

## Useful Contacts

### Physiotherapist

Name \_\_\_\_\_

Telephone number \_\_\_\_\_

### Occupational Therapist

Name \_\_\_\_\_

Telephone number \_\_\_\_\_

### Advisory Teacher

Name \_\_\_\_\_

Telephone number \_\_\_\_\_

### Continence Service

Name \_\_\_\_\_

Telephone number \_\_\_\_\_

### Other

Name \_\_\_\_\_

Telephone number \_\_\_\_\_

## Advisory Teaching Service

### BASES

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Glos. GL14 2DB

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forest.ats@gloucestershire.gov.uk

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chelt.ats@gloucestershire.gov.uk

Advisory Teaching Service  
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Beeches Green, Stroud, Glos GL5 4AE

☎ 01452 583728  
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Understanding and responding  
to pupils with

# Spina bifida

Information and advice for schools



Advisory Teaching Service

PD Team



Quality Assured 2018



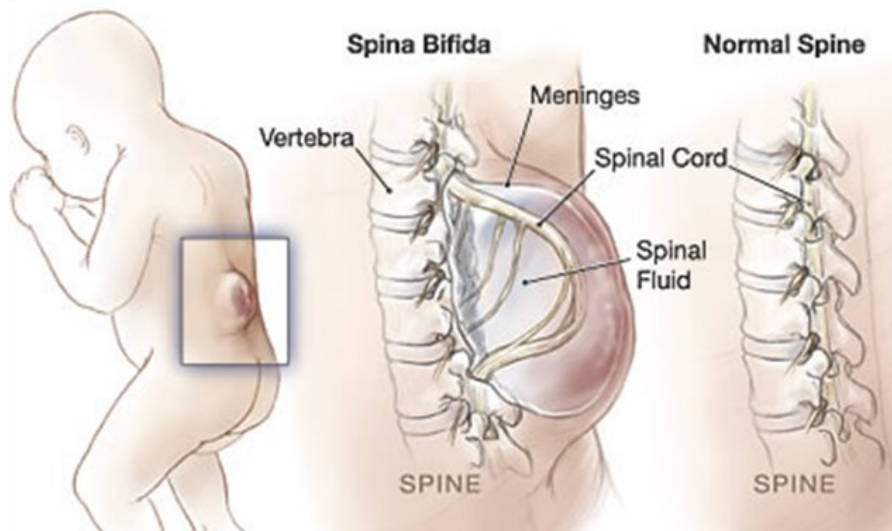
Gloucestershire  
COUNTY COUNCIL

## An overview of spina bifida & the central nervous system

### What is spina bifida?

Spina bifida literally means 'split spine'. The spinal column, consisting of ring-shaped bones (vertebrae) does not develop fully, resulting in a gap that leaves the spinal cord, which is usually encased by the vertebrae, exposed. To fully understand spina bifida it is important to know how the central nervous system works, and its relationship with the spine.

The central nervous system consists of the brain and the spinal cord. The brain receives information through the spinal cord from the various sensory systems of the body and also relays messages from the brain to control body functions. If the spinal column is damaged the pathway between the brain and parts of the body is therefore affected.



## In an educational setting

### How to help?

- ✓ Consider the **whole student**, i.e. social, personal and learning as well as physical needs
- ✓ Include advice from health professionals, e.g. physio and occupational therapists, into daily routine as appropriate
- ✓ Provide sensitive support for management of continence needs
- ✓ Use general and specialised equipment to ensure safe access to the curriculum, school site and school visits
- ✓ Ensure the safety of the student and staff working with them
- ✓ Decide priorities and establish short, medium and long-term goals
- ✓ Work closely with the student's family, especially at times of change
- ✓ Allow for extra time as appropriate, e.g. to move between different areas of the school
- ✓ Allow for fatigue and any other associated difficulties
- ✓ Refer to the school's Access Audit and Disability Equality Scheme and provide a risk assessment as appropriate
- ✓ Provide positive role models to pupils and their peers.
- ✓ Ensure that there are appropriate reading materials in classroom and libraries and displays represent all those in the school community

## In an educational setting

Most students with spina bifida have very successful school careers and enjoyable teaching and learning experiences.

### What are the challenges?

- ◆ Accessing some aspects of the school curriculum e.g. practical activities
- ◆ The amount of time required, e.g. to support continence management
- ◆ Reaching different areas of the school
- ◆ Ensuring pupils can sit correctly, comfortably and safely
- ◆ Some pupils may experience pain and/or fatigue which may affect their ability to focus in lessons
- ◆ Enabling self esteem, particularly in secondary schools e.g. overcoming stereotypical attitudes
- ◆ Ensuring appropriate facilities, protocols and practice to support continence management
- ◆ There is evidence that an individual who has hydrocephalus may have difficulties with some processing, memory and/or comprehension skills

### Useful websites

[www.shinecharity.org.uk](http://www.shinecharity.org.uk)

## An overview of spina bifida & the central nervous system

### How is spina bifida caused?

The causes of spina bifida are currently unclear. However, recent research indicates that a mother's diet maybe a key factor, particularly if it lacks folic acid.

### How is spina bifida diagnosed?

In most cases, spina bifida is diagnosed before birth via routine and more specialist scans. However, some mild cases may go unnoticed until after birth.

### How is spina bifida treated?

There is no cure for spina bifida. The nerve tissue that is damaged or lost cannot be repaired or replaced, nor can function be restored to the damaged nerves. Treatment depends on the type and its severity. Some individuals with spina bifida use mobility aids such as walking frames, crutches or wheelchairs. The location of the malformation on the spine often indicates the type of assistive equipment needed.

## Different types of spina bifida

### What are the implications of spina bifida?

The effects of spina bifida vary from person to person, as it is determined by the size and location of the malformation, whether it is covered by skin, and which spinal nerves are involved. However, as all nerves located below the malformation are affected to some degree, the higher the malformation occurs on the back, the greater the amount of nerve damage, loss of muscle function and sensation.

### What are the different types of spina bifida?

**Occulta** is the mildest and most common form in which one or more vertebrae are damaged. The name “occulta,” which means, “hidden,” indicates that a layer of skin covers the lesion, or opening in the spine. This form of spina bifida, presents in 10 to 20 percent of the general population, and rarely causes disability or symptoms.

**Closed neural tube defects** make up another type of spina bifida. This form consists of a diverse group of spinal defects in which the spinal cord is marked by a malformation of fat, bone, or membranes. In some individuals there are few or no symptoms; in others the malformation causes partial paralysis with urinary and bowel dysfunction.

## Different types of spina bifida

**Meningocele**, occurs when spinal fluid and the meninges protrude through an abnormal vertebral opening; the malformation contains no neural elements and may or may not be covered by a layer of skin. Some individuals with meningocele may have few or no symptoms while others may experience symptoms similar to closed neural tube defects.

**Myelomeningocele**, is the most severe. It occurs when the spinal cord/neural elements are exposed through the opening in the spine. This results in partial or complete motor paralysis and sensory deficits within the parts of the body below the spinal opening. The paralysis may be so severe that the individual is unable to walk and may have significant urinary and bowel dysfunction.

### Hydrocephalus

Many babies born with spina bifida have the associated condition of hydrocephalus. This occurs when the cerebrospinal fluid in the brain is prevented from circulating or being re-absorbed. This leads to increased pressure on the brain. In younger children, whose skull bones have not yet fused together, the size of the head may be noticeably larger than their peers.