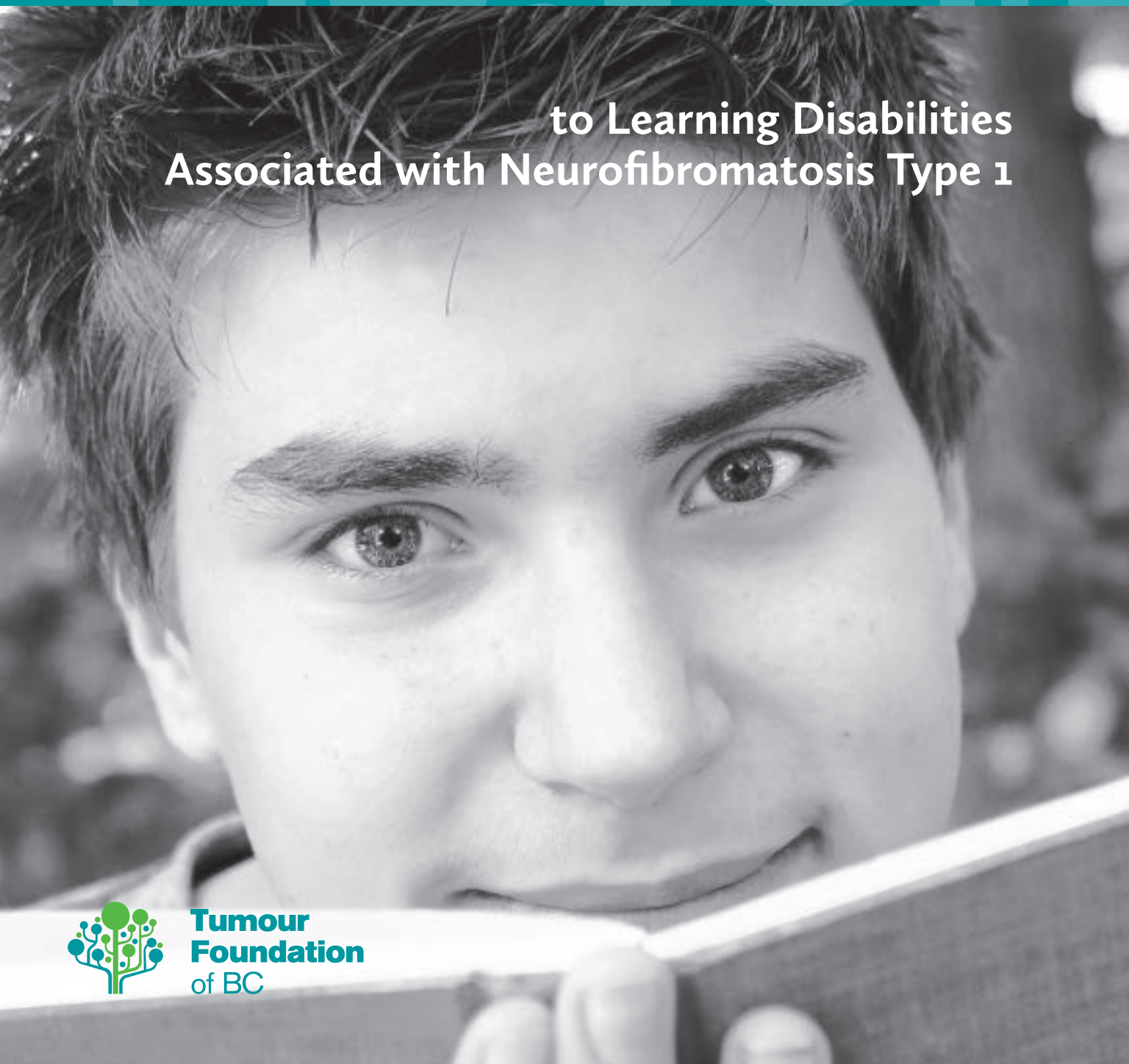
A PARENT'S GUIDE

to Learning Disabilities Associated with Neurofibromatosis Type 1



Tumour Foundation of BC

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"It has always seemed strange to me that in our endless discussions about education so little stress is laid on the pleasure of becoming an educated person, and the enormous interest it adds to life."

— Edith Hamilton

INTRODUCTION

As parents and educators we want to do the best we can to ensure that our children have the greatest chance for success and happiness. The goal of this guide is to support you, the parent (and co-educator) of a child with neurofibromatosis type 1 (NF1), in your efforts to help your child reach his or her educational potential. With proper understanding of the challenges specific to the education of children with NF1, and with strategies available for overcoming those challenges, we hope to dramatically increase the child's odds – and, later, that adult's odds – of living happy and productive lives.

This guide is designed as a resource for parents of children with both NF1 and learning disabilities - at all school ages. Whether your child is just entering kindergarten, or is into his/her high school years, you will find relevant material to address his/her educational needs.

Although most educators have an understanding of the complexities of learning disabilities and attention deficit hyperactivity disorder (ADHD), they may not necessarily understand the specific issues of children with NF1. It is, therefore, generally beneficial to the child with NF1 if his/her parents and educators have a common understanding of possible specific challenges that the child may experience due to NF1, and of the strategies that may need to be implemented to ensure that the child's educational experience is as successful as possible. The hope is that, with the right support, every child dealing with the challenges of NF1, can not just cope with school, but can thrive and grow within the school environment.

The information in this guide is intended to be used for general information only and should not replace consultation with a qualified healthcare professional. Consult your doctor before making medical decisions, or if you have questions about your child's medical situation. While the writers of this guide have made every effort to ensure that the information provided within is accurate and reliable, they cannot guarantee that it is error free or complete. This guide does not endorse any product, treatment or therapy.

The Tumour Foundation of BC has compiled this guide with the support of many individuals and organizations. We would like to express our gratitude to them and recognize their efforts towards creating more public awareness of the challenges that children with NF1 face.

We would like to acknowledge the **Variety Club of Canada**, for without their support of this organization, this guide would not be possible.

