



# Living Well with Spina Bifida: Ages 3 to 5



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Attention to Detail. Attention to Life.

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](http://www.hollisterpeoplefirst.com)

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# What to Expect

What a precious time the early years are as your child learns new words and experiences the world. This booklet is designed to guide you through the experience of raising a child who has Spina Bifida from the toddler through preschool stage.

The preschool and early school age 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. However, keep in mind at this stage, it is difficult to predict your child's abilities.

Remember, services are available for your child according to his or her needs. If your child struggles with basic dressing or grooming, an occupational therapist can help find alternate ways for your child to do basic things. A physical therapist can help with mobility issues. Provide your child with lots of opportunities to play with other children, so he/she can learn social skills.

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. Every day brings a chance to work with your child to develop self-care skills and increased independence. One strategy is to share the responsibility for Spina Bifida care. Shared responsibility is a process where parents work with children on a task, and then children gradually take on the task themselves as they age.

Parents need to have time set aside to relax and unwind. Find ways to relieve your stress and occasionally indulge yourself. Life is about maintaining a sense of balance, so plan your "escape" time and don't feel guilty about it. You are a better parent when you take care of yourself. Reach out to others for support. Friends, family members, other parents of children with Spina Bifida, and health care professionals are often willing to help. You are not alone on this journey.

All parents have dreams for their children. Remain optimistic. Have realistic expectations of your child. A child tends to live up to the expectations held by parents and teachers. 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](http://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](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.

The professionals that work with you and your little one will also be a helpful resource to your family. 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 to you.

### **Parenting Tips:**

- *In the early years, spend lots of time smiling, cuddling, hugging, kissing, and holding your child.*
- *Look at books together. Listen and respond to your child's cues.*
- *Let your child take the lead when you play with him/her. Learn all you can about your child's wants and needs and have fun together. Every day is a chance to work towards transitioning your child toward independence in life.*

# General Care of Your Preschooler

## Parenting

At this age your child will want to do a lot of things by him or herself. Remember this is a natural desire of children this age. Find things your child does well and give him or her lots of opportunities to develop those skills. Coloring, building castles and houses with blocks, and playing with simple games are all good activities. He or she will probably also like to help you put together a simple meal, clean dishes, or set the table. Allow him or her to help in any way he or she can. Praise your child often for his or her willingness to help.

Parenting strategies should emphasize providing appropriate challenges, facilitating social activities, and effectively coping with stress. Your child needs as much affection and attention as you can give him or her. Each child comes into the world with his or her own temperament: some like to be held, some like to explore, some are fussy, and some are “easy.” Parents need to adapt to and work with the child’s temperament.

## Feeding Your Child

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 three years old needs eight 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.

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 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. 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 impairments, like wheelchair basketball, swimming, 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 for the following:

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

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.

## **Latex Issues**

People who have Spina Bifida are at risk for developing a latex allergy. Allergic reactions can range from rash and watery eyes to severe shock. Latex is natural rubber and can be found in a variety of items. The best way to prevent your child from developing a latex allergy is to limit his/her exposure to latex. Use products with vinyl instead of latex. It is important to read labels. A list of items used in the hospital and in the community that frequently contain latex as well as latex-safe alternatives can be found at Spina Bifida Association's Web site, [www.spinabifidaassociation.org](http://www.spinabifidaassociation.org).

## **Social Development**

Social development continues throughout life. Your family provides the first place for your child to begin to learn about him or herself in relation to others. Your family also provides the love and nurturing that will help your child feel safe and secure. The make up of your family and the many other aspects of your child's environment influence the kinds of opportunities he or she has for social development. It is understandable to want to protect your child. However, it is also important to expose him or her to the outside world. As your child grows, he or she needs opportunities to be with other children.

Children with Spina Bifida benefit when they have access to as many different play experiences as possible. Parents can work with the occupational therapist and physical

therapist to obtain equipment and devise strategies that will enable the child to engage in as much active play as possible. There are important social aspects that are learned through play during this period. Engage in basic interactive games and activities with your child. Just watching your child at play has a powerful, positive impact, affirming your love and interest in what he or she is doing. Playdates with peers should also be arranged. At this age, children learn to share, cooperate, and engage in interactive play. Good preschool or school programs are valuable for these experiences.

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. 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.

