

# *Spina Bifida:*

*Your Guide to  
a Healthy Life*



# Orthopedics

For ages 0-18+



***Adapted from Guidelines for the Care of  
People with Spina Bifida, 2018***

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# Introduction

Orthopedic and musculoskeletal problems are common in people with Spina Bifida, including the following most prevalent issues:

## **Scoliosis and Kyphosis**

Spine problems, such as scoliosis and kyphosis (exaggerated forward rounding of the back), occur more frequently in myelomeningocele than in neurologically normal individuals and are more common in individuals with more severe levels of paralysis. The typical treatments for idiopathic scoliosis (scoliosis with no apparent cause) are problematic for patients with Spina Bifida. Body casting may cause skin breakdown due to insensate skin, and, while bracing can be used, there is little evidence that it works. Surgery is risky, and recent studies have questioned whether the functional gains from correcting scoliosis surgically are worth the surgical risks. Nevertheless, early onset scoliosis or gibbus deformity (when a few vertebrae collapse and lead to a sharp angular kyphosis) can affect how the lungs function, and in these cases, surgery may be necessary. Growing rods, which can be lengthened non-surgically as the child grows, are being used more frequently. However, more research is needed to understand the risks and benefits of spinal surgery versus leaving the spine untreated.

## Lower Limb and Foot Problems

Problems with the lower limbs include contractures (shortening of muscles with joint tightness) of the hip or knee and rotational deformities, all of which can affect function and gait. Release of contractures via surgery can help the foot or leg be more easily braced. Correction of rotational deformities, particularly external tibial torsion (twisting of the lower leg with the foot turning outward), can improve gait.

A variety of orthopedic strategies can be used to treat foot problems, including stretching, bracing, serial casting, and surgery. Braces such as ankle-foot orthoses (AFOs) can help support the foot, but some foot deformities may make bracing impossible. Since the feet of people with myelomeningocele often lack sensation, they are at risk for skin breakdown.

## Hip Problems

Hip dislocation and subluxation (partial dislocation) are common in myelomeningocele due to muscle imbalance, particularly in patients with mid-lumbar (and higher) lesions. Hip reduction surgery (putting the femoral head back in the socket) was the usual treatment, but is no longer as common because studies suggest that hip dislocation usually doesn't keep someone from walking. Most patients with hip dislocation or subluxation are not treated surgically, with the possible exception of someone with a low lumbar or sacral lesion that has hip dislocation on only one side.

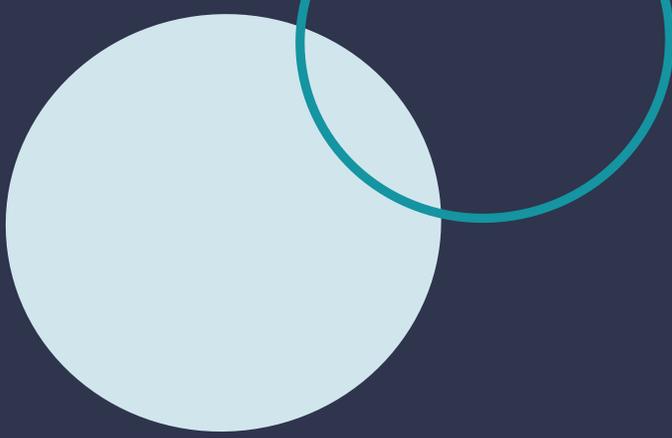


# Guidelines for Orthopedic Care



## 0-11 Months

1. Orthopedic evaluations are recommended every three months in the first year of life.
2. The child may have ultrasounds of the hips within the first six months of age. If the child has a lower lumbar or sacral lesion, he or she may need a brace to treat hip instability.
3. If the child has clubfoot or congenital vertical talus, the orthopedic surgeon may use Ponseti (serial) casting or heel cord release for treatment.
4. The child's spine will be examined and possibly X-rayed to monitor for scoliosis.
5. If the child's scoliosis is getting worse, your doctor may recommend bracing or casting.



