

# 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 (defect) in the abdomen, next to the belly button. Even though this sounds and looks scary, most babies born with gastroschisis do very well. After surgery and medical care during infancy, most grow up to live normal lives. Your baby does not feel pain with this abnormal intestine position.

### How does this happen?

The condition begins while the fetus is still developing. During the 6th week of pregnancy, it is normal for the intestine of the developing fetus to grow outside of the abdomen. The intestine usually returns to the abdominal cavity during the 10th week of pregnancy, and the abdominal wall then closes. In babies with gastroschisis, however, the intestine remains outside of the abdomen after the 10th week of pregnancy and never goes back in. The intestine can become swollen and irritated from sitting in the amniotic fluid.

### Why does this happen?

No one knows what causes gastroschisis, but cases are rising worldwide. Research is being done to learn more about the causes.

## Preparing before baby's birth

You can begin preparing for the birth of your baby now. 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 surgery nurse to:

- Learn more about gastroschisis, its treatment and complications
- Tour the hospital units and family resource facilities

Also, you will want to create a birth plan with your obstetrical team, who will deliver your baby.

- 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 Children's Hospital for transfer to Children's so treatment can begin right after birth. An adult may go with your baby in the ambulance or may follow your baby to Children's. You may join the baby as soon as you're discharged, or you can come visit daily if you will need to stay in the hospital longer yourself.

## 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. Your baby will be given antibiotics and then 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 breathing machine (called a ventilator) until after surgery. In preparation for surgery, your baby will have lots of medical tubes placed. An intravenous (IV) line is placed in a vein to give fluids, nutrition and medicine. A small nasogastric (NG) tube is placed into the stomach through the nose. This is to empty the stomach contents and keep the stomach pressure low. Your baby may also have a tube placed into the bladder to keep it empty. Your baby's condition will be continuously monitored during this time.

## The surgery

Surgery is done to put the intestine back inside and close the opening on the belly. Most of the time, surgery can be done on the first day of life as a single surgery. Sometimes, more than one surgery is needed to push the intestine back inside more gradually.

## What is involved in the surgery?

There are two 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 abdominal cavity, and upon the surgeon's assessment of the baby's condition.

- A primary closure is when the surgeon replaces the intestine into the abdomen and sews the abdomen closed in one surgery.
- A staged closure (also called delayed, primary closure) is done when the baby's intestine does not fit back inside the abdomen right away. This is because of intestinal swelling and small abdominal size. A staged closure is done using a "silo." A silo is a bag that protects the exposed intestine and is suspended from above. (See picture on page 6.) It may be placed at the bedside in the NICU or may be surgically sewn to the skin in the operating room.

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

Surgery to remove the silo and close the abdominal opening is usually done within 7 to 14 days. During that time, some babies remain on the ventilator, and others can come off.

## **After surgery care**

### **What should I expect after surgery?**

After surgery, your baby will go back to the NICU to be closely monitored. Your baby will receive pain medicine during the surgical recovery period. The NG tube will be used to keep the stomach empty until the intestine recovers and begins working. At that point, feeding can begin. Once your baby is able to breathe well without the ventilator, they will be moved out of the NICU to the surgical unit to continue the recovery.

### **What about feeding my baby?**

The hospital staff will do everything they can to support your breast-feeding goals. If you are planning to give your baby 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.

In the first few days after surgery, it is not safe to breast- or bottle-feed your baby. The intestine has to recover from the surgery and the exposure to amniotic fluid. Your baby's food will be provided during this recovery 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 directly breast-feeding. 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, 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. Your baby will be ready to go home once they have recovered from surgery and can gain weight without needing the IV nutrition. Infants may be in the hospital from 2 weeks to 6 months, depending upon the recovery and complications. Most babies are hospitalized for at least 1 to 2 months total. The first 1 to 2 weeks of that time is usually spent in the NICU. Factors such as the type of surgical closure, intestinal function 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.

**Ileus.** The intestine may not squeeze (push food) 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.

**Malabsorption.** Most babies with gastroschisis have intestine that is shorter than normal. This can cause problems with absorption of food (malabsorption). The problem usually improves with time, but for some babies, it can take months. Feedings are introduced slowly and may be done as a combination of feedings by mouth, by NG tube and by IV. Feeding schedules and formulas can be changed to help with absorption.

**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 may require a second surgery, usually 4 to 6 weeks after the main surgery to close the hole in the abdominal wall.

**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, stool cannot pass and surgery may be needed to relieve the blockage.

**Acid reflux.** Gastroesophageal reflux (frequent vomiting) is common among babies in general, and even more so for babies with gastroschisis. This is likely because of the high pressure and position after the intestine is replaced inside. Keeping your baby in an upright position, medicines, and slower feeding rate can all help treat reflux.

