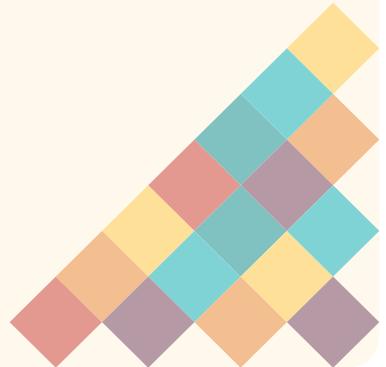


⋮ Neonatal Intensive  
⋮ Care Unit (NICU)

# Having a Baby with Congenital Diaphragmatic Hernia

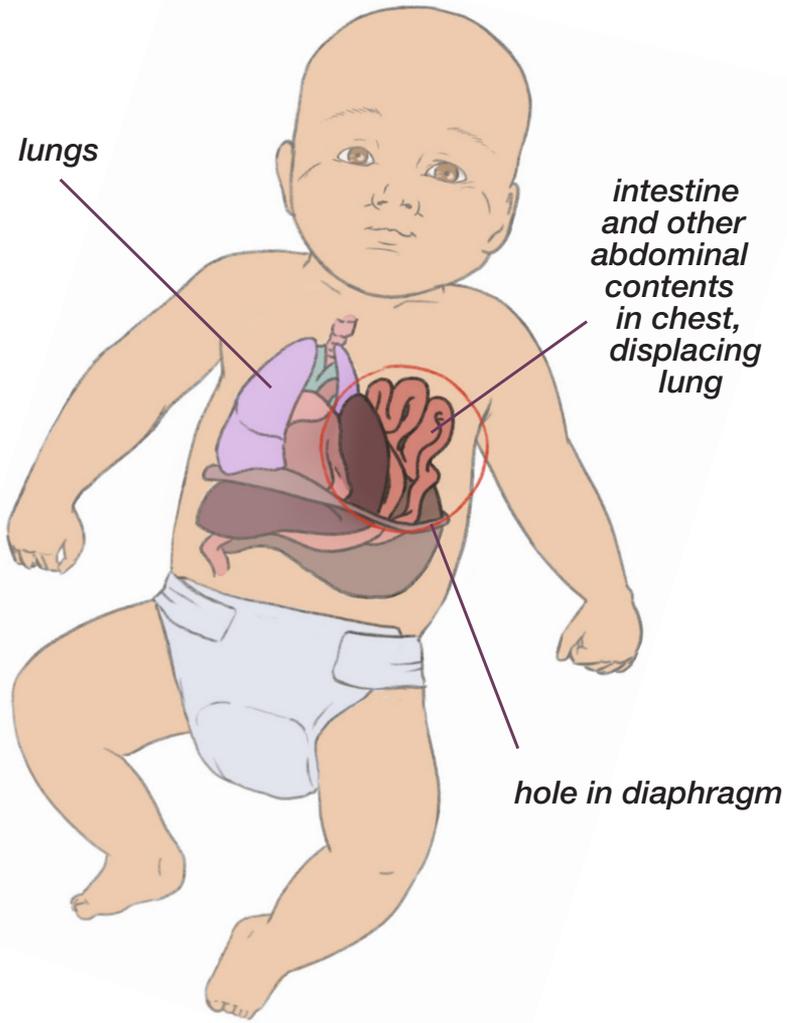


# What is Congenital Diaphragmatic Hernia?

Congenital diaphragmatic hernia (CDH) is a condition affecting a newborn in which an opening exists in the muscle that separates the abdomen from the chest, called the diaphragm. The opening happens early on in pregnancy and is most commonly on the left side. The intestines and other abdomen contents push up (or herniate) through the opening, taking up space normally needed for the growing lungs. The lungs are affected in their development such that they may not exchange oxygen and carbon dioxide well after birth. Some babies with CDH have additional medical issues involving the heart, kidneys, bowels, and even brain. While most babies with CDH will survive, some do not if there are severe problems with lung development and/or other serious medical issues. Some surviving babies have long-term challenges in their physical and cognitive development.

## Giving Birth to a Baby with Congenital Diaphragmatic Hernia

Generally a baby with CDH can be born vaginally. Some babies with CDH need to be born by caesarean section generally for the same reasons as babies born without CDH. For example, if the baby is not in a head-down position, a caesarean section may be most appropriate. Since babies with CDH require special care after birth, families expecting a baby with CDH are recommended to relocate to Edmonton approximately 3 weeks before their due date.



