Let's Talk About...

Spina Bifida and Orthopedic Management

What is orthopedic management and why does my child need it?

In children with spina bifida, their spine, hips, legs, and feet often do not develop or work properly. This requires orthopedic [or-tho-PEED-ik] management. This includes careful assessment and checking of the spine, hips, legs, and feet. The goal is to increase your child's function and independence.

Why do these problems happen?

Nerves tell your body parts how and when function. In spina bifida, the nerves below the spina bifida area (lower spine) are not formed properly. If the nerves don't work properly, the parts of the body to which the nerves are connected to these nerves don't work properly either. The bones and muscles of the spine, hips, legs, and feet are the parts that are most affected.

In most cases, the upper chest and arms are usually okay. However, if the spina bifida is higher up on the spinal column, there will likely be more bone and muscle problems higher up (see Figure 1).

An example of a problem that could occur if a child has spina bifida in the area of the 4th lumbar bone is seen in Figure 2. The muscles that bring the hips toward the belly are be strong, and the muscles that bring the hips away from the belly are weak. A child in this situation would likely have problems using the muscles below the knees. As a result, the child would always tend to be in a seated position with unbent knees. Over time, this position would cause hip dislocation and difficulty with walking. However, with orthopedica management, braces, and other tools, the child may be able to walk.

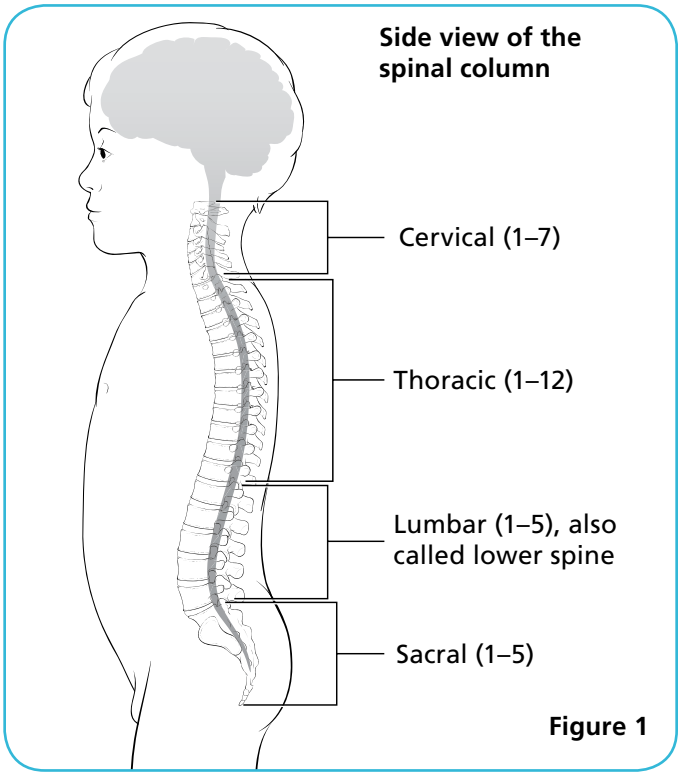


Figure 1

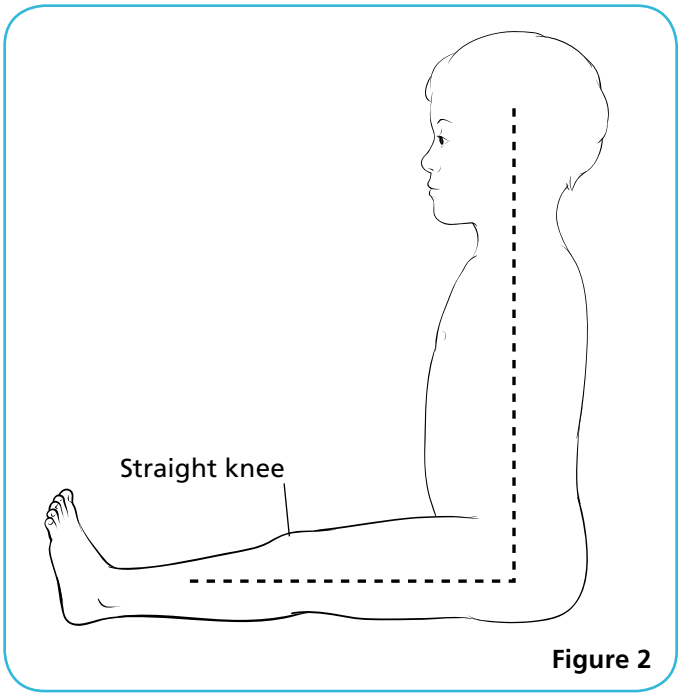


Figure 2

What are common orthopedic problems and treatments?

