

Neural tube defects (NTDs): open spina bifida (also called spina bifida cystica)

Information for parents

WITHDRAWN FEBRUARY 2019



Information sheet to help you understand more about open spina bifida (also called spina bifida cystica).

This is the most serious type of open spina bifida which accounts for approximately 75% (75 in 100) of all cases of spina bifida.

1. What is open spina bifida?

Open spina bifida is an 'open 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 spine don't form properly. With open spina bifida, a sac (also called a myelomeningocele) of spinal fluid (cerebrospinal fluid) comes out through an opening in the baby's spine. The sac may also contain some spinal cord, which can become damaged.

The condition appears to be caused by a combination of genetic and other factors. Around 70% (7 in 10) of children with open spina bifida also develop hydrocephalus – too much cerebrospinal fluid in the brain.

2. How common is it?

Open spina bifida occurs in about 6 of every 10,000 births.

3. How is it diagnosed and confirmed?

Open spina bifida is usually noticed 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?

After the birth of your baby, your health professional will talk to you about the various treatment options. These will depend on the position, size and complexity of the open spina bifida. In most cases of spina bifida, the baby needs an operation after birth.

If the baby develops hydrocephalus, this will also need to be treated with surgery because extra pressure on the brain can cause brain damage. During this operation, the fluid is drained by inserting a small tube (called a shunt) from the brain into the baby's abdomen (tummy). This often needs to be replaced as the child grows as it can become blocked or infected.

5. What is the outlook for the baby?

The outlook for your baby will depend on the size and location of the open spina bifida and the amount of damage to the spinal cord and nerves. The outlook will also depend on whether your baby develops hydrocephalus.

In mild cases, your baby is unlikely to have any major problems. Children with open spina bifida frequently have problems controlling their bladder and bowels. In more serious cases, your baby may have problems walking or not be able to walk. Hydrocephalus can cause some learning difficulties.

6. What happens next?

You will be given the chance to talk to specialists about what having a baby with open spina bifida might mean for you and your family.

They will offer you another scan to check whether the baby has other disorders and discuss tests such as CVS (chorionic villus sampling) or amniocentesis to check for genetic disorders. There is more information on CVS and amniocentesis in leaflets called *Chorionic villus sampling (CVS) – information for parents* and *Amniocentesis test – information for parents*. These are available on our website at www.fetalanomaly.screening.nhs.uk/publicationsandleaflets

Your doctor may talk to you about the option of having a termination to end your pregnancy. You will have the opportunity to discuss the possible implications of continuing or ending your pregnancy.

If you choose to continue your pregnancy, your healthcare team will help you plan how your care, including delivery, is managed. You will be offered regular ultrasound scans to monitor the baby. Arrangements will be made for you to meet some of the paediatric team, including one of the paediatric surgeons, who will care for your baby after the birth.

If you choose to have a termination, your health professional will talk to you about the procedure and support you through the process.

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 future pregnancies than to have another baby with this condition.

Anyone can have a baby with open spina bifida. If you have had one baby with open spina bifida, there is a 3% to 4% (3 to 4 in a 100) chance of having another baby with this condition. If your baby's open spina bifida was part of a genetic syndrome, the chances can be much higher – up to 25% (25 in a 100).

If there is a history of this condition 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 neural tube defects or have a family history of neural tube defects are advised to take a higher dose of 5 milligrams of folic acid, prescribed by their GP, as this has been found to reduce their chances 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@ansnc.co.uk.

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).

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

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