*lungs*

*intestine  
and other  
abdominal  
contents  
in chest,  
displacing  
lung*

*hole in diaphragm*

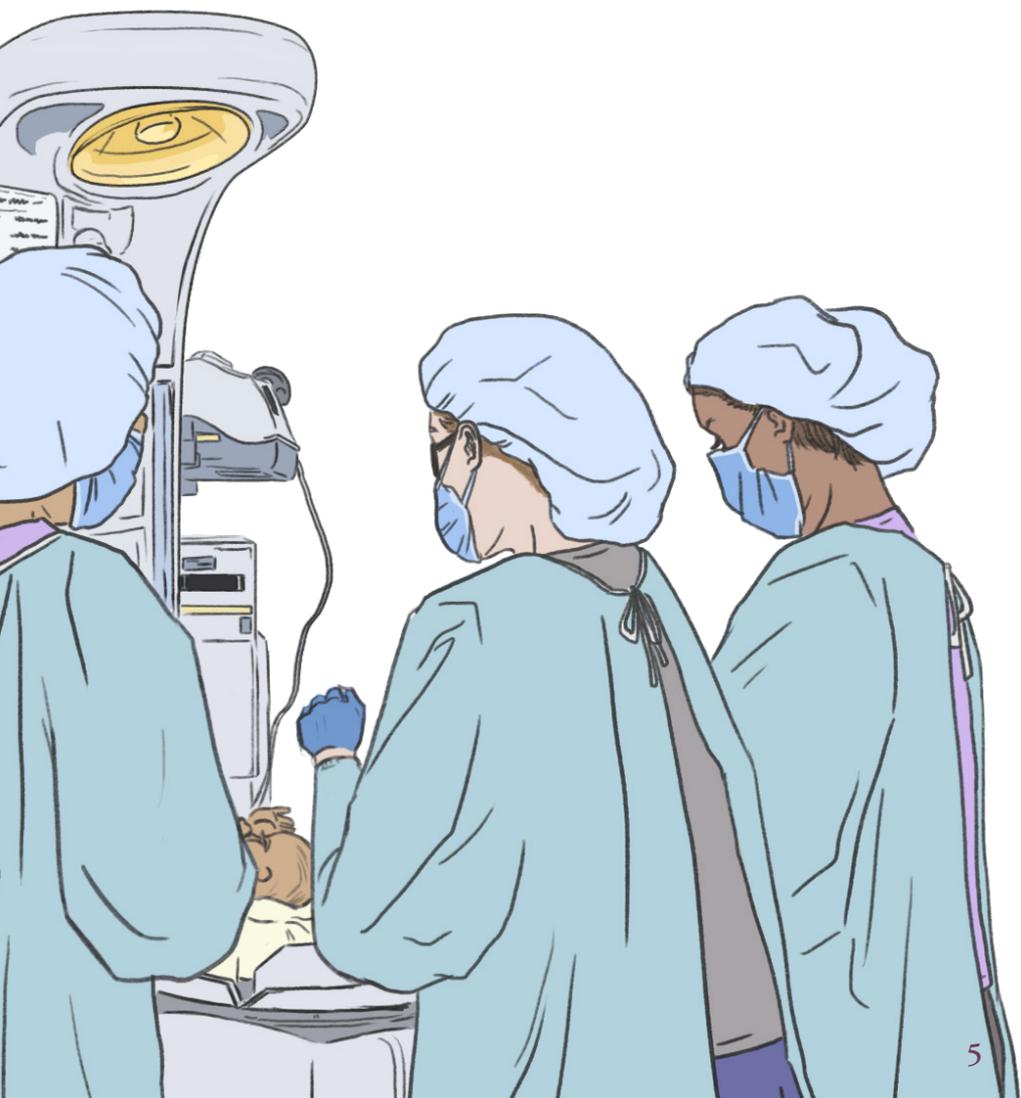
# Once the Baby is Born

Babies with CDH need special care as soon as they are born. A team of newborn specialists is at the birth. A breathing tube is needed to support the baby's breathing such that you may not hear your baby cry at birth. We also start intravenous (IV) lines to give medications to keep the baby comfortable and to relax the breathing muscles. Usually these lines are inserted into the belly button where the baby cannot feel any pain. Medications may also be needed to support the heart pump or relax the lungs.

