



Illuminations for Teens

Guide for Teens with Spina Bifida



Introduction

Being a teenager with Spina Bifida can be hard because there are a lot of complex issues that you have to face and manage. This booklet is a handy tool to help you and your family work through those issues together.



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Chapter 1: How to Talk about Spina Bifida

You should only share what you are comfortable with. Don't be afraid to speak up for yourself. Sometimes it can be hard to explain to others what Spina Bifida is and how having Spina Bifida influences your life. Here are some examples of what to say when you're telling others about your Spina Bifida.

Say something like this to people you are just getting to know:

“Spina Bifida is a birth defect that can occur in any family”

“Every person’s ability to move and feel is different with Spina Bifida”

“Some people with Spina Bifida may walk on their own or with support, such as braces or crutches, or use a wheelchair”

“No one knows exactly why some people are born with Spina Bifida. Researchers think there are several different factors that may interact to cause Spina Bifida, such as genetics or environmental influence”

“We know that folic acid helps reduce the risk of having a pregnancy with Spina Bifida, but taking folic acid is not a guarantee that a pregnancy won't be affected by Spina Bifida.”



Say something like this to people you know and feel more comfortable sharing information about yourself with:

- Spina Bifida can cause a person to move, learn, and go to the bathroom differently.
- Spina Bifida is a birth defect that occurs within the first 28 days of pregnancy. It is different from a spinal cord injury that can occur after a person is born, such as from a car accident or sports injury.
- Because folic acid helps make the spinal tube close, it may help reduce the chances of having a baby born with neural tube defects, such as Spina Bifida. But a mother can do everything right—like take folic acid—and still have a baby with Spina Bifida because it can also result from genetic or environmental factors. There may be many other causes that are still unknown.
- People with Spina Bifida have problems with certain parts of their body. The systems most affected are the nervous system (brain and spine), the urinary system (bladder and bowel), and the orthopedic system (bones and joints). People with Spina Bifida may also have learning issues.

Be Your Own Advocate

Self-advocacy

means speaking up for yourself and making your own decisions. Being your own advocate will help you with any challenges you may face as you transition from being a teen to an adult.



Know yourself

Know your strengths, weaknesses, goals, and responsibilities—whether you're at school, at a job, or in any other setting. Know what accommodations you need and what ones are available to you. These could include:

- Moving class locations for wheelchair accessibility
- Longer testing times and/or having tests read to you
- Identifying support systems, including doctors and teachers
- Anything else you might need to carry out your areas of responsibility

Ask questions

It is okay to ask questions. You don't know if you don't ask—right? There are many times when you might want to ask questions

- Ask for help if there's something you don't understand.
- Ask yourself if a situation that feels uncomfortable is right or not.

When you are meeting with someone, such as your doctor, teacher, or advisor, write down different questions that you would like to ask in advance. During the meeting, ask the questions you wrote down and take notes to help you remember what you discussed.

If your questions are not answered right away, you may be tempted to give up. But don't be so quick! Ask your questions again or ask someone else who may know more. It is your right and responsibility to gain your own independence and get what you need.

Who Are Your Advocates?

Advocates are people you can approach with questions or problems.

They may be your:

- **Parents**
- **Teachers**
- **School officials**
- **Social worker**
- **Classmates or coworkers**
- **Organizations, such as your local Vocational Rehabilitation or Centers for Independent Living**

Self-advocacy is not something that you can learn just by reading these few words—you have to practice it every day. This booklet gives you some practical steps that you can take to be your own advocate in different areas of your life: school, managing your health, and career planning.

Activity

Think about these questions, write down your answers, and keep what you have written in a safe place. When you need to speak up for yourself, read what you have written to remind yourself that self-advocacy is important and that you are worth it!

- What matters do *you* need help with?
- What are *your* hopes for your future?
- Who are *your* advocates and how can they help you advocate for the matters you need help with?

List your advocates by name.

Chapter 2:

Strategies and Tools for Learning in School

Like all students, students with Spina Bifida have to work hard to be successful in school. But, while students with Spina Bifida often show strengths in learning verbal and social skills, many have to work especially hard to pay attention, focus, and remember information because differences in their nervous systems could affect how they learn.

Attention

Attention is the ability to concentrate and remain focused on one thought, task, or thing regardless of other activities and thoughts that compete for your attention. Paying attention can be very difficult to do because lots of things are competing for your attention.



Games like *Simon Says* and *Now You See It* can help you work on your attention skills.

Simon Says is a game for three or more people that requires players to pay close attention to directions.

One of the players is assigned the role of “Simon.” Simon asks players to do a task by saying “Simon says” and then giving instructions. When Simon says to do something, all players have to follow the directions. Those who don’t are eliminated from the game. However, if Simon asks players to do something without saying “Simon says” first, players are not supposed to do what Simon says. Those who do what Simon says are eliminated from the game.

Now You See It, Now You Don't...: You can play this game by yourself or with others. This game will help you practice paying attention to details and build your memorization skills.

Use a tray or a large plate. Place 10-15 objects on the tray. Test yourself by memorizing the items on the plate for one minute. When the time is up, cover the plate with a cloth or towel. Write down all the items you remember seeing on the plate. Can you remember all the items?

Strategies to help with paying attention

Here are some things that may make concentrating and staying focused a little easier for you. If you become distracted, that is okay. Staying focused on one thing takes practice. Keep trying!

- Find a time and place that is best for you to do your homework — a quiet, clear space with minimal distractions to maintain focus. Some students work best right after school or immediately after dinner. Once you determine what time of day and place work best for you, work at that same time every day.

