

Your child and their stoma

The aim of this information sheet is to answer some of the questions you may have about your child's stoma. If you have any further questions or concerns, please speak to a doctor or nurse caring for your child.

What is a stoma?

A stoma is an opening from the body which allows stool (poo) to drain out. A stoma might be performed in babies for a number of reasons, and your nurse or doctor will help explain these reasons to you. Your baby will need to have a general anaesthetic while the stoma is formed. If you would like more information about this, please ask for a copy of our leaflet, **Your child's general anaesthetic**.

What does a stoma look like?

Stomas are red, like the inside of your mouth, and are soft and moist. They have a lot of blood vessels, so may bleed a little when they are touched, but they have no feeling and so will not hurt. Stomas can differ from child to child and may differ from pictures you see. They can differ in their size and shape. Some may stick out more than others or may be located on different areas on the abdomen (tummy).

Types of stoma

There are two different types of stoma – one is called a colostomy and the other, an ileostomy.

A colostomy is a stoma that is formed from a part of the colon or large bowel. When undigested food enters the colon, water is absorbed and stool is stored in the colon until it is passed out of the body via the stoma. The type of stool that comes from a colostomy can either be liquid or more solid in consistency.

An ileostomy is a stoma that is formed from a part of the ileum, which is part of the small bowel. The ileum contains digestive enzymes which help to break down food and absorb nutrients from our diet. The type of stool that comes from an ileostomy is generally more liquid in consistency than stool that comes from a colostomy. Because of the digestive enzymes in the ileum, the stool can damage the skin if it has contact with it.

In some cases, two stomas can be formed from the same area of the bowel. They are referred to as the proximal and distal stomas. The proximal stoma is the one that produces the stool, while the distal stoma (also known as the mucous fistula) is said to be non-functioning, but may produce mucous and gas. The distal stoma may be used for a procedure known as 'recycling'.

Recycling involves putting back some of the stool into the distal stoma. This is done with a syringe and a catheter (tube), and is done to stimulate the part of the bowel which has been



working since the surgery. This is usually done in preparation for an operation in which the stoma is reversed (see p3 for more details on this).

Following your child's operation, the surgeon will explain to you exactly what surgery your baby has had.

Are there any risks?

The main risks of having a stoma are listed below

- **Skin irritation**

Although the stoma itself has no sensation, the skin surrounding it does and it can become irritated by both the adhesive of the stoma bag, and also by the stool itself. Often, these irritations can be minor, but in some cases they can start to cause the skin to break down. The nursing staff and the stoma nurse specialists will observe for early signs of irritation.

- **Prolapse**

A prolapse is when the bowel becomes longer and protrudes through the opening of the stoma. Although this can be very frightening for parents, it is not usually serious. As long as the bowel remains pink and active, we will simply keep a close eye on it.

- **Retraction**

Retraction (also known as inversion or 'moating') of the stoma is when the stoma sinks below skin level. This can lead to problems with applying the bag. The nursing staff and stoma nurse specialists will have suggestions on how to help.

- **Bleeding**

The stoma will occasionally bleed, especially when touched. This is normal unless the bleeding does not stop.

What happens after my baby's surgery?

After the operation, there is likely to be a small dressing over your baby's wound and stoma. Initially the stoma may not look as it was described earlier, but it is also normal for the stoma to be slightly dusky in colour. It may also develop a scab due to bleeding that may have occurred after the operation. You may be able to see stitches, which will eventually dissolve on their own. The nursing and medical team will keep a close eye on the stoma and keep the area clean and dry.

The staff will also be watching for when the stoma begins to produce stool. After surgery, the bowel stops moving food along the digestive tract, and the time it takes for this to start again varies. It may happen within the first few days, or it may take longer, and this will depend on why your baby needed a stoma, and the type of surgery your baby has had.

Once the stoma is active, the nursing staff will put a stoma bag on. There are many types of stoma bag and we may try a number of different bags until we find the one that is best for your baby. The distal (non-functioning) stoma will either be covered with the bag, or it will have a dressing over the top of it.



How do I care for my baby's stoma?

One of the first things that you will learn is how to empty the bag. This is usually done by inserting a syringe into the bag and drawing the fluid up to measure how much stool has been passed. You may also hear this referred to as 'output'. The inside of the bag does not have to be cleaned once emptied, but it may be beneficial to wipe the end of the bag to prevent any stool from getting on your baby's clothing.

The bag only needs to be changed once it is no longer secure. This is something that can vary between babies, but a bag will generally stay secure for two to three days. When changing the bag, it is important to ensure that the new bag fits snugly around the stoma, so that stool is prevented from going directly onto the skin. Your nurse and or the stoma nurse specialist will show you how to do this.

When can I start feeding my baby?

Decisions about when to start feeding your baby will depend on why your baby has had the stoma formed and what type of stoma they have. Usually, feeding won't start until the stoma is active, however it could be up to two weeks or even longer before milk can be given. Once you begin feeding, the nursing staff make notes on how much stool your baby is producing. This is particularly important if your baby has an ileostomy, as the stool can be more liquefied. What we are looking for is that your baby's output is less than what he or she is receiving. This is important as it helps us to ensure that your baby is absorbing the nutrients that he/she needs in order to grow.

Caring for my baby at home

The length of time that your baby will need the stoma for will depend on the reason that the stoma was needed in the first place. In some cases you will take your baby home with the stoma. This will be scary, but staff will ensure that you are confident in caring for the stoma beforehand, and that you have all the information and support you need at home.

Your baby will not need special clothes, but you should avoid clothes that may rub against the stoma, or prevent the bag from filling. Similarly, your baby will not need special nappies. The nurse will show you how to apply the nappy over the stoma bag.

You can bathe your baby with the stoma bag on or off, but you should avoid using oily soaps or lotions, as these can stop the bags from sticking to the skin.

Taking your baby home with a stoma is not always possible. If you are not able to take your baby home with a stoma, it is usually because they are unable to tolerate 'full milk feeds', meaning that your baby is not able to get their entire nutritional requirement through milk. If this is the case, what generally happens is that the stoma will be reversed (closed, and so a stoma bag will no longer be required). Reversing the stoma is another operation, and so it is usually done when your baby is well and a little older. Your surgeon will be able to give you more information if they feel that your baby's stoma should be reversed.

Appointments at King's

We have teamed up with King's College Hospital in a partnership known as King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at King's. To make sure everyone you meet always has the most up-to-date information about your health, we may share information about you between the hospitals.

Contact us

If you have any questions or concerns, please contact the Neonatal Unit on
t: 020 7188 8846 and ask to speak to the nurse in charge.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.evelinalondon.nhs.uk/leaflets

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

t: 020 7188 3003 10am to 5pm, Monday to Friday **e:** letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch.

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch.

t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership

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