



The Association of Paediatric Chartered Physiotherapists

APCP Information - Spina Bifida in Children Information for Parents and Carers

What is spina bifida?

Spina bifida is when a baby's spine and spinal cord (neural tube) does not develop properly in the womb, causing a gap in the spine. The cause of spina bifida is unknown, although it has been linked to genetic and environmental factors.

There are different types of spina bifida which can be described as open or closed. (10)

Closed spina bifida:

- The most common presentation is **spina bifida occulta**. This is when there is a small gap in the bones of the spine, but nothing pushes through it. There's no opening on the baby's back. Often people are unaware they have it.
- **Lipomyelomeningocele** is where the spinal cord is tangled in a benign fatty lump

Open spina bifida:

- **Meningocele** is when a sac containing spinal fluid pushes through the gap in the spine. This can be seen on a baby's back. The spinal cord remains in the correct place.
- **Myelomeningocele** is when a sac containing part of the spinal cord pushes through the gap in the spine and the skin. You can see it on the baby's back.

How could spina bifida affect my child?

Spina bifida causes damage to the nerves in the spinal cord. This damage can disrupt messages to the brain. It often affects movement and sensation in the legs, as well as bladder and bowel function.

The specific muscles affected depends on the level of your child's spina bifida. This is sometimes referred to as the 'level of lesion'. It is common for each side of the body to be affected differently.

Some children may have other conditions associated with spina bifida for example:

- Hydrocephalus - a build-up of fluid in the brain
- Chiari II - a malformation of the top of the spine and part of the back of the skull
- Orthopaedic conditions affecting the spine, hips and feet
- Tethered cord - the spinal cord is attached to the surrounding tissues of the spine

How is spina bifida treated?

Treatments for the symptoms or conditions associated with spina bifida include:

Surgery

Surgery is done soon after birth and, in some cases, in – utero while the mother is still pregnant. Surgery aims to close the opening in the spine. Although surgery will repair the neural tube defect, it cannot reverse any nerve damage.

Therapy

Physiotherapy, occupational therapy, podiatry and orthotics aim to support independence and comfort of day-to-day activities.

Other treatments include management and treatment of bowel and bladder complications and orthopaedic conditions associated with spina bifida.

How can physiotherapy help my child?

- Support strength and flexibility of muscles through activity and exercises.
- Support body and postural alignment to help maintain a straight spine and keep feet and legs in position for weight bearing activities. This may include assessing for equipment such as specialist seating or standing frames, orthotics and splinting.
- Promote independent activity. This may include helping your child to use mobility aids such as walkers and wheelchairs.
- Advice on keeping skin safe, teaching parents/carers and child to monitor high-risk areas daily e.g., feet, legs, buttocks, spine.
- Support a child to manage their bowel and bladder from a physical perspective.
- Assess and help manage associated conditions e.g. hydrocephalus, Chiari II and tethered cord.
- Work as part of your child's multi – agency team to ensure your child is supported at home, in school and in their community.

What supportive equipment might my child need?

This will depend on the level of the lesion.

Orthotics may include different types of splints and supportive footwear. These can help to keep joints in alignment, prevent deformity, or provide support so that a child can stand or take steps.

Standing frames provide the opportunity for your child to weight bear. This is good for bone health and may help with digestive, cardiovascular and respiratory health. Standing also gives a great stretch to the muscles in the legs to stop them from getting tight.

Specialist seating helps support your child to use their hands better and concentrate more on activities like eating, playing or schoolwork.

Wheelchairs or walking aids can help to promote early mobility and independence in line with their peers.

What types of therapeutic activities might be helpful for my child?

There are many different things that can help children with spina bifida to develop sensory and motor skills and confidence.

What your child is offered will depend on how they are affected by their spina bifida and what services your therapy team is able to offer.

- Aquatic therapy – activity, exercise and swimming in water can help to improve core strength, balance, walking speed and quality of life. It's also a super fun thing to do as a family! (4)
- Horse riding therapy – using horses as part of a therapeutic plan can help improve balance, wellbeing, quality of life, trust, reducing spasticity, increasing self-esteem, pleasure and a sense of accomplishment. (5, 6)
- Rebound therapy – using a trampoline as part of a therapy program can be a fun way of helping your child develop strength, balance, co-ordination and even communication skills. (7)
- Electrical stimulation – there is early evidence to support significant benefits to strength, sensory awareness, circulation and even bowel function using electrical stimulation under the supervision of a qualified therapist. (8)
- Physical activity and movement is very important for all children and should be incorporated into everyday life (9). Examples include parking a bit further away and walking to school/shops, climbing upstairs, throwing rolled up socks into the drawer, setting the table or any other household tasks, sitting on a gym ball or wobble cushion for seated activities etc.
- Check out local councils and charities for sports and activity groups which are held in your local area. Regular exercise can be a useful way to promote cardio-vascular activity which we all benefit from, in addition to helping reduce the risk of becoming overweight which can affect children as they get older.

Further Information

- Shine is a charity that supports people with spina bifida and their families from diagnosis throughout life. There is a lot more information about spina bifida and the free support they offer, available on their website www.shinecharity.org.uk
- The APCP has lots of tips and ideas you can use to help your child's development - [The Early Years Movement Hub](#)

References

[Spina bifida - NHS \(www.nhs.uk\)](http://www.nhs.uk)

[Guidelines for the Care of People with Spina Bifida - Spina Bifida Association](http://www.spina-bifida.org.uk)

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[An Exploratory Electrical Stimulation Protocol in the Management of an Infant With Spina Bifida: A Case Report \(sagepub.com\)](http://sagepub.com)

[UK Chief Medical Officers' Physical Activity Guidelines \(publishing.service.gov.uk\)](http://publishing.service.gov.uk)

[what-is-spina-bifida---updated-january-2020.pdf \(shinecharity.org.uk\)](http://www.shinecharity.org.uk)

This leaflet has been produced following a review of relevant literature and where there is lack of evidence, a consensus of expert opinion is agreed, correct at time of publication.

APCP

<https://apcp.csp.org.uk>

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