Consider using a non-latex squeeze ball or a fidget spinner to help with focus.

At the end of each 15-minute interval, get up, move around, and stretch!

- Practice keeping yourself focused on the work you need to complete. Set a goal of finishing a certain amount of work in 15 minutes. Then try to work without getting distracted for that time. Use a watch or a timer to keep track of the minutes.

For example:

- o I will learn three spelling words in 15 minutes.
- o By 7:15, I will have three math problems finished.
- o I will memorize five vocabulary words in 15 minutes.

- In school, sit at or near the front of the class. It is easier to pay attention if you are close to the action with no one in front of you to distract you.

Taking medication to help you focus

If you have problems paying close attention or are easily distracted, you are not alone! Many teens with Spina Bifida are diagnosed with attention deficit/hyperactivity disorder (ADHD), and may be prescribed medications to help them pay attention.

To know if you have ADD or ADHD, you must see a health care provider who specializes in mental health issues and can decide if taking a special kind of medicine may help you focus. If your doctor prescribes you medication:

- **Make sure that you understand how much to take and when.**
- **Ask your doctor to write down the specific instructions to take home.**
- **Make sure the instructions include the time and amount you are supposed to take. That way, you and your doctor can figure out the right amount of medication for you.**

Remember, any medication use should always be monitored by your doctor.



Memory

Your memory is like your closet: it holds things. But instead of shirts and shoes, your memory holds things like names, ideas, and facts and helps you recall that information when you need it. There are two types of memory: short-term and long-term.



Short term memory means remembering information for a short period of time. This could be:

- What you ate for dinner yesterday
- Part of a book you read a few days ago
- Recalling a conversation you had with a friend this morning

Long term memory means remembering information for a long period of time. This could be:

- Important dates (birthdays, weddings, anniversaries)
- Skills you learned in school

You use short-term and long-term memory in school:

- You need short-term memory to remember the instructions for taking a test and following directions.
- You need long-term memory for adding new information to your memory “closet.”

Most information has to go through your short-term memory to the long-term memory part of the memory “closet.” You can make the most of your memory by learning ways to help you remember things.

- Tools you can use include:
 - Note cards
 - Online study tools, such as Quizlet (<https://quizlet.com/>), Kahoot! (<https://kahoot.com/>), Brainscape (<https://www.brainscape.com/>), and Course Hero (<https://www.coursehero.com/>).
 - Rewriting notes
- Talk to your teacher, counselor, or a reading specialist in your school to help figure out what memory-building strategies could work best for you.

Organization

Organization means arranging things and tasks in a certain order. Being organized means having a place for everything and knowing where that place is. A lot of people with Spina Bifida say that they really have to work at organization; it does not come easy. But learning to be organized will make your life more comfortable and less stressful. Staying organized is hard work, but you can do it! In school, being organized means:

- Knowing what the work is, getting that work finished, and turning the work in when it is due
- Knowing where your work is and where you keep your school supplies

Having Spina Bifida means that it’s also important to be organized about how you manage your physical health. For example:

- Know when and where you will use the bathroom so that you can maintain your hygiene. This means you need to plan to have enough hygiene supplies on hand and know where the closest restrooms are.
- If you have less feeling in your bottom, legs, and feet, you’re at risk for skin damage since you can’t feel cuts, bruises, sores, or other problems with your skin. Plan to check your skin every day to avoid skin damage.



Tips for staying organized

1. Write things down on a sheet of paper or in a planner or create task lists on your phone or computer. Check off each task when you've completed it.
2. Make schedules, set deadlines, and add appointments to your calendar—whether it's a paper calendar or the calendar you use in your electronic device.
3. Keep your workspace clean and quiet.
4. Don't procrastinate.

Tips for organizing your school life

1. Anticipate! Get in the habit of thinking ahead or “rehearsing” what you will need for an activity—hygiene supplies, specific clothes, medicine, etc. Write down what you will need and check the list before you leave for school or activities.
2. Follow the same routine every day. If you do the same thing every day at the same time, you will develop a pattern. If you forget to do part of the job, it will feel funny and you will be reminded to think about what you may have forgotten. This is helpful for organizing your hygiene habits or developing study habits.
3. Keep your supplies for school together in a backpack. At night when you finish your homework, pack up your backpack with everything you will need for school so the only thing you have to do is pick it up in the morning.
4. Keep your school papers and homework in one place. Some students like to use eight-pocket folders. There is a pocket for each subject, and you can keep your homework in the pockets as well. When your teacher asks for the homework to be turned in, all your homework will be in one place, with each subject in a different pocket. Your eight-pocket folder is what you will carry back and forth with all your assignments.
5. Write down tasks and assignments and check them off when complete. Use an assignment book, planner, or to-do list.

Example of a To-Do List:



October 25

1. Complete Math problems #1-10.
2. Read Chapter 3 of book for English.
3. Practice spelling words (write down and review with an adult).
4. Place school work in backpack on bench by front door.
5. Shower and do bowel/bladder routine.
6. Lay out clothes for school tomorrow.

Strategies for Taking Notes

When you are in school, you're supposed to take notes for just about everything. Here are some strategies to help make note-taking easier:

1. Pair up with another note-taker to compare, review, and fill in notes.
2. Use a recording device in the class and refer to the recording when reviewing your notes.
3. Ask the teacher for a copy of the class outline and then fill in important notes.
4. Find a note-taking system that works well for you.

