

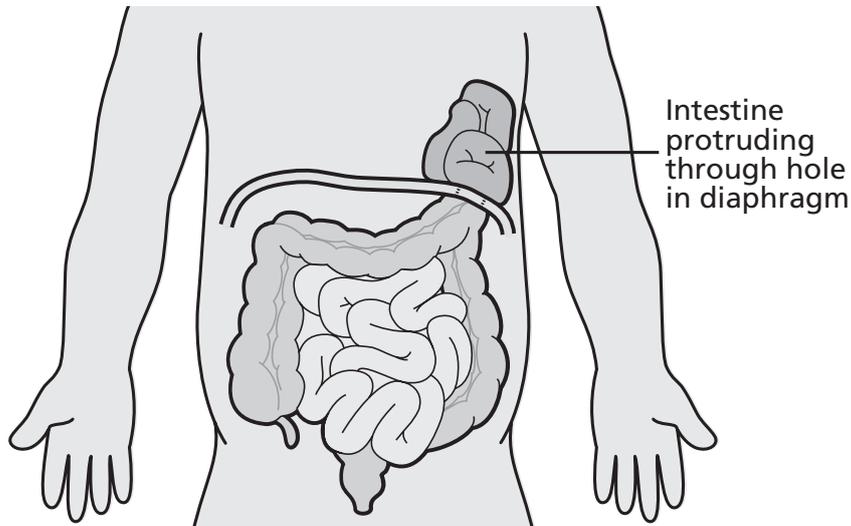


# Diaphragmatic hernia

This leaflet explains about diaphragmatic hernias, how they are treated and what to expect when your child comes to Great Ormond Street Hospital (GOSH) for treatment.

## What is a diaphragmatic hernia?

The diaphragm is a curved muscle that separates the contents of the chest from the abdomen (tummy). Diaphragmatic hernias occur when the diaphragm does not form completely, leaving a hole. This usually happens early in pregnancy at around six to eight weeks.



The hole can be on either side, but in most children it is on the left side. You may hear the term Bochdalek hernia, which is the medical term for this type of diaphragmatic hernia. The hole in the diaphragm allows part of the intestine (gut) to move into the chest, which can squash the lungs and can stop them developing properly before birth.

Other abdominal organs can also move into the chest area, such as the liver, stomach and spleen, squashing the lungs even more.

We do not know exactly what causes diaphragmatic hernias. Doctors think that a number of factors can have an effect on diaphragmatic hernia development.

They are very rare, occurring in one in around 2,500 babies. They are more common in boys than girls. Diaphragmatic hernias can be associated with other problems, so the doctors will examine your child closely to check if this is the case.

## How is a diaphragmatic hernia diagnosed?

A diaphragmatic hernia can often be diagnosed by a routine ultrasound scan during pregnancy. Otherwise, it is diagnosed soon after birth when a baby shows signs of breathing difficulties. A chest x-ray will show which organs are in the chest area and how much they are squashing the lungs. Blood tests to show how much oxygen is contained in the blood are also commonly used.

## How is a diaphragmatic hernia repaired?

Diaphragmatic hernias are repaired in an operation under general anaesthetic. The surgeons will only carry out the operation once your baby's breathing and heart are stable.

Depending on your child's size and how stable they are, the operation will either be carried out using keyhole surgery or by traditional open surgery. Your surgeon will tell you which approach is more likely, but there is a chance that they may need to switch from keyhole to open surgery once the operation has started.



## **Are there any alternatives?**

Not really, no. Diaphragmatic hernias inevitably require treatment, because if they are not repaired your baby's breathing problems would get worse as they grow. Feeding problems would also get worse with time.

