



Living Well with Spina Bifida: Ages 6 to 9

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A message from Hollister Incorporated:

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:

www.hollisterpeoplefirst.com

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What to Expect

The school age years can be a challenge for any parent. This booklet is designed to guide you through the experience of raising a child who has Spina Bifida during the early school years.

These years can be rewarding and exciting for your child. He or she will be exposed to many new concepts and activities. Just like other children, there will be some things your child will do well and other things that he or she will do that require more help. The important thing is to make sure that the tasks that are within your child's ability are done independently. Sometimes you might be tempted to help, just because you can, or because it would be quicker, but the more your child performs a task, the better and faster he or she will be able to complete it independently. Success will motivate your child to keep trying. Your loving attitude toward your child and the realistic expectations you set will help him or her to develop a positive self-image.

At this stage it may still be difficult to predict what your child's abilities will be. 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. Provide your child with lots of opportunities to play with other children, so he or she can learn social skills. 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. Your child's healthcare team may be able to give some guidance in achieving these goals. Parents of other children with Spina Bifida might also have valuable suggestions and ideas.

Every day brings a chance to work with your child to develop self-care skills and increased independence. Include your young child in your everyday family activities and strive to give him or her as much independence as he or she can handle. One strategy is to share the responsibility for the care your child needs day to day, such as catheterization. This is a process where parents work with children on a task, and then children gradually take on the task themselves as they get older.

Having time for yourself, your spouse, and other family remains essential for maintaining your own mental health. Find ways to relieve your stress and occasionally indulge yourself. You are a better parent when you take care of yourself. Friends, family members, other parents of children with Spina Bifida, and health care professionals are often willing to give you the support and help you need. Remember that you are not alone.

All parents have dreams for their children. Have realistic expectations of your child. A child tends to live up to the expectations held by parents and teachers, so encourage your child to live up to the goals you have set together. Your child may need more help and more time, but having a successful, confident, and happy child is the ultimate goal.



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 www.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 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 for the Spina Bifida Association Chapter nearest to you.

Parenting Tips:

- *Taking care of yourself is the single most important thing you can do for your child. It's up to you to ensure that you take care of yourself. Your child needs you.*
- *Every day is a chance to work towards transitioning your child toward independence in life. Encourage your child to build friendships. Activities like sports or scouting give your child a chance to get to know other children and to increase their social skills*
- *Validate your child's experiences. During the early school years, your child will learn more about how he/she is different from other children and things that he/she shares in common. Talk with your child about how he/she may have different mobility but highlight the common things that all children share, like homework or wanting to play. The key message is that your child is much more than his or her disability. Your child should reach high and pursue his or her dreams one step at a time.*

General Care of Your School Age Child

Parenting

Find things your child does well and give him or her lots of opportunities to develop those skills. Group sports, scouts, art projects like coloring, drawing with pencils, stringing small beads, and jigsaw puzzles are all good activities. He or she may also like to help you put together a simple meal, clean dishes, or set the table and should be encouraged to do so. Allow him or her to help in any way he or she can. Praise your child often for his or her willingness to help.

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. When the chores are finished, there are so many educational and fun things you can do as a family with school age children: visiting museums, zoos, and aquariums; swimming; going to the movies; watching sports activities; and having picnics in the park. Spending time together as a family creates memories that will last a lifetime.

Parenting strategies should emphasize providing appropriate challenges, facilitating social activities, and effectively coping with stress. Although development during the middle childhood period is not as rapid as it was during infancy, it is no less complex. Children at this stage continue to develop mentally, physically, and socially. Emotional development and the development of behavioral self-control become more prominent during this period. It is important to continue to be a good observer of your child. Talk and play with your child and listen to him or her carefully. Try to eliminate distractions (phone calls, work-related activities) so that you can attend fully to your child.

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. 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 have soft formed bowel movements 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 five to his or her age. This equals the grams of fiber your child needs each day. For example, a child who is seven years old needs 12 grams a day.

