



Public Health
England



NHS Fetal Anomaly Screening Programme

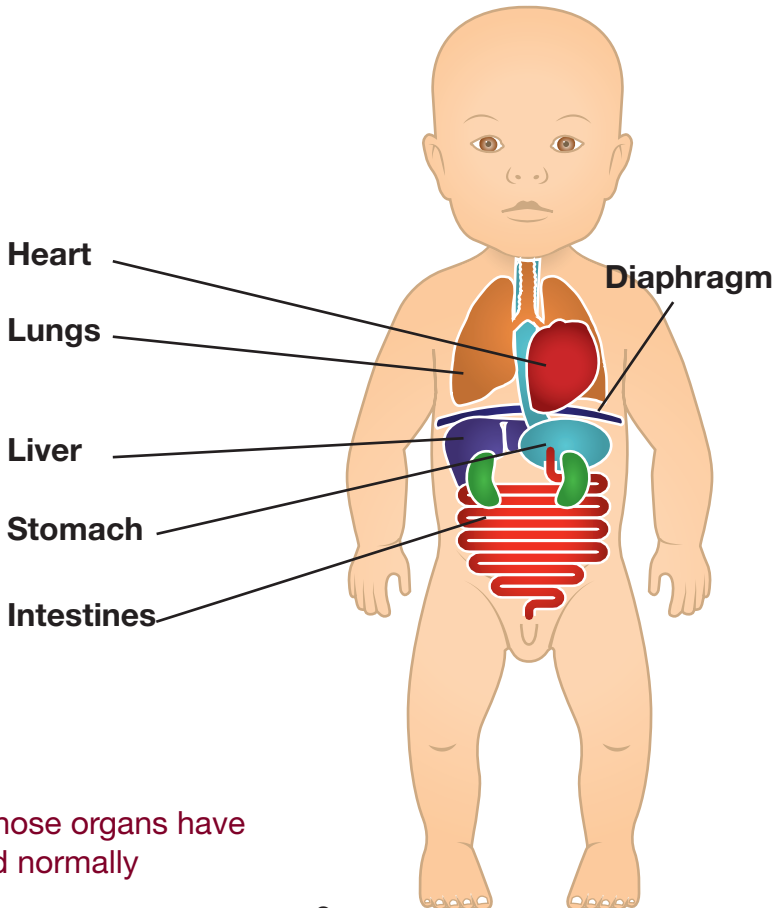
Congenital diaphragmatic hernia (CDH):
information for parents



This leaflet is for pregnant women whose baby is suspected of having a **congenital diaphragmatic hernia** (CDH). It can help your health professional talk through the next stages of your care.

About CDH

Congenital diaphragmatic hernia (CDH) is a condition where the baby's diaphragm does not form as it should. The diaphragm is a thin sheet of muscle that helps us breathe. It also keeps the heart and lungs separate from the organs in the abdomen (tummy).