- Take traditional notes on the right side of the page, leaving space to go back and write your own notes/comments on the left side.
- Use online note-taking applications. Some of the many note-taking systems include Microsoft OneNote, Apple Notes, Google Keep, Evernote (<https://evernote.com/>), Notability (<https://www.gingerlabs.com/>), and Whink (<http://whinkapp.com/>).

5. Use visuals, diagrams, and charts to help organize your notes. One such method is called mind-mapping. You can find more information about it here: <https://www.mindmapping.com/mind-map>.

6. Develop your own shorthand system. Use your own abbreviations or symbols for words you use often. For example, use "b/c" for "because."

Ask for the Accommodations You Need

Speak up for yourself to get the accommodations, or adjustments, you need. Here are some specific questions that you could ask:

“May I record this class?”

“Can I be paired with another note-taker?”

“May I have a copy of the class outline?”

“May I take the tests orally/individually/by appointment?”

Becoming comfortable with asking these questions will help you advocate—or speak up for yourself—in all other areas of your life, like participating in a recreational activity in your community, ensuring that you are getting the health care services that you need, and making sure that you are being treated fairly at work.

How Federal and State Laws Help Students with Spina Bifida

You may be receiving special education services through a federal law called Individuals with Disabilities Education Act (IDEA) and through other federal and state laws. IDEA says you have the right to a free, appropriate education—an education that takes your special needs into account and is provided at no cost to your family.

You also have the right to have special education accommodations written into your Individualized Education Program (IEP). These accommodations are necessary to help you learn in school and might include tutoring, access to a resource room, special accommodations for writing, physical or occupational therapy, assistive technology, and even arrangement for catheterization.

The law says the IEP should be reviewed and updated with new goals each year. You should be encouraged to participate in those IEP meetings, together with your teacher and parents.

Your IEP should include a transition plan. This is a plan for what you intend to do after high school and how you intend to achieve your goal. For instance, you might plan to attend a four-year college, community college, or vocational school or get a job. How you explore these possibilities should be written in your transition plan.

For details on how IEPs work in your state, search online for “IEP state resources.”

Chapter 3: How to Build Your Social Skills



Having good social skills will help you be a good friend, make good friends, and have positive relationships. Good social skills can even help you find a good job.

Having good social skills takes practice, and you might make some mistakes along the way. That's okay! You have many opportunities to practice good social skills every day. For example:

- **Listen when people are talking. Look at them when they are speaking to you. If you don't see a lot of people in person during the day, practice this skill while you watch movies or television.**
- **Be aware of other people's personal space and maintain an appropriate distance when you're speaking.**
- **Do not interrupt when someone is talking.**
- **When it is your turn to talk, stay on the same topic. Respond with statements that show others that you are listening to them, such as, "I understand where you are coming from."**
- **Compliment others.**
- **Take note of facial expressions or body language that others may use to communicate with you.**
- **Always shower and wear clean clothes before going to school or work or meeting with friends and family. Cologne and perfume only cover odor for a short period of time and should not be used as a substitute for bathing.**

Other Things You Can Do to Build Your Social Skills

You can improve your social skills by role-playing good social skills and by engaging in activities that require their use.



Role-play: Ask a friend, a parent, or a school counselor to help you practice how you would act or react in different situations:

- What non-verbal messages are you expressing by how you sit or stand (your posture) when you're speaking or listening to someone? Does your body slouch or do you lean forward? Nod your head up and down to show that you are listening.
- Move about an arm's length closer or farther from each other to practice giving others the right amount of personal space.
- Pretend greeting a person who you're meeting for the first time. Should you shake their hand or wave—or is smiling and saying "hello" enough? How is greeting someone you just met different from greeting a close friend or family member?
- Practice giving and receiving eye contact when speaking or listening to each other.
- Practice how you will react and what you will say when you realize you've had a bladder or bowel accident. Would what you say and do be different if you were at school, work, or home? What about if you were with new friends or with friends you have known for a long time?
- Watch television or a movie with your friends, siblings, or parents. Then talk with them about the interactions between the characters depicted in a particular scene and why they are behaving that way.

Remember that hygiene—or staying clean—is important to building social relationships. It is difficult to make friends in person when your body does not smell good.

Volunteer: Volunteering for an organization can help you practice social skills that you can use at school and at a job. Volunteering can also help you:

- Meet people from a variety of backgrounds and experiences
- Boost your confidence from knowing that you were able to help others
- Have positive interactions with others, which will encourage you to display positive social skills with others

Seek volunteer opportunities or ways to connect with other teens with Spina Bifida in your area. You can ask your school counselor, your local hospital or Spina Bifida clinic staff, and nonprofit organizations like the Spina Bifida Association Chapter nearest you, the Spina Bifida Association's National Resource Center, and the local Center for Independent Living (<https://www.ilru.org/projects/cil-net/cil-center-and-association-directory>).

What Is Nonverbal Learning Disorder?

Nonverbal learning disorder (NLD) can impact your ability to do things that require you to recognize patterns and ways that things are done or how situations happen. Having NLD can affect:



- **How you interact with people;**
- **How you solve problems;**
- **How you make plans or organize your thoughts; and**
- **Even your physical coordination.**

If you've been told that you have NLD, this means that you may need extra practice in:

- **Learning to start a conversation**
- **Knowing how to build and maintain friendships**
- **Learning to listen**
- **Learning to interact in groups**

Additional Aspects of Social Skills

Building social skills is not just about making friends or getting along with others. Other things can affect how we interact with others.

Sexuality

Like many other teens, you may have the goal of finding a life partner someday. Communication is a critical skill in establishing friendships and romantic relationships. We express ourselves through the clothes we wear, the words we say, and the things we do. **There are a few things to think about:**



- Be aware of your body and how you present yourself to others.
- Consider other people's feelings.
- Think about how your actions affect others.
- Practice being honest and open so that you can talk about your needs.

