Neural tube defects (NTDs): anencephaly

Information for parents
Information to help you understand more about anencephaly.

1. What is anencephaly?

Anencephaly is a neural tube defect (a condition where the brain or spinal cord of an embryo does not develop properly). It happens when the bones of the skull do not form properly. This results in severe damage to the baby’s brain when it is developing. Anencephaly happens during the first 24 days after the egg is fertilised by the sperm.

The exact cause of anencephaly is not known although genetic and environmental (for example, dietary) factors are involved.

2. How common is it?

Anencephaly occurs in about 6 of every 10,000 births.

3. How is it diagnosed and confirmed?

Anencephaly may be noticed at the dating scan if that scan is carried out after 11 weeks of pregnancy.

However, it is usually identified at the Fetal Anomaly ultrasound scan carried out between 18 weeks and 21 weeks of pregnancy.

You may need a second scan to confirm the diagnosis.

4. Is there any treatment?

Unfortunately, there is no treatment for anencephaly.

5. What is the outlook for the baby?

Sadly, babies with anencephaly die before they are born or shortly after birth. On very rare occasions babies can live for a few days.

6. What happens next?

You will be given the chance to talk to specialists about your options. You will have the opportunity to discuss the possible implications of ending or continuing your pregnancy.

You will be offered a termination to end the pregnancy. If you choose to have a termination, your health professional will talk to you about the procedure and support you through the process.
If you choose to continue your pregnancy, your healthcare team will help you plan how your care, including delivery, is managed. As there is no cure for anencephaly, doctors will discuss palliative care with you. Palliative care is care aimed at relieving the symptoms of a condition rather than treating or providing a cure. You may be referred to the children’s palliative care team and the local bereavement service.

Whatever you decide, your decision will be respected and you will be supported by your midwife and doctor.

7. How likely is it to happen in a future pregnancy?

You are much more likely to have a normal, healthy baby in your next pregnancy than to have another baby with anencephaly.

Anyone can have a baby with anencephaly. Because you have had an affected pregnancy, there is a 2% chance (1 in 50) of it happening again.

If there is a history of this condition or other neural tube defects in your family, you will be given the opportunity to see a genetic counsellor to discuss your chances of having another baby with this condition.

All women are advised to take a supplement of 400 micrograms of folic acid for at least three months before getting pregnant and up to the end of the 12th week of pregnancy. Women who have had a previous pregnancy affected by a neural tube defect or have a family history of a neural tube defect are advised to take a higher dose of 5 milligrams of folic acid, prescribed by their GP, as this has been found to reduce the chance of having another baby with a neural tube defect.

8. Where can I get more information and support?

You may feel you only want to talk to your family and friends, or a particular doctor or midwife from the hospital. However, there are other people and organisations that can provide information, help you make your decisions and support you in your pregnancy and afterwards. You may also want to talk things through with the hospital chaplain or your own minister or faith leader.

9. Further information, charities and support organisations

The following organisations can offer you support. There are details of other support organisations on our website at www.fetalanomaly.screening.nhs.uk. If you have any questions about the information in this leaflet or where the information came from, email us at enquiries@ansnsc.co.uk.
Anencephaly.co.uk
Email: richard@anencephaly.co.uk
Email: joanne@anencephaly.co.uk
Website: www.anencephaly.co.uk

Anencephaly.co.uk’s aim is to provide a place for people in the UK to talk to other families within the UK who have had experiences with anencephaly.

Antenatal Results and Choices (ARC)
Email: info@arc-uk.org
Helpline: 0845 077 2290
Website: www.arc-uk.org

Antenatal Results and Choices (ARC) provides information and support to parents before, during and after antenatal screening and diagnostic tests, especially those parents making difficult decisions about testing, or about continuing or ending a pregnancy after a diagnosis. ARC offers ongoing support whatever decisions are made.

SHINE, previously the Association for Spina Bifida and Hydrocephalus (ASBAH)
Information line: 0173 355 5988
Email: info@shinecharity.org.uk
Website: www.shinecharity.org.uk

SHINE is the leading UK registered charity providing information and advice about spina bifida and hydrocephalus to individuals, families and carers. SHINE offers services to the those affected by, or with an interest in, spina bifida or other neural tube defects – from before birth (with advice and support, whether or not the pregnancy continues).

If you have any comments or feedback, email them to us at enquiries@ansnc.co.uk.

This information has been produced on behalf of the NHS Fetal Anomaly Screening Programme for the NHS in England. In other countries, check with a health professional to find out whether there are any differences in approaches to screening.

This leaflet has been developed through consultation with the NHS Fetal Anomaly Screening Programme expert groups. All of our publications can be found online at www.fetalanomaly.screening.nhs.uk.

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