



# Living Well with Spina Bifida: Ages 10 to 12

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*Hollister Incorporated is happy to continue supporting the Spina Bifida Association through this unrestricted educational grant. Hollister Continence Care shares the Spina Bifida Association's ongoing commitment to serve adults and children who live with the challenges of Spina Bifida.*

*Hollister Continence Care offers research-driven urological products and services to help provide independence to people whose lives have been affected by Spina Bifida. Everything we do is informed by a single guiding principle: People First.*

*Our products and services are testimony—first and foremost—to the assurance that quality of life needn't be compromised by managing one's continence.*

*To learn more about Hollister Continence Care, visit our website:*

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# What to Expect

Continue to encourage your child to live up to the goals you have set together. It is always difficult to be an adolescent. Moodiness and occasional outbursts can be expected. An adolescent with Spina Bifida will have additional challenges to face.

A child tends to live up to the expectations held by parents and teachers. Your child may need more help and more time, but having a successful, confident, and happy child is the ultimate goal.

Success will motivate your child to keep trying. Just like other children, there will be some things your child will be good at and other things that he or she will need help with. Remember services are available for your child depending on his or her needs. All parents have dreams for their children. Remain optimistic. Have realistic expectations of your child.

## ***Developing Social Skills***

Developing good social skills will help your child, as he or she grows, to find and maintain a job, have supportive friendships, and support a meaningful social life.

These are essential steps towards developing social skills in children who have Spina Bifida:

- Learning to strike up a conversation
- Knowing how to behave in order to enhance friendships
- Learning to listen (many children need extra help learning this skill)
- Developing a positive attitude
- Learning to interact in groups
- Learning to put others at ease about Spina Bifida

## Support from Other Parents

Other parents of children with Spina Bifida understand what you are going through and can provide emotional support. The SB Parents ListServ at [spinabifidaassociation.org](http://spinabifidaassociation.org) offers one way of getting support from other parents. To add yourself to the ListServ, send an email to: [SBParents-on@lists.sbaa-communities.org](mailto:SBParents-on@lists.sbaa-communities.org) and leave the subject line and the body blank. Sharing with other parents and learning that they have similar feelings can be very helpful.

Many states and regions have local Spina Bifida Association chapters which can also be a great resource and support system. Visit [www.spinabifidaassociation.org](http://www.spinabifidaassociation.org) for the Spina Bifida Association chapter nearest you.

### Parenting Tips

- *If your child struggles with basic dressing or grooming, seek help. An occupational therapist can help find alternate ways for your child to do basic things.*
- *If your child struggles with social skills, find more opportunities for him or her to play with others, or seek the guidance of someone who specializes in social skills training (e.g., a psychologist or social worker).*
- *If your child needs extra support to achieve academic success, talk to his or her teacher and school administrators. Many modifications can be put in place to help your child attain educational goals.*
- *Taking care of yourself is the single most important thing you can do for your child.*

# Neurologic Progress

By now your child may have had several shunt revisions or might be lucky enough to have the original shunt. Either way it is important to remember that a shunt malfunction is always possible.

## Hydrocephalus

### *Signs and Symptoms of Shunt Malfunction*

- Headaches
- Vomiting
- Decreased upper extremity tone
- Regression in milestones or school performance

### *Treatment*

- Shunt revision
- Consideration of third ventriculostomy (pronounced ven-trick-you-**lost**-a-mee), a procedure in which a new pathway for cerebral spinal fluid is created as an alternative to the traditional shunting procedure.

## Tethered Cord Syndrome

By definition, tethered means to “restrict” or “bind with.” Therefore, “tethered cord” may be defined as a spinal cord that is bound down or restricted by scar tissue. The tethered cord can not move freely as the child bends and moves about, and the small blood vessels nourishing the cord are stretched. This problem may become evident during periods of rapid growth.

The potential for development of the tethered cord syndrome essentially begins with the closure of the myelomeningocele defect. Magnetic Resonance Imaging (MRI) of the spinal cord performed at nine to twelve months of age documents the finding of a tethered cord in almost all infants with Spina Bifida. Treatment is not recommended unless the infant or child begins to show clinical symptoms of the tethered cord syndrome.

