Neuromuscular scoliosis

Cause

Neuromuscular scoliosis is curvature of the spine, which occurs because of a neurological or muscular condition.

Neurological conditions affect the body’s nervous system. Examples are cerebral palsy and spina bifida. Neurological conditions happen when there is damage to the brain or nerves caused by illness or injury.

Muscular conditions such as Duchenne muscular dystrophy or spinal muscular atrophy stop the muscles from working. When the muscles do not work, scoliosis can develop. Patients with these conditions often develop scoliosis or kyphosis, or both. As the patients grow and their trunk muscles get weaker, the spine gradually begins to collapse, which creates a long, C-shaped, collapsing scoliosis.

Treatment

Patients with neuromuscular scoliosis should be seen by a scoliosis specialist. Children with neuromuscular conditions will be monitored by specialist doctors from a young age. This monitoring is essential to make sure that curvatures do not get too big. X-rays of the spine will be taken to measure the size of the curve. MRI scans of the brain and the spine may be needed to rule out any other problems. The treatment of neuromuscular scoliosis will be tailored to the needs of each individual patient. They will need to have a number of specialists involved in their care.

Scoliosis can make walking more difficult. For wheelchair users it can affect stability and comfort when seated.

Bracing might be used to provide support for the patient’s trunk (central part of the body) when they are sitting but it will not usually stop the curve from progressing (getting bigger). Adjustments and aids for seating such as inserts into wheelchairs may help with the positioning and comfort of a child, but these will not correct the scoliosis.

A key issue for families and their doctors is whether surgery is the best choice. Surgery would aim to help the child to keep the ability to sit. The question would be whether that surgery would maintain or improve the child’s quality of life and function’ (In medical language, function is a word to describe the normal and proper action of any body-part or organ.)

For some children with cognitive or sensory impairment, these decisions are difficult. Parents often struggle with the fact that they can’t explain to the child why they are having surgery. It can be very hard or even impossible to help them understand the pain that goes along with this operation. These can be difficult issues to deal with when taking into account the risks and the recovery process of this type of surgery.

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These decisions should be made with great care. Talking with other families who have been through this decision process is very helpful. SAUK can put families in touch with other members who have first-hand experience of neuromuscular scoliosis. In the end, it will often be down to the parents to make this difficult decision for their child.

**Surgery**

Surgery is usually offered only to patients who have a progressive (growing) curve that interferes with ‘function’, affects breathing ability, causes pain, or is likely to cause difficulties in the years ahead.

Surgery may also be offered to patients with curves larger than 50 degrees. The patient may have a tilted pelvis (pelvic asymmetry) as well as a large spinal curve. In these cases the spine and the pelvis will be operated on to correct the asymmetry. (The pelvis is the large frame at the bottom of the spine. The legs are attached to it.)

The aim of surgery is to rebalance the spine and preserve function, comfort, and quality of life. The spinal curve(s) are partly corrected but the main aim is to stop the curve from getting worse. Although many patients are severely disabled, they can usually live fulfilling and productive lives.

**Prognosis (the outcome)**

Scoliosis is common in neuromuscular conditions and often occurs when a child is young. Because it is important to spot scoliosis early, children with neuromuscular conditions need to be checked every year for any problems with the spine. Treatment is usually an operation, and it is usually necessary to fuse (join together) a large section of the spine. In many cases spinal fusion surgery has improved the quality of life for children with neuromuscular conditions.

**Definitions**

**Cognitive** - Mental activities such as thinking, understanding, learning, and remembering

**Function** - The special, normal, or proper action of any body part or organ

**Sensory** - Sight, smell, taste, touch, or hearing