Is there a support group?

Cherubs UK
The Association of Congenital Diaphragmatic Hernia Research,Advocacy and Support.
Tel: 0800 731 6991
Website: www.uk-cherubs.org.uk

BLISS
BLISS is a support group which is able to offer support to families with babies with a range of conditions
68 South Lambeth Road
London SW8 1RL
Helpline: 0870 7700 337
Email: information@bliss.org.uk
Website: www.bliss.org.uk

Birmingham Children's Hospital NHS
NHS Foundation Trust

Information for Parents / Carers

Congenital Diaphragmatic Hernia

Southern West Midlands Newborn Network NHS

Staffordshire, Shropshire & Black Country Newborn Network

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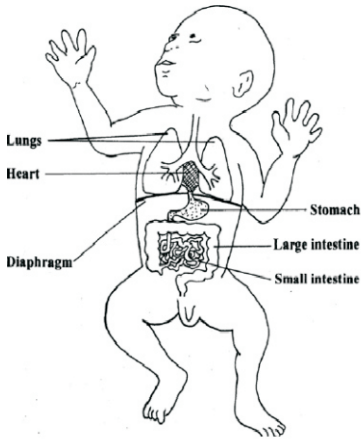
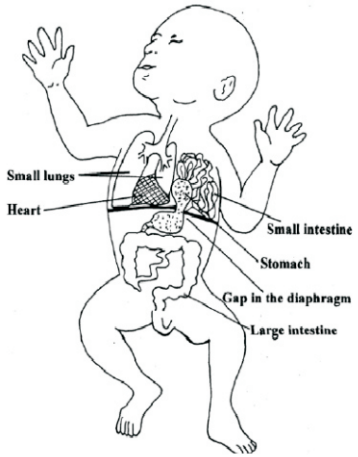
Your baby has been diagnosed with a congenital diaphragmatic hernia. This means that there is a hole in the diaphragm (the thin muscle between the lungs and tummy area). Some of the contents of the tummy (i.e. bowel or liver) can go up into the chest. The picture below shows this.

Normal Baby



Baby with diaphragmatic hernia



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

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.

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

Congenital diaphragmatic hernia

Congenital diaphragmatic hernia is a serious problem. It occurs when the diaphragm does not form completely, leaving a hole. The hole can be on either side, but in most children it is on the left side. This allows part of the intestine (gut) to develop in the chest. In addition the lungs are often small.

In up to 40% of cases there are additional problems. There may also be chromosome problems or heart problems. Generally, if a baby with congenital diaphragmatic hernia has either of the above abnormalities the expectations overall for the baby are very poor.

If these additional problems and other complications have been ruled out, then the outcome for these babies is significantly better. (In the range of 70-80% survival.)

During pregnancy

Detailed ultrasound scans will be performed and the baby's heart will be checked in detail which may require further referral for specialist heart scan.

In babies where the diaphragmatic hernia is the only problem seen, the most serious risk to the chances of the baby living is that the lungs do not develop properly, this is known as pulmonary hypoplasia. The risk of the baby having this complication is increased

by the size of the hernia and if the liver has moved up into the chest.

For this reason, you will need to have an ultrasound scan, and perhaps a special scan called an MRI, at 24 to 26 weeks into the pregnancy. This will help us to decide whether there is liver in the baby's chest. The ultrasound will also allow us to check other measurements and we can discuss the risks of pulmonary hypoplasia (poor lung growth) with you. Even if we carry out these tests, we can still never be certain how the lungs have grown and it is only once the baby has been born that we can be certain how the lungs have developed.

The chromosome problems can be excluded by a test during pregnancy. This can be done by a test called amniocentesis and/or by blood sampling from the baby. Amniocentesis involves using a needle to take a sample of the fluid that surrounds the baby in the womb and testing it. This in itself carries a very small risk of miscarriage, but this is less than 1%. We will discuss these tests with you to help you to decide if you want to have a test and if so which one. It is your choice if you want to have the test done or not, because if you prefer this can be checked after birth. We will need to arrange further scans of your baby to check that the baby is growing as it should. These will be at least every 4 weeks.

feeding properly and gaining weight. We will send you a letter with details of your outpatient appointment soon after your child leaves the hospital.

