

SPINA BIFIDA

This fact sheet has been written by parent carers for parent carers.



What is spina bifida?

Spina bifida is a congenital disorder in the growth of the spine and spinal cord that leaves a gap in the spinal column – the bone that protects the nerves. It is sometimes known as ‘split spine’. The mildest form of spina bifida (spina bifida occulta), is very common and may affect as many as five to ten per cent of people and yet as symptoms are rare, most will not know they have it. More serious forms of spina bifida occur in about 1 in 1,000 births in the UK.

Characteristics of spina bifida

Spina bifida is usually evident from birth. It causes a range of signs and symptoms that vary in each individual. The severity of symptoms depends on where the opening occurs on the spine and whether the baby also develops hydrocephalus, or excess fluid on the brain, which can result in learning difficulties. Other symptoms may include paralysis and/or muscle weakness, bowel or urinary incontinence.

Types of spina bifida

The three main types of spina bifida that are present at birth are:

- **Spina bifida cystica** The visible sign of spina bifida cystica is that there is a sac or cyst, similar to a blister on the back, covered by a thin layer of skin. This type of spina bifida has two forms:
Type one is called **Myelomeningocele** – this is the more common of the two types of cystic spina bifida. It is also the more serious form of the condition. The sac contains tissue, cerebro-spinal fluid and also nerves and part of the spinal cord, which is damaged or not properly developed. As a result of this, there is usually some paralysis and loss of sensation below the sac. Many people will also have bowel and bladder problems, too. Most babies with this form of the condition will also have hydrocephalus, an accumulation of cerebro-spinal fluid and problems with it draining. You can find out more about hydrocephalus on the Shine website at: www.shinecharity.org.uk.
Type two is known as **Meningocele** – this is the least common form of spina bifida. The sac contains spinal cord tissue and cerebro-spinal fluid. Surgery usually corrects the problem but some people still experience bladder and bowel issues.
- **Spina bifida occulta** (hidden form) – this is the mildest form and it is very common. Symptoms are rare, so most people with this form may not even know they have it, as the opening in the spine is so small that it is not visible to the naked eye. However, for about 1 in 1,000 people with spina bifida occulta, there can be issues. This tends to become apparent during adolescence when a rapid growth spurt can cause difficulties because the part of the spine is tethered to the backbone. This can result in continence issues, scoliosis (curvature of the spine) and some reduced sensation in the legs.

Types of treatment

Treatment for spina bifida will depend upon its type and severity, which will vary from person to person. The following are the most common forms of treatment:

- **Assistive Technology** – mobility aids like wheelchairs and walking frames help children to improve their mobility and control of their symptoms.
- **Occupational Therapy (OT)** – if your child finds everyday tasks difficult, a therapist can identify solutions and help your child to develop skills to maximise their independence.
- **Physiotherapy** – helps people with spina bifida maximise their mobility and movement and builds



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strength in the leg muscles.

- **Surgery** – usually takes place about 48 hours after birth to repair the spine and put any exposed nerves or tissue back into the spinal column. Other surgery may be needed in the event your child has scoliosis or dislocated joints. If your child develops hydrocephalus, a tube called a shunt may be inserted to drain excess fluid to another part of the body.
- **Treating incontinence** – there are various interventions used to help children achieve greater bowel and urinary continence, including medication, dietary changes, catheterisation and surgery.

Ask about

- **Information, Advice and Support (IAS)** – Amaze supports families of children and young people with SEN and disabilities in Brighton and Hove. We have a helpline, publications and a website. We also run workshops and courses and can offer one-to-one support with EHC planning and making DLA and PIP claims. Call Amaze on: **01273 772289** or visit: **www.amazebrighton.org.uk**.
- **Chailey Heritage Clinical Services** – a range of services and therapies available to children with complex physical or neurological physical disabilities. Tel: **01825 722112**.
- **Compass Card** – a free leisure discount card administered by Amaze for 0 to 25 year olds with significant additional needs who live or go to school in Brighton and Hove or West Sussex, or who are looked after by social services in these areas. Call Amaze on: **01273 772289**.
- **Independent Support** – Amaze's Independent Supporters provide extra advice and support to young people and parent carers who are going through the process of getting an EHC Plan in Brighton and Hove and Sussex. For Brighton and Hove Independent Support, call: **01273 772289**. For Sussex Independent Support, call: **0300 123 7782**.
- **Integrated Child Development and Disability Centre (Seaside View)** – where many children will be diagnosed and where services work together to treat and support them. Referrals will usually be via a health or education professional but you can contact Seaside View direct on: **01273 265780**.
- **Making a claim for DLA** – if your child's care or mobility needs are significantly greater than the needs of their peers you may be able to claim Disability Living Allowance for them. Find out more at: **www.gov.uk**. Amaze can give you advice and practical support with making a claim. Call the helpline on: **01273 772289** or email: **helpline@amazebrighton.org.uk**.
- **SASBAH (Sussex Association for Spina Bifida and Hydrocephalus)** – offers advice and support services across Sussex but welcome enquiries from Brighton and Hove families too. Also has some resources online. Tel: **01903 230782** or go to: **www.sasbah.org.uk**.

Further reading and useful links

- **Through the Maze** – Amaze's handbook for parent carers of children and young people with SEN and disabilities (0-14) includes lots of information on education, money matters, social care, health, leisure and more. It's free to parent carers of children who live or go to school in Brighton and Hove. Call the Amaze helpline to request a copy on: **01273 772289**.
- **Headway** – an organisation that deals with brain injuries and conditions, its website has useful information about hydrocephalus. Go to: **www.headway.org.uk**
- **Local Offer** – the local authority's online listing of all the services and support that are available to families with children with SEND in the area. Visit: **www.brighton-hove.gov.uk/localoffer**.
- **Shine Charity** – go to: **www.shinecharity.org.uk**.

