

NEUROFIBROMATOSIS

Background

Neurofibromatosis (NF) is a genetic neurological disorder affecting the brain, spinal cord, nerves and skin. Genetic mutations cause the body to produce small benign growths, called neurofibromas that can grow around nerves and on the skin. Sometimes a benign tumor can grow inside the body, pressing on vital organs and affecting function. NF may lead to developmental abnormalities and/or increased risk of learning disabilities. Although neurofibromatosis is not a cancer, some forms of NF can be associated with certain malignancies. Neurofibromatosis has been classified into three distinct types: NF1, NF2 and schwannomatosis.

NF Type 1 (NF1) is the most common form and usually diagnosed in childhood. Signs of NF1, such as patches on the skin that are darker than the surrounding area called café- au-lait spots, can be present at birth and grow in number. Occasionally, tumors may develop in the brain, spinal cord, or optic nerve. Signs and symptoms of NF1 include:

- Skin spots
- High blood pressure
- Skeletal abnormalities like short stature and scoliosis
- Changes in vision or vision loss

NF Type 2 (NF2) is less common. Symptoms of NF2 usually begin in adolescence or adulthood. The most common tumors associated with NF2 may grow along the auditory nerve causing changes in hearing loss, ringing in ears, and poor balance. NF2 can also cause abnormalities of the eye and increased tumor growth lining the brain and spinal cord.

Like features of NF2, schwannomatosis is a disorder characterized by uncontrollable growth of specialized cells that normally form an insulating layer around the nerves. These tumors, called schwannomas, cause chronic pain and debilitating pain and present during early adulthood.



Top Takeaways for School Considerations

Neurofibromatosis (NF) is a group of conditions known as neurocutaneous disorders that affect the skin and the nervous system, causing the growth of tumors on and under the skin. NF Type 1 (NF1) is the most common in children.

Physical complications include fatigue, dizziness, clumsiness and stomachache. The growth of tumors can also cause gross and fine motor impairment.

Most children with NF1 will have some degree of learning disability affecting memory, attention and processing.

Visual-motor, visual-spatial and visual-perception impairment may require advanced planning.

The student may experience difficulties with organization and impulse control.



Considerations for the Individualized Healthcare Plan (IHP)

- Nursing diagnosis of risk for injury, impaired thought process and pain (acute/chronic)
- Current diagnosed health condition including date of diagnosis, progress of disease process and other chronic health conditions
- Current medication and treatment orders (consider schedule, equipment needs and side effects)
- Activity, positioning, transferring (consider precautions and/or restrictions)
- Consider emergency care plan(s) (ECP) and emergency evacuation plan(s) (EEP) as related to medical needs in the school setting, and staff education/training, as appropriate

Discussion Starters for Educational Team

1. Has the school staff been trained to implement the student-specific emergency plan?
2. Would the student benefit from evaluations or assessments in any of the following areas: physical therapy, occupational therapy, speech and language therapy, assistive technology, adapted physical education, functional behavior, psychology, hearing and vision?
3. Would the student benefit from additional academic support and/or modified education (e.g., copies of notes, extra time, reduced workload, simplified instructions, alternative formats for presentation of material, 504/IEP)?
4. Can strategies be implemented to assist the student with executive function (e.g., plan, prompts, organizers, agendas)?
5. Does the student need support with gross or fine motor skills in the classroom?

Resources

Kennedy Krieger Institute: Neurology and Neurogenetics Clinics
[kennedykrieger.org](https://www.kennedykrieger.org)

Children's Tumor Foundation
<https://www.ctf.org/>

Neurofibromatosis Network: Understanding Neurofibromatosis
<https://nfnetwork.org/data/uploads/nf1-educational-materials/understanding-nf-3rd-edition.pdf>



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