

Stoma care nursing service

When your baby is receiving medical and nursing care in hospital, it can be a very frightening time for parents, and the idea of surgery and formation of a stoma often adds to that anxiety.

This information is designed as an aid to understanding about stoma care for babies, and practical issues around stoma care. This is purely meant as a reference and supplement to what the surgeon, medical staff, nurses and specialist nurses discuss with you.

The Stoma Care Specialist Nursing Service at Addenbrooke's Hospital is designed to meet the needs of babies (and their families) who have undergone stoma forming surgery.

The Clinical Nurse Specialists in Coloproctology/Stoma Care believe that each patient undergoing surgery resulting in a stoma is entitled to access to a high quality, comprehensive specialist nursing service, within the resources available.

We work closely with other healthcare professionals, and with the patient and family/carers, acting as a resource.

The Stoma Care Nurses are:

Marie Waller, Anna Brewer & Vanessa Coleman

We are qualified nurses who have chosen to specialise in this area and have been specifically trained in this aspect of nursing.

We would prefer you to call us by our christian names; however, if you do not feel comfortable with this you can refer to us as Sister.

We can be contacted:

Monday – Friday 08.00 – 16.00 hrs

52 weeks of the year

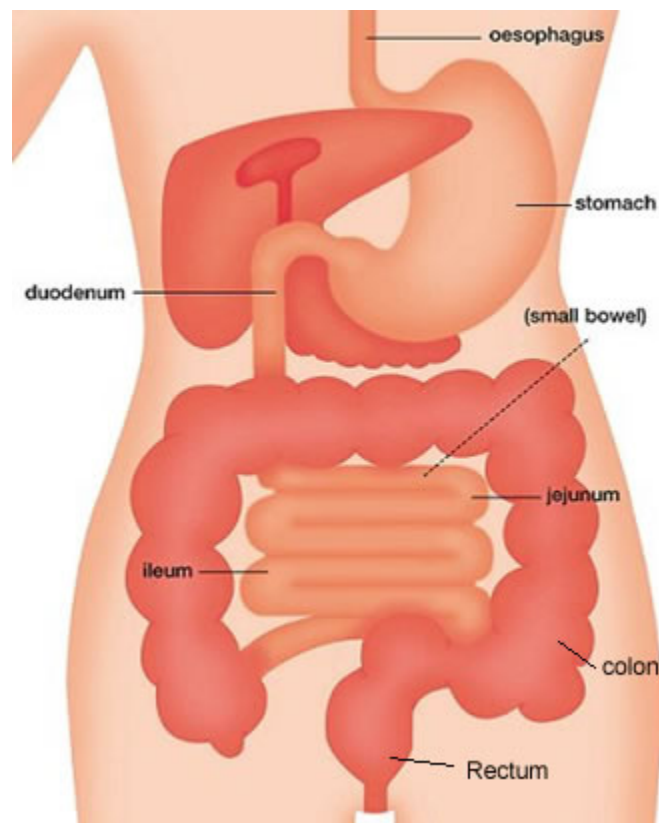
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(answerphone)

THE DIGESTIVE SYSTEM

The purpose of the digestive system is to break food down into basic components, so that nutrients can be absorbed and waste products excreted. The system is a complex structure and finely balanced to serve this purpose adequately. However, because of its complex nature, problems can occur and lead to a need for a stoma to be formed, either in the short or long term.



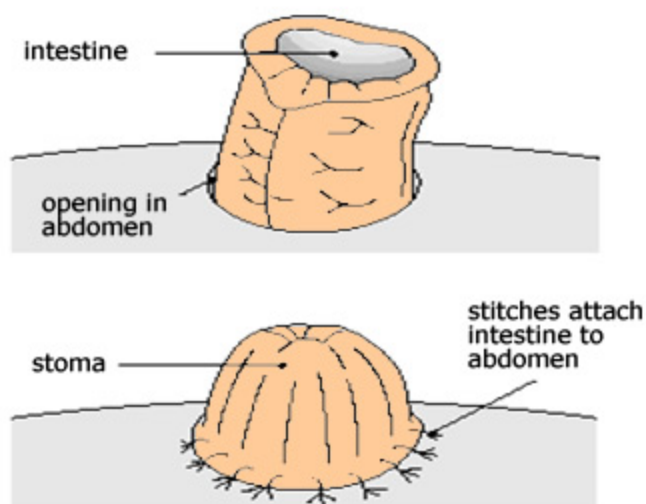
The digestive system can be classed as 'upper gastrointestinal tract' which includes the mouth, stomach and small intestine (ileum), and 'lower gastrointestinal tract'

which includes the large bowel (colon) and rectum / anus (back passage). Digestion begins in the mouth, whereby food is chewed into smaller bits, continuing in the stomach which regulates food being passed into the ileum, where acids and enzymes digest food and where most absorption of nutrients takes place. As this undigested food then passes through the colon water is absorbed, leaving semi-solid waste matter (faeces) to be stored in the rectum until sphincter muscles in the anus push the faeces out.

