

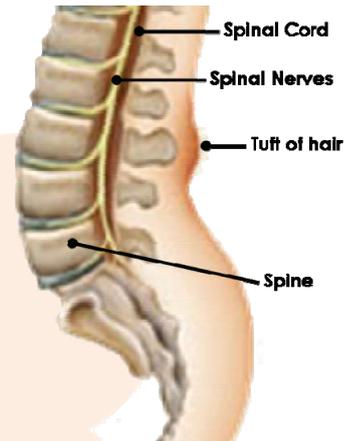


What is Spina Bifida Occulta?



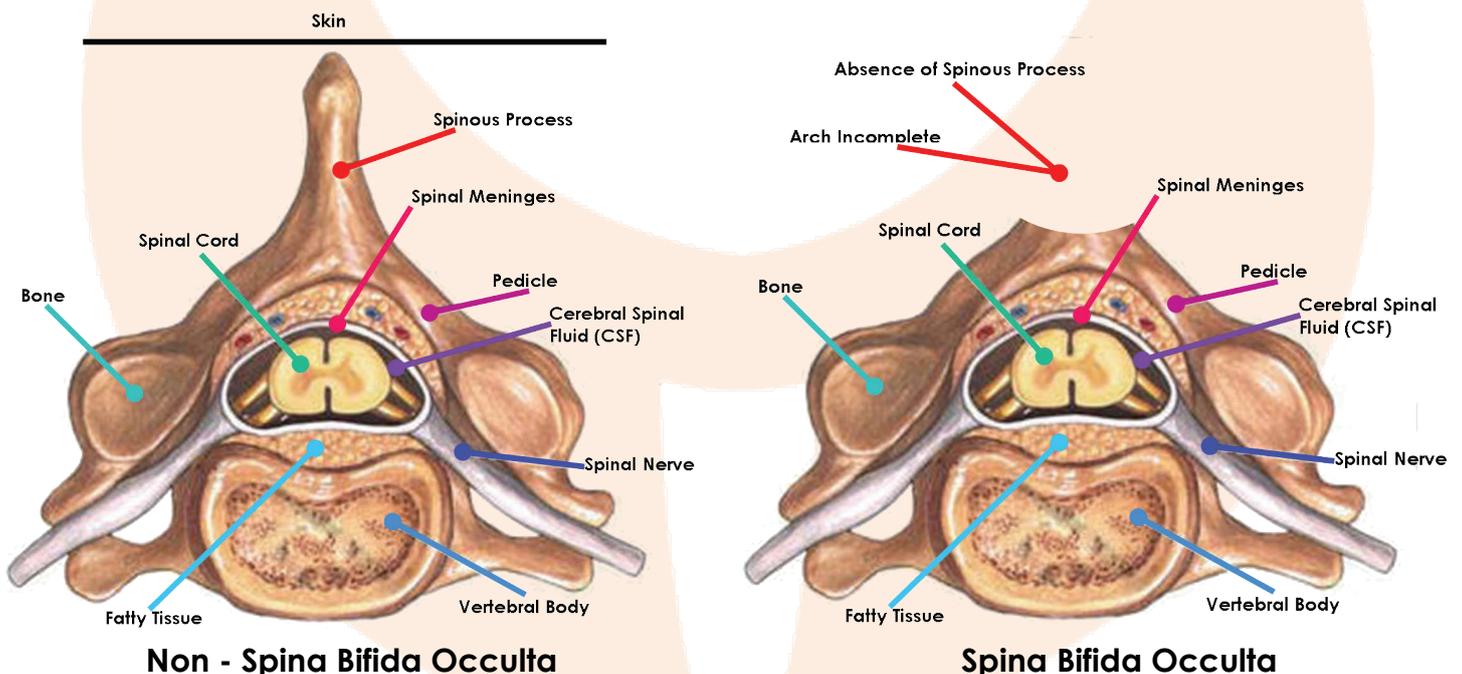
“Occulta” Means Hidden

Spina Bifida Occulta is not easily detected because skin covers the area, such as the spinal cord, spinal bone or nerve roots, which may be affected. Spina Bifida Occulta can affect any level of the spine, but is usually found in the lower part of the back. This condition is a result of a spinal underdevelopment and is associated with disrupted development of the spinal nerve roots and spinal cord. The only thing to see on the back may be a dimple, tuft of hair, or a red mark.