## **What happens before the operation?**

Your baby will be admitted to GOSH 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 (nasogastric 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 machine will be used to help your baby to breathe before the operation. In most cases, this will be a ventilator or an oscillator. If your baby has problems with ventilation, they may be referred for extra-corporeal membrane oxygenation (ECMO) support. The ECMO machine is similar to a heart-lung bypass machine using during open-heart surgery. It gives your child's body a chance to rest his or her heart and lungs for a short while. The doctors will explain all about ECMO if it is needed and you can also read our booklet on ECMO. The surgeons will only operate to repair the hernia when your child is stable on ventilation.

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

## **What does the operation involve?**

During the operation, the surgeon will move your child'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 your child'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. This will not usually cause your baby any long-term problems unless a large portion has to be removed.

## **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 child antibiotics before the operation.

After treatment, there is a chance that the hole in the diaphragm could come back, which would require another operation to repair it. This risk is higher if your child has needed a patch repair.

Every anaesthetic carries a risk of complications, but this is very small. Your child's anaesthetist is a very experienced doctor who is trained to deal with any complications.

## **What happens afterwards?**

Your baby will come back to the ward to recover, and you will be able to visit as soon as they are settled. For a while after the operation, your baby will need help with breathing so will be connected to a ventilator. All babies are closely monitored after the operation, and so your baby will be connected to monitors to check his or her breathing, heart rate and oxygen levels. They will also be given pain relief through a 'drip'. Occasionally there may be a tube from the operation site (chest drain) to drain off air and fluid so that the lungs have room to expand. This will be removed as soon as it is no longer needed.



Your child's lungs may not have developed properly by being squashed by the intestines in the chest. The length of time that your baby needs the ventilator depends on the condition of their lungs. If this is likely to cause long term problems, the doctor will explain all about it to you.

While your baby's intestines recover and start to work, they may be fed through a tube into their veins (total parenteral nutrition or TPN). This will gradually be replaced by breast or bottled milk given through the naso-gastric tube when your baby is ready for this. As your baby recovers, you will be able to feed them from the breast or bottle. Over time, the drips and monitors will be removed one by one.

The nurses on the ward will encourage you to look after your baby as much as you feel able while they are recovering. This can be daunting, especially while your baby is connected to drips and monitors, but it will become easier with time. If you are worried about caring for your baby, please talk to the nurses.

You will be transferred to another ward within GOSH or to your local hospital once your baby is feeding properly and gaining weight. We will send you a letter with details of your outpatient appointment soon after your child leaves the hospital.

## What is the outlook for children with diaphragmatic hernias?

This depends on how quickly the condition is diagnosed and how much the lungs were damaged before birth. The outlook is improving all the time, as better treatment is developed. Children who would previously have not survived are now growing up and we will only know the long-term effects

of diaphragmatic hernia by studying these children closely. However, there are a couple of side-effects which you should know about, should they arise in the future.

Sometimes it takes a while for your baby's intestine to work properly, so your child may need extra nutrition. This will enable your child to gain weight to reach the right size and weight for their age. Please speak to the dieticians about this.

Some children who have had a diaphragmatic hernia develop a problem with gastro-oesophageal reflux when they are older. This is where the contents of the stomach flow back up the oesophagus (gullet) causing pain and irritation. For more information about this, please read our leaflet *Gastro-oesophageal reflux: information for families*.

A small number of children continue to have lung problems so need to have oxygen or medications to help them breathe. Children may also seem to be 'behind' in their developmental milestones, which means that they sit, walk and talk later than other children their own age. Many children catch up in the end and have few long term problems.

## Support groups

The support organisation for families of children affected by diaphragmatic hernia is **CDH UK**. Call their free helpline on 0800 731 6991 or visit their website at [www.cdhuk.co.uk](http://www.cdhuk.co.uk)

You should call your local hospital if your baby:

- vomits when feeding
- has a swollen stomach
- vomits green liquid
- is not gaining weight

The doctors there will discuss any concerns with the team at GOSH.

Compiled by the General Surgery department and Neonatal Intensive Care Unit in collaboration with the Child and Family Information Group

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