



NF1

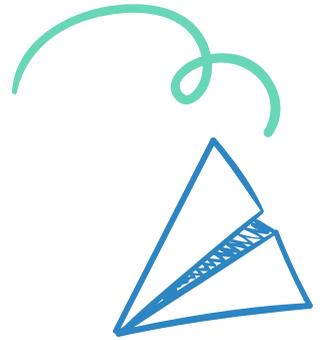
A Guide for Educators

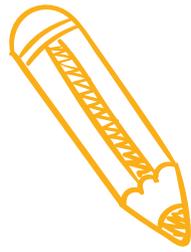


CHILDREN'S
TUMOR
FOUNDATION
ENDING NF
THROUGH RESEARCH

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INTRODUCTION

A diagnosis of neurofibromatosis type 1 (NF1) in a child raises many important issues for care, whether in the doctor's office, at home, or in school. Children with NF1 often enjoy good health and academic success, but many need accommodations—especially in a school environment. Proper attention to their needs can dramatically increase the chances that children with NF1 will do well, both in school and in later life.

Classroom and special education teachers, school psychologists and counselors, occupational therapists, speech pathologists, and school nurses can make a significant difference in the lives of children with NF1 by gaining knowledge about the condition, and providing early intervention when and if needed.

We thank you for your concern and interest in reading this brochure. This is a time of exciting progress in our understanding of NF1, and we welcome you to the care team.





ABOUT NF1

Neurofibromatosis type 1, or NF1, is a genetic condition that causes tumors to grow on nerves anywhere in the body. It is a lifelong condition that affects all populations equally, regardless of gender, race, or ethnicity. People who have NF1 can lead full lives, but they often require specialized medical care by a team of healthcare providers familiar with the condition.

NF1 occurs in about 1 in every 2,500 births. Even though individuals have NF1 when they are born, it may not be diagnosed right away because some manifestations (signs or features) only appear over time. This brochure is meant as a guide for teachers and educators who may have children or young adults in their programs living with the condition.

The features of NF1 vary greatly from one person to the next. Some children are quite severely affected, while most have considerably milder cases. Although many children with NF1 generally enjoy good health, the condition can lead to blindness, disfigurement, bone abnormalities, learning disabilities, disabling pain, and cancer.

Research indicates that approximately 50-60% of all children with NF1 have some form of learning challenges. Many will require individualized services to address learning difficulties, speech problems, motor deficits, or psychosocial problems. There is also a higher incidence of attention-deficit/hyperactivity disorder (ADHD) or autism spectrum disorder (ASD) among children with NF1 compared to the general population. In addition to the potential for cognitive difficulties, some children may have visible manifestations of NF1 that draw attention and cause added stress for them in social situations.

WHAT CAUSES NF1?

NF1 is caused by a change, or pathogenic variant (formerly called a mutation), in the structure of a gene. Because of this, a child can inherit NF1 from a parent who has it. About half of the time, however, a child with NF1 is the only person in the family who has the condition. In such instances, the NF1 gene change occurred spontaneously—a random error in the process of copying genetic information to produce sperm or egg cells.



NF1 is not the consequence of drug, alcohol, or X-ray exposure, or any other factor under the control of the child's parents. NF1 is not contagious.

DIAGNOSING NF1

NF1 is generally diagnosed by a geneticist, pediatric neurologist, or a dermatologist using defined diagnostic criteria. However, school nurses and teachers can play an important role in identifying children who may have NF1 and who should be referred to a physician knowledgeable in NF1 for medical evaluation and assessment.

A diagnosis of NF1 is often made by the presence of six or more pigmented spots on the skin (called café-au-lait spots), in combination with other hallmark features of the condition. Genetic testing is available to confirm most cases of asymptomatic NF1 in children (where there are no visible or clinical features).

A separate brochure called **Diagnosed with NF1** is available from the Children's Tumor Foundation at ctf.org/education. It provides more specific information on the diagnosis and management of NF1.



MEDICAL COMPLICATIONS OF NF1

Generally, it is the job of medical professionals, not school personnel, to monitor the health of children with NF1. However, it is also helpful for educators to be aware of some of the potential complications and manifestations of NF1 that can affect children.

Tumors: Because NF1 is associated with tumor formation, one of the most feared complications is cancer. Fortunately, the most common tumors associated with NF1 (called neurofibromas) are not typically malignant. They may, however, require surgery to allay the chance that serious complications could develop. It is important to note that any sudden growth or persistent pain in a neurofibroma can be a sign of malignancy onset, and should be brought to the attention of a medical specialist.