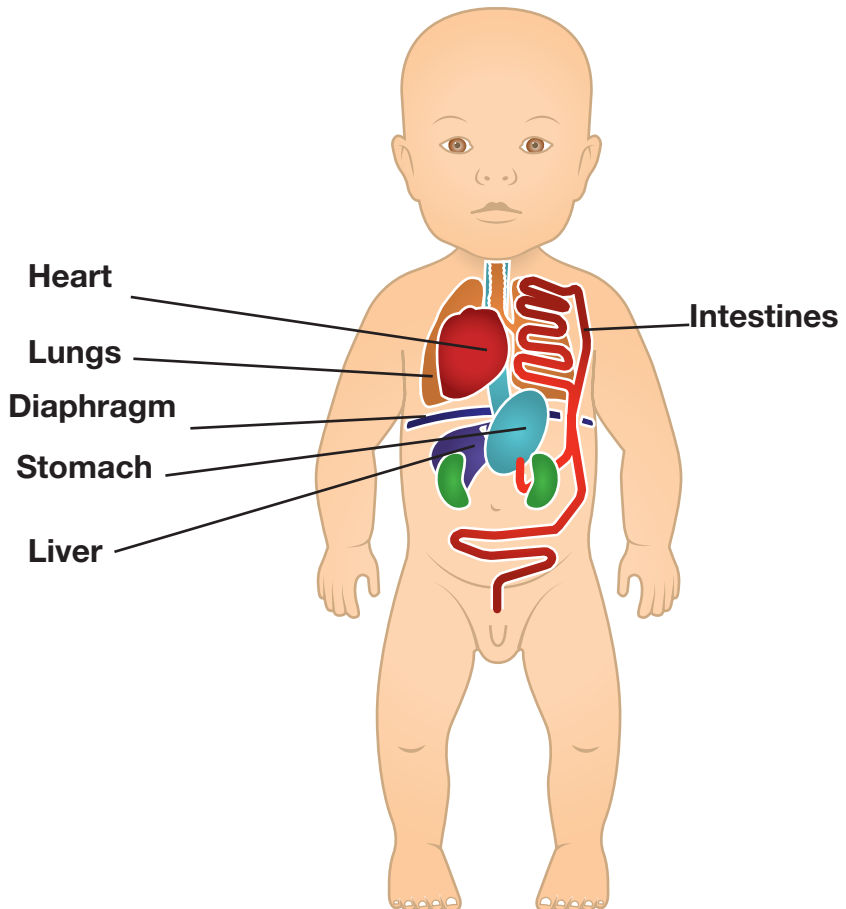


A baby whose organs have developed normally

CDH happens very early in the baby's development. The lungs have less space so they cannot grow and develop normally.

In some babies with CDH the organs in the abdomen, such as the stomach, bowels and liver, go through the hole in the diaphragm. This is called a hernia.

These organs take up the space where the lungs and heart should be and this means the lungs do not grow normally.



A baby with a congenital diaphragmatic hernia

Complications

Many babies with CDH will also have a problem called pulmonary hypertension caused by high blood pressure in the lungs. This might mean the heart cannot pump blood into the lungs. This makes it more difficult for the lungs to take in oxygen. Organs need oxygen to work. Not getting enough oxygen causes serious problems.

The baby's lungs do not need to work in the womb because the baby gets oxygen from the mother's bloodstream through the placenta. After birth, the baby's lungs need to supply the body with oxygen. If the lungs are small or not developed as expected they may not work properly.

Possible outcomes and treatments

We do not fully understand why CDH occurs but it is found in about 4 in every 10,000 births. About half (5 in 10) of babies born with CDH survive. The chance of them doing well depends on how the lungs have developed and if they have any other conditions.

CDH is usually found during the fetal anomaly ultrasound scan between 18 weeks and 21 weeks of pregnancy. Sometimes it is found at later scans or after the baby is born.

All babies with CDH need to be born in a maternity unit with a neonatal intensive care unit on site. After birth the baby will need specialised medical attention in a unit that is experienced in caring for babies with CDH to help with their breathing. An operation to close the hernia is usually needed. This can be performed after birth once the baby is well enough.

Follow-up tests

You will be referred to an expert doctor in a fetal medicine unit if CDH is suspected at the fetal anomaly scan. They will:

- confirm if the baby has CDH
- talk to you about the condition
- talk through the options for the baby's birth

They may also introduce you to a paediatric surgeon (a healthcare professional who specialises in caring for and operating on babies and children). They will explain the type of operation or other treatment the baby may need after birth.

CDH can sometimes be linked with other conditions. In up to 1 in 10 (10%) of cases, CDH may occur alongside other problems such as heart conditions or chromosomal conditions like Down's syndrome, Edwards' syndrome or Patau's syndrome.

You may be offered the choice of having an amniocentesis test in case the CDH is part of a chromosomal or genetic condition. This is where a small amount of amniotic fluid (the water around the baby inside your womb) is taken for testing. The sample contains some of the baby's cells, which contain genetic information.

More information about amniocentesis can be found in the PHE Screening leaflet '[CVS and amniocentesis: information for parents](#)'. This can be downloaded from www.gov.uk. Simply search for CVS and amniocentesis diagnostic tests: description in brief.

Next steps and choices

You will be able to talk through your choices. This may include continuing your pregnancy or terminating your pregnancy.

If you choose to continue your pregnancy, your healthcare team will help you plan your care for pregnancy and birth of the baby. You will be given the chance to talk to specialists about what may happen if the baby is born with CDH.

If you choose to have a termination, your healthcare team 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.

Having a baby with CDH in this pregnancy does not mean it is likely to happen again in another pregnancy. You are much more likely to have a healthy baby in your next pregnancy. For women who have a baby with CDH there is a 2 in 100 (2%) chance of CDH in another pregnancy.

Sadly, there is no way to prevent this condition and it is not always known why it happens. It is not caused by anything you have or have not done.

More information

Antenatal Results and Choices (ARC):

- www.arc-uk.org

The Congenital Diaphragmatic Hernia Charity (CDH UK):

- www.cdhuk.org.uk

NHS Choices:

- www.nhs.uk/conditions/hernia

Find out how Public Health England and the NHS use and protect your screening information at www.gov.uk/phe/screening-data.

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More information about screening: www.nhs.uk/anomalyscan

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