



**TRANSITIONING TO
ADULTHOOD: A GUIDE
FOR INDIVIDUALS WITH
NEUROFIBROMATOSIS-1**

children's
HOSPITAL • ST. LOUIS
BJC HealthCare

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INTRODUCTION

Neurofibromatosis Type 1 (NF1) is a common genetic condition that can affect many organs in the body, including the skin, eyes, bones, and nervous system. NF1 should not be confused with Neurofibromatosis Type 2 (NF2), which is a completely separate medical condition that affects people much differently than NF1. Though NF1 is usually diagnosed in children, it is a lifelong medical condition. However, NF1 should not hold you back from accomplishing what you want in life. Most people with NF1 lead full lives, and have loving spouses, happy families, and rewarding jobs.

As a child and adolescent, you may have become used to seeing an NF1 doctor regularly with your parents and family. Hopefully, you have learned a little bit about NF1 and how it can affect you. One of the most important periods in the life of an individual with NF1 is the transition from an adolescent to an independent adult. There are aspects of this process that need to be considered beforehand in order to make this transition as smooth as possible. In this booklet, we have addressed some of the issues that you and your family should discuss before moving on to the next phase of your life as an adult. With the right help and preparation, you can be ready for any challenges you may face in the future.



Medical Support and Healthcare

During the transition to adulthood, you will begin to assume the responsibility for your own healthcare needs. Because different types of medical problems can arise in adults with NF1, it is important that you remain under the care of an NF1 specialist. Typically, adults see their NF1 doctors at least once every 2 years. You should begin to schedule your own appointments and develop a plan for how you will get from your home to the doctor's office and back (for example: driving yourself, getting a ride from a family member or friend, or public transportation).



While your NF1 specialist will check for any serious complications caused by NF1, all of your other healthcare needs will be managed by a "general" doctor. As a child and adolescent, you may normally have gone to a pediatrician for minor illnesses, like stomachaches, colds, or vaccinations. You and your family may have become very comfortable with your pediatrician over the years, but most pediatricians stop seeing patients after they turn 21 years of age. Well before you reach this age, you should start thinking about transitioning your overall healthcare to an internal medicine doctor (internist) or a family medicine doctor. Switching from your pediatrician does not have to happen immediately. We recommend a slow transfer, which involves meeting your new adult doctor while still under your pediatrician's care. Often times, your pediatrician will recommend an internist or family medicine doctor that they know and trust, which should make you feel more comfortable.

When you visit these general practice doctors, they will typically perform a thorough physical examination and sometimes order additional tests (e.g., blood tests). Even though these doctors will have access to your medical history, it is important to let them know you have NF1 and who your NF1 specialist is. Seamless communication between your NF1 specialist and your internist or family medicine doctor is critical for your overall well-being.

Health Insurance

Maintaining active health insurance is extremely important and provides you with the ability to see the doctors you need to stay healthy. Since September 2010, under The Affordable Care Act, you can remain under your parent's health insurance plan(s) until 26 years of age. However, once you get married, you can no longer use your parent's insurance. Because states may have different rules and regulations, you should check this information for your specific state using the resources at the end of this booklet.

If you plan on attending college, many colleges offer health services for students and affordable insurance plans. The health center at college should never substitute for appointments with your NF1 specialist, but you can go there for minor medical problems while in school.

When you get your first job, you should check with your employer to learn more about the healthcare insurance plans they offer for their employees. It is important to understand the benefits you will receive when deciding where to work and what they require from you in order to keep your healthcare insurance. If you plan on starting a family during this time, you must also make sure what benefits from your employer's healthcare insurance plan can be extended to your spouse and children.

If you encounter any problems trying to obtain healthcare insurance, you can speak with your NF1 specialist to help resolve these issues.

Life after High School

Graduating from high school is one of the biggest accomplishments in your life. What you decide to do after high school depends on what you envision for your life and what career would make you most happy. Many people with NF1 decide to go to college, while others directly enter the workforce. The direction you choose depends on your preferences and aspirations.



Higher Education – Going to College

Just like your classmates, an important part of the transition to adulthood begins with college. You should spend a good deal of time during high school discussing college options with your guidance counselor. It is well known that individuals with NF1 often have difficulties with reading, math, and focusing attention during tests or assignments. Many student with NF1 receive special education or extra help for these learning issues. It is important that you discuss these issues with your guidance counselor, since accommodations can be made when taking the SATs and other standardized college entrance examinations.

There are many factors you should consider when deciding on what type of college to attend. It is important that you give yourself enough time in advance to explore all of these programs and determine what best suits your needs. For example, there are large colleges and universities, community colleges, and technical institutes. Many of these schools offer 4-year or 2-year programs. You can even begin with a 2-year program, and once you feel comfortable with the college environment and system, transfer to a 4-year institution. If you have any physical disabilities, it is important to visit the campus and classrooms to make sure they are accessible and provide a comfortable place for you to learn and get around.

Once in the college setting, you may be wondering whether to tell your classmates or teachers about your NF1. In the end, there is no right or wrong answer. This is really a personal decision. If you feel comfortable telling your friends or teachers about NF1, it is a great opportunity for you to educate them. On the other hand, many people may never realize you have NF1, and therefore you may feel that it's not important to bring it up.

