

## Exomphalos

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

The section below 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.

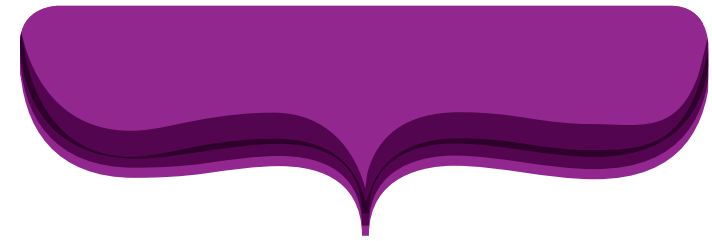
T: 020 8846 6727  
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## Exomphalos

### Information for parents

Choose  
**Chelsea and Westminster**

Chelsea and Westminster Hospital   
NHS Foundation Trust

## Exomphalos

Exomphalos is a condition in which the wall of the abdomen does not develop properly in the womb. It usually occurs early in a pregnancy. This causes an opening in the abdomen which allows the intestines to develop outside the body with a sac covering them. They can either be large or small defects and will sometimes contain the liver and other abdominal organs as well.

### What causes Exomphalos?

It is not known exactly what causes Exomphalos. It occurs in 1 in 5,000–6,000 births and can be associated with other conditions. The doctors will carry out investigations to find out if this is the case.

### 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. After birth your baby will be transferred to the Neonatal Intensive Care Unit. A plastic sheet is used to cover the exposed intestines to protect them and to prevent your baby from losing heat from them. It also allows staff to observe the intestines. He or she will be nursed in an incubator or an infant warmer.

A nasogastric tube (NGT) is passed into the stomach through the nose to drain any fluids and air that may be present. Intravenous lines (IVs) are put into the 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 to closely check 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?

If the defect is small, your baby will usually be taken to theatre within a day of birth. Under general anaesthesia, the intestines are put back into the abdomen. The opening is then sutured and a dressing applied to the wound site. This is called a 'primary closure'.

If the defect is a large one, it may be difficult for all the intestines to be put back in at once. The repair therefore is carried out in stages. The first stage is to place the intestines in a bag called a 'silo' which is suspended above your baby. This allows the intestines to return to the abdomen by gravity. The sac is tightened regularly until

all or most of the intestines are back inside the abdomen. This can take a few days to happen. Your baby is then taken to theatre. Under general anaesthesia the rest of the intestines are put back in, the skin is sutured and a dressing is placed over the site.

In both cases a scar will be present. The surgeon will discuss the operation with you, explaining the risks involved. We will ask for your consent to do the surgery.

### What happens after the surgery?

Your baby will require help with breathing, so a tube will be inserted into the trachea (wind pipe). He or she will be connected to a ventilator which will help breathing. Your baby's heart rate, breathing, blood pressure and oxygen levels will continue to be monitored closely. Blood tests will also be performed to make sure your baby is stable. Medicines will be given for pain and will be adjusted according to what your baby needs. No feeds will be given until the intestines start to work properly. This may take some time. Your baby therefore 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 can 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 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, feeding well and growing adequately. There will be follow-up appointments with 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 follow up on your baby's progress. A dietician may be involved to help monitor your baby's feeding and growth.

## Available support

The nurse caring for your baby is available every day for first point of 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 and support each other. A clinical psychologist is accessible for one-to-one meetings by appointment.

### Support Groups

#### **GEEPS (Gastroschisis, Exomphalos and Extrophies Parent Support)**

104 Riverside Road  
Romford, Essex RM5 2NS

**T:** 01708 738134

**W:** [www.geeps.co.uk](http://www.geeps.co.uk)

**E:** [contact@geeps.co.uk](mailto:contact@geeps.co.uk)

#### **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)