Common orthopedic problems associated with spina bifida and their treatments include:

- **Clubfoot.** Children with spina bifida may be born with a foot turned inward. The outer part of the foot is curved, and the ankle is bent downward. Correction surgery is usually performed after 6 months of age. During surgery, the position of the foot bones are adjusted and the tendons are lengthened or released, allowing the foot to go back to the correct position. Children need braces after this surgery.

  Clubfoot is sometimes treated with a cast on the foot instead of surgery. The cast is placed soon after birth. The orthopedic surgeon changes the cast every 1 to 2 weeks. This is called serial casting. The child's skin will need to be checked often for sores above and below the cast.

- **Ankle equinus** [EH-kwin-us]. When your child's calf muscles (muscles at the back of the lower leg) are weak or don't work at all, the ankle may bend the wrong way. This makes it difficult to brace the leg. In some cases, surgery may be needed to cut or "release" a small part of the muscle so that the foot can support a brace. This is a simple outpatient procedure. A cast is needed for about 4 weeks after surgery.

- **Ankle valgus** [VALL-gus]. Sometimes, a child's ankles bend the wrong way because the calf muscle is weak or does not work. This causes the inner anklebone to stick out, which interferes with bracing. If your child is 7 years or older, the surgeon may place a screw along the inner part of the ankle where it is still growing. This is procedure called a medial [MEE-dee-uhl] malleolar [MALL-ee-oh-lur] epiphysiodesis [ep-eh-fiz-ee-OH-dee-sus]. The screw slows growth on the inner side of the ankle. The outer part of the ankle grows normally and the ankle gets straighter as your child gets older. If ankle valgus is corrected early, your child will usually have fewer bracing problems as they get older.

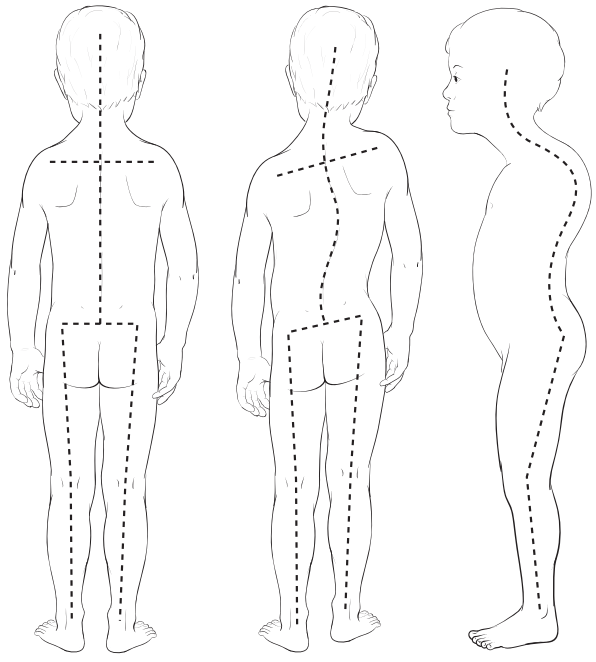
- **Hip and knee bending.** Many children who are in a wheelchair develop hip and knee bending, or flexion [FLEK-shun] problems. These problems rarely interfere with sitting. However, they can become so severe that the child has trouble getting in and out of a wheelchair. In this situation, the surgeon may recommend release of both hip flexors and knee flexors. (A flexor is a muscle that moves a joint.) This will make it easier for your child to transfer in and out of a chair and perform other activities.

- **Hip dislocation.** Muscle imbalance can dislocate the hips. This is a frequent problem. There are no surgical procedures that can completely restore balance through the hip. Children can walk well with both hips dislocated.

  Dislocated hips are rarely painful. However, if one hip is dislocated and the other is not, your child may need surgery. Uneven hip dislocation can tilt the pelvis and cause other spine problems. If both hips are dislocated, they are usually not replaced into the socket. Even if the surgeon places the hip back in the socket, the procedure often doesn't work. For this reason, the surgeon has to evaluate your child's symptoms carefully.

- **Scoliosis** [skoh-lee-OH-sis] **and kyphosis** [kie-FOH-sis]. Many children with spina bifida develop serious spine alignment problems (the bones of the spine don't curve normally). Figure 3 shows a normal spine along with spines with scoliosis and kyphosis.

Figure 3



These spine problems can interfere with your child's ability to sit. Kyphosis, or the bulging outward of the back, can produce sores and skin breakdown over the spine. Your child may need surgery to correct the spine and make the upper body stable for sitting. During surgery, the surgeon fuses the affected part of the spine and places a series of hooks, bolts, and rods to help hold the spine in position.

