

Information leaflet for Parents

Stoma Discharge Advice



You are about to go home with your baby. It can be worrying taking any baby home from hospital especially if the baby has a stoma. We want to reassure you that most babies with a stoma thrive at home and the care of the stoma usually proves to be easier than expected. If there are any difficulties with the stoma we at Birmingham Women's and Children's Hospital will help and support you. Below are some of the things that you may need to look out for over the weeks and months ahead.

Most stomas are temporary and the length of time that your baby will need the stoma will depend on the reason that the stoma was formed in the first place.

Stoma equipment

The ward will provide you with one week's supply of stoma equipment. Gail Fitzpatrick, Paediatric Stoma Nurse, will arrange a home visit and will order future equipment to be delivered to your home

Feeds

Many babies can breast feed normally, but there are some who need extra help to grow. While in hospital your baby may have been seen by a Dietician and may have started a special type of feed. This is the feed that best suits your baby and will help them to gain weight and thrive. Please continue with the prescribed feed until told otherwise. Your baby should be weighed regularly by your Health Visitor. They will also be reviewed by a Dietician if needed. Your Health Visitor and Dietician can give you advice about weaning.

Medications

If your baby is sent home on medicines please do not stop these until you are told to by a healthcare professional. Your GP should prescribe these on repeat prescription for you and you will be able to collect them from your local pharmacy.

Dehydration

Any child can develop diarrhoea and can become dehydrated, especially if they drink less or have vomiting. Dehydration occurs when too much fluid is lost and not enough is absorbed. For some babies with a stoma, especially an ileostomy, dehydration can happen very quickly when there is a high output from the stoma.

What to look for and when to seek medical help:

- Large watery stoma output
- Your baby is quieter than normal
- Dry nappies or dark urine
- Dry lips and mouth
- Sunken or dark eyes
- Sunken soft spot on the head

Babies with a stoma can become dehydrated very quickly. You should become familiar with what is a normal amount of stoma output for your baby. Be able to recognize if the fluid has become more watery and if you are needing to empty the bag more often.

If the amount of stoma output increases and you notice signs of dehydration then take your baby to see the GP urgently.

Leaking stoma bags

Although the stoma itself has no sensation, the skin surrounding it is sensitive and can become red and sore if the stoma fluid leaks onto it. As well as being uncomfortable, sore skin may stop the stoma bag sticking. If the stoma bag leaks more than once a day, contact Gail Fitzpatrick, Paediatric Stoma Nurse, or the Ward where your baby was a patient, for advice.

Changes in the appearance of the stoma

You may notice a change in the shape and size of the stoma. The stoma may prolapse and become longer or larger than it had been. It may retract and get smaller and sink slightly below the level of the skin. These changes can be normal and shouldn't be of concern but may cause the stoma bag to leak more frequently. Report any changes to Gail Fitzpatrick and she can make suggestions to help you. Occasionally a stoma can prolapse many centimetres and then a urgent surgical review is required.

Occasionally, the colour of the stoma will change. If the colour change is temporary – less than a few minutes – it is usually nothing to be concerned about. If the stoma becomes dusky for more than a few minutes, then help should be sought.

Reduced Stoma Output

If you notice the stoma output has become much less than normal or stopped completely then this could be a sign that the bowel is blocked. A bowel blockage is often associated with abdominal distension and vomiting. Following any operation on the bowel there is always a small risk of a blockage (obstruction) happening in the future.

Signs of a bowel obstruction are:

- Green vomiting,
- Pain and crying,
- Abdominal distension (swollen tummy)
- Refusing feeds
- a change in stoma output

If your child has these symptoms take him/her to a doctor at your local hospital or to the Emergency Department at Birmingham Children's Hospital.

Follow up appointments

Following discharge home, your baby will have regular check-ups in the Outpatient Department in order to monitor their progress. We will send you details of your outpatient appointment in the post, soon after you leave hospital.

Who should I contact if I have any concerns?

If you have any questions or concerns, please contact Gail Fitzpatrick (Paediatric Stoma Nurse)

Mon. to Fri. 9am-5pm Tel 07557001653

Or the Neonatal Surgical Ward on 0121 333 9022 and ask to speak to the Nurse in Charge.

Looking after and sharing information about your child

We have a duty of care to help patients and families understand how information about them is kept and shared and we include the following information in all our patient leaflets:

Information is collected about patients relevant to their diagnosis, treatment and care. We store it in written records and electronically on computer. As a necessary part of that care and treatment we may have to share some patient information with other people and organisations who are either responsible or directly involved in the patient's care. This may involve taking the patient's information off site. We may also have to share some information for other purposes; such as research etc. Any information that is shared in this way will not identify the patient unless we have the patient's and parent's/carer's consent. If you have any questions and/or do not want us to share that information with others, please talk to the people looking after your child or contact PALS (Patient Advice and Liaison Service) on 0121 333 8403.

Birmingham Women's and Children's NHS Foundation Trust
Steelhouse Lane Birmingham B4 6NH
Telephone 0121 333 9999
Fax: 0121 333 9998
Website: www.bwc.nhs.uk

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