The prevalence of Occulta is not known, but it is probably the most common type of Spina Bifida. In the mid 1980's a study carried out in Great Britain suggested that 22% or 23% of people have Spina Bifida Occulta.

Spina Bifida Occulta is usually discovered accidentally when the person has an x-ray or MRI for some other reason. Most people will not even be aware that they have Spina Bifida Occulta unless it shows up on an X-ray which they have for some unrelated reason. It usually shows itself as just a small part of one vertebra low in the back which is missing. See the diagrams below that show cross sections of one vertebra.



Ref: Hydrocephalus.org, asbah.org.uk, asbah.org.au



What is Spina Bifida Occulta?



Complications and Symptoms

Spina Bifida Occulta is rarely linked with complications or symptoms. Although there may be a slightly increased chance of a slipped disc; very few people with Spina Bifida Occulta will ever have any problems because of it. If a person has no symptoms from Spina Bifida Occulta as a child, then it is unlikely that they will have any as an adult.

Like most conditions, there are different severities of Spina Bifida Occulta:

The most minor form will present as the plates of bone that form the spinal arch fail to fuse completely. This variation generally only affects one vertebra, particularly the vertebra lying lowest in the small of the back. Because there are no associated irregularities of the spinal cord or nerve roots, there are no leg, bladder or bowel problems.

However, for some people (about 2% of those who have Spina Bifida Occulta) there can be other problems. These problems arise because there are other things involved around the area where the vertebra has not formed properly. For this small percentage of people the problem with the spine can also be more extensive than just a small piece of missing bone.

Spina Bifida Occulta Vs Occulta Spinal Dysraphism

When more than one vertebra is involved and these vertebrae have not developed fully Spina Bifida Occulta can be referred to as Occult Spinal Dysraphism (OSD). This may cause the person's back to be slightly short and often stiff. The natural curves of the back may be exaggerated and there may be an abnormal curvature of the spine or a bony protrusion in the midline of the back. There may be a bony peg at one level of the spinal canal, or a fibrous band running across it and dividing it into two. The spinal cord may become excessively wide because of abnormal fat or fibrous tissue lying inside the spinal canal. Leg, bladder, or bowel function may also be affected.

Some of the other things which can occur around this site and affect a person's functioning are:

- Distortion of the spinal cord and the nerve roots coming from the spine by fibrous bands or adhesions
- Fatty tumours in the spine, under the skin or in surrounding tissues
- Cysts in the skin or just under it
- Cysts filled with cerebrospinal fluid in the spine (syrinxes)
- Divisions in the spinal cord
- Spinal cord tethered or held down at the site (unable to move freely in the spinal canal)

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Spina Bifida Occulta Vs Occulta Spinal Dysraphism cont...

In addition to these structures which are usually hidden from view, there are a number of signs which may appear on the skin (cutaneous signatures) and give a clue to the underlying problems with the central nervous system.

These signs can appear on their own but quite often they appear in combination. Some common ones are:

- An abnormal hair growth over the thoracic or lumbar spine
- A dermal sinus or small tract which leads from the skin surface down through to the spinal cord. Blind sinuses or pits which do not lead into the spine are common in newborns especially in the crease of the bottom and do not indicate underlying problems.
- A fatty mass (lipoma) just under the skin
- A rudimentary tail
- A capillary haemangioma (stork bite) over the lower spine. Haemangioma over the back of the head are more common and do not indicate underlying problems.

A word of warning: This sounds as if there is clear difference between Spina Bifida Occulta and Occult Spinal Dysraphism (OSD). In practice, this is not always the case. The best test available at the moment is the MRI (Magnetic Resonance Imaging), but sometimes it is not easy to determine whether or not there is any neural (nerve) involvement.

How can Occulta Spinal Dysraphism affect functioning?

