

What is Spina Bifida?

June 2007

Spina bifida literally means 'split spine'

A fault in the development of the spinal cord and surrounding bones (vertebrae) leaves a gap or split in the spine. The spinal cord has not formed properly, and may also be damaged. To help understand what it is, it is useful to explain the composition of the nervous system.

The Central Nervous System

The central nervous system consists of the brain and the spinal cord. All activities are controlled by the brain which receives information from touching, seeing, feeling, tasting and hearing – responding to this information by initiating the appropriate movements of different parts of the body. Messages from the brain are carried to different parts of the body by the spinal cord which runs down the centre of the spinal column. This communication system for the body is very important and needs protection.

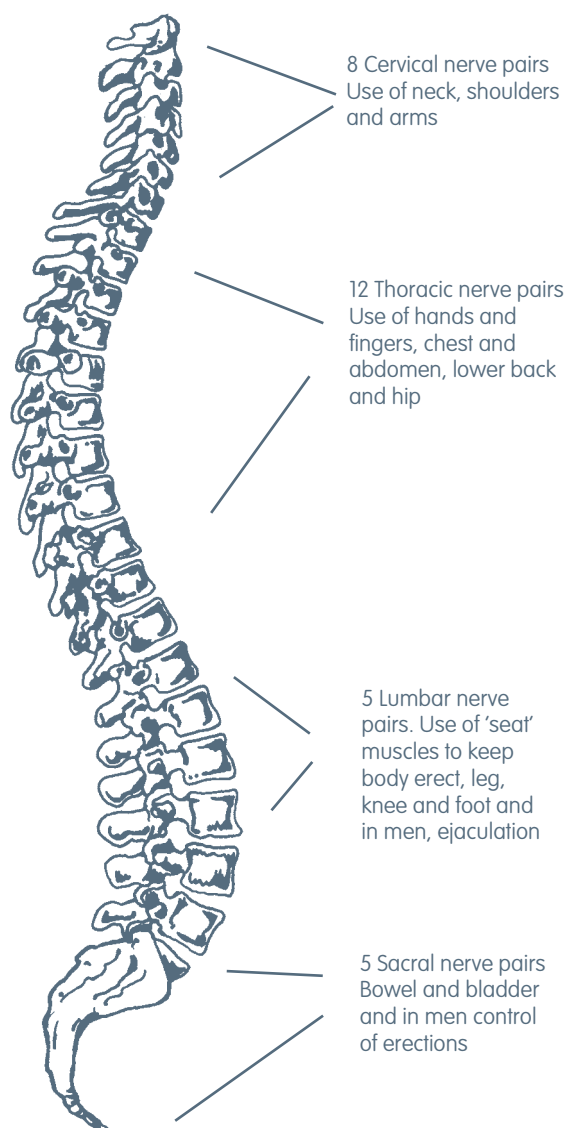
The Spine

The spine is made up of 33 bones or vertebrae. The vertebrae have two main functions. One is to provide anchorage for muscles so that we can move as the brain dictates to those muscles. The other is to provide protection to the spinal cord.

The Neural Tube

The central nervous system and spine develops between the 14th and 23rd day after conception. Spina bifida occurs when the neural tube fails to close correctly. The vertebrae also fail to close in complete rings around the affected portion of the spinal cord. This leaves a gap posteriorly (at the back), involving one or more vertebrae. The fault may occur in one or more of the vertebrae but it is most common around waist-level.

Nerves which control the movement of different parts of the body



Types of Spina Bifida

The three main types of spina bifida always present at birth are:

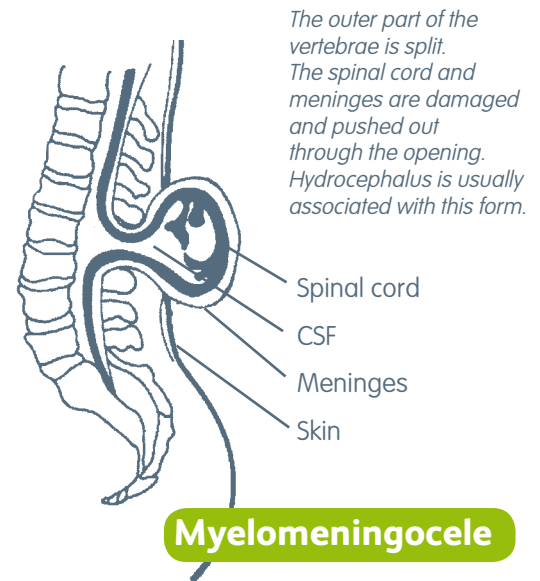
Spina Bifida Cystica (cyst-like)

The visible signs are a sac or cyst, rather like a large blister on the back, covered by a thin layer of skin.