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 occur. 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. Providing a full water bottle to your child during the day is a good way to remind him or her to drink plenty of water. Limit soda and caffeinated beverages because they tend to be dehydrating. Encourage your child to choose a variety of healthy beverages:

- Water
- Low-sugar sports drinks
- Low-fat milk
- Fruit smoothies
- Juices (100% juice, not sugary water) such as apple or cranberry juice (in moderation)



Exercise

Children with Spina Bifida have a tendency to become overweight as they get older. If mobility is limited, your child won't burn calories like a more active child. As a result, weight might limit your child's mobility and ability to do self-care tasks, like getting dressed or doing chores. It can also put your child at risk for high blood pressure, skin breakdown, and poor self esteem. Being aware of the potential to become overweight might help you prevent this from happening to your child. It is easier to prevent excess weight than to worry about losing pounds.

Staying active will be helpful to you and your child. Exercise promotes strength, flexibility, burns calories, and helps you feel good. 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 challenges, like wheelchair basketball, swimming, sledge hockey, or Special Olympics. Your child's physical therapist may also be able to recommend additional appropriate activities.

Skin Care

Review the steps in daily skin care with your child. Your child can begin to do these steps on his or her own with your supervision. Every day, you and your child should look at areas on his or her body where they have little or no sensation, such as feet, legs, and buttocks. You can teach your child to use a hand-held mirror for places he or she cannot see. You should look for any:

- Red marks
- Cuts or scratches
- Blisters
- Burns
- Bruises

If your child uses braces, it is VERY important to check skin under the braces. When the braces are new, it should be done every two hours or so for the first few days.

All of the above can become open sores within as little as three hours unless pressure is removed. It is much easier to prevent pressure sores (also called pressure ulcers) than to treat them. A few key steps in preventing breakdown include the following:

1. Inspect skin at least once a day (see above)
2. Prevent dry skin
3. Bathe with mild soaps and warm vs. hot water
4. Keep skin surfaces dry OR use a moisture barrier if incontinent
5. Maintain good nutrition and hydration
6. If your child is in a wheelchair, have them shift their weight frequently. Using a watch with an alarm or timer helps to remind your child that it is time to do this. The use of foam, gel or air cushions can also help relieve pressure. Your child's physical therapist will help determine which cushion is best. The cushion should be reassessed at least yearly.
7. **Finding any irritation early is key in preventing breakdown or ulcers that might require months to heal.**

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.

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 that might contain latex. 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. Your child should wear a Medic-alert™ bracelet and carry an Epi-pen™ if this is the case. A list of items used in the hospital and in the community that frequently contain latex as well as latex-safe alternative can be found at Spina Bifida Association's Web site, www.spinabifidaassociation.org. It is important to inform the school about your child's sensitivity or allergy to latex. Your child's healthcare team can help to do this as well.

Social Development

Children take on many new challenges at this stage like riding a school bus, talking to peers, following directions from teachers, mastering the academic challenges of the classroom, and figuring out the game-playing and social situations of the playground. Your child will constantly encounter new challenges and learn new skills. During this stage, you must work to ensure that your child finds challenges that are neither too easy nor too difficult. Your challenge is to monitor the level and type of situations that your child confronts in school, at home, and in the community. Failure, frustration, and anxiety are certainly a normal part—and a key ingredient—of growing up. Do not try to shield your child from all of these experiences. But be vigilant to prevent situations where your child is regularly overwhelmed by challenges that are far beyond his or her skills.

As with any child, carefully monitor his or her behavior. Signs of potential mental health problems include changes in diet or sleep, a drop in academic performance, withdrawal from friends, extended periods of sadness and bad mood, making frequent negative statements, and oppositional behavior or anger. If you see signs of trouble, seek assessment to see if there is a significant problem and a need for treatment. A number of professionals can help, including your child's pediatrician, healthcare team, psychologists, psychiatrists, social workers, and counselors.