What is the outlook for children with congenital diaphragmatic hernia?

This depends on how early the condition presents and how much the lungs were damaged before birth. The outlook is improving all the time, as better treatment is developed. Children who would previously have not survived are now growing up and we will only know the long-term effects of diaphragmatic hernia by studying these children closely.
Sometimes it takes a while for your baby's intestine to work properly, so your child may need extra nutrition. This will enable your child to gain weight to reach the right size and weight for his or her age. Please speak to the dieticians about this.
Some children who have had a diaphragmatic hernia develop a problem with gastro-oesophageal reflux. This is where the contents of the stomach flow back up the oesophagus (gullet) causing pain and irritation. This will need treatment and possibly an operation. Your local hospital will continue to monitor your child as they grow up and will be able to support you if this problem develops.

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'. Occasionally there may be a tube from the operation site (chest drain) to drain off air and fluid so that the lungs have room to expand. This will be removed as soon as it is no longer needed.

While your baby's intestines recover and start to work, he or she will be fed through a tube into their veins (total parenteral nutrition or TPN). This will gradually be replaced by breast or formula milk given through the naso-gastric tube when your baby is ready for this. As your baby recovers, you will be able to feed him or her from the breast or bottle. Over time, the drips and monitors will be removed one by one.

Your child's lungs may not have developed properly by being squashed by the intestines in the chest. The length of time that your baby needs the ventilator depends on the condition of their lungs. If this is likely to cause long term problems, the doctor will explain all about it to you.

The nurses on the ward will encourage you to look after your baby as much as you feel able while he or she is recovering. You may feel anxious, especially while your baby is connected to drips and monitors, but it will become easier with time. If you are worried about caring for your baby, please talk to the nurses. You will be transferred to another ward within the hospital or to your local hospital once your baby is

Delivery

How and when your baby will need to be delivered will be discussed with you in the Antenatal Clinic. This condition does not mean that caesarean delivery will be needed unless there are other reasons. In most cases delivery is usually arranged at the end of 41 weeks aiming for normal delivery, unless labour has already happened naturally by then.

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

Treatment and care after delivery

When your baby is born, it will be assessed immediately by the Neonatalogists (doctors specialising in the care of newborn babies). It is extremely common for all babies with congenital diaphragmatic hernia to need help with their breathing by ventilation. The baby would then be transferred to the Intensive Care Baby Unit for assessment and therapy.

Neonatologists will discuss with you your individual baby's condition and whether or not the baby's lungs

are working as they should. Other additional treatments your baby might need will be discussed on an individual basis.

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

The timing and type of operation will be decided by the Surgeons and Intensive Care doctors at the hospital where your baby's operation will take place. Often, surgery is not performed until the baby is more stable which may be 3 days or so. This will be discussed with you so you understand when your baby will be moved and what the operation involves.

Diaphragmatic hernias are repaired in an operation under general anaesthetic (so that your baby is deeply asleep). The surgeons will only carry out the operation once your baby is stable on a ventilator. Diaphragmatic hernias must be treated in this way, because if they are not repaired your baby's breathing problems would get worse as he or she grew. Feeding problems would also get worse with time.

During the operation, the surgeon will move your child's intestine back into the abdomen and repair the hole in their diaphragm. Sometimes, the surgeon may need to use a 'patch' of special material to close this hole, but this will not cause any problems in the long term. If your child's intestine has become twisted while it is in the chest (which is not uncommon) the surgeon will correct this during the same operation.

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

All operations carry a small risk of bleeding, during or afterwards. 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.

After Surgery

Your baby 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. For a while after the operation, your baby will need help with breathing so will be connected to a ventilator. All babies are closely monitored after the operation, and so your baby will