We insert a soft, plastic tube through the nose or mouth, referred to as a nasogastric (NG) tube or orogastric (OG) tube, to help keep the stomach and bowels empty to avoid pressure on the lungs from a distended abdomen. The newborn team is experienced in helping babies with CDH. If other medical issues exist, other medications or interventions might be required after delivery.

It is important for parents to spend time with their babies, and if the baby is stable, we try to help parents see and touch their baby before they are moved to the Neonatal Intensive Care Unit (NICU). Parents should let the medical team know of any special wishes they have for the delivery so we can do our best to accommodate these requests when possible.





# Preoperative Care

Although a baby with CDH will eventually require surgery at the University of Alberta Hospital, it is important to give a baby time to stabilize before transfer. Usually stabilization happens in the delivery room or in the Royal Alexandra NICU. Stabilization prior to transfer may typically take hours or rarely days with the use of breathing machines and various intravenous medications. Specialized IVs are inserted through the belly button (umbilical lines) or elsewhere on the body through a vein in an arm, leg, or scalp (peripherally inserted central catheter, PICC line). Since babies with CDH are unable to eat after they are born, we provide nutrition intravenously. This is called total parenteral nutrition, or TPN, and includes everything the baby needs to grow: sugar, protein, and fat.

When the NICU team feels the baby is stable for transfer, the baby is brought to the University of Alberta Hospital by a specialized transport team. The team uses an incubator that looks like a plastic box with monitors and machines fastened to an ambulance stretcher. This transport incubator keeps babies warm, secure, and protected as we keep providing medical treatments in the ambulance.

Usually, it is a calm, slow ambulance ride to the University of Alberta Hospital. Mothers have to remain at the birth hospital until they have recovered. Other family members can follow the ambulance by car and come directly to the University of Alberta Hospital NICU. Typically mothers delivering vaginally may be discharged within a day of delivery. Mothers delivering by caesarean section usually require three to five days of hospitalization, however they may receive passes to visit the NICU earlier depending on their recovery. Parents are essential to their baby's care in the NICU and are welcome at anytime of the day or night.

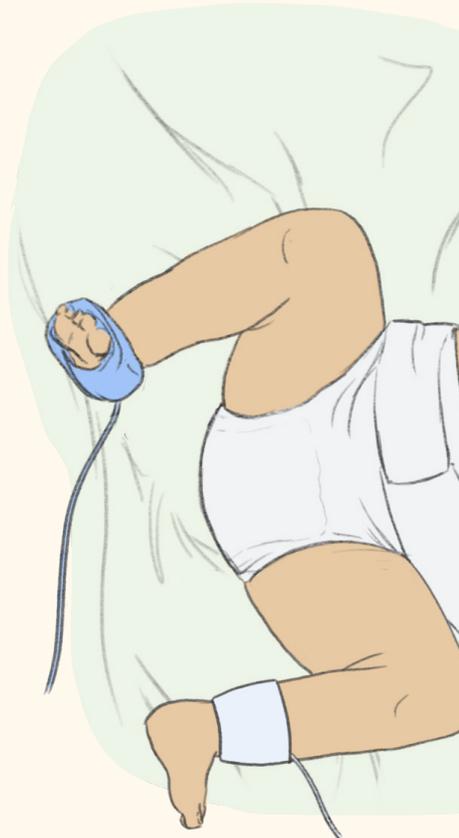


The University of Alberta NICU team, including the pediatric surgeon, examines babies with CDH after they arrive. Usually, even after arrival to the University of Alberta Hospital, the baby needs additional time in the magnitude of days to a week for further stabilization before surgical repair. We also routinely do head and abdomen ultrasounds and genetic testing to look for additional medical issues.

Rarely, the use of a heart-lung bypass machine is discussed for stabilization (extracorporeal membrane oxygenation (ECMO) also known as extracorporeal life support (ECLS)). There are significant risks such as bleeding, infection, or brain injury associated with this therapy such that it is ultimately the parents' choice as to whether use of the heart-lung bypass machine is appropriate for their child. Sometimes, it becomes apparent during this period of stabilization that the lungs are too underdeveloped or that other medical issues exist making survival impossible.

