

Congenital Diaphragmatic Hernia (CDH)

What is congenital diaphragmatic hernia (CDH)?

The diaphragm is the large muscle that separates the chest from the stomach area, and helps with breathing. Congenital diaphragmatic hernia occurs when the diaphragm does not form completely, and instead has a hole. Organs that should be in the abdomen slip through the hole in the diaphragm, into the chest. Once in the chest, these organs take up space that should be available for the lungs to grow. The intestine is the most common organ to slip through the hole, but others include the stomach, liver, spleen, and kidneys.

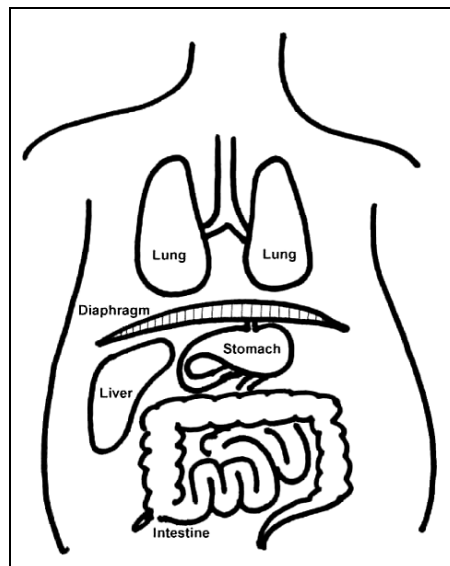
How does the health care team know my child has a congenital diaphragmatic hernia?

In many cases, the diagnosis is made before birth by prenatal ultrasound. Intestine or other organs can be seen in the developing baby's chest during routine, prenatal ultrasound. Small lung size can also be identified by ultrasound before birth.

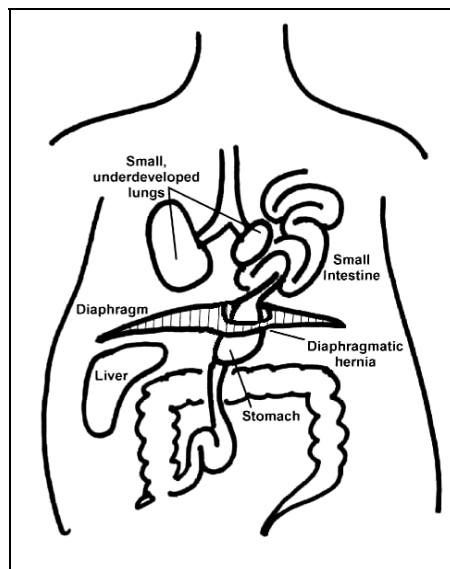
If not found during pregnancy, the condition may be found soon after birth when your baby has trouble breathing. In either case, because of the breathing difficulty at birth or because of diagnosis by ultrasound during pregnancy, an X-ray of your baby's chest is done. The X-ray can show that organs belonging in the abdomen are in the chest. The lungs may look smaller, and the heart and lungs may be shifted to one side. In some cases, another test called a CT or CAT scan is done to find out more.

Less commonly, diaphragmatic hernia is found in an older infant or child who has frequent

respiratory illnesses, but the condition is less serious.



Normal Anatomy



Diaphragmatic Hernia

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How did my child get this condition?

Congenital diaphragmatic hernia occurs early in pregnancy while the muscle is forming. The exact cause is not known at this time.

CDH may run in families and research is being done to look at the roles of certain chemicals and nutrients. Without knowing the cause, there is no way to prevent CDH.

How is congenital diaphragmatic hernia fixed or treated?

Surgery is needed to move the organs from the chest back down to the abdominal cavity, and to close the hole in the diaphragm. Surgery is usually done within the first two weeks of life. Although your baby will be monitored and treated in the Neonatal Intensive Care Unit (NICU) right after delivery, surgery is not usually done right away after birth. The surgery involves a cut in the chest or abdomen. Drain tubes are left in place afterward to allow extra fluid to drain out.

Most infants will be on a breathing machine (ventilator) before and after surgery to help with breathing. Some infants also require ECMO (Extra Corporeal Membrane Oxygenation), which is a type of bypass machine that allows blood to receive oxygen outside the lungs. You will have a chance to learn more about this treatment if your child needs it.

Babies with diaphragmatic hernia usually have small, stiff lungs. There is no cure for this problem other than time. Over time, your child's lungs slowly grow larger, and the stiffness improves. Oxygen, medications, and sometimes ECMO are used to help in the beginning.

Will my baby be in pain?

The hole in the diaphragm and position of the intestine in the chest at birth does not hurt. This is simply the way the organs developed. The medical team pays close attention to pain both

before and after surgery and will give your baby pain medicine to maintain comfort.

How serious is congenital diaphragmatic hernia?

It depends upon the size and development of the lungs. If the hole in the diaphragm is small and the lungs are of good size and function, your child may have little trouble breathing after surgery. If the hole is larger and the lungs are small and stiff, your child may need breathing support and to stay in the hospital for a longer time.

Preparing before the baby's birth

You can begin preparing for the birth of your baby now through prenatal counseling with the general surgery team at Children's. You can ask questions and get to know the team who will be caring for you and your baby. You can learn more about congenital diaphragmatic hernia, its treatment and complications. You can also take a tour of the hospital units and family resource facilities to better plan for your time here.

You will also want to create a birth plan with your obstetric team who will deliver your baby. Congenital diaphragmatic hernia does not require cesarean section and vaginal delivery is safe unless there are other health concerns for you or the baby. The decision will be up to your obstetric team.

