

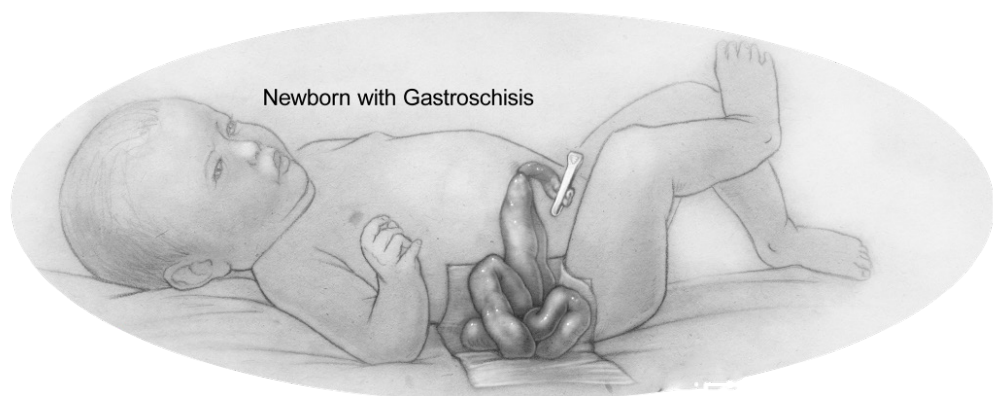
Gastroschisis and My Baby

Gastroschisis is a condition where a baby is born with the intestine outside the body.

Learning about the diagnosis

What is gastroschisis? (pronounced gas-tro-SKI-sis)

Gastroschisis is a condition where a baby is born with the intestine outside the body. The intestine comes through an opening in the belly (abdomen), next to the belly button. The intestine can become swollen and irritated from sitting in the amniotic fluid. Even though this sounds scary, most babies born with gastroschisis do very well. After medical care during infancy, most grow up to live normal lives.



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How does this happen?

The cause of gastroschisis is not known. The condition happens while the belly (abdominal) wall of the fetus is still developing. Researchers are studying to learn more about the cause. Gastroschisis does not usually run in families (not inherited).

How common is gastroschisis?

Gastroschisis is very rare. It only affects 1 in 2,500 children in the United States. It happens to children all over the world and is happening more often than in the past.

To Learn More

- General Surgery
206-987-2794
- Ask your child's healthcare provider
- seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your 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.

Preparing before baby's birth

Usually, gastroschisis does not require Cesarean section and is safe for vaginal delivery. The decision will be up to your obstetric team. It is recommended that you deliver your baby close to Seattle Children's Hospital for transfer to Seattle Children's, so treatment can begin right after birth. You may join the baby as soon as you are able to leave the hospital.

You can begin preparing for the birth of your baby now. Seattle Children's surgery team offers prenatal counseling for you to ask questions and get to know the team who will be caring for you and your baby. Arrange to meet with one of the general surgeons and a nurse to:

- Learn more about gastroschisis, its treatment and complications
 - Tour the hospital units and family resource facilities
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What happens when my baby is born?

Right after delivery, a clear plastic bag is placed over your baby's belly, covering everything from feet to armpits. The bag protects the exposed intestine and reduces heat and water loss. To care for your baby, several medical tubes are used. An intravenous (IV) line is placed in a vein to give fluids, nutrition and medicine. A nasogastric (NG) tube is placed into the stomach through the nose or mouth. This is to empty the stomach contents.

Soon after delivery, your baby will go by ambulance to Seattle Children's Hospital. At Seattle Children's, your baby will go to the Neonatal Intensive Care Unit (NICU). Your baby's condition will be continuously watched during this time.

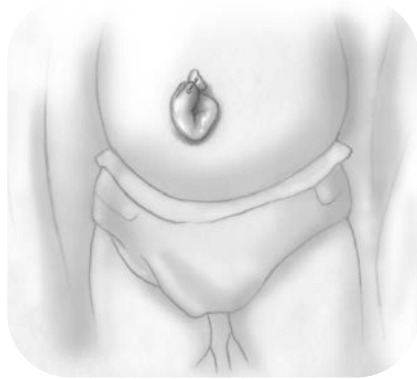
Closing the abdomen

A procedure is done to put the intestine back inside and close the opening on the belly. Most of the time, this can be done on the baby's first day of life during one procedure. Sometimes, more than one procedure is needed to push the intestine back inside more gradually.

