What Is Scoliosis?

Scoliosis, a curvature of the spine, is common in children and adults who have OI. Many people with mild OI and almost everyone with the more severe forms of OI develop some degree of scoliosis. Kyphosis is another form of spinal deformity seen in people with OI. Compression fractures of the spine can also lead to deformities of the individual vertebrae.

What is scoliosis?

It is a spinal curvature as seen from the front or back of the person who has it. It usually causes the spine to assume an “s” or “c” shape instead of being straight. Some curves get progressively worse. The curve is measured in degrees, and curves over 30 degrees need to be carefully watched because they can worsen rapidly. Once the spine has developed a significant curve, even surgery will not be able to make it perfectly straight again. Scoliosis occurs in many people, but it is seen more often in people with OI than in the general population.

What causes Scoliosis?

Scoliosis is probably caused by two aspects of OI – the associated laxity of the ligaments seen in OI, and deformation of the vertebral bones themselves. Long periods of sitting can aggravate the problem of lax (overly relaxed or loose) ligaments and weak muscles in the back and chest. Many children and adults also experience painful compression fractures of the vertebrae (spine). These fractures can be caused by any activity that jars the spine. Over time, these fractures deform the bones of the spine and contribute to a worsening of scoliosis.

Can scoliosis be detrimental to an OI person’s overall health?

Scoliosis increases pain and the collapse of the trunk, and it can cause rotation of the ribs. The effects of scoliosis can make the child or adult significantly less mobile. Less mobility will limit the child’s ability to develop bone mass and contributes to a loss of bone density in the adult. Progressively deforming scoliosis can also lead to life-threatening heart and lung problems.

Why is scoliosis a problem for many children and adults who have OI?

Severe scoliosis decreases lung function and the ability to breathe normally. This happens only in severe cases, and is not a worry for people with mild scoliosis. But for people who have more severe curves, lung capacity can become so reduced that the person takes very shallow breaths and does not get enough oxygen into their body to stay healthy. Often supplemental oxygen is needed. Individuals with severe curves should consult with a doctor who is a respiratory specialist to have their lung capacity tested.

How is scoliosis treated?

Once scoliosis is identified it should be watched. The degree of curve should be regularly checked to see if there are any changes. In mild to moderate cases, it does not need any treatment beyond maximizing overall fitness and bone density. In growing children with Type I OI, there may be some benefit to bracing for mild curves. This is decided on a case-by-case basis because the pressure exerted by a back brace can injure the fragile rib cage and chest deformities can get worse.

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Parents should watch their backs...

Parenting a child with OI can be hard on the back. A typical day might involve lifting and carrying the child, lifting and carrying chairs, walkers, or other equipment, transferring the child to/from wheelchairs, beds, bathtubs, vehicles...

All of this takes a toll, especially if the parent isn’t lifting or carrying the weight properly.

Typically, most back injuries occur when lifting and twisting at the same time. According to a study by the U.S. Department of Labor, recurrence of back problems is very common after the first injury, due to weakened muscles.

Common back injuries stemming from child care occur when lifting the child from the side, carrying the child on a hip, or lifting and twisting to put the child in a crib, playpen or wheelchair.

There are some simple steps you can take to avoid injury:

- Stretch and flex before lifting any heavy object.
- Get assistance (or use a slide, sling or wheeled device) if lifting or moving more than 30 pounds.
- Always check for obstacles in your path before you begin the carry.
- Bend the knees and use the hips, knees, and leg muscles to lift.
- Tighten your stomach muscles, which stabilizes the pelvis and spine.
- Keep your feet shoulder width apart, and your center of gravity low.
- Keep the child close to your body and centered, do not carry a child on your hip.
- Do not lift higher than waist level.
- Move your entire body as one unit. Do not twist at the waist. Turn your entire body, moving your feet, as well.
- Use your hips, knees and legs when setting a child down.
- Lift in stages, by placing tables or braces of various heights near changing tables, highchairs, etc.
- Remove the side arm from a wheelchair before making a transfer, and if possible, use a sliding board rather than trying to lift and carry.
- Consider hydraulic lifts for bathroom lifts and transfers.

Your overall physical health has a great impact on your ability to lift and carry safely and properly. For instance, strong abdominal muscles are essential to maintaining proper posture and a strong, healthy back. Maintaining a healthy body weight prevents your back from carrying extra weight.

Of course, always consult with your and your child’s primary care physician and/or occupational and physical therapists about proper/safe lifting and carrying techniques.

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For more severe curves (over approximately 45 degrees), surgery is recommended to straighten and fuse the curved part of the spine using rods and bone grafts. Both adults and children can be candidates for this surgery, but children undergo the procedure more readily and recover faster.

What can a person with OI and scoliosis do to protect their health?

Everyone who has OI should make it a habit to always protect his or her spine by learning safe ways to bend, walk and sit. Twisting motions and anything that jars the spine should be avoided. Children and adults with scoliosis, especially serious curves, should also pay close attention to their respiratory health. Consulting with a respiratory specialist is one way to monitor how well one’s lungs are working. In addition, don’t smoke, avoid second hand smoke and work with a doctor or physical therapist to develop a safe exercise program. These are things that can be done to promote respiratory health. Of course, it’s especially important to check with an orthopedic surgeon knowledgeable about scoliosis to get the best recommendation appropriate for each individual’s situation.