In babies born with severe CDH the doctors may speak to you about a treatment called ECMO. This is where a bypass machine is used to put oxygen into the body. In Scotland, this treatment is only offered in Glasgow. This is a high-risk treatment and not all babies are suitable for ECMO.

If the scans suggest that your baby has severe CDH, your doctors may recommend that your baby is born in Glasgow in case they need ECMO.

Who else could give me information?

You will have an opportunity to speak to a neonatologist and a paediatric surgeon who have experience of caring for babies with CDH. They will be based in the hospital where your baby will be delivered.

Where can I get further information and support?

The fetal medicine, paediatric surgical and neonatology teams will be able to answer any questions that you have during your appointments.

In 2018, the Surgery for Conditions Affecting Newborns in Scotland (SCANS) was formed. This is a national network of doctors, midwives, nurses and parents. It was set up to produce standards of care so that you and your baby receive the best treatment. You can find more information at www.scans.scot.nhs.uk. We have listed other support groups below.

Other useful sources of information

www.cdhuk.org.uk

www.arc-uk.org

SCANS collects anonymised data (information that you and your baby cannot be identified from) about the different conditions we treat. We use this information to plan and deliver services to children with these conditions, understand how we can improve patient care and provide it in the best way possible for all of our patients. All information is handled securely and confidentially by NHS staff and we do not share it with outside organisations. If you have any questions or concerns about the information we collect or your data protection rights, please email nss.scans@nhs.scot.

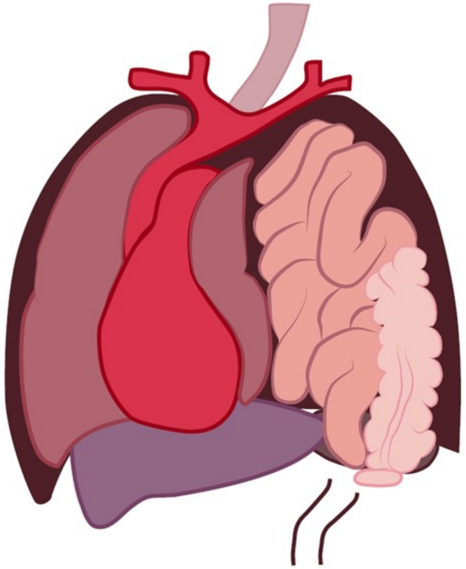
You can find more information about how the NHS handles your personal information at NHS Inform.

NHS
National Services Scotland

SCANS

Congenital diaphragmatic hernia

Information for parents and carers



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Your baby has been diagnosed with a condition called congenital diaphragmatic hernia. We understand this may be a worrying and stressful time for you. This leaflet explains a bit more about this condition.

What is congenital diaphragmatic hernia (CDH)?

CDH occurs when a baby’s diaphragm does not form properly. 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 abdominal organs, such as the bowel and liver, go through a hole in the diaphragm early in pregnancy and take up space where the lungs should be growing.

CDH can happen on either side of the diaphragm but is much more common on the left.

What is the problem in CDH?

The main problem in CDH is that the lungs are squashed and cannot grow to their full size. In the womb, there is no need for the lungs to work as the placenta supplies oxygen. At birth, when the umbilical cord is clamped, the lungs need to absorb oxygen into the blood during breathing. Our organs need oxygen to work. A lack of oxygen will lead to organ failure unless this is corrected. Many babies with CDH also have high blood pressure within the lungs (pulmonary hypertension). This can make it difficult for their heart to pump blood to the lungs to absorb oxygen.

How common is CDH?

CDH occurs in about 1 in every 3000 babies. Around 25 babies are born with CDH in Scotland each year.

What will happen during pregnancy?

CDH is usually found at the routine ultrasound scan at 18 to 20 weeks. After this, you will be offered an appointment with a fetal medicine specialist. They will discuss the results of your scan and may consider the following further tests.

Amniocentesis – This is where a sample is taken from the fluid around your baby in the womb to check for genetic abnormalities. You may get an initial result after two days, but a full result can take up to 14 days.

Detailed ultrasound scans - The size of the lungs can be measured and is often calculated using the lung-to-head ratio (LHR). This estimates how severely the lungs are affected. Ultrasound also checks if the liver has moved into the chest and if there is too much fluid around your baby (polyhydramnios).

MRI scan - You may be offered an MRI scan to further assess your baby.

Could my baby have other problems?

Up to 20% of babies with CDH have other problems, including heart defects or genetic abnormalities.

Many babies with CDH that are discharged home have no long-term health problems, but some need other surgery or treatment.

What are my choices?

If your baby’s lungs are very small, and especially if they have another major abnormality, you may choose not to continue with your pregnancy and have a 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 your doctors may recommend fetal therapy to try to help your baby’s lung grow while in the womb. This therapy is not suitable for all babies and is not without risk.

If CDH is found during a scan later in pregnancy, you may not be offered the tests above as they may not change the advice about whether to continue with your pregnancy.

Where will my baby be delivered?

Babies with CDH are cared for at neonatal surgical centres at Royal Aberdeen Children’s Hospital; Royal Hospital for Sick Children Edinburgh; or Royal Hospital for Children, Glasgow.

Your delivery will be planned for around 39 weeks at the maternity unit near one of these centres. If your labour starts early and there is no time to transfer you to one of these units, your baby will be moved there once they have been stabilised.

What is the likely outcome for my baby?

The chances of your baby surviving depend on how well their lungs develop in the womb and whether your baby has any other major problems, such as genetic abnormalities or serious heart defects. While treatment of CDH is improving all the time, unfortunately some babies are so ill they cannot be saved. Overall, around 50 to 75% of babies born with CDH will survive.