# Living Well with Spina Bifida: Newborn to Age 2

SPINA BIFIDA ASSOCIATION®

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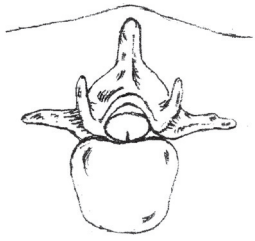
# What to Expect

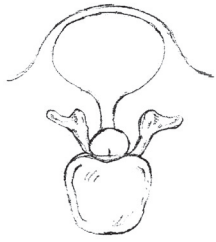
Congratulations on the birth of your baby! Whether you are a brand new or a seasoned parent, you probably have lots of questions about raising a child with Spina Bifida. Having a baby with Spina Bifida will take you down a different path than originally planned. While some times you may feel guilt, anger, and sadness; at other times you will experience moments of great joy, as you celebrate the multiple accomplishments of your child. This booklet is a guide to help you though the experience of raising a child with Spina Bifida from the newborn to toddler stage. It will answer your basic questions and direct you to additional resources.

## What and Why?

Spina Bifida is a neural tube defect that occurs when the spinal column of the baby fails to close during the early days of the pregnancy. The cord and nerves squeeze through this opening and protrude out into a sac on the baby's back.



**Normal Spine Side View**



**Split Spine Side View**

Birth defects can happen in any family. Although we do not know exactly what causes Spina Bifida, we do know folic acid plays a role. All women of childbearing age should take a vitamin with 400 micrograms (mcg) folic acid every day—even when they are not planning to become pregnant. (This amount is also written as 0.4 milligrams (mg)). Women can also get this amount through eating fortified grain or cereal products, in addition to a healthy diet. Although the naturally occurring form of folic acid can be found in dark green leafy vegetables, beans, and liver, it is very difficult to ensure that you are getting enough folic acid through diet alone. Women who have already been pregnant with a baby with a neural tube defect are at higher risk for having a baby with Spina Bifida. These women are advised to consume 4000 mcg of folic acid daily by prescription for one to three months before becoming pregnant. (This amount is also written as 4.0 milligrams (mg)). You will need to plan your next pregnancy and see your health care provider.

Many things can affect a baby, including your family genes and things you may come in contact with during pregnancy. Spina Bifida can happen in any family. Sometimes women who have taken folic acid still have a child with Spina Bifida. Taking folic acid before and during early pregnancy reduces the risk of Spina Bifida and other neural tube defects but it cannot guarantee having a healthy baby.

## Caring for Your Baby

Every child with Spina Bifida is different. In most cases, except for learning a few special medical procedures, caring for your little one with Spina Bifida will be much like caring for any infant. Your doctor and nurses will give you specific instructions for the care of your child before you take him/her home.

It is difficult to predict at this stage what your baby will eventually be able to do. Your loving attitude toward your baby and the realistic expectations you set as he/she grows will help your child develop a positive image of himself/herself. Treat your child, as much as possible, as you would treat a child without Spina Bifida. Spend lots of time smiling, cuddling, hugging, kissing, and holding each other. Look at books together, listen and respond to your child's cues. Learn all you can about your child's wants and needs and have fun together.

## Support from Other Parents

Other parents of children with Spina Bifida understand what you are going through and can give emotional support. The SB Parents ListServ at www.sbaa.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.

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.sbaa.org to find the Spina Bifida Association chapter closest to you.

## Genetic Counseling

Genetic counseling is recommended for parents of children with Spina Bifida. The genetic counselor can help you understand why this has happened to your child. Many parents report that feelings of doubt and guilt have been eased by the understanding

that comes with genetic counseling. If you are considering having more children, you will be told what your chances are of having another child with Spina Bifida. Information you provide, when added to information from other families, may lead to a better understanding of the causes of Spina Bifida. Please speak to your health care provider about an appropriate referral to a genetic specialist. Visit www.sbaa.org for the Spina Bifida Clinic Program closest to you.