THE STOMA

'Stoma' is a Greek word literally meaning 'mouth' or 'opening'. In terms of your baby's surgery, it is a surgically-made opening for diverting faeces away from the part of digestive system below this point.

'Ostomy' is an extension of the word 'stoma' and usually follows the specific part of body that it has the opening to.



The end of the intestine is pulled through an opening made in the abdominal wall (top). The intestine is then folded outwards onto itself (bottom) and attached to the abdomen with stitches

A **colostomy** is the specific term used for the part of the digestive system that has been used as 'diversion' - the colon.

A healthy colostomy appears pink/red and moist, very much like the inside of the mouth.

Which part of the colon is brought forward as the stoma will determine how much of the water has been absorbed in the system, and therefore how formed the faeces is.

A healthy **ileostomy** appears pink/red and moist, very much like the inside of the mouth. Because of the loose nature of faeces that is produced in the ileum and all the digestive acids/enzymes contained, an ileostomy is usually formed into a spout protruding through the skin.

STEP BY STEP GUIDE TO CHANGING YOUR BABY'S STOMA BAG

This is not a sterile procedure, but regular hand-washing is important.

1. Collect all necessary clean equipment:
 - New bag (and stick on soft tie if not built in)
 - Nappy sack
 - Dry wipes/gauze/kitchen roll
 - Bowl/pot of plain warm water
 - Scissors and Template (if already made and correct fit).
2. Empty bag first.
3. Carefully remove soiled bag – peeling off from the top and using a finger against baby's tummy to reduce 'pulling' quite so much.
4. Lay soiled bag on the newspaper.
5. Clean skin and stoma using the wipe/tissue and warm water. Wipe gently but firmly to ensure skin clean.

6. Dry skin thoroughly using wipes/tissue. Check dryness with fingers.
7. Check template / stoma size and cut hole for bag, being careful not to cut through the bag itself!
8. Position bag on skin around stoma, trying to mould adhesive to skin contours. Smooth firmly in place.
9. Wrap soiled bag in newspaper and seal in nappy sack before placing in rubbish bin.

DISCHARGE FROM NEONATAL UNIT

Before your baby is allowed to be discharged from hospital, you need to feel confident with managing his/her stoma care. There will be appropriate community neonatal and nursing follow-up arranged (discuss with Unit/ward staff) and you will see one of us to discuss Stoma Care Nurse follow-up, how to get supplies, post-discharge expectations etc.

HOW TO OBTAIN STOMA BAGS/EQUIPMENT

You will need to obtain a prescription, either direct from the GP, or a delivery company will obtain it on your baby's behalf.

BABIES/CHILDREN AND NURSING MOTHERS ARE EXEMPT FROM PRESCRIPTION CHARGES. However, 'dry wipes' are NOT available on prescription. Suggestions for substitutes are tissues and kitchen roll, although they tend not to be very soft or

strong when wet, or baby nappy liners which are soft and strong and can be bought in most chemists.

TRANSFER OF YOUR BABY TO ANOTHER HOSPITAL/AREA

Your baby will be given supplies of approximately 10 stoma bags to take with them – either from the Neonatal Intensive Care Unit (NICU) or from the Stoma Care Department.

We need to be informed of the transfer of your baby, as soon as possible, so that relevant and timely documentation can be sent with your baby.

We will inform the local Stoma Care Nurse(s) of the transfer – when and where, how to contact you, and of any relevant stoma care details.

If your baby is being discharged home :-

We will give you a card with details on it for the stoma bags/equipment that are required on prescription. Obtaining the first batch of supplies will be discussed with you.

WHAT MIGHT HAPPEN?

Bleeding from the stoma

As the stoma has such a good blood supply, slight bleeding may occur when cleaning it, or when your baby cries. There may also be slight bleeding from where the stoma is stitched to the skin. This is nothing to worry about. It may also occur if the bag is too tight causing rubbing or irritation.

However, if you see bleeding coming from the opening of the stoma (from within), contact your doctor or us.

Leakage of faeces

Leakage can be due to a number of reasons, or even a combination – for example, the hole of the bag being the wrong size, stoma being flat or jagged-shape, the skin not being completely dry, the adhesive being stuck over-top of skin creases, the faeces being liquid and seeping underneath, explosive faeces and flatus, or the bag being left on too long.