## ***Symptoms of Tethered Cord***

### **Loss of Neurological Function**

Progressive lower extremity weakness, representing a significant change, usually indicates a tethered cord. This change is most often signaled by increasing difficulties with walking or decreased use of the lower extremities. The change or difficulty in walking is due to weakness or increased muscle tone (spasticity). Spasticity or increased tone requires an individual to use more energy to make the extremities move. Movements are therefore slower and decreased. Increased tone can also cause joints to become deformed and makes treatment difficult.

It is important, however, to consider other causes for changes in walking patterns or use of extremities. These may include weight gain or improperly fitted shoes or braces. These problems are readily identified, and, when corrected, no further functional loss is to be expected. If progressive loss of function does occur, it is often associated with tethered cord. Regular follow-up evaluation of muscle function is important.

### **Pain**

Back pain and unexplained leg or knee pain caused by a tethered spinal cord typically occurs with activity and improves with rest. The pain tends to worsen with time until the child undergoes surgical intervention. Pain is not present in all individuals who clearly have clinical signs of the tethered cord syndrome.

### **Changes in Bladder and Bowel Function**

Complaints of wetness in a previously dry child may be caused by a urinary tract infection, but can also be caused by deterioration of spinal cord function due to tethered cord syndrome.

Children who have been dry on a clean intermittent catheterization program or other bladder management program should be assessed by the urologist as well as the neurosurgeon. Deterioration in bladder function is one of the most common signs of tethered cord syndrome.

Any significant changes in bowel function should also be reported.

## **Scoliosis**

Scoliosis (pronounced school-ee-**oh**-sis) is common in children with Spina Bifida and can have a variety of causes. If other causes are not found, rapidly progressive scoliosis may be a symptom of tethered cord syndrome.

Surgery to untether the cord should be done before the curve becomes so severe that it limits function and mobility. If the scoliosis does not stabilize or improve following release of the cord, then a spinal fusion may be necessary.

## ***Monitoring for Tethered Cord Syndrome***

When concerns of tethered cord arise, the following studies are done and compared with the baseline information:

- Magnetic Resonance Imaging (MRI) of the complete spine and lower part of the brain
- Manual Muscle Test (MMT) and dynamometer readings
- Urologic assessment, including a urodynamic study

The child is followed at close intervals by the neurosurgeon, or surgery is recommended. Retethering is not uncommon, so it is extremely important to continue monitoring for signs and symptoms of tethered cord syndrome.

## ***Surgical Correction***

The decision to release the tethered cord is complex and needs to be discussed with a neurosurgeon. Every child with Spina Bifida is different.

After surgery, your child will rest in bed for several days. He or she will be discharged from the hospital about one week after surgery, and be able to resume full activities, including school, within four weeks after surgery.

## ***Possible Complications After Surgery***

Studies have shown an increased risk of shunt malfunction after tethered cord surgery. This can occur up to six months after surgery, but the greatest risk is within the first month. Your child should be followed closely for signs and symptoms of shunt malfunction (see the section on hydrocephalus).

Improvement in functioning after surgery varies from child to child. Improvement from surgery may take up to two years. Regardless of the outcome, no further progression of problems should occur, unless the cord begins to tether again.

It is not unusual to have transient (come and go) worsening of muscle or bladder function after surgery. Most children, though, will eventually return to their previous level of function. Recurrent procedures for retethering carry greater risk for loss of neurological function.

## Seizures

Some children with Spina Bifida may have seizures. Seizures may be caused by a problem with the shunt, or may occur as part of the neurological issues associated with Spina Bifida.

If there is a problem with your child's shunt, revising the shunt is the first line of treatment. If seizures reoccur when the shunt is functioning well, medications may be recommended. You will likely be referred to a neurologist for treatment. The doctor may also conduct an electroencephalogram (pronounced ee-**leck**-tro-en-**sef**-a-lo-gram, or EEG), CT scan, or MRI scan to find out exactly what is happening in your child's brain.

