

Going home and longer term follow-up

Babies with gastroschisis generally stay in the hospital from two weeks to three or four months. They are discharged from hospital when they are taking all their feeds by mouth, gaining weight and passing bowel motions. After discharge from hospital, your baby will need follow up for some time to ensure that they are growing well. Some babies may have ongoing problems with reflux or difficulties with digestion.

Future pregnancies

It is extremely unlikely that this would occur in a future pregnancy.

Your options

We acknowledge that even though the majority of cases have a good outcome, gastroschisis is still a significant finding with impacts for your baby and your family as a whole. This may leave you and your whānau in the very difficult situation of deciding whether or not to continue on with the pregnancy. We aim to provide you with as much information and support in order to make the best decision you can at this difficult time. If you decide you do not wish to continue with the pregnancy, your medical team will guide you through the next steps.

Supports available

Talk with your MFM service, midwife or health provider about supports available to you. These could include:

- Access to counselling, cultural and spiritual supports, through your local services or the MFM service for you and your whānau.
- Financial help with travel and accommodation when attending MFM specialist appointments away from where you live may be available.
- Parent to Parent New Zealand: www.parent2parent.org.nz

***Support groups may change over time -
check with the MFM team***

References and acknowledgements

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/media2965116gastroschisis-silo.gif>

**For more information please contact
your nearest NZ MFM unit**

Auckland

Auckland Hospital
2 Park Road
Grafton, Auckland 1023
Phone: 09 367 0000 extn 24951

Wellington

Wellington Hospital
Riddiford Street
Newtown, Wellington 6021
Phone: 04 806 0774

Christchurch

Christchurch Women's Hospital
2 Riccarton Ave, Christchurch 4711
Phone: 03 364 4557

Health New Zealand Te Whatu Ora

About Wāhi Rua:

<https://www.healthpoint.co.nz/public/wahi-rua-new-zealand-maternal-fetal-medicine/>

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Wāhi Rua
New Zealand
Maternal
Fetal Medicine
Network

Gastroschisis

What is gastroschisis?

Gastroschisis is a structural difference, where there is a gap in the pēpi/baby's abdominal wall (stomach area). This usually occurs to the right side of the umbilical cord. The exact cause is unknown, but may be due to an early abnormality in the blood supply to that area of abdominal wall. Because of the gap, some of the baby's abdominal contents are able to protrude out (stick out) through the abdominal wall. Usually this affects the small bowel but sometimes can affect other abdominal organs as well. The portion of bowel that comes out through the gap floats in the amniotic fluid surrounding the baby in the womb. This will need to be replaced in (put back into) the abdomen after birth and the gap in the abdominal wall will be surgically repaired.



Gastroschisis occurs in approximately 1 in 2,000-2,500 pregnancies. It is most common in women under 24 years of age. Gastroschisis is usually isolated but sometimes there can be other structural differences. It is rarely associated with a chromosomal or genetic difference.

How is gastroschisis diagnosed?

Gastroschisis is usually detected on your routine scans, either at 12-14 weeks or at the 18-20 week anatomy scan. Prior to around 12 weeks it is a part of normal development for the bowel to protrude from the abdomen for a short while, and therefore the diagnosis is not made earlier than this. When gastroschisis is suspected, you will be referred to the MFM service for assessment and planning of your baby's ongoing care.

At your fetal medicine appointment you will have a detailed ultrasound scan to confirm the diagnosis and to rule out other conditions such as an omphalocele. An omphalocele is a different type of abdominal wall defect. It is important to differentiate (be able to tell apart) between the two because they carry quite different implications (effects) for your baby. The ultrasound will also look for any signs of complications from the gastroschisis, or any other associated structural differences.

Your fetal medicine doctor will discuss the scan findings and how this will affect your baby, and together you will come up with a plan for management of your pregnancy. You may be offered additional testing for genetic/chromosomal differences, particularly if there are other associated findings.

What does this mean for my baby?

In most cases, the outcome from gastroschisis is good, with survival rates of around 90%. Most of these babies will grow and develop normally after the gastroschisis has been treated. However, it is important to be aware of possible complications which can occur both during pregnancy and after birth. Fetal growth restriction is common and affects up to one third of babies. There is a risk of stillbirth of around 6-10%. Your unborn baby will need to be monitored closely and an earlier birth could be planned. Approximately one third of babies will be born preterm, often due to concerns about their growth or wellbeing.

In most cases, the affected bowel can be gently replaced in the abdominal cavity after birth and the gap closed, with no further surgical treatment required. However, about one third of babies will require additional surgery such as removal of part of the bowel due to bowel complications such as blockages or narrowing, or other damage to the bowel from being exposed to the amniotic fluid. These bowel complications may not be able to be seen on scans before baby is born. In <5% of cases a significant length of bowel may need to be removed and this can lead to issues with food and fluid absorption and long term complications related to nutrition (known as short gut syndrome).

You will be offered the opportunity to meet with a neonatologist and/or paediatric surgeon for more detailed discussion of management after birth.

Treatment and monitoring of your pregnancy

At present there are no proven treatment options to resolve this issue during the pregnancy. Management focuses on monitoring your baby during pregnancy and then treating the gastroschisis after birth. Regular monitoring of your pregnancy is important to help recognise and manage any complications. This will involve regular ultrasound scans, and additional monitoring in the later part of your pregnancy. This may be done at your fetal medicine unit or more locally depending on your overall circumstances.

Labour and delivery

Your baby will need to be born in a tertiary hospital that has a neonatal intensive care unit (NICU) and paediatric surgical services. Birth is recommended at 37-38 weeks due to a higher risk of stillbirth if the pregnancy continues beyond this time. Continuous monitoring of your baby's heart rate is recommended in labour, and caesarean section will be recommended if there are concerns with this.

What will happen to my baby after birth?

The neonatal paediatricians will be present at your birth and will wrap your baby's tummy in a type of plastic wrap to protect the exposed bowel. Your baby will then be transferred to the NICU where they will be monitored. A nasogastric tube will be inserted to prevent extra distension of the bowel. Once baby is stable, the neonatal team will help you with baby cares and cuddles. Your baby will not be able to be fed by mouth straight away – nutrition will be provided via a drip, and you will be supported to express and store breast milk if you wish to breastfeed.

Surgery

Baby's surgery to return the bowel and close the abdomen (tummy wall) is usually done within 24 hours of birth. 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.

Occasionally, it will be possible to immediately return the exposed bowel into your baby's abdominal cavity. This could happen in NICU or in theatre.

Sometimes, it is not possible to return all of the bowel to the abdomen straight away, as this can cause an increase in pressure inside the tummy, and affect baby's breathing. Because of this, a frequently used technique is to temporarily cover the bowel with a silo bag (see picture below) to allow the bowel to slowly descend back into the tummy with the aid of gravity prior to closure of the overlying skin.



Sometimes there are small segments of the bowel that are blocked or not formed (called atretic segments) which need to be repaired by the paediatric surgeon before your baby can feed. Your team will talk with you in detail if they think your baby needs a procedure to resolve a blockage or to remove damaged segments of bowel.

Feeding your baby

Your baby may need breathing support and IV feeding for some time after surgery. Once oral feeds start, this will be given via a nasogastric tube. Overtime, baby will transition to breast or bottle feeding. If you are unable to breast feed or supply breast milk, the neonatal team will discuss the option of donor breast milk or formula feeding.