

A Summary Of The Parents Guide To Learning Disabilities Associated with NF1

BC Neurofibromatosis Foundation

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- **Explaining NF1 to Educators:**

NF1 is largely unknown or misunderstood in the general population and educational community. Usually the job of educating the educator falls largely to the parent of the child. While it is certainly not necessary to describe all the details of the disorder, some general facts and the challenges will give the educator a better understanding and how best to meet the needs of this student. Some general information that you might want to share:

- NF1 is the most common gene disorder affecting the nervous system that causes the growth of tumours (called neurofibromas), on the nerves, anywhere in the body, at any time. Puberty is often associated with an increase in the number and size of neurofibromas.
- Approximately 1 in 3,000 people have NF1 is defined as a genetic disorder
- NF1 is not contagious
- NF1 affects each person differently and severity varies from one person to the next
- NF1 is most commonly characterized by the presence of café-au-lait spots, auxiliary freckling, cutaneous neurofibromas or tumours, and Lisch nodules (freckles on the iris of the eye)
- NF1 occurs with equal frequency in both males and females and has been identified in all ethnic groups.
- Each child with NF, even those in the same family, can be affected to a different extent

- **You are your child's best advocate to getting the best education possible:**

An important first step is for your child to be assessed to help identify his/her cognitive strengths and weaknesses. You will then have a better idea of the remedial strategies that your child might need. It is important that you find out what various funding and resources are available. Your school's counsellor can help you with this. Other resources include: family doctor/pediatrician, local child and family government services, a local chapter of a neurofibromatosis or learning disabilities association in your area. It will be largely up to you, the parent, to advocate for your child getting their needs met in the school system.

Once the testing is complete, or at the first sign of challenges, you will need to create a "learning team" for your child. A learning team consists of you (and your partner), your child and the school-based team. Be mindful of whether the suggestion or strategy you are reading might work best if implemented in the home and/or the school. The school-based team is often comprised of the school's principal, teacher(s), special needs counselor, assistants/aids, appropriate therapists (occupational, speech, physio), and perhaps the school nurse, psychologist, or counselor.

It is imperative that you stay in close communication with the entire learning team. You will be the

most consistent presence in your child's team, so your determination to help your child get the resources he/she needs will be key in creating the best learning environment for him/her.

If a child is identified as having learning disabilities, it's important that the learning team work on creating a plan. One formalized plan that may be available, is called an **Individual Education Plan (IEP)**. An IEP is a written statement that provides key information to assist educators in planning and meeting a child's educational needs. The plan details the student's strengths & weaknesses, as well as the specific areas where the student will receive help and how. It also outlines measurable goals, and strategies for achieving these goals. It documents who will do what, when and why. This plan accompanies your child and should be reviewed regularly.

Your child's teacher(s) will use the IEP to pass along their knowledge about your child to your child's next teacher or school. The school-based team has a perspective of your child that is unique to the institutional learning environment - a perspective that a parent may not have, thus, the IEP is an important educational tool to enhance your child's education by providing continuity through the ongoing recording, evaluating and adjusting of goals and successes. If you plan to move out of your school district, confirm that the IEP will be moving with you.

Having a documented plan of measurable goals and who will do what, by when and why will go a long way in getting your child the help that he or she needs. Share with your child's learning team whatever they need or want to know about NF1. Let them know that you are open and approachable. The information that you share may be what makes your child's good education a personal goal of the members of the team. Let them know of other resources for information like the Internet, the main library and the local chapter of an NF Foundation.

The study environment could mean the school classroom, resource room, and/or library, or your home. Creating a study area that is free of sensory distractions can really support your child's learning process. And finally, please understand that we, as fans and supporters of our children, are doing the very best we can with the resources that we currently have and we need to pat ourselves on the back whenever we can. Encouragement to ourselves, from ourselves is essential.

- **Cognitive Functioning:**

Academic difficulties are the most common reported complications of NF1 in childhood. Cognitive deficits are wide ranging which can have direct implications on their functional abilities. The most common problems include sustained attention deficits (the most common specific deficit), visuo-spatial deficits, and executive dysfunction. Difficulties with academic achievement (reading, spelling and mathematics) are also present. Some also fulfill the diagnostic criteria for ADHD. One or more areas of cognitive functioning are moderately to severely affected in more than 80% of children with NF1. It is important for each individual to determine which cognitive deficits are likely to impact learning in the classroom, and which cognitive strengths can be used to compensate. Although the frequency of cognitive functioning deficits is higher in the NF1 population than in the general population, the types of cognitive and behavioral problems are the same as what is found in the general population and they are likely to respond to the same approaches are used in

children that do not have NF1.