## 1-2 Years

1. The orthopedic surgeon will use X-rays if necessary to monitor the child's spine, the orthopedic surgeon will discuss with the neurosurgeon to determine whether a tethered cord or syrinx (a fluid-filled cyst in the spinal column which can cause neurological problems) may be causing the problem.
2. If the child's scoliosis is getting worse, your doctor may recommend bracing or casting.
3. If the foot cannot be put into braces, the orthopedic surgeon might address foot problems such as calcaneus foot (when the heel is down) or equinovarus foot (when the heel is up) with tendon releases or transfers.
4. Twister cables may be recommended to help align feet and facilitate walking until surgery is appropriate.
5. Surgery to correct rotation of the tibia or femur is recommended only if it is limiting further motor development and/or causing difficulty with bracing.
6. Families should be aware of the increased risk for leg fractures in their children and what to watch for. Leg fractures in Spina Bifida can often seem like an infection because the leg may be warm, red and swollen.

## 3-5 Years

1. The orthopedic surgeon will monitor the child's gait for orthopedic problems that make it difficult to walk and may require surgery.
2. If the child's leg rotation makes it difficult to walk, the orthopedic surgeon may consider a derotational osteotomy surgery to correct it. The word osteotomy means cutting the bone to correct the problem.
3. The surgeon may consider treating problems in the feet with stretching, casting, bracing, soft tissue release or tendon transfers that make it possible for the child to use orthotics.
4. The child will be monitored for scoliosis every one to two years, including using X-rays if necessary. The orthopedic surgeon will work with neurosurgery in cases of worsening scoliosis to determine if it is being caused by a problem with the spinal cord.
5. Bracing might be recommended for scoliosis in the 25-50-degree range.
6. Surgery might be necessary if the scoliosis doesn't respond to bracing or other non-surgical treatments.
7. The surgeon may recommend surgery for a gibbus deformity (when a few vertebrae collapse and lead to a sharp angular kyphosis) to help avoid skin breakdown or to free up the arms for independent sitting.
8. Families should be aware of the increased risk for lower leg fractures in their children and what to watch for. Leg fractures in Spina Bifida can often seem like an infection because the leg may be warm, red and swollen.



## 6-12 Years



1. The child's surgeon will monitor gait, rotational problems and foot position.
2. The surgeon may recommend addressing problems with the foot via surgery to make it possible to use orthotics. This could include soft tissue release, tendon transfer and osteotomy.
3. Surgery may be necessary on the upper or lower legs if their rotation is making walking and bracing difficult.
4. Computerized gait analysis, when available, could be helpful for children with low lumbar or sacral level lesions who have gait problems. This information will be helpful when making decisions regarding surgery or bracing.
5. The surgeon will continue to monitor for the development of scoliosis/kyphosis, using X-rays if necessary.
6. Surgery might be necessary if the scoliosis doesn't respond to bracing or other non-surgical treatments. Studies have indicated that the use of growing rods, which can be expanded non-surgically as the child grows, are effective in correcting scoliosis while also allowing the child to develop.
7. The surgeon may recommend surgery for a gibbus deformity to help avoid skin break down or to free up the arms for independent sitting.
8. Families should be aware of the increased risk for lower leg fractures in their children and what to watch for. Leg fractures in Spina Bifida can often seem like infection because the leg may be warm, red and swollen.



## 11-17 Years

1. The child will be monitored for the development or progression of scoliosis, using X-rays if necessary. If the curve has progressed to 50 degrees or greater, your surgeon will discuss with you the risks and benefits of surgery.
2. The child's gait will be monitored for signs of deterioration. The surgeon will look for things that can lead to the gait getting worse, such as hip or knee contractures or rotational deformities. Computerized gait analysis may be useful for decision-making regarding treatment.
3. The child should see an orthopedic surgeon yearly, unless more frequent visits are needed.

## 18+ Years

1. Work with your orthopedic surgeon to develop a transition plan to an adult provider.
2. The surgeon can advise you on potential orthopedic problems that can arise with age. You may be encouraged to consider bracing across the knee, such as a KAFO, to support the knees. Use of forearm crutches can help with stability while walking.
3. The surgeon can advise you on fractures and how to avoid them.