Much of the information in this resource was based on the research of **Shelley Hyman** (PhD) and her colleagues at **The Children's Hospital at Westmead**, Australia (Hyman, SL, Shores, AE & North, KN, Neurology, in Press). We would especially like to acknowledge **Shelley Hyman** for her guidance in editing. Her patience and the generous donation of her time were very much appreciated, as well as her insight, and concern into the psychological implications of the NF1.

Dr Belinda Barton, Psychologist, Neurogenetics Research Unit at **The Children's Hospital at Westmead**, Australia, many thanks for her valuable input.

A huge thank you to **Marian Taudin Chabot** for the donation of her time, her patience, and her understanding of the English language.

And a great deal of thanks to the community of the **Tumour Foundation of BC** who gave their time and energy to create this guide for parents.

Updated in 2018 by Desirée Sher.
Tumour Foundation of BC

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EXPLAINING NF1 TO EDUCATORS

Although NF1 is one of the most common genetic disorders, it is largely unknown and misunderstood in the general population. This lack of understanding is true within the educational community as well. Unfortunately, the job of educating the educator about NF1 falls to the parent of the child with NF1. While it is certainly not necessary to describe all the details of the disorder, some general facts about the disorder and the challenges it presents will give the educator a better understanding of the needs of their student with NF1.

NF1 IS NOT CONTAGIOUS. NO AMOUNT OF CONTACT CAN TRANSMIT THE CONDITION.

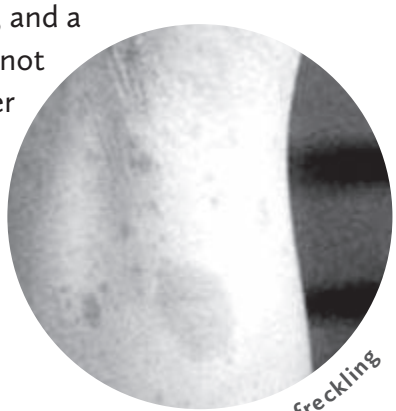
As a parent you are probably well versed in Neurofibromatosis Type 1. Here is some general information you can share with educators:

NF1 is the most common single gene disorder to affect the human nervous system.

Approximately 1 in 3,000 people are affected by this disorder.

NF1 is defined as a genetic disorder 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.

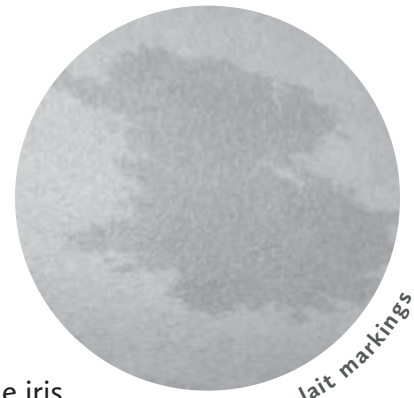
NF1 is not contagious. Contact between an unaffected child, and a child with NF1, will not result in the disorder being transmitted.



Axillary freckling

NF1 affects each person differently. Some people are severely affected and require constant medical treatment. Other Individuals are mildly affected, and may never know they have the disorder. Each child with NF1 - even those in the same family - can be affected to a very different extent. Overall, it is estimated that about half of the people with NF1 are 'mildly' affected by the disorder.

NF1 is most commonly characterized by the presence of café-au-lait spots, auxiliary freckling, cutaneous (skin) neurofibromas or tumours, and Lisch nodules (freckles on the iris of the eye).



Café au lait markings

NF1 is associated with a wide variety of complications affecting almost every system of the body.

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.

Half of the cases of NF1 result from a spontaneous genetic mutation, while in the remainder of the cases it is inherited from one, or both parents.

Behaviour and Cognitive Consequences: intelligence is usually within the normal range, but at least 40% to 80% of children who have NF1 have moderate to severe impairment in one or more areas of cognitive functioning. This can result in learning difficulties, attention and social challenges.

Dermal neurofibromas (surface tumours which are usually benign) are small lumps in or under the skin, which do not usually develop until preadolescence, with an increase in the number and size of tumours during adolescence, young adult years and pregnancy. Between the ages of 10 and 19, half of children with NF1 will develop these tumours, to some degree.

Plexiform neurofibromas are larger internal growths of the body that involve a group of nerves. They are usually engorged with blood vessels that can grow large quite quickly, without being malignant. Their growth and location is unpredictable and about 25% of individuals with NF1 have one plexiform neurofibroma. These tumours can have significant impact on the child with NF1 depending on their location, size and growth rate, and may be associated with cosmetic disfigurement.

Scoliosis (curvature of the spine) can develop in children with NF1, and may require bracing or surgical intervention.

Macrocephaly, a large head circumference (>97th percentile) occurs in around 30% of children with NF1. Current research indicates that there is no association between macrocephaly and intelligence or cognitive functioning.

Optic glioma, a benign tumour that can develop on the nerve pathways to the eyes, occasionally causing problems with vision. Optic gliomas occur in about 15% of children with NF1. In the majority of cases these tumours do not cause any problems; they only require treatment if they become symptomatic. Symptoms of these tumours generally appear during the first six years of the child's life.

Complications that occur with less frequency involve bone problems, such as a marked bowing of the shinbone (tibia), or pseudoarthrosis (in 2% of cases), which is the failure of a fracture to heal, resulting in a false joint, (usually affects the shinbone). There can also be spinal deformities that involve the vertebra and thickening of the outer layer of nerves and or the outer casing of the spinal cord (dura mater), brain tumours, blindness, and even cancer.

