

students with neurofibromatosis

What is neurofibromatosis (NF-1)?

Neurofibromatosis type 1 (NF-1) is a genetic condition that can cause changes in the central nervous system and skin. Symptoms vary widely among children, and severity can range from mild to severe. Signs of NF-1 often appear in early childhood and may include learning challenges.

Many children with NF-1 enjoy good health and succeed academically. When special needs are present, early support and attention can help students thrive. Some children with NF-1 may develop tumors, most commonly low-grade brain tumors or benign nerve tumors.

Common Physical Characteristics of NF-1

- Light brown skin spots (café-au-lait marks)
- Small skin bumps (neurofibromas)
- Tumors on the optic nerve (optic gliomas), which may affect vision
- Spots on the iris of the eye (Lisch nodules)
- Bone issues such as bowed legs, curved spine, or thinning of the shinbone
- Larger benign nerve tumors (plexiform neurofibromas)

Treatment

Children with NF-1 may receive care from:

- Neurologists and neuro-oncologists
- Genetic counselors
- Nursing care coordinators
- Neuropsychologists (for learning and behavior evaluations)
- Ophthalmologists (for vision assessments)

Treatment may include hormone therapy, radiation, or chemotherapy if a brain tumor is present.

How can neurofibromatosis affect a student at school?

About half of children with NF-1 experience learning difficulties. The other half perform well in school. The most common school-related challenges for students with neurofibromatosis include:

- **Academic:** frequent absences, learning disabilities or low academic achievement, difficulty with writing and math, visual-motor challenges, language difficulties, visual spatial challenges, visual-perceptual issues, ADHD like symptoms
- **Social/Emotional:** low self-esteem, anxiety, depression, inflexibility
- **Physical:** fatigue mistaken for non-compliance, clumsiness due to perceptual issues, dizziness, fatigue, stomachaches, difficulties with fine motor skills, possible vision, hearing or speech issues

How can schools support students with neurofibromatosis?

Academic

- Start academic interventions under **Section 504** or **IDEA** (Other Health Impairment).
- Conduct **evaluations** for speech, OT/PT, vision/hearing, assistive technology, as needed.
- Assign a **manageable workload** focused on **quality over quantity**.
- Allow **extra time** for assignments, projects, quizzes, and tests.
- Provide **assistive technology** (computer, tablet, word processor).
- Use **organizational tools** such as checklists, planners, and visual schedules.
- Use **multi-sensory teaching methods** (visual, auditory, tactile) and repetition.
- Record lessons and offer **memory-building** activities.
- Review previously introduced **abstract concepts** daily before introducing new ones.
- Offer **handwriting** practice with shorter assignments.
- Reduce **visual distractions** on worksheets and books.
- Use spelling rules and encourage **verbal explanations** of spelling choices.

Social and Emotional

- Provide **counseling or emotional** support as needed.
- Limit **competitive activities** to reduce stress and prevent discouragement.
- Create opportunities for academic and social success and highlight the student's strengths to **build confidence**.

Physical

- Provide **staff training** and share relevant information about the condition.
- Offer **unrestricted clinic/nurse passes**.
- Permit **rest breaks** or shortened school days as needed.
- Maintain **regular communication** among the student, family, school staff, and medical team.

More Resources

- **Children's Health - Pediatric neurofibromatosis (NF)**
childrens.com/specialties-services/conditions/neurofibromatosis
- **Children's Tumor Foundation - Guide for Educators**
ctf.org

SCHOOL SERVICES

For more information, visit childrens.com/school-services