- **Perceptual Ability:**

The ability to correctly perceive information from our five senses. The most common perceptual problem to affect learning in the classroom is a difficulty in perceiving visual information, as the majority of information is presented visually especially once reading and writing are introduced. Some examples include:

- Problems in the perception and judgment of placement of lines and objects. Unable to judge whether two lines are parallel, or if two objects are in the same position
- Extreme problems copying accurately from the blackboard
- Poor visual orienting
- Mistakes reading computational signs (+/_/x or ÷).
- Visual information overload
- Poor learning and memory of nonverbal information. Difficulty matching shapes visually.
- Reversing, rotating and omitting of letters, numbers, words and even sentences when reading, copying or writing (E is seen as 3; "w" as "m"...)

Coping with difficulties in perception:

- Encourage the use of computers or word processors
- Support the development of strong keyboarding skills
- Make sure the student is seated close to the teacher, board or work area
- Present information verbally, or offer a verbal explanation along with a visual presentation

Creating a study area that is free of sensory distractions

- Use a phonic approach to reading
- Focus on reading for meaning - slow the child down
- Place a note card or use his or her finger under each line to help keep his or her place while reading
- Practice oral reading, making sure that the child is in a judgment-free study environment
- Give the child the clearest copy of the photocopied worksheets
- Enlarge text on photocopied materials with proportioned and well-spaced type
- Avoid cluttered worksheets and long written assignments - ask teacher to modify where possible.
- Avoid having the child copy from a blackboard or books; where copying is necessary, check for accuracy
- Write as clearly and neatly as possible on the board and on worksheets
- Introduce new vocabulary in context before a reading assignment
- Use of level-appropriate educational software at home can make the repetition necessary for learning spelling and language skills more bearable
- Pair students for reading assignments, ensuring that the partner displays patience and understanding
- Use of word blanks is helpful. E.g.: The dog _____ to the bone
- Provide talking book tapes whenever possible. Often these are provided for the visually impaired. Especially helpful in middle or high school.

- Well-organized textbooks that have bold headings and easy to understand charts and diagrams
- Provide raised line paper for writing (available in different line widths)
- Highlighting: highlight parts of the page to pay special attention to, highlight the operation symbol in the math question (+ -), highlight the problem number on a math question so that it is not confused with the problem itself.

- **Executive functioning deficits:**

The ability to focus attention, process different pieces of information, solve problems and make decisions, plan and organize tasks, as well as monitor one's own behaviour. A student may know his math facts, but be unable to organize the information to solve problems effectively; or he may have studied for a test, but is unable to answer the questions presented in a novel format. May have poor self-control, impulsivity, erratic and careless responses, poor initiation skills and inflexible attitudes. Professionals see a strong relationship between executive function and ADHD. For this reason it is a good idea for the learning team to look at indications and remedial strategies of both ADHD and executive functioning.

Children may be considered “lazy” or “unmotivated”, with the appropriate intervention and support, their situations can change. So it is vitally important that executive problems are identified and students are given the strategies to help maximize their potential. Students may also experience social problems, which might extend well beyond the school years. As executive skills evolve slowly over time and are only beginning to be fully established around the age of 12, executive skills need to be broken down and taught explicitly according to appropriate age-related developmental stages.

Strategies for minimizing the effects of executive deficits:

- Provide an agenda or organizer and teach the student how to use it
- Provide a support aid in the classroom to help with organizing homework, assigned tasks and projects
- Do not punish or offer incentive for educational motivation
- Break projects down into small, manageable tasks - providing sequential steps, and suggested timelines for each of the steps
- Have two sets of books (one at home and one set at school)
- Use checklists, not only to keep the child on task, but to give her/him a sense of accomplishment as items are crossed off the list
- It may help to use a different colour notebook for each subject.

It is important that both you and the learning team monitor your child's work to ensure that concrete coping and study skills are being taught and understood. Students are more likely to succeed if they are taught explicit strategies, which will vary, depending on the age of the student and his particular learning style.

Planning tools such as master calendars, electronic organizers, day-timers, watches with alarms and timers are often very helpful; but the child must be given explicit training & support as to how

incorporate these tools into her or his life. The computer can be another valuable tool for many of these students.

The child will benefit greatly from the practice of brainstorming, and generating different ideas or alternatives to solve a problem. These students need to be explicitly trained in the systematic and careful comparison of information, specifically looking at each idea, seeing if it is valuable, prioritizing which idea is worth trying and in what order, as well as getting and giving feedback and most importantly, trying a new idea if this one does not work. Self-monitoring is another important area that children with executive deficits and/or impulsivity have difficulty with. Children, and especially adolescents, may need help in this area.

