

What is Spina Bifida?

Spina bifida literally means 'split spine'

Spina bifida is a condition which affects approximately 1 in every 1,000 children born per year in Ireland. Ireland has one of the highest incidences of spina bifida births in the developed world. It is the most common neural tube defect (NTD) which causes incomplete development of the spinal cord.

The Central Nervous System (CNS)

The nervous system is essentially a biological information highway, and is responsible for controlling all the biological processes and movement in the body. At the centre of this system is the Central Nervous System (CNS), consisting of the brain and the spinal cord. It is responsible for receiving and interpreting messages, and also sends out messages, either consciously or unconsciously.

The Spine

The spine is made up of separate bones called vertebrae, which normally cover and protect the spinal cord. With 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, covered by a thin membrane.

The Neural Tube

In the developing vertebrae, the neural tube is the embryo's precursor to the central nervous system. The CNS and spine develops between the 14th and 23rd day after conception.

Spina bifida occurs when the neural tube fails to close correctly. The vertebrae also fail to close in complete rings around the affected portion of the spinal cord. This leaves a gap posteriorly (at the back), involving one or more vertebrae. Spina bifida may occur in one or more of the vertebrae but it is most common around waist-level.

Types of Spina Bifida

Spina Bifida Occulta

This is known by some people as 'hidden' spina bifida. The split of the bone of the spine is small and the spinal cord and main nerves cannot bulge out and so little or no damage occurs.

The only thing to see on the back may be a dimple, tuft of hair, or a red mark. Someone with spina bifida occulta may not have any issues at all and probably wouldn't know they had this condition unless an x-ray of the back was taken. Antenatal tests usually do not detect this type of spina bifida before birth.

When more than one vertebrae is involved and these vertebrae have not developed fully, spina bifida occulta can be referred to as Occult Spina 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 in two. The spinal cord may become excessively wide because of abnormal fat or fibrous tissue lying inside the spinal cord.

Meningocele (Pronounced: men-in-jo-seal)

In this type of spina bifida, the split in the bones is not big enough for the spinal cord to extend through, but a 'balloon' of skin filled with fluid and blood vessels bulges out.

This fluid which comes from around the spinal column is called cerebrospinal fluid (CSF). Usually the nerve supply is not affected. The degree of disability is usually less severe than myelomeningocele, but can only be determined as the child develops.

Myelomeningocele (Pronounced: my-lo-men-in-jo-seal)

This is the most common form of spina bifida. The areas affected are dependent on the location of the split. The split contains the spinal cord and nerves are held in the sac which will also be filled with fluid.

The spinal cord and nerves become exposed and the degree of damage will determine the extent of the disability. A myelomeningocele is most frequently found in the lumbar area, but can occur anywhere along the spine.

Encephalocele (Pronounced: en-cef-a-lo-seal)

In the minority of cases of NTDs, the split is high up and involves the back of the head (skull). There is a balloon-like swelling but this does not contain important nerves of the spinal column. Some encephaloceles are small, covered with skin and the children affected usually grow up without major implications. Sometimes, however, it is large and may contain some of the brain and

this can severely affect the baby's eyesight and can cause learning disabilities.

In other cases, however, they can contain large volumes of brain tissue, so that the remaining brain is small, poorly developed, and severely hydrocephalic.

Anencephaly (Pronounced: an-en-cef-a-lee)

Anencephaly results in only minimal development of the brain. Often the brain lacks part or all of the cerebrum (the area of the brain that is responsible for thinking, vision, hearing, touch, and movement).

Due to the extent of under-development of the brain, babies affected by this condition are unlikely to survive outside the uterus, may be stillborn, or die shortly after birth. Treatment is supportive.

What are the Effects of Spina Bifida?

In the past, spina bifida was considered to be potentially fatal. Yet with a greater level of medical understanding, it is now possible to treat symptoms and create a higher quality of life.

The effects of spina bifida vary enormously, depending on the type, the location, and the severity of the condition. There are a number of lifestyle and treatment factors to take into consideration when focusing on a higher quality of life.

Latex Allergy

People with spina bifida may be allergic to latex. This is an allergy to products made from natural rubber latex or foods such as: apple, avocado, banana, carrot, celery, chestnut, kiwi, melons, papaya, raw potato, and tomato.

Products made from natural rubber latex usually contain several chemicals and some people are allergic to the chemicals rather than the latex itself.

Sex and Reproduction

The male and female reproductive organs develop normally in the person with spina bifida. Nerve damage may, in some cases, affect the function of the reproductive organs.

The desire to have sexual intercourse or a sexual relationship can be as strong in someone with spina bifida as anyone else. Many people with spina bifida and hydrocephalus live happily with a partner enjoying a satisfying sexual relationship, and have families of their own.

