

Information leaflet for Parents

Congenital Diaphragmatic Hernia (CDH) Discharge information



By your side

Congratulations on having your new baby. It is a daunting task taking any baby home from hospital especially if they have had surgery. We at Birmingham Women's and Children's Hospital will always be here to help and support you. Below are some of the areas that you may need to look out for over the weeks, months and years ahead.

What are the long term effects and after care?

Babies born with diaphragmatic hernia will need regular follow-up in clinic after going home from the hospital. Some may have long-term problems.

Most will be able to attend school normally and have a good quality of life.

Respiratory Issues:

Infants with CDH often have respiratory problems. This is due to a problem with lung growth (lung hypoplasia) which occurs before birth. Some children with respiratory problems may require oxygen at home. Supplemental oxygen helps to maintain a normal blood oxygen level and decreases the work of breathing (sparing calories needed for growth).

Children with CDH are more susceptible to Respiratory Syncytial Virus (RSV) infections. Respiratory Syncytial Virus (RSV) is a common cold virus. CDH Babies on home oxygen are thought to be most vulnerable. We therefore recommend that they receive Synagis® immunisation to prevent RSV infection. This injection is given monthly during RSV season, usually November through March. You may need to ask for a referral for this.

Pectus chest wall deformity

Some children with CDH may develop a depression of the sternum, or breastbone. This is called a pectus excavatum. This may occur as a result of the increased work of breathing or differences in the two sides of the chest. In most children this causes no risk to health, however it will be monitored by the surgeon in clinic.

Feeding:

Children with CDH have much higher energy and protein needs. This is for many reasons including supporting the still growing lung, the increased work of breathing and the surgical healing. Some babies will have difficulty growing. This is known as failure to thrive. The children with the most serious lung problems are most likely to have growing problems. Most often children with CDH need breast milk or formula that is more concentrated than normal. This can be prepared at home with a recipe you would receive from your dietician. Your babies growth will be closely monitored at home by your health visitor and/or dietician.

Oral Aversion:

Some CDH babies may be reluctant or refuse to feed orally. This can be due to long periods of not feeding by mouth and being on the ventilator while in hospital. If this is the case your baby will need to be fed via a small tube in the nose and will be seen by the Speech and Language Therapist. The nurses will teach you how to give the feed by tube when you go home.

Reflux:

Many babies reflux (frequent milky vomiting), however CDH babies are particularly prone to it. Acid and fluids from the stomach move up into the oesophagus (the tube that leads from the throat to the stomach), and can cause heartburn, vomiting, and feeding problems. If your baby has reflux it can often be treated effectively with medications. For children who do not get better with medicines they may require a separate operation (Nissen Fundoplication) to treat the reflux.

Bowel obstruction:

Before the CDH operation, some of your baby's abdominal organs were in the chest. During the operation the surgeon moved these organs back into the abdomen and repaired the opening in the diaphragm. Because of this operation your child may form adhesions (scar tissue) within the abdomen that can cause the bowel to kink and block. This is called a bowel obstruction. Signs of a bowel obstruction are:

- Green vomiting,
- Pain and crying,
- Abdominal distension (swollen tummy)
- Refusing feeds
- a change in bowel motions

This is a rare but serious problem and is considered an emergency. If your child has these symptoms take him/her to a doctor at your local hospital or to the Emergency Department at Birmingham Children's Hospital.

Re herniation:

This is uncommon, but can be serious if it happens. The hole in the diaphragm re-occurs enabling the organs to go back up into the chest causing breathing problems and/or causing a bowel obstruction. The signs that this may have happened are as follows:

- The same as above and/or difficulty breathing

If you notice any of these signs take him/her to your local hospital or to the Emergency Department at Birmingham Children's Hospital.

Developmental delay

Children who have been ill and hospitalized for prolonged periods are at risk of delay in normal development. They may not roll over, sit, crawl, stand, or walk at the expected time. Physical therapy, speech therapy, and occupational therapy are often helpful for these babies to gain muscle strength and coordination. It is important to identify any developmental delay as early as possible in order to begin treatment in a timely manner to maximize your child's potential.

Basic life support:

The thought that you may one day need to resuscitate your baby is a very frightening one. The need very rarely arises, however it will increase your confidence enormously if you can learn some basic first aid techniques. Many units have 'dolls' on which you can practice resuscitation and videos demonstrating what to do.

Follow up:

Following discharge home, your baby will have regular check-ups in the Outpatient Department in order to monitor their progress and to answer any questions you may have. It may be necessary to arrange for further investigations and treatment. We will send you details of your outpatient appointment in the post, soon after you leave hospital.

If you are worried, the neonatal unit or ward where your baby was nursed will be happy to speak to you over the telephone.

Further information and support:

The nurse and neonatal team looking after your baby will be happy to answer any further questions you may have before discharge.

For more information and support you may find the following websites useful:

CDH UK Support charity- www.cdhuk.org.uk/

Cherubs CDH charity: www.cherubs-cdh.org

Contact a Family: www.cafamily.org.uk

Contact numbers: If you have any concerns after discharge you can call for advice.

Neonatal Surgical Ward, Birmingham Children's Hospital Tel. 0121 333 9022

Looking after and sharing information about your child

We have a duty of care to help patients and families understand how information about them is kept and shared and we include the following information in all our patient leaflets:

Information is collected about patients relevant to their diagnosis, treatment and care. We store it in written records and electronically on computer. As a necessary part of that care and treatment we may have to share some patient information with other people and organisations who are either responsible or directly involved in the patient's care. This may involve taking the patient's information off site. We may also have to share some information for other purposes; such as research etc. Any information that is shared in this way will not identify the patient unless we have the patient's and parent's/carer's consent. If you have any questions and/or do not want us to share that information with others, please talk to the people looking after your child or contact PALS (Patient Advice and Liaison Service) on 0121 333 8403.

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