

# section

13

Resilience, Transition to Adulthood,  
and Future Success

## resilience

Resilience is the ability to overcome hardship and adversity and to achieve good personal adjustment in spite of difficult circumstances. All children have this capacity. The purpose of this section is to give your family the tools to strengthen your child's resilience and ability to cope with neurofibromatosis.

In spite of your best efforts to manage the impact of your child's learning or behavioral difficulties, he or she may continue to experience daily challenges and setbacks that may persist into adolescence or even adulthood. Keep the following question in mind to help you stay on the path to resilience:

*"In spite of my child's current struggles and setbacks, what can I do to help my child to still feel good about himself or herself?"*

### Protective Factors

Three categories of protective factors encourage the development of resilience:





## relationships

### Caring Relationships

---

A caring relationship provides frequent unconditional affection and lets your child know that he or she is important and matters in this world. Focus on your child's strengths and express empathy before trying to solve his or her problems. Try to validate your child's agenda and schedule quality time to strengthen your relationship.

### High Expectations—Competency

---

Your expectations should be clear and positively stated, and they should be supported by structure at home and with positive discipline strategies. Parents' expectations are founded on the strengths, interests, hopes, and dreams of the youth, but they must also be based on their child's developmental abilities and skills. Use your expectations to communicate belief in your child.

- Are you focusing on how hard your child tries?
- Is your child doing better than before?
- Are you are taking the time to teach new skills?

express empathy

---

# participation

## Opportunities for Participation and Contribution

Give your child an opportunity to contribute at home by speaking his or her language and communicating in a way that he or she can understand.

Here are some tips to help encourage your child to participate successfully:

- Make difficult tasks easier by breaking them down into smaller tasks
- Show tolerance for making mistakes
- Demonstrate appropriate coping strategies
- Permit your child to make daily decisions; for example, about hair or clothes
- Allow a chance for your child to solve his or her problems
- Expect your child to contribute to family chores
- Involve your child in the development of house rules, routines, and priorities
- Allow his or her participation in group activities that require cooperation

Encourage problem solving and involvement in the decision-making process.



## teen development

### Typical Teen Development

---

During adolescence, your child is learning to define his or her own identity and moving from dependence to independence. Hormonal changes can trigger rapid physical development, sexual maturation, and emotional volatility, and your child may be experiencing alterations in sleep patterns and duration. As a teen develops more sophisticated reasoning abilities, he or she can be susceptible to the “pack mentality”—the development of a tribal mentality when one assumes the identity of the clique he or she hangs out with, and think of every member as a friend. The driving force behind the behavior of most teens is to fit in with their peers.

### Challenges Teens With Neurofibromatosis Face

---

Parents who understand the challenges of adolescence will be better prepared to deal with this stage of life. When adolescence is coupled with neurofibromatosis, these challenges are far more difficult.

Teens often seek increased freedom from parental control and need greater involvement in decisions that affect them. They are concerned about peer acceptance, so teens may resist any decision that makes them feel different from their peers. The teenage years are emotionally volatile, so choose your battles wisely and keep in mind that this is a difficult time for your teen.

### Focus on preserving your relationship with your teen by being flexible.

- Increase the focus on your teen’s agenda and values (for example, your teen wants to choose tech school over a 4-year college)
- Provide your teen with more choices and responsibility for his or her own decision making
- Include your teen as a partner in the problem-solving process

## becoming an adult

### Developing Skills to Becoming an Adult

The home environment lays out the blueprint for children who are developing into young adults. Parents are the teachers, teaching their children how to become adults.

#### Consider these questions:

- What kind of teacher do you remember who made a difference in your life?
- What kind of teacher do you want to be for your teen?

As children become teens and young adults, their desire for independence increases, as does the demand for good executive function skills, such as reasoning, prioritizing, planning, organizing, getting started, and managing time. Many teens with neurofibromatosis lack these necessary executive function skills. It is essential that they start early to learn how to set up systems that work and counteract the executive function deficits, as teens who fail to learn these skills will feel overwhelmed and may shut down.



# teen development

## What Your Teen Should Learn



### Healthcare

- Scheduling doctor visits, seeking help as needed, and asking questions regarding his or her health problems



### Education

- Learning to advocate for oneself
- Working toward a career
- Becoming independent



### Life

- Learning how to find a job
- Managing money and independent living
- Developing social skills
- Maintain relationships with friends and family
- Engaging in a romantic relationship

## money management

### Teaching Your Child Money Management Strategies

The development of money management strategies is of high importance as your teen readies himself or herself for success in the adult world. Parents can begin these lessons early with the implementation of an earned allowance plan that teaches a child the value of money and mimics an adult work/payment scenario. Children can earn a set amount based on the chores or tasks they perform, and they can earn bonus cash for extra accomplishments.