### **Parenting Tip:**

- *Your child should not be losing function. Contact your health care provider immediately if your child begins to have problems in new areas or shows any loss or decline in functioning.*



# Urologic and Bowel Progress

At this stage your child may or may not have achieved social continence. Do not get discouraged, and keep working with your health care team. Remembering to catheterize and do a bowel program may be difficult for your child. Help him or her to develop a reminder system or schedule, and remember to celebrate success.

Some children are not able to perform self-catheterization through the urethra. In this case, your child's urologist may recommend surgery to create a catheterizable stoma in the belly button or on the side of the abdomen. This option has made it possible for many children and young adults to handle catheterization independently.

## Urologic Surgeries

- *Catheterizable urinary stoma (also referred to as “mitrofanoff,” “MIC,” or “continent vesicostomy”):* Surgical techniques vary, but the result of these surgeries is to create an opening from the abdominal wall into the bladder, allowing a catheter to be passed through to empty the bladder. The stoma is usually located in the belly button or abdominal wall. After surgery, the patient usually has a catheter left in the stoma until healing has occurred. Then, the catheter is removed to allow intermittent catheterization through the stoma. This surgery usually requires a short hospital stay (unless done in conjunction with a bladder augmentation) and recovery time is brief.
- *Bladder augmentation:* This operation increases the capacity of the bladder. Surgical techniques vary, but the result of this surgery is that a portion of the stomach or bowel is used as a patch to increase the bladder's size. The expanded bladder stores more urine at lower pressure. This surgery usually requires 5–7 days hospitalization and several weeks for recovery. Patients go home with a suprapubic catheter in place until the bladder heals. Post-operative testing is usually done before the catheter is removed, at about 6 weeks after surgery. After the augmentation, urine may contain mucous strands secreted by the patch. Bladder irrigation is usually required to manage the mucous. It is important to carefully evaluate fever or abdominal pain. Urologic follow up is essential for a lifetime, and includes periodic testing and cystoscopy examinations.
- *Surgeries to the bladder neck:* Although surgical techniques vary, the purpose of these surgeries is to increase resistance of the bladder neck and improve continence by wrapping muscle or tissue around the bladder neck to tighten the outlet. This surgery usually requires several days of hospitalization. Recovery time is 2 to 3 weeks.

- *Injections to the bladder neck:* This is a procedure that narrows the opening between the urethra into the bladder by building up tissue. This increases the resistance of the bladder neck and improves continence. The operation is usually done as an outpatient procedure, and recovery time is brief. The injection may need to be done more than once to achieve the desired result. Over time, the procedure may have to be repeated to maintain continence.

## Bowel

Bowel management becomes more important as the child gets older. Bowel continence is essential for positive social interaction. If conservative measures (timing, oral preparations, suppositories, and/or small volume enemas) are not reliable, alternatives can be considered. Large volume enemas (with fluid based on the weight of your child) or antegrade enemas (given through a surgically-created conduit through the abdominal wall) are two more common management options.

During the school years, teach your child to participate in his or her bowel management program. Children can often learn to remove and replace clothing, insert suppositories, assemble supplies, and eventually take over responsibilities for managing bowel programs. Learning to clean up and change after a bowel accident is an important life skill for your child to achieve.

## Bowel Surgeries

- *Catheterizable Bowel Stomas:* Malone Antegrade Colonic Enema (MACE; also called antegrade colonic enema (ACE)): Although techniques vary, the result of this procedure is the creation of a conduit from the abdominal wall into the bowel to instill fluid to flush the bowel. The fluid and stool are evacuated through the anus into the toilet. Flushing of the bowel usually takes 30–45 minutes or more and is done every 1 to 3 days. This method of bowel management has proven effective in achieving social continence and independence. After surgery, a catheter is often left in the stoma until healing has occurred. It is then removed and reinserted for each enema flushing. This surgery usually requires an overnight stay at the hospital (unless done in conjunction with another surgery), and recovery time is brief.

