# What is **Spina Bifida?**

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality


## What is Spina Bifida?

Spina bifida is a fault in the development of the spinal cord and surrounding bones (vertebrae) which can leave a gap or split in the spine. The spinal cord does not form properly, and may also be damaged.

## To help understand what spina bifida is, it is useful to explain the composition of the nervous system.

The central nervous system consists of the brain and the spinal cord. Everything we do is controlled by the brain, including breathing and maintaining our body temperature.

Our senses send information to our brain, which deliver messages to different parts of the body via the spinal cord and pairs of nerves that emerge at each vertebra.

### The spine

The spine is made up of 33 bones or vertebrae. The vertebrae have two main functions- to protect our spinal cord, and to provide anchorage to our muscles.

The central nervous system and spine develop very early in pregnancy, between the 14th and 23rd day after conception.

Spina bifida occurs when the neural tube, the structure in the embryo that becomes the brain and spinal cord, fails to close correctly. The vertebrae also fail to form complete rings around the affected portion of the spinal cord. This leaves a gap at the back, involving one or more vertebrae, most commonly around waist-level.

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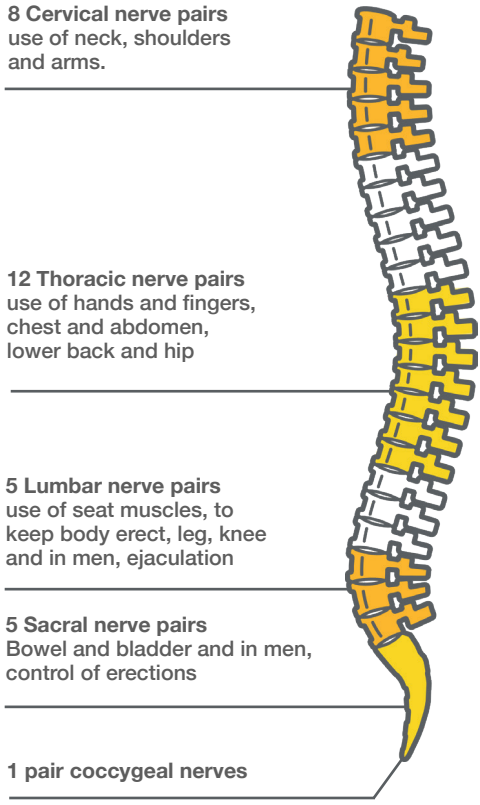


# How is spina bifida diagnosed?

**Open spina bifida, is usually detected at the antenatal mid-term ultrasound (20 week) scan.**

The appearance of the skull bones and cerebellum - part of the back of the brain - show particular signs that lead the sonographer to look for tiny changes in the spine.

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).

**Important to know:**

Closed spinal lesions such as *lipomyelomeningocoele* are often not detected at the antenatal mid-term ultrasound scan: the brain and skull will usually look normal so the changes to the spine may not be detected.

# How is open spina bifida treated?

Most commonly the baby will be seen by a paediatric neurosurgeon shortly after birth. The surgeon will then decide whether the baby should have surgery to repair the defect in the back: this surgery will take place in a specialist unit usually within 48 hours.

Sometimes, in large lesions or premature babies, there may not be enough skin available to close the lesion right away, and the Plastic Surgery Team may be involved.

It may be possible, under certain circumstances, to operate on the baby's lesion in the womb, before 26 weeks of pregnancy.

**Recommended reading...**

Visit our website for information about pre-natal surgery, and talk to your Fetal Medicine clinicians urgently if you are pregnant and would like to know more. ***www.shinecharity.org.uk/prenatalsurgery***

# What are the effects of spina bifida?

**The effects of spina bifida vary greatly. Even people with a lesion of similar size and position may experience different impairments to varying degrees.**

Generally, people with lesions at waist level (L1 or above) will use wheelchairs full-time, while most people with lesions at the bottom of the spine (sacral) will be able to walk as adults.

Many children with lesions in the mid lumbar area walk during childhood, but choose to use a wheelchair for longer distances, sports, or as they get older. Splints often help support the feet and ankles.

Loss of skin sensation can lead to sores, especially on the feet, through injury or shoes that rub.

Burns to the feet and legs are also common. It's important to protect the feet, by having correctly fitting shoes or splints, covering hot pipes and carefully checking the bathwater before getting in.

Because spina bifida changes the way the brain develops, there can be also be an impact on learning and behaviour.