One of the best ways to ensure that students who have executive functioning deficits are successful is to give them extra assistance and support specifically in the area of organization. If your school learning team can provide support with an aid, this can make a difference in your child's attitude towards school and in his/her school performance. If the school cannot provide this level of support, enlisting the assistance of another student to be a peer tutor can be very helpful to keep track of major assignments, homework, deadlines, and obligations. The use of an agenda or day-timer is imperative in maintaining the communication link between school and home, although the maintenance can be very challenging for the child. This is where school support can make a significant difference.

- **Attention Deficits:**

The most common cognitive functioning problems for children with NF1 are attention deficits. Attention difficulties can greatly undermine performance in the classroom. Many fill the criteria for ADHD - this may be helpful for some children, as their teachers and schools may know how to cope with ADHD. However, this is not applicable to all NF1 children so it is imperative to monitor this situation to get the proper support.

Myths about ADHD: Clarifying myths about ADHD can help the learning team better understand:

- Children have to be physically hyperactive to have ADHD
- Kids will outgrow the disorder
- Kids with ADHD are being difficult on purpose
- Kids with ADHD can never pay attention
- Medication is the answer
- The child with ADHD will never amount to anything
- Factors that cause ADHD - Poor parenting, Family problems, Bad teacher/ineffective schools, Too much television, Refined sugars, Food allergies, Diet

Strategies for the success of the child with attention problems

- Carpeting in the study environment can reduce auditory distractions
- Seat students at the front of a class in order to keep the activities of the other children out of view
- Keep the study environment decor to a minimum
- Do not seat the student near air conditioners or heaters, high track areas, doors or windows
- Use of headphones for desk work will keep auditory distraction out

- Keep the blackboard simple
- Keep the desk area free of clutter; only the essentials should be on hand
- If possible, seat students with attention deficits with good role models

Instructional suggestions for ADHD

- Maintaining eye contact during verbal instruction
- Physical proximity and touch may also help the child refocus
- Breaking large tasks down into smaller, more manageable tasks
- Making directions very clear and concise and being consistent with daily instructions
- Simplify complicated directions, and ensure that they are manageable, try to avoid multiple commands
- Frequent checks for assignment progress and completion can help the child stay on task
- Make sure the child fully understands the instructions before he/she begins the exercise
- If the student asks for the instructions to be repeated, do so in a calm and positive manner

Modifications for the student with attention deficits

- Adapt and modify tests - make assignments test knowledge and not attention span. Less is more in determining whether or not the child with an attention deficit knows the subject matter
- Give extra time for certain tasks, understanding that the child with attention deficits may work slowly
- Ensure that the learning team works with the child's calendar to help him/her to stay on task and not become overwhelmed
- Understanding that a student with ADHD has an extra challenge concentrating on evening homework, thus his/ her evening workload may need to be adjusted. Assign homework accordingly.

The three subtypes of ADHD: predominantly hyperactive-impulsive type (that does not show significant inattention); predominantly inattentive type (that does not show significant hyperactive-impulsive behavior); and the combined type (that displays both inattentive and hyperactive-impulsive symptoms). Children with NF1 most often experience the predominantly inattentive type as well as the combined type, with the hyperactive-impulsive type occurring very rarely on its own.

Strategies for coping and compensating for the child with ADHD

- A student may need breaks where he/she can move around a bit
- Try to prepare student ahead of time for times of change, such as field trips, assemblies, or when the regular teacher will be away
- Respect - treat the student as you would any other student - especially in front of his/her peers
- Consistency with directions and discipline is very important. It is imperative that the student understands both the rules and the consequences for breaking them
- Raising your voice can be completely ineffective as he/she may not understand the meaning, or may not even hear the raised tone

- The use of positive language can really help him/her focus on the desired behavior outcome. Letting the child know what you do want rather than what you do not want can be very helpful
- The child often responds well to being given choices where appropriate. It is, however, best not to give him/her more than two choices to pick from
- A child with ADHD may need very specific directions. To help him/her understand, it may be necessary to actively get child's attention, then tell him/ her exactly what you want. Making the directions simple and short, in a series of 2 to 3 tasks and asking the child to repeat the directions can be very effective.
- A 'quiet zone' in his/ her study environment can be very helpful for the child. Helping the child to learn and practice stress management techniques, and to understand that he or she needs emotional 'time outs' to regroup after an upset are all conducive to setting the child up for success.
- Help the child find areas/subjects in which he/she excels. Children with ADHD often feel that they are not good at anything. If the child is able to feel good about a particular skill or ability, he/she can use this as compensation for other limitations.
- Help others to understand the child with ADHD. If others understand the reasons for this child's behavior, they often become more accepting of this individual
- Fitting into the institutional environment and the 'norm' can be very stressful and children may have problems monitoring appropriate behaviours. Thus, having a 'time out' process set up beforehand can reduce stress for both the student and the teacher
- Make certain that the teacher knows that you, the parent, are available for consultation, and that you may have knowledge or strategies that can help him/her