Practice good hygiene:

- Take a shower or bath every day.
- Wear clean clothes every day.

For more information about sexuality and sexual health, search these organizations for materials and webinars on sexuality for people with Spina Bifida and other disabilities:

Spina Bifida Association (<https://www.spinabifidaassociation.org/>):

- Urology and Sexual Health Guidelines
- Health Care for Women
- Men's Sexual Health

Pacer Center, an organization that provides information and support to young adults with disabilities and their families (<https://www.pacer.org/>):

- Disability and Sexuality
- Consent and Kids with Disabilities

Sexual Abuse

People with disabilities are two to three times more likely to experience sexual abuse than the general population. As a teen with Spina Bifida, you need to be aware of this in case anyone tries to touch you inappropriately or makes you feel uncomfortable. If you have been sexually abused, remember—**it is not your fault**. You need to tell someone immediately. You should report any inappropriate behavior to your parents and the proper authorities in your area, such as the police, social services, or your health care provider.

For more information:

- Call the National Sexual Assault Hotline at 800-656-HOPE or visit the Rape, Abuse & Incest National Network (RAINN) (<https://www.rainn.org/>) website.
- Visit the National Sexual Violence Resource Center website (<https://www.nsvrc.org/organizations>).
- Search online for sexual abuse support organizations or groups in your area.

Bullying

Any teen can be a bully or be bullied. Bullies normally pick on those who are younger than they are and those who seem to have few friends, are different than they are, or are easily intimidated. If you are being bullied, **it is not your fault**. Bullying can include:



Physical bullying

hitting, punching, kicking, and destruction of your property

Verbal bullying

teasing, name-calling, taunting, racial slurs, gossip or malicious rumors



Cyberbullying

harassing over social media, texting, and spam accounts

If you are bullied, what should you do?

- Stay calm, and maintain your composure. Reacting will only reinforce the bullying.
- Tell the bully, “I want you to stop now,” and then leave.
- Share your concerns: Talk to your parents, teachers, school counselor, or any trusted individual. You have the right to feel safe.
- Follow up. Keep talking with your parents and school officials if the bullying continues.

You should also...

- Engage in positive activities.
- Get involved in things that make you feel good about yourself, like sports, music, or art.
- Talk with other friendly students in your class.
- Stick with a friend or group of friends while on the bus, in the cafeteria, or wherever the bullying seems to happen.

The Pacer Center has a variety of resources for teens to help you understand just what bullying is and what you can do if you are being bullied. Visit www.pacer.org/bullying.

Are you a bully? Take the Pacer Center quiz:

<https://www.pacerkidsagainstbullying.org/do-you-bully/>



Chapter 4:

Strengthen Your Social and Emotional Health



Your emotional health and well-being guides how you feel, think, and act when faced with life's situations. It impacts how you view and think about yourself, your life, and the other people in your life.

Create a Social Life That Works for You

Part of having a healthy social and emotional well-being is having a social life that works for your personality and circumstances. Different people have different needs for socializing and interacting with others. Some people thrive on constant interaction with friends and family, while others prefer to spend much of their time by themselves. Some people like to have both.

There are many ways that you can create a social life that works for you:

- **Spend time with friends:** If in-person contact is possible, you can visit the mall, go to lunch, explore a path or trail that is accessible to you and your friends, or see a movie together. You can hang out at home and watch TV, play a board game, or exercise together. If you are not able to meet in person, use a video conferencing system.



- **Join a club:** Your school and your community will have opportunities to join different groups, depending on your interests. Talk with your school counselor about the groups or clubs that are available at your school, such as bowling, archery, swimming, or book clubs. You can also ask your social worker what opportunities there are in your community.

- **Volunteer:** Helping others can make you feel good. It's a way to meet new people that share your interests, and it can even help you build skills that you can use to apply to a job in the future. Your parents, school counselor, Spina Bifida clinic coordinator, social worker, and others can help you find ways to volunteer.

Sometimes, it's just not possible to meet with friends in person or online.

Here are ways you can enjoy time on your own:

- Find a park or path that you can safely take on your own.
- Ask your school librarian for book or movie suggestions.
- Ask your parents how you can help them around the house.
- Explore a craft or hobby you can do on your own, such as painting, drawing, singing, or journaling.
- Join Meetup or other special interest/hobby groups that match your interests and circumstances.



Anxiety and Depression

Preparing for adulthood and independence is exciting, but it can also make you feel scared, anxious, and even depressed. As you transition into adulthood, you will have to confront new problems and challenges, explore choices, and make decisions that others might have once made for you.

As you navigate this new world, it is important that you believe in your own value and know that you are not alone.

Every person goes through periods of worry or feeling down. Many teens with Spina Bifida also experience anxiety and depression, and they experience these in different ways and at different times.

There may be specific physical and social-emotional reasons why you feel anxious or depressed.



