



Living Well with Spina Bifida: Teens



SPINA BIFIDA
ASSOCIATION

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

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

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

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

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What to Expect

Teens with Spina Bifida face the same emotional roller coaster that other teens experience. Tears, moodiness, and occasional outbursts can be expected. It is always difficult to be an adolescent and an adolescent with Spina Bifida will have additional challenges to face.

Some teens will balk at doing things they were doing so well a few years before. Although this period is known as a time of rebellion, your teen needs to realize that cathing and taking prescribed medications are mandatory, not optional. Serious consequences to their medical health are not worth the risks of a little freedom.

Teens **do need** to feel, though, that they have some control over their lives. Give your teen lots of opportunities to make decisions about things that are not life-threatening. Allow your teen to have fashion and hairstyle preferences, shut his or her bedroom door for privacy, and choose friends and activities (within reason). Be available to your teen for support and heart-to-heart talks, but let your teen decide when these chats will occur and how much to share. In other words, your involvement needs to be just as intense as it was when your child was younger, but somehow you have to figure out how to do it in a less direct way.

Parents of teens walk a tricky path and often make mistakes. Sometimes parents may need to reach out for professional guidance.

Neurological Function and Progress

Your teen will continue to have regular visits to the neurosurgeon to monitor for an intermittent or poorly functioning shunt. Signs of an intermittent or poorly functioning shunt include:

- Neck pain
- Headache
- Loss of balance
- Change in the functioning of upper extremities

These symptoms may also signal Chiari malformation or tethered cord.



Chiari malformation

Headaches

Headaches are common in adolescents and do not always indicate shunt malfunction, but the shunt should always be checked. Some headaches are positional. The neurosurgeon may ask you and your adolescent to monitor the effect of lying and sitting positions.

The neurosurgeon may also refer your teen to a neurologist, who can further assess the headaches, recommend treatment, and consider prescribing preventative medication.

It is important to give both doctors an accurate description of the pain associated with the headache in order to determine the appropriate treatment.

Parenting Tip

- *Encourage your teen to continue seeing a neurologist for regular checkups. If your teen has a shunt, help your teen keep track of and monitor the warning signs of shunt failure.*



Urologic and Bowel Function and Progress

Bladder

Routine visits to the urologist for testing are still important even after your teen's physical growth is complete. Renal and bladder stones may still develop, and early detection often results in less invasive treatment. Changes in bladder dynamics from tethered cord are still a risk, although no less so than when your child was younger. During the teen years, compliance with bowel and bladder programs often becomes an issue. Be cautious in transitioning complete responsibility for care to the teen or young adult. An accountability structure must be in place to protect the health of the young person who is transitioning to independent self-care. If remembering is an issue, help your teen to develop a schedule or other type of reminder system for cathing or taking medications. Programming a wrist watch can help, as can setting an alarm on a cell phone so that your teen can "take the call." This technique avoids possible embarrassment caused by needing to leave at certain times to take care of personal needs. If your teen is not independent in this area, consider surgical options if appropriate.

Bowel

Social interactions during the teen years make a reliable bowel program more important than ever. Independence becomes a central issue as the teens prepares for independent living at college or in the work force. Your teen is most likely to comply with a program when the program has proven to work well. Surgical stomas for antegrade enemas should be considered, if needed, to achieve independence. You and your teen can also look into health care aid services for assistance in carrying out bowel and bladder care.

Transition Skills

Teens should learn to manage their medication and supplies, including ordering refills early enough to avoid running out. Encourage your teen to consult with you, and then schedule his or her own appointments with the urologist and Spina Bifida clinics. Teens should talk directly with health care providers and medical suppliers when possible. Help your teen to find a method of organizing health care information, such as the one found in the Spina Bifida Association's publication, *Health Guide for Adults Living with Spina Bifida*.

Parenting Tips

- *Some teenagers rebel by neglecting CIC or bowel programs, or even refusing to take their medications. Help them understand the health and social consequences of non-compliance. Reward good behavior by increasing privileges.*
- *Teens need to achieve independence in bowel and bladder programs. Social continence affects future jobs and relationships.*

Orthopedic Function and Progress

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

Teens should learn to maintain their orthotics and wheelchairs by keeping them in good repair and checking daily to be sure that pressure-relieving cushions are working properly. Daily foot and skin checks are extremely important.