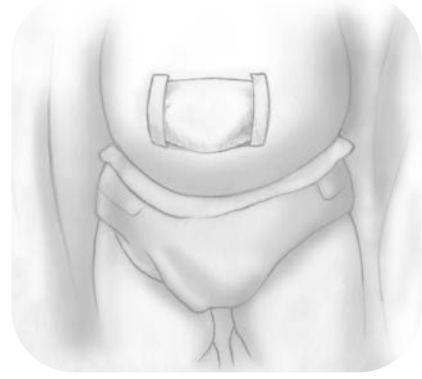
What is involved in the procedure?

There are several ways to close the hole on the belly. The type of closure depends upon the size of the exposed intestine compared to the size of the belly cavity, and upon the surgeon's assessment of the baby's condition. Your baby will be placed on a breathing machine (ventilator) for these procedures.

- **A primary umbilical closure** is the most common type of closure done at Seattle Children's. In this type of closure, the surgeon places the intestine into the belly and wraps the umbilical cord over the hole. A dressing placed over the top keeps the area clean and secure while it is healing underneath.



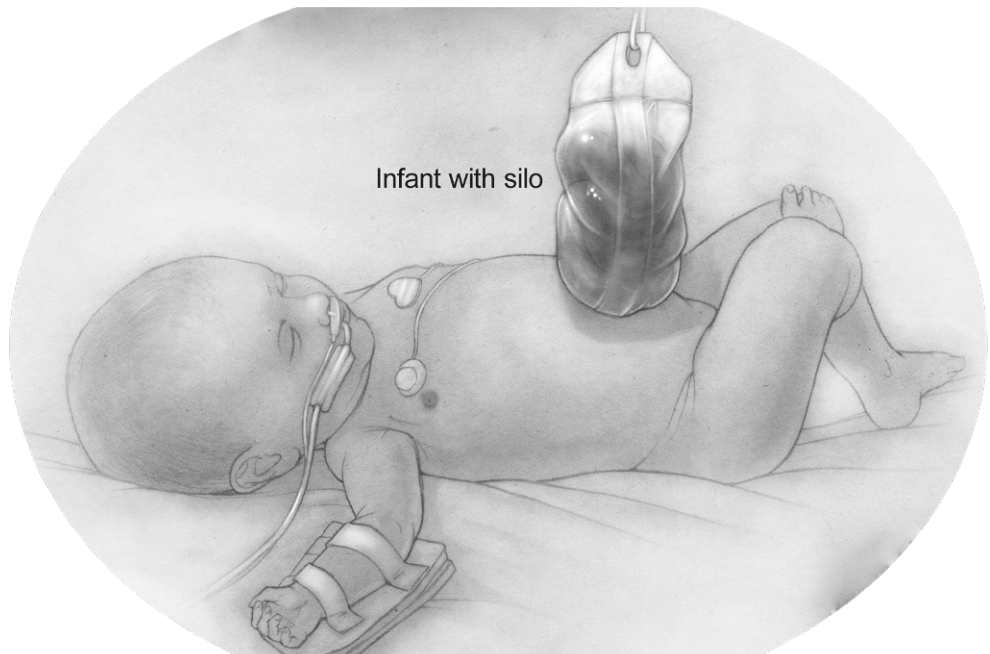
Primary umbilical closure



**Primary umbilical closure
with dressing**

- **A primary surgical closure** is when the surgeon places the intestine into the belly and sews the abdomen closed in one surgery.
- **A staged closure** (also called delayed, primary closure) is done using a “silo.” A silo is a bag that protects the exposed intestine and is suspended from above. It may be placed at the bedside in the NICU or it may be done in surgery.

The silo keeps the intestine protected, while the intestine is gradually pushed into the belly cavity over several days. During that time, intestinal swelling goes down and the baby’s belly increases in size.



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After closure care

What should I expect after the hole is closed?

After the closure, your baby will be watched in the NICU. Your baby will receive pain medicine during the recovery period. The NG tube will keep the stomach empty until the intestine recovers and begins working. At that point, feeding can begin. Once the hole is closed, the ventilator is off, and your baby is recovering well, your baby will move out of the NICU to the surgical unit.

What about feeding my baby?

The hospital staff will do everything they can to support your breast-feeding goals. If you are planning to use breast milk, it is important to start breast pumping after your baby is born. In order to breast-feed later, you need to keep your milk flowing. You can store pumped milk in the freezer at the hospital.

Before your baby can eat, the intestine has to recover from the procedure and from the exposure to amniotic fluid. During this recovery your baby's food will be given through the IV with a mix of protein, sugar and fat, called TPN (total parenteral nutrition).

