Congenital diaphragmatic hernia (CDH)

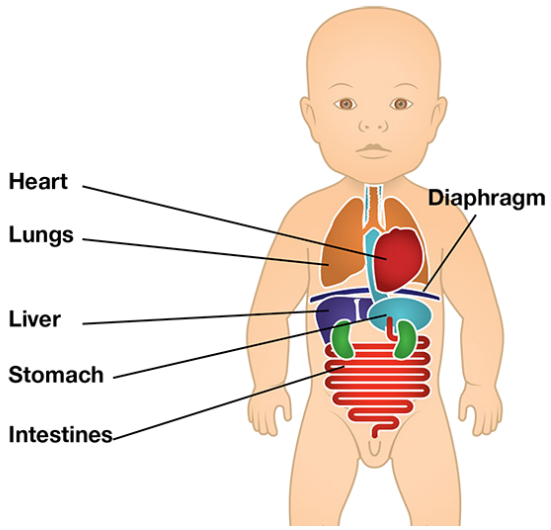
A scan has shown that your baby has a condition called congenital diaphragmatic hernia (CDH). This factsheet has been designed to accompany the individualised discussions you will have about your care and the care of your baby both during pregnancy and after your baby's birth.

We hope it will help to answer some of the questions you may have. If you have any further questions or concerns, please speak to a member of the fetal medicine or neonatal surgical team.

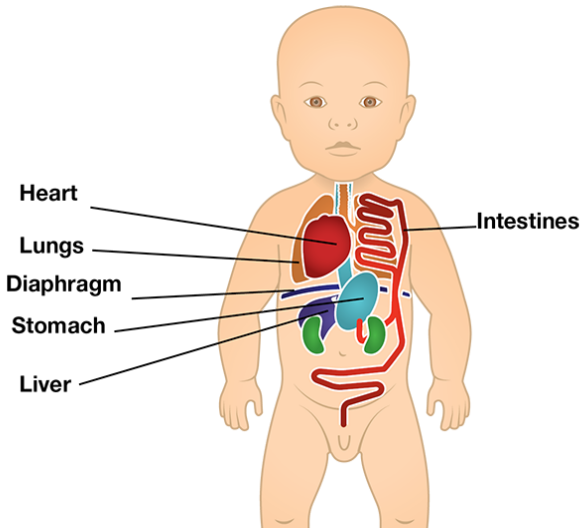
What is congenital diaphragmatic hernia (CDH)?

CDH is a condition where the baby has a hole in the layer of muscle that separates the chest and the abdomen. This is called the diaphragm. This muscle helps us to breathe. It also keeps the heart and lungs separate from the abdominal organs, such as the stomach, liver and bowel.

If there is a hole in this muscle the abdominal organs can move up (herniate) into the chest cavity. This causes a baby's lungs to become squashed, which stops them developing properly before birth. Sometimes, the baby's heart is also pushed over to the 'wrong' side of their chest (as shown below).



A baby whose organs have developed as expected



A baby with CDH

What causes CDH?

The cause of CDH is unknown. It is a rare condition and affects approximately one in 2,500 babies. CDH occurs very early in pregnancy, at around six to eight weeks when a baby's diaphragm is developing.

Identifying additional conditions

CDH can be an isolated condition (which means no other condition occurs with it), but it is also more common in babies who have a condition which affects their heart, or those who have a genetic or chromosomal condition.

You will be offered a detailed scan of your baby to examine their development and growth. Please be aware that antenatal scans have limitations and are not always 100% accurate.

You may also be offered a diagnostic test to determine whether or not your baby has a genetic or chromosomal condition. Diagnostic tests include chorionic villus sampling (CVS) and amniocentesis. The fetal medicine team will discuss diagnostic tests with you in more detail. It is important that you take time to consider your options and ask any questions you may have before you decide whether or not having a diagnostic test is the right choice for you.

What does this mean for your baby during pregnancy?

Your baby's wellbeing during pregnancy and after birth will depend on:

- the size of the hernia and the organs which have moved into the chest cavity (herniated)
- how well your baby's lungs are developed
- the presence of any additional chromosomal conditions
- whether any of your baby's other organs, including their heart, are affected

Sadly, only approximately half of babies diagnosed with CDH during pregnancy will survive to be discharged home.

Your care during pregnancy will involve us monitoring you and your baby very carefully to:

- identify any additional conditions which may affect your baby's wellbeing after birth
- minimise the likelihood of your baby being born prematurely (before 37 weeks)

Minimising the likelihood of your baby being born prematurely (before 37 weeks)

Too much amniotic fluid around your baby, a complication known as polyhydramnios, is associated with CDH.

We will offer you frequent scans to measure the amount of fluid around your baby. If polyhydramnios does occur, we will discuss treatment options with you. These options include:

- medication to reduce the amount of fluid you produce
- amnio-reduction (a procedure, similar to an amniocentesis, which removes some of the excess fluid and alleviates your symptoms)

If either option is appropriate for you and your baby, we will discuss them with you and answer any questions you may have.