SUGGESTED WEBSITES

www.tumourfoundation.ca ↗

www.nfnetwork.org ↗

www.understandingnf1.org ↗

www.ctf.org ↗

www.friedmanlab.org ↗

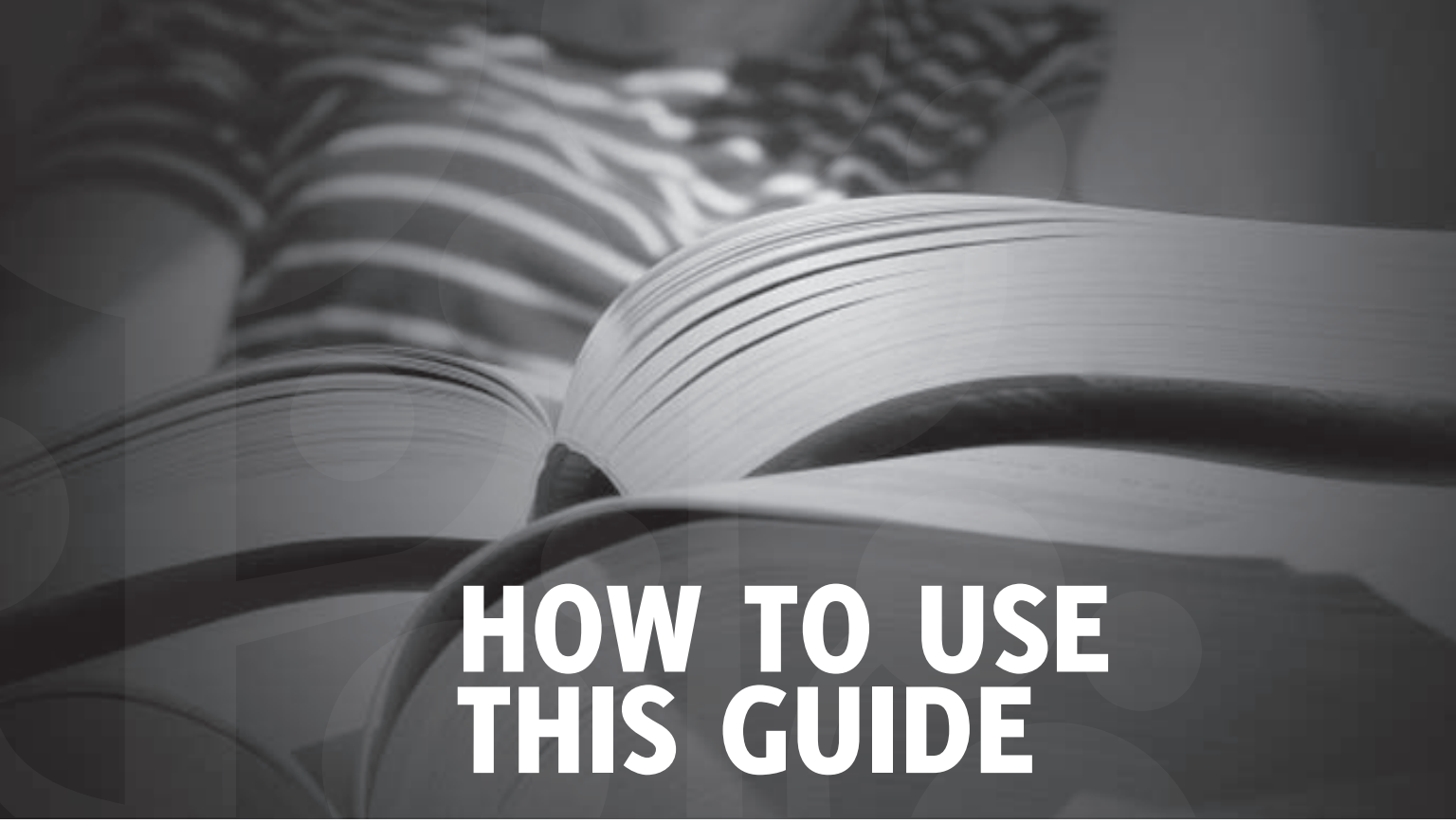
MOST DOCTORS STILL USE VISIBLE SIGNS SUCH AS THE CAFÉ AU LAIT MARKS, LISCH NODULES, SURFACE NEUROFIBROMAS, PLEXIFORM NEUROFIBROMAS TO MAKE A DIAGNOSIS.

THE DIAGNOSIS OF NF1

Often, the diagnosis of NF1 can remain uncertain for a few years.

This is due to the fact that many features of NF1 are age dependent. Symptoms may not be seen in very young children, but may then appear, as a child gets older. Most physicians use visible signs, such as the café au lait marks, Lisch nodules, surface neurofibromas, and plexiform neurofibromas to make a diagnosis. It is important to note that, while it is common in the general population to have one or two café au lait spots, six or more spots are a concern.

At the time of printing this guide, no particular medication had been found to shrink or prevent neurofibromas, but research is ongoing. Treatments are presently aimed at controlling symptoms. Surgery can help some bone malformations. For scoliosis, bone surgery may be combined with back braces. Surgery can also remove painful or disfiguring tumours; however, there is a chance that the tumours may grow back, and in greater numbers, so surgery is done sparingly, usually with mobility and comfort as the main criteria for operating. In the rare instances when tumours become malignant (3% to 5% of all cases), treatment may include surgery, radiation or chemotherapy.



HOW TO USE THIS GUIDE

GETTING THE BEST EDUCATION YOU CAN FOR YOUR CHILD WITH NF1.

Making certain your child gets a good education is a concern for every parent. When you add additional challenges like an abundance of specialist's appointments, attention deficits, and learning disabilities, you may feel that you have more than you can handle. This guide is intended to help ease that load a little. Its intention is to provide you, the parent, with some sense of direction and understanding of how best to meet the extra challenges that schooling your child with NF1 may present. This guide offers information and suggestions; **take from it what makes sense to you, and for your child.**

YOU ARE YOUR CHILD'S BEST ADVOCATE.