***Parenting Tips:***

- *Taking care of yourself is the single most important thing you can do for your child. It will ensure that you have the strength and stamina for the entire journey.*
- *Make the most of your medical appointments. Arrive on time, or early, and allow extra time for traffic jams, parking problems, and bathroom breaks. Always bring your child's insurance card, a referral if your insurance requires one, and your checkbook for co-payments. Bring snacks, books, and activities for long waits, as well as bathroom supplies.*

# General Care of Your Baby

All of the members of the family are affected by the birth of a child who has Spina Bifida. Feelings of doubt, anger, sadness, and guilt are normal as you adjust to this new child. It is important to keep the lines of communication open and be patient with one another.

## Parenting

Taking time to play with your baby or toddler is just as important for a child with Spina Bifida, as it is for any child. All young children need to have playtime for stimulation and growth. For some period each day, try to eliminate distractions (phone calls, work-related activities) so that you can attend fully to your child. Remember to include your young child in your normal family activities and strive to give them as much independence as they are able to handle. Soon you will observe that your child (like every toddler) is trying to assert his/her autonomy in various ways. You have a chance to transition your baby toward his/her toddler years and eventually toward their ultimate independence in life by allowing them to do more and more each day.

Infants with parents who respond quickly and appropriately to their needs learn how to trust and love their caregivers. This love and trust serves as an important foundation

for the infant's security and willingness to approach the world. A baby who is cuddled, sung to, rocked, and generally nurtured in a loving manner will seek interactions with the friendly beings in his/her world. Eventually this willingness to respond will extend to others.

## Feeding Your Baby

Feeding your baby/toddler with Spina Bifida is in most cases no different than feeding any other child. **Promoting healthy eating lifestyles begins in infancy.** Whether you are breast-feeding or bottle-feeding, observe your baby for cues that will tell you when he/she is hungry or full. Feed only when hungry and stop feeding when your child indicates he/she has had enough.

Some children with Spina Bifida have a tendency to gag, especially with solid, chewy foods such as meats. Gagging tends to decrease as the child gets older. Slowly adding foods with texture will help. If your child gags a lot and/or vomits frequently inform the neurosurgeon. In some cases, treatment may be necessary.

## Proper Positioning

Your baby will be required to remain off his or her back for the first few days after surgery. Babies should not sleep on their stomachs due to the risk of sudden infant death syndrome (SIDS). The best sleep position for your child is on his or her side, propped with supportive pillows. Until the surgical incision on the back is healed, your baby may lay in any position he or she finds comfortable, except his or her stomach.

Since your baby may not be able to move easily, you will want to change your baby's position fairly often. Doing this will help decrease pressure on bony areas. It will reduce the chance of deformities to legs and spine, and increase your baby's contact with the environment. Your Spina Bifida Clinic nurse coordinator can help you with proper positioning for your baby.

## Care in Changing Your Baby's Diaper

At the newborn stage, you will want to make sure that stool does not get on the surgical site until it is completely healed. When caring for your baby, be careful not to apply direct pressure to the surgery site. A member of your health care team will teach you how to care for the surgery site. Close attention needs to be given to the skin in the diaper area. If the infant has frequent stools, a moisture barrier may need to be used

on a regular basis to protect the skin. If measures to protect the skin are not effective, contact your health care provider.

## Skin Care

Babies who have Spina Bifida usually cannot feel anything on their skin below the level of their lesion. This is called insensate skin. Take special precautions to protect your baby's skin. Listed below are a few points to keep in mind when caring for your child's skin:

- Early treatment of diaper rash is important.
- Be sure socks are smooth and straight and shoes and braces fit properly.
- Always test the warmth of the bath water before your child gets into the tub.
- Remember car metal seat buckles and other metal objects get hot in the warm sun.
- Blacktop and sand also get hot so it is best to keep shoes and socks on your child's feet at all times.
- Regularly inspect your child's skin for bruises, scratches, redness, and swelling. It's possible for your child to break a bone and not feel it, so if one leg looks bigger than the other, or is warm to the touch or red, it may indicate a fracture and will need medical attention.

## Latex Issues

People who have Spina Bifida are at risk for developing a latex allergy. Latex is natural rubber and can be found in a variety of items. Even some diapers may contain latex. The best way to prevent your child from developing a latex allergy is to limit his/her exposure to latex. Allergic reactions can range from rash and watery eyes to severe shock. 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 SBA's website, www.sbaa.org.

## Social Development

Social development begins at birth and continues throughout life. Your family provides the first place for your baby to begin to learn about him or herself in relation to others. Your family also provides the love and nurturing that will help your baby 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/she has for social development.