- **Social problems related to NF:**

Almost 40% of children with NF1 experience social problems (combined with attention problems) in the borderline/clinical range. Children with learning disabilities may: appear to be disinterested in the opinions of others or impatient with them as they speak, misinterpret the feelings of others, be unaware of when his or her behaviours are annoying, or have visual spatial difficulties and problems with self regulation, resulting in standing too close to someone during conversation, or not understanding when it might be appropriate to touch.

- **Physical Capacity:**

- In general, children with NF1 do not require special protection. Most are capable of participation in a full range of normal activities. The only exception is for those who have specific complications that may place them at risk for injury. However, It is clear that children with NF1 have an increased challenge in the development of skills in both the fine and gross motor areas.
- It is important that the effects of fine motor control on the child's learning process be recognized. The deficit can contribute to very slow and illegible handwriting. The learning team should create realistic and mutually agreed upon expectations for neatness, and avoid pressures of speed and accuracy on the child. Statements such as "I hate to draw", "I hate writing" may be a child's way of expressing frustration with his/her inability to master the coordination of motor skills necessary to feel competent in these areas. These expressed

dislikes can sometimes serve as a cue for the learning team to look for underlying deficits in the areas of fine and gross motor control.

- **Occupational therapy:**

Developing fine motor skills at an early age: Any activity involving the use of the exact finger movements, such as cutting pictures out of newspapers or magazines, can be effective in fine motor development. Enlarging the thickness of the proposed cutting line increases the child's success level in this exercise.

Other activities may include beading, building blocks (such as Lego or Tinker Toys), peg boards, wooden puzzles, finger painting, pencil and crayon work all give the child practice with fine motor skills.

Fine Motor Adaptations for Middle or High School: Turn lined paper vertically to help students organize math problems. This will help keep the ones, tens, and hundreds places lined up correctly.

- Use large graph paper if turning the paper vertically does not correct the problem. One numeral can be written in each square. Gradually make the transition to regular paper
- Provide photocopied notes from a lecture or blackboard in addition to child taking notes
- Allow extra time for written assignments
- Provide tape recorders to supplement note taking
- Allow use of the calculator
- Allow oral answers vs. written ones
- Modify hands-on tasks and provide extra support, either with an assistant, or a supportive peer
- In severe cases, provide a scribe who records or transfers written work into good copy form.

Gross Motor Adaptations for Middle or High School:

- Focus on fitness rather than competitive sports
- Encourage repetitive motion sports such as swimming or track
- Encourage non-competitive sports, or non-team sports
- Find out if the child can participate in an individualized program for PE, where he/she can perform a physical activity or sport he/she feels competent in, while keeping track of the hours for school credit.

- **Psychological implications of learning difficulties in NF**

- Speech therapy and occupational therapy at a young age, although highly necessary, set the child up from a young age as "different". Once school begins and learning difficulties arise, failure at tasks and the need for remedial help further reinforce this.
- Poor motor coordination and clumsiness also isolate the NF1 child at school especially in sporting activities. Socially, children with NF1 are frequently teased and have fewer friends.
- Difficulties in maintaining friendships may place individuals with NF1 at an increased risk for poor social support, which may result in further poor self-concept.

- Children with NF1 are at increased risk of becoming enmeshed in a “failure cycle”. As the child loses confidence in their abilities they often began to increasingly avoid tasks that involve the skill they find difficult. However, by explicitly linking success with effort and practice, these children can be encouraged to persist and gain satisfaction from their achievements.
- One of the most important aspects to minimizing the psychological effects of these cognitive problems in children with NF1 is the accurate dissemination of knowledge about this disorder. Many parents complain that their children are “punished” for their behaviours and often have to stay behind after class during recess or lunch.
- It is vital to set realistic expectations for the child. It is important that children with NF1 are rewarded for their effort and motivation rather than just for the outcome of their behaviour. It is also important for the teacher not to minimize the abilities of the child with NF1 or set too low expectations.

- **Get the support you need**

As parents we can only give what we have, and sometimes we need to refuel. There is support out there. The Internet is a wonderful tool for seeking out answers and support.

There are also specific associations that are dedicated to improving the lives of the people that are living with NF, learning disabilities, ADHD as well as other associations that focus on the many challenges of simply parenting.

The information brought forth in this document, does not represent official statements or views of GeneFo. As always, we strongly recommend that each person consults with their treating physician before making any changes to treatment/educational plans.