

Further Information

We hope this information leaflet has been useful and will help you to understand all about your child's condition. However some medical information can be difficult to understand. If you need more information or have any concerns please speak to a member of the medical team caring for you or your baby.

Looking after and sharing information about you and your child

Information is collected about your child 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 of that information with other people and organisations that are either responsible for or directly involved with your child's care. If you have any questions please talk to the people looking after your child or contact PALS (Patient Advice and Liaison Service) - you can do this by calling the hospital main number and asking to be put through to PALS.

Information for Parents / Carers

Exomphalos



Southern West Midlands
Newborn Network **NHS**

Staffordshire, Shropshire & Black Country
Newborn Network

Your baby has been diagnosed with exomphalos (also known as omphalocele). This means that some, or a lot of the contents of your baby's tummy are lying in the umbilical cord. This is shown in the picture below:



This leaflet will give you more information on the condition and what you can expect during pregnancy, delivery and after your baby is born.

Exomphalos

This may be seen at the first scan or in many cases at your 20 week scan.

An exomphalos can often be corrected after the baby is born. However, it may be associated with the following:

1. In around half of cases there will be other problems (e.g. with chromosomes or the heart).
2. In rare cases this may be associated with genetic problems. If you have chosen for your baby to have its chromosomes checked, we will also screen the baby to exclude Beckwith-Wiedemann syndrome.

Please use this space to write down any notes or questions you might have

Contact a Family

A UK wide charity offering support, advice and information regardless of a child's condition or disability. Through their Making Contact service they may also be able to put you in touch with other families who are affected by the same disability / medical condition as your child.

Contact a Family

209-211 City Road

London EC1 1JN

Freephone Helpline: 0808 808 3555

Email: helpline@cafamily.org.uk

Website: www.cafamily.org.uk

These issues will be discussed with you from the detailed scan, and also the option of checking the baby's chromosomes will be discussed with you.

The overall outlook for a baby will in general depend on whether it is just the exomphalos or if there are other problems alongside it as well. If other problems are found then the outcome for the baby is poorer than if these were excluded. If it is just the exomphalos by itself, then the outcome overall will depend upon the size of the exomphalos.

During Pregnancy

Scans will be performed regularly, about every 4 weeks, to look at your baby's growth and to monitor the fluid around the baby and the placenta. If a scan has identified other possible abnormalities as well as the exomphalos you have the option to have the chromosomes checked today. There are different ways this can be done and these will be discussed with you and your choices explained. You will also be offered the chance to have the baby's heart scanned at 20 weeks.

Delivery

If the exomphalos is small then your baby is usually delivered by 41 weeks of pregnancy. Ideally the baby will be born via normal vaginal delivery. We will discuss with you how and when the delivery will happen at Antenatal clinic.

If the exomphalos contains liver or is large, then the baby will need to be delivered by Caesarian section at 39 weeks as this is safer for your baby.

When considering delivery, we need to make sure that there are neonatal and surgical beds available for your baby once he/she has been born. We will only know this definitely on the day of your admission and may mean that the induction/ Caesarian is delayed or on rare occasions that you would transfer to another unit for delivery and/or surgery.

Treatment And Care After Delivery

If the exomphalos is large and contains liver, as well as bowel, once the baby is delivered the Neonatologists (doctors specialising in the care of newborn babies) will see if your baby will need any help with breathing. It is usually the babies with a very large exomphalos that may need such help with their breathing.

The neonatal doctors and nurses will assess the baby and then once respiration and circulation are established, the exomphalos sac is often covered with moist gauze and placed in a plastic bag. This is to make sure the area stays moist and warm.

Often babies will need an intravenous drip to provide them with fluids and medication. They will often also need a naso-gastric tube. This is where a tube is

Your child will have a scar which he or she could feel self-conscious about in later life. There are plenty of options for reducing the appearance of scars, which include silicone gel, steroid injections or plastic surgery. and how to deal with them, please ask to see an occupational therapist. Another alternative that covers up scars rather than reducing them is cosmetic camouflage.

Is there a support group?