### **Parenting Tip**

- *Think about ways your child can participate in his or her bowel program. If your child has not achieved social continence, talk with your health care team. Social continence is important for your child's future.*

# Orthopedic Function and Progress

Growth during the school years accounts for many orthopedic deformities that may develop. A child's feet need to remain in a plantigrade (foot flat on floor) position in order to fit into braces for walking. Contractures of the hip, knee, and ankle may occur despite an active stretching program.

Decisions on how to treat these deformities will be made by the orthopedic surgeon, with input from the physical therapist and the orthotist. Encourage your child to walk for a portion of each day to keep bones and joints in good condition.

As a child grows and body proportion changes, it often becomes more physically demanding to walk. Many older children elect to use the wheelchair as their primary way of getting around. This frees their hands, reduces energy expenditure, and allows them to keep pace with their friends. Help your child choose a lightweight, maneuverable chair, and work with him or her to build up endurance and acquire wheelchair skills such as managing curbs.

Your child's weekly routine should include physical activity such as wheelchair sports or aerobic cycling. He or she also must learn and practice how to check insensate skin areas.

## Surgeries

*Lower extremity surgery:* Surgery to correct lower extremity deformity to facilitate ambulation may be done during the school age years. These surgeries may include soft tissue releases and/or bone surgery for alignment. Casting is often used for a short time after these surgeries. Your child's activities may be restricted until adequate healing has taken place after surgery. These surgeries usually require several days of hospitalization and 2 to 3 months for recovery. Physical therapy is often recommended.

Begin to teach your child how to care for braces and a wheelchair. Be sure he or she understands the importance of proper fit and daily skin checks.

### Steps in Daily Skin Care:

1. Every day, you and your child should look for the following:
  - Red marks
  - Blister
  - Bruises
  - Cuts or scratches
  - Burns

It is much easier to prevent pressure sores (also called pressure ulcers) than to treat them. All of the above can become open sores within as little as 3 hours unless pressure is removed.

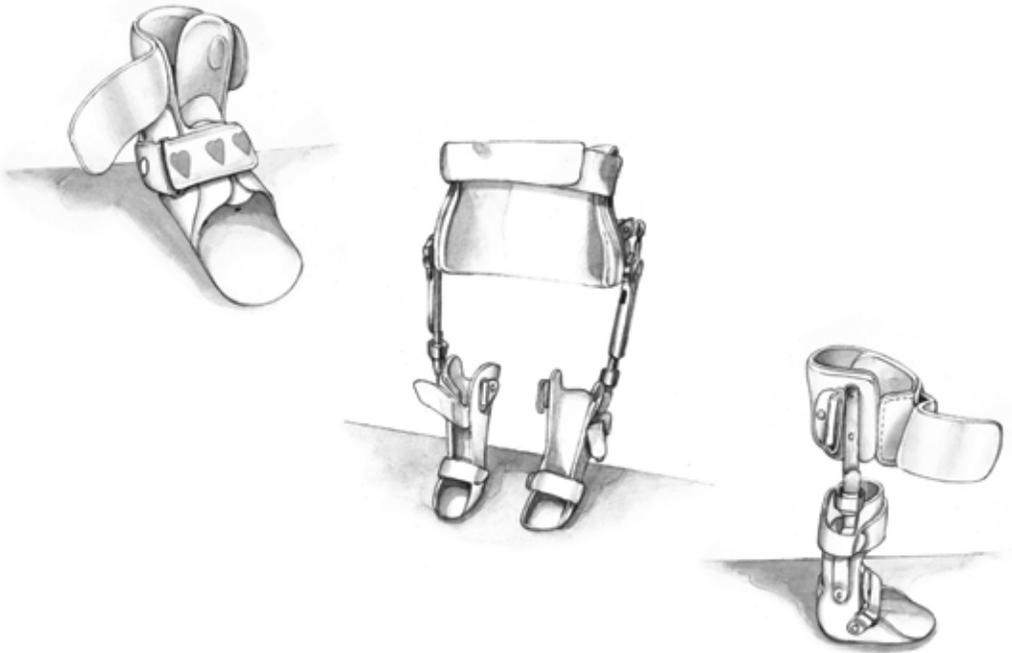
2. Be sure that your child's braces, shoes, and wheelchair fit properly. Break in new equipment gradually.
3. Observe the way your child transfers. It is important that your child tries to lift his or her body to transfer rather than sliding, which creates friction burns. Your child must learn how to protect his or her lower extremities during transfers. A physical therapist can teach your child the proper technique for safe transfers.
4. If your child spends time crawling on the floor, be careful to prevent carpet burns and other skin damage.
5. If your child primarily uses a wheelchair, get him or her in the habit of doing wheelchair lifts and shifts. Every 15 to 20 minutes, your child should lift his or her buttocks off the wheelchair, or at least shift his or her weight to relieve pressure.
6. If your child's skin becomes reddened, determine the source and relieve the pressure. For example, if the problem is improperly fitting braces, remove and replace the braces; or if the cause is sitting for extended periods without relief, be sure your child changes position more often. Ask your child to stay off the affected area until his or her skin color returns to normal. If the skin does not return to normal color within 20 to 30 minutes, seek care from a health care provider.
7. If your child has an area of skin breakdown, special dressings or treatments will usually be necessary to help heal the sores. Have your child assist in applying the treatment that his or her health care provider has selected. The following are typical wound care products:
  - Transparent films: Used to treat reddened areas
  - Foam dressings or hydrocolloids: Used to treat draining wounds
  - Hydrogels: Used to treat dry wounds