Surgeries

Many young people with Spina Bifida have spinal fusion surgery during their early teens. This surgery stabilizes the scoliosis curve and prevents the curve from getting worse. Fusion of the spine often uses rods that run the full length of the spine, into the pelvis. Walking and other activities are usually restricted for the first months after surgery. Full bone fusion does not usually occur until about a year after surgery.

Teens must be in optimal physical condition – with good nutritional habits and no open skin breakdown – prior to surgery. Before surgery takes place, shunt revision and renal function should be evaluated, urinary bacteria should be treated, and the bowel should be cleared of backed-up stool. This surgery usually requires a hospital stay of a week or more, and has an extended recovery time that spans several months.

Parenting Tips

- *If walking is becoming more difficult for your teen, consider a wheelchair, crutches or other assistive devices.*
- *The most important thing you can do for the health of your teen's bones and muscles is to provide and encourage good nutrition and regular exercise. This will also help your teen maintain a healthy weight.*

General Health Promotion

Family Health

Families of teenagers often struggle to maintain a sense of balance. Both parents and teens are going through an adjustment phase. As a parent, you are giving up some control and your teen is taking on additional responsibility. Parents have to be sensitive to the varying degrees of maturity shown by teens. Some teens sail through adolescence, while others need a little more time and patience.

No matter what your teen's abilities or limitations are, planning for the future is important during this stage. In most cases, children outlive their parents, so it is unrealistic to think that you will always be there for them. Whether they will eventually live on their own, or live in a more supported environment, teens will need life skills.

Your teen's peers are driving, working part-time jobs, and socializing in groups or dating. These milestones are important and should be encouraged for your teen with Spina Bifida too. They want to be like their friends, so look into helping your teen succeed in these areas. School staff and community agencies are there to help you. If your teen feels good about himself or herself, it is much more likely that others will include him or her in their social activities.

Parenting

Continue to include your teen in daily family activities and strive to give him or her as much independence as he or she can handle. Adolescence is a time of "shared responsibility" for medical self-care, just as in middle childhood.

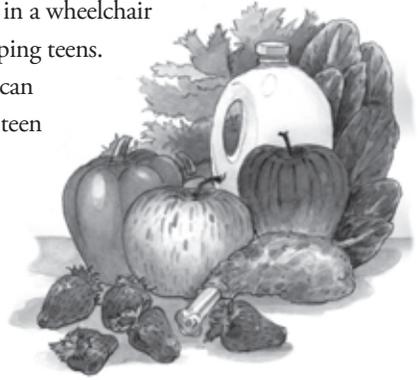
Keep your teen engaged with peers on a regular basis, either via one-on-one contacts or through after-school programs and clubs. Help your teen learn appropriate social skills, such as how to start a social interaction, how to listen and respond to others, and how to talk to adults and other teens.

Weight Maintenance, Healthy Diet, and Exercise

In order for your teen to maintain an appropriate weight, he or she will have to continue monitoring portion sizes and following a healthy diet. This task is challenging and requires motivation and perseverance. Through education, role modeling, and encouragement, teens learn to make healthy food choices and develop proper eating habits.

Maintaining a healthy weight is difficult for teens with Spina Bifida due to their decreased activity level. Inactive teens who primarily sit in a wheelchair require significantly fewer calories than typically developing teens. With encouragement and guidance, though, your teen can successfully maintain a healthy lifestyle throughout the teen years and into adulthood.

Physical activity is important for muscle strength, as well as to burn calories. Look into wheelchair sports programs that your teen might enjoy. If there are no local teams, check out therapeutic recreation programs in your community. Swimming is usually an excellent activity for individuals who do not have the use of their lower limbs. Sometimes a little adaptation is all that is necessary to make an activity possible for your teen. Physical therapists may be able to help you locate activities in your community as well as suggest additional exercises you teen will be able to do. The trick is to make it fun. If it is going to work, it needs to be something your teen will enjoy.



Skin Health

By the teen years, your child should have had plenty of practice taking care of his or her skin and thus be fairly independent in this area. With increased body weight and the tendency to sit more, the risk for developing pressure sores is greater. Again, prevention is the key, so daily checks and wheelchair pushups are critical.

Because many individuals with Spina Bifida have foot deformities, the feet need special care. It is hard for a teen who may want to wear the latest fashionable shoes to be content with bigger, bulkier shoes that are usually necessary to assure proper room and fit for toes, feet, and braces. High heels, pointed toes, open-toed shoes, and sandals with straps are not recommended. Careful inspection of the entire foot – top, bottom, and in between toes for redness, blisters, sores, cracks, peeling, and swelling – needs to occur every day. A medical specialist should periodically assess your teen's feet.