The support group for families of children with abdominal wall defects is:

GEEPS

104 Riverside Road
Romford RM5 2NS
Tel: 01708 738 134
Email: contact@geeps.co.uk
Website: www.geeps.co.uk

BLISS

Another group which offers general support to families is BLISS
68 South Lambeth Road
London SW8 1RL
Helpline: 0870 7700 337
Email: information@bliss.org.uk
Website: www.bliss.org.uk

but it will become easier with time. If you are worried about caring for your child, please talk to the nurses.

Your child will be transferred to another ward at the hospital or to your local hospital, once he or she is feeding properly and gaining weight. By this time, the dressing will have been removed and the operation site should be healing nicely. The nurses on the ward will explain any special care needed for the operation site. We will send you details of your outpatient appointment in the post, soon after you leave hospital.

You should call your local hospital if you are concerned.

The Outlook for children with Exomphalos

The outlook for children with exomphalos varies, depending on the size of the defect and any other problems. Many children grow up to lead normal lives.

Sometimes it takes a while for your child's intestine to work properly, so your child may need extra nutrition. This could involve special feeds or continuing TPN for a longer period so that your child can gain weight to reach the right size and weight for his or her age. He or she may seem smaller than other children of the same age for the first few years, but the majority catch up in time. Dieticians will be available to discuss this with you and offer advice.

passed through the nose into the stomach. This will drain off the contents of the stomach and stop your child feeling and being sick. It also releases any excess air that is in the stomach and intestine which could make your child uncomfortable.

The timing and type of operation will be discussed with you following assessment, as this will be different for each baby.

Although your baby cannot take milk at this time, if you plan to feed your baby breast milk later on (either by breast feeding or by bottle) you should start expressing breast milk within 6 hours of birth. When your baby has recovered from the operation they can then receive your milk. The nursing staff on the unit where your baby is will be able to show you how to express and store your milk and arrange for you to have access to a breast pump. Providing breast milk for your baby improves their chances of overcoming the challenges they face whilst in intensive and special care.

Surgery

This depends on the type of abdominal wall defect your baby has. The surgeon will explain about the operation or treatment in more detail. This will be discussed with you as not all babies will need an immediate operation. When surgery is to take place an anaesthetist will also visit you to explain about the anaesthetic.

All the doctors who perform this operation have had lots of experience and will minimise the chance of these risks.

All surgery carries a small risk of bleeding during or after the operation. Every anaesthetic carries a risk of complications, but this is very small. Your child's anaesthetist is a very experienced doctor who is trained to deal with any complications.

Small exomphalos

This usually involves an operation under general anaesthetic where the surgeons move the intestines back inside the abdomen and then close up the muscles and skin, making a belly button at the same time. This is called a 'primary repair' and is used when the child has a small amount of intestine outside the abdomen. This operation tends to take around half an hour. The operation site may be covered in a dressing to protect the wound.

Large exomphalos

There are two ways of treating this. Which operation your child has, depends on the size. The first type is similar to the operation explained above and takes around an hour. The surgeons may need to use a special material if there is not enough skin to close the abdomen. The operation site may be covered in a dressing to protect the wound.

The second method of repair is called a 'staged repair' and tends to be used if the exomphalos is too large to be repaired as above. This may involve regular dressings being applied and surgery being delayed and this method of treatment can take many weeks or months.

After Surgery

Your child will come back to the ward to recover, and you will be able to visit as soon as he or she is settled back in the incubator. All babies are closely monitored after the operation, and so your child will be connected to monitors to check his or her breathing, heart rate and oxygen levels. He or she will also be given pain relief through the 'drip'.

While your child's intestines recover and start to work, he or she will be fed through a tube into the veins (Total Parenteral Nutrition or TPN). This will gradually be replaced by breast or formula milk given through the naso-gastric tube when your child is able to tolerate this. As your child recovers, you will be able to feed him or her from the breast or bottle. Over time and depending on how quickly your child is recovering, the drips and monitors will be removed one by one.

The nurses on the ward will encourage you to look after your child as much as you feel able while he or she is recovering. You may feel anxious, especially while your child is connected to drips and monitors,