Parenting Tips:

- *Review all of the challenges in your child's day—whether 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 support, and offering incentives for greater independence.*
- *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 or expecting him or her to do it solo.*
- *Talk to your child regularly about having Spina Bifida. Help him or her to develop a positive self-concept. Help your child develop responses to questions people ask about Spina Bifida.*
- *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!*

Neurological Function and Progress

Your child's neurological status and progress is monitored closely to help prevent loss in function. Generally, a neurosurgeon will work with you to determine what tests need to be completed and/or treatments that are indicated for your child.

Hydrocephalus

If your child has a shunt, it is important to know the placement of your child's shunt. This information is important for monitoring your child's shunt function. As a precaution, you will need to check with your neurosurgeon about considering antibiotics before any surgical or dental procedure. It is also very important to be aware of signs and symptoms of shunt malfunction:

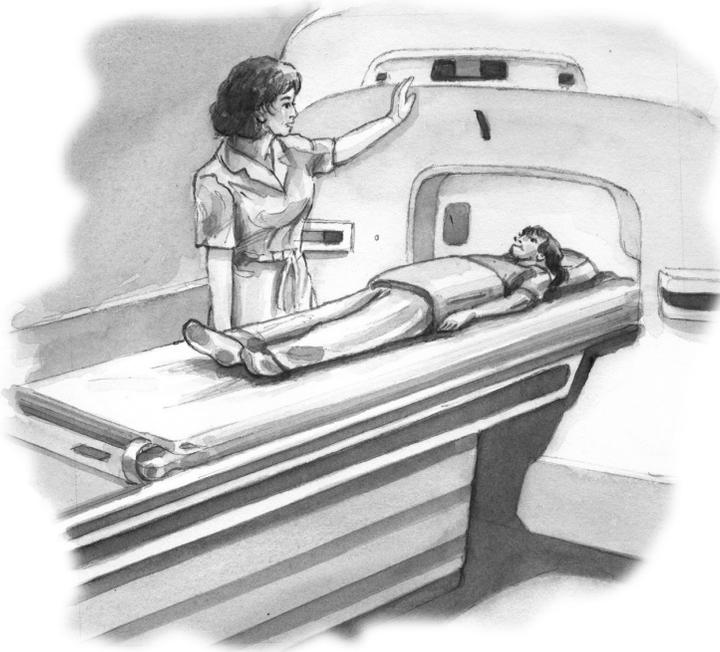
- Headaches
- Lethargy
- Vomiting
- Decline in schoolwork
- Unusual eye movement

CT scans, shunt films and/or a shunt tap (a procedure where a small needle is inserted into the shunt to check the flow of cerebrospinal fluid) may help to determine whether the shunt is functioning properly. Treatment for shunt malfunction includes a shunt revision. In some cases, the neurosurgeon may consider a 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

Tethered means to “restrict” or “bind with.” “Tethered cord” is a spinal cord that is bound down or restricted by scar tissue. The tethered cord cannot 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 but can occur at any time.

The potential for development of the tethered cord syndrome essentially begins with the closure of the myelomeningocele defect. When your child was a baby, most likely an MRI (Magnetic Resonance Imaging) of the spinal cord was performed to see whether there was a tethered cord. Often a tethered cord is seen by MRI; however, treatment is not recommended unless your child begins to show signs of the tethered cord syndrome.



Signs of Tethered Cord Syndrome

It is important to watch your child for signs and symptoms of the tethered cord syndrome. The signs of tethered cord syndrome include:

- Loss of neurological function: increasing difficulties with walking, decreased use of the lower extremities, or change in shape or appearance of toes or feet
- Pain: back pain and unexplained leg or knee pain that worsens over time
- Bladder and bowel function: any significant changes in bladder or bowel functions; changes should be assessed by the urologist as well as the neurosurgeon
- Scoliosis (schol-ee-oh-sis): rapidly progressive curving of the spine

It is important to also consider non-neurological 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 should be expected. If progressive loss of function does occur, it is often associated with tethered cord; therefore, regular follow-up evaluation is important.

