



Scoliosis and Marfan Syndrome

WHAT IS SCOLIOSIS?

Scoliosis is a curving of the spine to one side. About 6 in 10 people with Marfan syndrome (MFS) have scoliosis, but only 1 in 3 need medical treatment for it. People need treatment when they have back pain, major changes in posture and body shape, or are likely to have breathing problems later in life. Scoliosis can be in any part of the spine, but is most common in the upper spine.

Scoliosis can be mild to severe, based on the size of the curve. Mild scoliosis is a small curve less than 20 degrees; moderate scoliosis is a medium-sized curve of 20 to 40 degrees; severe scoliosis is a large curve greater than 40 degrees.

Children with MFS who have scoliosis should be checked by an orthopedist (doctor who specializes in bones) 1 to 2 times a year. Adults with scoliosis should be checked every 1 to 3 years.

WHAT CAUSES SCOLIOSIS?

Scoliosis is caused when ligaments in the spine are so loose they cannot firmly hold the vertebrae (bones in the spine) in place. The rapid growth seen in a child with MFS can also make scoliosis increase. This often happens with the growth spurt during adolescence (teen-age years).

WHO NEEDS TREATMENT FOR SCOLIOSIS?

Whether or not a person needs treatment for scoliosis depends on the size of the curve and how much more a person will grow. Children are likely to need treatment for scoliosis as they have many years to grow. The younger a child is when scoliosis begins, the more likely the curve will increase.

For example, a child less than three years old with a curve of only 10 degrees may need treatment later in life while a 14-year old with a small curve (less than 20 degrees) might not. People of all ages with large-sized curves (greater than 40 degrees) almost always need medical treatment.

HOW DO DOCTORS MEASURE EXPECTED BONE GROWTH?

Doctors use a Risser Scale (or Risser Score) to measure how much more bone growth a child is likely to have. This is based on findings from an x-ray of the hip bones (pelvis.) The Risser Scale goes from 0 to 5, with 0 being the most expected bone growth and 5 being the least. Children with a Risser Score of 0 to 2 are likely to have several more years of bone growth and are at risk for scoliosis to get worse.

HOW IS SCOLIOSIS TREATED?

Scoliosis can be treated in one or both of these ways:

- **Back brace.** A back brace can be used to straighten the back of a child. While the spine is straighter when the brace is in place, the curve almost always goes back to the original shape when the brace is taken off. This happens slowly over time.



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- **Surgery.** Doctors recommend surgery when the scoliosis curve is 40 degrees or more. An orthopedic surgeon is the doctor who does this type of surgery. In surgery, the spine is straightened with metal rods. The vertebrae are also fused to keep the spine straight. The rods do not hurt after the surgery has healed. In children under 10 years old whose spines are still growing, an orthopedic surgeon may use special “growing rods” that can be made longer as the child grows. Surgery is done either through the back (posterior approach) or from the front (anterior approach), depending on the size and kind of curve. Scoliosis surgery has a high success rate. Most people return to school or work 1 to 2 months after surgery.

WITH RODS, CAN YOU STILL HAVE AN MRI TEST?

Yes. People often ask if they can have MRI studies when they have rods in their spine. MRI studies are possible no matter what kind of metal rod is used. The rods show up on the MRI as a “halo” or invisible area. Titanium (one kind of metal) rods make the smallest halos.

HOW DOES SCOLIOSIS TREATMENT DIFFER FOR SOMEONE WITH MFS?

Scoliosis treatment may differ due to its cause. The most common cause of scoliosis is called “idiopathic scoliosis.” This is different from scoliosis caused by MFS. Talk with your doctor about how treatment might affect you. Here are some facts to know:

- There is a lower success rate for using a brace to treat Marfan scoliosis than for idiopathic scoliosis. Most children with MFS who have a curve of more than 25 degrees and a Risser score of 0 to 2 will at some time need surgery, even after using a brace.
- In 1 in 4 people with MFS, pedicles (a part of the vertebrae) are narrow and thin. When this happens, using screws to keep the spine rods in place may not work. If so, the surgeon will need to use other methods to keep the rods in place.
- The dura (tube around the spinal column that holds the spinal fluid) is weak in people with MFS. This increases the risk of spinal fluid leaking during surgery. The surgeon must take special care when the dura is weak.
- People with MFS are more likely to have their scoliosis come back after surgery. This happens less often when surgeons fuse a large section of the spine.
- People with MFS may have an unusual scallop shape on the inside of their spinal column. The surgeon needs to use CT scans to understand this shape when planning surgery.
- The spine of someone with MFS may curve forward (kyphosis) as well as to the side (scoliosis). The surgeon may need to plan surgery to manage both the scoliosis and the kyphosis.

WAYS TO LEARN MORE ABOUT MARFAN SCOLIOSIS

- Call the National Marfan Foundation (NMF) Resource Center at 1-800-862-7326 ext. 26. You will speak with a nurse who can answer your questions and mail you information. She can also suggest articles your doctor can read about MFS.
- Talk with your doctor. Sometimes it helps to use the information you have from the NMF when you speak with your doctor.
- Visit the NMF website at <http://www.marfan.org> You can print out information from the “About Marfan Syndrome” and “Living with Marfan Syndrome” pages. You can also ask questions online by clicking: “Support Services: Ask a Question.”