A good skin care regime includes:

- Check skin for cuts, bruises, scratches, swelling, and red marks. Be sure to check the buttocks and all parts of the feet, including the skin between the toes.
- Use a large hand-held mirror to look at any place on your body you can not see.

- Shower or bathe daily. Check the water temperature before getting into your shower or bath. Dry skin well, especially the seat (pubic and anal areas) and between the toes.
- Use only soap and water. Avoid use of body creams or gels if they irritate your skin.
- Be careful with any item that has been heated.
- Apply sunscreen lotion with a protection factor of at least 15 (SPF 15) to all exposed skin before spending time in the sun. Wear a hat and avoid being out in the sun for extended periods of time. To protect the feet from sharp objects and rough surfaces, wear water shoes when at a pool, lake, or beach.
- Wear socks and shoes when you are awake and up and about.
- Care for nails and toes; cut toenails carefully or see a podiatrist (a foot doctor).
- Perform frequent wheelchair pushups/shifts.
- Maintain adequate inflation and cleanliness of wheelchair cushions.
- Don't smoke.
- Eat healthy foods.
- Drink plenty of water (6 to 8 glasses a day).

Latex

Teens who do not have a latex allergy should avoid latex as a preventative measure. Teens with a documented or suspected latex allergy must understand the signs and symptoms of a possible reaction and how to get help. They should wear a medical bracelet and know how to give themselves epinephrine (if prescribed). Teens must be able to explain latex allergy to medical professionals and request non-latex items. This becomes especially important as they transition into the adult medical world.

Parenting Tips

Expect your teen to participate in medical visits. Have him or her make a list of questions to ask the health care provider. Expect your child to answer the health care provider's questions, understand his or her medications, and order his or her own supplies and medications.

Mental Health

The teenage years are a time of great change for both the adolescent and the family. The key challenge for this age group is to prepare for adulthood and independence. As a parent, your job changes from supporting, protecting, and nurturing your child to gradually letting go and backing off as he or she takes on greater independence. When your child has Spina Bifida, this complex and frequently confusing process of transition can slow down or even get stuck. Parents may feel that the teen is not ready and that the world is not a supportive or receptive place for an individual with a disability, and so pull in the reins. Your teen may feel unprepared and rely more and more heavily on his or her parents and teachers. Teens often withdraw from their challenges and spend all their free time in self-soothing activities, such as video games or watching television.

Work to prepare your child for independence, step-by-step, building the competencies needed for adult life. Typically, this process takes more time than expected; very few adolescents, with or without disabilities, are truly independent at the age of 18 or even 21 or 25. Build on your earlier efforts to provide challenges at the appropriate level, teach independent self-care, support the emergence of a healthy self-concept, and facilitate an active social life.

Work with your child's school team to address the skills needed for success after graduation from high school. For some teens, this means preparation for college, further studies, and dorm life. For others, vocational and community living skills are the primary concern. Success with these endeavors leads to functional independence and the foundation for good adult mental health. Without this preparation, a young adult is vulnerable to being overwhelmed by the demands of independent living and at risk for depression, anxiety, and behavioral problems.

Continue to carefully monitor your child's behavior and emotional adjustment during the teenage years. This age group is particularly susceptible to mental health issues, and at this age behavioral issues may be more dangerous. Teenagers are more likely to engage in risk-taking behaviors, some involving drugs or alcohol, sexual activity, or violence. Suicide and other self-destructive behaviors are a significant risk during adolescence as well. For most adolescents with Spina Bifida, the bigger risk is "shutting down" or avoiding challenges, withdrawing from peers, and spending most of the time engaging in self-soothing behaviors such as watching television and playing video games. If you suspect that your teenager is struggling with any of these issues, contact a mental health professional to assess your child and provide needed treatments. Effective therapies for teens include individual counseling, family-based counseling, medication, and group therapy.

Signs of Possible Emotional or Behavioral Problems

1. Changes in appetite or sleep patterns.
2. Complaints of pain or fatigue (without an underlying medical cause).
3. Withdrawal from friends.
4. A drop in grades or academic performance.
5. Neglecting self-care responsibilities.
6. Frequent complaints of “being bored” or “not having any fun.”
7. Spending a lot of time alone watching TV or playing video games.
8. Negative self-statements (e.g. “I’m not good at anything” or “No one likes me.”).
9. Increasing oppositional or non-compliant behavior.
10. Starting arguments or acting in ways to draw attention to himself or herself.