Since some adults with NF1 have similar struggles with learning as children with NF1, you may wish to find out more about special accommodations offered by colleges and universities. Most colleges have learning centers or programs geared specifically for individuals with academic or attention problems. This information can usually be found through their website or through the school's admissions office. The services provided are specific to your needs, and may include tutors, note-takers, taped lectures and textbooks, alternate test locations, oral exams, and extended time for tests and assignments. Some schools also offer workshops on study skills, time management, and career services. A school may not charge students with learning problems more for participating in its programs or activities than it charges students who do not have these problems. You can find links to many schools that describe their services using the resources at the end of this booklet.

You should request academic adjustment from your college or university as early as possible since some academic adjustments may take more time to provide than others. You should follow your school's procedures to ensure that they have enough time to review your request and provide the appropriate adjustments.

Most importantly, have fun! College is an exciting time in your life. The information you learn during college will prepare you for a rewarding career.

Employment

Many individuals with NF1 decide that college isn't the best option for them, and opt to directly enter the workforce. Before you graduate from high school, you should start thinking about career choices. What are you good at? Where type of environment would you like to work in? What types of people would you like to work with? Many people like to gradually increase their involvement with a particular job until they reach a schedule they are comfortable with. This could mean starting with a part



time summer job or internship, where you only work a few hours a day. These brief exposures provide a sense of the job responsibilities, and once you feel you can manage these short hours, you may decide to increase the number of days or hours per day you work.

Vocational training is an opportunity offered by many school for you to learn a trade while still in school. You should discuss this option with your guidance counselor. Individuals with NF1 work in all types of fields, including education, culinary arts, healthcare, construction, and business.



Deciding whether to tell your employer about your NF1 is a personal decision. If you can perform your job without any problems and don't feel the need to tell people about your NF1, then you may decide not to disclose this medical information. However, if you need extra time or attention to complete your duties because of your NF1, you may wish to tell your employer. In addition, you want to make

sure that your employer provides a safe and comfortable environment for you to work in.

Importantly, you may need to miss certain days at work due to doctor visits, and, for this reason, you may decide to let your employer know about your NF1. As is the case with teachers and deans, your employer should keep your personal medical information strictly confidential and not inform anybody else about your health without your permission.

Social Life and Acceptance

During the transition to adulthood, many individuals may become more self-conscious about their appearance. Since neurofibromas tend to appear more frequently during adulthood, some people may be embarrassed by their physical appearance. It is always important to remember that NF1 is not your identity, and never will be. You define who you are and who you will become. The interactions with those who care about you will help you with these issues. If you feel that there are aspects of NF1 that are taking more of a toll on your life than you can handle,



be sure to discuss these concerns with your NF1 specialist. Though there is no magic pill to make NF1 go away, there are new medicines and procedures that might be able to minimize some of the features of NF1.

Starting a family

As you move into adulthood, marriage and starting a family may become a priority. You will need to discuss the decision to have children with your spouse, and ultimately decide what is best for you and your family. What one couple decides may not be the best decision for another couple or family. We know that when someone with NF1 has children, each child will have a 50-50 chance of having NF1. Speaking with a genetic counselor before deciding to have children is recommended to help you better understand the chances of having a child born with NF1, the spectrum of medical concerns associated with NF1, genetic testing, as well as alternatives such as adoption and artificial insemination. Genetic counselors help by providing additional information, but will not tell you and your family what you should do.

If you decide to have children, it is very important that an NF1 specialist examines your child during the first few months of life. Remember that NF1 can present very differently even within the same family. In this regard, just because you never had any major medical problems from your NF1 does not mean that your children may not be more severely affected.



Pregnancy (for Women with NF1)

It is important to let your NF1 doctor know if you are or planning on becoming pregnant. You should also make sure that your obstetrician (pregnancy doctor) knows that you have NF1. Women with NF1 may have special problems with pregnancy and delivery, which is due to the higher rate of Caesarian section (C-section) than women without NF1; but women with NF1 usually have regular deliveries that do not require a C-sections. In addition, neurofibromas can increase in number and size during pregnancy. This does not mean that your NF1 is getting worse, but is a result of the new hormones your body is experiencing because of the pregnancy.

Conclusion

Transitioning to adulthood is a significant time in your life. You will become more independent, go to college or get a job, begin thinking about your future, and possibly start a family. Working with your friends and family, you can adequately prepare in advance for any issues that may possibly arise. Most importantly, NF1 should never stop you from accomplishing any of your goals, during this exciting time in your life.

Other Resources

Washington University Neurofibromatosis Center

<https://nfcenter.wustl.edu>

St. Louis Children's Hospital

StLouisChildrens.org

Neurofibromatosis, Inc

Email: admin@nfnetwork.org; Internet: www.nfnetwork.org

Children's Tumor Foundation

Internet: www.ctf.org

National Conference for State Legislatures

Provides state-by-state information and resources regarding health insurance laws for individuals under their parents health plan.
<http://www.ncsl.org/default.aspx?tabid=14497>

The Individuals with Disabilities Education Act (IDEA)

Discusses the law ensuring educational services to individuals with disabilities.
<http://idea.ed.gov/>

The National Center on Secondary Education and Transition (NCSET)

Contains information on technical assistance related to secondary education and transition for youth with disabilities.
<http://www.ncset.org/default.asp>

Think College!

Provides resources, strategies, and training events for students with intellectual disabilities planning for college.
<http://www.thinkcollege.net/>

Colleges with Programs for Learning Disabled Students

Contains links to many colleges and universities that provide learning disabilities programs and contact information for staff that can answer other questions.
http://www.college-scholarships.com/learning_disabilities.htm

The National Council on Independent Living

Provides information and resources on employment, housing, transportation, and civil rights for individuals with disabilities.
<http://www.ncil.org/>



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<http://nfcenter.wustl.edu>

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