Testing for Tethered Cord Syndrome

When concerns of tethered cord come up, studies are done and compared with the baseline information. These studies may include:

- 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

Your child will be followed at close intervals by the neurosurgeon. Surgery is sometimes recommended to untether the cord. The goal of the surgery is to prevent further worsening of function. There may be some improvement in function after surgery; this will vary from child to child and may not be immediate. The amount of time your child is hospitalized and recovering may vary. If needed, a tutor can be arranged to help your child keep up with schoolwork during the recovery period. Studies have shown an increased risk of shunt malfunction after tethered cord surgery. Your child should be followed closely for signs and symptoms of shunt malfunction. It is not unusual to have transient (come and go) worsening of muscle or bladder function after surgery. Most children will eventually return to their previous level of function.

Retethering is not uncommon, so it is extremely important to continue monitoring for signs and symptoms of tethered cord syndrome.

Seizures

Some children with Spina Bifida may have seizures. Seizures are serious and 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.

The doctor may 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. A referral to a neurologist might be recommended to help manage the seizures.

How can I make sure my child is safe?

A seizure, in itself, is rarely a major hazard to a child. The hazards relate more to what your child is doing when a seizure happens. If seizures are under control for several months, most activities are safe. While it is important not to overprotect a child with seizures, always use caution when your child is bathing or swimming.

How can I help my child if he or she is having a seizure?

Help your child lie on his or her right side and turn the child's head to the side if possible, so that saliva or vomiting doesn't result in choking. Do not try to put anything in your child's mouth or between his or her teeth. Do not restrain flailing arms or legs.

Parenting Tip:

- *Your child should not lose neurological 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 Function and Progress

Children with Spina Bifida frequently have what is known as a neurogenic bladder and bowel due to damage to the nerves that control these organs. Sensation, voluntary emptying, and coordination may all be affected and interfere with normal bladder functioning. The urologist will order periodic tests to check your child's kidney and bladder function. These tests are repeated as needed over the developmental years to monitor renal growth and function, and then repeated less frequently throughout adult life.

Your child most likely is on a catheterization and bowel program or will be soon if not already. Clean Intermittent Catheterization (CIC) may be initiated during infancy or delayed until the child reaches the age for toilet training. CIC is simply emptying the bladder by inserting a clear plastic tube called a catheter into the bladder through the urethra, and draining the urine. The catheter is removed each time, and the procedure is repeated four to five times during the day. You may already work with your child to perform this on his or her own. Remembering to catheterize may be difficult for your child. Help him or her to develop a reminder system or schedule, and remember to celebrate success.

It remains important for your child to know the signs and symptoms of a urinary tract infection. Bacteria in the urine is common for anyone who is on a catheterization program and is not usually treated as a urinary tract infection if there are no other symptoms or if your child has urinary reflux.

Ask your child to let you and your health care team know if he or she experiences any one of these symptoms of a urinary tract infection:

- Chills or fever
- Foul smelling urine
- Cloudy or dark urine
- Blood in the urine
- Nausea or vomiting
- Pain (in the back or lower abdomen)
- Discomfort with catheterizations (if on a CIC program)
- Change in urinary continence (if on a CIC program)
- General signs of illness (e.g., not eating, not responding as usual)

Bowel Control

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 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.

Begin to 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.

Help your child avoid constipation by providing good foods with fiber and lots of healthy fluids. Medications and/or suppositories or enemas may be needed to help your child have a bowel movement. Your pediatrician or clinic nurse will advise you about maintaining a bowel program for your child.

A key goal of bowel management is to give your child good social continence, especially during school hours. It may take time to find the most reliable program, but the effort is essential for good social adjustment in school, and in the future with relationships and jobs. Ask your nurse coordinator for help if necessary.

