

## Spina Bifida Guideline

# Orthopedic guidelines for the care of people with spina bifida

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**Abstract.** Orthopedic or musculoskeletal problems are common in individuals with spina bifida. They can affect function and mobility and, in the case of spinal deformity, affect pulmonary function. We discuss the current treatment guidelines developed through collaboration with the Spina Bifida Association and the Orthopedics and Mobility working group using a specific methodology previously reported [1,2]. General considerations are discussed followed by evaluation and treatment guidelines for specific age ranges. References are provided where applicable, but where data is lacking treatment guidelines fall under the umbrella of clinical consensus. This leaves “research gaps” where areas of possible future study could be considered.

**Keywords:** Spina bifida, myelomeningocele, neural tube defects, healthcare guidelines, scoliosis, kyphosis

### 1. Introduction

Orthopedic problems and musculoskeletal deformities are common in patients with spina bifida. Deformities can affect function, preclude lower extremity bracing and contribute to skin breakdown.

The prevalence of spinal deformities including scoliosis and kyphosis is proportionate to the severity of the neurologic lesion. Spinal deformities can be challenging to treat. Body casting that can be used in idiopathic early onset scoliosis may cause skin breakdown due to insensate skin. Bracing can be used, but there is limited data to support it. Surgical treatment carries high risks including infection, pseudarthrosis, and loss of mobility. Recent studies have questioned the effect of

surgery on overall function [3–7]. Nevertheless, patients with early onset scoliosis or gibbus (kyphus) deformity present special challenges due to concerns about pulmonary function. Growing rod strategies such as spine to spine or rib to pelvis distraction are increasingly used for these patients, but the small size of the patient relative to the construct and poor soft tissue envelope remain as challenges [8–10]. Further studies are needed to understand the risks and benefits of spinal surgery versus acceptance of the natural history of the spinal deformity.

Lower limb deformities can also be problematic and can affect function and gait. These can include contractures of the hip or knee or rotational deformities. Correction of rotational deformities, particularly external tibial torsion, has been shown to improve gait parameters on computerized gait analysis testing [11]. Release of contractures can also render the limb more amenable to bracing.

Hip subluxation and dislocation are common due to muscle imbalance, particularly in the patient with

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a mid-lumbar lesion. In previous times, hip reduction surgery, including bone procedures and muscle transfers were commonly performed. A recent study suggests that hip reduction surgery is of questionable benefit in myelomeningocele while computerized gait analyses show that contracture, not subluxation, has a deleterious effect on ambulation [12]. Therefore, the use of hip reduction surgery has waned in recent decades, with the possible exception in individuals with low lumbar or sacral neurologic levels. Thus, the present guidelines do not recommend routine surveillance of the hip or surgical treatment of hip subluxation/dislocation, although patients with a low lumbar or sacral lesion with unilateral dislocation could be considered an exception and must be treated on an individual basis [13,14].

The non-plantigrade foot is a frequent problem in myelomeningocele. The feet typically manifest sensory impairments and consequently, skin breakdown can occur. Orthoses such as ankle-foot orthoses (AFOs) can support the foot in patients with motor impairments, but some foot deformities may preclude bracing. A variety of orthopedic strategies, both operative and non-operative, can be used to treat foot deformities. These include stretching, bracing, serial casting, and surgery. Surgery can include tendon releases and resections, tendon transfers, joint capsular releases, osteotomies, and fusions. In general, the younger, less rigid foot may respond to soft tissue procedures while the older or more rigid foot may also require osteotomy. A classic dictum is that fusions should be avoided when possible as they render the foot more rigid which can increase the risk of skin breakdown (clinical consensus). Nevertheless, some deformities may be sufficiently severe as to require salvage procedures such as talectomy, subtalar arthrodesis [15] or triple arthrodesis [16].

The proper timing for foot surgery is debatable. However, a foot deformity that has become so severe as to be unbraceable in someone who still wants to pursue ambulation is certainly an appropriate indication. However, some surgeons may take a more proactive approach, performing tendon balancing surgery earlier in life to prevent bony deformity later. For example, a patient with an L4-level lesion with an unopposed anterior tibial tendon function will generally develop a calcaneus deformity. With time, weight bearing will be only on the calcaneus with no weight bearing through the forefoot. This can lead to calcaneal skin breakdown. Anterior tibial tendon transfer to the Achilles or merely anterior tibial tendon release done at an early age can improve or prevent this. If done later in life, a calcaneal osteotomy may be necessary [17]. Ultimately, the ap-

proach that is taken in the treatment of foot deformities (proactive or reactive) will be at the discretion of the surgeon and the family.