Once the intestine begins working and your baby is ready for feeding, your stored breast milk will be used to feed your baby. Formula is used if you don't have breast milk. Very small amounts of breast milk or formula are given at first. Feedings may be done by mouth or by small feeding tube. 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 breast-feeding. Nurses and the infant feeding team 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, while others still do a combination of eating by mouth and by tube.

How long will my baby be in the hospital?

Every child's recovery is different. Babies are ready to go home once their abdomen is healed and they can gain weight without needing the IV nutrition. Most babies are hospitalized for 6 weeks. The first days are usually spent in the NICU. Factors such as how well the intestines work and complications can all affect the length of stay.

What are the complications or problems with gastroschisis or the surgery?

Infections and blockages in the intestine can be common complications with this condition. Here is a list of issues that may arise. Your surgical care team will explain these to you.

Acid reflux. Gastroesophageal reflux (frequent vomiting) is common among babies in general, and for babies with gastroschisis. Keeping your baby in an upright position, medicines and slower feeding rate can all help treat reflux.

Atresia. A blockage or gap in the intestine called an atresia may be present at birth. This occurs in 10% of babies with gastroschisis. This condition requires additional surgery.

Ileus. The intestine may not squeeze normally for the first week or more after surgery. This is called ileus. Babies cannot eat during this time and receive all nutrition by IV.

Infections and liver problems. While in the hospital and using IVs, your baby is at risk for infections and liver problems. The swollen and irritated intestine allows germs to pass into the bloodstream more easily, which can cause infections. Being on IV nutrition (TPN) can also cause damage to the liver over time. Usually, the liver heals once IV nutrition is stopped. Labs are checked regularly to look for signs of infection or liver damage, and treatment can include medicines and changes to the feeding schedule.

Intestinal obstruction. The intestine may be too narrow in places or become tangled in old scar tissue, causing obstruction. Babies with gastroschisis also have “malrotation,” or abnormal position of the intestine, because the intestine did not develop normally in the belly cavity. If obstruction occurs for any of these reasons, surgery may be needed to remove the blockage.

Malabsorption. Most babies with gastroschisis are born with intestines that are shorter than normal. This can cause problems with absorption of food (malabsorption). The problem usually improves with time. Feedings are introduced slowly. Feeding schedules and formulas can be changed to help with absorption.

NEC. Necrotizing enterocolitis (NEC) is a serious condition of the intestinal wall tissue. When it occurs, babies require rest for the intestinal tract (no feedings), IV antibiotics and close monitoring, with frequent X-rays and exams. Sometimes, surgery is needed.

How can I care for my baby in the hospital?

You can care for and comfort your baby from the very beginning. We encourage you to touch and talk to your baby, and spend as much time as possible together. Once the intestine is inside, you can hold your baby. When your baby can't be held, you can be right at the bedside holding your baby's hand, changing diapers and comforting your baby. Your baby knows and prefers your voice and your face. You will quickly find that you know your baby best and are the center of the care team.

Will my baby have pain?

Even though it may look uncomfortable, the position of the intestine outside the belly at birth does not hurt. This is simply the way the intestine developed. The medical team pays close attention to pain, both before and after surgery, and will give your baby pain medicine to maintain comfort.

What can I expect for my child with gastroschisis long-term?

Most babies with gastroschisis go on to live normal, healthy lives. The first year is usually the most difficult. It is full of medical appointments, with close attention to growth and nutrition. Your baby needs a regular primary care provider (pediatrician or nurse practitioner) for routine check-ups and will also see the surgical team at Seattle Children's after going home.

When should I call the doctor?

Be on the lookout for warning signs of possible problems. Please call General Surgery or your child's primary care provider if your baby has any of the signs listed below, or even if you just have the feeling that something is not right.

Go to the Emergency Department if you see green vomit. This is an emergency, as it may be an intestinal obstruction. If possible, bring the clothes that your baby vomited on to show the staff.

For the rest of the symptoms below, you may call your baby's primary care provider first:

- Fever of 101.5 F or greater
- Not able to feed – seen as belly pain or swelling, or nausea and vomiting
- Diarrhea – frequent loose or watery stools
- Constipation – no stool at all for 1 to 2 days
- Low urine output (fewer than 6 wet diapers per day)
- Increased reflux symptoms (throwing up)
- Pain not helped by medicine or comfort measures
- Redness, swelling or drainage from the surgical site

Who can answer my questions?

Please call us any time if you have questions or concerns.

During the day, call the General Surgery clinic at 206-987-2794.

At night or on the weekend, call and ask for the general surgeon attending on-call at 206-987-2000.

To learn more about the success of gastroschisis procedures at Children's, visit: seattlechildrens.org/conditions/gastroschisis .