An important first step is for your child to be assessed. A psychometric assessment will help identify his/her cognitive strengths and weaknesses, and assist in getting a 'school designation' in place. An educational or developmental psychologist generally conducts the assessment. Once this has been done, you will have a better idea of the appropriate remedial strategies that your child will need. A designation comes from the results of the testing. If your child meets a certain criteria, she/he then will qualify for appropriate resources meant to assist in his/her education. It is important that you find out what the various designations are and what they mean in terms of funding and resource availability. Your school's learning assistance teacher or a school counsellor should be able to guide you through this. Other resources would be your family doctor, paediatrician, local child and family government services, or a local chapter of a neurofibromatosis or learning disabilities association in your area. In some cases you can begin testing and developing specific learning strategies for your child's special needs at the pre-school level. The designation that your child receives will have everything to do with the kind of additional assistance that she or he will receive in school. Your child may not need much help, and there may not be a need for additional funding, as some simple remedial measures may make all the difference, others may need a great deal more resources to get the same education. It will be largely up to you, the parent, to advocate for your child getting their needs met in the school system.

AN IEP

An Individualized Educational Plan details the student's strengths and weaknesses, the specific areas where the student will receive help and how, and it outlines measurable goals, and strategies for achieving these goals, as well as documents who will do what by when and why.

Whether you begin 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 if appropriate), your child and the school-based team. When the guide refers to the 'learning team', be mindful of whether the suggestion or strategy you are reading might work best if implemented by you in the home, as opposed to, or as well, as the school-based team.

The school-based team is often comprised of the school's principal, teacher(s), resource room teacher, special needs or LD counselor and/or assistants/aids, appropriate therapists (occupational, speech, physio), and perhaps the school nurse, psychologist, or counselor. As you are your child's best advocate and mentor, it is imperative that you stay in close communication with the entire learning team. You will be the most consistent element in your child's learning 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.

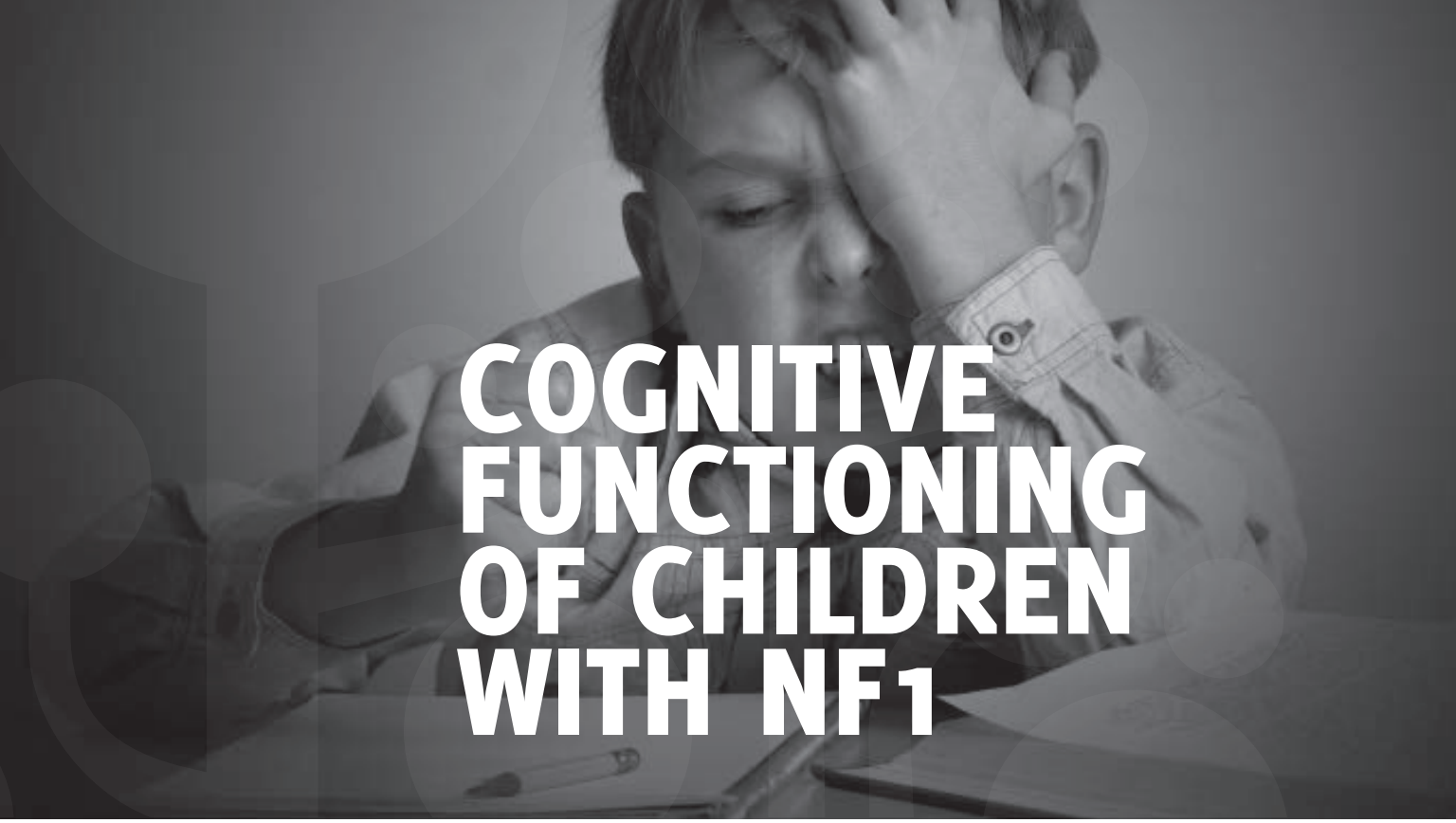
If a child is identified as having learning disabilities, it's important that the learning team begin work on creating a plan. One formalized plan that may be available to your child, depending on your school area and his or her designation is called an Individual Education Plan (IEP). An IEP is a written statement that provides key information to assist educators in planning and meeting a child's individual educational needs. The plan details the student's strengths and 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 by when and why. This plan accompanies your child throughout his/her school career and should be reviewed on a regular basis. Your child's teacher(s) will use the IEP to pass along their school specific 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. Whether you have something as formalized as an IEP or not, 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 to succeed in school.

