Belfast Health and Social Care Trust

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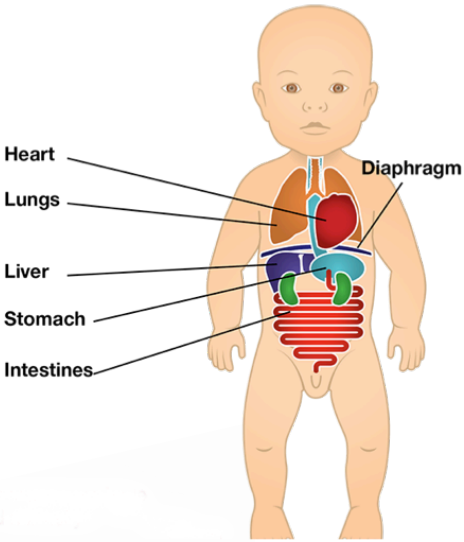
Congenital Diaphragmatic Hernia

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).

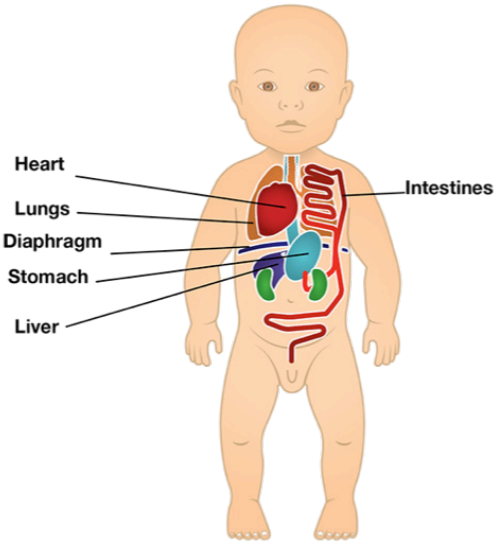
CDH happens very early in the baby's development. The lungs have less space so they cannot grow and develop properly.
In some babies with CDH the organs in the abdomen, such as the stomach, bowels and liver, go through the hole in the diaphragm. This is called a hernia. These organs take up space where the lungs and heart should be, and this means the lungs do not grow as expected.



A baby whose organs have developed as expected[1]

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.



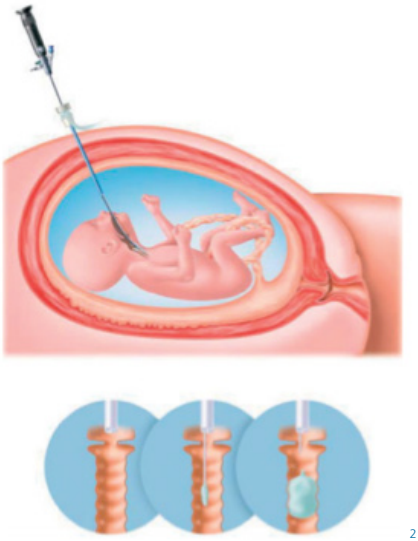
A baby with congenital diaphragmatic hernia[1]

Causes

We do not know exactly what causes CDH. It is not caused by something you have or have not done. It is sometimes linked to other medical conditions, like those affecting your baby's chromosomes (genetic information) and heart. You will be able to discuss your individual circumstances with a specialist team. CDH happens in about 4 babies out of every 10,000 (0.04%).

Treatment before Birth

Some babies with the smallest lungs on fetal scans are suitable for treatment before birth. There are several international trials running which your baby maybe eligible to enter. These involve inserting a balloon into your babies wind-pipe which is predicted to force their lungs to grow and improve their chances of survival. The balloon is removed before birth. Centres in London and Belgium offer this therapy as part of a trial (TOTAL trial). Should this become relevant to your babies care we will let you know.



How we find congenital diaphragmatic hernia

We screen for CDH at the '20-week scan' (between 18+0 to 20+6 weeks of pregnancy). Otherwise, it is diagnosed soon after birth when a baby shows signs of breathing difficulties.

What happens before the operation?

The baby will be admitted to the neonatal unit soon after birth. To begin with, they will be nursed in an incubator and will have a tube passed through their nose into their stomach (naso-gastric tube or NG tube). This will release any excess air that is in the stomach and intestine, which also relieves the pressure on the lungs.

They will also have a 'drip' (intravenous infusion) to give fluids and medicines directly into their bloodstream. A ventilator will be used to help the baby to breathe before the operation.

The surgeon will explain about the operation in more detail, discuss any worries the family may have and ask them to sign a consent form giving permission for your baby to have the operation. An anaesthetist will also visit to explain about the anaesthetic.

What does the operation involve?

During the operation, the surgeon will move your baby's intestine back into the abdomen and repair the hole in their diaphragm. Sometimes, the surgeon may need to use a 'patch' of special material to close this hole. If a baby's intestine has become twisted while it is in the chest (which is not uncommon), the surgeon will correct this during the same operation. If the intestine has been damaged by being squashed in the chest, the surgeon may remove a damaged portion.

Are there any risks?

All operations carry a small risk of bleeding, during or afterwards. There is a chance that the intestines or other abdominal organs could be damaged when they are moved back into the abdomen but this is very rare. If damage occurs, this can be fixed in the same operation. There is a small risk of infection but this is minimised by giving your baby antibiotics before the operation.

After treatment, there is a chance that the hole in the diaphragm could recur (come back), which would require another operation to repair it. This risk is higher if your baby has needed a patch repair. Every anaesthetic carries a risk of complications, but this is very small. The anaesthetist is a very experienced doctor who is trained to deal with any complications.

Longer term health

CDH is a wide and varied condition. It can be straightforward to treat, or complicated (and more serious) if there are other health issues as well. About 5 in 10 (50%) children born with CDH will survive. The chance of them doing well depends on how the lungs have developed and if they have any other conditions. The possible outlook for you and your baby will depend on your individual circumstances. The specialist team will support you whatever the situation.

CDH can sometimes be linked with other conditions such as Down's syndrome, Edwards' syndrome, Patau's syndrome or heart conditions. This happens in up to 1 in 10 (10%) cases.

Next steps and choices

You can talk to the team caring for you during your pregnancy about your baby's CDH and your options. These will include continuing with your pregnancy or ending your pregnancy. You might want to learn more about CDH. It can be helpful to speak to a support organisation with experience of helping parents in this situation.

If you decide to continue with your pregnancy, the specialist team will help you:

- plan your care and the birth of your baby
- prepare to take your baby home

If you decide to end your pregnancy, you will be given information about what this involves and how you will be supported. You should be offered a choice of where and how to end your pregnancy and be given support that is individual to you and your family.

Only you know what the best decision for you and your family is. Whatever decision you make, your healthcare professionals will support you.

Future pregnancies

If you decide to have another baby, they are unlikely to have CDH. For women who have a baby with CDH there is a 2 in 100 (2%) chance of CDH in another pregnancy.

1. https://www.gov.uk/government/publications/cdh-description-in-brief/congenital-diaphragmatic-hernia-cdh-information-for-parents
2. Reproduced with permission from UZ Leuven, Leuven, Belgium.

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More Information
CDH UK supports patients, families and clinicians in looking after children with CDH https://cdhuk.org.uk/about-cdhuk/

TOTAL trial website https://totaltrial.eu/

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