

The Children's Hospital

Congenital diaphragmatic hernia

Information for parents/carers



What is a diaphragmatic hernia?

The diaphragm is a curved muscle which sits in the upper chest. Its major role is in the action of breathing. However, it also separates the organs in the abdomen (tummy) from the chest.

A diaphragmatic hernia occurs when there is a hole in this muscle. This then allows part of the intestines to develop in the chest.

What problems could this cause?

If the intestines are pushed up into the chest, both the developing gut and the lungs can become squashed. As a result of this, it is possible that your baby could have problems with feeding and breathing.

To help this, your baby may need to be placed on a machine to help their breathing (ventilator). A tube will be fed into their tummy through one of their nostrils or their mouth (nasogastric/ orogastric tube). This will help to drain off their stomach contents and stop your baby feeling or being sick.

Can it be treated?

Yes, but this will require an operation. If we leave the hernia alone, it will cause on-going problems with your baby's development. It will keep squashing their lungs and will affect their breathing and feeding.

What will happen to my baby in the hospital?

When your baby arrives at the unit they will be examined by one of the doctors. Some tests and X-rays will need to be done to confirm that your baby has a diaphragmatic hernia. The doctor will explain the operation to you and talk with you about any concerns you may have.

An anaesthetist will also visit you to discuss the anaesthetic your baby will have for the operation. They will also talk with you about the pain relief which your baby will need after the operation.

We will ask you for your written consent for the operation to go ahead. If there is anything you are unsure about, or if you have any questions, please ask the doctor before signing the consent form.

If your baby has been diagnosed with a diaphragmatic hernia before birth, they will need to be delivered in hospital. They will then have the nasogastric or orogastric tube passed immediately into their stomach. Your baby may also be placed immediately on a ventilator to help them breathe.

Your baby may need monitoring in the baby intensive care unit for several days before an operation is performed. Once your baby's breathing is stable and they have settled in to the intensive care unit, the surgeon will explain the operation to you.

What does the operation involve?

The operation is done under a general anaesthetic, which means your baby will be asleep throughout the operation. You can go with your baby to the anaesthetic room and stay with them until they are asleep. The nurse will then take you back to the ward

The main purpose of the operation is to repair the hole in the diaphragm and return the intestines to the abdomen. If the hole in the diaphragm is large, we may use a special patch to close it.

What are the main risks of the operation?

Surgical risks:

The risks associated with the operation are:

- bleeding
- infection
- damage to nearby organs
- breathing difficulties
- vomiting (being sick).

Other risks and how likely they are will be explained to you before you give your consent for the operation to go ahead.

Anaesthetic risks:

In modern anaesthesia, serious problems are uncommon. Risk cannot be removed completely, but modern equipment, training and drugs have made general anaesthesia a much safer procedure in recent years.

Most babies recover quickly after their operation and anaesthetic. Some babies may suffer side effects like sickness. These usually last only a short time and there are medicines available to treat them if necessary.

The exact likelihood of complications depends on your baby's medical condition and on the nature of the surgery and anaesthesia they need. The anaesthetist can talk to you about this in detail prior to the operation.

What happens after the operation?

After the operation, your baby will be returned to the ward where you will be able to visit them. Depending on how developed your baby's lungs are, they may need to spend some time using a ventilator to help them breathe.

Any pain following the operation will be controlled with regular pain medication. This will be given through a vein at first as this is the quickest way to get the right amount of medicine into your baby. Your baby will be connected to a monitor to follow their heart rate, pulse and how much oxygen is in their blood.

Your baby will be assessed regularly for pain using a pain assessment chart. This will help the nurse to effectively manage your baby's pain after the operation.

As your baby improves, the amount of monitoring and ventilator support they need will reduce and they will be moved into a cot.

When can I feed my baby?

In the early days after the operation, your baby may not tolerate milk well. They will be fed via a tube into a vein. This is called Parental Nutrition (PN) and will be continued until your baby's intestines have recovered enough to cope with milk.

Until your baby is able to start feeding by mouth, either from the breast or bottle, you may wish to express your milk so that it can be stored ready for use. If you need any help with this please ask one of the nurses.

Initially small amounts of milk will be given through the nasogastric tube. As these amounts increase, the PN will be stopped. Once your baby is ready to feed by mouth, you can start to either breastfeed or bottle feed.

If you choose to breastfeed, please ask for a copy of our leaflet 'Successful breastfeeding', as well as for support from the midwives in the Women's Centre.

When can we go home?

As soon as your baby is feeding and gaining weight, you can go home. You will have regular visits from your health visitor or community paediatric nurse to provide you with further support at home.

Signs to look out for

When you get home, if you are concerned about your baby's breathing, or if they begin to have difficulty feeding, are being sick with each feed or their sick is green, please contact the Ward.

If at any point you are extremely concerned about your baby's breathing please dial 999.

How to contact us

If you have any questions or concerns about your baby, either whilst in the hospital or when you return home, please speak to their nurse or doctor.

Please call:

Tom's ward

Tel: **01865 234 109** or **01865 234 111** (24 hours)

If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALSJR@ouh.nhs.uk**

Authors: Ifor Capel, FY1 in Paediatric Surgery
Kokila Lakhoo, Consultant Paediatric Surgeon
Fiona Mills, ACNP
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Oxford University Hospitals NHS Trust
Oxford OX3 9DU
www.ouh.nhs.uk/patient-guide/leaflets/library.aspx

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