

## Congenital Diaphragmatic Hernia

This leaflet gives a brief explanation about Congenital Diaphragmatic Hernia and the treatment and care your baby will receive while on our unit.

A section is provided for you to write questions to ask your baby's nurses, doctors and surgeons.

### Contact details:

Neonatal Intensive Care Unit  
Chelsea and Westminster Hospital  
369 Fulham Road  
London SW10 9NH

T: 020 8846 7883/7884

## Membership and Patient Advice & Liaison Service (M-PALS)

If you require information, support or advice about our services, you can contact the M-PALS office on the ground floor of the hospital just behind the main reception.

Alternatively, you can feedback your comments/suggestions on one of our comment cards, available at the M-PALS office or on a feedback form on our website [www.chelwest.nhs.uk](http://www.chelwest.nhs.uk).

We value your opinion and invite you to provide us with feedback of the service you received via the Patient Experience Tracker (PET). Please ask your nurse for more information.

T: 020 8846 6727  
E: [pals@chelwest.nhs.uk](mailto:pals@chelwest.nhs.uk)



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## Congenital Diaphragmatic Hernia

### Information for parents

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**Chelsea and Westminster**

Chelsea and Westminster Hospital   
NHS Foundation Trust

# Congenital Diaphragmatic Hernia

Congenital Diaphragmatic Hernia is an abnormal opening in the diaphragm (a muscle that separates the chest from the abdomen and helps us to breathe). This opening allows organs in the abdomen such as the intestines, liver and spleen to move into the chest. This can prevent the lungs from developing properly which leads to breathing difficulties. The intestines may be damaged because they do not develop in the correct place.

## What causes Congenital Diaphragmatic Hernia?

It is not known exactly what causes Congenital Diaphragmatic Hernia. It occurs in about 1 in 2,500 births. The condition can occur in either early or late pregnancy and is identified by either ultrasound scan or soon after birth. The opening can occur on either side but is usually seen on the left side. It seems to occur more in boys than girls. It can be associated with other conditions and the doctors will carry out investigations to find out if this is so.

## What happens after birth?

Your baby is usually born in a hospital that has the necessary equipment and staff to care for him or her. Soon after birth a tube will be inserted into the trachea (wind pipe) and your baby will be connected to a ventilator to help him or her to breathe. Because the lungs have not developed properly, the baby may require additional support for their breathing with a gas called nitric oxide.

A nasogastric tube (NGT) is passed into the stomach through the nose to drain fluids and air. If these are not drained they can press on the lungs. Intravenous lines (IVs) are put into your baby's veins to give fluids. Medicines such as antibiotics are given to help prevent infections and to stabilise your baby. Monitors will be attached for close monitoring of your baby's breathing, heart rate, blood pressure and oxygen levels. X-rays are also taken to assess your baby's condition.

## How will it be repaired?

Congenital Diaphragmatic Hernia is repaired by surgery. It may take some time for your baby to be well enough to have the operation. This depends on the extent of lung development. The purpose of the operation is to return the

abdominal organs to their correct place and to close the hole in the diaphragm. Sometimes a patch is needed to close the opening. The operation will be explained to you by the surgeon who will tell you about the possible risks involved. We will ask for your consent to do the surgery.

## What happens after the surgery?

Your baby will still require help with breathing and he or she will remain connected to a ventilator. Your baby's heart rate, breathing, blood pressure and oxygen levels will continue to be monitored closely. A drain may be inserted into the chest area to remove any air and fluid that might be present. This allows room for the lungs to expand. Blood tests are performed to make sure your baby is stable. Medicines will be given for pain. These will be adjusted according to what your baby needs. No feeds will be given until the intestines start to work properly which may take some time.

Your baby will be fed through the veins with Total Parenteral Nutrition (TPN) which provides all the necessary nutrients, vitamins and calories needed for growth and healing. When the intestines start to work, your baby will be fed small amounts of milk at first. Breast milk is used on our unit. However, some babies may not digest this well if the intestines are not working properly. In this case a special formula, which is easier for the baby to digest, may be used. If these feeds are tolerated, the milk is slowly increased and the TPN and other fluids given by us will be reduced. They will gradually be removed and your baby will be fed by your preferred feeding method. As your baby's condition improves the amount of monitoring will be reduced. You will be encouraged to participate in your baby's care and to express your breast milk.

## How long will your baby be in hospital?

We cannot say how long your baby will be in hospital. It may take some time for the lungs and intestines to work properly. Your baby will remain in hospital until this occurs. If you or your baby were transferred from another hospital to our unit, you may be sent back to your local hospital to recuperate.

The surgeons will continue to be involved in your baby's care. A baby usually goes home when they are maintaining their temperature, breathing well, feeding well and growing adequately. There will be follow-up appointments by the surgeons in the outpatients department.

## Who will be involved in your baby's care?

The neonatal team is made up of consultants, nurses, specialist registrars, and senior house officers. The community nursing team will aid in your transition home. The surgical team will perform the operation and will follow up on your baby's progress. A physiotherapist may be involved to aid your baby's breathing. Occasionally a dietician will be involved to help monitor your baby's feeding.

## Available support

The nurse caring for your baby is available every day to offer you support. The medical and surgical teams are also available. There are parent group meetings in the parent room on Tuesdays at 11am where you can speak to other parents to offer each other support. A clinical psychologist is accessible for one-to-one meetings by appointment.

## Support Groups

### CHERUBS

43 Vancouver Avenue  
Kings Lynn, Norfolk PE30 5RD

**T:** 01553 762884

**E:** brakha88@hotmail.com

### Diaphragmatic Hernia Support Network (Patches)

16 Hilson Drive  
Fareham,  
Hants PO15 6EX

**T:** 01329841436

### Contact a Family

209-211 City Road  
London EC1V 1JN

**T:** 0808 808 3555 (Helpline)

0808 808 3556 (Textphone)

Freephone for parents and families Mon–Fri,  
10am–4pm and Mon 5:30–7:30pm

**W:** [www.cafamily.org.uk](http://www.cafamily.org.uk)

**E:** [info@cafamily.org.uk](mailto:info@cafamily.org.uk)