Treatment Options

Medications

It may be necessary to begin urologic medications even in a young child. These medications are used to improve bladder capacity, tighten the sphincter muscle, decrease bladder pressure, or reduce infection. Some medications typically used are:

- *Anticholinergics* (pronounced **ann-tee-ko-li-neh-r-gix**) to relax the bladder muscle so it can hold more urine under lower pressure.
- *Alpha-adrenergics* (pronounced **al-fa-ad-reh-neh-r-gix**) or *alpha-agonists* (pronounced **al-fa-ag-oh-nists**) to help tighten the sphincter muscle.
- *Antibiotics* to reduce urinary tract infection.

These medications may come in pills or liquids taken by mouth, a solution that can be instilled into the bladder, or a patch that can be placed on the skin.

Surgeries

Sometimes it may be necessary to treat bladder or bowel issues with surgery. The most common surgeries are:

- **Reimplantation of ureters:** If reflux (backward flow of urine into the kidneys) does not improve with CIC and medication, gets worse, or causes repeated urinary tract infections, your child may need corrective surgery. This surgery requires that the ureters are detached from the bladder and reimplanted at a different angle. This operation is usually very effective and normally requires several days of hospitalization and several weeks of recovery.
- **Injections to bladder-ureter junction (also referred to as “deflux”):** This is a procedure that narrows the openings between the bladder and the ureter by injecting material to build up tissue. This narrowing prevents the urine in the bladder from refluxing into the kidneys. This is usually done as an outpatient procedure, and recovery time is brief. The injection may have to be repeated to get optimal results. Over time, the procedure may also be repeated if reflux reoccurs.
- **Vesicostomy:** If bladder pressure remains high and is not managed adequately by CIC and medication, a vesicostomy (pronounced ves-ih-**co**ss-toe-mee) may be done. This surgery involves making a small opening through the lower abdomen and into the bladder to allow urine to leak out onto a diaper continuously, keeping pressure in the bladder low. This operation usually requires a brief hospitalization and recovery time. Vesicostomies are normally closed before a child begins school.
- **Bladder augmentation:** This is a procedure done to enlarge the bladder using either a piece of intestine or stomach. It is done if a bladder has not responded to medications to decrease pressure and increase capacity, and is done to prevent kidney damage. The operation may take several hours and usually requires a one to two week hospitalization. Recovery at home may take several weeks.

Parenting Tips:

- *Remembering to catheterize may be difficult for your child. Help him or her to develop a reminder system or schedule, and remember to celebrate success.*
- *Begin to 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 very important for your child’s future.*

Orthopedic Function and Progress

Encourage your child to walk for a portion of each day to keep bones and joints in good condition. An active stretching program is also very important. 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. Recommendations on how to treat these deformities will be made by the orthopedic surgeon, with input from the physical therapist and the orthotist. Surgery and physical therapy may be part of a treatment.

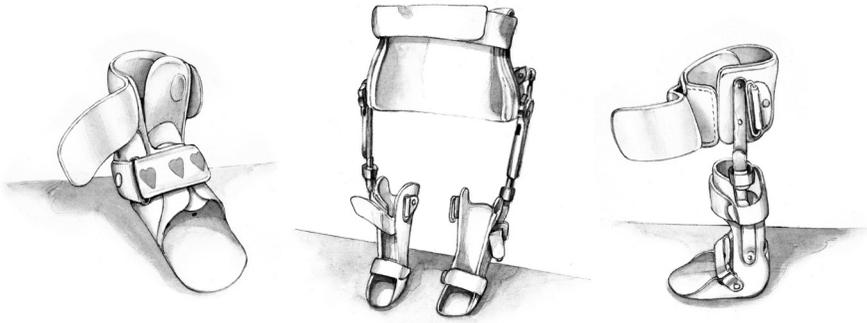
As a child grows and body proportion changes, it often becomes more physically demanding to walk. Many older children elect to use the wheelchair as their primary way of getting around. This frees their hands, reduces energy expenditure, and allows them to keep pace with their friends. If your child chooses to use a wheelchair, it should not be looked upon as a failure or that they are giving up. The use of the chair can enable them to be more independent and functional. 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 (areas that have no feeling).

