



# Gastroschisis

## Whānau/Family Information – Neonatal Services

Your pēpi/baby has been diagnosed with gastroschisis. This leaflet has been designed to accompany the discussions you will have about your care and the care of your pēpi both during pregnancy and after your pēpi birth.

### What is gastroschisis?

Gastroschisis is a congenital defect which occurs during early pregnancy when a pēpi abdominal (tummy) wall does not fully close. This leaves a hole in their abdominal wall (usually to the right side of their tummy button) which allows the bowel (intestine) and sometimes the stomach to come through to hole to the outside of their abdomen.



The part of the intestine that comes out through this opening is not in a protective membranous sac and therefore it is exposed to the amniotic fluid (the liquid that surrounds the pēpi in the womb) so there is a chance the intestine can become irritated, swollen or shortened. A thorough assessment of your pēpi bowel will be carried out after birth.

### Why does it occur?

Gastroschisis is a rare condition with only 4 to 5 pēpi out of every 10,000 births born with it. It is usually isolated and not linked to any genetic syndrome. While the exact cause of gastroschisis is not known, it is more common in young women (ie., under 20 years of age) which suggests that environmental factors may be relevant. Most pēpi have a very good outcome.

### What care will my pēpi need?

Several people will become involved in the care of you and your pēpi before, during and after delivery. These include the Foetal Anomaly Advice Committee (deals with high-risk pregnancies). Neonatologists (specialised pēpi doctor) Paediatric Surgeons (specialised in children's surgery) Obstetricians (care for women and pēpi during pregnancy, labour and delivery).

A meeting will be arranged for you to meet with the Paediatric Surgeon and Neonatologist to discuss the condition, possible complications and treatment. It is necessary for your pēpi to be born in a neonatal unit experienced in caring for pēpi with gastroschisis and has paediatric surgical services available.

Your pēpi will need to be delivered at Christchurch women's Hospital. You will have the opportunity to look around the Neonatal Intensive Care Unit (NICU) with a member of the nursing staff before your pēpi is born. You can learn more about the Christchurch Women's Hospital Neonatal Unit by visiting their website: [www.cdhb.health.nz/health-services/neonatal-service](http://www.cdhb.health.nz/health-services/neonatal-service)

### How will my pēpi be born?

Pēpi with gastroschisis are more likely to be born before 37 weeks of pregnancy. A caesarean section is not indicated unless other issues arise.

### What will happen after birth?

At delivery the bowel will be wrapped in transparent plastic to help reduce fluid and heat loss. This will also allow staff to monitor the colour of the bowel and check its loops are not getting kinked. A tube will be passed through your pēpi nose or mouth, down into their stomach to keep it empty of air and fluid.

Your pēpi will then be transferred to the NICU where he/she will be monitored. Intravenous lines (drip) will be placed in the pēpi hands or feet, so fluids can be given directly into their veins to make sure they are hydrated.

## Surgery

Your pēpi will need to have an operation to return the bowel into the abdomen and repair the hole in their abdominal wall usually on the day they are born. The surgeon and anaesthetist will explain about the operation and anaesthetic and discuss any worries you have. They will ask you to sign consent forms giving permission for the operation and general anaesthetic.

The operation is done under a general anaesthetic. This means your pēpi will be asleep throughout the operation. The surgeons can usually do a single operation to place the intestine into the abdomen, close the muscles and skin and make a tummy button.

However, if the gastroschisis is too large to be repaired in this way, then a see-through sack (silo bag) will be placed over your pēpi exposed intestine allowing it to slowly descend back into the tummy (which can take about a week) before the abdominal opening and muscles can be closed.

In addition to the above operations your pēpi may need to have a part of their intestine removed if it has been damaged. A temporary stoma may be formed. This is where the two cut ends of the intestine are brought out through a hole in their abdomen. Stools (poo) can pass into a small bag which is placed on the outside of your pēpi abdomen. Another operation in the future closes the stoma and to join the two ends of the intestine.



## After surgery

After the operation, your pēpi will be returned to the NICU where you will be able to see your pēpi. Your pēpi will be monitored closely and will initially be on a ventilator (breathing machine) until they are ready to breathe on their own. Pain relief drugs will be given through an intravenous infusion. A small catheter (tube) will be inserted into your pēpi bladder to drain urine for a while.

Your pēpi will continue to be fed intravenously. This is called total parental nutrition (TPN) and will be continued until your pēpi is ready to have small amounts of either breastmilk or formula through the tube into the stomach. As the milk feeds increase the TPN will decrease until your pēpi is fully milk fed. Once your pēpi is ready to feed by mouth you will receive lots of help and support.

## How long will my pēpi stay in hospital?

Sometimes after surgery the bowel may be very slow to work and your pēpi could be in hospital for many months. Some pēpi have problems with vomiting, gastro-oesophageal reflux (stomach contents are released back up towards the mouth causing pain and irritation), diarrhoea or constipation. Your pēpi will be allowed home once fully orally fed, gaining weight and passing stools (poo).

It is perfectly normal for you to feel anxious and worry. All the monitoring, intravenous infusions, tubes, the length of time in hospital and the number of people involved in your pēpi care can be very daunting. You will receive lots of guidance and support but please do not hesitate to ask your nurses, doctors and NICU social worker if you have any questions or concerns and what you can do to care for and bond with your pēpi.

## Follow up

**If at any time following discharge from NICU your pēpi has green vomiting, a bloated tummy, no interest in feeding it is important you contact your GP or hospital immediately as there may be adhesions, a kink or obstruction in the bowel.**

To monitor your pēpi progress regular outpatient check-ups will be arranged.

At these check-ups please ask questions and express any concerns you may have.