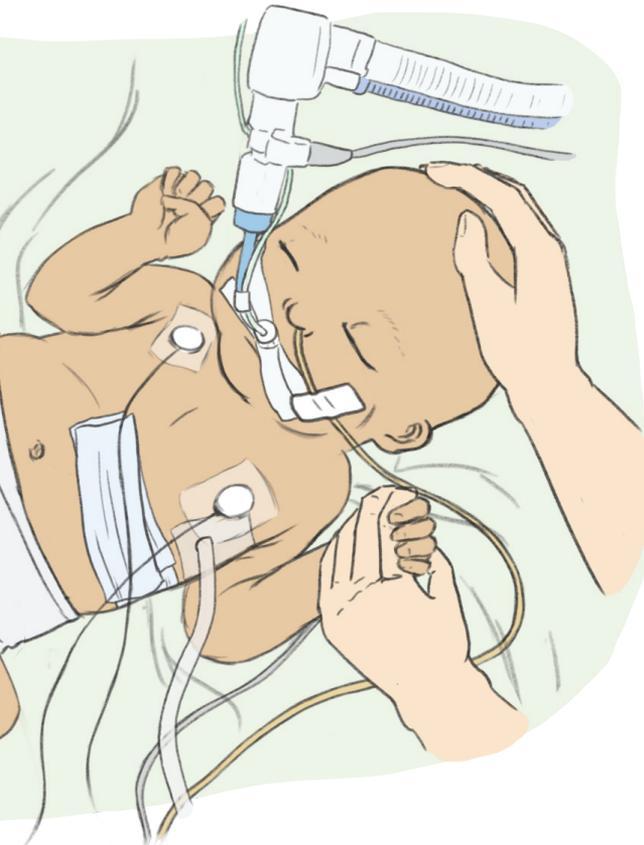
# Surgical Treatment and Postoperative Care of CDH

If surgery is possible, the baby is taken to the operating room for the surgery. The surgery consists of moving the intestines and other abdomen contents back into the abdomen and closing the diaphragm opening with stitches. Sometimes a prosthetic patch is used to close the gap in the diaphragm. The baby will return from the operating room with a surgical wound on the left side of their chest. After surgery, babies might need even more breathing support and medications as the lungs need to recover from the stress of surgery. As the baby gets better, we slowly decrease the breathing support and medications. Over time, the space of the chest that had been filled with bowel or other abdominal contents fills with fluid. It can take days or even weeks to decrease the breathing support and remove the breathing tube. Even once off the breathing machine, many babies will continue to need breathing support such as a facemask or nose prongs to make breathing easier.