**Important to know:**

Children with spina bifida should have their childhood vaccinations just like other children.

## Continence management

Most people with spina bifida have varying degrees of neuropathic bladder and bowel problems.

These are caused by damage to the nerves which interferes with normal bladder and bowel working.

It is very important to manage continence well, and to have regular assessments from infancy through adulthood, to protect the kidneys and reduce the risk of damage.

**Recommended reading...**

**You can find lots more information about the effects of spina bifida on our website:**

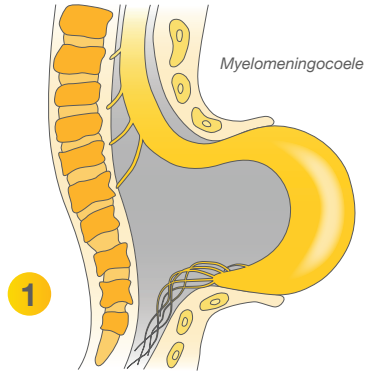
Skin care:
*www.shinecharity.org.uk/skinandtissue*

Learning and behaviour:
*www.shinecharity.org.uk/behaviour*

For lots more information about Bladder and bowel issues:
*www.shinecharity.org.uk/continencecare*

# Types of spina bifida

**There are a number of different types of spina bifida. It is present at birth and can take several forms.**




## 1 Myelomeningocoele (meningomyelocoele)

Myelomeningocoele is the most serious and more common of the two forms of cystic spina bifida. Here the cyst not only contains tissue and cerebrospinal fluid (CSF) but also nerves and part of the spinal cord.

The exposed spinal cord is damaged by the fluid in the womb during pregnancy and may also not develop properly. As a result, there is nearly always some resulting paralysis and loss of sensation.

Nerves to and from the spinal cord emerging below the damaged region may not pass messages to the brain. The extent of this can be patchy and difficult to predict.

## 2 Meningocoele

In this form, the sac contains meninges (tissues which cover the brain and spinal cord) and CSF, but no spinal tissue. Development of the spinal cord may be affected, but impairment is usually less severe than myelomeningocoele. Meningocoele is the least common form of spina bifida.

**Recommended reading...**

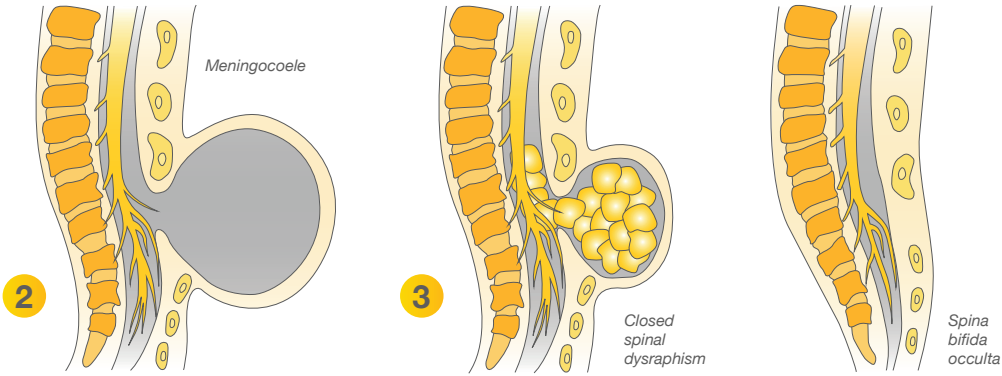
## 3 Closed Spinal Lesions (spina bifida occulta and other dysraphisms)

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.

SBO affecting only one or two bones, and with no other complicating features (such as lipoma or fatty filum), should have no impact on people’s lives

### Lipomyelomeningocoele

Lipomyelomeningocoele is a closed lesion where the spinal cord is tangled in a benign fatty lump. The exact cause is still uncertain, but it begins in early pregnancy.




**For more about the condition, visit: *www.shinecharity.org.uk/spinabifida***

A layer of cells (which will develop into the skin) may detach from the neural tissue too early, allowing fat cells to attach to the spinal cord, where they grow into a lump.

These fat cells prevent the spinal bones closing completely, leaving the 'spina bifida' gap. It is present from birth and around 90% of people with lipomyelomeningocoele have markers on their back such as fatty lumps, birthmarks or deep dimples.

Because they prevent the spinal cord from moving up inside the spine during growth, detethering surgery is often needed at some point. Any condition which can cause tethering can result in muscle weakness, bladder/ bowel issues and pain.

