Scottish SPINA BIFIDA Association

Spina Bifida Occulta
(Also know as 'Spinal Dysraphism')

One of a series of fact sheets produced by the Family Support Service

What is Spina Bifida?
Spina bifida (meaning split spine) is a fault in the spinal column in which one or more vertebrae (the bones which form the backbone) fail to form properly. This leaflet is about the "hidden" form of spina bifida called spina bifida occulta.

What is Spina Bifida Occulta?
This 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.

Why do some people have complications?
The term 'spina bifida occulta' is, in fact, not one but two separate conditions which have completely different consequences. This leads to confusion when such a diagnosis is used without qualification.

For the majority of people with spina bifida occulta, it is a minor fault involving one vertebra in the lower back. The unfortunate use of this term for such a minor fault can lead to distress for the person concerned. However, it should be considered as insignificant, both for that person and his or her children.

For a small number of people with spina bifida occulta the fault is more extensive. Either the split in the spine is bigger, or may involve two or more vertebrae. There may be visible signs on the skin such as a mole or naevus (birth-mark), a dimple or sinus (hole), or a patch of hair. If these are positioned above the level of the buttocks and in the midline (centrally) there may well be a significant underlying spina bifida occulta. A dimple or sinus that is below the level of the buttocks is usually innocent and does not usually indicate an underlying spina bifida occulta.

For people with spina bifida occulta, there may be associated difficulties which can include: deformity, weakness and reduced sensation of the legs, change in hand function, bladder infections and incontinence and bowel problems.

These problems arise because the spinal cord becomes tethered to the backbone. Often a child who is previously symptomless may experience difficulties during the rapid growth of adolescence. This is because the nerves of the spinal cord are stretched and the symptoms may become progressively worse.

It is important to consult a GP, who, if appropriate, can refer to a Neurosurgeon. Specialist scanning procedures such as Magnetic Resonance Imaging – (MRI) give a clear picture of the nerves and spinal column and the Neurologist will be able to advise on the most appropriate treatment.

People with spina bifida occulta and progressive (worsening) symptoms of a stretched or tethered spinal cord need to have an operation on their lower spine to release the tension in the spinal cord. This is often a fairly simple and effective procedure, but occasionally the operation is very complicated and involves a (2% - 5%) risk of failure. It is often possible to improve symptoms in the legs with this operation, but it is rare for bladder function to return to normal. The main purpose of a "detethering" operation is to stop any further deterioration in leg or bladder function and it is important that a neurosurgical assessment is made as early as possible after the onset of symptoms. The operation is probably best done by those Neurosurgeons who have a special interest in the condition.

What are the implications?
For the vast majority of people with the non-significant form of spina bifida occulta, there are no known complications and there is no higher risk of having children with spina bifida than there is in the general population.

For those with the more complicated spina bifida

occulta, there maybe neurological problems which may or may not be present at birth and may be progressive.

Those with significant spina bifida occulta have a risk, higher than in the general population, of having a baby with spina bifida which could be cystica or occulta. This risk is between 2% and 4% and is the same risk that those with spina bifida cystica have of passing on the condition.

However, the risk of having a baby with spina bifida can be reduced by taking folic acid (a B-group vitamin).

Reducing the risk of having a baby with spina bifida

The non-significant form of spina bifida occulta carries no more risk of having children with spina bifida than that for the general population. However, the Government recommends that all women of childbearing age take a daily supplement of 0.4mg of folic acid for 12 weeks before conception and for the first three months of pregnancy as well as eating a diet rich in folic acid.

For those with the more complicated spina bifida occulta, and therefore an increased risk of having children with spina bifida, it is necessary to take a higher daily dose of folic acid for the same period. This 5mg tablet is available only on prescription.

More information and advice

If someone suspects that they have occult spina bifida and is experiencing any of the problems described above, they should ask their GP for referral to a Neurologist who can investigate and advise about treatment.

Women who know they have spina bifida occulta and are planning to have a baby can ask for a referral to a Geneticist who will consider both the family history and individual medical circumstances and advise on the risk of having a baby with spina bifida.

If you have any questions or would like further information, please do not hesitate to contact the Family Support Workers at:

Scottish Spina Bifida Association - Family Support Service

Address: The Dan Young Building, 6 Craighalbert Way, Cumbernauld, G68 0LS • Tel: 01236 794516 • Fax: 01236 736435

Lo-Call Helpline: 08459 11 11 12 • E-mail: familysupport@ssba.org.uk • Web: www.ssba.org.uk