usually avoid having to do this outside the home. Never rely on this though. A travelling kit can often save the day, and it takes up so little space that it is worth carrying for the peace of mind that it gives.

Never delay changing a leaking pouch for any reason. It only takes a short while for the skin to become sore. The equivalent of a bad case of nappy rash on the tender skin of a baby's stomach is to be avoided at all costs.

Remember, when in a hot country, make sure your child drinks plenty of fluids.



### Informing others

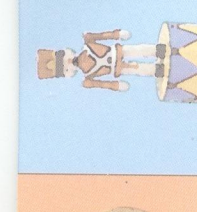
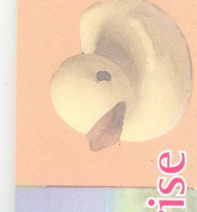
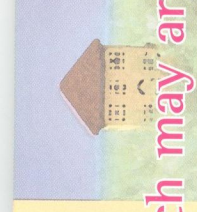
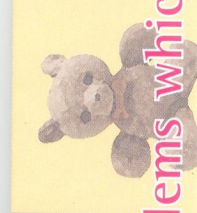
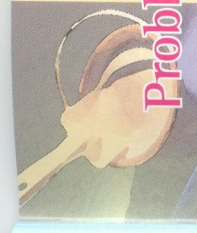
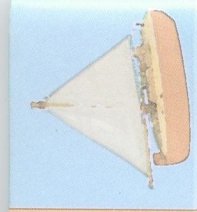
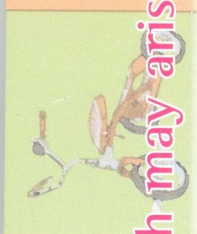
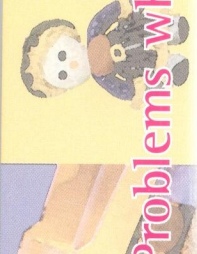
You will decide as to who you want to inform about your child's stoma and what you wish to tell them. Obviously anyone who will be looking after your child will need to be given practical information about how to look after your child's stoma.

Planning what you are going to say to whom is recommended to help prevent embarrassing conversations. It can be a good idea to discuss your plans with your stoma care nurse or a trusted friend.

As your child gets older you can discuss giving explanations with them. It is usually a good idea to have a simple explanation ready for answering other children's questions, as once children's curiosity is satisfied they lose interest more quickly than if an atmosphere of secrecy prevails.







## Problems which may arise

### skin soreness

Leakage is the most common cause of skin soreness. Try to avoid this by making sure the pouch fits well around the stoma. Always ensure waste matter does not come into contact with the surrounding skin and thoroughly clean the skin at each pouch change.



Removing the pouch too frequently (or too harshly) can cause problems. Try not to change a pouch unnecessarily – babies and children can be bathed quite successfully without removing the pouch.

Another cause of skin soreness can be allergies to adhesives, soaps or creams etc. Use warm water for cleaning and avoid using harsh soaps.

Skin soreness is much easier to prevent than cure. Once a child's skin becomes sore, it may become difficult to get the pouch to adhere to the skin – thus increasing the likelihood of leaks and making the skin even worse. Try to clear up skin problems as soon as possible – the longer they last, the harder they can be to cure. Always seek help from your doctor or stoma care nurse.

### bleeding or change in stoma size.

Surface bleeding of the stoma is quite normal and nothing to worry about. Bleeding can happen when washing or when a pouch is fitted too tightly and irritates the stoma. Cleaning more gently or adjusting the fitting of the pouch will help to stop bleeding.

Bleeding from inside the stoma is not normal and this, or any sudden change in stoma size, should be reported to your doctor.

### Diarrhoea or constipation

There is no reason why a child with a stoma should experience diarrhoea or constipation anymore than anyone else.

If your child is constipated make sure they drink plenty of fluids and, if weaned, give them fruit juice and fruit purees. (In a child with an ileostomy constipation presents as waste matter being too thick.)