### 1.1. Guidelines, goals, and outcomes

The following outcomes were chosen by the Orthopedics/Mobility working group. The outcomes were chosen to be both practical and aspirational. As individuals with spina bifida vary, particularly regarding neurologic function and thus ambulatory potential, not all outcomes are applicable to every individual. The primary outcome chosen concerned the maintenance of a stable, balanced spine with optimum length. The working group felt that this was important for ambulatory and non-ambulatory individuals. As a secondary outcome, maintenance of a plantigrade foot without skin breakdown was chosen. Although prevention of foot deformity may be more important for ambulators, even non-ambulators may require plantigrade feet for transfer and can experience skin breakdown of the feet. As a tertiary outcome, the optimization of gait and prevention or correction of lower extremity deformity was chosen. This outcome is most applicable in ambulatory individuals.

#### Primary

1. Maintain a stable and balanced spine.
2. Optimize pulmonary function and avoid restrictive pulmonary disease.
3. Optimize spinal growth.
4. Avoid or facilitate healing of sacral/ischial decubiti.

#### Secondary

1. Maintain plantigrade feet.
2. Prevent skin breakdown.

#### Tertiary

1. Preserve or improve gait efficiency.
2. Early identification and stabilization, or correction, of lower limb deformities.

## 2. Methods

A specific methodology was followed in the development of the Orthopedic and Mobility guidelines [2]. First, the previous version of the Orthopedic guidelines was reviewed.

A literature search was carried out to locate publications that had emerged since the previous version of the guidelines that related to orthopedics and mobility.

Table 1  
Clinical questions that informed the orthopedic guidelines

Age group (from guidelines)	Clinical questions
0–11 months	1. What are the consequences of early onset scoliosis, kyphosis and pulmonary insufficiency syndrome in patients with spina bifida? 2. Which foot deformities merit correction in the child 0–11 months old, and what is appropriate treatment?
1–2 years 11 months	1. What is the proper timing for correction of rotational deformities of the femur and/or tibia? 2. Are twister cables useful for rotational deformities? 3. What is the role of bracing or Mehta casting for early onset scoliosis? 4. Should gibbus deformity be treated surgically? 5. Is rib to pelvis distraction rather than kyphectomy the optimum treatment for gibbus deformity?
3–5 years 11 months	1. Is bracing effective for early onset, non-congenital scoliosis? 2. Is rib-pelvis distraction versus the spine-based growing rod construct the optimal treatment for progressive scoliosis?
6–12 years 11 months	1. Is bracing effective for early onset, non-congenital scoliosis? 2. Is rib-pelvis distraction versus the spine-based growing rod construct the optimal treatment for progressive scoliosis?
13–17 years 11 months	1. What is the impact of scoliosis/kyphosis on gait, sitting balance, and upper limb function? 2. What is the relationship between spinal deformity and skin breakdown? 3. Which patients benefit from spinal deformity surgery? 4. How can spinal deformity surgery be safely accomplished? 5. In lumbar scoliosis, how high must the fusion extend?
18+ years	1. What is the optimal orthopedic transition plan? 2. What degenerative issues can be expected for specific levels of function (e.g., knee arthrosis for mid-lumbar lesions with valgus thrust gait pattern) and what treatments can mitigate against these problems (e.g. knee, ankle, and foot orthosis (KAFO) or crutches for the above example)

The working group then reviewed the applicable literature and came to a consensus about the selection of outcomes and clinical questions. These were selected based on the clinical experience of the working group members as it relates to issues that are important in the overall musculoskeletal function of individuals with spina bifida. The available literature was then further vetted to answer these questions. Where the clinical questions could not be specifically answered by the available literature, the “best practice” was determined through the consensus of the working group and further vetted by the described guideline methodology [2].

### 3. Results

The guidelines for the orthopedic care of individuals with spina bifida are listed in Table 2. Of note, the hallmark of the clinic visit is evaluation by history and physical exam. Radiographs are reserved for deformity suspected on physical exam or to evaluate for specific complaints. The spine, extremities, peripheral neurologic exam, and gait are evaluated. It is further recommended that the orthopedist communicate with Neurosurgery if there are any concerning neurologic findings or deformities such as new onset of cavus feet or rapidly progressive scoliosis that might be indicative of tethered spinal cord. Surgical deformity correction

should be reserved for those deformities that are either presently or anticipated to be affecting function. Most guidelines are repeated in multiple age groups.