Possible physical causes of anxiety and depression

Your doctor can help you determine if there are physical causes for the way you are feeling and will suggest how to treat these causes:

- **Hydrocephalus/shunt failure**
- **Traumatic brain injury**
- **Neurochemical imbalances that impact emotions and behaviors**
- **Neurocognitive issues (e.g., problems with memory and organization)**
- **Other physical health problems**

Possible social-emotional causes of anxiety and depression

Day-to-day circumstances and challenges can cause you to feel sad for long periods of time. If you feel this way, talk to your doctor, who can explain how a mental health professional can help you better understand your feelings and determine healthy ways to deal with them. Here are some examples of social-emotional causes of anxiety and depression:

- **Struggling with classes and grades**
- **Bullying**
- **Financial stress in your family**
- **Pain or health problems that won't go away**
- **Frustration at not being “normal” or meeting “normal” milestones**
- **Barriers due to mobility**
- **Incontinence issues**
- **Socio-political turmoil or injustice**
- **Prejudice/discrimination**
- **Feeling lonely**
- **Concerns about your future and being dependent on, or independent from, your family**

How do you know if you're depressed?

Feeling down, sad, or hopeless and having little interest or pleasure in doing things for two weeks or more may indicate that you are depressed. Depression can interfere with your daily activities, physical movements, speech, appetite, and sleep.

If you have one or more of these signs, tell an adult, a trusted friend, or a health professional:

- **Feeling sad without a good reason**
- **Feeling emotionally numb**
- **Feeling worthless, down, or hopeless most of the time**
- **Not being able to sleep or wanting to sleep all the time**
- **Lacking motivation or interest in things or activities you used to like**
- **Not caring about your physical health and hygiene, your doctor's appointments, whether you take your prescriptions or other medications, or how you look or dress**
- **Loss of appetite or overeating**
- **Having frequent negative or self-critical thoughts**
- **Thinking about harming yourself or feeling that life is not worth living**
- **Frequent crying or inability to cry**
- **Frequent and sudden anger, irritation, and outbursts**
- **Increased aches and pain**

How do you know if you have anxiety?



There are many reasons to feel anxious, but people with anxiety can feel a variety of symptoms that repeat or remain for longer periods of time.

Some of the signs include:

- Replaying or worrying about past mistakes and upsetting events and imagining future negative outcomes.
- Following rituals to avoid triggers/bad outcomes or isolating yourself to avoid certain places or circumstances that cause anxiety.
- Nightmares and/or flashbacks
- Chronic agitation
- Frequent irritation or anger
- Panic attacks, which can involve a racing heart, dizziness, shortness of breath, nausea, fainting or feeling like you're about to faint, fear of death and dying, and the urge to flee, freeze, or flop

How do you treat anxiety and depression?

Three common ways are:

- 1. Counseling:** Professional help can help you better understand your feelings and determine healthy ways to deal with these feelings.
- 2. Physical activity:** Exercise can have a positive effect on your mood and self-esteem.
- 3. Medication:** Your health care provider may want to prescribe anti-depression medications.



If you are anxious or depressed, here are a few things you can do:

- Speak with your health care professional about being screened for depression, and seek a qualified mental health professional who matches your needs and personality.
- Get enough sleep, physical activity, and proper nutrition.
- Try mindfulness exercises and spend a balanced amount of time in solitude.
- Spend time with family and friends—whether in person or online.
- Join an emotional support group.
- Ask trustworthy, supportive people to help you with errands or tasks you are having a hard time completing.
- Attend activities with others, even if you don't feel like doing a lot of talking.
- Follow a healthy diet to increase your energy level and maintain a healthy lifestyle.
- If your health care provider prescribes anti-depression medication, be sure to follow the directions and take your pills as prescribed. Do not stop taking your medication on your own. If you want to stop taking your anti-depression medication, ask your health care provider how to safely wean yourself off the medication.
- Volunteer! Helping other people is a guaranteed way to help you feel better.
- Break stressful or daunting tasks into smaller pieces.

For more information, search for materials and webinars on mental health on the Spina Bifida Association's YouTube channel or on [spinabifidaassociation.org](https://www.spinabifidaassociation.org):

- **SB-YOU: Take Care of Your Mental Health**
- **How is COVID-19 Affecting Your Mental Health?**
- **Mental Health Guideline**
- **Spina Bifida Mental Health & Well Being Checklists**



Do you feel frustrated or irritated? You can do this anytime, anywhere!

1. Close your eyes.
2. Take a deep breath through your nose, slowly and quietly.
3. Hold it for a few seconds.
4. Let it out, quickly and noisily through your mouth. Imagine that you are blowing away a worry or problem that you have.
5. Repeat several times.

Chapter 5:

Manage Your Physical Health



If you're like many teens with Spina Bifida, you may be used to your parents or other adults taking the lead when it comes to managing your physical health. Make the most of their support now by learning from them how to manage your own health care. Learning this vital skill will help you throughout your life.

Manage Your Bowel and Bladder Routine

You should participate in and manage your bowel and bladder care. Important steps for being fully responsible for managing your own bowel and bladder care include:

- **Getting supplies ready**
- **Knowing what times throughout the day you should do your catheterization**
- **Knowing when you should do your bowel program**
- **Taking medications that help with your bowel and bladder care**
- **Learning how to refill medications**
- **Learning to clean up and change after an accident**

Bowel and bladder accidents can and will happen, but being prepared to clean up well and as quickly as possible helps you regain control and is an important skill that will serve you all of your life. When you're away from home, always have a bag with you that holds:

- **An extra change of clothes**
- **Wipes to clean yourself up until you can get home and take a shower**
- **Empty plastic bags for your dirty clothes**

For more information, search the Spina Bifida Association (<https://www.spinabifidaassociation.org/>) website and YouTube channel for materials and webinars on about bowel and bladder management:

- **SB-YOU: our Bowel Management Program – It's All in The Routine!**
- **Self-Management and Independence Guideline**
- **Bowel Function and Care Guideline**

Latex Allergy

Many people who have Spina Bifida are allergic to latex (natural rubber). Allergic reactions can range from less severe to more severe. Less severe reactions include:

