

Information leaflet for Parents/Carers

Discharge Advice for Exomphalos Major



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Dressings

Skin will gradually grow over the exomphalos sac over a period of several weeks/months. In this period there is an increased risk of infection. The dressings will help to protect the sac and reduce this risk of infection.

If you are worried your baby may have an infection, take him/her to your GP or local hospital.

Signs of infection are

- Refusing feeds
- High temperature
- Irritable or too quiet
- Changes in the exomphalos sac
- Vomiting

While your baby is in hospital you will be taught how to change the dressing on the exomphalos. At home this is likely to be needed once or twice a week. You will be given a supply of dressings to take home from hospital. These will be available on repeat prescription from your GP.

Surgical Outreach Service

The Surgical Outreach nurses will help you to change the dressing. You will need to attend either your local hospital or Birmingham Children's Hospital to meet with the Surgical Outreach nurses to do these dressings. Once you are confident you will be able to do the dressing changes at home with support from your Health Visitor/Community Nurse.

When you change the dressing at home your Health Visitor will weigh your baby and you will be able to give your baby a bath. Do not add any soap to the bath water until the skin has covered the sac. You can wash your baby's hair separately with shampoo.

Feeding

Continue with breast feeding or giving your baby expressed breast milk.

Babies who have exomphalos sometimes suffer from frequent milky vomiting (reflux) and may have been started on treatment for their symptoms. Continue the prescribed treatment until the clinic appointment. It may help to keep your baby upright after feeds for at least 30 minutes.

Green (bilious) vomit can mean there is a serious problem with the bowel and you should take your baby urgently to a doctor at your local hospital or to the Emergency Department at Birmingham Children's Hospital, if this ever happens. Thankfully this problem is rare.

Growth

Babies with exomphalos may require more calories whilst the skin is healing and may be slow to gain weight. Their growth will be closely monitored by your Health Visitor.

Bowels

Some babies can experience either diarrhoea or constipation. If this happens the Surgical Outreach Nurse or your Health Visitor can help.

Follow up appointments

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

The nurse and neonatal team looking after your baby will be happy to answer any further questions you may have before discharge.

Support

For more information and support you may find the following websites useful:

GEEPS : www.geeps.co.uk

Contact a Family: www.cafamily.org.uk

Contact numbers:

If you have any concerns after discharge you can call for advice :

Neonatal Surgical Ward, Birmingham Children's Hospital Tel. 0121 333 9022

Neonatal Surgical Outreach Nurses **Mon-Friday 8am to 5pm.**

Sr. Bernadette Reda Tel. 07795061660

JSR. Louise Lawrence Tel. 07769367483

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.

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