Spina Bifida Occulta
What is spina bifida occulta?

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 occulta means “hidden spina bifida” and is very common. Most people will have one vertebrae involved which is insignificant and will have no consequence 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. However the split is still too small for the spinal cord to protrude.

What are the signs of spina bifida occulta?

Spina bifida occulta is usually detected when an X ray of the spine is carried out for an unrelated problem such as an accident or back injury and the diagnosis can be confirmed by carrying out Magnetic Resonance Imaging (MRI) by a Neurologist. There may be visible signs on the skin on the lower back above the level of the buttocks such as a dimple, lipoma, mole, birth mark or hairy patch. A dimple or hole below the level of the buttocks does not usually indicate occulta. The physical symptoms can vary enormously but there may be back pain (which arises because the spinal cord becomes tethered to the spine particularly during adolescence when there is rapid growth), slight loss of sensation in the legs, mobility difficulties such as tripping and stumbling and occasionally bowel and bladder problems.

Continued on the next page
**What treatment is available?**

There is no cure for spina bifida occulta and the aim of treatment is to relieve the symptoms. There are many modern methods of managing these (see separate information sheets on Bowel and Bladder Management). Back pain can be relieved by a variety of painkilling medication, Transcutaneous Electrical Nerve Stimulation (TENS), homeopathic treatments and relaxation techniques. We would recommend referral through your GP to a Pain Management Clinic based at your local hospital to discuss your symptoms and treatment options. It is important that physiotherapy, exercising and other therapies such as osteopathy and chiropractic are only carried out following recommendation by a Neurologist. If back pain is caused by the spinal cord becoming tethered to the spine, an operation called de-tethering can be carried out and should be discussed fully with your Consultant.

---

**What is the risk of having a baby with spina bifida?**

For the vast majority of people with the non-significant form of spina bifida occulta there is no higher risk than there is in the general population. For those with occulta involving two or more vertebrae it is generally considered the risk is 1:25 and it is recommended a daily folic acid supplement of 5 milligrams prescribed by your GP, is taken 12 weeks before and 12 weeks after conception. There is evidence to suggest this reduces the risk significantly. We would also recommend Genetic Counselling before starting a family in order to assess the risk more fully and a referral can be made by your GP or one of the Direct Services Team at Spina Bifida Hydrocephalus Scotland (SBH Scotland). (See separate information sheet on Genetic Counselling).

---

**Where can I get further advice?**

If you suspect you may have spina bifida occulta, and are experiencing any of the problems described, you should ask your GP to be referred to a Neurologist for further discussion and investigations. If you experience difficulty in doing this then the SBH Scotland Direct Services Team can help.

*Continued on the next page*
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

This fact sheet is for informational purposes only. It is not intended to replace or be relied on as medical or professional advice. Contact us if you require this publication in another format or language.

Spina Bifida Hydrocephalus Scotland is a trading name of the Scottish Spina Bifida Association.
Registered Scottish Charity No. SC013328. Registered office: The Dan Young Building, 6 Craighalbert Way, Dullatur, Glasgow, G68 0LS.
A company limited by guarantee. Registered in Scotland Number 213050.

Updated August 2016 by SBH Scotland’s Medical Advisory Group.