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

#### What is Duodenal Obstruction?

Normally, food which is swallowed passes through the esophagus, then the stomach and into the small intestine (bowel), then the large intestine and the contents which have not been digested pass out through the anus. The duodenum is the first part of the small intestine. In some cases, there is a blockage or obstruction in the duodenum.

The blockage can happen in two ways:

Sometimes, the tube that is meant to become the duodenum stays solid and does not open up as well as it should. This causes a blockage. This problem happens around 9 to 10 weeks of pregnancy. Blockages in the duodenum can be complete, called a duodenal atresia, or incomplete (partial). In the case of partial blockages, small amounts of fluid may still travel from the stomach through the duodenum to the small intestines.

Other times, structures around the duodenum push on it and cause an obstruction. This sometimes happens when another organ called the pancreas does not develop as a single structure behind the duodenum but wraps around the duodenum. This kind of pancreas is called an annular pancreas.

Duodenal obstruction is rare and happens in about 1 in 5000 babies.

#### How does a duodenal obstruction happen?

A duodenal obstruction may be isolated, meaning that is the only problem that the fetus has. It can also be associated with other problems with the heart, the kidneys, the spine, the ribs or the bowel.

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 duodenal obstruction when there is a chromosomal condition. Three out of 10 babies with duodenal obstruction have Down Syndrome or Trisomy 21.

Occasionally, there will be other changes in the genetic make-up that may or may not be detectable but will be the cause of the duodenal obstruction.

In more than half of babies with a duodenal obstruction, no cause can be found.

#### Should I have more tests done?

You will likely be offered tests to help determine the reason for the duodenal atresia. The exact tests offered will depend on whether your baby has other anomalies, your medical and pregnancy history, and results from any earlier testing you may have had. You may also be offered a consultation with a Genetic Counselor, a medical professional with special training in genetic conditions.



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Tests that may be offered include:

- **Detailed ultrasound examination**: This is to carefully look at your baby for any other structural anomalies. Ultrasound can identify many but not all anomalies.
- Fetal echocardiogram: This is an ultrasound which looks at the baby's heart in detail.
- **Amniocentesis**: This is a test that removes a small amount of water from around the baby with a thin needle. This can be used to perform genetic diagnostic tests.
- **Cell-free fetal DNA:** This is a blood test that looks at your baby's cells that are in your blood. It is a very good genetic screening test for certain conditions, such as Down syndrome, but it is not as accurate as an amniocentesis.

## What are the things to watch for during the pregnancy?

Babies with duodenal obstruction are at risk of some problems during the pregnancy. Most specialists will recommend regular ultrasound examinations, commonly every 4 weeks.

If there is a blockage in the duodenum, amniotic fluid (water around the baby) that is swallowed by your baby, cannot pass through the duodenum as it should. This can cause an excess of amniotic fluid in the sac around the baby. Ultrasound examinations will help identify if too much amniotic fluid is accumulating around the baby. The presence of too much amniotic fluid is called polyhydramnios. You should alert your doctor or midwife if your belly feels tense or stretched, if you experience difficulty lying down to sleep or have problems breathing as this could be a sign of polyhydramnios. When this condition is severe, your doctor may recommend withdrawing a large quantity of the amniotic fluid to increase your comfort and prevent early labour. This is a procedure called amnioreduction and is done with a thin needle inserted in your belly and the sac around the baby.

The extra water around the baby can also stretch the uterus too much and cause early labour well before the due date. Knowing this in advance, your doctor or midwife can help with decreasing the risk of an early birth. Should you experience frequent contractions, low back pain that feels like your periods, leakage of fluid or a "balling up" of your abdomen, you should contact your doctor or midwife immediately.

Babies with duodenal obstruction combined with other anomalies have a high risk of having sudden death during pregnancy. Some studies state that this will happen in up to 1 in 6 babies. Monitoring the pregnancy in a specialised center is recommended but it may not be preventable.

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

The biggest problem for babies with duodenal obstruction is that they cannot digest swallowed food or milk. If these babies are fed, they will vomit to release the pressure in the stomach and duodenum.

Babies who also have anomalies in other organs or a problem with their chromosomes may have even more problems after being born. The outcome depends on the type of anomalies that the baby has.

After birth, the baby will be admitted to an intensive care unit for evaluation and treatment. Additional imaging studies may be done to confirm the obstruction and to make sure the baby has no additional problems.



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When the baby is stable, a surgeon will correct the blockage and create a normal passage from the stomach through the duodenum to the small intestines. The baby will stay in the intensive care unit in a specialized hospital for a few weeks after birth to recover from the surgery.

Babies with Down Syndrome and duodenal obstruction usually need to stay longer in hospital compared to babies without a chromosomal anomaly. Down Syndrome babies often also have other anomalies, particularly heart abnormalities, which may require a longer stay.

Typically, when they grow up, babies who have had surgery for duodenal obstruction without other problems have no long term complications.

#### Will it happen again?

When no other genetic reason is found to explain the duodenal obstruction, the risk of this happening again is less than 1 in 100. If there is a genetic reason, then the risk depends on the genetic problem. Consultation with a specialist may be helpful.

## What other questions should I ask?

- Does this look like a typical duodenal obstruction?
- Are other anomalies identified?
- Should an amniocentesis be performed to look for chromosome anomalies?
- Is there a normal amount of amniotic fluid or is there too much fluid?
- 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 in advance the team of doctors that will be looking after my baby when it is born?

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