Some foods do have a tendency to cause diarrhoea. With a little detective work you can soon discover the culprit and adjust your child's diet accordingly. It is also important for a child with diarrhoea to drink plenty of fluids as diarrhoea can cause considerable loss of salt and water leading to dehydration. A baby with diarrhoea can become very ill, very quickly. If in doubt consult your doctor.

Certain medicines e.g. antibiotics can sometimes give rise to constipation or diarrhoea. Keep a close eye on your child if they are on a new medication. If you notice any changes contact your doctor.

### Accidents

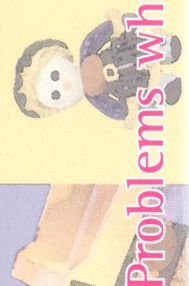
Stoma pouches have improved tremendously in recent years and accidents where the pouch comes off are much more unlikely. However, some adhesive materials suit one child better than another. Experiment to find the best pouch that suits your child.

### Odour and wind

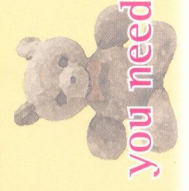
Modern pouches are designed to be odour-proof and odour should only occur when changing. There is a range of deodorants on the market now, some to be used inside the pouch or some as sprays.

In the case of a urostomy, urine which comes into contact with the adhesive skin protector can cause a smell. Make sure you clean the area around the stoma carefully before applying a new pouch and check the pouch fits snugly around the stoma to prevent leakage.





## Problems which may arise



## When you need advice, support or just a chat

Wind can be caused by certain foods but this will be individual to each child. If wind is a problem you should find which foods to avoid by trial and error. For the older child yoghurt may help. Filters, which help to reduce the build-up of gas, are available on modern pouches. Ask your stoma care nurse for advice on how to control the filter.

### Prolapse

Sometimes the muscles holding the stoma weaken and allow the bowel to slide out, increasing the length of the stoma. Although it can look quite frightening prolapse does not usually cause any pain or affect the way the stoma works. This may happen after a bout of coughing or crying, and will sometimes remedy itself after a period of rest, but the doctor should be informed.

### Retraction

This is the opposite of prolapse. The stoma can sink below the level of the abdominal skin. This makes it difficult for the pouches to stay on as the waste can leak more readily under the flange. If the stoma is functioning well do not worry but do inform your doctor.

### Rectal discharge

This happens when some of the waste or yellowish mucous which lubricates the bowel passes through the rectum. Unless the discharge is offensive there is nothing to worry about. On these occasions children who are no longer wearing nappies can use incontinence pads.

When your child has a stoma, initially your main source of help will be the surgeon, stoma care nurse or ward sister at the hospital your child attends. Jot down a note of any queries you have to help you remember when you speak to them.

### Stoma care nurse

If you are not fortunate enough to find a stoma care nurse at the hospital, you may well find that one is available in your home area. Your local surgery will usually give you a telephone number to contact. Stoma care nurses are specially trained and provide an excellent source of advice and support.

### Health visitor

Another great source of help can be your health visitor, she will know of the local stoma care facilities and be able to advise you on welfare benefits and other local services you may find useful e.g. many local authorities provide incontinence pads, disposable nappies or a laundry service.

### Social worker

The hospital social worker is also a good source of information on local services especially regarding financial issues and benefits you may be entitled to.

