

Information leaflet for parents / carers

# Congenital Diaphragmatic Hernia

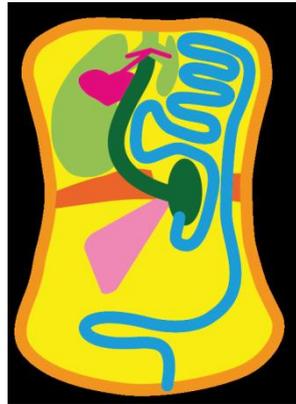


## What is a diaphragmatic hernia?

The diaphragm is a curved muscle that separates the contents of the chest from the abdomen (tummy). Diaphragmatic hernias occur when the diaphragm does not form completely, leaving a hole. This usually happens early in pregnancy at around six to eight weeks. The hole in the diaphragm allows the abdominal contents to pass (herniate) into the chest cavity, which in turn prevents the lungs from developing properly. Depending upon at what stage the abdominal contents herniated,, how much, and the size of the hole in the Diaphragm will determine how much your unborn baby's lungs and other internal organs, such as the heart, have been affected.



Correctly formed Abdomen



Example of CDH abdomen

## What causes it?

We do not know exactly what causes diaphragmatic hernias. They are very rare, occurring in one in around 2,500 babies. They are more common in boys than girls. Diaphragmatic hernias can be associated with other problems such as chromosomal syndromes and heart defects, so the doctors will examine your child closely to check if this is the case.

## What to expect during pregnancy:

- Extra ante-natal appointments to closely monitor the pregnancy and the baby. This may involve a referral to a Fetal Medicine unit.
- MRI (Magnetic Resonance Imaging) may be recommended in an attempt to obtain the size and volume of the baby's lungs, although this does not offer certainty regarding long term outcomes.
- Amniocentesis to check for chromosomal abnormalities, because rarely CDH is associated with other syndromes. It is entirely your choice whether you opt for this test.
- A referral to a tertiary centre such as Birmingham Women's and Children's Hospital, which is a specialist centre that has the experience to look after your baby during your pregnancy and after he or she is born. The opportunity to meet with the medical team who will be caring for you and baby during and after the birth. This will include a neonatologist (newborn baby doctor), and a Paediatric Surgeon (a doctor who specialises in carrying out surgery on babies and children).
- You may also be given the opportunity to have a look around the neo-natal intensive care unit (NICU) so that you know what to expect when baby arrives and the opportunity to look around paediatric Intensive Care (PICU) so you know what to expect when your baby is transferred for surgery.

## **Delivery of your baby:**

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 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:**

Usually babies with congenital diaphragmatic hernia have breathing difficulties at birth which will require immediate support. Your baby will be admitted to the neonatal unit after birth and will need a machine to help your baby to breathe. In most cases, this will be a ventilator.

They will also have a tube passed through their nose into their stomach (nasogastric tube or NG tube). This will release any excess air that is in the stomach and intestine, which also relieves the pressure on the lungs. They will also have a 'drip' (intravenous infusion) to give fluids and medicines directly into their bloodstream.

## When will my baby be transferred for Surgery?

Surgery will usually be delayed until the baby's condition is stable. This may take up to 2 weeks. During this time the baby will be receiving intensive care and breathing support from the ventilator. This will be supervised by the consultant neonatologists. Your baby will also be under the care of one of our surgeons.

When the timing is right your baby will be transferred to PICU at Birmingham Children's Hospital where they will be prepared for surgery.

### Surgery:

The surgeon will explain about the operation in more detail, discuss any worries you may have and ask you to sign a consent form giving permission for your child to have the operation. An anaesthetist will also visit you to explain about the anaesthetic.

The surgery may be carried out through an incision on the abdomen or through key hole incisions. 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.

The baby will still require help with breathing after surgery, so intensive care will continue.

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.