### 4. Discussion

The goal of orthopedic treatment of individuals with spina bifida is to render the musculoskeletal system as functional as possible for a given individual’s neurologic function. As such, not every patient will have the same orthopedic needs. Furthermore, deformities of the spine, lower extremities and feet vary greatly as does their impact on function. Consequently, it is not possible to make definitive statements about the need to correct certain deformities and therefore treatments need to be individualized.

Deformities may be present at birth or may develop over time due to muscle imbalance or weakness. Furthermore, lower extremity deformities do not have impact on function until the child begins ambulating. Therefore, the age at which orthopedic correction takes place varies widely. During the process of writing the guidelines, we were tasked with breaking up the guidelines by age group. To a certain extent, this is contrived and many of the guidelines are repeated in multiple age groups and correction of deformities may take place at any age. Again, this made it difficult to make defini-

Table 2  
The orthopedic guidelines

Age group	Guidelines	Evidence
0–11 months	1. Perform neonatal kyphectomy, if required to facilitate skin closure.	[18]
	2. Orthopedic evaluations are recommended every three months in the first year of life.	Clinical consensus
	3. Consider hip imaging using ultrasound in the infant and anteroposterior pelvis radiographs after 6 months in patients with low lumbar and sacral lesions. Consider using a rigid abduction orthosis to treat hip instability, but only in children with low lumbar and sacral lesions.	Clinical consensus
	4. Ponseti casting or release is recommended for clubfoot or congenital vertical talus deformities.	[19–21]
	5. Perform spine evaluations by conducting a physical exam. Obtain scoliosis radiographs if a spinal deformity is suspected and monitor the spine for progression of the deformity. In children who have not achieved sitting balance, perform the radiographs in a supine position. Once sitting balance is achieved, perform spinal radiographs in a sitting position.	Clinical consensus
1–2 years 11 months	6. Consider bracing or casting when there is a documented progression of scoliosis.	[22]
	1. Monitor the spine for development or progression of a deformity that may be due to a tethered cord or syrinx. Obtain anteroposterior and lateral scoliosis radiographs if a deformity is suspected on clinical exam. Perform radiographs in a sitting position if the patient is able to sit but not able to stand or in a standing position if the patient is able to stand. Repeat radiographs every one to two years if the deformity is present, depending on rate of progression.	Clinical consensus
	2. Evaluate for neurologic changes or progression of scoliosis and discuss with neurosurgery.	Clinical consensus, Neurosurgery guidelines
	3. Initiate treatment for progressive early onset scoliosis that may involve casting or bracing.	[22]
	4. Consider tendon releases/transfers for unbalanced foot deformities such as the calcaneus foot, if the foot is unbraceable, to facilitate orthotic management.	[23]
	5. Consider twister cables for significant rotational deformities to facilitate ambulation until surgical correction is appropriate.	[24]
	6. Surgical correction of rotational deformities of the tibia or femur is recommended only if they are limiting further motor development and causing difficulty with bracing.	Clinical consensus
3–5 years 11 months	7. Teach families about fractures and related precautions.	Clinical consensus
	1. Evaluate gait with careful attention to orthopedic deformities that render gait inefficient and preclude orthotic management.	Clinical consensus
	2. Consider derotational osteotomy when rotational abnormality adversely impacts ambulation.	[25]
	3. Consider treating foot deformities with stretching, casting, bracing, soft tissue release or tendon transfers to facilitate orthotic management.	Clinical consensus
	4. Evaluate the spine clinically and obtain scoliosis radiographs every one to two years if a progressive spinal deformity is suspected. Perform radiographs in a sitting position in children who can sit but not stand and in a standing position in children who can stand.	Clinical consensus
	5. Work with Neurosurgery to determine whether a neurogenic cause of scoliosis progression is present.	Clinical consensus Neurosurgery guidelines
	6. Consider bracing for progressive, non-congenital scoliosis in the 25 to 50 degree range.	Clinical consensus
	7. It is recommended that surgical treatment of scoliosis be reserved for a progressive deformity that is unresponsive to non-operative management. An example is when the scoliosis has progressed in spite of bracing and after a neurosurgical cause, such as a tethered cord, has been ruled out. It is also recommended that management with growing rod surgery and fusionless technique should include spinal cord monitoring in patients with distal neurologic function.	[26]
	8. Consider surgical treatment of gibbus deformity for intractable skin break down or to free up the upper limbs for independent sitting.	[27]
6–12 years 11 months	9. Teach children and families about fractures and related precautions.	Clinical consensus
	1. Monitor gait, rotational deformities and foot position.	Clinical consensus
	2. Consider correction of foot deformities to facilitate orthotic management with soft tissue release, tendon transfer and osteotomy, if necessary. It is recommended that fusion be avoided if possible.	Clinical consensus
	3. Consider correction of tibial and femoral rotational deformities when they are interfering with gait and precluding orthotic management.	[25]
	4. Consider conducting computerized gait analysis when available, in children with low lumbar or sacral level lesions who have atypical gait abnormalities. This information will be helpful when making decisions regarding surgery or bracing.	[28]
	5. Monitor for the development of scoliosis/kyphosis.	Clinical consensus
6. Obtain anteroposterior and lateral scoliosis radiographs every one to two years if deformity is suspected clinically. Do so more frequently in patients with progressive spinal deformity. Perform radiographs in a sitting position in children who can sit but not stand and in a standing position in children who can stand.	Clinical consensus	