Some children with NF1 develop brain tumors. The most common of these are optic gliomas, involving the optic nerve which controls vision. Typically, these are asymptomatic and do not require treatment, although they can cause problems with vision or stimulate the early onset of puberty. In such cases, effective treatments are available. Other types of brain tumors are rare in children with NF1, and may be preceded by headaches, seizures, or changes in behavior. Any or all of these should be medically evaluated as soon as possible after onset. Most such changes are not indications of a brain tumor, but medical evaluation is important.

Migraines: Some children with NF1 have a migraine syndrome that can include a headache, abdominal pain, nausea, vomiting, malaise, fatigue, or dizziness. The headache may be a minor feature, or may not be present at all. These children may miss school or be sent to the school nurse. The good news is that children with NF1 often respond to appropriate medications for prevention



and treatment of migraines. Only rarely are these findings concerning for more serious complications of NF1.

Scoliosis: Children with NF1 are at higher-than-average risk for scoliosis (abnormal curvature of the spine) which can appear at a much younger age than is typical in the general population. This can be detected by regular screening, but early management is critical to preventing serious complications.

Bone defects: Abnormal bone development may occur in some individuals with NF1. Most NF1 bone defects will be evident at birth or shortly thereafter. Some, such as curvature of the spine (scoliosis), can appear later. They can occur in almost any bone, but are seen most often in the skull and limbs.

High blood pressure: Children with NF1 are also at a higher-than-average risk for high blood pressure, and again, this can appear at a much younger age than in the general population. This can be detected by regular screening and appropriately managed.

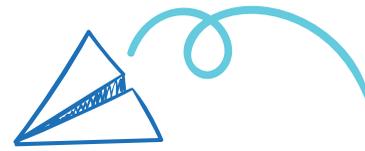
Speech and motor deficits: These are often associated with NF1. Children exhibiting these problems tend to benefit greatly from early intervention through speech and occupational therapy.



PHYSICAL ACTIVITIES FOR CHILDREN WITH NF1

In general, children with NF1 are not unusually fragile and do not require special protection. They are capable of participation in a full range of normal activities. The only exception is for those who have specific complications (for example, those relating to bone defects, scoliosis, or tumors) that may place them at risk for injury. In these cases, the child's physician will point out any restrictions on physical activity.





COGNITIVE & BEHAVIORAL CONSEQUENCES OF NF1

Ensuring early recognition of cognitive or behavioral problems in children with NF1 is a critical piece of a family's partnership with school personnel. It is important to remember that at least half of all children with NF1 have some degree of cognitive or behavioral difficulties.

The possibility of such problems should be kept in mind for any child with NF1. Many physicians suggest that all children with NF1 be formally evaluated for cognitive function—either through diagnostic testing in the schools or a neuropsychological examination by a medical specialist.

It is believed that cognitive and behavioral problems may be caused by changes in the structure and/or function of the brain due to NF1. No specific profile of cognitive or behavioral impairment seems to be unique to NF1. Rather, problems overlap with those seen in the general population—and children with NF1 respond to the same interventions that are used for children with cognitive or behavioral impairment who do not have NF1.

However, it is equally critical to recognize that roughly half of all children with NF1 have no cognitive or behavioral complications. There can be a tendency toward “over-diagnosing” or “over-analyzing” the condition and assuming that such problems will be present in a child with NF1. For this and many other reasons, it is important for educators and parents to work together in evaluating whether a problem exists.

INTELLIGENCE & NF1

As in the general population, intelligence in children with NF1 spans the entire range, from below average to above average. Studies have shown a tendency for intellectual functioning, often measured by IQ scores, to be shifted slightly lower in NF1, but still generally falling in the average range. There does not seem to be a consistent discrepancy between verbal and performance IQ in NF1. Severe problems (classifiable as intellectual disability) are rare and these are generally evident in the first few years of life.





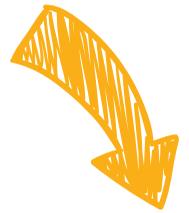
NF1-ASSOCIATED LEARNING DISABILITIES

A learning disability is defined as a problem with a specific cognitive function that is necessary for learning in individuals with average, or even above-average intelligence. As in the general population, there is a wide range in the character and severity of learning disabilities that can be observed in children with NF1.