Parenting Tips

- *Support independence by allowing greater freedom and facilitating more social activities outside the family.*
- *Work with the school team to ensure that your teen is developing the academic, social, vocational, and independence skills that will be needed after high school graduation.*
- *Monitor your child’s behavior for signs of depression, anxiety, and withdrawal from challenges.*
- *Continue to provide active parenting support for your child through his or her twenties.*

Social Development

The teen years present their own set of challenges in many families. The early teen years are an ideal time to objectively evaluate the progress your teen has made. Remember that social development is a continuing process. It is important to build on your teen's strengths. It is also important to recognize weaknesses that limit his or her social development. Many teens have trouble in areas such as problem solving, using good judgment, and making decisions. Teens with Spina Bifida have the added challenge of taking on more self-care. Your teen's progress in self-care and his or her developing independence directly affect his or her social progress.

The good news is that young people with Spina Bifida tend to stay more closely connected to their parents during adolescence. Capitalize on this opportunity to promote positive social behavior.

Your teen's school is the major setting for social interactions and progress. Building relationships with peers at school is an important aspect of your teen's school experience. Developing friendships and long-term positive relationships with peers is a continuing goal for social development. Your teen should be able to answer questions about living with Spina Bifida in a matter-of-fact, non-threatening way that can help other people feel comfortable. When your teen is comfortable with him or herself, others will be comfortable being around him or her.

Developing Social Skills

Here are things that encourage social development in teens who have Spina Bifida:

- Involvement in structured social skills programs
- Structured social situations
- Identifying specific areas of weakness
- Opportunities to practice in different situations

Factors that Encourage Social Progress

- Building on established social relationships with peers and childhood friends
- Having a significant, meaningful relationship with a friend
- Positive school experiences

- Participation and involvement in school activities
- Recreational interests and hobbies
- Participation in extra curricular activities such as scouting, sports, or playing in a band
- Camp experiences, perhaps leading to a role as a camp counselor

Factors that Challenge Social Progress

Learning challenges are cognitive and learning issues that affect the ability to develop social skills, solve problems, use judgment, and read social cues.

- Negative feelings about being handicapped
- Labels (“retarded”, “handicapped”)
- Avoiding social situations
- Limited mobility or periods of immobility
- Contenance or hygiene issues
- Depression

Things Parents Can Do to Help

- Continue to be actively involved in arranging situations that promote the development of friendships and relationships
- Give clear feedback about social behavior as part of good communication
- Encourage interactions with positive role models
- Know the people with whom your teen is spending time
- Initiate participation in mentoring programs
- Be alert to signs of social isolation, loneliness, or depression
- Consider a driving evaluation and driver’s training in school
- Identify challenges, barriers, and delays in social progress and help to alter the situation

Sexuality

We are all sexual beings. Our sexuality is expressed through the clothes we wear, the words we say, and the things we do. Everything a man or a woman does to express being male or female is part of his or her sexuality. Hopefully, your child has been developing positive feelings regarding his or her sexuality since early childhood. As issues related to sexuality assume a more central role during the teen years, young people with Spina Bifida face unique challenges.

The specific nature of these challenges varies greatly among teens with Spina Bifida. Personal hygiene, continence, and appearance are among the many things that may affect a teen's perception of him or herself. These also affect the way their peers and others perceive and respond to them.

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

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

Your child may choose to become sexually active even if you don't think that he or she is ready. Be proactive and talk with your teen about sex. Help him or her to understand the difference between love and sex. Reinforce the importance of good decision-making, knowing the qualities of true friendship, and understanding how sexuality can relate to positive relationships.

Remember that anyone can feel like an outsider in junior high or high school – even the kids everyone thinks are popular! To broaden your teen's world beyond the school and neighborhood, encourage him or her to participate in safe online chat groups and keep in touch with friends by email and instant messaging.

Teach your teen to:

- Be aware of his or her body and personal space
- Practice good hygiene by bathing regularly and doing daily skin checks
- Self-manage his or her bowel and bladder program
- Consider other people's feelings
- Think about how his or her actions affect others

Sexual Functioning

Just as with any other teen, it is very important to talk with your teen about sex. It might be difficult, but being honest with your teen will help your teen later on, because the act of sex requires more planning for people with Spina Bifida. Spina Bifida does affect some areas of sexual functioning – depending on the level of the Spina Bifida lesion.