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. They may have many questions. The information that you share with them may be what makes your child's good education a personal goal of the members of the team. As well, let them know of other resources for information like the Internet, the main library and the local chapter of an NF Foundation.

Throughout this guide, we refer to the 'study environment', which could mean the school classroom, the resource room, and/or library, or your home. As parents reading the guide, please be mindful of the study environment in your home. Creating a study area that is free of sensory distractions can really support your child's learning process at home.

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. 'Way to go' for picking up this guide and for making a difference in your child's life!



COGNITIVE FUNCTIONING OF CHILDREN WITH NF1

Academic difficulties and school failure are the most common reported complications of NF1 in childhood. Cognitive deficits are wide ranging and can be responsible for significant difficulties in daily activities, especially in the school environment.

Over the past decade, a number of studies have investigated the cognitive profile of children with NF1. The majority of studies have shown IQ within the average to low average range. Despite only minimal influence of the NF1 gene upon general intellectual functioning, more significant specific cognitive deficits have been reported in several areas, including planning, organization, attention, language, motor skills, and visual perception.

ACADEMIC DIFFICULTIES AND SCHOOL FAILURE ARE THE MOST COMMON REPORTED COMPLICATIONS OF NF1 IN CHILDHOOD

Children with NF1 may have a broad array of cognitive deficits, which can have direct implications on their functional abilities. The most common problems include sustained attention deficits (about 60%), visuo-spatial deficits (just over 50%), and executive dysfunction (about 40%). Difficulties with academic achievement (reading, spelling and mathematics) are present in 51% of children with NF1, with specific learning disabilities (as defined by IQ-achievement discrepancies) present in 20% of children. 35% of these children 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.

Sustained attention deficits are the most common specific deficit in children with NF1. Studies comparing children with NF1 with their unaffected siblings have shown children with NF1 test significantly poorer in both receptive and expressive language skills, with more than 35% of the children with NF1 benefiting from speech therapy. As well, both fine motor coordination and motor speed have tested significantly lower in children with NF1 than their unaffected siblings, with almost 30% of them requiring some form of occupational therapy. Students with NF1 often have poor handwriting skills, with 52% of their parents reporting a challenge in this area.

The cognitive deficits associated with NF1 are broad ranging, thus 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 for these problems. 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 that are found in children with NF1 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

Perceptual ability is 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.

CHALLENGES SPECIFIC TO PERCEPTUAL DIFFICULTIES:

Children with perceptual difficulties may experience:

- Problems in the perception and judgment of placement of lines and objects. They may be unable to judge whether two lines are parallel, or if two objects are in the same position.
- Extreme problems copying accurately form the blackboard.
- Poor visual orienting.
- Mistakes reading computational signs (+/_/x or ÷).
- Visual information over-load.
- Poor learning and memory of non-verbal 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"...).
- Difficulty discriminating the difference between shapes, numbers, letters, hands on clock, coins, and math symbols.
- Significant problems with organization.

STRATEGIES FOR COPING WITH DIFFICULTIES IN PERCEPTION:

The following accommodations may help children with perceptual difficulties:

- Encourage the use of computers or word processors such as an Alpha Smart (a simple laptop type word processor - often supplied by the school) for written assignments.
- 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.

