Spina Bifida Occulta

Closed Spinal Dysrphism / Spina Bifida Occulta

Spina bifida occulta (SBO) is a type of spinal dysraphism or ‘closed’, skin-covered form of spina bifida. Estimates vary, but between 5% and 10% of people may have spina bifida occulta. For most people affected, SBO will have no impact on their lives. Often people only become aware that they have the condition after having a back x-ray or scan for an unrelated problem or for back pain.

However, for some people, there can be associated problems which can have a significant impact on their lives and abilities. The term ‘spina bifida occulta’ is also used sometimes to refer to other skin covered lesions (such as lipomyelomeningocele or diastematomyelia - see below).

For most people with spina bifida occulta, one vertebra in the lower back is slightly open. In children, this can be a normal part of development, with some of the lowest vertebrae not closing completely until the teenage years. Provided the spinal cord or nerves are not affected, there should be no impact on walking or bladder and bowel function. Although it can be uncomfortable to hear a diagnosis of spina bifida occulta, MRI can identify or exclude anything which might cause problems, so if your MRI shows no abnormalities other than a gap in the vertebrae, you should not experience any problems stemming from this finding.

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. It may be associated with a fatty lump embedded in the spinal column (lipomyelomeningocele), or a piece of bone which divides the spinal cord (diastematomyelia).
There may be visible signs on the back such as a lump, a haemangioma or naevus (strawberry birthmark), a deep dimple or sinus (hole) above the cleft of the buttocks, or a tuft of hair (similar to head hair, rather than downy back hair).

The effects and complications of spina bifida occulta are caused by nerves and spinal tissue being trapped, caught up on abnormal pieces of bone, or tangled in fatty lumps, which prevent the spine moving freely inside the spinal column (see our information sheet on tethered cord). However, because the lesion is covered in skin, the spinal cord is protected from the damaging effects of the fluid in the womb experienced in myelomeningocele (open spina bifida). Effects may, very occasionally, be present from birth, but more commonly come on during times of rapid growth in childhood, or during middle age. They can include:

- Back pain
- Turning in of the feet (Talipes)
- ‘Growing pains’, pain, weakness or fatigue during walking
- Cramp or pins and needles in the feet and legs
- Thinning of the calf muscles
- Numbness or lack of sensation on the skin to the feet
- Bladder and/or bowel problems.

**Lipomyelomenigocele**

Lipomyelomeningocele is a form of closed spina bifida in which part of the spinal cord and nerves are tangled in a benign fatty tumour. Like other forms of spina bifida, it develops during early pregnancy. The exact cause is still uncertain, but it is thought that a layer of cells (which will develop into the skin) detaches from the neural tissue too early, and allows fat cells to become attached to the spinal cord, where they grow to form a lump. These fat cells prevent the spinal bones closing completely, leaving the ‘spina bifida’ gap. It is present from birth and is often seen as a skin covered lump on the baby’s back at birth. Around 90% of people with lipomyelomeningocele have markers on their back such as fatty lumps, birthmarks or deep dimples.

Lipomyelomeningocele accounts for around 15% of cases of spina bifida. It is usually not detected at the antenatal mid-term ultrasound scan. In open spina bifida, the appearance of the skull bones and cerebellum - part of the back of the brain - show distinct signs to lead the sonographer to look for tiny changes in the spine.
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For example, the bones to the sides of the head can look pinched, and the cerebellum looks long, thin and wrapped around the spinal cord, instead of being round (Chiari II). In lipomyelomeningocele, the brain and skull will usually look normal so the changes to the spine may not be detected.

As lipomyelomeningocele is skin covered, no ‘back closure’ surgery is needed at birth. It also differs from open spina bifida as it is usually not associated with brain development problems such as Chiari II, so learning and general development should also follow typical patterns. Around 5% of people with lipomyelomeningocele have aqueduct stenosis (blockage cause by narrowing) which can lead to hydrocephalus.

Problems associated with lipomyelomeningocele are caused by the spinal cord and nerves being trapped within the fatty lump, and the lump putting pressure on the spinal nerves. This stops the spinal cord from moving freely inside the spinal bones, and with growth the nerves become stretched and damaged; this is what is meant by ‘tethered cord’. (See Shine’s information sheet on tethered cord.) Problems can also develop if the person gains weight – because the lump is made of fat cells, they become larger with weight gain like other fat cells in the body. Fat cells may also be present at the bottom of the spinal cord (fatty filum terminale).

Lipomyelomeningocele often affects the bladder and bowel, so difficulty with potty training, frequency or urgency of passing urine, a poor, ‘dribbling’ stream of urine in boys, or urine infections may occur. It is very important that all children with conditions which affect the nerves to their bladders have their bladder function checked regularly by a Urologist. Constipation or frequent soiling may be experienced too, and several options for good management are available, such as washout systems.

Treatment for lipomyelomeningocele, if needed, is usually by surgery to release the nerves from within the fatty lump, which will be done by a Neurosurgeon.

Neurosurgeons differ in their approaches to surgery; some will operate within the first year of life, others prefer to wait until signs or symptoms begin before operating, as scar tissue from the surgery can cause further tethering, and waiting may result in fewer detethering operations over the person’s lifetime. Sometimes, the nerves are entangled in the fatty lump, and it is not possible to free all the nerves or remove all the fat.

Your neurosurgeon should monitor this regularly, but if you notice any changes, contact your neurosurgeon for an appointment, rather than waiting until the next routine appointment.
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Diastematomyelia

This is a condition in which the spinal cord is divided into two (lengthways), usually in the lumbar area. (The spinal cord may join up again, but if it doesn’t, it is referred to as diplomyelia.) Around half of people with diastematomyelia have their spinal cord divided by an extra piece of bone or band of fibrous tissue in the spinal canal. The spinal cord can become tethered because of the extra bone or tissue. Treatment usually involves surgery to remove the bone and to free up the spinal cord (detethering). People without the extra bone only occasionally develop symptoms, if the cord becomes tethered. Diastematomyelia can occur alone, or with lipomyelomeningocele.

More information and advice

If someone suspects that they have spina bifida occulta and is experiencing a few of the problems described above, they should ask their GP to arrange to investigate. Depending on the findings, a referral to a neurosurgeon might be appropriate.

Shine’s national and regional staff, area and specialist advisers will give personal advice and support whenever possible.