As your child becomes a teen, you can help him or her to set up a simple budget and a bank account. You can assist your child in learning about the responsible use of a checking account and possibly even a prepaid credit card with a predetermined amount and usage plan.

*What happens when you discover that your teen filled out a form and has received a \$5,000 credit line for a credit card?*

Create a proactive plan for such a possibility. Tear up all credit card solicitations when they arrive in the mail. Set aside \$5 a week in a special account for your teen's future. If a teen overspends on a credit line, these savings can help to pay for the mistake.





## self-advocacy

### Student, Parent, and School Counselor Roles

A student with a disability must understand and be able to verbalize the nature of his or her disability. It is helpful if the student understands his or her strengths and weaknesses and is aware of how he or she learns best. A student needs to be a self-advocate. A self-advocate is able to speak up in logical, clear, and positive language to communicate with others about his or her needs. Self-advocates can take responsibility for themselves, and they are comfortable describing their disability and needs to others.

*Remember—At the college or employment level, the individual with the disability holds the sole responsibility for self-identification and advocacy.*

Counselors and parents must help the student with disabilities to

- gain self-knowledge
- understand their legal rights and responsibilities
- develop a transition plan for the postsecondary education or employment arena
- understand the college testing and application process



Print this page for your child!

s u c c e s s

## Students' Keys to Success



responsibility



# jobs

## Finding a Job

---

Finding a job or career path of interest can be a difficult task. Begin by encouraging your teen to consider and answer the following questions:

- What are the things I like to do?
- What things do I do well?
- What kind of work environment works best for me?
- What types of jobs are *not* for me?

Once your teen has an idea of what area might be of interest to him or her, begin with a list of potential jobs and employers that may appeal to him or her and would be supported by his or her current skills. Ensure that your teen is prepared to complete a standard job application and write a short resume. Within these pieces be sure that your teen includes his or her accomplishments, awards, and extracurricular activities. Identify potential references and have your teen talk with each of them to receive their permission and current contact information.

Once an interview has been scheduled, try to prepare a list of some standard interview questions for your teen to consider and practice answering. Talk to your teen about proper dress and grooming for an interview. Finally, cheer him or her on throughout the employment process, and celebrate when your teen becomes employed!



Job acquisition is a  
huge accomplishment!

## the road ahead

### Moving Forward

#### What My Teen Should Know

---

You have stood beside your child over the years, teaching and guiding him or her along the way. Be proud of yourself. Have confidence that you have instilled good values in your teen and adequately prepared him or her for the road ahead.

Some thoughts for your teen might include the following reminders:

- Neurofibromatosis is a lifelong disorder
- Learning disabilities and behavior problems can be and are treated successfully
- Medication management is extremely important
- Being a self-advocate is an important goal to work toward
- Managing neurofibromatosis involves many facets, including learning to navigate school, money, and future plans
- Don't hesitate to reach out for help. There are coaches and experts in the field of neurofibromatosis who can help those with the disorder manage their daily life activities



## celebrate success

### Next Steps for Your Family

The material presented within this manual is designed to support you through your challenges as a parent of a child who has neurofibromatosis. It is up to you to decide how to implement and follow what you have learned from this material. Each family, and each child, is different, and each may require a different solution to the challenges he or she faces. What is most important is that you know that you are not alone. There are support groups available that may help you proceed down the road ahead. You can also participate with and receive guidance from the Children's Tumor Foundation (CTF) and Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD).

New information is always becoming available to help us further understand neurofibromatosis and its challenges. Continue your learning over time to give your family the best opportunity as you move ahead. Most important, celebrate your success—the success of your parenting, the success of your family, and the success of your child! You might even consider helping other families who have a child with neurofibromatosis.







activity to share with your child

13



Print this page for your child!

**empower yourself**

As you get older, it's important that you know not only **what** you need to be successful in school and in the future but also **how** to get it. Moxie and Sparx call this skill **self-advocacy!**

In the space below, describe a situation that might require you to request adjustments or changes you need to complete a task. Think about what you need to do to get them. This situation could be related to a class you're in now, or a situation you see in your future, such as finding a job.

**Describe the place or situation:**

.....  
.....  
.....

**What type of accommodations or help would you request?**

.....  
.....  
.....

**Why would you need these accommodations?**

.....  
.....  
.....





Print this page for your child!

**empower yourself**

Whom would you speak with about getting these accommodations?

.....

.....

.....

What should you remember about how you talk to these people? (For example, how you use your body language, tone of voice, word choices, etc)

.....

.....

.....

Remember this term!

**Accommodations** = any adjustments or changes you may need to complete a task.

