

Spina Bifida and Hydrocephalus



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What is Spina Bifida?

Spina Bifida is a deformity occurring during to the foetus during early pregnancy when the bones of the spine are not closed completely leaving the nerves, spinal cord and their protective sheathing exposed. This can result in damage to the spinal cord and nerves. The physical consequences depend upon the level of lesion (or break) and the amount of damage to the spinal cord. In general there are three types of Spina Bifida.

1. *Spina Bifida Occulta* - an opening in one or more of the vertebrae (bones) of the spinal column without apparent damage to the spinal cord.
2. *Meningocele* - the protective covering around the spinal cord pushed out through the opening in the vertebrae in a sac called the "meningocele" with the spinal cord remains intact.
3. *Myelomeningocele* - the most severe form of spina bifida, in which a portion of the spinal cord itself protrudes through the back.

Some degree of paralysis may occur and loss of sensation in the parts of the body below the level of the damage. The upper limbs may also be affected.

What is Hydrocephalus?

Hydrocephalus is caused by an excess of fluid that may exert pressure on the brain. In some children the fluid drains away on its own, if not the ventricles of the brain swell and the brain tissue is stretched and squashed. The skull bones in babies and young children are not fixed together as they are in later life, and the pressure causes the head to increase in size. However it is important to realise that hydrocephalus can also

arise in older children and in adults, when the skull bones are fixed and the head cannot increase in size.

In some cases a device known as a 'shunt' is implanted to help the fluid drain. Shunts usually work very well but some children have problems with them from time to time e.g. a blockage or infection.

Living with Spina Bifida and Hydrocephalus

Some children have poor co-ordination, which may affect handwriting, games and activities. In particular ball-handling skills may prove difficult for these children. They are often fluent talkers and may give the impression that they understand without, in fact, doing so. Hydrocephalus can lead to learning difficulties. They may have difficulty with paying attention, expressing or understanding language, and grasping reading.

In the more severe forms of Spina Bifida children are paralysed in the lower limbs, and therefore use a wheelchair. Access to buildings and facilities may need to be considered.

Practical Tips

Exercise is very important, especially for those who are partially paralysed. This will help to improve the functioning of many of the body organs. Movement also aids circulation so it should be encouraged, following discussion with parents.

Children with Spina Bifida are prone to kidney damage and are often encouraged to drink a lot of fluid to keep the kidneys functioning well. They may therefore need extra drinks during hot

weather. Parents and medical advisers will be able to give you details of a child's requirements.

Try not to make too many assumptions.

Telephone: 0131 332 0743

Fax: 0131 343 3651

Web Site: www.ssba.org.uk

What else do I need to know?

It is advisable to discuss the parent's method of recognising an incorrectly working shunt (it is usually distinctive) and the course of action to take, as the child will need urgent medical help.

If a child with Hydrocephalus develops a severe headache, drowsiness or vomiting this may indicate that the shunt is not working properly and medical attention should be sought immediately.

If a child with Spina Bifida develops a high temperature this may be indicative of a urinary infection and the parents should be contacted immediately for medical attention.

Some children with myelomeningocele Spina Bifida may need training to manage their bladder and bowel functions or have little or no control of their functions. In some cases this may require the need for catheterisation. Discuss with the individual and parents/guardian/carer the implications this may have for nights away.

Further Information

Discuss with the individual and/or parents the extent to which help is needed and learn any practical tips they can offer.

Support Organisations

ASBAH

Association for Spina Bifida & Hydrocephalus

42 Park Road

Peterborough

PE1 2UQ

Telephone: 01733 555988

Fax: 01733 555985

Email: info@asbah.org

Website: www.asbah.org

Scottish Spina Bifida Association

190 Queensferry Road

Edinburgh

EH4 2BW