Follow-up

After discharge from hospital, your baby will need follow up for some time to ensure that he/she is growing well. Some babies have ongoing problems with reflux or difficulties with digestion and so follow up is important.

Future Pregnancies

Gastroschisis is not thought to be inherited so it is extremely unlikely that this would occur in a future pregnancy. We recommend that you take vitamins such as folic acid before pregnancy and avoid smoking and other drugs so that a future baby gets the best start to life.

Support

Having a baby with gastroschisis can be a difficult thing for parents to cope with. However, you should never feel that you are alone. Great support and advice is available for parents who have a pregnancy diagnosed with gastroschisis.

You will be able to access pregnancy and genetic counselling through your Fetal Medicine Unit for you and your whanau.

www.parent2parent.org.nz/

Parent to Parent New Zealand is an information and support network for parents of children with special needs ranging from the very common to the very rare conditions. The service is free to families.

References

Brighton and Sussex University Hospitals NHS Trust Gastroschisis leaflet

Leeds Teaching Hospitals NHS Trust Gastroschisis leaflet

Chelsea & Westminster NICU Gastroschisis leaflet

Wessex Fetal Medicine Network Parent information leaflet GASTROSCHISIS

Images

Gastroschisis:
http://lucinafoundation.org/birthdefects-gastroschisis.html

Silo:
http://www.pedsurg.ucsf.edu/media/2965123/gastroschisis-silo.gif

Reviewed: October 2015

For more information please contact your local NZMFMN Unit

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Gastroschisis

New Zealand Maternal Fetal Medicine Network

What is gastroschisis?

Gastroschisis is a birth defect known as an abdominal wall defect where a baby's intestine (bowel) sticks out of the body through a hole that is to the side of the umbilical cord (usually the right). Sometimes other organs can also come out through the defect.

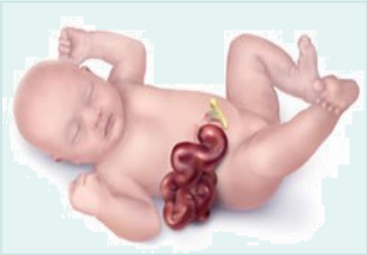
The portion of intestine that comes out through this hole continues to develop outside the baby's abdomen and floats in the amniotic fluid. It is thought that contact with the fluid can cause thickening of the bowel wall. This often means that the baby cannot feed properly after birth.

Commonly, there are small segments of the bowel that are blocked or not formed (called atretic segments) and these need to be repaired by the Paediatric Surgeon before the baby can feed.

Gastroschisis is usually isolated and not linked to any genetic syndrome.

Gastroschisis occurs in approximately 1 in 2,000-2,500 pregnancies. There has been an increase in this condition recently; however the reason for this is unknown. It is most common in women under 24 years of age.

An omphalocele is a different type of abdominal wall defect in which the baby's intestine, liver and occasionally other organs stick out of the umbilicus (belly button) in a sac. This is completely unrelated to gastroschisis.



How is gastroschisis diagnosed?

Gastroschisis is usually noticed at the anatomy scan carried out at 20 weeks of pregnancy, but may be seen sooner if an earlier scan is done. It is not usually picked up before 12 weeks of pregnancy because a baby's abdominal wall does not normally close before this time.

When gastroschisis is diagnosed you will be referred to your local Fetal Medicine Unit for initial assessment and planning of your baby's on-going care.

An amniocentesis (a test where a needle is inserted into your uterus and a sample of water from around baby is taken and tested for chromosomal abnormalities) is not usually needed unless there are other abnormalities present. A detailed anatomy scan will be needed.

Other concerns for babies with gastroschisis

There are several known complications in pregnancies diagnosed with gastroschisis which include slow fetal growth, premature birth and stillbirth. Regular monitoring of your pregnancy will help recognise and manage these complications. This will include:

- Continued regular visits with your LMC (Lead Maternity Carer)
- 4-weekly ultrasound scans from diagnosis until 32 weeks pregnant
- Weekly surveillance from 32 weeks until 37 weeks when an induction of labour will be scheduled.
- Counselling with Neonatology and Paediatric Surgical Services ante-natally to discuss treatment and care after birth
- Regular ultrasound scans may be performed where you live with the results sent to the Fetal Medicine Unit for review as needed.

Labour and delivery

The Fetal Medicine Unit recommends that babies with gastroschisis are delivered at 37 weeks due to the risk of stillbirth if the pregnancy continues beyond this time. A caesarean section is not indicated unless other issues arise. You will have continuous monitoring in labour and the paediatricians will be called to the room as your baby is born.

You will need to have your baby in a tertiary hospital that has a neonatal intensive care unit and paediatric surgical services.

Baby's stay in hospital

The Paediatricians will wrap your baby's tummy in glad wrap to protect the exposed bowel. Your baby will then be transferred to the Neonatal Intensive Care Unit (NICU) where he or she will be monitored.

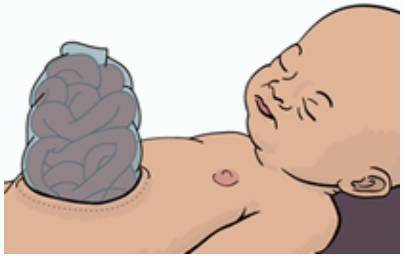
Occasionally it will be possible to immediately return the exposed bowel into your baby's abdominal cavity and this could happen in NICU. More commonly, formal surgery is done in the operating theatre within 24 hours to return the bowel and close the abdomen (tummy wall).

Another frequently used technique is to temporarily cover the bowel with a silo bag (see picture) to allow the bowel to slowly descend back into the tummy with the aid of gravity prior to closure of the opening.

Seventy-five percent of babies will have uncomplicated surgery to place the bowel back into the abdomen but some babies may need more than one surgical procedure. Regardless of the strategy used your baby may need breathing support and IV feeding for some time after surgery. Once oral feeds start, we recommend breast milk which will be administered via a nasogastric tube. The Paediatricians will let you know when you can commence breastfeeding. The midwife looking after you will help you to express and store breast milk to ensure you have good amounts for when your baby is ready.

Babies with gastroschisis generally stay in the hospital from two weeks to three to four months. They are discharged from the hospital when they are taking all their feeds by mouth, gaining weight and passing bowel motions.

Gastroschisis Silo



Rarely, the postoperative period can be very complicated due to a number of reasons such as the bowel being slow to work or being quite short. When this happens baby may be in hospital for many months.

At home

After your baby has been discharged from hospital he or she is at risk of a bowel obstruction. This is due to scar tissue or a kink in a loop of bowel caused by the operation. Bowel obstruction symptoms include:

- Green vomiting
- Bloated stomach
- No interest in feeding

If any of these symptoms occur, contact your GP or local hospital immediately.