### **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.*
- *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.*
- *Playdates are important for your child. Take the time to arrange them. Occasionally leave your child in the care of other qualified adults.*

# Neurological Function and Progress

As you know, the brain and spinal cord, which make up the central nervous system, are affected in a variety of ways with Spina Bifida. Your child's neurological status and progress is monitored closely to help prevent change or loss in function. Generally, a neurosurgeon will work with you to determine what tests need to be completed and/or treatments 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:

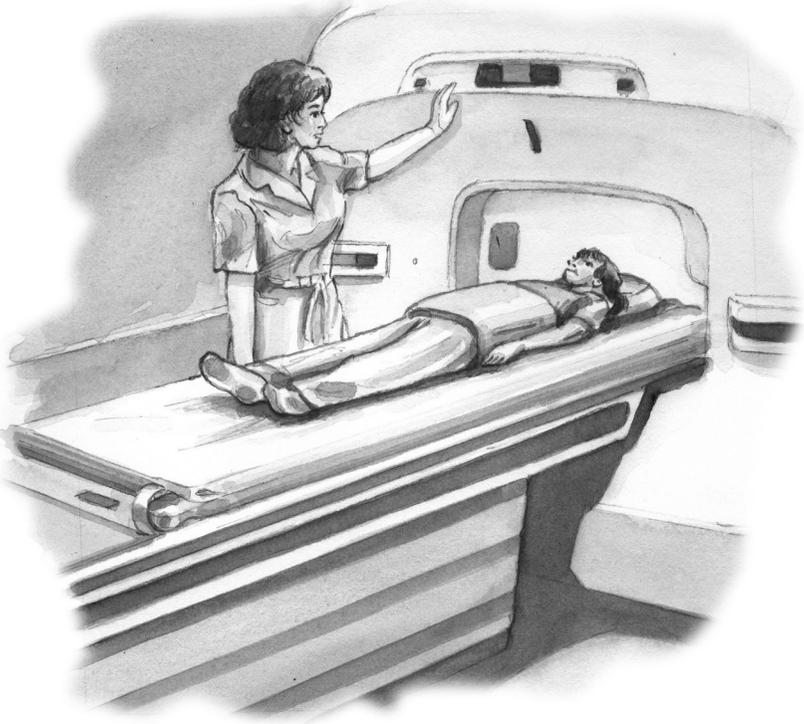
- Increasing head size
- Decreased upper extremity tone
- Regression in milestones

Treatment for shunt malfunction includes a shunt revision or 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

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 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. 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 found; 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 or decreased use of the lower extremities
- **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 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 of muscle function 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 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 retether the cord. Every child with Spina Bifida is different. Improvement in functioning after surgery varies from child to child and may take up to two years. After surgery, your child will need to 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.

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 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.

### ***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. The body's messages for 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 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. The procedure is not difficult to do and is usually learned quickly by parents and family.

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

Let your health care team know if your child experiences any one of these symptoms.

### ***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**

Most children with Spina Bifida also experience difficulty in controlling bowel movements. As a result of the nerve damage, the anal sphincter which closes the anal opening and normally holds back stool between periodic bowel movements, may be paralyzed or weakened. Also, the nerves that signal the need for a bowel movement may be interrupted.

Between the ages of two to three, or when your child is ready to sit independently on a potty chair or adaptive toilet seat, start a regular toileting time. Shortly after meals is normally the best time. Let your child's feet rest on a stool or other support, and encourage him or her to "bear down" to attempt to have a bowel movement. This gets your child in the habit of regular toiling, and helps create a pattern of consistent elimination. 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 initiating and maintaining a bowel program for your child.

## Preparing for School

In preparation for school, your child needs a definitive program for bowel and bladder management. CIC should be started, if it is not already part of the routine. Teaching your child to participate in his or her catheterization is very important. Children differ in their abilities, but children often can begin practicing self-catheterization skills from preschool age. At first, your child can handle washing hands, gathering supplies, and removing clothing. Later he or she will be able to insert the catheter and drain the bladder.

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. 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-**nehr**-gix**) to relax the bladder muscle so it can hold more urine under lower pressure.
- *Alpha-adrenergics* (pronounced **al-fa-ad-reh-**nehr**-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:

- 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.
- 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.

## **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 important for your child's future.*

# Orthopedic Function and Progress

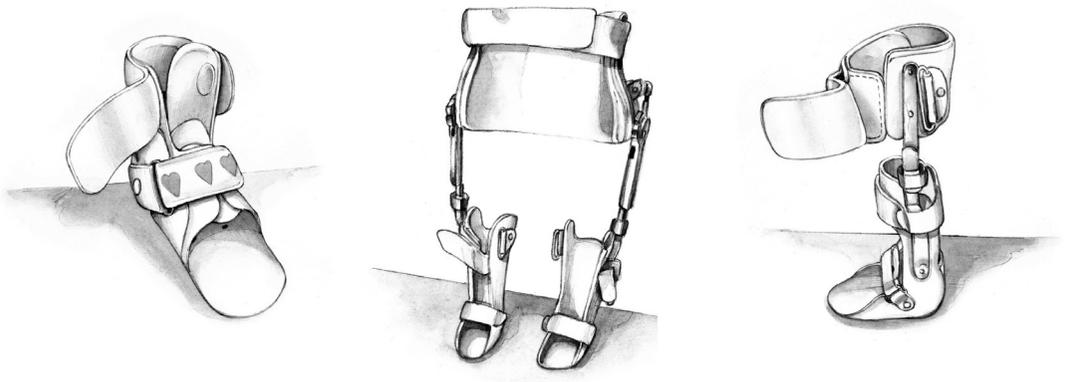
The orthopedist on your child's health care team will monitor your child with periodic examinations and x-rays. Along with the physical therapist, your orthopedist will decide what kinds of surgery, equipment, or braces your child may require as he or she grows. Children who have Spina Bifida have abnormalities of the bony spine. There are missing or malformed vertebrae at the level of the defect. Congenital scoliosis (side to side curve) or kyphosis (pronounced kie-**foe**-sis, meaning up and down curve) may be present at birth. These curves need to be monitored and treated by the orthopedic surgeon. You will work with your child's orthopedist and physical therapist to plan the most appropriate program of stretches and exercises for your child.

