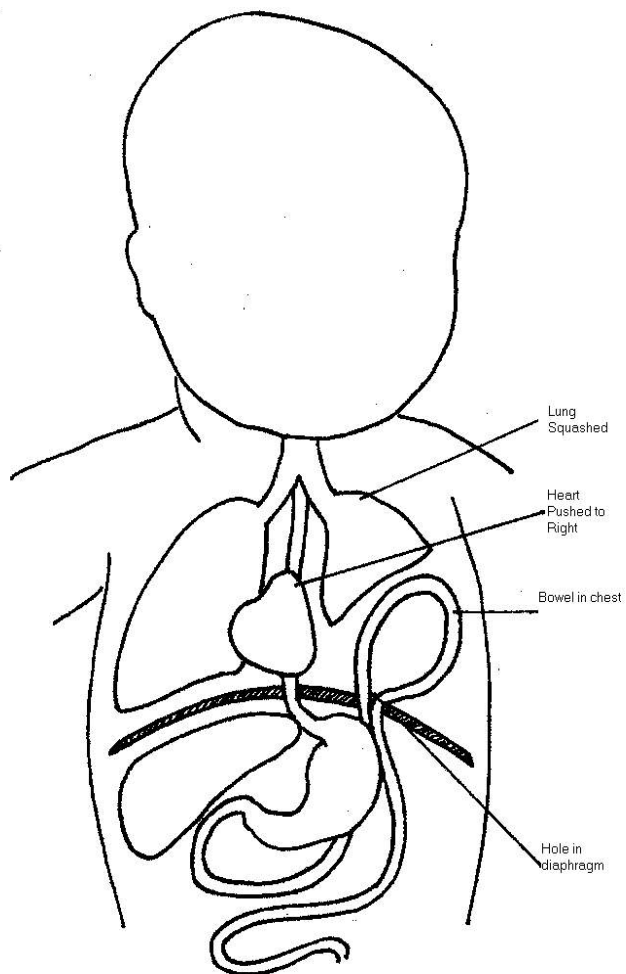


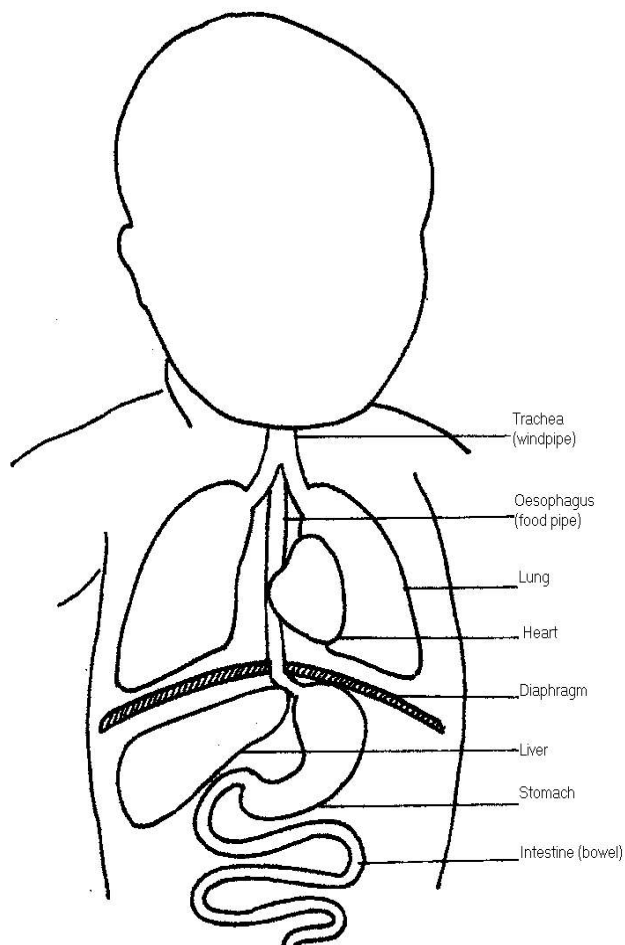
CONGENITAL DIAPHRAGMATIC HERNIA

WHAT IS IT?

The diaphragm is a sheet of muscle, which separates the chest from the abdomen. A congenital diaphragmatic hernia (CDH) is a hole in the diaphragm, which the abdominal organs (bowel, stomach and liver) can slide through. This squashes the lungs and pushes the heart over to one side of the chest.



Congenital Diaphragmatic Hernia



Normal Anatomy

WHAT CAUSES IT?

The diaphragm muscle does not develop properly in early pregnancy. We do not know why this happens. This is something, which can not be prevented.