- **Watery, itchy eyes**
- **Skin rash**
- **Coughing**
- **Sneezing**



More severe reactions include:

- **Swelling of lips and face**
- **Difficulty breathing**
- **Death**



Make sure that you are aware of some latex-containing items that are often found in schools:

- **Art supplies**
- **Balloons**
- **Latex gloves**
- **Balls**



For more information about latex, visit:

- **Asthma & Allergy Network**

<https://allergyasthmanetwork.org/allergies/latex-allergy/>

- **Asthma & Allergy Foundation of America**

<https://www.aafa.org/latex-allergy/>

Weight Management and Physical Activity

Weight management and being overweight are often challenges for people who have mobility issues. The best and safest way to lose weight and improve your health is to eat a balanced diet, reduce the number of calories you eat daily, and participate in some form of physical activity or exercise each day.



Physical activity and exercise are important parts of a healthy lifestyle. The benefits of regular physical activity and exercise are:

- **Feeling good about yourself**
- **Increased energy and flexibility**
- **Activities of daily living are easier to do**
- **Weight maintenance**
- **Improved general health**
- **Improved bowel function**
- **Healthy bones**
- **Decreased risk of diabetes**



Find out what exercise programs and recreational activities are available in your community by talking to a physical therapist or with friends or by contacting your local department of recreation. Also remember that the ADA ensures that people with disabilities have the right to participate in the same recreational activities as everyone else. Exercise can have a positive effect on your mood and self-esteem!

Call ahead before visiting a fitness or recreation facility to determine the accessibility of the areas that you would like to use. Here are some things to ask about:

- **Are the locker rooms, swimming pools, or any programs you're interested in accessible to you?**
- **Is accessible parking offered?**
- **Where is the accessible entrance?**
- **If you are unable to use the entire facility because it is not accessible to you, do they provide a sliding fee scale?**

If you have trouble getting into an exercise facility, your state representative's office is a good place to go for help. Each office has a health staff member who can help you get access to exercise and recreational activities that should be open to you under the ADA.

For more information, search these organizations for materials and webinars on physical activity for people with Spina Bifida:

Spina Bifida Association website and YouTube channel:

- **SB-YOU: Get Fit and Stay Healthy**
- **Physical Activity Guideline**

National Center on Health, Physical Activity and Disability (<https://www.nchpad.org/>) website:

- **Teens on the Move: An Exercise Video for Teens with Spina Bifida**
- **Exercises for Individuals with Spina Bifida**
- **Nutrition Spotlight: Nutritional Considerations for Adults with Spina Bifida**

Hydrocephalus

Some teens who have Spina Bifida have hydrocephalus. This happens when spinal fluid, which nourishes the nervous system inside the brain, cannot get out. Instead of going out and down the spinal cord, it builds up inside the brain.

Putting a shunt (tube) inside the brain helps drain the fluid to an open area around the stomach. The fluid then goes back into the blood like it is supposed to. People cannot tell if you have a shunt by looking at you—it is inside your body. Not all people with Spina Bifida have hydrocephalus and a shunt.

Sometimes a shunt stops working because it comes apart, gets plugged up, is too short, or falls apart. If that happens, a neurosurgeon—a specialty surgeon who operates on the brain and spinal cord—will operate and fix what is wrong. Without the operation, your symptoms may get worse and could lead to death. If you respond quickly to warning signs, the shunt can be easily repaired or replaced.

Common signs that the shunt is not working are:

- **Vomiting**
- **Headaches**
- **Vision problems (cross-eyed, double vision)**
- **Feeling more tired than usual**
- **Becoming easily upset**
- **Generally not feeling well**



The shunt can stop working at any time, especially as you grow. If you are having problems, call your family doctor or neurosurgeon.

For more information about hydrocephalus, search these organizations:

Spina Bifida Association website and YouTube channel:

- **Guidelines for the Care of People with Spina Bifida**
- **Hydrocephalus and Shunts**

Hydrocephalus Association (<https://www.hydroassoc.org/>)

- **Teens and Young Adults**

Chapter 6:

Transition Planning to Help You Find and Keep a Job



If you want to live independently, you need to find and keep a job that supports your physical needs. To do so, you need to apply and build on the independent living skills you learned at home and school.

What Would You Like to Do after High School?

Maybe you've always known what you want to do when you are an adult. Most students, however, don't know what they want to do after high school. A good start is to think about what interests you.

- **What kind of work would you feel comfortable and successful doing?**
- **Are you interested in technology, writing, cooking, helping people, arts, or other activities?**
- **Think about what you are good at: Are you good at math? Do you have good writing skills?**
- **Think about your personality: Are you energetic? Outgoing? Do you like to work with others or work alone?**
- **Think about your hobbies: How do you spend your free time?**
- **If you've had vocational training, did the results of the testing truly reflect your interests and abilities?**

Getting a seasonal or summer job can help you see what things you like and dislike at work, and it can help you decide what you want to do in the future (and what skills you need to work on).

To help you decide what kind of job you want after high school, look at things the other way around—research different jobs and then see if they look interesting.