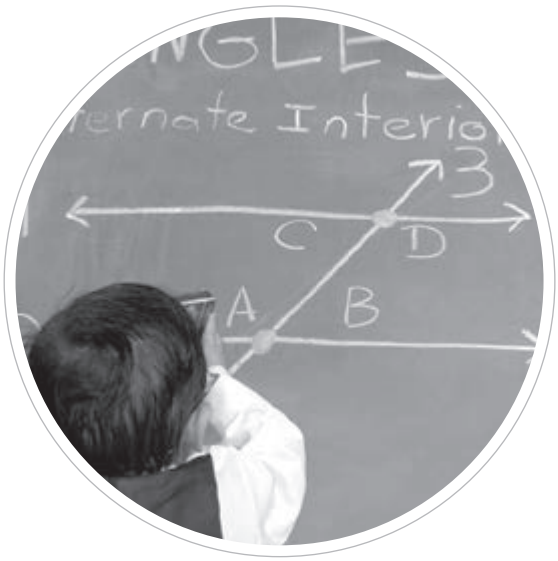
CREATING A STUDY AREA THAT IS FREE OF SENSORY DISTRACTIONS

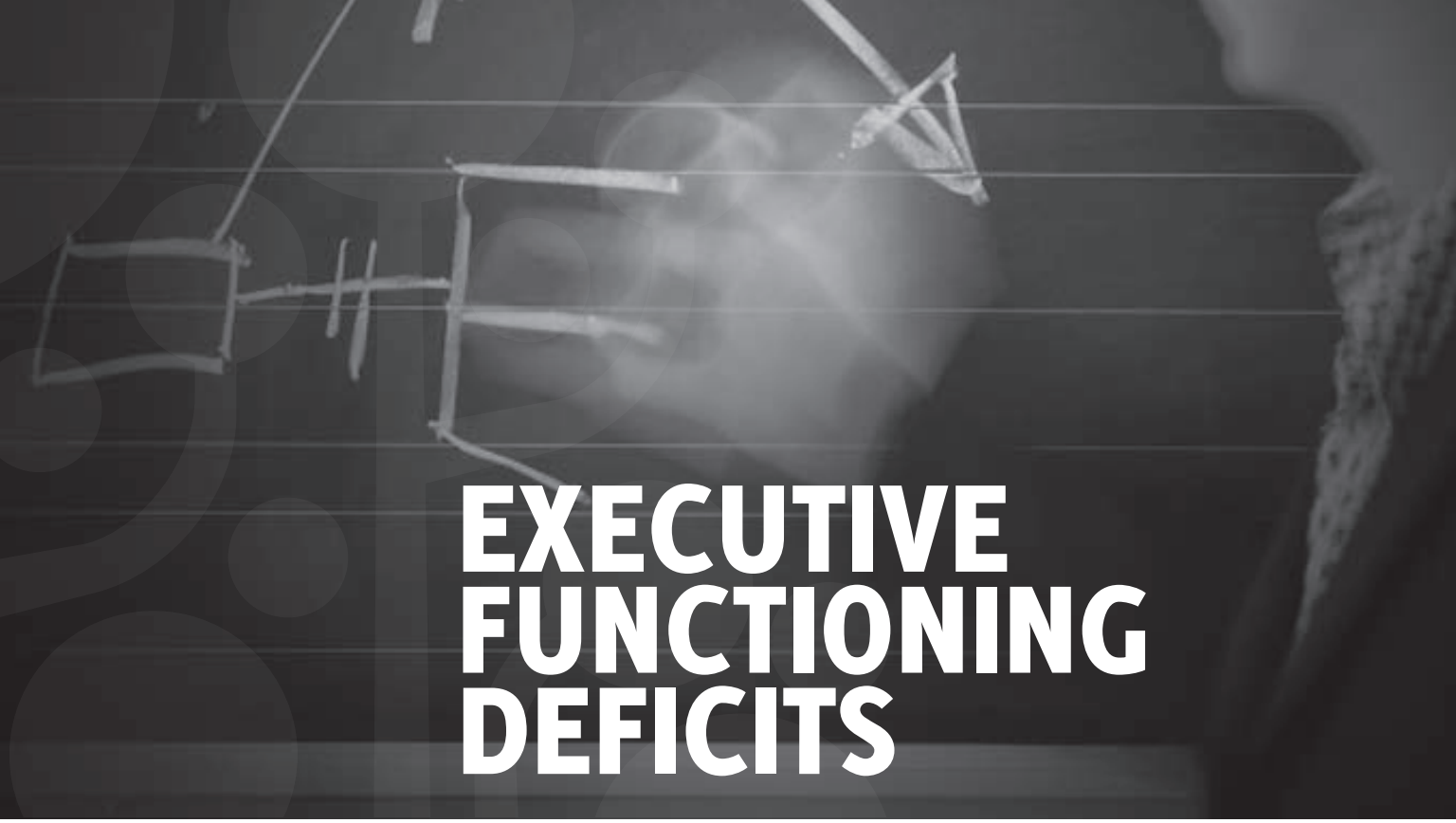
- Use a phonic approach to reading.
- Focus on reading for meaning - slow the child down.
- Place a note card or use his or her finger under each line to help slow the child down and keep his or her place.
- Practice oral reading, making sure that the child is in a judgment-free study environment
- Give 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 the work for accuracy.
- Write as clearly and neatly as possible on the board and on worksheets to increase the child's ability to understand what is written.
- Introduce new vocabulary in context before a reading assignment.
- Encourage the student to use a marker or finger to keep their place while reading.
- 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 chosen displays some patience and understanding.
- Use of word blanks is helpful. E.g.: The dog _____ to the bone.
- Provide talking book tapes whenever possible. Often these resources are provided for the visually impaired and may be available for your child's use as well. They are especially helpful in middle or high school.

"ONE OF THE MOST SIGNIFICANT FACTORS TO IMPACT THEIR CHILDREN'S CLASSROOM PERFORMANCE IS COPYING FROM THE BLACKBOARD"

FROM AUSTRALIAN STUDY OF NF1 PATIENTS

- Provide 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 can be very helpful**
- Highlight parts of the page that the child should pay special attention to, such as instructions or warnings.
- 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

WHAT IS EXECUTIVE FUNCTIONING?

Executive Function is 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. We use executive functioning every time we confront a task to be done. Executive function can be as straightforward as performing mental math computations, or as complex as listening to a college lecture, organizing the information, and relating it to previously acquired knowledge.

Executive functioning can impact a student's grades independent of his skill level in a subject area. A student may know his math facts, but be unable to organize the information to solve math word problems effectively; or he may have studied for a test, but is unable to answer the questions presented in a novel format.

Professionals see a strong relationship and over-lap between executive function and ADHD (Attention Deficit Hyperactivity Disorder). 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. ADHD is usually diagnosed early in a child's life, whereas executive functioning problems are generally not seen until greater challenges - involving organization of thought and process - are asked of the child in middle, or high school.

HOW DO EXECUTIVE FUNCTION DEFICITS AFFECT MY CHILD'S LEARNING?

Children with executive problems may have difficulty planning, organizing and managing time and space. They often have poor self-control, impulsivity, erratic and careless responses, poor initiation skills and inflexible attitudes.

Children with executive functioning difficulties may experience significant challenges in any of or all of the following areas:

- Problem solving
- Abstract concept formation
- Planning and organizing
- Shifting attention
- Something that requires a certain amount of mental flexibly
- Monitoring their behaviour

Some of these children may be considered "lazy" or "unmotivated" by others. However, with the appropriate intervention and support, their situations can change, and many new doors can be opened. It is vitally important that executive problems are identified so that students with these difficulties are identified and given the strategies they need to help maximize their potential.

Students with executive problems 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. In other words, a 10 year old is only able to grasp certain concepts and notions; by the time he is 16, he is ready for another round of strategies aimed at an older level. Teaching social skills will help children with executive functioning problems to develop a gamut of skills appropriate to their age and social situation - skills that other children learn intuitively.

HAVE TWO SETS OF BOOKS - ONE AT HOME AND ONE AT SCHOOL!

STRATEGIES FOR MINIMIZING THE EFFECTS OF EXECUTIVE DEFICITS:

- Provide an agenda or organizer and teach the student how to use it.
- Provide support in the form of an aid in the classroom to help the child specifically with organizing homework, assigned tasks and projects.
- Do not punish or offer incentive for educational motivation; remember, the student may be doing the best he/she can.
- Break projects down into smaller, 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 check lists, not only to keep the child on task, but to give her/him a sense that they are accomplishing something as items are crossed off the list.
- It may help to use a different colour notebook for each subject.
- Fade support only after skills have been well accomplished.