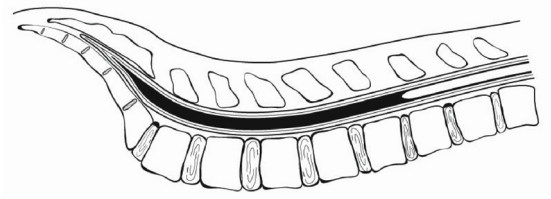
It is understandable to want to protect your child. However, it is also important to expose him/her to the world around him/her. As your baby grows, he/she needs opportunities to be with other children. Early opportunities for positive social experiences are needed for future social progress.

***Parenting Tips:***

- *Work with your Occupational Therapist and Physical Therapist to create a play environment that allows your child the widest range of activities.*
- *Spend time watching your child play and engage in interactive games, like "peek a boo" with him/her.*
- *Arrange play dates with friends and relatives to give opportunities for social play.*
- *Support his/her early striving for independence by letting him/her explore and make choices.*

# Neurologic Function and Progress

The spinal cord develops in the embryo as a long flat layer of cells which forms a tube-like structure called the neural tube. By the 28th day of pregnancy the tube is already closed.



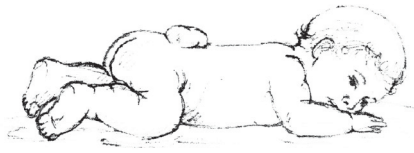
**Normal Spine**

## Types of Spina Bifida

Spina Bifida is a defect of the spinal column that results from the failure of the spine to close properly. The brain and spinal cord, which make up the Central Nervous System (CNS) are affected in a variety of ways. Much care is taken during and after birth to prevent further damage of this area. Generally a neurosurgeon will close the open back within the first few days after birth. The purpose of this surgery is to return the spinal cord to as normal a position as possible and to prevent infection. It is important to understand that no surgery or treatment can repair nerve damage.

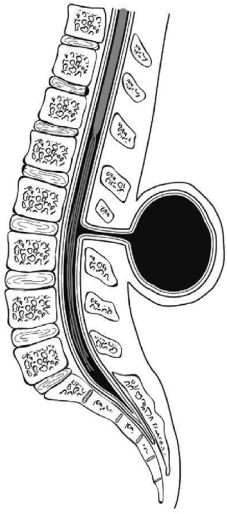
### *Myleomeningocele*

The bones of the spinal column do not come together and usually there is not complete skin over the open spinal cord. The infant has a portion of the spinal cord protruding through the open bones and skin. Surgery is done within the first hours of life to return the spinal cord to as normal a position as possible and to prevent infection.



**Back prior to surgery**

**Back after surgery (repair)**



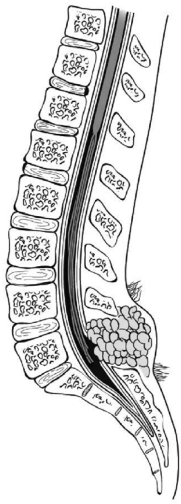
### *Meningocele*

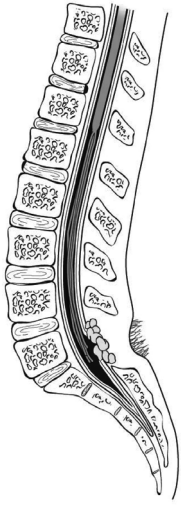
Protective coverings (meninges) of the spinal cord, but not the cord itself, come through the openings on the back. There is usually no nerve damage, but problems can develop later in life.

There are other types of Spina Bifida that do not require immediate surgery. These are evaluated by a neurosurgeon and treatment is individualized.

### *Lipomeningocele*

A lipomeningocele is a collection of fatty tissue near the spine. This is similar to myleomeningocele. A baby born with a lipomeningocele will need much of the same care as a baby born with myleomeningocele. The initial surgery, however, may not be necessary during the first few days of life, since there is not an open sac, but rather a bulge or dimple on the back.





### *Spina Bifida Occulta*

There is no opening on the back or nerve damage, however the bones of the spine fail to close completely. There may be hair or a dimple on the back. Most people do not even know that they have this condition. Some people, however, may develop problems such as back pain later in life.