- **When you are out, watch people at work. If it is appropriate, ask them questions about their job.**
- **Talk to friends and family members about the work they do and ask them what they like and don't like about their jobs.**
- **Research job openings online. You can find listings in your local newspaper, you can check your local Center for Independent Living, and you can review job openings and their descriptions on LinkedIn.com and Indeed.com.**
- **Ask your school guidance counselor about local or online jobs or volunteer opportunities.**

Build on Skills You Learned in School

Many of the practical day-to-day skills and habits you already use at home and in school will apply to life after high school and beyond:

- Staying on a schedule and arriving to school, work, job interviews, or medical appointments on time will show that you're reliable.
- Using a planner, to-do list, or reminders on your phone will help you track the work you need to complete or appointments you are expected to keep. Find a system that works for you.
- Having a good work ethic—meaning working hard at something, even when it is boring, complicated, or difficult—will make you a better student and employee.
- Taking care to be well-groomed, clean, and neatly dressed will make a good first impression. (You don't need expensive designer clothes to look good, clean, and neat.) Neither school staff, classmates, nor employers want to be with or hire people who look sloppy and disorganized or who don't smell good.
- Paying attention to good manners—like greeting people when you or they enter a room or online meeting and saying “please” and “thank you”—will help you get along with your classmates and coworkers.
- Having a positive attitude, even when you don't love the tasks you have an obligation to complete, will make your classes or work more enjoyable!

You can build on these skills by taking part in various activities at home, at school, and in your neighborhood:

- Learn how to play an instrument, join the choir, take part in a school athletic team or the school science fair, help with a school play, or join other non-academic activities at school or in your community.
- Practice phone skills—call the doctor’s office with your parents to make appointments.
- Set your alarm to get up in time for school or for other appointments and to remind you when tasks are due.
- Learn how to type on a computer keyboard and how to use basic word processing and spreadsheet software.
- Do as many jobs around the house as possible:

- Do laundry
- Wash dishes
- Help clean rooms in your house, including bathrooms



Chew on This

Many employers consider chewing and popping gum bad manners—especially when it’s chewed with an open mouth.

Do You Have a Resume?

A resume tells a person who might hire you if your skills and experience match their needs. It highlights your strengths and skills related to the job you are applying for.

- Your resume must be typed neatly with correct spelling and accurate information.
- If you get called to an in-person interview, take an extra copy with you for the interviewer.
- You may also use the information on your resume to complete a job application.

Your school guidance counselor can show you examples of resumes for high school students. For more information, check these resources:

- The Pacer Center - Getting and Keeping the First Job (<https://www.pacer.org/transition/resource-library/publications/NPC-41.pdf>)
- Indeed.com - High School Resume Tips and Example (<https://www.indeed.com/career-advice/resumes-cover-letters/high-school-resume-tips>)

Why Volunteer?

- Helps you explore what jobs you'd like to do in the future
- Helps you get started in a career where jobs are scarce
- Looks good on your resume
- Makes you happy because it feels good to help others
- Gives you a chance to practice job skills, like working with other to solve problems

Learn more about why volunteering is good for all at [TheArc.org](https://www.TheArc.org).



Tools to Help You Transition to Life in Your Community after High School

Individualized Education Programs and Section 504 Plans

Individualized Education Programs (IEPs) and Section 504 Plans are tools you may already be using at school. But did you know they can also help you plan for your future? By age 16, your IEP or Section 504 Plan can include a plan to help identify the specific skills you need to transition from school to work.

For example, your IEP/Section 504 transition plan could help you find:

- Strategies to help you learn how to drive a car with hand controls
- Information on using public transportation
- Places to explore job opportunities
- Ways to make plans for college
- Vocational assessments (testing) to predict what kind of job will be successful for you
- Training for a specific job
- Instructional support, such as tutoring or seeking guidance from a learning assistant
- Community experiences, which may include volunteering or a part-time job
- On-the-job training at your work site
- An opportunity to shadow a job that you have an interest in
- College planning resources
- Independent living resources

Did You Know?

You can invite a counselor from your local vocational rehabilitation office to join your IEP/Section 504 meetings. If the counselor determines that you qualify to receive vocational rehabilitation services, you and your assigned counselor will develop an Individual Plan for Employment (IPE) that identifies the services you'll need. Services could include self-determination and self-advocacy training and placement in suitable employment.

Use the IEP and Section 504 Plan meetings to express what supports you'd like to have

If you haven't attended or participated in your IEP, Section 504, and/or transition plan meetings—it's not too late to start! These meetings are about you and your needs. If you don't participate, you won't be able to express your wants, needs, concerns, or questions about your life at school now or about the transition support services you are entitled to receive.

Tell your school officials at this meeting about your needs and goals. For example, if one of your long-term goals is to have a full-time job by the time you graduate from high school, the transition planning team might list these short-term goals to help meet your long-term goals:

- Student will have a vocational assessment to determine interest and strengths.
- Student will spend two hours a day working at school or in the community.
- Student will successfully manage his or her own transportation needs.

What if you have worked with your school and are not satisfied that a reasonable effort has been made to address your transition needs?

You may want to find an advocate or a lawyer to help you. To get help, look up Legal Aid Society online, or look up and call Lawyer Referral and Information Services. Your health professional care team may be able to refer you to other helpful agencies in your community.



Tools to Get Around

Most jobs require that you work from their location at least some of the time. If you don't have your own car or your family cannot take you to work, public transportation is usually your best option. Here are some suggestions to get to know and use your local public transportation system like a pro.

- If you live near public transportation, visit their websites to learn about their cost, possible discounts, methods of payment, and how to travel with a wheelchair or service animal. Check their routes to see where they can take you.



- Team up with a friend or family member who knows the public transportation system well and take a trip to the mall, the library, the zoo, the park—where do you want to go?

o Some cities have buses equipped with wheelchair lifts. Your city may also have specialized buses or vans that go door-to-door. Ask a friend, your doctor, a nurse, or a therapist about your special transportation.