- It is recommended that you deliver the baby close to Children's Hospital for transfer to Children's right after birth for treatment.

Please plan to have another adult follow your baby to Children's while you're still in the hospital. You may join the baby as soon as you are discharged, or come to visit daily if you will need to stay in the hospital longer yourself.

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What happens when my baby is born?

Right after delivery, your baby will be examined by specialized pediatricians called neonatologists. If your baby is having difficulty breathing, oxygen or a ventilator will be used to help. Your baby will be taken by ambulance to Children's Hospital.

At Children's Hospital, your baby will go to the neonatal intensive care unit (NICU). Your baby may need a ventilator until after surgery. Your baby will have lots of medical tubes placed. An intravenous (IV) line is placed to give fluids, nutrition, and medicine into the vein. A small nasogastric (NG) tube is placed into the stomach through the nose to empty the stomach and keep the stomach pressure low. Particular attention is paid to blood pressure and breathing. Your baby's condition will be continuously monitored during this time.

What about feeding my baby?

If you are planning to breastfeed your baby, the hospital staff will do everything we can to support your breast feeding goals. It is important to start breast pumping after your baby is born. In order to breastfeed later, you need to keep your milk flowing, which means pumping at least eight times a day. You can store pumped milk in the freezer at the hospital. Breast feeding or pumping moms receive "breast feeding mom" food trays from the hospital cafeteria three times a day.

During the evaluation period in the NICU and the first few days after surgery, it is not safe to breast or bottle feed your baby. All your baby's food will be provided through the IV with a mix of protein, sugar, and fat. This special mixture is called TPN (Total Parenteral Nutrition).

Once your baby is ready for feeding, formula or your stored breast milk is slowly introduced. Very small amounts of breast milk or formula are given at first. Feedings may be done by mouth or by a small NG feeding tube. Then, your baby will

gradually be offered more breast milk or formula and less IV nutrition (TPN). Once your baby can handle a reasonable amount at a time, you can begin directly breastfeeding. Feedings by mouth require lots of energy and coordination on the part of your baby, and can be stressful for some babies with breathing problems from a diaphragmatic hernia. Nurses and infant feeding therapists can help with the transition to feeding by bottle or breast. By the time they go home, some babies are able to eat everything by mouth, but many still do a combination of eating by mouth and by the NG tube.

How long is the hospital stay?

Every child's recovery is different. Your baby will be ready to go home once he or she has recovered from surgery and can gain weight without the feedings from the IV. Most newborns with congenital diaphragmatic hernia are in the hospital for several weeks to several months depending upon the recovery and complications. The first part of the hospitalization will be in the NICU, followed by a period of time on the surgical unit.

When it's time to go home, many babies with diaphragmatic hernia still need oxygen and an NG tube to support continued growth. The nurses will help set these up for home use. You will have plenty of time to practice and become comfortable using them if your child will need to take them home. Usually these treatments can be stopped after a few months when your child outgrows the need.

What is the long-term outlook for my baby?

Children with this condition often have some long-term issues around feeding or breathing. The number and seriousness of these problems varies from child to child. Some children have no significant long-term problems from CDH, but many children have at least some.

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Your child will be followed closely for any long-term issues around feeding or breathing. The problems may include:

- **Gastroesophageal reflux (GER):** The backward flow of stomach contents into the esophagus is common in infants with diaphragmatic hernia. This can be uncomfortable, and make feeding more challenging. Reflux can also worsen some of the breathing symptoms. In some cases, it can be so severe as to cause choking or allow stomach contents to enter the lungs (aspiration). For this reason, many children are placed on medicines that help to decrease the production of acid in their stomach and help to heal the lining of the esophagus. They may also need to remain in an upright position to reduce reflux and vomiting. Feeding routines can also be adjusted. For example, slow, gentle feeds of low volumes, with concentrated formula can help with reflux symptoms.
- **Feeding problems:** These may be related to reflux, or from not learning to eat as a newborn during the surgical and recovery period. Many children will be fed through a nose-to-stomach tube (nasogastric tube) in order to provide gentle, safe feedings until the child grows out of the reflux and learns to eat safely.
- **Frequent serious colds:** The lungs of children with CDH are still smaller and stiffer than normal during the first few years of life. This makes some children with CDH much more susceptible to colds and respiratory illnesses than other children. When they get colds, these children have less reserve, and are less able to fight colds by themselves. Sometimes an infant with CDH will be re-admitted to the hospital for support such as fluid and oxygen during a bad cold.

- **Asthma:** Your child has a greater chance of getting asthma later on. Avoiding typical irritants such as smoke, dust, and some animals may help minimize these symptoms.

Where can I get more information?

- Library and Information Commons (located in the Whale zone, 6th floor)
- The American Pediatric Surgery Association (APSA) website:
www.eapsa.org/parents/resources/diaphragmaticHernia.cfm
- Contact CHERUBS, a parent support group offered through The Association of Congenital Diaphragmatic Hernia Research, Advocacy and Support

CHERUBS
P.O. Box 1150
Creedmoor, NC 27522
Tel. (888) 834-8158 or (919) 693-8158
E-mail: info@cherubs-cdh.org
Web site: www.cherubs-cdh.org

TO LEARN MORE

- **General Surgery (206) 987-0237**
- **Your Child's Health-Care Provider**

Children's will make this information available in alternate formats upon request. Please call the Family Resource Center at (206) 987-2201.

This handout has been reviewed by clinical staff at Children's Hospital. However, your child's needs are unique. Before you act or rely upon this information, please talk with your child's health-care provider.