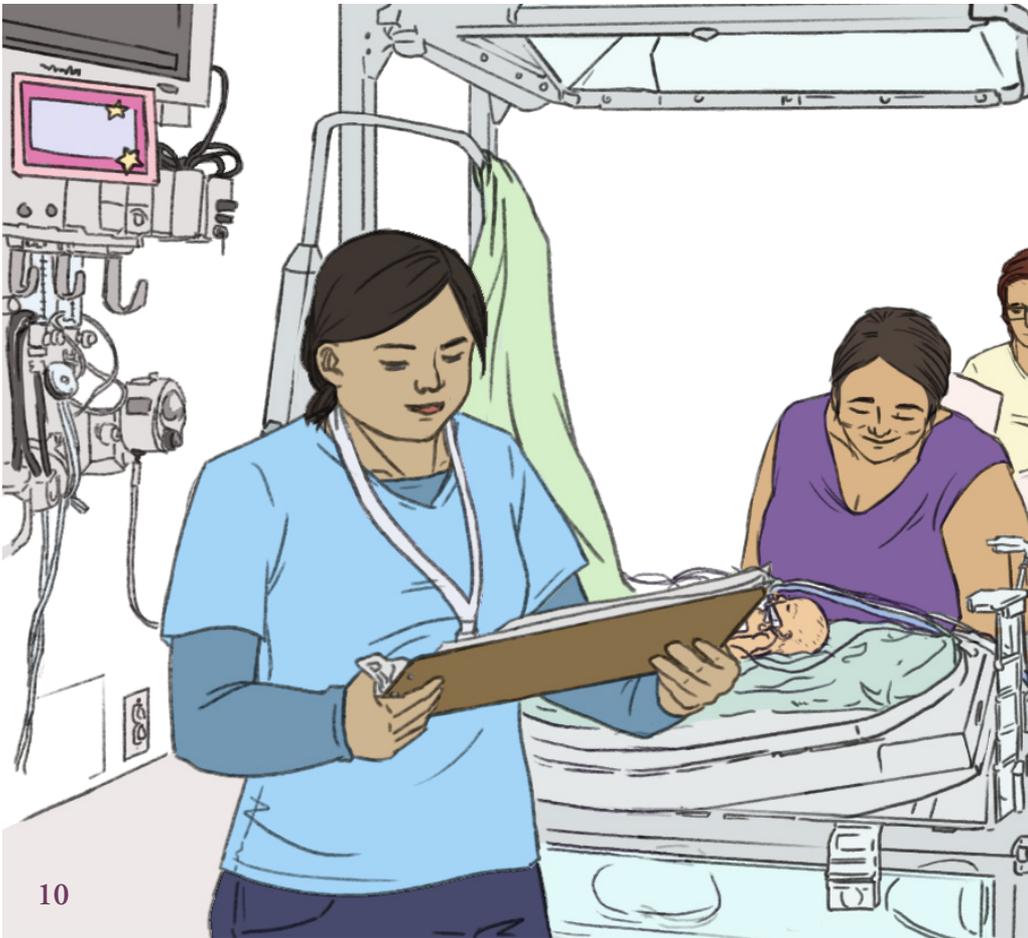
The bowels, having been replaced back in the abdomen, also need days and sometimes weeks to recover. When there are signs that the bowels are recovering, such as the passage of stool, we slowly start small amounts of milk or formula feeds through the NG or OG feeding tube. This first feed can be pumped breast milk. Once the baby tolerates these feeds then we help mothers and babies as they begin breastfeeding or bottle-feeding. Figuring out breast or bottle-feeding can take a few to many weeks after the surgery.

The nurses will help mothers to start pumping breast milk as soon as possible after delivery to establish and maintain their milk supply. A lactation consultant is available to support parents.



# Being a Parent in the NICU

Being a parent in the NICU can be an overwhelming experience. We recognize that it can be alarming for a parent to see their child connected to medical monitors, intravenous lines, and other medical equipment. We understand that seeing all of this might make bonding between parents and their children harder. Contact is important for the wellbeing of parents and their babies. During the days or weeks that babies with CDH are on a breathing machine, it is important for parents to touch, talk, and be present to their babies even though it might not be possible for them to hold them out of the bed. Your team can suggest alternative methods to



cradle or hold your baby in the bed. As soon as we can, we help parents hold their babies. As a NICU team, we support families and value their voices.

There will always be nurses and respiratory therapists present to make sure a baby receives the care they need. The medical team can help explain the various medical equipment and procedures. Every morning, a whole team of doctors, nurses, and other practitioners see the babies and decide about care. We call these “morning rounds” and parents are encouraged to be there to ask questions and express concerns. As well, every family meets a social worker who will provide support and help access resources.

Parents are welcome to bring personal and comforting items for their baby such as photos, small stuffies, blankets and clothing – best if the clothing is not knitted or woven as these could get caught on some of the supports and equipment

like IV’s. Diapers and other supplies needed for daily care are provided. Family and friends can come visit the baby. There is a reception on the unit for safety and security.



## Preparing for a Hospital Stay

We suggest that parents prepare for a hospital stay of 6 to 12 weeks after birth to include a typical hospital course. Often, the baby will be moved to another Edmonton-area NICU or to a general pediatric unit of the University of Alberta Hospital following surgery. Complications or additional medical problems may necessitate a longer hospital stay or use of medical treatments after babies are discharged such as tube feeds, home oxygen, or even home breathing machines. We talk about everything with parents as soon as we anticipate or notice a complication happening. Children born with CDH remain at risk for breathing concerns in childhood.

Before families go home we make sure that babies have a primary care provider (family doctor or pediatrician) and follow-up arranged with their pediatric surgeon. Babies with CDH are also invited to follow-up with the Infant Development Program through the Glenrose Rehabilitation Hospital, which can be arranged for you while you are in the NICU.

