organs that were in the chest will be returned to the abdomen and the hole in the diaphragm will be repaired. If the hole is large, an artificial patch may be needed to close the hole.

Unfortunately, not all babies will be suitable for surgery or ECMO treatment.

After surgery

As your baby's condition improves, the support from the ventilator will gradually be reduced until the ET tube can be removed. Oxygen will then be given for as long as your baby needs it.

Once the CDH is repaired, your baby can start on milk feeds. Until on full milk feeds, TPN will continue to be given. The length of time taken to achieve full milk feeds is very variable – a few weeks to many months.

What is the outlook for your baby?

Babies born with CDH and chromosomal or other birth abnormalities have a much lower chance of survival than babies with CDH alone. The long term outcome for babies with only CDH depends on how long the baby needed ventilation.

The outlook for babies born with CDH is increasingly positive. However, they can have problems that need long term follow up after going home, such as:

Chronic lung disease. This may require oxygen or medication such as inhalers.

Gastro-oesophageal reflux (GOR). Here, stomach acid and food move back into the oesophagus. This can lead to vomiting and heartburn. It is initially treated with medication but some children may need an operation.

Failure to thrive (poor growth). Extra calories or tube feeding may be needed.

Developmental problems. It may take longer for babies who have been very sick to reach normal milestones such as sitting and walking. This will be assessed regularly. Physiotherapy and Speech and Language Therapy may be helpful.

Hearing loss. This has been identified as a potential problem. Regular hearing screening will be carried out.

Recurrence. If a patch has been used, it may come apart as the child grows, causing a further hole. This can be repaired. We will let you know what to look out for and we will do regular X-rays at follow-up to check for this.

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

Postnatal

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.

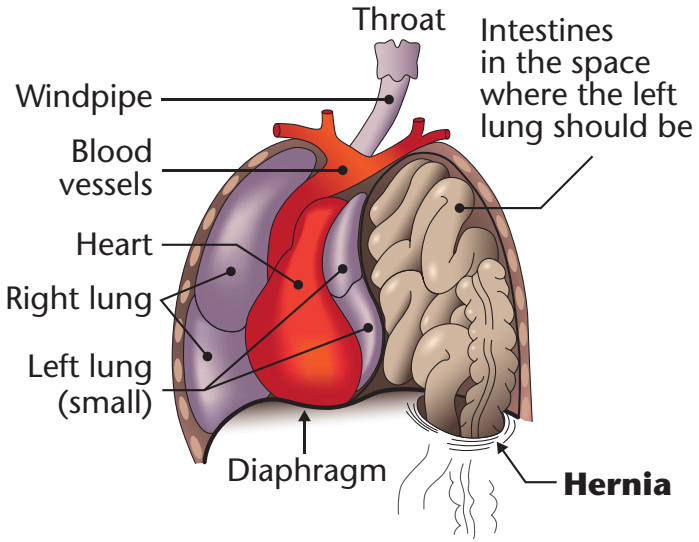
With CDH, some of the baby's abdominal organs, such as the bowel and liver, go through a hole in the diaphragm at about 10 to 12 weeks into the pregnancy and take up space in the chest where the lungs should be growing. CDH occurs on either side, but much more commonly on the left.

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 must breathe independently.

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.



Treatment of CHD after birth

CDH is a very serious problem for your baby. Immediately after delivery we will pass a tube into the windpipe (ET tube) and attach your baby to a ventilator to help with breathing. Your baby will be nursed in the neonatal intensive care unit and will be closely monitored. The nurse caring for your baby will explain what all the equipment is for and senior doctors will keep you fully informed about how your baby is progressing.

In addition to supporting your baby's breathing, other treatments will be required.

Treatments include:

- Intravenous infusions (drips) to give your baby fluid, medicines and nutrition (TPN).
- A nasogastric tube passed through the nose into the stomach to keep the stomach empty and reduce further pressure on the lungs.
- Medicines to make sure your baby is comfortable and, if necessary, to help with blood pressure.
- X rays, ultrasounds and a scan (echocardiograph) to check the heart.

Depending on your baby's condition, advanced treatments such as high frequency (an alternative type) ventilation and inhaled Nitric Oxide (treats pulmonary hypertension) may be used.

If your baby's condition does not improve with these therapies, a senior doctor will discuss your baby with the Scottish ECMO Centre in Glasgow. ECMO is a form of extracorporeal (outside the body) mechanical support for the lungs.

Surgery

An operation to fix the hernia will only be undertaken once your baby's condition is improving and requiring less support from the ventilator and medicines. This will take a number of days and possibly longer. Repair of the hole is necessary, but will not, by itself, correct the problem of lung hypoplasia and pulmonary hypertension. It may worsen breathing problems for some time.

The surgeon will explain about the operation in more detail closer to the time and will discuss any worries you may have and ask you to sign a consent form.

During the operation, the abdominal