The best way to try and prevent leakage is through being prepared before changing bag; good technique; having a second person to help 'smooth' baby's skin contours, if possible; emptying the bag frequently (no more than 1/3 full), and changing the bag regularly – every 3-4 days or if the adhesive is turning 'white'. If having problems with leakage of your baby's stoma bag, please consult us.

Skin problems

Babies' skin can become very sore, very quickly. This may be due to leakage of faeces, allergic reaction to the adhesive or plastic, rash from sweating or infection, being too harsh when changing bag, or changing the bag too frequently.

Again prevention is better than cure, especially because of the discomfort for baby caused by the skin being sore or broken and potential difficulty in getting a bag to stick properly to 'wet' skin. There is a wide range of bags and products nowadays to help prevent/treat skin problems.

If your baby's skin becomes sore, please contact us, as we can advise on appropriate action and/or products to help.

Diarrhoea

Diarrhoea, or frequent passing of watery faeces, can be due to diet/feeds, medication such as antibiotics, or a tummy upset. Diarrhoea tends to be more smelly and messy and can cause potential bag leakage, but the more urgent concern with babies is that they can lose a lot of water and salt very easily, and so

become dehydrated. If your baby has an ileostomy and has sustained liquid faeces, or has a colostomy with prolonged diarrhoea, contact the doctor without delay.

Soiled nappies

If your baby has an intact anus, there may be occasional staining or soiling of the nappy with faeces, dark blood and/or mucus. This is nothing to worry about. The old faeces and blood will probably be from when the surgery was done, which can take substantial time to come out. The mucus (clear, jelly-like substance) is produced naturally to aid lubrication and passage of faeces through the bowel.

Change in colour of stoma

You will become used to the stoma being a certain colour – usually pinkish-red. If you notice a sustained change in colour, such as becoming and staying very dark, you should contact the Stoma Nurse, ward/unit or Dr. Often when babies cry, for example, the stoma mucosa colour changes, but it should return to its usual colour afterwards. Prior to contacting anyone, it may be worth changing the bag and wiping over the stoma with a wet cloth, as the discolouration may be due to other factors, such as dried mucus/faeces or residue from the bag adhesive.

Stoma prolapse

The stoma may protrude more out of the skin than usual, often after a bout of crying or coughing where pressure in the tummy has increased, pushing the stoma out more. This often resolves itself, but if it persists contact your doctor. As long as the stoma is still pink/red in colour and moist, this is not usually a problem which affects the function of the stoma. However, it can be concerning for yourselves and it may make applying stoma bags more troublesome. Please contact us if this is the case.

FREQUENTLY ASKED QUESTIONS

CAN I BATH MY BABY?

Yes, you can bath your baby with or without the bag on. The bags nowadays are waterproof, so should be easily towel-dried. Try to avoid using oils in the bath water, as these may reduce the 'stickiness' of the bag. However, ordinary baby bath is fine to use.

DO I NEED SPECIAL CLOTHING FOR MY BABY?

No, ordinary baby clothes are fine. All in one clothing is particularly good for keeping baby's fingers away from the stoma bag, especially as your baby gets older. Easy access to the stoma bag, such as poppers to free the legs, makes frequent emptying of the stoma bag much easier. Generally this type of baby clothing is widely available in the high street.

WHERE DO I STORE THE BAGS?

In a cool, dry place out of direct sunlight. A spare bag and changing/emptying equipment may be kept in a changing bag, but be aware that if the bag becomes too warm, the adhesive may be less effective.

DOES MY BABY NEED SPECIAL FEEDS?

If your baby has a colostomy; unless there is another medical problem affecting diet, there is no reason why your baby should need a special diet. Weaning should not be affected by having the stoma.

If your baby has an ileostomy; an intolerance to a certain sugar (lactose) may develop, which means that he or she will need to have special feed, such as Pregestimil, which contains pre-digested sugar. During weaning, milk-free food needs to be given. However, this intolerance appears to only be temporary, and usually resolves when the stoma is closed. Whilst your baby has an ileostomy,

excess salt can be lost in the faeces, which means that regular monitoring of sodium (salt) levels is done and supplements given if appropriate.

ANY TIPS FOR EMPTYING OF THE BAG?

Position the bag at an angle to the body, so that the bottom opening is on the outer edge of the thigh. You may find it easier to suck up the faeces with a syringe and kwill (as done in hospital), although this is not required – we usually recommend 'smoothing'/emptying the bag directly into the nappy before disposal. The choice is yours; practice will make you more proficient and confident.

