



# Congenital Diaphragmatic Hernia (CDH)

## What is congenital diaphragmatic hernia (CDH)?

The diaphragm is the large muscle that separates the chest from the stomach area (abdomen), 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 other possibilities include the stomach, liver, spleen and kidneys.

## How does the healthcare team know my child has a CDH?

In many cases, the diagnosis is made before birth during a routine prenatal ultrasound. During the ultrasound, intestine or other organs can be seen in the developing baby's chest as well as smaller lung size.

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 organs that belong in the abdomen are in the chest. The lungs may look smaller, and the heart and lungs may be shifted to one side.

Diaphragmatic hernia may also be found in an older infant or child who has frequent respiratory illnesses. This is less common and less serious.

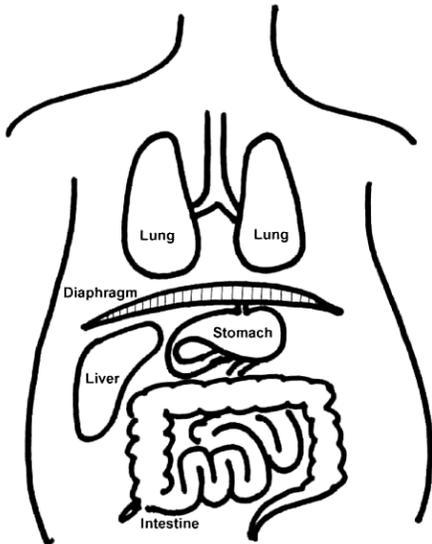
## How did my child get this condition?

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

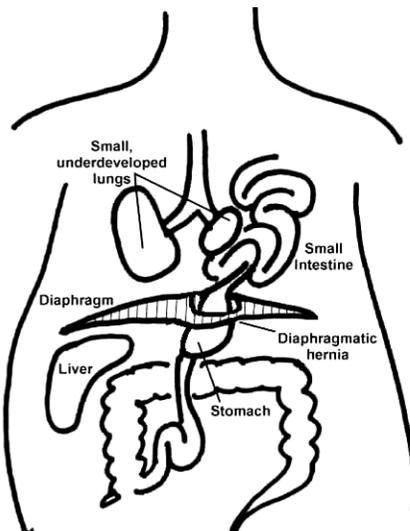
Rarely, CDH may run in families and research is being done to look at the roles of certain chemicals and nutrients. Without knowing the cause, there is no way to prevent CDH.

## How is congenital diaphragmatic hernia fixed or treated?

Your baby will be monitored and treated in the Neonatal Intensive Care Unit (NICU) right after delivery. Surgery is needed to move the organs from the chest back down to the abdomen, and to close the hole in the diaphragm. Surgery is often done within the first two weeks of life. During surgery a cut is made in the chest or abdomen. The abdominal organs in the chest are moved into the abdomen and the hole in the diaphragm is sewn closed. Drain tubes may be left in place afterward to allow extra fluid to drain out.



Normal anatomy



Diaphragmatic hernia

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While surgery is important to fix the hole there are other problems that babies with CDH might have. Most of them will have some degree of pulmonary hypertension. This means the heart has trouble pumping blood to the lungs because the arteries to the lungs are thicker and stiffer than normal. Surgery does not cure this problem. Over time this usually gets better on its own.

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

Babies with CDH usually have small, stiff lungs. There is no cure for this problem but over time, your child's lungs slowly grow larger, and the stiffness in the lungs and the arteries to the lungs improves. Oxygen, medicines, 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. We partner with you to prevent and relieve pain as completely as possible.

After a surgery your baby is likely to have some pain and discomfort. We will give your baby pain medicine to keep them comfortable. In addition to medicine, we will work with you to create a plan that encourages coping activities to treat pain and provide support.

### **How serious is congenital diaphragmatic hernia?**

It depends on the size and development of the lungs. If the hole in the diaphragm is small and the lungs are a good size, 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. This can be a very serious problem and some babies die from CDH. Sometimes the doctors can give some prediction of how serious the CDH is from measurements taken on prenatal ultrasounds, but sometimes it is hard to know until your baby is born. Your doctor will discuss this with you after your baby is born and the medical team has a better understanding of your baby's condition.

### **How can I prepare for the birth of my baby?**

You can begin to prepare for the birth of your baby now through prenatal counseling with the General Surgery team at Seattle 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 CDH, 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. CDH 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 Seattle 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 leave the hospital, or come to visit daily if you need to stay in the hospital longer yourself.

### **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 a hard time breathing, oxygen or a ventilator will be used to help. Your baby will be taken by ambulance to Seattle Children's.

At Seattle Children's, your baby will go to the NICU. Your baby will probably need to be on 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. We will closely watch your baby's 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 8 times a day. You can store pumped milk in the freezer at the hospital.

Breastfeeding or pumping moms can get 3 days of food vouchers from the hospital cafeteria. The vouchers will be for \$5 per meal for 3 meals a day.

During the evaluation period in the NICU and the first few days or weeks after surgery, it may not be 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. Your baby will need a lot of energy and coordination to feed by mouth; this can be stressful for some babies with breathing problems from a diaphragmatic hernia. Nurses and infant feeding therapists can help you and your baby 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 feed both by mouth and NG tube.

### **How long is the hospital stay?**

Every child's recovery is different. Your baby will be ready to go home once they have recovered from surgery and can gain weight without the feedings from the IV. Most newborns with CDH are in the hospital for several weeks to several months depending upon the recovery and complications. The first part of the hospital stay 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. 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.

Your child will be followed closely by our Surgery Pulmonary Follow up Clinic (SPF) for any long-term issues. In this clinic, you will meet a general surgeon, lung doctor, dietitian, and nurse to help you coordinate any follow up visits and address any long term concerns. These 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 changed. 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 likely to get colds and respiratory illnesses than other children. When they get colds, these children are less able to

### To Learn More

- General Surgery  
206-987-2794
- Ask your child's nurse or doctor
- [www.seattlechildrens.org](http://www.seattlechildrens.org)

### Free Interpreter Services

- In the hospital, ask your child's nurse.
- From outside the hospital, call the toll-free Family Interpreting Line 1-866-583-1527. Tell the interpreter the name or extension you need.

fight colds by themselves. Sometimes an infant with CDH will need to come back 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 common irritants such as smoke, dust, and some animals may help reduce these symptoms.
- **Pulmonary hypertension:** Sometimes this problem lasts longer in babies and they need to go home on oxygen and medicines to help the blood flow better from the heart to the lungs. These babies may need to be seen for follow-up in the Cardiology Clinic.

### Where can I get more information?

- The Family Resource Center (level 7, River zone)
- The American Pediatric Surgery Association (APSA) website: [www.eapsa.org](http://www.eapsa.org)
- Contact CHERUBS, a parent support group offered through The Association of Congenital Diaphragmatic Hernia Research, Advocacy and Support

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