

Supports available

Talk with your MFM service, midwife or health provider about supports 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

www.parent2parent.org.nz

An information and support network for parents of children with special needs ranging from the very common to the rarest conditions.

Whetūrangitia

<https://wheturangitia.services.govt.nz/>

Information for family and whānau experiencing the death of a baby or child.

Baby loss NZ

<http://www.babyloss.co.nz/practical-info/>

SANDS

sands.org.nz

A network of parent-run, non-profit groups supporting families who have experienced the loss of a baby.

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

For more information please contact your NZMFM 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

Te Whatu Ora

Health New Zealand

About Wāhi Rua:

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

Updated October 2023



Wāhi Rua
New Zealand
Maternal
Fetal Medicine
Network

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Anencephaly

The purpose of this consumer pamphlet is to provide information from the Maternal Fetal Medicine (MFM) service about Anencephaly, including:

- Causes and diagnosis
- The outlook for your pēpē
- Seeing the Maternal Fetal Medicine Service
- How likely is this to occur again? Future pregnancies
- Supports available

What is Anencephaly?

Anencephaly is a major structural difference where a baby is born without parts of their brain and skull.

Around 5 to 6 pēpē in every 10,000 pregnancies are affected by anencephaly.

The condition anencephaly relates to the neural tube – a thin channel that folds and then closes as part of the developing fetus' brain and spine (around 3-4 weeks in pregnancy - often before you know you are pregnant). The closing of the tube causes the brain, spinal cord and its covering to form.

If the top of the tube doesn't close, this results in major portions of the brain, skull and scalp failing to develop (anencephaly).

A pēpē born with this condition will have no forebrain (front part of the brain) and no cerebrum (coordinating and thinking part of the brain). Often the rest of the brain is not covered by bone or skin.

What causes Anencephaly?

The exact cause of anencephaly is not known. Genetic and environmental factors are thought to play a part. Chromosomal differences account for less than ten percent of all babies with anencephaly. Studies have shown that taking folic acid supplements for at least 1 month before getting pregnant and 3 months into pregnancy can reduce the risk of having a pēpē with anencephaly.

How is Anencephaly diagnosed?

Anencephaly is diagnosed by ultrasound scan. It is most often detected at the 20 week anatomy scan but can sometimes be detected in earlier scans.

What is the outlook for my baby?

There is no cure or treatment for anencephaly. It is a structural difference that is incompatible with life - this means that, sadly, your baby cannot survive. Most babies born with anencephaly pass away within a few hours or days after birth. Some babies with anencephaly will pass away in the womb before they are born (stillborn).

Further information:

<https://www.healthnavigator.org.nz/health-a-z/a/anencephaly/>

<https://my.clevelandclinic.org/health/diseases/15032-anencephaly>

Seeing the Maternal Fetal Medicine (MFM) service

The MFM team will do further scans and check to confirm the diagnosis of anencephaly.

When the diagnosis is confirmed, you will be given time to make a decision about what happens next. You may choose to continue your pregnancy. If this is the case, the MFM team will make a plan with you for your care which will continue under your Lead Maternity Carer (LMC) with Obstetrician input through your local hospital.

If you decide not to carry on with your pregnancy, a plan will be made with you, together with the MFM team. Whatever you decide, your decision will be respected and you will be supported by the team.

How likely is this to occur again? Future pregnancies

You are much more likely to have a healthy pregnancy and baby next time. However, the risk of recurrence after one pregnancy being affected by anencephaly is around two in 100 pregnancies. A prescribed dose of Folic acid supplement taken daily three months before getting pregnant and three months into pregnancy can reduce the risk of recurrence significantly. Your GP or specialist can prescribe this for you. A diet rich in Folic acid is important but not enough to provide you with this high dose of Folic acid so it is important to take a supplement.