Communicating about sex is a skill that grows over time. Be honest and open so that your teen can talk with you about his or her needs. Just like any other teen, your teen will need to talk with you about sex and related issues like birth control. Make sure your teen knows:

- It is possible for girls who have Spina Bifida to become pregnant and for boys who have Spina Bifida to father a child.
- Sexually transmitted diseases are an issue for everyone.

If your teen decides to become sexually active, talk with him or her about using latex-free condoms to help avoid latex exposure. This section outlines other key topics that you should discuss with your teen in more detail.

Sexual Activity

Because the act of sex requires more planning for people with Spina Bifida, it is important to speak with your teen about sex before he or she chooses to become sexually active.

For both men and women with Spina Bifida, it is very important to apply water-soluble lubricant to the genital areas. Applying lubrication before and during sexual activity is important in order to avoid getting pressure sores and irritated skin.

Here are a few things your teen can do to prepare his or her body before sex:

- Practice good hygiene to prevent urinary tract infections. Wash yourself and empty your bladder and bowel before intercourse. (Remember to also empty the bladder soon after intercourse.)
- Have lubrication available to apply before and during sex.

Depending on the location of their lesion, young women with Spina Bifida may or may not have difficulty experiencing an orgasm. Above T11, a woman will most likely not have an orgasm, but she can enjoy the intimacy and excitement of sex. Below T11, women may experience an orgasm.

Men who have Spina Bifida may use erection aids to help with sexual intercourse. Encourage your teenage son who may be considering becoming sexually active to speak with his health care team about erections and erection aids for people who have Spina Bifida.

Sexually Transmitted Diseases

Let your teen know that sexually transmitted diseases (STDs) such as herpes and HIV/AIDS can be passed on to a partner during sexual contact. Latex-free condoms are the best protection against STDs for people who have Spina Bifida.

Before your teen becomes sexually active, it is important that he or she learns about the potential partner's sexual history. While it can be uncomfortable asking these questions, it's crucial for their health and well-being. If your teen has sex with a new partner and does not use a condom, or if your teen does not know his or her own HIV status or that of the partner, your teen should get tested for AIDS and hepatitis as soon as possible.

Fertility and Birth Control

Young women with Spina Bifida have normal fertility and can get pregnant. Fertility varies for young men who have Spina Bifida, but men should assume they are fertile unless proven otherwise by medical testing.

Your teen's health care team can help to determine which birth control method is best if he or she chooses to become sexually active. Birth control options include barrier methods that prevent fertilization (latex-free condoms or diaphragms), medications (birth control pills), injections, implants, or surgical procedures. Sexual activities other than intercourse (such as abstinence or mutual masturbation) are your teen's best protection against pregnancy.

People with Spina Bifida should use latex-free condoms with spermicidal cream. This is important for both young men and young women, as either partner may have a latex allergy. Condoms made from animal skin are available, and work as birth control, but they do *not* protect from HIV/AIDS or other sexually transmitted diseases.

Women can use spermicidal foam or a latex-free diaphragm with spermicidal cream, birth control pills (unless the risk of blood clots is high), injections, patches or implants. Tubal ligation is a surgery where the tubes are tied to prevent pregnancy. This is permanent and usually not reversible.

Men can have a vasectomy, a surgery that makes them sterile. It is permanent and usually not reversible. A vasectomy does not interfere with the ability to ejaculate, but the ejaculate does not contain sperm.

Gynecological Care

For young women with a mobility-impairment like Spina Bifida, a gynecological examination may offer unique challenges. Some providers of gynecological care have accessible clinics for women with disabilities. If you are interested in locating such a clinic, ask your health care provider or contact a rehabilitation facility in your region. A health care provider who has not worked with women with disabilities but who is sensitive, caring, and flexible can also be an option. Encourage your teen to have open communication with her health care provider about her unique needs and concerns.

Sexual Abuse

People with disabilities have been reported to be at increased risk for sexual abuse compared to the general population. It's important to be aware of this so that you can educate your teen to be his or her own advocate. If your teen has been sexually abused, it is not your fault or your teen's fault. You and your teen should report any inappropriate behavior to the proper authorities in your area.

