

Support

Having a baby with an omphalocele can be a difficult situation for you and your family to cope with. You should never feel that you are alone. You will be able to access counselling through your Fetal Medicine Unit for you and your whanau.

Other places to find support

Mothers of Omphaloceles (MOO):

<https://www.facebook.com/groups/omphalocele>

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 most rare conditions. The service is free to families.

www.parent2parent.org.nz

References

Wessex Fetal Medicine Unit

<http://www.uhs.nhs.uk/Media/SUHTInternet/Services/FetalMedicineUnit/Exomphalos.pdf>

NHS screening programmes, Abdominal wall defects: exomphalos (omphalocele): Information for parents.

www.fetalanomaly.screening.nhs.uk/leafletsforparents#fileid11080

Image:

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

For more information please contact your local
NZMFMN Unit



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Omphalocele



What is an omphalocele

An omphalocele is a defect where your baby 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 hasn't closed around the base of the umbilical cord meaning that some organs protrude outside the body. It is usually just the intestine (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 with an omphalocele have other problems such as heart defects and chromosomal (genetic) disorders which can be serious.



What causes an omphalocele?

We don't know why the abdominal wall muscles sometimes do not develop properly. It is not caused by anything you did or didn't do.

How is an omphalocele diagnosed?

An omphalocele is usually noticed at your anatomy scan (20 weeks), but may be seen sooner if an earlier scan is done. It is not always seen at your 12 week scan as your baby's abdominal wall has not fully closed by this time. Your LMC will refer you to your local Fetal Medicine Unit for further discussion and scanning.

Other concerns for babies with an omphalocele

We know that many babies with an omphalocele have other problems as well. Chromosomal abnormalities are more common in babies with this condition.

The most common associated structural problems are heart defects; however, other problems can include defects of the pelvis and thorax (chest cavity). The Fetal Medicine Unit will perform a thorough ultrasound scan to check for any other abnormalities.

Invasive testing (amniocentesis) will also be discussed at your first visit. You may choose to go ahead with this or not.

We will fully discuss the implications of an omphalocele for you and your baby (regardless of whether there are other abnormalities or not) and make a plan for care that suits you and your whanau.

In hospital

All babies with an omphalocele need to be born in a tertiary hospital with a Neonatal Intensive Care Unit (NICU), a Paediatric Surgical Unit and doctors who are used to caring for babies with abdominal wall defects. If the defect is large then a caesarean section may be offered to you.

We will offer you the option of meeting with the paediatric surgeon and/or neonatologists antenatally to discuss your baby's care once he/she is 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. Rarely, if the heart is also outside the body, there may be nothing the surgeons can do and a palliative care approach is taken. This can be seen antenatally and would be discussed with you in your Fetal Medicine appointment.

At home

The outlook for your baby depends on whether your baby has an omphalocele or also has other complications. If your baby only has an omphalocele there is a good chance of having a normal life. If your baby has other disorders, the chances of survival depend on how serious these other disorders are.

Future pregnancies

An omphalocele 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 in life.