- **Structural malalignment of the bones.** Sometimes bones are in the wrong relationship to each other (not angled properly or rotated), there are 2 surgeries that can help:
  - **Growth arrest or epiphysiodesis** [EP-ih-fizz-ee-OH-deh-sis]. The surgeon puts a staple on one side of the affected bone to slow the bone's growth on that side. The surgeon removes the staple when the bone is corrected and the bone grows normally after that. This is considered to be a safer and simpler procedure than an osteotomy.
  - **Osteotomy** [oss-tee-AH-toe-me]. The surgeon cuts the affected bone and may take a piece of the bone out. The surgeon inserts something to keep the bone in place, for example a screw, pin, plate, or rod. The child may have a cast after surgery. The surgeon removes the screw, pin, or other device after the bone has healed.

How would a brace help my child?

Braces help support weak muscles or keep the legs in proper position for standing and walking. For example, a child with spina bifida in the lower part of the back may have a weak calf muscle. An ankle-foot brace (ankle-foot orthosis [or-THO-sis] or AFO) may help support the leg and allow your child to walk. If the spina bifida is higher up the spine, the brace may cover more of the leg (called hip-knee-ankle-foot or HKAFO).

Braces have their own set of problems. They may be awkward, heavy, and big. Some children get tired quickly when wearing the brace. This reduces the brace's benefits. Bracing is also expensive. Bracing or physical therapy may not prevent bone and muscle problems as your child grows.

For these reasons, think carefully about how a brace might help your child and whether it is the best choice. When deciding on braces, consider your child's ability to move, strength, any joint problems, and their personal goals. Instead of braces, you may decide that a wheelchair would be a better option.

What are the different types of braces?

Braces are usually named according to the joints the brace crosses and the location of the brace on the body. The following are the most common types of leg and foot braces.

- **Foot orthosis (FO):** The brace keeps the foot from turning downward, keeps the arch of the foot from flattening, and prevents the ankles from rolling inward.
- **Supramalleolar orthosis (SMO):** The brace extends above the ankle bones to provide increased support to the ankle while allowing the ankle to move.
- **Ankle-foot orthosis (AFO):** This brace gives maximum support to the foot and ankle and extends up the calf to just below the knee. The brace can be solid at the ankle to stop ankle motion. Some are hinged at the ankle to allow some motion.
- **Floor reaction or solteil braces:** These are an ankle-foot brace that help the child walk in a more normal position.
- **Knee-ankle-foot orthosis (KAFO):** This brace supports the knee. It has thigh cuffs and jointed metal supports that extend from the thigh cuff to the ankle and foot. The knee joints can be locked or unlocked to allow sitting in the brace.
- **Hip-knee-ankle-foot orthosis (HKAFO):** This brace come with a pelvic band to support the hips, or with both a pelvic band and a chest strap if more support is needed. Otherwise, it is identical to the KAFO. It is also called a "long-leg brace."

- **Reciprocating gait orthosis (RGO):** This is an HKAFO-type brace with a chest support. The 2 braces work together through a series of cables which allows for better walking.
- **Dynamic ankle-foot orthosis (DAFO):** This is a molded foot, ankle, and lower leg brace that helps with walking.

Will my child be able to walk?

Walking is important for all children, even those with spina bifida. A coordinated effort between your child, family, physical therapist, and other healthcare professionals can help your child walk successfully. Whether your child will be able to walk, and how long they continue walking, depends on these factors:

- Your child's motivation and ability level
- Your family's motivation and follow-through
- Therapeutic intervention
- Bracing and assistive devices

Keep in mind that walking is only 1 method of getting around. The most important factor is that your child becomes as independent as possible with whatever method of mobility is used.

Questions for my doctor

_____

_____

_____

What are some of the assistive devices to help my child walk?

Assistive devices help provide proper body alignment, balance, and less effort during walking. How much support your child needs during walking will determine which of the following aides to use.

- **Walkers:** There are 2 different types of walkers.
  - Reverse walkers allow your child to stand within the support base and pull the walker while walking. Children usually prefer this walker because they can stand more upright and it provides a broader base of support.
  - With forward walkers, the base of support is in front of the child. The child pushes the walker. This walker is helpful if a child is afraid of falling forward while walking.
- **Forearm crutches:** These crutches have a cuff, which fits around the forearm, and a hand piece for your child to lean on while walking. Forearm crutches provide balance and can be used to go up and down stairs. A child may start out with 2 crutches and progress to using 1 crutch, depending on their need.
- **Wheelchairs:** Wheelchairs help with proper body alignment and mobility. Your child can be fitted for a wheelchair around age 2 or 3, even if your child is able to walk. Your child may use walking to get around most of the time but may need a wheelchair for long distances.

  The decision to get a wheelchair can be emotional for your child and family. Having a wheelchair does not mean that your child needs to stop walking. That decision needs to be made by your child and the family. The wheelchair can help your child keep up with their walking peers. It can also help your child take part in sport and exercise programs that may not be possible with crutches or walkers. A wheelchair is an alternative form of mobility and, as with walking, your child's well-being and independence is of the utmost concern.

Intermountain
Primary Children's Hospital
The Child First and Always®