There are two forms:

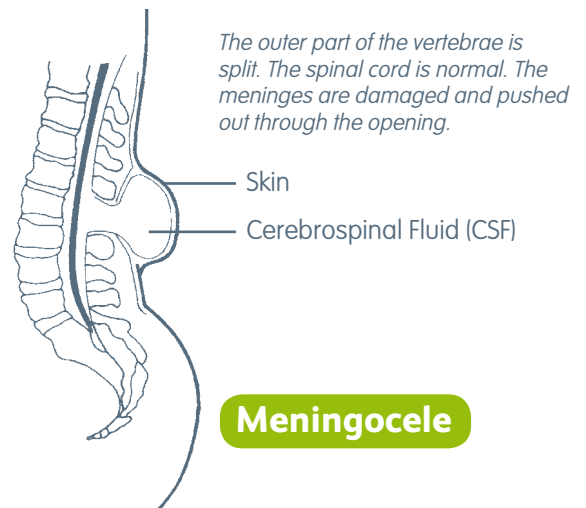
1) Myelomeningocele (meningomyelocele)

Myelomeningocele is the most serious and more common of the two forms of cystic spina bifida. Here the cyst not only contains tissue and cerebro-spinal fluid but also nerves and part of the spinal cord. The spinal cord is damaged or not properly developed. As a result, there is always some paralysis and loss of sensation below the damaged region. The amount of disability depends very much on where the spina bifida is, and the amount of affected nerve tissue involved. Bladder and bowel problems occur in most people with myelomeningocele, as the nerves come from the bottom of the spinal cord, so are always below the lesion. It is also necessary to have intact nerve pathways to the brain for complete control and sensation.



2) Meningocele

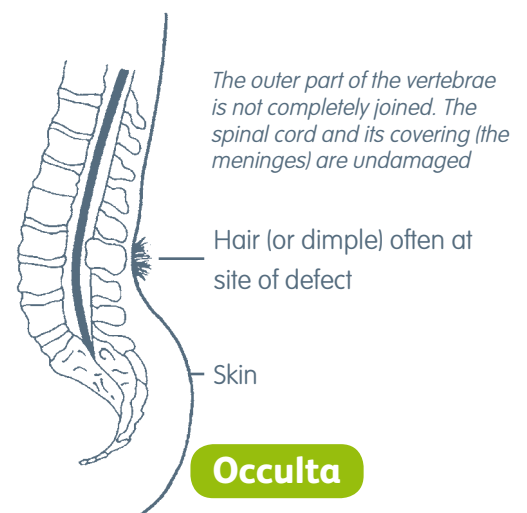
In this form, the sac contains meninges (tissues which cover the brain and spinal cord) and cerebro-spinal fluid, which bathes the central nervous system. Development of the spinal cord may be affected, but impairment is usually less severe than myelomeningocele. Meningocele is the least common form of spina bifida.



Spina Bifida Occulta (hidden form)

This is a mild form of spina bifida which is very common. Estimates vary but between 5% and 10% of people may have spina bifida occulta. It must be emphasised that, for the vast majority of those affected, having spina bifida occulta is of no consequence whatsoever. Often people only become aware that they have spina bifida occulta after having a back x-ray for an unrelated problem.

However, for a few (about 1 in 1,000) there can be associated problems. See ASBAH's information sheet on 'Spina Bifida Occulta'.



Encephalocele

This is a sac which is formed when the bones of the skull fail to develop. It may contain only cerebro-spinal fluid or part of the brain may also be present in the sac, resulting in brain damage.

Anencephaly

This is where the brain does not develop properly or is absent, and the baby is either still born or dies shortly after birth. Contact ASBAH for further information.

Hydrocephalus

Most babies born with myelomeningocele also have hydrocephalus (from the Greek hydro, meaning water, and cephalie meaning brain). This is an accumulation of cerebro-spinal fluid which arises from an imbalance in the production and drainage of that fluid. Further information about hydrocephalus is given in ASBAH Information Sheet 'What is Hydrocephalus?.'

Why does Spina Bifida happen?

At present causation is unknown and research continues. However, we do know that taking folic acid supplements can reduce the risk of spina bifida in unborn babies. For families with no history of spina bifida the Dept. of Health recommends women take an 'over the counter' dose of 400mcg daily. For families where there is a history of spina bifida, a prescription dose (5mg) of folic acid is needed.

Folic acid should be taken daily for at least one month prior to conception and through to the 12th week of pregnancy. Even with fortification of flour products with folic acid, a supplementary tablet is needed.

The exact reasons why the neural tube develops incorrectly are not yet known but it is probably connected with both genetic and environmental factors.

How is Spina Bifida treated ?

The baby will be seen by a paediatric surgeon or paediatric neurosurgeon shortly after birth.

The surgeon will then decide whether the child should have surgery to repair the defect in the back: this surgery will take place in a specialist unit usually within 48 hours.

Some surgeons do not close the back surgically but leave it to heal without intervention.

Genetic Counselling

Prospective parents who have had a baby with a neural tube defect, or who have a close relative with a neural tube defect, should be referred to a genetic counsellor for advice.

Support

ASBAH plays a leading role in providing support, through national and regional offices and local associations, it offers information and practical advice. Families who have a child or adult with a disability can sometimes feel very isolated and ASBAH can provide often much-needed contact with other families.

Information and publications are available on all aspects of care and management. Our national and regional staff, area and specialist advisers will give personal advice and support whenever possible.

Our services are available to individuals with the disabilities, parents, health professionals, schools, local authorities and other interested organisations. **Further details about our services can be obtained on request from our Helpline Telephone Services 0845 450 7755 between 10.00am & 4.00pm Monday to Friday. Alternatively, you can email your query to helpline@asbah.org**

Link magazine

The essential magazine for people with hydrocephalus and spina bifida.

Link is published quarterly (Winter, Spring, Summer and Autumn) and is packed with the latest news, events and issues for individuals, carers and people living with hydrocephalus and spina bifida. To subscribe contact **ASBAH's Helpline 0845 450 7755** email:helpline@asbah.org or visit our web site: www.asbah.org and click on the publications page.



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