Your child's health care provider will decide what will work best for your child's situation. Mobility needs will change as your child grows. If walking is becoming more difficult for your child, consider a wheelchair, crutches, or other assistive devices. The most important thing you can do for the health of your teen's bones and muscles is to provide and encourage good nutrition and regular exercise. This will also help your child maintain a healthy weight.

Your child will continue with annual visits to an orthopedic surgeon, who will periodically order x-rays. Children at this stage should focus on flexibility, with position changes, stretching, and exercise. Regular aerobic exercise, upper body weight training, and recreational sports can help your child maximize his or her abilities.

### **Parenting Tips**

- *Teach your child how to care for braces and a wheelchair. Be sure he or she understands the importance of proper fit and daily skin checks.*
- *Mobility needs will change as your child grows.*



# General Healthy Practices

Families with school age children are typically very busy. Keeping up with school and extra-curricular activities can be exhausting for parents, but your child will thrive on lots of opportunities to be with children his or her own age. He or she needs to participate in both structured and unstructured activities.

Everyone in the family should participate in household chores. All children can do something, and should have responsibilities. It will make them feel important and give them a sense of belonging.

Children continue to develop cognitively, physically, and socially. Moreover, emotional development and the development of behavioral self-control become more prominent during this period. As was the case during earlier stages of development, it is important to be a good observer of your child.

Give your child chores to do: answering the phone, folding laundry, feeding pets, straightening his or her room, or helping with dinner and household chores. A small allowance helps teach financial responsibility, especially if expected to cover specific expenses!

## Healthy Diet and Exercise

A healthy diet consisting of a wide variety of foods is important for everyone. A child who has Spina Bifida needs to maintain a healthy diet for many reasons: a healthy body weight, optimal mobility, and bladder and bowel functioning.



## Fiber

Involve your child in planning healthy meals and choosing healthy snacks. Foods with fiber are especially important for children with Spina Bifida. You can help your child prevent constipation, a common problem in people with Spina Bifida, by encouraging him or her to eat a diet that contains plenty of healthy fluids and foods that contain fiber. An easy way to determine the amount of fiber your child needs is to add 5 to his or her age. This equals the grams of fibers your child needs each day. For example, a child who is 3 years old needs 8 grams a day.