Stretching programs and developmental exercises can assist in maintaining flexibility and avoiding contractures. Keep your child active in his or her stretching program. These stretches and exercises are an important part of your child's orthopedic function and progress. The stretching programs and developmental exercises will help in avoiding contractures (tightness) at the hip, knee, and ankle. This is very important for brace fitting later on and for future success in daily living activities.

## *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.



## Preparing for School

Children need an independent mode of mobility before they start school. If your child needs a wheelchair, attain one and allow the child to use it before school begins. Trays, bags, or baskets can be attached to wheelchairs or walkers to facilitate function at school. Being mobile and comfortable with the preferred means of mobility will help your child with social functioning.

### *Orthopedic Problems and Treatment*

Growth during the preschool years may contribute to some orthopedic deformities. Spinal curvatures, progressive foot deformities, and contractures are among the most common. Abnormalities of the spinal cord such as syrinx (a fluid-filled cavity) or tethered cord (when the spinal cord is scarred and stretched too tightly) can cause orthopedic changes. Any rapid changes call for a referral to the neurosurgeon to make sure there is no underlying neurological cause. A child's feet need to remain in a plantigrade (foot flat on floor) position in order to fit into braces for walking.

Decisions on how to treat these orthopedic problems 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.

### **Parenting Tips:**

- *Help your child to develop fine motor skills. Hide objects in Play-Doh® and dry pasta. LEGO's® and other building and stacking toys are also great ways to increase your child's fine motor skills.*
- *Continue stretching exercises especially if your child has difficulty walking at all or minimally.*
- *Teach your child how to put his or her braces on and off or assist you in this task.*

# Learning

At age three, your child may qualify for free public preschool, if available in your area. Educational and therapy services vary from state to state. The time to contact the public school is when your child is 2½ years old. If your child has been enrolled in an Early Intervention program, the specialists will assist you with this transition. Eligibility testing is conducted to see if your child qualifies for special needs services. Moving from Early Intervention services into the public school is a big transition for you as well as your child. It may help to talk to other parents who have already completed this step in their journey.

The preschool period is a time of much activity and discovery. Children at this age naturally desire some independence and want to be able to do things for themselves. Although mastering skills such as dressing, grooming, and moving about may be more difficult for your child, your child should be given the opportunity to try to learn these skills. Physical (PT) therapists and occupational therapists (OT) in the schools and community are trained to help your child gain control over his or her large and small muscles. If PT/OT is written as a service for your child in his or her Individualized Education Program (IEP), he or she will receive this service free at school. Many children at this age, however, may need more therapy than the school can offer. Your health care provider may recommend community therapy.

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. Work with your school system and medical institutions to get needed testing and evaluation of your child.

## 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 his or her self-esteem.

## Parent Advocacy

As the parent of a child with Spina Bifida, you are becoming a specialist! Every parent is an advocate for his or her child, but when your baby was born with Spina Bifida, this role became even more important. In these early years, you will come to know your child and his or her special needs better than anyone else. Your knowledge will help the providers who work with you plan for the best outcomes for your child. It is good to ask questions, state your opinions, and be persistent in your quest for the services you feel your child deserves. Taking a positive approach will benefit you the most in the long run. By learning this role well now, you will be able to help your child learn to be his or her own advocate in later years.

# 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](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 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

Your child wants to have a sense of control and you should let your child make whatever decisions he or she can. 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 of the most important things you can do right now is to keep up-to-date 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."

Take time to maintain your relationships and your lifestyle. It is important to find time for you and those significant people in your life (your best friend, your spouse, or another member of your family) to spend a few hours together. You are a parent, but remember that you also have many other roles in life which are also important to your well-being. Remember – you are not alone in dealing with the challenges of Spina Bifida.

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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](http://www.spinabifidaassociation.org) or 800-621-3141.



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