## Are there any risks?

- All operations carry a small risk of bleeding, during or afterwards.
- There is a chance that the intestines or other abdominal organs could be damaged when they are moved back into the abdomen but this is very rare. If damage occurs, this will be fixed in the same operation.
- There is a small risk of infection but this is minimised by giving your child antibiotics before the operation.
- After treatment, there is a chance that the hole in the diaphragm could come back, which would require another operation to repair it.
- 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.

## How will I Feed my baby:

While your baby's intestines recover and start to work, they may be fed through a tube into their veins (total parenteral nutrition or TPN). When your child is ready this will gradually be replaced by breast or formula milk given through the naso-gastric tube.. As your baby recovers, you will be able to feed them from the breast or bottle.

Breast milk is very important for every baby but especially sick babies and even more so for those with bowel/ stomach problems. Breast milk is far more than just food, it contains essential nutrients your baby needs to grow, develop, and recover from surgery or illness.

Although your baby cannot take milk at this time, in order to establish and/or maintain your breast milk supply for when they are well enough to feed, we encourage you to express your breast milk. It is important that you start expressing milk within 6 hours of birth and continue to do this at least 8-10 times a day, including at least once every night.

There is a quiet, private area on the ward that you can use to breast feed your baby or express breast milk. Expressing milk can be done by hand, which is useful in the first few days after birth when you can expect to express small amounts of sticky clear or yellow fluid called 'colostrum'.

Electric breast pumps are available for use on the ward. Your expressed breast milk will be stored safely until your baby is well enough to feed. The nursing staff will be able to show you how to express and store your milk and arrange for you to have access to a breast pump.

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 breathing for themselves, feeding properly and gaining weight.

## What are the long term effects and after care?

Babies born with diaphragmatic hernia will need regular follow-up in clinic after going home from the hospital. Some may have long-term problems, most will be able to attend school normally and have a good quality of life.

Infants with CDH often have respiratory problems and may require oxygen at home.

Many babies reflux (frequent milky vomiting), however CDH babies are particularly prone to it. If your baby has reflux it can often be treated effectively with medications.

They have much higher energy and protein needs and may have difficulty growing. This is known as failure to thrive. Often babies with CDH need breast milk or formula that is more concentrated than normal. Your babies growth will be closely monitored at home by your health visitor and/or dietician.

Some CDH babies may be reluctant or refuse to feed orally. This can be due to long periods of not feeding by mouth and being on the ventilator while in hospital. If this is the case your baby will need to be fed via a small tube in the nose and will be seen by the Speech and Language Therapist.

On rare occasions the hole in the diaphragm re-occurs enabling the organs to go back up into the chest causing breathing problems and/or causing a bowel obstruction. This is uncommon but can be serious if it happens and would require another operation.

For more detailed information on long term care for CDH children please see the CDH UK website.

## **Support groups**

The support organisation for families of children affected by diaphragmatic hernia is CDH UK.

Call their free helpline on 0800 731 6991 or visit their website at [www.cd huk.co.uk](http://www.cd huk.co.uk)

### **Cherubs UK**

The Association of Congenital Diaphragmatic Hernia Research, Advocacy and Support.

Tel: 0800 731 6991

Website: [www.uk-cherubs.org.uk](http://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

[information@bliss.org.uk](mailto:information@bliss.org.uk)

[www.bliss.org.uk](http://www.bliss.org.uk)

### **Contact a family**

Contact a family supports families with children with disabilities or health conditions.

[www.cafamily.org.uk](http://www.cafamily.org.uk)

## 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 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 your information with other people and organisations who are either responsible or directly involved in your child's care. This may involve taking your child's information off site. We may also have to share some of your information for other purposes; such as research etc. Any information that is shared in this way will not identify your child unless we have your 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 Children's Hospital**  
Steelhouse Lane Birmingham B4 6NH  
Telephone 0121 333 9999  
Fax: 0121 333 9998  
Website: [www.bwc.nhs.uk](http://www.bwc.nhs.uk)

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