### Support groups

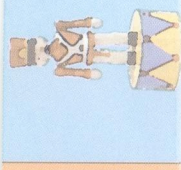
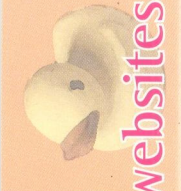
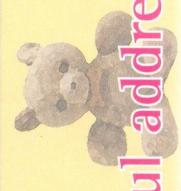
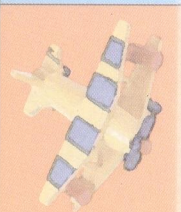
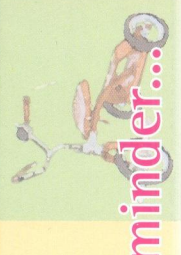
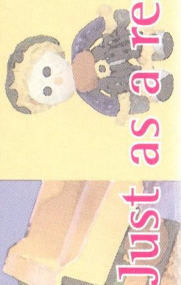
A selection of these are included at the back of this booklet. Getting together with people in like situations and chatting can be very helpful both for you and for your child, easing the sense of isolation felt by so many. Many groups hold meetings and social events for the parents and have newsletters that contain helpful suggestions.

### Stoma pouch manufacturers

There are many different types and makes of pouches and accessories available. What suits one child does not necessarily suit another so if you would like to try a different pouch most manufacturers are only too happy to provide product samples free of charge.

A full list of manufacturers, with addresses and telephone numbers, is available from the N.A.S.P.C.S.





## Just as a reminder...

## Useful addresses and websites

- ➔ Never rush. Take time to cleanse properly as good skin care is the key to success.
- ➔ Prepare everything in advance.
- ➔ Keep a note of all the medical supplies codes and keep extras to a minimum. If your pouch adheres well and the skin is good there is no need to introduce anything else.
- ➔ Always have a pouch prepared (pre-cut) especially for overnight and travelling.
- ➔ Watch your stock levels. Never let yourself have less than a week's supply.
- ➔ Once a pouch leaks change it as soon as possible.
- ➔ Have a list of all the people and their phone numbers who are involved in your child's care.

This booklet is published on behalf of N.A.S.P.C.S. by CliniMed Limited, Please do not hesitate to phone or write to CliniMed with any requests for samples or queries on stoma care and the CliniMed range of products.

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[www.clinimed.co.uk](http://www.clinimed.co.uk)

### The British Colostomy Association

15 Station Road  
 Reading  
 Berks RG1 1LG  
 Freephone 0800 3284257

### Macmillan Cancer Relief

89 Albert Embankment  
 London SE1 7UQ  
 Tel: 0207 840 7840

### Urostomy Association

Buckland  
 Beaumont Park  
 Danbury  
 Essex CM3 4DE  
 Tel: 01245 224294

### The National Advisory Service for Parents of Children with a Stoma (NASPCS)

51 Anderson Drive  
 Darvel  
 Ayrshire KA17 0DE  
 Tel: 01560 322024

### The Ileostomy and Internal Pouch Support Group (ia)

Central Office  
 PO Box 132  
 Scunthorpe, DN15 9YW  
 Freephone 0800 0184724

### Bacup

Cancer Information Service  
 3 Bath Place  
 Rivington Street  
 London EC2 3JR  
 Freephone 0800 800 1234

### National Association for Colitis and Crohn's Disease

4 Beaumont House  
 Sutton Road  
 St Albans  
 Herts AL1 5HH  
 Tel: 01727 830038

### Royal Association for Disability and Rehabilitation (RADAR)

12 City Forum  
 250 City Road  
 London EC1V 8AF  
 Tel: 0207 250 3222

## Websites

- [www.bcass.org.uk](http://www.bcass.org.uk)
- [www.cancerbacup.org.uk](http://www.cancerbacup.org.uk)
- [www.clinimed.co.uk](http://www.clinimed.co.uk)
- [www.ileostomypouch.demon.co.uk](http://www.ileostomypouch.demon.co.uk)
- [www.macmillan.org.uk](http://www.macmillan.org.uk)
- [www.nacc.org.uk](http://www.nacc.org.uk)
- [www.radar.org.uk](http://www.radar.org.uk)
- [www.uagbi.org](http://www.uagbi.org)
- British Colostomy Association
- Bacup
- CliniMed Ltd
- The Ileostomy and Internal Pouch Support Group
- Macmillan Cancer Relief
- The National Association for Colitis and Crohn's Disease
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- Urostomy Association