### *Pre-surgical Care*

For all types of Spina Bifida, the neurosurgeon will try to determine how much movement and feeling the baby has before the surgery takes place. The point at which function is affected is referred to as the "level" of Spina Bifida. The level would be defined as cervical, thoracic, lumbar, or sacral and the nerve root identified as a number. For example, L2 equals second lumbar vertebrae level. Each nerve affects certain functions of the body. In general, babies who have Spina Bifida at a higher level

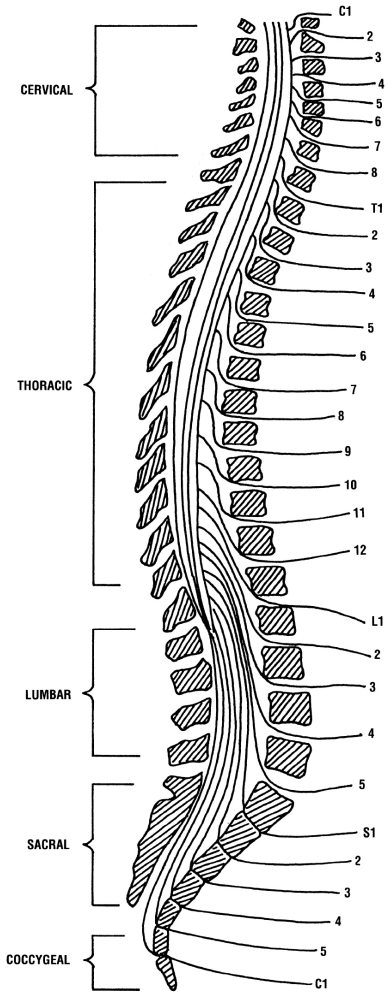
on the spinal cord usually have more difficulties than those who have it at a lower level.

### *Post-surgical Care*

Your baby will lay on his/her side with a dressing in place. Preventing infection is very important so the wound will be monitored carefully by doctors and nurses. Stitches are generally removed seven days after the procedure.

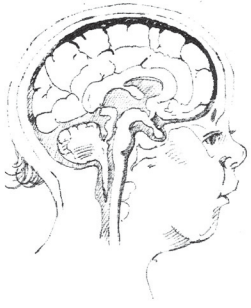
## Hydrocephalus

Hydrocephalus literally means: hydro–water, cephalus–of the brain. It is an excessive amount of cerebral spinal fluid (CSF) collecting in the cavities or ventricles of the brain. CSF is normally produced and absorbed at a constant rate in the brain. Hydrocephalus results from either an over production of CSF or a deficient absorption of cerebral spinal fluid because of abnormal circulation. The cause of hydrocephalus in Spina Bifida is associated with the Chiari malformation.




SIDE VIEW OF THE SPINAL CORD AND NERVE ROOTS

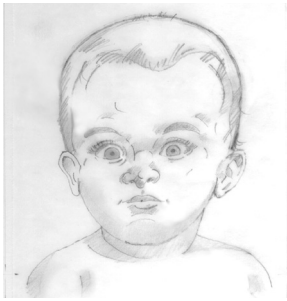
The Chiari malformation is a malformation of the brain involving the lower brainstem and the lowermost portion of the cerebellum. The malformation occurs in 85-90% of children born with spina bifida, but only 3% of the children show symptoms and problems that eventually require surgical management. If fluid accumulates, early signs or symptoms may occur.



**Chiari malformation**

**Early Signs of Increased CSF in Babies:**

- Head growth above "normal" or showing abnormal increased rate of growth.
- Soft spot is bulging and tense.
  To check the infant's soft spot (fontanel), be sure to have him/her in a sitting position and not crying.
- Change of behavior-usually hyper-irritable, may become very tired.
- Vomiting or lack of desire to take food.
- Prominent scalp veins.
- Eyes may have sunset appearance (looking down with more white of the eyes showing).



**Sunset eyes**

**Early Signs of Increased CSF in Children Once Soft Spot has Closed are:**

- Irritability and/or tiredness, "WHINY."
- Headache.
- Loss of appetite.
- Vomiting.
- Visual disturbances.
- Abnormal increased rate of growth of head.
- Developmental progress change.