- If your city does not have public transportation or you cannot get to the bus stop or station, search your city’s website for what kind of transportation it offers people with physical disabilities.

- If taking public transportation won’t work for you, talk to your parents or other trusted adults about using taxis or ridesharing companies like Uber and Lyft. Be sure to check their prices, their tipping policies, and whether they are equipped for people who use wheelchairs before you request the ride!

- Learning to drive may be another option for you. There are hand controls that attach to the steering wheel for people who cannot operate foot pedals. Ask around in your community to find out where you can learn how to drive. Think about how you would manage the expense of driving a car. Gasoline, insurance, and repairs can be expensive.



Tools to Help You Manage Your Money

Using money wisely is critical to being able to live independently. Here are some ideas for getting the practice you need:

- Ask your parents, guardian, or school guidance counselor to help you make a budget that shows what you need to buy versus what you want but don't need.
- Ask for instructions and support with budgeting to be included in your IEP, transition plan, or Section 504 Plan.
- Ask your parents if you may have an allowance to help you practice using money wisely.
- Go with your parents to the bank and open a savings and a checking account. When you open your bank accounts, ask the banker to teach you
 - o **how to set up and manage your account online;**
 - o **how to write a check;**
 - o **how often and how much to save; and**
 - o **how to use a credit card, debit card, and ATM card.**

Make sure you save money every month—even if it's just a few dollars. Saving money is one of the most important life skills you can have.

In addition to saving money:

- Learn how to manage your money to cover your expenses and save for your future. If you are no longer in high school, ask for help at your bank. Call and make an appointment with a manager. Tell them that you need help managing your money.
- Learn about paying taxes. The Internal Revenue Service website (www.irs.gov) has all the forms for paying taxes. Ask a parent, older friend, or sibling to help find out if you owe taxes and to help fill out your federal and state returns.



Organizations That Provide Work-Related Tools

State Vocational Rehabilitation Agencies (SVRAs) are programs that help people with disabilities prepare for and find work. If you are old enough to work, this agency can help you. Services include evaluation, counseling, obtaining aids and devices, and job placement. For a state directory of SVRAs, visit <https://rsa.ed.gov/about/states>.

National Council on Independent Living is a network of agencies that provide services to people of all ages who have disabilities, including housing information, independent living skills training, community service information and referral, and peer support. For the location of a Center for Independent Living near you, visit www.ilru.org/projects/cil-net/cil-center-and-association-directory.

Goodwill Industries provides job training to men and women with disabilities who are at least 18 years old. Goodwill Industries offers a range of services, including work evaluation, occupational skills training, supportive employment, live virtual online classes and training, and job placement. Jobs may be at a Goodwill agency or in the community. To learn more, visit www.goodwill.org.

Jewish Vocational Services provides a broad range of vocational services to help people in Michigan with disabilities obtain employment and fit into the community. Services provided include on-site training, job coaching, job placement, work adjustment training, and more. Jewish Vocational Services provides services to the total community.

United Cerebral Palsy provides therapeutic, educational, and support programs to people of all ages who have disabilities. Services at some centers might include social skills training, supported employment, computer skills training, training in using attendant care, and independent living.

Tools That Protect Your Employment Rights

The ADA protects your rights to equal opportunities for jobs and services. It does so by prohibiting many different kinds of discrimination against people with disabilities. Where employment is concerned, the law says that:

- An employer is not allowed to ask you about your disability during an interview or make you take a medical exam. (You do not need to include information about your disability on your resume or job applications.)
- An employer may ask if you can perform specific job functions or activities. For example, can you lift 20-pound items? Are you able to run a cash register?
- An employer must make reasonable accommodations (changes) for your disability. For example, you might need to sit instead of stand to operate the cash register.
- You will want to share your needs with your employer so that reasonable accommodations can be made. For example, you might need an accessible bathroom.



Do you think you've been discriminated against?

The National Disability Rights Network (<https://www.ndrn.org/>) directory can help you find your local disability rights organization. You can also learn about the U.S. Equal Employment Opportunity Commission (EEOC) (<https://www.eeoc.gov/overview>) and find the EEOC field office (<https://www.eeoc.gov/field-office>) in your area.

Should You Continue Learning after High School?

Yes! Many adults have found that a high school education is not enough to find a job that will support them in the future. Education after high school is key to living as independently as possible once you are an adult.

Your parents and school guidance counselor can help you explore your options and include them in your IEP/Section 504 transition plan:

- Vocational education (hands-on training in job skills such as cosmetology, welding, medical assistant, or car repairs)
- Technical education (training programs lasting several months to several years leading to specialized skills such as drafting, computer repair, or commercial photography)
- Junior or community college
- College or university



Will you live at home or on campus?

If you live at home, living expenses will be less. On the other hand, living on campus gives you the experience of being on your own.

Are you ready for work?

Answer these true/false questions to find out.



___ I believe that I am capable of work, and I expect to have a job someday.

___ I am independent with dressing, hygiene, and transfers.

___ I manage my bowel and bladder and stay clean and dry.

___ I can use public transportation or drive a car.

___ I know how to save money and use money to pay for things.

___ I spend time thinking about the kind of work I want to do.

If you answered true to all of these statements, you are doing great! Keep it up—you are on the road to work.

If you answered false to any statement, you will need to make a change. Decide to learn the skills you need to get ready for work! Talk to your parents, school counselor, health care professionals, and/or IEP team for help. You can be successful!

Keep Going...

Continue to practice the skill-building tips and suggestions in this booklet and look up additional resources. The time you invest in yourself now will pay off—and **you are worth it!**



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