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 two to three months for recovery. Physical therapy is often recommended.

Orthopedic goals

An overall goal of orthopedic treatment for the child with Spina Bifida is to provide support for normal development and function. As your child grows, he or she will adjust to being upright, learn to balance, and use his or her arms for assistance in ambulation.

Ankle-foot orthoses (AFOs) or dynamic ankle-foot orthoses (DAFOs) are often needed to maintain foot position or give support for standing. Be sure that your child's braces, shoes, and wheelchair fit properly. Have your child practice putting on and taking off braces and shoes. Remember to break in new equipment gradually. Being mobile and comfortable with the preferred means of mobility will help your child with social functioning and in getting around at school.



Parenting Tips:

- *Continue stretching exercises especially if your child has difficulty walking at all or minimally.*
- *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.*
- *Mobility needs will change as your child grows.*

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.

Educational and therapy services vary from state to state. Public schools are required by a federal law referred to as the Individuals with Disabilities Education Act (IDEA) to provide a free appropriate education for your child. They must provide for his or her transportation to and from school, and accommodate your child's medical needs while he or she is at school. If your child is not already enrolled in the school system, you will need to contact your local school before your child reaches kindergarten age. A multidisciplinary evaluation will be conducted to determine the services your child will need while at school.

Baseline testing and evaluation should be used to set educational goals and plan for your child's future education. Neuropsychological testing is very helpful in determining your child's abilities, challenges, and can be helpful in directing the kind of educational setting and approach from which your child will most benefit. Work with your school system and medical institutions to get the testing and evaluation your child needs.

If your child has minimal supplementary educational needs, he or she may not qualify for special educational services. If that is the case then a simple plan, referred to as a 504, can be drawn up to address cathing and other medical needs. If your child qualifies for special education, the services he or she needs will be addressed in a more formal document called an Individualized Education Program (IEP). The fact that your child needs educational support does not mean that he or she will be segregated from his peers or taught in a special class. For example, your child may just need additional support for math, extra tutoring, or more time to take tests. Physical, occupational, and speech services may also be provided. The amount of support your child receives is based on the results of his or her evaluation and input from the team. Remember that you are an important member of that team.

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 now or in the future, you can strive to have evaluations completed and services implemented quickly. Self-esteem is often affected when children struggle in school. Children at this age need to feel successful and industrious. Help your child find and develop a skill that promotes your child's self-esteem.

Parent Advocacy

Even if your child has a well-written IEP, you will need to stay involved and make sure that school staff follows the plan as written. You have the right to ask for changes and additions if you feel your child is not succeeding in school. You can request a meeting at any time to address your concerns. Know the laws and your rights regarding special education so that you feel empowered to voice your views in support of your child. Again, talking to other parents who have successfully worked with the school can be helpful. The health and support professionals your child sees can also be good resources.

If your child did not originally qualify for special education services and does not have an IEP, but still seems to be struggling in school, you can request another evaluation. A child's needs for special education services can change as he or she advances in school and the requirements become more difficult. Just because your child did not qualify initially does not mean that he or she will never qualify. Succeeding in school is important for a child's self-esteem and future vocational years. It may take a lot of persistence on your part to assure the best possible school experience for your child, but the efforts will pay off in the future.

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! Bring in handouts that 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 800-772-1213. For more information on income requirements, visit 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/.

Thinking about the Future

Let your child make whatever decisions he or she can. Include your child in your everyday family activities and strive to give him or her as much independence as he or she can handle. Your child wants to have a sense of control.

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 to 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.

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Attention to Detail. Attention to Life.

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 or 800-621-3141.



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