**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.

**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 bacteria 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.

### **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, talk to and sing to your baby, and simply spend as much time as possible together. Even though you may not be able to hold your baby at first, 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.

### To Learn More

- General Surgery  
206-987-2039
- Your child's  
healthcare provider
- [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.
- For Deaf and hard of hearing callers  
206-987-2280 (TTY)

## 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 continue to see the surgical team at Children's for a while after going home. You may wonder about scars. See the pictures on page 6 of an infant after surgical repair and of age progression showing scar.

## 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 were soiled by vomit 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
- Feeding intolerance – 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 don't hesitate to call us at any time if you have questions or concerns. During the day, call the General Surgery nurses at 206-987-2039. At night or on the weekend, call the General Surgery resident on-call at 206-987-2000.

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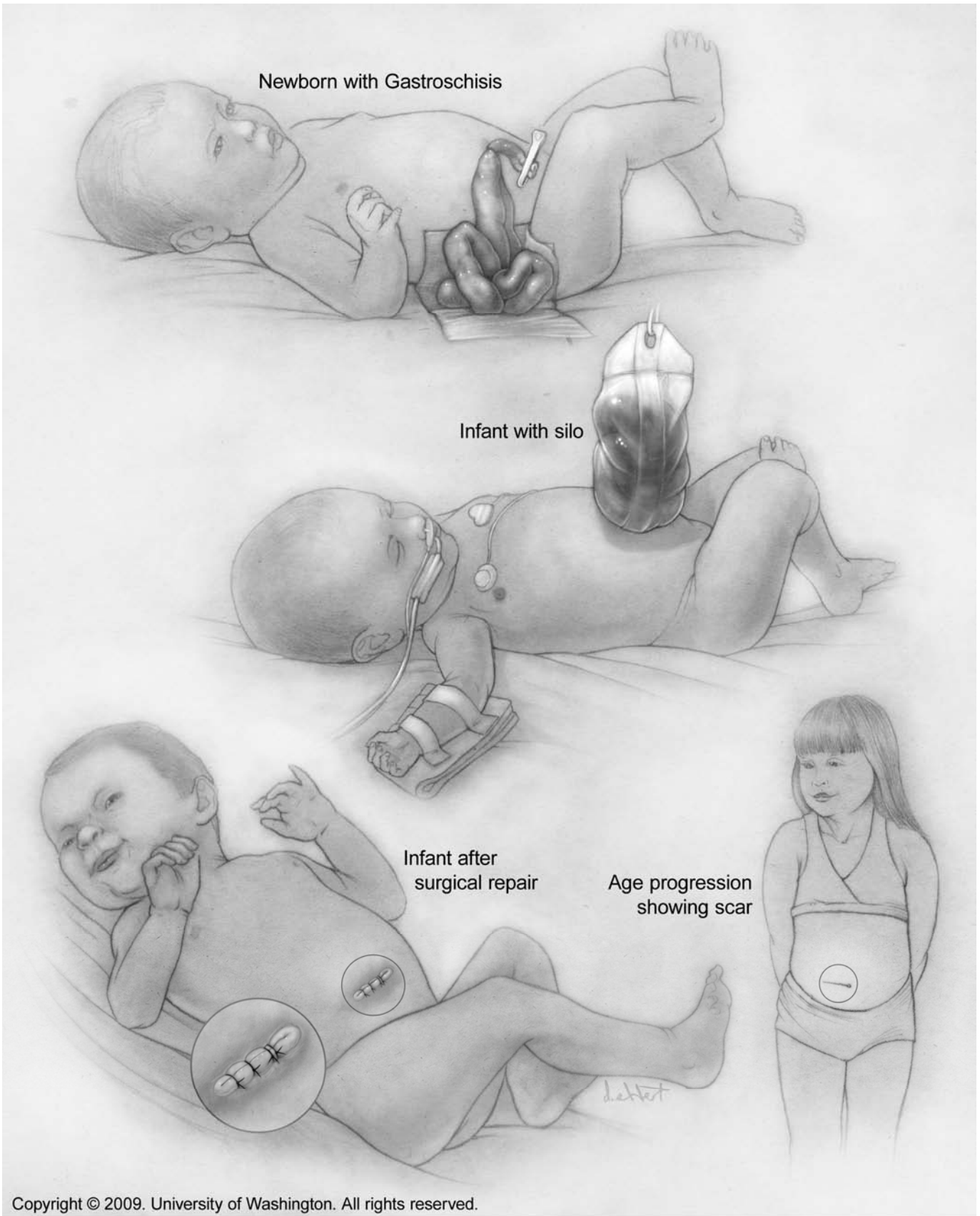
Seattle Children's offers interpreter services for Deaf, hard of hearing or non-English speaking patients, family members and legal representatives free of charge. Seattle Children's will make this information available in alternate formats upon request. Call the Family Resource Center at 206-987-2201.

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

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