Because the spine and the nerve roots at the site of the lesion are affected, in theory any problem from the waist down can be due to OSD. Depending on the amount of neural involvement, symptoms can be absent, minimal, or severe. Symptoms can include:

- Weakness or sensory loss in the legs, feet
- Leg length difference
- Foot deformity
- Problems with gait (walking)
- Bowel or bladder infection or incontinence
- Constipation
- Scoliosis (sideways curvature of the spine)
- Back pain

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How can Occulta Spinal Dysraphism affect functioning? cont...

Contenance problems may present as

- Bedwetting which persists well into childhood
- Lack of awareness of need to pass urine until it is urgent
- Inability to hold on, even for a few minutes
- Dribbling of urine between visits to the toilet
- Recurrent urinary tract infections
- Constipation

For parents of young children with these problems, it is important for you to:

- Not lose patience with your child. Discipline or behaviour management rarely solves this problem.
- The self-esteem of your child is of paramount importance.
- Try to establish a toileting routine eg toileting first thing in the morning, at morning tea, lunchtime, after school, after dinner and just before bed. Ensure the last drink is several hours before bedtime if possible. Adequate fluids throughout the day are essential though.
- Talk to your child's school. Let them know about your child's toileting needs, so that the school can accommodate them.
- Ask your GP for a referral to a urologist (a specialist in urinary problems).
- Talk to a Contenance Adviser regarding continence aids.

For constipation, seek advice on management from a Contenance Adviser (*Contact your Family Support Worker who can put you in touch with the SBHI Contenance Adviser*). This problem can be treated more effectively if treated early. A well-balanced high fibre diet is important.

Lower limb problems

Most children and adults with OSD have no orthopaedic (muscle and bone) problems. When problems do manifest though, a GP should be consulted who may refer to an orthopaedic surgeon.

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How can Occulta Spinal Dysraphism affect functioning? cont...

Back pain

Back pain may be a significant problem for people with OSD. It is sometimes present even in young children. It may be difficult or impossible to say that OSD is actually causing the pain.

Back pain is very common in our society. Many people suffer back pain for a great variety of reasons and those reasons may be present with or without OSD. For a person experiencing back pain it is appropriate to look at what other factors may be influencing the pain. The fact that a person has OSD cannot be changed, but many other factors can.

It is important to be aware of good back care eg correct lifting methods, good posture, appropriate exercise etc. A physiotherapist can give advice in these areas.

Tethering of the spinal cord

The normal spinal cord moves freely in the spinal canal. However sometimes in OSD, the cord becomes tethered or stuck down. This can cause stretching of the cord and affect the blood flow to the area, especially during times of rapid growth. Some of the symptoms of a tethered spinal cord are:

- Increased weakness or loss of muscle function
- Increased muscle tone
- Deterioration in gait
- Worsening of bladder function
- Progressing scoliosis
- Back pain

All of these symptoms can have other causes and should be investigated. The spinal cord can be tethered with no symptoms. If it is warranted, an operation can be performed by a neurosurgeon to 'detether' the spinal cord.

This procedure will usually not restore lost functioning, but in most cases it is able to halt the worsening of symptoms.

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Corrective Surgery

OSD develops during the first month of pregnancy and cannot be corrected. However, surgery can assist with some aspects. Apart from spinal cord de-tethering, surgical procedures

- can remove fat or fibrous tissues which are affecting the functioning of the spinal cord,
- can drain syrinxes or cysts in the spinal canal to reduce pressure on the spinal cord
- can be performed on the legs or feet to improve their functioning

Support

At Spina Bifida Hydrocephalus Ireland (SBHI) offers a number of supports to individuals, families, carers and professionals through our Family Support Services.

The aim of the service is to work with our members, their families and carers, by providing guidance and information in an environment which is conducive to their needs.

The Family Support Worker (FSW) will visit individuals and/or families in their own home, in hospital, in school or in the work place. The nature and delivery of our service is a direct response to the needs of our service users, their families and carers. This information, support and guidance is available from the time of diagnosis, which can occur during pregnancy or at the time of birth, through to adulthood.

The role of the FSW is very diverse and is guided by the needs of our members, their families and carers. Our aim is to work with our members, their families and carers by providing guidance, advocacy, emotional and practical support.

We also provide healthcare professionals, education professionals and those working within the disability sector with information, resources and guidance, ensuring that our members receive the best possible provisions from their multidisciplinary team.

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