The birth of your baby

Place of birth

We recommend that you give birth to your baby on the main labour ward at Princess Anne Hospital in Southampton. Your baby will require extra care and support from our neonatal (baby) surgical team immediately after birth.

We will arrange for you to meet with the neonatal medical and surgical team during your pregnancy. This will provide you with the opportunity to discuss the care your baby will receive once they are born. They will also offer you a tour of the neonatal unit and answer any questions you may have.

Giving birth to your baby
For most babies with CDH, a vaginal birth at around 38 weeks of pregnancy is recommended unless there are other reasons why a caesarean section is needed. Your baby's wellbeing will be closely observed throughout your pregnancy.

Your baby's care immediately after birth
When your baby is born, they will be looked after by the neonatal team who will assess their wellbeing. Once transferred to the neonatal unit, your baby will be weighed and nursed in an incubator or heated cot. Almost all babies with CDH require help with their breathing from the time of birth. To do this your baby with have a breathing tube passed into their airway and will be connected to a ventilator which supports their breathing.

Your baby will have a cannula (small tube) placed into a vein, to allow us to give them intravenous fluids via a drip, as they will not be able to feed at first. This tube will also be used to give your baby any medicines that they need.

Your baby will be fed intravenously (straight into their veins) through a central line with a special drip called total parental nutrition (TPN). The central line will be placed in a small vein in your baby's arm or leg and fed through into a larger vein. You will be given a separate factsheet about TPN.

A small tube (nasogastric tube) will also be passed through your baby's nose or mouth, down into their stomach to drain away the fluid that collects there because your baby is not feeding orally (by mouth). This will help to stop your baby being sick. It will also release air trapped in your baby's stomach, which will relieve the pressure placed on their lungs.

The neonatal team will involve you as much as possible in your baby's care and will explain the reason for any treatment they are receiving. They will also be happy to answer any questions you may have.

If you are planning to breastfeed your baby, you will be given support to express and store your milk until your baby is ready for milk feeds.

Treatment

Only once your baby's breathing is stable enough will we consider doing the operation to repair the hernia. Sadly some babies never become stable enough and do not survive beyond the first few days of life. The timing of the operation will depend on your baby's wellbeing, but it will usually be performed in the first few weeks after their birth.

During the operation, your baby's bowel and other abdominal organs will be moved back into their abdomen, and the hole in their diaphragm will be repaired. If part of your baby's intestine has been damaged or has become twisted from being squashed in their chest, it may need to be removed. Unless a large section of their intestine has to be removed, this is unlikely to cause your baby any long-term problems.

The operation is carried out under a general anaesthetic (medicines used to send your baby to sleep).

After the operation

Breathing support

After the operation, your baby will be monitored closely and will continue to receive support with their breathing until their lungs recover. The length of time that your baby needs support with their breathing will depend on how their lungs have been affected. If long-term support with breathing is thought to be necessary, the neonatal team will discuss this with you.

Feeding your baby

After the operation, your baby will continue to be fed intravenously (straight into their veins) with TPN through their central line.

As your baby's bowels recover, we will slowly introduce milk feeds through your baby's nasogastric tube, increasing the amount and frequency as your baby is able to tolerate them. As the milk feeds increase, the TPN will decrease until your baby is fully milk-fed. Once your baby's bowel has recovered, your baby should be able to feed normally by breast or by bottle.

Long-term care and follow up

After your baby leaves the neonatal unit, you will be offered regular appointments to monitor their progress. We will try to arrange these appointments to suit your family's needs. In some situations, Southampton may not be your local hospital. If this is the case, we may transfer your baby's care to your local hospital. This will not happen until the neonatal team are happy with your baby's progress.

Most babies who have a successful operation will make a good recovery and lead a normal life. However, a small number of babies will:

- continue to have lung problems and may need oxygen or medication to help them breathe
- develop acid reflux (when food and drinks mix with stomach acid and flow back up the oesophagus causing pain and irritation) when they are older
- develop another hole in their diaphragm which will require another operation to repair

Contact us

If you have any questions or concerns, please contact us.

Specialist midwives in fetal medicine
Telephone: **023 8120 6025**

Surgical specialist nurses
Telephone: **023 8120 8564**

Your GP, midwife and obstetrician may also be able to give you more information.

For urgent enquiries outside of this time, please call the labour ward on **023 8120 6002**.

Useful links

Antenatal Results and Choices (ARC)

ARC is a national charity that supports people making decisions about screening and diagnosis and whether or not to continue a pregnancy.

Website: **www.arc-uk.org**

The Congenital Diaphragmatic Hernia Charity (CDH UK)
CDH UK is a registered charity which offers information and advice to patients, families, clinicians and other organisations on CDH from diagnosis to childhood and beyond.

Website: **www.cdhuk.org.uk**

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For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **www.uhs.nhs.uk/additionalsupport**

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