Parenting Tips

- *Encourage your child to join a club or group, and consider helping him or her to identify good choices. Art, drama, choir, chess, and science clubs can be great places to make friends. Community or religious youth groups are often happy to welcome new members. If your child loves something that he or she really cannot participate in, help the child to find a special or supporting role. For example, if sports are the passion, keeping score, making signs, and being the announcer are all ways to participate.*
- *Be ready to talk openly with your child about sex. Encourage your teen to discuss questions about sexual function with a health care provider.*

Learning

The teen years are the time to start planning and setting goals for education and work beyond high school. Hopefully, you have already exposed your child to the idea of work and explored potential jobs and interests with him or her. Between ages 14 and 16, your child should begin attending his or her own IEP meeting. At this time, the transition plan should include vocational/academic goals. If your child plans to pursue higher education, discussions can revolve around preparation for that goal: what courses and credits are needed, and how to fill out college applications and apply for scholarships, etc. If your child will be entering the work force after high school, the discussions can revolve around skills that he or she needs to make that possible (e.g., computer skills, resume writing, and vocational training, etc.)

If your teen is identified as needing a special education program, you have the option of keeping him or her in the school setting up to age 22. This allows for extra time for attendance in vocational programs at the school's expense. Your teen can still participate in the graduation ceremony with his or her classmates, but will not officially receive a diploma at that time. Once your teen leaves school, state vocational rehabilitation programs may be able to support him or her with job training, advanced education, placement, transportation, and special equipment and aids to help achieve eventual employment. Employment options for individuals with disabilities range from sheltered employment to regular competitive employment.

Parent Advocacy

This period is an important time to work on the transition from parent advocacy to self-advocacy. Your teen has had you as a role model all these years. Encourage your child to speak up at the IEP meetings and state his or her viewpoints and suggestions. Your child will need to have some understanding of what his or her learning needs are and have the confidence and social skills to know how to obtain what he or she needs. This ability does not come easily or develop overnight. Remember how long it took for you to be able to face all those professionals and demand services for your teen? You will not be accompanying your teen to college or to a job site, so use these interim years to practice shifting the responsibility from you to him or her.

Optimize your teen's self-care skills, including bathing, dressing, getting a haircut, and going shopping. Can your teen prepare at least simple meals, wash his or her own clothes, and tidy up the house? Emphasize how important it is for your teen to:

- Be a good and reliable worker
- Have excellent hygiene and social continence
- Have good social skills

Teach your teen financial responsibility, including how to open a bank account, write checks, balance a bank statement, and manage credit cards. An allowance is a great teaching tool, especially if it's expected to cover specific expenses. Discuss budgets, including household expenses and salaries or wages.

If your teen is capable of driving, he or she should learn how to drive. Cars and vans can be adapted or modified to meet your teen's needs. Driving will increase your teen's independence and make getting to a job easier. Encourage your teen to become familiar with the various transportation options in your community for other options to get around.

Parenting Tips

- *Let your teen get organized for medical visits. Have him or her keep a list of questions to ask the doctor.*
- *Help your child to gain experience in at least one working situation as an intern, volunteer, or paid employee during the summer months. Help your teen practice interviewing skills, filling out employment applications, and writing a resume. Encourage him or her to develop a professional image. Occasionally bring your child to work, and discuss and explain your job. This introduction to the working world may lessen anxiety when it's time for him or her to join that world.*
- *Missing school for surgeries may be a big problem for teens thinking of college and 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

Parents sometimes 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. This guide features a section for parents and caregivers of children with Spina Bifida. In this section, you can learn how to assess your current financial situation, teach money management to your child, and support your child's educational goals. The guide will also lead you to additional helpful resources. This document is available online at sba-resource.org/NEFE/.

Thinking about the Future

If you have not done so already, this is the time to begin speaking to your teen about his or her future educational and career goals and how they might best be achieved. Your teen is learning to become an adult and wants to have a sense of control over their lives. Let your teen make whatever decisions he or she can and include him or her in any conversation about planning for adulthood. Give your teen as much independence as possible.

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

A Health Care Record for Adults is available in the SBA publication, *Health Guide for Adults Living with Spina Bifida*. Encourage your teen to start to keep their own health records using this guide. You can then compare it to the records you are keeping on the Parent Health Care Record to note differences.

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 important to your well-being.

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



**4590 MacArthur Boulevard, NW Suite 250
Washington, DC 20007
www.spinabifidaassociation.org**

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