

# Congenital Diaphragmatic Hernia (CDH)

**This leaflet offers more information about congenital diaphragmatic hernia. If you have any further questions or concerns, please speak to the staff member in charge of your baby's care.**

## What is congenital diaphragmatic hernia?

A congenital diaphragmatic hernia (CDH) is when the diaphragm has not formed completely and has left a hole, which results in the bowel entering into the chest cavity. The presence of the bowel in the chest cavity can prevent the lungs from growing normally. This is a serious diagnosis.

CDH occurs in 1 in 2,500 babies. There is currently no known cause or risk factor.

## Diagnosis and during your pregnancy

CDH is usually identified on your routine 20 week antenatal ultrasound scan.

In up to 40% of cases there may be additional problems affecting your baby. You will be offered further screening, which may involve taking a sample of amniotic fluid to test look at the baby's chromosomes and a detailed scan of the baby's heart. This scan is called an Echo.

Your baby will need to be admitted to the neonatal unit following birth to monitor them and to be helped with their breathing.

## Delivery

How and when your baby needs to be delivered will be discussed with you. You should be able to deliver your baby normally unless there are other reasons for requiring a caesarean section. When considering your delivery we need to make sure the neonatal unit has a cot available to ensure your baby's safety. Delivery should be in a hospital with experience in managing this condition.

Most babies will have breathing difficulties at birth and will need immediate support with their breathing. At birth your baby will be taken to the large cot (Resuscitaire) in the delivery room and their breathing will be supported on a ventilator. Your baby will be transferred to the neonatal unit (NNU) in a portable incubator on the ventilator. This will be carried out as quickly as possible in order to stabilise your baby. You will probably be unable to hold your baby after birth, but once they are stabilised you will have the opportunity to see your baby briefly before transfer. It may take a few hours before you can be next to your baby as the team will be working to stabilize them which would include careful management of ventilation, the placement of lines, x-rays, blood tests and other monitoring procedures.

You are welcome to visit the neonatal unit as soon as you are able to.

## Taking care of you baby over the next few days

The first 24 hours in NNU can be a critical time for your baby. He or she will need constant monitoring by the doctors and nurses. Your baby will remain on the ventilator until after surgery

and may require additional drugs to support their blood pressure and oxygenate the baby. This is because some of the lungs did not develop properly during the pregnancy while the bowel was in the chest cavity. Your baby may also receive an additional gas through the ventilator called Nitric Oxide (INO) which can assist with respiratory support. It is likely that your baby will be on medication to keep them very still (muscle relaxant).

## Feeding

Your baby will not be able to receive any milk until after surgery to repair the hole in their diaphragm. If you wish to breast feed, the nursing staff will teach you how to express and store your milk to feed to your baby when they are ready.

The baby will receive their nutrition from a drip (parental nutrition) through a long-line. This is usually placed in a small vein in the baby's foot or arm and fed into a larger vein.

## Surgery

The timing of surgery will depend on how much ventilatory help your baby requires. The operation is not performed until baby is stable and some of the additional life support has been reduced and the doctors are happy with the general progress. This period of stability may take up to five to seven days.

The surgeon will discuss with you the type of operation needed to return the bowel and any other abdominal contents back to the correct place and repair the hole in the diaphragm. Depending on the size of the hole the surgeon will decide whether to suture (stitch) the hole or to attach a patch to repair the hole. The patch of special material is called 'Gore-Tex®' and should not cause any problems in the long term. Your baby will still require ventilation and intensive care support following surgery. This will be reduced as your baby's condition improves.

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

This depends on how early the CDH was diagnosed and how much of the lungs affected before birth. There may be no long-term effects, however many babies will have gastro-oesophageal reflux. This is a condition where milk can flow back up the oesophagus (food pipe) causing irritation and pain. This will be treated with medicine. This medicine is usually started after the operation and your baby is discharged home on it and should be continued until he or she is six to twelve months old as advised by your surgeon. Some babies will have chronic lung problems or chest infections and may need repeated hospital admissions.

Your baby should have a chest x-ray before they are discharged home.

Following discharge from the unit there will be regular check-ups by the surgical team in order to monitor your baby's progress and there will be appointments in the neonatal respiratory clinic at St George's Hospital.

## If St George's Hospital is not your local hospital

Once your baby has had surgery and made a good recovery, i.e. when their specialist medical and nursing requirements are less, the baby will be transferred back to the care of your local

hospital. This transfer is a sign of progress and will not occur until the baby is ready. It will allow you to be closer to home and become familiar with your local healthcare professionals.

## Useful sources of information

### BLISS

**Bliss** is a support group which is able to offer support and advice 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](mailto:Information@bliss.org.uk)

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

Use your smartphone to scan the QR code (you may need to download a QR code scanning



### CDH UK

CDH UK consists of families, friends and medical professionals affected by Congenital Diaphragmatic Hernia (CDH).

“Our website aims to provide support, information and advice on CDH by sharing experiences, providing news and information, raising awareness and working together with families and medical professionals to improve treatments and to further research.”

Website: [www.cdhuk.org.uk](http://www.cdhuk.org.uk)

**For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit [www.stgeorges.nhs.uk](http://www.stgeorges.nhs.uk)**

---

## Additional services

### Patient Advice and Liaison Service (PALS)

PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9.30am and 4.30pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough Wing (near the lift foyer).

**Tel:** 020 8725 2453 **Email:** [pals@stgeorges.nhs.uk](mailto:pals@stgeorges.nhs.uk)

### NHS Choices

NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.

**Web:** [www.nhs.uk](http://www.nhs.uk)

### NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.

**Tel:** 111

