

A School Guide for Students with Neurofibromatosis

What is Neurofibromatosis (NF)?

Neurofibromatosis type-1 (NF-1) is an inherited (genetic) condition that can lead to abnormalities that most commonly affect the central nervous system and skin. There is much variability in the symptoms and severity of symptoms among children with NF-1. Symptoms of NF-1 generally are often apparent in early childhood and can sometimes include learning problems. Children with NF-1 can enjoy good health and achieve academic success. When children with NF-1 have special needs, the chances that they will do well will increase if given the proper attention. Finally, children with NF-1 can occasionally develop tumors. The most common types of tumors among children with NF-1 are low-grade brain tumors and often benign nerve tumors.

The following are physical characteristics associated with NF:

- light brown (café-au-lait) spots on skin
- pea-sized bumps (neurofibromas) on the skin
- Tumor on the optic nerve (optic glioma) that in some cases interferes with vision
- Spots on the iris of the eye (Lisch nodules)
- Bone defects such as a bowed leg, curvature of the spine or thinning of the shinbone
- Larger, benign tumors associated with the nerves (plexiforms)

Medical Services Received

Patients have routine visits with NF specialists (Neurologist, Neuro-Oncologist, Genetics counselor, Nursing Care Coordinator), an evaluation by a Neuropsychologist (for possible problems with learning and behavior), and an Ophthalmology Evaluation (vision). Treatment can include: hormone injections, radiation, or chemotherapy (in those cases in which a brain tumor requires treatment).

How Does NF Affect School Performance?

It is estimated that about half of children with Neurofibromatosis have some degree of difficulties in the school setting. On the other hand, about half of children with NF-1 will do well in school. We recommend that the possibility of such symptoms and school problems should be kept in mind for ANY child with NF-

- Learning disabilities or low academic achievement are common
- Difficulties with written expression and math
- Visual-motor difficulties: seen with fluency and efficiency of writing, copying and drawing skills
- Language dysfunction (weak verbal memory, verbal reasoning, understanding of word meanings, and interpretation of language; poor attention/ listening to verbal information, distracted in groups or for long periods of time)
- Visual-Spatial difficulties (interpreting, organizing and working with spatial information such as maps, diagrams, music and math; difficulty planning and organizing written material on a page)
- Visual Perceptual disabilities (reverse or rotate letters; misjudge distance, depth or position; overwhelmed by crowded worksheets; focusing on specific item instead of the rest of the background – unable to track left to right, might put math answer under the wrong problem)
- Emotional implications such as: low self esteem due to appearance changes; internalizing feelings; externalizing feelings verbally and physically; anxiety; depression; fear; inflexibility
- Lack of motivation due to misinterpretation of symptoms (i.e. child's fatigue mistaken for non-compliance; visual perceptual problems mistaken as being "clumsy") – overtime, child will eventually "give up."
- Similar symptoms related to ADHD are sometimes evident: Difficulty focusing/ short attention span; easily distracted; hyperactivity/ restlessness; impulsiveness
- Physical complications such as: dizziness; fatigue; stomachaches
- Possible problems with eyesight, hearing, and/or speech
- Possible fine motor and gross motor impairments
- Frequent absences due to illness

How can School assist students with NF?

Children with NF and Learning disabilities respond to the same interventions as any child with LD.

Academic

- Start academic interventions right away under one of two laws: IDEA (Other Health Impairment) or Section 504
- Provide assessment to determine specific academic needs and provide appropriate accommodations and modifications necessary (including speech, OT, PT evals)
- Providing an educational program tailored to the needs of the child.
- If needed, provide a moderate workload that emphasizes quality vs. quantity.
- Provide extra time for class work, homework, quizzes, and tests.
- To assist with fine motor delays, provide the student with a computer for note taking and assignments. Provide numerous handwriting opportunities and assign shorter tasks, focusing on quality of handwriting.
- Provide the student with an organizational checklist for routine activities, materials needed, and steps to follow, in order to assist with organization.
- To assist with visual or auditory memory, provide the student with more than one exposure to visual and/or auditory information prior to requiring student to remember it.
- To assist with visual perception difficulties, reduce visual stimuli on papers or books by covering the page except the activity on which the student is working.
- To assist with limited memory, use multiple modalities (auditory, visual, tactile) when presenting information. Also record information on tape and provide activities that practice recall skills.
- To assist with reading comprehension, teach the student to use context clues to identify the meanings of words and phrases. Also pre-record material, and highlight important points before reading.
- Review daily those abstract concepts which have been previously introduced (such as math skills). Introduce the new concepts only after the student has a mastery of those previously presented.

Social/Emotional

- Provide frequent counseling or guidance opportunities to address social and emotional affects of medical condition.
- Reduce the emphasis on competition. Competitive activities may cause undue stress, then causing the student to hurry and make mistakes. The repetitive failure may cause the student to avoid situations, assignments, or responsibilities.
- Provide the student with various opportunities to achieve academic and social success, making adjustments, if necessary.

Behavior

- Provide behavior plan for patient to address any potential ADHD characteristics or behavioral concerns in the classroom.

Physical

- School Nurse and staff become educated on NF and it's implications on school.
- Provide frequent access to school nurse, if necessary.
- Provide a shortened school day or rest period, if needed, due to fatigue and/or headaches.
- Provide a computer for note-taking and other assistive technology devices if handwriting difficulties are apparent and assessed.
- Provide Vision and Auditory impairment evaluations and provide the services necessary to address potential needs.

In the years following a child's NF diagnosis, it is important to make sure that the parent/guardian and school are communicating well. Frequent parent-teacher conferences can be helpful to assess any changes in learning the child may experience as a result of their condition and/or treatment. When parents and schools know what learning problems may occur over time, they can better anticipate the needs of the child.

For more information:

Please contact

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Resources

Neurofibromatosis Type One: A Guide for Educators; by Bruce R. Korf, M.D, Ph.D (Children's Tumor Foundation)

Achieving In Despite of...A Booklet on Learning Disabilities by Pamela Maniet Bellermand and Constance Veaco Dilts, Ph.D.

Guide to the Neurofibromatosis Clinic - Children's Medical Center of Dallas

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