

Your options

We acknowledge that an omphalocele, particularly if very large or with associated findings, is a very significant condition with considerable 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 not 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 that may be available to you such as:

- Access to counselling, cultural and spiritual supports for you and your whānau;
- Financial help with travel and accommodation when attending MFM specialist appointments away from where you live.
- Parent to parent New Zealand:
<https://parent2parent.org.nz/>
- Mothers of Omphaloceles (MOO):
<https://www.facebook.com/groups/omphalocele>

References and further information

<https://www.isuog.org/clinical-resources/patient-information-series/patient-information-pregnancy-conditions/abdomen/omphalocele.html>

<https://www.gov.uk/government/publications/exomphalos-description-in-brief>

<https://www.chop.edu/conditions-diseases/omphalocele>

Image

<http://www.nlm.nih.gov/medlineplus/ency/imagepages/9030.htm>

**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

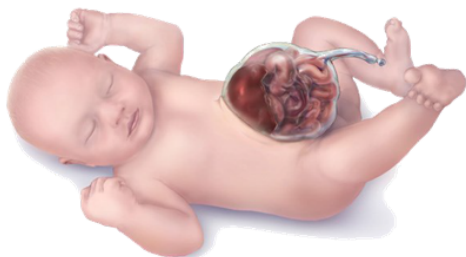
Omphalocele

Omphalocele

What is an omphalocele?

An omphalocele is a structural difference where your baby/pēpi has a hernia or weakness in the abdominal wall at the umbilicus (tummy button). It is sometimes called an exomphalos.

With an omphalocele, your baby's tummy wall has not closed around the base of the umbilical cord meaning that some organs protrude outside the body. It is usually just the intestine (gut or bowel), but sometimes the liver and other organs as well.



The organs outside the abdomen are contained within a sac or bag which is covered in a protective membrane made up of peritoneum (tummy wall lining), so it is like a balloon at the base of the umbilical cord.

The condition occurs in about 1 in every 3000 births and up to 80% of babies have additional findings or other concerns.

What causes an omphalocele?

We do not know why the abdominal wall muscles sometimes do not develop properly. In some cases it may be due to associated genetic difference or an underlying syndrome. We do know it is not caused by anything you did or did not do.

How is an omphalocele diagnosed?

An omphalocele may be detected at either your 12-14 week (nuchal/early anatomy) scan, or your 20 week anatomy scan. Before around 12 weeks it is a part of normal development for bowel to be outside of the abdomen for a short while, and therefore the diagnosis is not made earlier than this. If an omphalocele is suspected you will be referred to your local MFM service for further review.

How will this affect my baby?

We know that many babies with an omphalocele have other problems as well. You will have a detailed scan to assess the abdominal wall, as well as review baby's anatomy in full to look for other differences.

The most common associated structural problems are heart defects; however, other problems can include defects of the pelvis and thorax (chest cavity). Some babies are smaller or have increased amniotic fluid and will need monitoring for this.

Chromosomal or genetic differences are quite commonly found in babies with omphalocele (up to 40%). You will be offered diagnostic testing for this, either by chorionic villus sampling (CVS) if you are under 14 weeks, or amniocentesis if later.

We will fully discuss the implications of an omphalocele for you and your baby and make a plan for care that suits you and your family.

Labour and delivery

All babies with an omphalocele need to be born in a tertiary hospital with a neonatal intensive care unit (NICU), a paediatric surgical team and doctors who are used to caring for babies with abdominal wall defects.

A vaginal delivery is fine in most cases, however if the defect is large then a caesarean section may be offered to you. We will recommend baby is delivered by 38 weeks.

We will offer you the option of meeting with the paediatric surgeon and/or neonatologists before birth to discuss your baby's care once they are born. They will talk to you about the type of treatment your baby is likely to need, how long your baby may need to stay in hospital and long-term outcomes.

In some rare cases where the omphalocele is very large, your baby may be in hospital for a very long time (months) and need several operations to close the defect.

Long term outlook

If your baby has a small omphalocele with no other abnormalities or chromosomal/genetic differences, there is a good chance of having no long-term complications. If your baby has a very large omphalocele or other disorders, this will impact on the outcome.

Future pregnancies

The risk of an omphalocele occurring again is usually very low, but if the cause is related to an underlying genetic difference your team will be able to determine what the risk of recurrence would be and help you plan 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 in life.