Here are some ways to help your child get the foods with fiber that he or she needs:

- Buy many kinds of fruits and vegetables when you shop so you have plenty of choices and you don't run out. Buy fresh fruits and vegetables as well as frozen, dried, and canned.
- Introduce your children to new foods. Have a dark green salad with carrots, tomato, cucumber, and beans like kidney beans or chickpeas (garbanzo beans).
- Have a variety of vegetables at family meals, especially dark green and other colorful vegetables like spinach, broccoli, squash, or tomatoes.
- Keep a fruit bowl, small packs of applesauce, and raisins or other dried fruit on hand for snacks. Send fruit as dessert in your child's school lunch.
- Add fruit to your family's breakfast by drinking a 6-ounce serving of 100% fruit juice or by having fruit on bran or multigrain cereal.
- Choose whole grain varieties of bread, muffins, and rolls, such as multigrain bread, bran cereal, or oatmeal.

## Beverages

As you increase the amount of fiber your child eats, it is important to increase the amount of fluid he or she drinks. If you do not increase fluids, additional problems can be created. Your child should drink plenty of fluids so that his or her urine is clear and his or her skin is moist. Drinking plenty of fluids, especially water, helps to prevent urinary tract infections, kidney stones, and constipation. It also promotes healthy skin. Encourage your child to choose a variety of healthy beverages:

- Water
- Low-fat milk
- Juices such as apple or cranberry juice (in moderation)
- Low-sugar sports drinks
- Fruit smoothies

Limit soda and caffeinated beverages because they tend to be dehydrating. Children with Spina Bifida have a tendency to become overweight as they get older. If mobility is limited, your child won't burn as many calories as a more active child. Extra weight will limit your child's mobility and ability to do self-care tasks, like getting dressed or doing chores. Being aware of the potential to become overweight will help you to prevent this from happening to your child. It is easier to prevent excess weight than to worry about losing pounds.

Be creative to find physical activities and exercise that you can do together with your child. Your child might enjoy going for a swim with you or helping with house cleaning. Check out therapeutic recreation centers in your community for activities designed for children with physical impairments, like wheelchair basketball, swimming, or Special Olympics. Your child's physical therapist can recommend additional appropriate activities.

Getting involved in sports or other activities also helps your child socially and increases his or her self-esteem. At school, your child should participate in adaptive physical education. Ideally, this means adapting the same activities that the other children are doing so your child can participate.

## **Latex Issues**

As your child begins to increase his or her independence, it is important for him or her to be able to recognize and avoid common items. Now that much of your child's day is spent at school, make sure that he or she is aware of some latex-containing items that are often found in the school setting: art supplies, balloons, latex gloves, and balls. If your child has developed a latex allergy, increased precautions are needed. See SBA's Web site, at [www.spinabifidaassociation.org](http://www.spinabifidaassociation.org), for a list of common latex items and safe alternatives.

## **Mental Health**

Review all of the challenges in your child's day—whether academic, social, or physical. Make certain that your child is neither sheltered nor overwhelmed. Maximize your child's participation in self-care activities by teaching the necessary skills, providing supports, and offering incentives for greater independence.

Talk to your child regularly about having a disability. Help him or her develop a positive self-concept. Help your child develop responses to questions people ask about Spina Bifida and effective comebacks when children tease them. Monitor your child's behavior for problems that may reflect the beginning of mental health issues. Get professional help if you think there is a need for your child or family.

## Sexuality

We are all sexual beings. Our sexuality is expressed through the clothes we wear, the words we say, and the things we do. Everything a man or a woman does to express being male or female is part of his or her sexuality. Hopefully, your child has been developing positive feelings regarding his or her sexuality since early childhood.

Sexuality is an important aspect of social development. As a parent, you should begin to address sexuality during early childhood in simple and developmentally appropriate ways. Children who feel comfortable with their sexuality are more likely, as they grow older, to deal positively with aspects of Spina Bifida that affect sexuality. Feeling loved and respected provides the basis for healthy views of sexuality.

