

SPINA BIFIDA

This fact sheet has been written by parent carers for parent carers.
Clinical information has been approved by West Sussex practitioners.



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

Most cases of Spina bifida are found during antenatal scans. The condition 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 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.





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- **Physiotherapy** – helps people with spina bifida maximise their mobility and movement and builds 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** – various interventions can help children achieve greater bowel and urinary continence, including medication, dietary changes, catheterisation and surgery.

Ask About

- **Chailey Heritage Clinical Services** – a range of services and therapies available to children with complex physical or neurological physical disabilities. Tel: **01825 722112**.
- **Child Disability Service** – a social work service for children and young people with severe and/or complex disabilities, it works with families and other agencies to ensure they get the right support. Information can be found via the local offer website: <https://westsussex.local-offer.org/services/265-child-disability-teams-lifelong-services-social-care> or families should call the Integrated Front Door (IFD) for West Sussex Children Services on **01403 229900** or complete the online referral: www.westsussex.gov.uk/Raiseaconcernaboutachild.
- **Compass Card West Sussex** – a free leisure discount card for 0 to 25 year olds with SEND, which is run by Amaze. Find out more at: www.compasscard.org.uk or by calling: **0300 123 9186**.
- **Headway** – an organisation that deals with brain injuries and conditions, its website has useful information about hydrocephalus. Go to: www.headway.org.uk or call their helpline: **0808 800 2244**.
- **Portage** – a home-based educational programme tailored to a child's individual needs. Available to very young children. Chichester: **01243 536182**; Crawley and East Grinstead: **01293 572480**; Horsham: **01243 536182**; Mid-Sussex: **01444 243150**; Worthing: **01903 242558**.
- **Sensory toys** – available for parents and carers to borrow from a number of children and family centres and some libraries. Please visit: www.westsussex.gov.uk/education-children-and-families/support-for-families/toy-libraries
- **Shine Charity** – go to: www.shinecharity.org.uk.
- **Short Breaks for Disabled Children** – commissions holiday clubs, after school clubs, buddy schemes and short breaks at home or in the community. Tel: **0330 222 2562** or email: SENDCommissioningTeam@westsussex.gov.uk.
- **Sussex Association for Spina Bifida and Hydrocephalus (SASBAH)** – runs a number of services for children, adults and families including an advisory service, family support, a social programme and support groups that meet in Burgess Hill, Crawley and Worthing. Tel: **01903 230782** (advisor service), **01825 873045** (general enquiries) or go to: <https://sasbah.org.uk>.
- **West Sussex Children Services** – support from health and social care. If your child is under 18, call the Integrated Front Door (IFD) for West Sussex Children Services, tel: **01403 229888** or email: WSChildrenservices@westsussex.gov.uk. For over 18s call the Adults' CarePoint: **01243 642121**, or email: socialcare@westsussex.gov.uk.
- **Other resources** – the Ashdown club, Worthing: **01903 528607**; Kangaroos, Haywards Heath: **01444 459108**; PACSO, Chichester: **01243 533353**; Springboard Project, Horsham: **01403 218888**.

Further reading and useful links

- **Making Sense of it All** – our handy parent/carer guide contains information and advice on benefits, support for your child at school, getting help from social services and accessing social & leisure activities – www.reachingfamilies.org.uk.
- **Disability Living Allowance (DLA)** – your child may qualify for DLA, a state benefit that will help with their care. For further information visit: www.gov.uk/disability-living-allowance-children.
- **West Sussex Local Offer** – go to <https://westsussex.local-offer.org> and search for 'Spina bifida'.