## *Monitoring*

Monitoring signs and symptoms is very important. It is critical that you contact your neurosurgeon if you notice any changes. Early detection of problems can help prevent serious complications. Tests may be done to monitor hydrocephalus:

- Head size measurement.
- CT scan: The CT scan is an x-ray of the brain. It creates a picture of the brain and allows the doctor to look at the ventricles or openings of the brain.

- MRI scan: The MRI scan uses magnetic energy instead of an x-ray to create a picture of the brain. It creates a clearer picture than the CT scan, and in some cases gives better information for ventricular size and Chiari.
- Ultrasound of the head may be used until the soft spot is closed.

Surgical intervention involves placement of a shunt (tube) in the fluid cavities of the brain and passing the tube under the skin most often all the way into the abdominal cavity, where the fluid is reabsorbed by the body.

In some cases the end of the shunt is placed in different areas: heart, lungs, kidney, or gallbladder. If your child has a shunt with the lower end in the heart, check with your neurosurgeon about considering antibiotics before any surgical or dental procedure. You need to know where the end of your child's shunt is located.

***Parenting Tips:***

*Know the signs and symptoms of problems with the Chiari malformation:*

- *Respiratory distress (difficulty breathing)*
- *Apnea (cessation of breathing)*
- *Stridor (high pitched noisy breathing)*
- *Inability to swallow or a weak suck response resulting in feeding difficulties and inability to handle fluids (poor weight gain)*
- *Upper extremity weakness and numbness (funny feeling)*

*A shunt revision or shunting may be required if your child has these signs. The neurosurgeon who follows your child will determine treatment. Other surgery may be needed.*

*Sometimes your child may begin to show signs of a shunt malfunction or these could just be symptoms of coming down with a cold or flu. If necessary go to the Emergency Room. It is better to be safe than sorry!*

# Urologic and Bowel Function and Progress

Children who have Spina Bifida usually have damage to the nerves that control bowel and bladder function. Usually a renal ultrasound (an ultrasound of the kidneys), a voiding cystourethrogram (a test that shows if urine is flowing backwards into the

kidney), and a urodynamic study (a bladder pressure test) are done within the first few months of life. A blood test may also be done to measure kidney function.

In children with Spina Bifida, the connections between the brain, the spinal cord, and the bladder are damaged. Messages for sensation, voluntary emptying, and coordination may all be affected. Children with nerve damage to the bladder are said to have a "neurogenic bladder." Neurogenic bladders may not empty well (leading to urinary tract infection), may empty at high pressures (leading to backing up of urine into the kidneys that can cause permanent damage), or may empty at low pressure continuously (leading to incontinence). Early evaluation of the kidneys and bladder is very important in order to prevent kidney damage. The fundamental treatment for the prevention of kidney damage as well as provision of social continence is clean intermittent catheterization (CIC).

## Signs and Symptoms of Urinary Tract Infection (UTI)

It is important to be aware of possible urinary tract infection and contact your health care provider if you think your baby may have one. Symptoms of a urinary tract infection may include:

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

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

## Clean Intermittent Catheterization (CIC)

Clean Intermittent Catheterization (CIC) may be initiated during infancy or may be delayed until the child reaches the age for toilet training. The term "catheterization" is often shortened to "cathing." CIC is simply emptying the bladder by inserting a clear hollow 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. The decision on when to begin catheterization depends on several things. If the bladder function puts the kidneys at risk for deterioration from pressure or infection, CIC has proven to be an effective intervention and should be started. If the bladder function is medically safe, the choice of when to begin CIC is usually made by the family with the consultation of their urologist. Some families choose to begin CIC in infancy as part of an expected routine. Other families choose to wait until the age their child would developmentally begin toilet training.

If bladder pressures remain high and are not managed adequately by CIC and medication, a vesicostomy may be done. A vesicostomy involves making a small opening through the lower abdomen into the bladder that allows the urine to leak out onto the diaper continuously, keeping the pressures in the bladder low. This surgery usually requires a brief hospitalization and recovery time is short. Vesicostomies are usually closed prior to the child beginning school.

If reflux (backward flow of urine into the kidneys) does not improve with CIC and medication, gets worse, or causes repeated UTI's, surgery may be done to correct it. The ureters are detached from the bladder and reimplanted into the bladder at a different angle. This surgery is usually very effective. This surgery usually requires several days of hospitalization and several weeks for recovery.