The learning disabilities seen in NF1 can include dysfunction in visual or auditory perception (the ability to interpret sights and sounds); executive function; information integration (such as sequencing, abstraction, or organization); memory; language; gross motor, fine motor, or oral motor skills (causing clumsiness, poor handwriting, or poor articulation); and social skills or behavior (including misperception of social cues, attention deficit, impulsivity, or hyperactivity). They may present problems in reading, spelling, math, spatial ability, neatness, test taking, speech, ability to make friends, or many other functions.

Children with NF1-associated learning disabilities can benefit greatly from evaluating areas of strength and weakness, and from an Individualized Education Program (IEP) or a 504 Plan tailored to the unique needs of the child. With early and appropriate intervention, these children can succeed in school.

A separate brochure, **Learning With NF1**, is available from the Children's Tumor Foundation at ctf.org/education. The brochure outlines specific learning challenges and practical suggestions for parents and teachers that may be helpful.



BEHAVIORAL CHALLENGES

Behavioral challenges associated with NF1 may include attention deficit/hyperactivity disorder (ADHD), as occurs in the general population. Autism spectrum disorder (ASD) is also more prevalent in individuals with NF1 than in the general population. Although these challenges and differences are a result of this complex genetic condition, children with NF1 who have behavioral problems respond to the same interventions as any child: individualized attention, behavioral modification, and, in some cases, medication. Medication should never be used as a sole approach, but it can be helpful to some children with NF1.

PSYCHOSOCIAL CONCERNS

Children with learning disorders, attention problems, and other disabilities often also have challenges with peer relationships and may find themselves bullied by fellow students. The rare disfiguring complications of NF1 in childhood are often subject to questions or teasing from classmates, requiring a high level of sensitivity to both the child with NF1 and the other students. This behavior often is a result of ignorance among their peer group, and can be counteracted by providing accurate, age-appropriate information.

Children with NF1 often suffer from social isolation, poor self-esteem, anxiety, or depression. They may also have difficulty perceiving and understanding social cues, which may interfere with their ability to make or maintain friendships. For those coping with the combined burden of medical, learning, and social issues associated with NF1, the typical school day can be psychologically exhausting.

MAINSTREAM CLASSES OR SPECIAL EDUCATION?

Many children with NF1 benefit from special education services. If learning disabilities are present, there is no reason to wait to see if children will “outgrow” their deficits. Early intervention usually is available through the public school system as early as age three (from birth in some school districts) and should be sought out as early as possible (see the “Finding Help” section).





Children with learning disabilities resulting from NF1 may learn academic skills at a slower rate than their peers; however research informs us that many will, in time, learn the necessary materials at their own pace. Educators and parents should maintain high expectations for the child, but not demand mastery to the point of frustration. Children enrolled in special education classrooms should be evaluated regularly to assess whether special services continue to be needed, or if the child is increasingly capable of succeeding in mainstream education classes.

FINDING HELP

Some children with NF1 may not meet eligibility criteria for receiving special services based solely on evaluation within the school system. However, they are often eligible for special education under the category of “Other Health Impairment” as verified by a physician. Speech and occupational therapy may be provided as “Related Services” if needed. Assistive technology services, such as access to laptop computers if handwriting is a problem, are also helpful for many children.

COMMUNICATION AMONG FAMILIES & EDUCATORS

Because of the variability of features in NF1, some children are more obviously affected by the condition whereas others are not. It is important for educators to discuss with a child’s parents what the child knows about his or her condition. While there are no studies to help us determine the best age to share a child’s diagnosis, many experts believe that sharing the news early in a matter-of-fact way is a wise approach.

Parents often have mixed feelings about sharing their child’s diagnosis of NF1 with school personnel. Some parents fear that a child known to have NF1 will be assumed to have medical problems or learning disabilities, even if he or she does not. They worry that an assumption of learning disabilities may create a “self-fulfilling prophecy” that can lower a teacher’s expectations of the child—and, in turn, lower a child’s self-esteem and performance. For anyone involved with a child who has NF1, knowledge typically translates to better care.

The Children’s Tumor Foundation **NF Parent Guidebook** is a 160-page resource for families to help educate and offer strategies for learning, attention, social, and behavioral support. This is one of many CTF resources for parents and children that can be found at no cost at ctf.org/education.





Thank you for taking the time to learn about NF1.

Founded in 1978, the Children's Tumor Foundation (CTF) is a highly recognized global nonprofit 501(c)(3) organization dedicated to finding treatments for NF.

Our Mission:

Drive research, expand knowledge, and advance care for the NF community.

Our Vision:

End NF.

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To become involved and learn about local Foundation activities in your area, please visit our website or contact us at the email address or number below.

CHILDREN'S TUMOR FOUNDATION

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@childrenstumor #EndNF

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