We recommend pregnant women have steroid injections at around 34 weeks to help mature your baby's lungs.

Amniocentesis

A sample is taken from the fluid around your baby in the womb to check for chromosomal abnormalities. An initial result may be available after 2 days, but it can take up to 14 days.

Detailed Ultrasound scans to assess lung growth

Regular scans will be performed during your pregnancy. Ultrasound may be used to calculate the lung to head ratio (LHR), a measure of lung size. This estimates how severely the lungs are affected.

Ultrasound also checks if the liver has moved in to the chest and if there is too much fluid around your baby (polyhydramnios).

MRI scan

You may be offered an MRI scan during the pregnancy to further assess your baby. This does not involve irradiation and is safe for you and your baby.

Delivery and Transfer

The neonatal surgical centres in Scotland where babies with CDH are cared for are:

- Royal Aberdeen Children's Hospital
- Royal Hospital for Sick Children Edinburgh
- Royal Hospital for Sick Children Glasgow

Your delivery will be planned around 39 weeks at one of the maternity units near one of the surgical centres. If your labour starts early and there is no time to transfer you to one of these units, your baby will be transferred after stabilisation by a specialist neonatal transfer team.

What is the outlook for your baby?

The chances of your baby surviving depend on how well the lungs develop in the womb and whether your baby has any other major problems such as chromosomal or serious heart abnormalities in particular.

While treatment of CDH is improving all the time, unfortunately, some babies are so ill that they cannot be saved. Overall, between 50-70% (5-7 out of 10) babies born with CDH will survive.

Scottish Diaphragmatic Hernia Clinical Network (SDHCN)

The SDHCN is a nationally supported network that includes doctors, midwives, nurses and parents.

It was set up to produce and deliver best standards of care for CDH, so that you and your baby receive the best treatment.

The network routinely collects audit data to improve care.

Useful sources of information

www.sdhcn.scot.nhs.uk

www.cdhuk.co.uk

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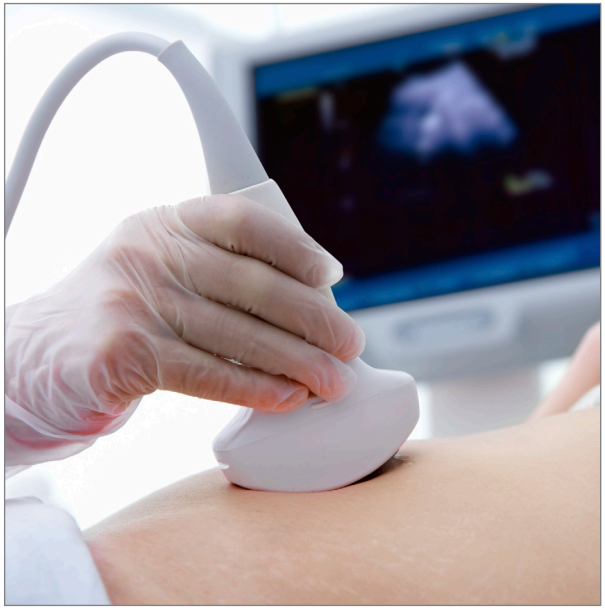
Scottish Diaphragmatic Hernia Clinical Network

Information for parents about

Congenital Diaphragmatic Hernia

Antenatal



You will have been told that your baby has a congenital diaphragmatic hernia (CDH). This leaflet will help you and your family understand what this means.

What is a Congenital Diaphragmatic Hernia (CDH)?

CDH occurs when the baby's diaphragm does not form properly in the womb. The diaphragm is a muscle that helps with breathing and separates the heart and lungs in the chest from the bowel and other organs in the abdomen.

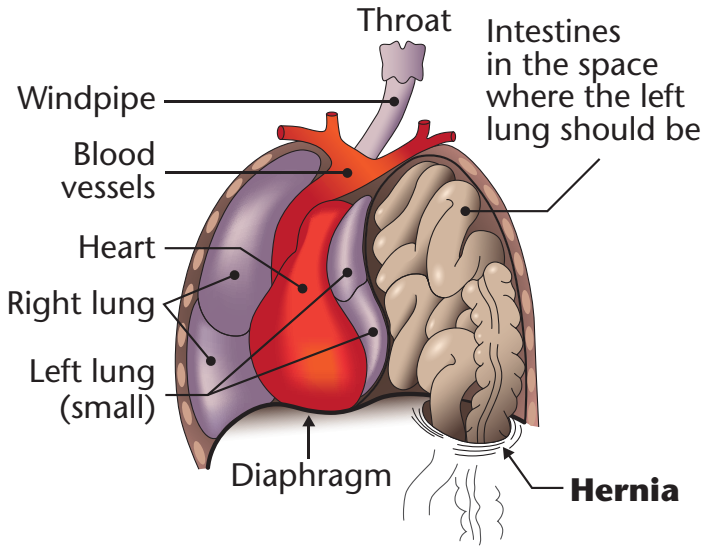
With CDH, some of the baby's abdominal organs, such as the bowel and liver, go through a hole in the diaphragm at about 10 to 12 weeks into the pregnancy and take up space in the chest where the lungs should be growing. CDH occurs on either side, but much more commonly on the left.

What happens in CDH?

The main problem in CDH is that the lung on the side of the hernia (and even the lung on the opposite side) is squashed by the abdominal organs that are in the chest and cannot grow to its full size. This is known as lung hypoplasia. In the womb there is no need for your baby's lungs to work as oxygen is supplied by the placenta. At birth, when the umbilical cord is clamped, the placenta is no longer available and your baby needs to use it's lungs to breathe.

Many babies with CDH also have a problem called pulmonary hypertension. This is due to a failure of the blood vessels in the lungs to relax after birth and let blood flow through them so that they can pick up oxygen from the lung air sacs (alveoli).

Body organs need oxygen to work and a lack of oxygen will lead to organ failure unless this is corrected.



The illustration above shows the position of the main body organs in a baby with CDH.

What causes CDH and how common is it?

We do not know what causes CDH. It is not due to anything you have done during your pregnancy. It may run in families, especially if the baby has other genetic problems.

CDH occurs in about 1 in every 3,000 babies and accounts for 8% of all major birth defects. Up to 20% of infants also have a chromosomal abnormality such as Down's or Edward's syndrome.

The chance of having another baby with isolated CDH (no other genetic condition) is 2%.

CDH during pregnancy

Many babies with CDH are detected at the 18-20 week fetal anomaly ultrasound scan (FAS) that is routinely offered to pregnant women. Sometimes it is detected during a scan later in your pregnancy.

If a CDH is suspected you will be offered a further detailed ultrasound assessment by a fetal medicine specialist. They will look at the CDH in detail and will also look for other abnormalities.

Counselling

The fetal medicine specialist will discuss the results of your scan and may offer you another test (amniocentesis – see next page) to look for chromosomal abnormalities.

You will also have an opportunity to speak to a neonatologist and a paediatric surgeon who have experience of caring for babies with CDH about what this might mean to you and your family. They will answer any questions you may have.

If the lungs are very small and especially if there is another major abnormality, you may choose not to continue with your pregnancy (termination). If you choose to continue with your pregnancy, the fetal medicine team will plan with you where and how your baby will be delivered.

In some severe cases the specialists may recommend referral for fetal therapy to try to improve lung growth while your baby is in the womb. This therapy is not suitable for all and is not without risk.