NHS Fetal Anomaly Screening Programme

Anencephaly: information for parents
Anencephaly is a life-limiting condition where the baby’s brain and spinal cord (the fetal nervous system) do not develop properly. This is a very serious condition where large parts of the baby’s skull and brain are missing. The baby’s face and neck may also be affected.

In the early stages of pregnancy, the nervous system of the developing baby starts as a single structure called the neural plate. By day 28 of pregnancy, the neural plate should fold over and close to form the neural tube. If the neural tube does not close completely it results in a neural tube defect (NTD) such as anencephaly.

We screen for anencephaly at the 18+0 to 20+6 weeks mid-pregnancy scan, which is also known as the ‘20 week scan’. Often anencephaly can be detected during the first trimester scan, which usually takes place between 11 and 14 weeks of pregnancy. We do not fully understand why anencephaly happens. It is found in about 5 in every 10,000 pregnancies (0.05%).

If the result of the scan suggests the baby may have anencephaly, you will be referred to a doctor specialising in obstetrics and/or fetal medicine. They will confirm if the baby has anencephaly, talk to you about the condition and talk through options for your pregnancy.
Treatment

Unfortunately, there is no treatment for anencephaly and most babies (up to 3 out of 4) with the condition are stillborn. Babies who survive throughout the pregnancy die shortly after birth. On rare occasions babies may live for a few days.

Next steps and choices

You can talk to health professionals about the condition and your options. These will include continuing with the pregnancy or ending the pregnancy. You might want to learn more about anencephaly. It can be helpful to speak to a support organisation for parents.

If you decide to continue your pregnancy, your healthcare team will help you plan your care and the birth of the baby. If you decide to end your pregnancy, you will be given information about what this involves and how you will be supported. Only you know what is the best decision for you and your family.

Whatever decision you make, your healthcare professionals will support you.

Future pregnancies

Future pregnancies are not likely to be affected by the condition. However, if you have had a baby with anencephaly, there is a small chance (up to 2% or up to 2 out of 100) of having another baby with the condition.
There is a possible link between anencephaly and low levels of folate (folic acid) in your blood. If planning future pregnancies, it is recommended that women who have had a previous pregnancy affected by anencephaly take a higher dose of folic acid (5 mg per day instead of the usual 0.4 mg per day) before getting pregnant and up until 12 weeks of pregnancy.

You may also be referred to a genetic counsellor to discuss future pregnancies.

More information

- **Antenatal Results and Choices (ARC)** is a national charity that supports people making decisions about screening and whether or not to continue a pregnancy: [www.arc-uk.org](http://www.arc-uk.org)
- **Shine** is a national charity providing specialist advice about, and support for, anencephaly across England, Wales and Northern Ireland: [www.shinecharity.org.uk](http://www.shinecharity.org.uk)