As a parent of a child with executive deficits, it is important that both 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;

BREAK PROJECTS DOWN INTO SMALLER, MANAGEABLE SIZE TASKS.

However, it is not enough to simply supply them to the child. A child with executive deficits must be given explicit training as to how incorporate these tools into her or his life, as well as much support in using them. The computer can be another valuable tool for many of these students, both for the word processing features and also the calendars and organizing tools. Again, it needs to be emphasized that students with executive problems must be explicitly trained in these skills. They are often lacking mnemonic devices and visual imagery for memory enhancement, self talk and self monitoring techniques to help sustain attention, as well as organizational strategies to address various reading and writing requirements. These skills cannot be addressed through the abstract - the student must be taught how to apply these strategies to his daily assignments.

The child with NF1 will benefit greatly from the practice of brainstorming, and generating different ideas or alternatives to solve a problem. This is an area that a deficiency in executive skills can impact greatly. 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.

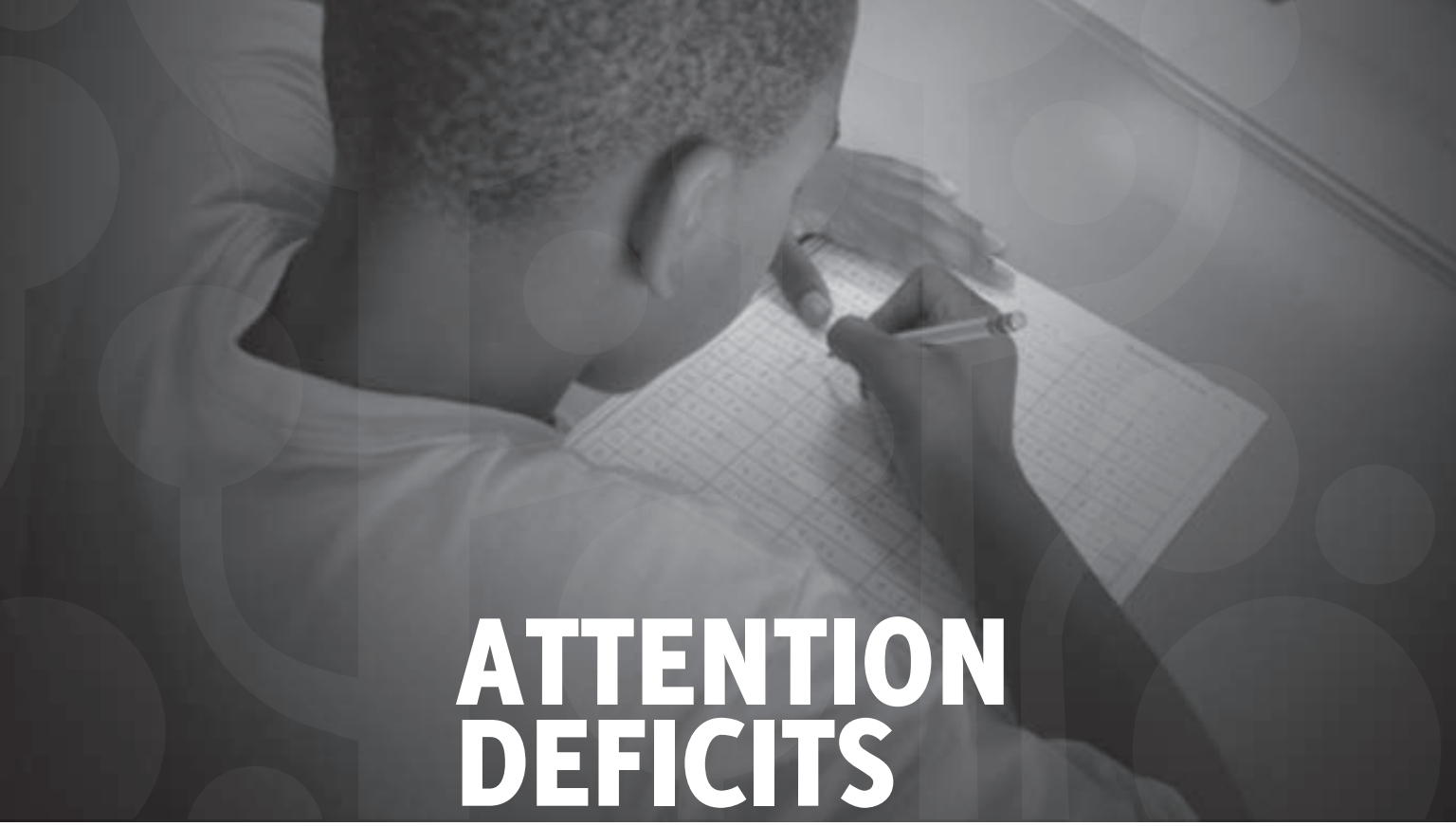
Self-monitoring is another important area that children with executive deficits and/or impulsivity have difficulty with. A deficit in this area can have a very negative impact on your child in all aspects of their lives. Children, and especially adolescents, with NF1 may need much help in this area. Studies have found that children with executive problems often have little insight into their own actions and the effects of these actions. They may pay little attention to the tasks they have performed; they may make simple errors on many tasks.

CHECK TO SEE IF THE TEACHER HAS A WEBSITE LISTING CURRENT ASSIGNMENTS.

In testing, it was found that these children rarely checked their work for mistakes, and yet when asked to check over answers they quickly realized their mistakes.

One of the best ways to ensure that students who have executive functioning deficits are successful in the school environment is to give them extra assistance and support specifically in the area of organization. If your school learning team can provide support - even part time - with an aid, this can make a large 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 for the middle or high school child with executive problems.

A designated student peer can assist in keeping your student organized by helping 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 of such an agenda can be very challenging for the child with executive problems. This is where school support can make a significant difference; the recognition of this disability, as well as the support of the child's learning team is key in helping him/her overcome roadblocks to learning.



