Congenital diaphragmatic hernia (CDH)

Information for parents
1. What is congenital diaphragmatic hernia (CDH)?

CDH is where the baby’s diaphragm does not form fully. The diaphragm is a muscle that helps us breathe. It also keeps the heart and lungs separate from the organs in the abdomen (tummy). With CDH, some of the baby’s abdominal organs, such as the bowel and liver, go through a hole in the diaphragm and take up some of the space where the lungs should be. The problem happens very early on in the development of your baby and results in the lungs having less space so they cannot grow and develop normally.

Your baby’s lungs do not need to work in the womb as your baby gets oxygen from your bloodstream through the placenta. After birth, your baby’s lungs need to supply the body with oxygen. If they are small or poorly developed they may not work properly.

Many babies with CDH will also have a problem called pulmonary hypertension. This is due to high blood pressure within the lungs that results in the heart not being able to pump blood into the lungs. This makes it more difficult for the lungs to absorb oxygen. Organs need oxygen to work and a lack of oxygen will lead to serious problems unless this is corrected.

2. How common is it?

CDH occurs in about 4 of every 10,000 births.

3. How is it diagnosed and confirmed?

Many cases of CDH are diagnosed during pregnancy. If a baby has CDH, it is usually noticed at the Fetal Anomaly ultrasound scan carried out between 18 weeks and 21 weeks of pregnancy. Sometimes it is noticed during a scan later on in the pregnancy. Some cases are diagnosed after the baby is born.

4. Is there any treatment?

The treatment you are offered will depend on a number of factors. You will be offered an appointment to talk to specialist doctors about the treatment options.

Babies born with CDH normally need immediate medical attention when they are born and help with breathing (ventilation). Your baby will go to the neonatal intensive care unit (NICU) to stabilise their condition. The decision on when and how to repair the hole in the diaphragm will be made after your baby responds to treatment, and this will often take many days in severe cases. Senior medical staff will keep you fully informed of your baby’s progress. Unfortunately some babies are born with lungs that are too small and they cannot be saved.
Your baby will need a general anaesthetic for the operation to repair the hole in their diaphragm. The operation involves putting the bowel (and any other structures) back into the abdomen and repairing the hole in the diaphragm. This will usually take one or two hours. If the hole is particularly large, an artificial patch may need to be placed over the hole.

After the operation, your baby will still need intensive care and help with breathing, so they will be closely monitored. How long your baby needs to be on a ventilator before and after the operation depends on how small and underdeveloped the lungs are. The bowel can also take a while to begin working after it has been moved back into the abdomen.

Research is being carried out to develop and evaluate new treatments that can be carried out on the fetus, such as FETO (fetoscopic tracheal occlusion). Your doctor will explain whether your baby may be suitable for this procedure. This procedure is only carried out in some specialist centres as it is currently part of a trial. Speak to your doctor or midwife if you have any specific questions.

5. What is the outlook for my baby?

Approximately 50% (5 in 10) of babies born with CDH survive. The chance of your baby surviving and doing well after the operation depends on how well the lungs have developed and whether your baby has any other conditions. In up to 10% of cases (1 in 10), CDH may be associated with other problems such as heart problems or chromosomal abnormalities (abnormalities in the number or structure of chromosomes).

6. What happens next?

You will be given the chance to talk to specialists about what having a baby with congenital diaphragmatic hernia might mean to you and your family.

They will offer you another scan to check whether the baby has other disorders, and will discuss tests such as CVS (chorionic villus sampling) or amniocentesis to check for genetic disorders. There is more information on CVS and amniocentesis in leaflets called Chorionic villus sampling (CVS) – information for parents and Amniocentesis test – information for parents. These are available on our website at www.fetalanomaly.screening.nhs.uk/publicationsandleaflets.

Your doctor may talk to you about the option of having a termination to end your pregnancy. You will have the opportunity to discuss the possible implications of continuing or ending your pregnancy.

If you choose to continue your pregnancy, your healthcare team will help you plan how your care, including delivery, is managed.

You will be offered regular ultrasound scans to monitor your baby. Arrangements will be made for you to meet some of the paediatric team, including one of the paediatric surgeons, who will care for your baby after the birth. There are a range of options for the delivery of your baby. Your health professional will discuss these options with you.
If you choose to have a termination, your health professional will talk to you about the procedure and support you through the process.

Whatever you decide, your decision will be respected and you will be supported by your midwife and doctor.

7. How likely is it to happen in a future pregnancy?

You are much more likely to have a normal, healthy baby in your next pregnancy than to have another baby with CDH. There is a 2% chance (2 in 100) of CDH in another pregnancy.

There is no way to prevent this condition. It is not due to anything you have or have not done.

8. Where can I get more information and support?

You may feel you only want to talk to your family and friends, or a particular doctor or midwife from the hospital. However, there are other people and organisations that can provide information, help you make your decisions and support you in your pregnancy and afterwards. You may also want to talk things through with the hospital chaplain or your own minister or faith leader.

9. Further information, charities and support organisations

The following organisations can offer you support. There are details of other support organisations on our website at www.fetalanomaly.screening.nhs.uk. If you have any questions about the information in this leaflet or where the information came from, email us at enquiries@ansnsc.co.uk.

Antenatal Results and Choices (ARC)
Email: info@arc-uk.org
Helpline: 0845 077 2290
Website: www.arc-uk.org

Antenatal Results and Choices (ARC) provides information and support to parents before, during and after antenatal screening and diagnostic tests, especially those parents making difficult decisions about testing, or about continuing or ending a pregnancy after a diagnosis. ARC offers ongoing support whatever decisions are made.
CDH UK – The Congenital Diaphragmatic Hernia Charity
Freephone: 0800 731 6991
Email: support@cdhuk.co.uk
Website: www.cdhuk.co.uk

CDH UK provide information, support and advice to families, friends and health professionals who are affected by or involved in the treatment of congenital diaphragmatic hernia. They also raise awareness of the condition and encourage research and study into causes, prevention and treatments.

This information has been produced on behalf of the NHS Fetal Anomaly Screening Programme for the NHS in England. In other countries, check with a health professional to find out whether there are any differences in approaches to screening.

This leaflet has been developed through consultation with the NHS Fetal Anomaly Screening Programme expert groups and is based on a leaflet issued by CDH UK. That leaflet is on the CDH UK website at www.cdhuk.co.uk.

All of our publications can be found online at www.fetalanomaly.screening.nhs.uk.

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