Remember to check and empty the bag regularly, for example when checking the nappy, or when the bag is no more than 1/3 full. Wipe the outside and inside of the bag opening with a wet wipe before rolling up the tie. If the faeces is very thick and difficult to ease out of the bag, a small amount of warm water added into the bag (from the bottom opening) may make it easier to empty.

THE BAG GETS FULL OF WIND. HOW DO I MANAGE THIS?

Regular emptying of the bag, even if very little faeces in it, will manage this to an extent. Neonatal/paediatric bags do not come with integral filters to deflate the bag, but stick on filters that need to be pierced can be obtained. Ask us for advice regarding this.

For babies that have been weaned, certain foods can cause excess wind or flatus, so it may be worth while considering what the diet is.

CAN THE STOMA GET DAMAGED EASILY?

Obviously care needs to be taken that the stoma is not knocked directly. However, everyday activities such as using a baby car seat, lying on the tummy and crawling (make sure the bag is tucked well into the nappy!), should not damage the stoma.

WHAT SORT OF SUPPORT IS AVAILABLE ONCE MY BABY IS HOME?

As well as family (as you feel appropriate to involve), there are health care professionals, such as the Health Visitor, Paediatric/Neonatal Community Nurse,

Stoma Care Nurse Specialists and your family doctor. The Surgeon will provide follow-up as appropriate.

There are support groups, such as the National Advisory Service for Parents of Children with a Stoma (NASPCS). You may also be entitled to benefits, such as the Disability Living Allowance, depending on the needs of your baby and dependant on your baby having had the stoma for at least 3 months.

Some SUPPORT GROUPS and ASSOCIATIONS

The Colostomy Association

2 London Court
East Street
Reading
RG1 4QL
Helpline 0800 328 4257
E-mail cass@colostomyassociation.org.uk
www.colostomyassociation.org.uk

Is a national registered charity, which represents the interest of people with a colostomy, providing support, reassurance and practical help.

The Ileostomy & Internal Pouch Support Group (ia)

National Office
Peveerill House
1-5 Mill Road
Ballyclare

County Antrium
BT39 9DR
Free phone 0800 018 4724
Fax 028 9334 4043
E-mail info@iasupport.org
www.the-ia.org.uk

The primary aim is to help people who have undergone surgery which involves the removal of their colon (colectomy) and the creation of either an ileostomy or an ileo-anal pouch

Family Fund

4 Alpha Court
Monks Cross Drive
York
YO32 9WN
Helpline 0845 4542 or 1904621115
E-mail info@familyfund.org.uk
www.familyfundtrust.org.uk

Is a registered charity which provides grants & assistance to families with severely disabled children to families ensuring they have choices & opportunities to enjoy life.

Hirschsprungs & Motility Disorders Support Network (HMDSN)

Livet House
34 Main Street
Tomintoul
AB37 9EX1
0044 7935 787776
www.hirschsprung.info

Is an organisation that makes it possible for people and families, whose children have hirschsprungs disease & other gastrointestinal motility disorders to support each other.

TOFS

St. George's Centre
91 Victoria Road
Netherfield

Nottingham
NG4 2NN
0115 961 3092
E-mail info@tofs.org.uk
www.tofs.org.uk

Dedicated to providing emotional support to families of children born with Tracheo-oesophageal fistula, oesophageal atresia & associated conditions.

Down's Syndrome Association.

The Langdown Centre
2a Langdown Park
Teddington
Middlesex
TW11 9PS
Helpline 0845 2300372 Monday- Friday 10-4.00 pm
E-mail info@downs-syndrome.org.uk
www.downs-syndrome.org.uk

GLOSSARY

Anus	The opening of the back passage to the body surface.
Bowel	Gut, intestine.
Colon	The large bowel or large intestine.
Colostomy	Surgically made opening using the colon to the skin surface.
Congenital	Existing at time of birth
Constipation	Infrequent passing of thick/hard faeces

Dehydration	Condition as result of excess loss of water from the body.
Diarrhoea	Frequent passing of watery faeces.
Diversion	Turn in another direction i.e. faeces away from the lower bowel and back passage.
Faeces	Waste matter in the bowel, motions, stool.
Flatus	Wind, gas, flatulence.
Ileum	Part of small bowel / small intestine.
Ileostomy	Surgically made opening using the ileum to the skin surface.
Mucus	clear, jelly-like substance secreted as lubrication.
Mucus fistula	A stoma made by the lower end of bowel being surgically brought through the skin surface – usually only produces mucus.
Ostomy	To form an opening, extension of stoma, suffix to specific part of body.
Prolapse	Slipping forward or out of place i.e. stoma.
Sphincter	Circular muscle that opens and closes i.e. anal sphincter to control passing of faeces from anus.
Stoma	artificial 'mouth' or opening i.e part of bowel visible on skin surface.