## 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 not be intact.

During the first years of life, it is important to avoid constipation. Infant's elimination can be varied as to frequency and amount. Constipation in infancy is defined as difficulty passing stool, hard and/or dry stool, and less than one bowel movement every three days. Stools that are firm and ball shaped are signs of constipation. Stooling patterns should be monitored closely to avoid constipation and prevent loss of bowel tone. Proper nutrition with adequate fiber and fluids will help. Often your child will need additional help such as suppositories, enemas, and/or medication. Your child's pediatrician or clinic nurse will help you with bowel management.

***Parenting Tips:***

- *Although cathing your child may seem overwhelming at first, it will soon become a part of your daily routine and you will become more comfortable with this procedure.*
- *It is helpful if you are able to teach a few trusted family members and friends who care for your child to share the responsibility of cathing your child.*
- *In the early years, prevention of constipation is one of the most important things you can do.*

# Orthopedic Function and Progress

Many babies with Spina Bifida have orthopedic problems, which might include: clubfoot, dislocated hip(s), spinal curvatures, and contractures (tightness) of the knee, hip, and/or ankle. The orthopedist on the team will monitor your baby 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/she grows.

Clubfoot deformity, if present at birth, may be treated initially with splinting or casting. Great care is needed when utilizing casting, as sensation to the foot is often decreased, and the risk for skin breakdown due to pressure is increased. If surgery is needed to correct the foot, it is usually done at the time of standing (around 9-12 months of age) in order to maintain the foot in proper alignment.

Hip dislocation does not influence the child's ability to walk and rarely is the source of pain. Currently, surgery to keep the hip in place is not routinely done. Each case must be evaluated and treated by an orthopedic surgeon on an individual basis.

Children with Spina Bifida are at increased risk for abnormalities of their spine. Congenital scoliosis (side to side curve) or kyphosis (up and down curve) may be present at birth. These curves need to be monitored and treated by the orthopedic surgeon.

Avoiding contractures (tightness) at the hip, knee, and ankle is important for brace fitting and performing activities of daily living. Often programs of stretching and developmental exercises can assist in maintaining flexibility.

An overall goal of orthopedic treatment for the child with Spina Bifida is to provide support for normal development and function. As children usually stand at about a year of age, children are often fitted at this age for a parapodium or stander to allow them upright posture. These frames are "pre-brace trainers" and allow the child to adjust to being upright, learn to balance their head over their body, and use their arms

for assistance in ambulation. Good head control is usually necessary to utilize this device. Ankle foot orthosis (AFO) or dynamic ankle foot orthosis (DAFO) are often needed to maintain foot position or give support for standing.

## Bracing

Bracing does not correct deformity but can be useful in maintaining position and in providing support to a weakened joint. Bracing for ambulation is usually begun around two to three years of age. Orthotics, such as an ankle-foot orthosis (AFO) may be used. Devices such as walkers, crutches or wheel chairs may be of benefit. Your physical therapist will help you decide with devices are best for your child.

## Surgeries

### *Foot surgery*

Surgery may be needed to position the foot for bracing and ambulation. These surgeries are usually done at about 9-12 months of age in preparation for standing. Post operatively the foot is usually casted for a short amount of time to allow healing and maintain a good position. An ankle-foot orthosis is usually worn after the cast is removed for support and maintenance of position. These surgeries usually require several days of hospitalization and recovery may be several weeks.

### *Fractures*

Children with Spina Bifida are at increased risk for fractures of their legs due to reduced bone quality. Often times, there is no known trauma, but the fracture limb will be swollen and warm to touch. The child may run a slight fever and not feel well. Swelling of only one lower extremity is usually treated as a fracture until disproved.

### *Casting*

Some fractures and some surgeries require the use of a cast for a short period of time. Great care must be taken when using a cast in a child with Spina Bifida who is unable to feel parts of his/her body. The cast must be well padded and caregivers must watch for any swelling, drainage, or foul odor in the area of the cast. (Nonlatex cast care products should be used.)

