

KEY ISSUES AND PLAYERS

Children with NF often have

poor handwriting and fine motor skills, and are often clumsy in gross motor skills. Early intervention by *occupational therapists, physical therapists, and adaptive P.E. teachers* can make a world of difference in how the child progresses motorically and socially.



Both verbal and non-verbal learning disabilities

are reported in children with NF. Thorough assessment coupled with diagnostic teaching by *classroom and special education teachers* is necessary in order to ensure that affected children make adequate academic progress.



Dysarthria (poor articulation), language delays & oral motor deficits

are common in children with NF.

Speech pathologists play an essential role in the necessary remediation process.



Children with NF often suffer from

low self-esteem, poor social skills, isolation, anxiety and depression. *School psychologists and counselors* must be aware of the emotional well-being of affected children.



Scoliosis (abnormal curvature of the spine), migraine headaches, high blood pressure, tumors & early or delayed puberty

are potential manifestations of NF that need to be monitored. *School nurses* are essential caregivers for children with NF.

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Be alert to any behavioral problems that arise.

A small number of children with NF-1 exhibit difficult, sometimes unusual, behaviors. These may include significant problems with attention and hyperactivity, social skills, vocal and motor tics, and oppositional behaviors. It is important to recognize that these are a function of the NF-1, which is a neurological disorder. These children require intervention by behavioral psychologists who understand this complicated paradigm and can provide support to families and teachers.

Common modifications:

- Give verbal praise, as often as possible.
- Seat the child near the front of the class.
- Create an assignment notebook that is checked daily by teachers and parents.
- Use raised lined paper to help with handwriting.
- Use grid paper to line up long math problems.
- Give unobtrusive cues to re-establish attention (a touch on the shoulder, a special word or signal).
- Monitor that assignments are begun correctly.
- Break tasks into small steps.
- Reduce the length of written assignments.
- Provide access to a computer and/or assistive technology devices.
- And, once more, give positive reinforcement to the child whenever possible.

For more information, contact the Washington Chapter of the National Neurofibromatosis Foundation at (425) 672-9610 or nf@nnffwa.org.

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Educating the Child with Neurofibromatosis Type 1

A Simple Framework for
Parents, Educators, and Health Care Providers

neuro·fibroma·tosis
THE NATIONAL NEUROFIBROMATOSIS FOUNDATION, INC.



There is a great deal of anxiety and uncertainty that comes with the diagnosis of Neurofibromatosis – Type 1 (NF-1) in a child. The manifestations are extremely variable and, currently, there is no method for predicting the physical or psychosocial consequences of NF-1 in any individual. In addition to medical concerns, approximately one-half of all children with NF have learning disabilities. Roughly one-half are in special education and one-third are retained a grade at least once. Approximately one-third carry an additional diagnosis of Attention Deficit Hyperactivity Disorder. As part of a neurological disorder, these problems are not unexpected. It is important for parents and educators to understand they are a consequence of the NF-1. Problems in school are often a huge issue for children with NF-1, and a source of great concern for their families. Social isolation, poor peer relationships, diminished self-esteem, and difficulties with attention, anxiety and depression are all common.

Through an informed, coordinated system of care, many of these concerns can be alleviated. We know that children with NF-1 can have successful school careers. The process begins with thorough, ongoing assessment of their medical, psycho-educational and emotional status. With that information in hand, an individualized program should be developed, implemented, and monitored.

The need for early intervention is critical.

We know that children with NF-1 are at-risk for a number of problems that will affect their school performance. There is no need to wait to see if children will “outgrow” their deficits. Early intervention is available through the public school system for children with special needs as early as age three, and from birth in some school districts. For children with NF-1, these services usually revolve around speech and motor deficits, and the skills they gain through therapy is remarkable. Talk to your school district about early services if you recognize any deficits in your child.

Use the primary grades to establish rapport with the school.

During the early years in school, many children with NF-1 begin to exhibit issues that could haunt them for years if they are not addressed. Poor handwriting, clumsiness, lack of attention and organizational skills, and diminished social relationships are problems commonly reported by teachers. These are all a function of NF-1 and need to be handled as such. Talk to the school’s teachers, administrators, nurse, and psychologist about NF-1 and how it is manifesting itself in your child. Children with NF-1 tend to do best with teachers who are sensitive yet structured. The need for routine is often strong in affected youngsters at this age. This may also be the time to refer for special education services if the child was not part of an early intervention program (if the child was, services will be carried automatically into elementary school).

Children with NF-1 are usually carried under the eligibility category of Health Impairment and the child’s medical doctor will need to sign a statement verifying the condition. Remember to ask that all problems be addressed in the Individualized Education Program that the school will develop with parental input. Again, speech, physical, and occupational therapies all should be provided as Related Services if needed.

Continue working to “strike a balance” as the child progresses in school.

Often, despite normal intelligence, children with NF-1 learn academic skills at a slower rate than their peers. Teachers and parents must continue to have high expectations for the child while being sensitive and patient if the child struggles. Research informs us that affected children will, in time, learn the necessary material but they often struggle with rote foundation skills despite average, or above, comprehension and understanding. Efforts must be made to expose the child to the subject matter, but not to demand mastery to the point of frustration. Be creative when working with children with NF-1. They often know more than they can show on paper. And, once again, their papers will often be sloppier than those of their classmates. Teachers simply must establish a different level of expectation for the child with NF-1 with regard to neatness and organization. But do establish expectations!

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