Table 2, continued

Age group	Guidelines	Evidence
6–12 years 11 months	7. It is recommended that surgical treatment of scoliosis be reserved for a progressive deformity that is unresponsive to non-operative management. An example is when the scoliosis has progressed in spite of bracing and after a neurosurgical cause, such as a tethered cord, has been ruled out. It is also recommended that management with growing rod surgery and fusionless technique should include spinal cord monitoring in children with distal neurologic function. Growing rod surgery with sacral-pelvic fixation is effective in correcting deformity and achieving growth.	[26, 29]
	8. Consider surgical treatment of gibbus deformity for intractable skin breakdown or to free up the upper limbs for independent sitting. The current literature describes multiple techniques.	[8, 9, 27, 30–33]
	9. Teach children and families about fractures and related precautions.	Clinical consensus
13–17 years 11 months	1. Monitor for the development or progression of scoliosis clinically, with radiographs as necessary, if indicated by physical exam. Perform radiographs in a sitting position in those who can sit but not stand and in a standing position in those who can stand. If the curve has progressed to an operative magnitude (50 degrees), discuss the risks and benefits of surgical treatment with the family.	Clinical consensus
	2. Monitor for the deterioration of gait and consider treatment of orthopedic deformities leading to deterioration such as hip and knee contracture or rotational deformities. Computerized gait analysis may be useful for decision-making in the case of children with low lumbar and sacral level lesions.	[14, 28]
	3. Conduct a history and physical exam (with radiographs, if indicated) on an annual basis unless greater frequency is indicated.	Clinical consensus
18+ years	1. Develop an orthopedic transition plan.	Clinical consensus
	2. Counsel the patient about potential orthopedic degenerative problems. Consider bracing across the knee such as the use of a KAFO, for patients with coronal plane valgus knee stress, or adding forearm crutches to decrease coronal and transverse plane trunk motion.	Clinical consensus Mobility guidelines
	3. Counsel the patient about fractures and related precautions.	Clinical consensus

tive statements about undergoing corrective surgery in specific age groups.

Much of the orthopedic literature on spina bifida concentrates more on how rather than why to correct deformities. Natural history and outcome studies on specific deformities are lacking. Case series are common but control groups are lacking. Most studies on the orthopedic care of these patients are Level 4 data. For all of the above reasons many of our recommendations fall under “clinical consensus”.

Lastly, many of the guidelines relate to the office practice of orthopedics as it relates to individuals with spina bifida. Such questions as whether screening radiographs of the spine should be carried out in individuals who did not clinically appear to have spinal deformity caused significant debate. Another question was how often to evaluate patients in different age groups. The available orthopedic literature does not address these questions but through the experience of the members of the working group and the process outlined for the creation of these guidelines [2], clinical consensus was achieved.

Future studies need to concentrate on the effect of orthopedic problems and various modes of mobility on health-related quality of life. National registry data such as the National Spina Bifida Patient Registry can be queried to add statistical power to studies where only small case series have existed previously. Furthermore, surveys of patients and caretakers are presently being performed through initiatives sponsored by the Spina

Bifida Association. It can be surprising to the orthopedist caring for these individuals that musculoskeletal problems or deformities that seem quite impressive are far down the list of the patient’s priorities. Orthopedists and physiatrists who take care of individuals with spina bifida should pay close attention to these types of surveys and studies to inform their treatment and develop ideas for future research.

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The Spina Bifida Association has already embarked on a systematic process for reviewing and updating the guidelines. Future guidelines updates will be made available as they are completed.

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#### Conflict of interest

The authors have no conflicts of interest to disclose.

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