***Parenting Tips:***

- *It is important to exercise your baby's legs at home. Turn on the radio or a CD, and dance with your baby!*
- *For fine motor exercises, hide objects in Play-dough® and dry pasta.*
- *Lego's® are great to increase your child's fine motor skills once you're sure he/she won't swallow them.*

# Learning

From ages zero to two, children's brains develop rapidly and in an organized way. They become aware that things in their life don't "go away" just because they are out of their sight. Despite this development, they are only able to view the world from their own perspective. During these young ages, parental engagement with the child and parent-child play is very stimulating and will encourage cognitive development. In addition to parent involvement, special programs exist to help the child reach his or her full potential.

States are required by the federal government to provide Early Intervention services to children zero to three years with special needs. Children who are at risk for or have developmental delays benefit from such programs. Developmental delays means that the natural progression of development is not achieved on time and/or not achieved at all due to physical and/or mental limitations. Most often, an infant with Spina Bifida is referred to programs that provide Early Intervention services as soon as they are discharged from the hospital. The earlier services begin, the better chance for making significant differences. Depending on where you live, you may be able to choose between receiving services in your home or in a school-like setting. Regardless of the setting, a specialist will work with you and your child to find ways to stimulate your child and help him/her achieve specific goals which are determined by both you and the specialist(s). Many of the goals for infants with Spina Bifida revolve around physical mobility. One example might be to find ways to position your child for optimal exploration of his/her environment. The Early Intervention specialist(s) or therapist will help you achieve this goal. Other specialists such as physical, occupational, and speech therapists are often involved with your child at this time depending on your child's needs.

## Parent Advocacy

As the parent of a child with Spina Bifida, you are becoming a specialist in Spina Bifida. Every parent is an advocate for their child, but when your baby was born with Spina Bifida, this role became even more important. In these first years, you will come to know your child and their 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 alright 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/her own advocate in later years.

***Parenting Tip:***

- *Don't be afraid to be honest about your child's needs, and be willing to brainstorm about possible solutions.*

# Financial Planning and Assistance

## Supplemental Security Income

The social worker at the hospital where your baby receives initial treatment, or at the clinic where your baby receives follow up care, can help you understand requirements for financial assistance and the application process.

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. It can help pay for medications or equipment. Children who have Spina Bifida may be eligible. However, a child cannot receive SSI payments and take part in the Aid to Families with Dependent Children (AFDC) program. If eligible for both programs, you must choose the one that is best for your family.

Your family can have assets and income and still qualify for SSI. Some of the parents' assets and income will be considered to be the child's. To qualify, you must be a citizen of the United States or a legal immigrant and you must live in the United States. Many babies and 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.

Payments are effective the day of application, so it is important to apply promptly. However, your baby must be home from the hospital before you can apply. When you apply, be sure you take the following things:

- Social Security card or number.
- Birth certificate/proof of child's age.
- Information about your income (payroll slips, tax returns, bank books, insurance policies, and auto registration).
- Your home mortgage or lease.
- Your child's medical information, including names and addresses of all doctors and hospitals that have treated your child.

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 baby's hospital or clinic is a good source of advice on financial matters like Medicaid and how to apply in your area. Your child will get a Medical Assistance Card if he/she receives any SSI payment. 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 Developmental Disabilities Board or a Disabled Children's Program that may offer some financial aid for such items. The social worker at your baby's hospital or clinic is a good source of advice on local financial assistance and the application process.

## Planning Ahead

Caught up in the day-to-day responsibilities and tasks of caring for a child with Spina Bifida, parents can 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

It may be hard to think about what's next for your and your baby. Just like any other child, your baby will need the chance to explore and play. The need for exploration and experimenting with control becomes even more important for the toddler stage.

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 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, where you may download a copy of the Health Care Record for Parents from www.sbaa.org. Using the Health Care Record will help you organize your child's health information in a central place.

Having a baby with Spina Bifida will take you down a different path than originally planned. Take time to maintain your relationships and your lifestyle. It is important to find time for you and your significant other (your best friend, your spouse, or another member of your family) to spend a few hours together. It is important to communicate openly and be patient with one another. You are a parent, but remember that you also have many other roles in life which are also important to your well-being.

Like all parents, before your child came into the world, you held cherished hopes and dreams for your baby's future. Hold on to your hopes and dreams for your baby's future. You are not alone in dealing with the challenges of Spina Bifida.

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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.sbaa.org or 1-800-621-3141.

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