HOW OFTEN DOES THIS HAPPEN?

CDH occurs in about 1 in every 2,500 babies.

HOW DOES IT AFFECT THE BABY?

Unfortunately this is a serious problem. Half (50%) of the babies who have this problem do not survive.

Reasons why these babies sometimes die

Many babies with CDH have problems with the lungs. The lungs are small and squashed. This is because the hernia sits in the space where the lung should be and prevents the lung from growing. The baby's heart is pushed to one side and then the other lung also gets squashed. This means that the lungs do not work properly after the birth and sometimes the baby dies very quickly.

In about ¼ of babies with CDH there are other abnormalities as well. These abnormalities are divided into 3 groups.

- **Chromosomal abnormality.** Chromosomes are passed on from our parents. They carry the genetic instructions for our bodies to develop. Normally we have 46 chromosomes in all the cells in our bodies. Sometimes an extra chromosome is passed on. The most well known chromosomal abnormality is Down's syndrome when the baby has 47 chromosomes instead of 46.
- Sometimes the baby will have a rare **genetic syndrome**
- Babies with CDH can also have serious **heart problems**.

WHAT CAN WE DO TO HELP YOU?

It is very important to find out if there are other problems as well as the CDH. We would like to do 2 other tests, which will give us more information.

1. Amniocentesis

A very fine needle is passed into the womb in order to test the fluid around the baby. This test will check that the baby has the right number of chromosomes. There is a very small risk of miscarriage with this test (1/2 to 1%). Results may take up to 3 weeks. The results of this test are very reliable (99.9%)

2. Echocardiogram

This is a special scan of the baby's heart. It will tell us if there are any problems with the heart or the blood vessels around the heart.

If either of these tests show that there is a serious abnormality you will be given as much information as possible about the chances of the baby surviving and any special problems the baby may have. You will also have the option of continuing or ending the pregnancy.

WHAT HAPPENS NEXT?

During the pregnancy you will be offered scans every month to check on the baby's progress. The doctor will be looking closely at the baby's lungs to see how they are growing. It is very important that you keep your usual antenatal appointments with your midwife or GP. You might like to visit the special care baby unit to see where your baby will be looked after when he/she is born. You may find it helpful to talk to the staff there. It is also helpful for you to meet to the specialist doctor who may be looking after your baby in Alder Hey Hospital.

Advances in fetal medicine have meant that some conditions can be operated on while the baby is still in the womb. However, this is an area, which is still very new and is currently being evaluated in the United States.

The baby will be delivered around the time when he or she is due. The delivery will be timed so that the paediatricians are prepared for the arrival of your baby. Usually these babies are delivered normally unless there are any special reasons for a caesarian section.

After the delivery the baby is nursed on the special care baby unit. A ventilator will help the baby to breathe and the baby will need intensive nursing care. A small percentage of babies may have oxygen given directly into their bloodstream by a process known as ECMO (Extra Corporeal Membrane Oxygenation). When the baby is well enough he/she will be transferred to Alder Hey children's hospital. However, about 10% of all babies born with CDH are too ill to have surgery.

HOW CAN SURGERY HELP?

The surgeon will make an opening just under the ribs and push the bowel back down into the abdomen. The hole in the diaphragm is then repaired. If there is enough diaphragm then the two edges of the hole are stitched together. If not, then a patch is put in. The skin is then stitched as well. The baby will remain on a ventilator until the lungs are strong enough to work on their own. This may take days or weeks. Extra oxygen may be required for a little while after the ventilator has been discontinued. Some babies with very small lungs can have long term lung problems (including wheezing) and may need extra oxygen for some time due to underlying chronic lung disease. Most babies who do well after surgery are weaned off the ventilator quickly and do extremely well. These children do go on to lead normal lives after surgery.

CAN THIS PROBLEM HAPPEN AGAIN IN A FUTURE PREGNANCY?

The chance of your next baby having a congenital diaphragmatic hernia is very small. The risk is approximately 2 %.

For further advice or information please contact a Specialist Midwife at the Fetal Centre on 0151 702 4211

SUPPORT GROUPS

CONTACT A FAMILY

170 Tottenham Court Rd.

London W1T 7HA

Tel. 020 7608 8700

email; info@cafamily.org.uk

web; www.cafamily.org.uk

BIRTH DEFECTS FOUNDATION

Martindale,

Cannock,

Staffordshire,

WS11 2XN

Tel. 01543 468888

Fax. 0543 468999

Family Helpline. 08700 70 70 20

email; enquiries@birthdefects.co.uk

web; www.birthdefects.co.uk

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