Talk to your child about:

- His or her body, using correct terms for body parts
- Good touch versus bad touch
- Privacy

Appropriate touching and privacy are particularly important issues to discuss with young children. Caregivers are frequently required to touch genital areas when doing clean intermittent catheterizations (CIC), bowel care programs, and physical exams, and during hospitalizations. Maintaining privacy can be difficult in light of certain intrusive procedures. Young children can learn to value privacy and ask others to respect their privacy.

As issues related to sexuality assume a more central role during adolescence, young people with Spina Bifida face unique challenges. The specific nature of these challenges varies greatly among children with Spina Bifida. Personal hygiene, continence, and appearance are among the many things that may affect a child's perception of him or herself. These also affect the way their peers and others perceive and respond to them.

Spina Bifida does affect some areas of sexual functioning—depending upon the level of Spina Bifida. Encourage your child to discuss questions about sexual function with an appropriate health care provider.

Children at this stage can benefit greatly from your guidance and support. Continue to encourage self-respect and self-worth as you discuss the decisions they will face related to sexuality and sexual behavior. Strive to maintain open communication and provide opportunities for your teen to acquire accurate information about Spina Bifida and sexuality.

### **Parenting Tip**

- *Foster independence and teach responsibility at an early age. Catheterizing, taking medications, toileting, skin care, hygiene, and dressing are all tasks that your child should work toward mastering as early as possible. Begin by sharing the responsibilities with your child before permitting him or her to do it solo.*

## **Learning**

Although development during the middle childhood period may seem slower than it was during infancy, it is no less complex. During middle childhood, the school experience becomes more academic, and advances in cognitive abilities are expected. Even if your child has not had special education services up to this time, he or she may need it to tackle the heavier expectations of a 4<sup>th</sup>, 5<sup>th</sup>, or 6<sup>th</sup> grader. If your child is struggling ask for a multi-disciplinary evaluation to determine if he or she qualifies for an Individualized Education Program (IEP), a formal document which reviews the special education and services he or she needs.

Baseline testing and evaluation should be used to set educational goals and plan for your child's future education. Work with your school system and medical institutions to get the testing and evaluation your child needs.

Plan ahead—expose your child to the idea of work and explore potential jobs and interests with him or her. Between ages 14 and 16, your child should begin attending his or her own IEP meeting. At this time, the transition plan should include vocational/academic goals. Start working with you child on the idea of potential jobs by encouraging volunteering, a babysitting job, or more chores around the house.

## **Learning Challenges**

Many children with Spina Bifida and hydrocephalus have learning challenges. Areas where children typically have problems include:

- Organization
- Language: poor comprehension, sequencing problems, and trouble understanding directions

- Attention and memory
- Handwriting
- Mathematics
- Solving problems and making decisions

Numerous accommodations, strategies, and sometimes medications can help your child cope with these challenges. Be sure to monitor your child's academic progress consistently. If you notice your child struggling with some of the challenges mentioned above, you can strive to have evaluations completed and services implemented quickly. When children struggle in school, their self-esteem is often affected. Children at this age need to feel successful and industrious. Help your child find and develop a skill he or she can be proud of. Try not to let homework consume your evenings with your child and become a nightly struggle. Talk to your child's teacher and see what can be done to help reduce the load, if necessary. Although parents are expected to be involved with homework to some degree, it is unrealistic for them to spend endless hours teaching and helping their children at night with concepts they should be learning at school. Your child may qualify for additional tutoring.

## **Bullying**

Any child can be bullied at school. Bullies tend to pick on those who are younger than them, have few friends, are different than them, or are easily intimidated. Bullying can include:

- Physical bullying - hitting, punching, kicking and destruction of your property
- Verbal bullying - teasing, name-calling, taunting, racial slurs, gossip or malicious rumors
- Cyberbullying - harassing e-mails or text messages

Remind your child that bullying is not his or her fault.

Encourage your child to:

- Get involved in activities that make him or her feel good about himself or herself like sports, music or art.
- Talk with the friendly students in his or her class.
- Stick with a friend or group of friends while on the bus, in the cafeteria or wherever the bullying seems to happen.

