

FACTSHEET

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Lower limb paralysis and Spina Bifida

Leg strength and movement can vary with each person living with Spina Bifida. Any lower limb paralysis is determined by the location of the Spina Bifida lesion (myelomeningocele) on the spine and how much nerve and spinal cord damage is present. People with lesions low on the spine usually learn to walk independently, often with the aid of ankle foot orthoses (AFOs). People with higher lesions may need orthoses that give greater support of the legs. They may also need walking aids or a wheelchair for their mobility.

Mobility aids

There are many aids available to help people learn to stand, walk and move about. The type of aid needed will depend on the individual's degree of paralysis. These aids can change as a person grows. It is important that the aids are the correct size, to ensure the most effective use and to avoid skin pressure injuries. Aids are prescribed by Physiotherapist and Doctor.

Wheelchairs

Some people living with Spina Bifida will need to use a wheelchair as their main way of moving about. Others may find that using a wheelchair for activities that require them to mobilise over long distances, such as excursions or shopping, enables better involvement in these activities.

Children who need wheelchairs will be introduced to them during the preschool years. This allows greater independence and time for the child to develop safe wheelchair skills before they start formal school.

There are many types of wheelchairs. The Occupational Therapist will help you choose the most appropriate wheelchair and will teach the skills needed to use them.

Orthoses

These are custom made splints, moulded from special plastic and metal. These splints support the legs for walking, maintain foot positioning in a wheelchair, or at night to prevent muscles tightening across joints. Orthoses should be reviewed by an orthotist at least once a year for adults, and at least each six months for children. Orthoses need to be cleaned regularly and inspected for any signs of wear and tear. If they don't fit well, they could lead to a pressure injury. Your Orthotist should be contacted immediately if you have any concerns.

Walking frames, crutches, walking sticks

These aids support part of the person's weight as they stand and walk. They also help with balance. Practice is needed to develop good balance skills and confidence when walking on level ground, rough ground and also up and down ramps and stairs. Physiotherapists can assist in prescribing the correct walking aid and how best to use them.

Sensory function

The nerves in the spine affected by Spina Bifida are both motor and sensory. This means that people living with Spina Bifida can have weakness in the legs. They may also have difficulty feeling and sensing pain, temperature, touch and position. Careful positioning of the legs and

daily inspections of the skin is required to prevent pressure injuries, burns and other serious complications.

Tethered spinal cord

The damage to the motor and sensory nerves present at birth in Spina Bifida is permanent. Any further changes and deterioration in a person's mobility or movement as they grow older should be reported to the doctor, as this may indicate a tethered spinal cord. A tethered cord occurs when the spinal cord is caught by fibrous scar tissue or fatty tissue that prevents it from moving freely in the spinal column. This requires urgent medical attention and should not be ignored.

Symptoms and signs that may indicate a tethered cord include:

- Deterioration of walking ability.
- Lower back and or leg pain that is persistent and progressive.
- Onset of deformity in the feet not previously present.
- Changes in sensation in the legs.
- Changes in continence.

Read the fact sheet about Tethered Spinal cord syndrome for more information:

www.schn.health.nsw.gov.au/parents-and-carers/fact-sheets/tethered-cord-and-spina-bifida

Remember:

- There are many types of mobility devices and orthoses suitable for people with spina bifida. The Physiotherapist, Occupational Therapist and Orthotist will explore suitable options for maximum independent mobility.
- Daily care routines and skin inspections are needed to prevent skin injuries and other injuries to the legs.
- Contact your Orthotist immediately if there are concerns with ill-fitting orthoses.
- Symptoms of a tethered cord should not be ignored. Contact your doctor immediately.