

### Support for parents and carers

Having a baby with Anencephaly can be a difficult situation for parents to cope with. However, you should never feel that you are alone. Great support and advice is available for parents who have a pregnancy diagnosed with anencephaly.

You will be able to access pregnancy counselling through your Fetal Medicine Unit for you and your whanau.

You may also like to contact:

#### Parent to Parent New Zealand

[www.parent2parent.org.nz](http://www.parent2parent.org.nz)

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.

#### SANDS

[contact@sands.org.nz](mailto:contact@sands.org.nz)

[info@sands.org.nz](mailto:info@sands.org.nz)

Sands New Zealand is a network of parent-run, non-profit groups supporting families who have experienced the loss of a baby.

For more information please contact your local  
NZMFMN Unit



Auckland: 09 307 4949 ext 24951



Wellington: 04 806 0774



Christchurch: 03 364 4557

New Zealand Maternal Fetal Medicine Network  
[NZMFMN@adhb.govt.nz](mailto:NZMFMN@adhb.govt.nz)

# Anencephaly



### **What is Anencephaly?**

Anencephaly is a serious birth defect in which your baby is born without parts of his/her brain and skull. It is a severe type of neural tube defect that is incompatible with life- this means your baby will not survive. This condition occurs because the neural tube does not fully close during the early stages of your baby's development in the womb (often before you know you're pregnant; in the first 24 days after conception).

The neural tube is a thin channel that folds and then closes between the 3<sup>rd</sup> and 4<sup>th</sup> weeks of pregnancy and results in the formation of the brain and spinal cord and its covering. Anencephaly occurs when the top or head end of this tube fails to close. This results in the absence of major portions of the brain, skull and scalp. A baby 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. If your baby is born alive he/she will only live for a few hours or possibly days.

### **Why does this happen?**

The exact cause of anencephaly is not known. Genetic and environmental factors are thought to play a part. 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 baby with anencephaly. Chromosomal abnormalities account for less than ten percent of all babies with anencephaly.

### **How is it diagnosed?**

Anencephaly is diagnosed on an ultrasound scan. It may sometimes be detected as early as 11 to 14 weeks on an ultrasound scan.

It is most often detected at the 20 week anatomy scan. A suspicion of neural tube defect can arise following a high level of a hormone called Alpha Fetoprotein (AFP) in the MSS2 bloods. AFP is measured in this test to screen for particular developmental abnormalities. An amniocentesis is not needed to confirm this condition.

### **How common is it?**

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

### **Is there any treatment?**

Unfortunately there is no cure or treatment for anencephaly.

### **What is the outlook for my baby?**

Unfortunately the prognosis for babies born with this condition is extremely poor. Most babies born with this condition die within a few hours or days after birth. Some babies with anencephaly will die before they are born (stillborn).

### **What happens next?**

Once a diagnosis of anencephaly is suspected your Lead Maternity Carer (LMC) will refer you to your local Fetal Medicine Unit. During this appointment you will have another scan to confirm the diagnosis and have an opportunity to discuss with the obstetrician what this condition is and what having a baby with anencephaly might mean to you and your whanau.

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 Fetal Medicine team will make a plan with you for your care which will continue under your LMC (Lead Maternity Carer) with obstetrician input through your local hospital.

If you decide not to carry on with your pregnancy a plan will be made with you by the Fetal Medicine team and you will be able to deliver at your local tertiary hospital. Whatever you decide, your decision will be respected and you will be supported by the Fetal Medicine team.

### **How likely is this to occur again?**

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 a major neural tube defect like anencephaly is 2% (1 in 50). A high dose of Folic acid (5mg) taken 3 months before getting pregnant and 3 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 sufficient to provide you with this high dose of Folic acid so it is important to take a supplement.