If your child is bullied, remind him or her to:

- Stay calm. Maintain his/her composure. Reacting will only reinforce the bullying.
- Tell the bully, “I want you to stop now,” and then simply walk away.
- Share your concerns. Talk to his or her parents, teacher, the school counselor and the school principal.
- Follow up. Keep talking with you (his or her parent) and school officials if the bullying seems to continue.

### **Parenting Tips**

- *Many teachers are not familiar with latex allergies and the way to avoid exposure. Use the Spina Bifida Association’s latex fact sheet to help educate them.*
- *To help teachers and classmates understand Spina Bifida, speak to the class and discuss what it means. Be ready to answer lots of interesting questions! Handouts might be helpful.*
- *Teachers and school nurses will appreciate receiving a detailed description of your child’s special needs, medical and educational issues, health care providers, and emergency contacts.*
- *Missing school for surgeries may be a big problem for a child who is striving for good grades. School districts are required to provide home-based tutors for special education students who are unable to attend school for extended periods. Contact your local school to make arrangements as soon as possible.*

# Financial Planning and Assistance

## Supplemental Security Income

Your family may qualify for Supplemental Security Income (SSI). SSI is a federal program that pays monthly checks to people who have disabilities and have limited income and assets. To qualify, you must be a citizen of the United States or a legal immigrant and you must live in the United States. Many children who have Spina Bifida receive SSI payments. If you think your child may be eligible, contact the Social Security office closest to you. To find the closest office, contact SSI at 1-800-772-1213. For more information on income requirements, visit [www.ssa.gov/pubs/11000.html](http://www.ssa.gov/pubs/11000.html).

## Medicaid

Medicaid pays for health care expenses. The social worker at your child's hospital or clinic is a good source of advice on financial matters like Medicaid and how to apply in your area. Medicaid helps to limit the significant financial burden that that may result from the treatment of Spina Bifida.

## Other Resources

At times your child's disability may require equipment that is not covered by private insurance or Medicaid. This might include things such as: bed rails, bath lifts, special auto seats, potty chairs, ramps, or even specially adapted bicycles. Certain states have a Developmental Disabilities Board or a Disabled Children's Program that may offer some financial aid for such items. The social worker at your child's hospital or clinic is a good source of advice on local financial assistance and the application process.

Parents sometimes tend to put off planning for the future. *Taking Charge of Your Future: A Financial Guide for People with Spina Bifida and Their Families* is a financial planning guide created for the Spina Bifida Community and is available online at [www.sba-resource.org/NEFE/](http://www.sba-resource.org/NEFE/).

# Thinking About the Future

If you have not done so already, begin speaking with your child about his or her future educational and career goals. Remember that your child wants to have a sense of control, so let your child make whatever decisions he or she can and include him or her in any conversations about planning for adulthood. Continue to include your child in your everyday family activities and give him or her as much independence as possible.

One of the most important things you can do is to keep current health care records for your child. This will help the health care team develop treatment and care options that are best for your child. Keeping a record of the health care services your child receives will help you track changes in your child's medications and treatments, teach your child about Spina Bifida, and prepare for and make health care appointments. The Spina Bifida Association has developed a Health Care Record for Parents. Using the Health Care Record will help you organize your child's health information in a central place. This Health Care Record is available in the Spina Bifida Association publication, *Health Guide for Parents of Children Living with Spina Bifida*.

You are not alone in dealing with the challenges of Spina Bifida. Try to find time for you and all the significant people in your life (your best friend, your spouse, or another member of your family). You are a parent, but remember that you also have many other roles in life which are also important to your well-being.

A full version of the *Health Guide for Parents of Children Living with Spina Bifida* is available through the Spina Bifida Association's Resource Center. The Resource Center can be accessed at [www.spinabifidaassociation.org](http://www.spinabifidaassociation.org) or 800-621-3141.



**4590 MacArthur Boulevard, NW Suite 250**  
**Washington, DC 20007**  
**[www.spinabifidaassociation.org](http://www.spinabifidaassociation.org)**

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