

Intestinal or Midgut Volvulus

Patient Information Series – What you should know, what you should ask.

What is intestinal or midgut volvulus?

Intestinal or midgut volvulus happens when either small bowel loops or the first part of the large bowel (colon) twist around the superior mesenteric artery, the main artery of the bowel. This results in blockage of the bowel loops and inadequate blood flow to the bowel. Eventually this can result in the death of a part of the bowel. This finding is rare in prenatal life.

How is intestinal or midgut volvulus detected?

Intestinal or midgut volvulus is a diagnosis detected on ultrasound examination, most of the time after 27 weeks of pregnancy duration. An ultrasound can be performed during pregnancy as a routine check for the growth of the baby. However, sometimes there is another reason to perform an ultrasound, like a decrease in fetal movement, a tense or stretched feeling of the mother's abdomen indicating an increase in amniotic fluid or during a follow-up ultrasound in case of a suspected problem with the fetal bowel.

What causes intestinal or midgut volvulus?

There are several causes for intestinal or midgut volvulus.

Abnormal twisting of the bowel

In most cases, midgut volvulus occurs simply due to a problem with the normal twisting of the fetal bowel. In early pregnancy, the bowel starts out as a straight structure, and in the very early portion of pregnancy, it twists and rotates. Volvulus can occur if this process is does not proceed normally.

Structural problems with the bowel or structures in the abdomen:

Sometimes problems with the bowel itself, including an interruption in the bowel tube or a cyst in the abdomen may cause volvulus.

Cystic fibrosis

Cystic fibrosis is a genetic disease that can affect the lungs and bowels, causing thickened mucus to build up in those organ systems. It can be difficult for the baby to have the first bowel movement after he or she is born, also known as meconium ileus and it has been seen in babies with volvulus. In order for a baby to have cystic fibrosis, it must have two copies of the abnormal cystic fibrosis gene. One abnormal gene copy is inherited from each parent, who are carriers for the disease (meaning they are healthy but have one normal gene and one abnormal gene).

Chromosomal abnormality

An abnormal number of chromosomes will change the genetic makeup of the baby, and many organ systems, including the bowel, can be affected. An example is Trisomy 21, also known as Down Syndrome, where the baby has three (instead of two) copies of chromosome 21. There are often other ultrasound findings in addition to volvulus when there is a chromosomal condition.

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Should I have more tests done?

You will be offered additional testing to help determine the reason for the volvulus. The exact testing offered will be based on the presence or absence of other ultrasound findings, your medical and pregnancy history, and results from any earlier testing you may have had. You may also be offered consultation with a Genetic Counselor, a medical professional with special training in genetic conditions.

Tests that may be offered include:

- **A detailed ultrasound examination:** This is to carefully look at your baby for any other ultrasound findings or abnormalities. Ultrasound can identify many but not all abnormalities.
- **Amniocentesis:** This is a test that removes a small amount of fluid from around the baby by a thin needle. The fluid can be tested for chromosomal abnormalities as well as fetal infections.
- **Maternal blood test for cystic fibrosis:** Because cystic fibrosis is a genetic condition, you only need to be tested for it once. Your results will never change. It may have already been done as part of your normal pregnancy labs.

What are the things to watch for during the pregnancy?

Babies with intestinal or midgut volvulus are at risk of several problems during the pregnancy. Most specialists will recommend regular ultrasound examinations to monitor the baby. The ultrasound will help identify if the baby is having problems due to the poor blood flow to the bowel.

Some women will also accumulate extra amniotic fluid around the baby. This condition is called polyhydramnios. The extra fluid can stretch the uterus too much and cause early labour well before the due date. You should alert your doctor or midwife if your abdomen feels tense or stretched, if you experience difficulty lying down to sleep or have breathing difficulties as this could be a sign of polyhydramnios. You should also report any decrease in fetal movement as this may be associated with a change in the baby's condition.

Does this baby need to be delivered early?

In case of an intestinal or midgut volvulus the gynaecologist and pediatric surgeon can decide it's better for the baby to be born early. This team decision is made after discussing the balance between the risk of additional bowel injury due to the volvulus versus the risks of a premature baby.

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What does it mean for my baby after it is born?

When the baby is stable, a surgeon will perform one or more surgeries to attempt to fix the problem in the bowel. Sometimes a piece of the bowel must be removed. Babies with volvulus often requires complex care in a specialized hospital for weeks after birth.

Babies who also have cystic fibrosis often have other problems after being born and require life-long specialized care.

Babies who have had intestinal or midgut volvulus may have problems with their bowel, due to “short bowel” syndrome. Short bowel syndrome means that due to the surgery, children have less bowel length than normal and have difficulty absorbing nutrients and calories from the food that they eat.

Will it happen again?

If no genetic reason is found to explain the intestinal or midgut volvulus, the risk of this happening again is small. If there is a genetic reason, the specific genetic problem will determine the risk, and a consultation with a specialist may be helpful.

What other questions should I ask?

- Are there any other abnormalities on the ultrasound?
- What kind of genetic testing will I need to have?
- How often will I have ultrasound examinations done?
- Where should I deliver?
- Where will the baby receive the best care after it is born?
- Can I meet the team of doctors that will be assisting my baby when it is born in advance?

Last updated October 2020