## Diastematomyelia

This is a condition in which the spinal cord is divided into two (lengthways), usually in the lumbar area.

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 lipomyelomeningocoele.

# Related conditions

**There are a number of conditions that share features with, or are otherwise closely linked to spina bifida.**

## Encephalocele

This is a sac which is formed when the bones of the skull fail to develop. It may contain only cerebrospinal fluid (CSF) or part of the brain may also be present in the sac, resulting in brain damage.

## Tethered cord

For a number of reasons, people with spina bifida can often find their spinal cords restricted or 'tethered' which can sometimes lead to Tethered Cord Syndrome.

## Chiari II

Chiari II is a developmental condition of the cerebellum in the brain, strongly associated with the myelomeningocoele (MMC) form of spina bifida. It is always present from birth, although symptoms may not develop until adulthood, if at all.

## Anencephaly

This is where the brain does not develop properly or is absent, and the baby is either still born or dies shortly after birth.

**Important to know:**

## Hydrocephalus

Most babies born with myelomeningocoele also have hydrocephalus (Greek - meaning water, and kefale meaning brain).

This is a build-up of excess cerebrospinal fluid (CSF) in the chambers of the brain, it compresses the surrounding tissue and raises the pressure inside the skull.

**Recommended reading...**

You can read more about these related conditions on our website: ***www.shinecharity.org.uk/relatedconditions*** or, for an in-depth look at hydrocephalus, ask for a copy of our leaflet titled ***"What is Hydrocephalus"***


# Why does spina bifida happen?

**At present we don't know exactly why spina bifida develops, but research is ongoing.**

However, we do know that taking folic acid supplements before getting pregnant can reduce the chance of spina bifida in unborn babies.

For families with no history of spina bifida the Department of Health recommends women take an 'over the counter' dose of 400mcg daily.

For families where there is a history of spina bifida, or other neural tube defects, a prescription dose (5mg) of folic acid is needed.

Folic acid should be taken daily for at least 8 weeks prior to conception and through to the 12th week of pregnancy.

The exact reasons why the neural tube develops incorrectly are not yet known but both genetic and environmental factors are known to contribute.

Shine also recommends taking a supplement of B12 (2.5mcg or more) for three months before pregnancy.

**"Folic acid should be taken daily for at least 8 weeks prior to conception and through to the 12th week of pregnancy"**

**Recommended reading...**

**You can find our more about the role of Folic Acid in pregnancy on our website**

Folic for Life:
*www.folicforlife.com*

Find out more about our campaign for the mandatory fortification of flour:
*www.shinecharity.org.uk/flourpower*

# Shine's specialist services

**If you have spina bifida, live with or care for someone who does, are a professional providing support or are expecting a baby with spina bifida - we're here to help.**

## Support and Development Workers (SDW's)

Shine employs a team of SDW's across England, Wales and Northern Ireland. They are on hand to help you make important choices

### Can advise on:

- Conditions and treatment
- Healthy lifestyles
- Independent living
- Relationships and social life

...and more.

## Your SDW can also refer you to one of the following:

## Health Team

Shine's Health Team understand the worries, concerns and frustrations you are dealing with. They provide one to one support for individuals, parents, pregnant women, relatives, carers and fellow professionals.

### Can advise on:

- Planning healthy pregnancies
- Personal care
- Anxiety and depression
- Effects of aging
- Orthopaedics

...and more.

## Educational Advisers

Our Educational Advisers know all about the challenges of getting a good education and can support you to ensure the very best experience for your child.

### Can advise on:

- Finding the right school
- Ensuring good support
- Mobility and accessibility
- School transitions

...and more.

