SBH Scotland. There for the journey.

Spina Bifida
Hydrocephalus
Scotland

Spina Bifida

What is spina bifida?

The spine, brain and spinal cord develop between the 14th and 23rd day after conception and make up the central nervous system. All bodily functions are controlled by the brain when it receives information from nerves throughout the body. This information enables the brain to pass messages to different parts of the body through the spinal cord which runs down the centre of the spine.

The spine is made up of 33 separate bones called vertebrae which cover and protect the spinal cord.

In spina bifida some of these vertebrae are not completely formed. Instead, they are split and the spinal cord and its coverings usually protrude through a sac-like bulge on the back. Spina bifida means "split spine" and this split may involve one or more vertebrae and usually occurs around waist level or below.

What are the types of spina bifida?

There are 3 forms of spina bifida:

- **Myelomeningocele: (pronounced my-lo-men-injo -seal)**

  This is the most common type. The "sac" contains nerves, part of the spinal cord and cerebrospinal fluid. The nerves are damaged and this damage affects the functions in the body below the location of the split such as bowel and bladder control and mobility although these effects vary enormously.

- **Meningocele: (pronounced men-injo-seal)**

  In this milder form of spina bifida, the split in the vertebrae is not big enough for the spinal cord to come through, but a "balloon" of skin filled with cerebrospinal fluid and blood vessels bulges out. The nerves are not usually damaged and therefore the effects, if any, are very mild.

- **Spina Bifida Occulta:**

  This means "hidden" spina bifida and is very common. Most people will have one vertebrae involved which is insignificant and will have no effect whatsoever. However for a small number of people the fault is more extensive where the split in the spine is bigger and two or more vertebrae are affected. In this form there may be visible signs on the skin on the lower back such as a dimple, mole, lipoma, birth mark or patch of hair. (See information sheet on Spina Bifida Occulta)

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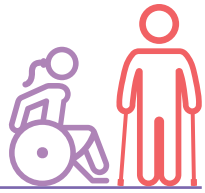

What causes spina bifida and other neural tube defects?

The exact cause is unknown but it is thought to be a combination of genetic and environmental factors and Spina Bifida Hydrocephalus Scotland continues to work closely with research organisations. What is evident though, is that taking a daily folic acid supplement of 400 micrograms at least 12 weeks prior to conception and 12 weeks after can help reduce the risk.

Is there a risk of another pregnancy being affected?

There is a 1:25 risk if there has been a previous pregnancy where spina bifida has been detected or if there is a family history of the condition. In this case a referral to a Geneticist to determine the risk is recommended before planning a pregnancy and an increased daily 5 milligrams dose of folic acid should be prescribed by your GP. (See separate information sheet on Genetic Counselling).

How is spina bifida diagnosed?

Women are offered a blood test between 15 and 20 weeks of pregnancy which detects the level of Alpha Feto Protein (AFP). A raised level can indicate a number of things including spina bifida. A scan will then be recommended which shows the spine in detail and spina bifida is visible in 90 per cent of cases. However further scans will be recommended.

How is spina bifida treated?

The baby will be seen by a Paediatric Surgeon immediately after birth to assess the need for an operation to close the back which will then be carried out within 48 hours. Careful observation will also be carried out for signs of hydrocephalus. The main reason for surgical closure of the back is to prevent infection and is not a cure as the nerve damage cannot be repaired. However there are many methods of managing the physical effects of this damage. The baby will be assessed for sensation and movement in the lower limbs and gentle exercises and specialised aids such as splints may be recommended.

If there is impairment in the function of the bowel and bladder, there are various modern methods available to manage these (see separate information on bowel and bladder management).

These assessments combined with specialist tests and treatments if required will continue throughout the child's life by the family's Health Professional Team. The Direct Services Team at Spina Bifida Hydrocephalus Scotland (SBH Scotland) is also there throughout to support and offer information and advice.

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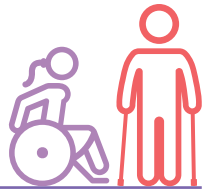


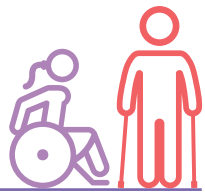
Hydrocephalus

In 80 – 90 per cent of pregnancies with spina bifida, there will be a condition called hydrocephalus. The brain and spinal cord are surrounded by a clear fluid called cerebrospinal fluid (CSF). This fluid is produced and stored in cavities (called ventricles) in the brain and protects and nourishes the brain, supplies important chemicals and nutrients and carries away waste from the brain cells. Any excess fluid drains away and is absorbed by the body but in Hydrocephalus the CSF is unable to drain away and almost always a shunt is required to be inserted. (See separate information sheet on Hydrocephalus).

Other forms of neural tube defects

Encephalocele (pronounced en-cef-alo-seal) is a sac which forms when the bones of the skull fail to develop fully. It may contain only cerebrospinal fluid or part of the brain resulting in brain damage.

Anencephaly (pronounced an-en-cef-aly) is where the brain does not develop or is absent and sadly babies will not survive with this condition (see separate information sheet on Anencephaly).



If you have questions or would like further information, please call the **SBH Scotland Helpline** on **03455 211 300** or email **support@sbhscotland.org.uk**
For general enquiries call **03455 211 811** or visit **www.sbhscotland.org.uk**

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