Spina bifida is a condition that affects the spine and spinal cord.

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.

Spina bifida is a neural tube defect (NTD) where part of the baby’s neural tube does not develop or close properly. This leads to the baby’s spinal cord (the big bundle of nerves running from the brain down the baby’s back) or vertebrae (the bones of the spine) not developing as they should.

The 2 types of spina bifida are:
- closed spina bifida (spina bifida occulta)
- open spina bifida (spina bifida aperta)
Closed spina bifida

Closed spina bifida, or spina bifida occulta, is less serious than open spina bifida. The spinal bones alone have not formed properly, but the spinal cord is covered by skin (see centre illustration above).

Closed spina bifida can be linked with deep dimples or fatty lumps (lipomas) on the baby’s back where the condition is, which can affect the way the nerves work. However, many people with closed spina bifida may not have any other symptoms.
Open spina bifida

The spinal bones, spinal cord and nerve tissue along part of the spine do not form properly in people who have open spina bifida. This results in a sac coming out of the opening in the spine, leaving spinal tissue uncovered (see right-hand illustration on page 3).

The brain and spinal cord are covered in spinal fluid (cerebrospinal fluid). In babies with spina bifida this fluid comes out through the sac in the baby’s spine. The sac may also contain some spinal cord and nerves which can become damaged. This can happen anywhere along the spinal cord although it is most common in the lower back.

How we find spina bifida

We screen for spina bifida at the 18+0 to 20+6 weeks mid-pregnancy scan, which is also known as the ‘20 week scan’.

Closed spina bifida is difficult to detect before birth.

We do not fully understand why spina bifida happens but it is found in about 6 babies out of every 10,000 (0.06%).
Follow-up tests and appointments

If the result of the scan suggests the baby has spina bifida you will be referred to a team specialising in fetal medicine.

This is a team of experts in caring for babies before they are born. The fetal medicine team will confirm if the baby has spina bifida, the type of spina bifida, and what this means for you and the baby.

It may be useful to write any questions down that you want to ask before you see the fetal medicine team.

Treatment

Members of the fetal medicine team will talk to you about the condition and how you can prepare for the birth of the baby. They will also talk to you about how they would treat the baby after the birth. Possible treatment will depend on how serious the condition is and where the spina bifida is on the spine.

The fetal medicine team may also offer you an appointment with a paediatric neurosurgeon who specialises in performing surgery on babies and children with this condition. They will be able to explain the type of operation or other treatment the baby might need to close the spina bifida.

In some cases, open spina bifida can be closed while the baby is still in the womb. This is called fetal surgery. The fetal medicine team will discuss with you if this surgery might be an option.
You might be offered a test, called an amniocentesis test, if the fetal medicine team think the spina bifida could be part of a more complicated condition. In most cases, spina bifida happens by chance during the baby’s early development. However, in rare cases, it can be part of a genetic condition that runs in families. For more information please see [nhs.uk/conditions/genetics](http://nhs.uk/conditions/genetics).

For more information about amniocentesis, please see the Public Health England screening leaflet [CVS and amniocentesis: information for parents](http://cvr-screening.org.uk/).  

**Longer term health**

The long-term health of babies who have open spina bifida will depend on:

- the size and position of the spina bifida
- whether there is damage to the spinal cord and nerves and, if so, how much

It will also depend on whether the baby develops hydrocephalus, which is a build-up of fluid in the baby’s brain caused by open spina bifida. Many babies with spina bifida will either have, or will develop, hydrocephalus.

Babies with open spina bifida often have problems controlling their bladder and bowels. In more serious cases, they may have problems walking or may be unable to walk. Spina bifida and hydrocephalus can cause some learning difficulties. Babies with closed spina bifida may need checks to see if their bladder is working properly and may need surgery in later life.
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 spina bifida. 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 spina bifida, there is a small chance (up to 4% or up to 4 out of 100) of having another baby with the condition.

If the baby’s spina bifida was part of a genetic condition, the chances of having another baby with spina bifida can be higher – up to 25% (25 out of 100). If this is the case, you may be referred to a genetic counsellor to discuss future pregnancies.
There is a possible link between spina bifida 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 spina bifida 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.

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)

- **NHS.UK** has a complete guide to conditions, symptoms and treatments, including what to do and when to get help: [www.nhs.uk/conditions/Spina-bifida](http://www.nhs.uk/conditions/Spina-bifida)

- **Shine** is a national charity providing specialist advice about, and support for spina bifida across England, Wales and Northern Ireland: [www.shinecharity.org.uk](http://www.shinecharity.org.uk)