It is advisable to take the higher dose (5 milligrams) of folic acid prior to conception.

Urinary and bowel incontinence can be an issue, but they do not make sexual relations impossible.

Pressure sores

A pressure sore is a sore on an area of skin where there is continuous heavy pressure, leading to a reduced flow of blood to the area causing tissue to erode and die. People with spina bifida, especially wheelchair users, are prone to developing pressure sores because of insensitive skin or paralysis.

Paralysis and loss of Sensation

In the case of myelomeningocele, the spinal cord protrudes from the spine throughout the pregnancy and is closed by either prenatal or post-natal surgery.

(For more information on prenatal surgery for myelomeningocele please visit our website www.sbhi.ie).

As a result, the spinal cord is almost invariably damaged and defective, the nerves being disorganised and broken. Messages from the brain (controlling and initiating movement) and those from the body to the brain (giving the sensations of touch, pain, and position) are impaired. However, paralysis, muscle weakness, and loss of sensation occur only at the level of the lesion and downward.

Due to lack of skin sensation and decreased mobility, skin tissue breakdown may occur resulting in pressure sores. In most cases, the head, upper trunk, and arms are not affected. The level of impairment varies considerably depending on location and nerves involved.

Lack of Bladder and Bowel Control (Incontinence)

The nerves that control the bladder and bowel are in the lowest region of the spinal cord. Consequently, incontinence is a major problem particularly in the case of myelomeningocele.

Lack of bladder control presents two immediate dangers: infection and back pressure on the kidneys which, without proper management, can lead to renal problems.

Hydrocephalus

Hydrocephalus is the retention of fluid in the brain and is a potentially dangerous condition involving excessive accumulation of spinal fluid within the brain caused either by over production of the fluid or more usually by an obstruction to its normal circulation.

While it is a complication of spina bifida occurring in approximately 90% of cases, hydrocephalus is by no means exclusive to spina bifida.

Scoliosis

Scoliosis describes a 'twist' or curvature in the spine. Scoliosis can occur in a person with spina bifida, due to the spine not forming completely and therefore causing the spine to twist.

Obesity

Obesity is one of the most common nutritional problems in people with spina bifida. Obesity may be a cosmetic concern for affected individuals.

More importantly, however, obesity is a major health threat. In adults, obesity has been linked to high blood pressure, diabetes, osteoarthritis, abnormal cholesterol metabolism, heart disease, sleep apnoea, and psychological problems. Similar health consequences occur for children and adolescents who are obese. Psychological problems are of special concern for developing children, who may be negatively stigmatised by others if they are obese and thus develop poor self-esteem, greater risk for isolation from peers, and depression.

Mental Health

Individuals with spina bifida may become more prone to mental health issues including depression and anxiety. This can present as mood swings, lower self-worth, self-hatred, self-harming, aggressive behaviour, insomnia, and lack of motivation. Professional help may be needed to cope with these symptoms.

Pain

Pain can be caused by problems with internal organs (visceral pain). Common locations of visceral pain include upper and lower abdomen, chest, pelvis, jaw, neck, upper arm, and upper or lower back.

Pain associated with spine and spinal cord problems can affect any areas of the body, but often involve the back, neck, arms or legs.

As people with spina bifida age, they often have pain associated with degenerative conditions that affect the spine, joints, or muscles (musculo skeletal pain).

In spina bifida, commonly seen conditions such as arthritis, osteoporosis, carpal tunnel syndrome - is a common condition that causes pain, numbness, and tingling in the hand and arm, and tethered cord syndrome.

Back pain is common in adults and can be very debilitating.

Hypertension (High Blood Pressure)

Hypertension (high blood pressure) at a relatively young age is a problem in many people with spina bifida. It may be due to many factors linked to spina bifida, but this is unclear. It is recommended that regular routine blood pressure checks are important to maintain a healthy heart and blood vessels.

Support

Spina Bifida Hydrocephalus Ireland (SBHI) offers a number of supports to individuals, families, carers, and professionals through teams such as our Family Support Service. Please see our Family Support Service leaflet for more information.

Contact details

01-4572329

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www.sbhi.ie

Fundraising

SBHI relies on the generosity and support of the public so we can help our 1000 plus members who live with spina bifida and/or hydrocephalus, and thousands of other people who are affected by the conditions including family, friends, carers, and the education and medical professionals who interact with our members on a regular basis.

To donate to SBHI, please visit <http://www.sbhi.ie/donate>; call us on 01 457 23 29, or to donate €4 to SBHI via text message, please text GIVE to 50300.

100% of the text cost goes to Spina Bifida Hydrocephalus Ireland (SBHI) across most network providers. Some providers apply VAT which means that a minimum of €3.25 will go to SBHI.

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