NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.℠

Helping Hand™ Health Education for Patients and Families

Management and Treatment of Neuromuscular Scoliosis in Spina Bifida

The spine helps keep us upright when we are sitting and walking. When a person who has spina bifida (spy na BIFF e da) also has scoliosis (sko lee O sis), or spinal asymmetry, the spine is not straight. It may be because of curvature or twisting of the spine, usually in an "S" or "C" shape. This can progress over time.

Scoliosis occurs in about half of the people with spina bifida. Neuromuscular scoliosis can progress more quickly and to a larger curve in children with Spina Bifida than in those who do not have it. If scoliosis is diagnosed, the risk that the curve can get worse is higher during growth spurts. We will keep monitoring your child until he or she has finished growing.

Cause

The cause of scoliosis in those with spina bifida is not known, but it is likely related to other abnormalities of the spine, nerves and muscles. Scoliosis is not contagious - you cannot "catch" it from another person.

There is no known cure, but the condition can be managed with treatment.

Risks

Those with a family history of scoliosis are more likely to have it.

Signs and symptoms

Some of the early signs of scoliosis are:

- **Shoulders or hips appear asymmetrical (one side looks higher or lower)**
- One side of the chest or back sticks out or appears more prominent
- The child leans to one side when standing or sitting

Later you may see these signs:

- Trouble breathing
- Pressure sores
- Decreased mobility or flexibility of back and spine
- Your child is unable to sit upright in a wheelchair without leaning forward or to the side, or the wheelchair is not supporting the child as it did when he or she first got it.

Diagnosis

- A clinical exam will be done to look signs of scoliosis. We will check for:
  - spinal asymmetry, one side of the of the back looks different than the other
  - differences in height and shape of shoulders, hips, back and spine
- If the exam shows scoliosis is possible, x-rays (one from the front and one from the side) will be taken to measure any curvature of the spine.
- A curvature of 10 degrees or more meets the diagnosis for scoliosis.

Treatment

Picture 1 Bending Brace

- For curves under 20 degrees that do not get worse, routine x-rays will be recommended. These x-rays keep track of changes until your child has finished growing.
- If the curve progresses over 20 degrees, and your child is still growing, a brace may be recommended to keep the curve from worsening. Depending on your child's age and the curve (C or S shaped) a nighttime bending brace (Picture 1) or a Boston-style brace will be prescribed. We will watch the curve by taking x-rays while your child is out of the brace. The brace will likely be worn until your child has finished growing.
  - **A nighttime bending brace** is worn at night only. It will bend the spine in the opposite direction of the curve.
  - **A Boston-style brace** is usually worn for 23 hours of the day. It used to keep the spine upright and minimize the curve while worn.
  - Bracing does not always help. It usually is not recommended if your child is near full growth. It is not used to correct the curve, but to keep the curve from getting worse.

- If a brace is prescribed for your child, the orthotist who specially makes the brace will explain how to wean your child into it. X-rays with the brace in place will follow. This is to ensure the brace is reducing the curve while it is worn. Once the brace is shown to give adequate correction for the curve while worn, routine follow-up will include x-rays outside the brace to measure the curve.
- If a brace is prescribed, it is important to check the skin often to reduce risk of a pressure sore or skin breakdown.

3. If the curve of the spine progresses and reaches over 40 to 50 degrees, there is more risk of the curve continuing to progress over time into adulthood. This lessens the amount of room for your child's lungs and organs as an adult, as well as increasing the risk of skin breakdown.
   - If the curve is over 40 to 50 degrees and the child is young and continuing to grow, surgery may be recommended. A growing construct or rods that can be made longer over time are placed near the spine to keep the curve from worsening. It gives some correction, and will be lengthened over time as your child grows.
   - If your child is skeletally mature and is finished growing with a curve over 40 to 50 degrees, a spinal fusion may be recommended. This keeps curvature from worsening during adulthood. The goal of spinal fusion is to make the spine straighter and make the size of the curve smaller. It will fuse the vertebrae of the spine together. The fusion will not allow the curve to continue to progress. Rods are also placed alongside the spine, fixed by screws, and will stay in place unless there is a problem. Some mobility of the spine will be limited after a fusion, but most of the motion to the hips will remain.

What to do and watch for at home

Watch your child's position. If you feel his or her position is rapidly changing, call for a follow-up. Watch for these signs of tethered cord syndrome:

- worse back pain that shoots to arms or legs
- new muscle weakness or less function of legs
- more or worse spasms or shaking of legs
- change in position of feet (higher arches, curled toes)
- change in bowel and bladder function
- more accidents, leaking, or wet time.

Activity and diet

Scoliosis is usually not associated with back pain. There are no activity restrictions. Children are able to take part in activities as they please. If your child has back pain and tethered cord is ruled out, other treatment will be discussed.

Follow-up appointments

If your child has been diagnosed with scoliosis, you and your child can expect to have regular follow-up appointments with the doctor. These appointments usually occur every 6 months to a year, until skeletal maturity.

Other information (write on another sheet if needed.)

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