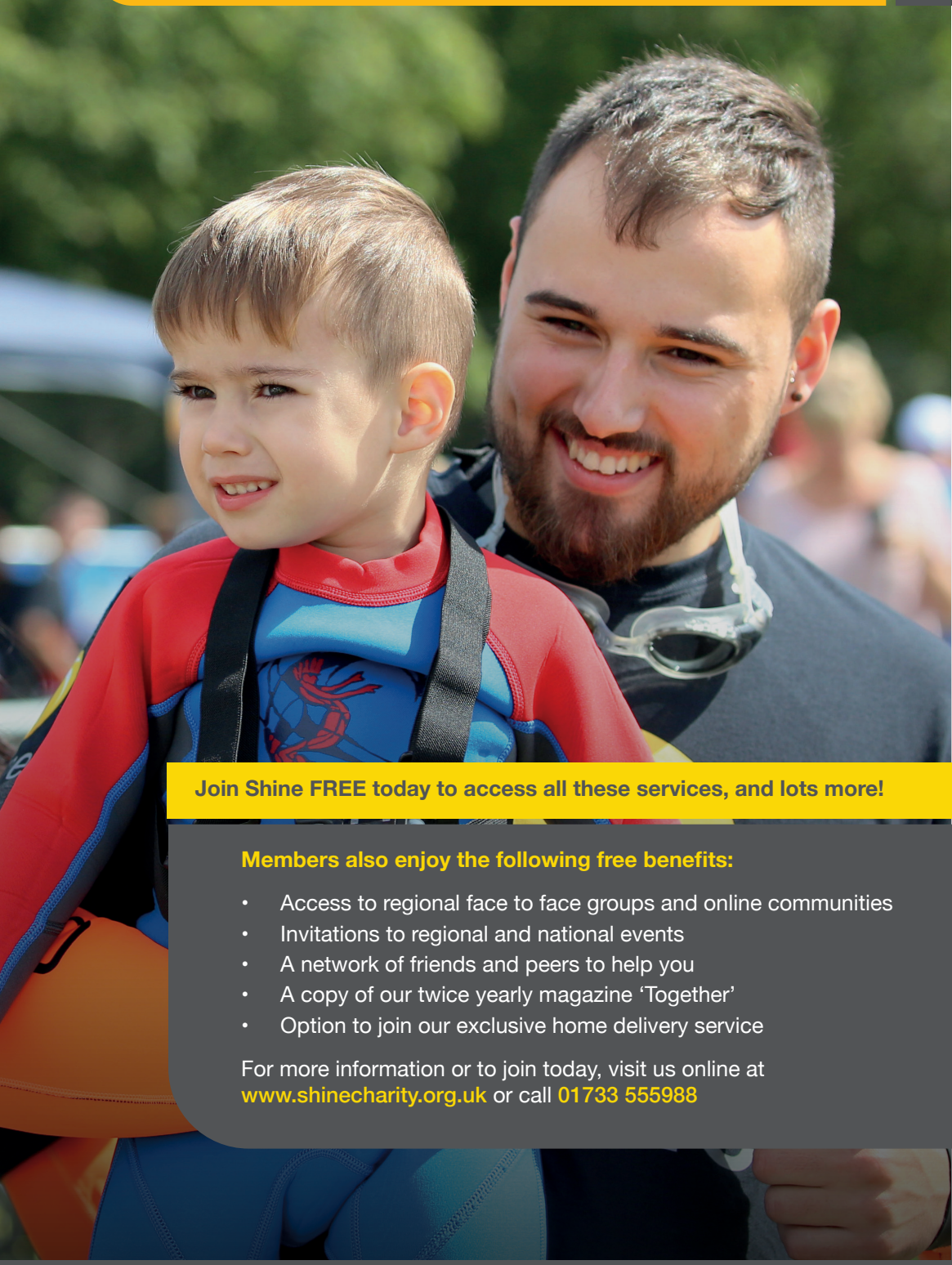
## Benefits Advisory Service

Offering one to one advice and support, we are here to support Shine members to access key disability benefits.

### Can advise on:

- Specific benefit issues
- Applications and claims
- Appealing a decision

...and more.



**Join Shine FREE today to access all these services, and lots more!**

**Members also enjoy the following free benefits:**

- Access to regional face to face groups and online communities
- Invitations to regional and national events
- A network of friends and peers to help you
- A copy of our twice yearly magazine 'Together'
- Option to join our exclusive home delivery service

For more information or to join today, visit us online at **www.shinecharity.org.uk** or call **01733 555988**

# Who are Shine?

With around 12,000 members across England, Wales and Northern Ireland, Shine is Europe's leading charity for people affected by spina bifida and hydrocephalus.

For over 50 years, we've been at the centre of developments which have improved the lives of thousands of people, enabling and empowering our members to lead the lives they want to live.

**Get in touch and join today for FREE!**

## Shine is almost entirely funded by the generosity of the public

Without your support, we could not offer vital services that help improve the lives of children, families and adults affected by hydrocephalus.

Please continue to support us in giving our members the best quality of life.

Donate today at:
**shinecharity.org.uk**

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