

Spina Bifida:

*Your Guide to
a Healthy Life*



Mobility

For ages 0-18+

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

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Introduction



Mobility is defined as the ability of a person to move within his or her environment and community. Mobility can be achieved by a variety of methods. Some people are able to ambulate (walk) with minimal impact from their Spina Bifida, while others may require braces or assistive devices such as crutches or wheelchairs. In children and adults with Spina Bifida, the level of the lesion and damage to the spinal cord are the main factors that define an individual's potential for mobility.

Mobility has a positive impact on a person's development and participation in their community at all ages. In young children, mobility improves cognitive (thinking), physical, and social skills. Mobility allows people at any age access to the physical activity and exercise that is important to a healthy lifestyle. Mobility levels may change with age, especially as physical and social demands increase (*Physical Activity Guidelines*).

The benefits of maintaining mobility include:

- Keeping bones and joints healthy
- Improved cardiovascular health
- Greater strength and endurance
- Greater community engagement and ability to navigate the household
- Increased bone density
- Better bowel and bladder function
- Improved ability to perform self-care activities
- Reduced risk for pressure wounds



Neurologic Level of Lesion and Anticipated Mobility

Thoracic/upper lumbar level (L1):

- Walking at this level is not common, and mobility is typically achieved using a wheelchair. There may be some hip movement but no knee extension (ability to straighten the knee).
- Household/therapeutic walking requires the use of a hip-knee-ankle-foot-orthosis (HKAFO) or reciprocating gait orthosis (RGO). Standing may be achieved using standers.

Mid to high lumbar level (L2-L3):

- Mobility is predominantly achieved using a wheelchair for community distances, although those with an L3 level lesion (who have the ability to straighten the knee) may use a wheelchair and also walk with crutches or a walker.
- Hip flexion present, but not glute function.
- Walking requires ankle-foot orthoses (AFO) or knee-foot orthoses (KAFO) and usually crutches or a walker.

Lower lumbar (L4-L5):

- Fair to good potential for walking in both the household and community.
- Use of AFOs is common, and an individual may use forearm crutches to improve walking.
- May use a wheelchair for long distances or sports participation.
- Has the ability to flex the foot upwards (necessary for walking).

Sacral level:

- Ability to walk but may need orthoses for foot and ankle support.
- There may be some movement and sensation in the feet depending on the nerve function.

Guidelines for Mobility



While there is limited research about mobility in people with Spina Bifida, these guidelines are based on best practices in Spina Bifida clinics.

0-11 Months

1. Healthcare providers will monitor your baby's movement and sensation, as well as developmental milestones that are specific to your child.
2. Your child will be referred to early intervention programs for physical and occupational therapy to work to develop skills toward developmental milestones. The first goal for therapy will be for your child to develop good trunk (body) control, as this will allow your child to sit up and use their hands to hold and play with things.
3. The best practice for children this age is to place them on their back to sleep, and on their tummy for play time (the "Back to Sleep, Prone to Play" model). Tummy time helps ensure that your baby develops the muscles that are the foundation of movement. Lack of tummy time is linked to developmental delays in typical infants and therefore is of even greater importance for children with disabilities.
4. Your baby might receive casting, splinting, and braces to support and maintain alignment and movement. It's important to check your baby's skin for sores and breakdowns if using any of these corrective devices.
5. Your baby should be encouraged to try developmental skills seen in all children, such as pushing up while on their stomachs, getting into a crawling position, sitting up, and getting into a supported standing position. These skills encourage not only physical but cognitive development. Remember to celebrate their achievements!
6. Like all babies, babies with Spina Bifida enjoy and benefit from being spoken, sung, and read to.

1-5 Years

1. Healthcare providers will monitor your child's movement and sensation, as well as developmental milestones that are specific to your child. Your child will also be monitored for changes in walking, bowel and bladder function, and body developments.
2. If your child is not yet pulling to stand, your providers may consider using a standing device.
3. Your child should have access to different options for being mobile, including walkers and wheelchairs. Even children that have potential to walk may be delayed in doing so.
4. Your child may need bracing to assist weak muscles and protect the lower limbs from excessive twisting.
5. It's important that your child's wheelchair fit properly so it's not too tiring to use and doesn't put excessive strain on the body.
6. Research your health insurance plan's Durable Medical Equipment (DME) coverage so you understand what your child qualifies for. Many plans limit the number of devices they cover.
7. Encourage weight-bearing activities every day to promote bone health.





6-12 Years

1. Healthcare providers will monitor your child's movement and sensation, as well as developmental milestones that are specific to your child. Your child will also be monitored for changes in walking, bowel and bladder function, and body developments.
2. Your child's providers can explain the different types of equipment available to help your child move. This may include walking aides and wheelchairs.
3. Your providers will monitor your child's walking or wheeling ability with standardized outcome measures. They may recommend a walking study if ambulation is changing or to get information that will improve bracing.
4. Your child should continue flexibility, range of motion, and strengthening exercises to maintain mobility goals, whether he uses an ambulation device or a wheelchair.
5. Your child should be encouraged to put on and take off braces independently.
6. Your child should be educated about the importance of staying physically active to overall health. Adapted physical education and recreation therapy is helpful and can involve the whole family (*Physical Activity Guidelines*).
7. Children should start being involved in their own care. They should be taught to watch for signs of pressure sores, fractures, and changes in movement/sensation (*Self-Management and Independence Guidelines*).
8. It's important that your child's wheelchair fit properly so it's not too tiring to use and doesn't put excessive strain on the body.
9. Your child should be encouraged to engage in weight-bearing activities every day to promote bone health (clinical consensus).
10. Your child should be encouraged to be socially active with peers, as many types of social activities increase movement.

13-17 Years

1. Healthcare providers will monitor the teen's movement, sensation and changes in strength. Your teen will also be monitored for changes in walking, bowel and bladder function, and musculoskeletal developments.
2. Some adolescents have a harder time getting around in school and the community and may need to explore other ways of getting around, such as using wheelchairs or scooters.
3. Your teen should continue therapy or home programs to maintain mobility goals, emphasizing flexibility, range of motion, and overall strengthening.
4. Your teen should know how to check skin that lacks sensation, especially after activity, and how to address friction and pressure (*Integument (Skin) Guidelines*).
5. Your teen may need supportive orthoses or devices for balance. They should protect joints and the upper body from excessive twisting and strain.
6. Your teen should be monitored for secondary injuries that could result from their way of getting around — such as to the knees and ankles for children who walk, and to the shoulders and wrists of those who use wheelchairs. (*Orthopedic Guidelines*).
7. Therapy should be continued to maintain mobility, if needed.
8. Your teen should be encouraged to be socially active with peers, as many social activities increase movement.





18+ Years

1. Your healthcare providers will monitor your movement, sensation, and changes in strength. You will also be monitored for changes in walking, bowel and bladder function, and body developments.
2. Your providers will continue to discuss the benefits of being involved in physical activities.
3. You should continue with home programs to maintain flexibility, range of motion, and strengthening as this will impact mobility.
4. You may need supportive braces or devices for balance. They should protect joints and the upper body from excessive twisting and strain.
5. It is important to know how to identify issues with your braces and equipment and who to call when you have problems, as well as the details of your health insurance coverage and benefits. Your providers and therapists can help with this.
6. Your providers will discuss with you the importance of preventing loss of mobility (both walking and wheelchair) through the use of appropriate techniques and maintaining a healthy weight and level of strength.