ATTENTION DEFICITS

The most common cognitive functioning problems for children with NF1 are attention deficits. Attention difficulties can greatly undermine performance in the classroom. Problems with sustained attention impact about 63% of children with NF1, with about 35% of children with NF1 fulfilling the diagnostic criteria for ADHD. The ADHD diagnosis may be helpful for some children, as their teachers and schools may know how to cope with ADHD and, therefore be able to implement strategies in the classroom. However, the ADHD diagnosis is not applicable to all NF1 children who exhibit attention problems, and the children that fall through this gap may well have attention problems that impact them academically, just as severely as those with the ADHD diagnosis.

Children who have attention deficit problems have difficulty paying attention and/or concentrating. They may have trouble sitting still and listening at school. It often appears as though they are willfully not listening. They may have difficulty finishing a task, unless it is especially interesting or exciting to them. They often have active minds that will wander off when they are supposed to be focused on schoolwork or a specific, required activity.

MYTHBUSTERS

Myth 1: **Children have to be physically hyperactive to have ADHD.**

Although highly active kids are the ones that are noticed first, many children with attention problems do not show obvious physical signs of hyperactivity like constant fidgeting or toe tapping.

Myth 2: **Kids will outgrow the disorder.**

Children may learn to manage their ADHD, but the disorder often persists into adulthood.

Myth 3: **Kids with ADHD are being difficult on purpose.**

Children with ADHD may be trying desperately to sit still or follow the rules. In spite of their best efforts, they may appear disobedient.

Myth 4: **Kids with ADHD can never pay attention.**

Children with ADHD often have an increased challenge staying attentive to tasks that they have little interest in, or to tasks that involve a lot of repetition. Alternatively, they may be quite alert when it comes to an activity they enjoy, or have great interest in.

Myth 5: **Medication is the answer.**

Medication, such as Ritalin, helps some children to focus and experience less hyperactivity; however medication must be part of a larger treatment plan that may include diet, exercise, parenting strategies and behaviour modification treatment. Ritalin is an amphetamine and has its own set of complications.

Myth 6: **The child with ADHD will never amount to anything.**

Many famous artists, scientists, business owners, politicians and other successful individuals have ADHD; some claim their successes are a result of the qualities that come with ADHD, as opposed to in spite of ADHD.

Factors that have been proven NOT to be the cause of ADHD:

- Poor parenting
- Family problems
- Bad teacher/ineffective schools
- Too much television
- Refined sugars
- Food allergies
- Diet

Clarifying some of the common myths around ADHD with the learning team can go a long way to understanding.

STRATEGIES FOR THE SUCCESS OF THE CHILD WITH ATTENTION PROBLEMS

Establish an Effective Learning Environment for a child with attention problems by reducing the risk of distraction. The following suggestions may be helpful both in the school and at home:

Environmental Factors:

- Carpeting in the study environment can greatly reduce auditory distractions.
- Seat students with attention deficits 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 traffic areas, doors or windows; these can all be distractions.
- Use of headphones for desk workwill 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

The following list of suggestion can help in the child understanding instructions:

- » 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.
- » Simplifying complicated directions, and ensuring that instructions are manageable, trying to avoid multiple commands.

- Frequent checks for assignment progress and completion can really help the child stay on task.
- Checking in to make sure the child with attention deficits fully understands the instructions before he/she begins the exercise.
- If the student asks for the instructions to be repeated, doing so in a calm and positive manner helps with his or her comprehension.

MODIFICATIONS FOR THE STUDENT WITH ATTENTION DEFICITS

- Adapt and modify tests - make certain that 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, under standing that the child with attention deficits may work slowly.
- Ensure that your child's learning team works with his/her agenda or calendar. This is the most important tool you will have for helping 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. If a child is medicated for improved attention span during the day, often this benefit is no longer avail able to them in the evening, which can present a huge challenge for the child. Assign homework accordingly.

ADHD SPECIFIC INFORMATION

Although this section is about ADHD specifically, you may find that some of the information or strategies may be very helpful to the child that has sustained attention problems but not ADHD.

It is now considered that there are three patterns of behavior that indicate ADHD. Children with ADHD may show several signs

of being consistently inattentive. They may have a pattern of being much more hyperactive and impulsive than others of their age, or they may show all three types of behavior. The three subtypes of ADHD recognized by professionals are the predominantly hyperactive-impulsive type (that does not show significant inattention); the predominantly inattentive type (that does not show significant hyperactive-impulsive behavior) sometimes called ADD-an outdated term for this entire disorder; 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.

Symptoms usually begin before the age of seven and can cause serious difficulties in home, school and in public. ADHD can be managed through behavioral or medical interventions, or a combination of the two. It is most commonly diagnosed in children when they reach school age.

Hyperactive - Children with hyperactivity type ADHD can look as if they are constantly in motion. They may touch or play with whatever is in sight, or talk constantly. They may experience great challenges sitting still at the dinner table or in a classroom. Often listening to a story can be a very difficult task for a child with ADHD. These students may squirm and fidget in their seats or roam around the room,wiggle their feet or noisily tap their pencil. Hyperactive teenagers or adults may feel internally restless. They often report needing to stay busy and may try to do several things at once.

Impulsivity - Children with impulsivity type ADHD seem unable to curb their immediate reactions or think before they act. They may blurt out inappropriate comments or answers before the whole question has been asked. They may display their emotions openly and without restraint, or act without concern for later consequences. Their impulsivity may make it hard for them to wait for things they want or to take their turn in games. They may grab a toy from another child or hit when they're upset. As teenagers or adults, they may

impulsively choose to do things that have an immediate, but small payoff, not being able to wait for greater, but slower reward.

Inattentive- Children with predominantly inattentive type have a hard time keeping their minds on any one thing and may get bored with a task after only a few minutes. If they are doing something they really enjoy, they have no trouble paying attention. Focusing deliberate, extended attention to organizing and completing a task or learning something new can be very difficult for these children. They may look like they are daydreaming, spaced out or easily confused, or lethargic. They may have difficulty processing information as quickly and accurately as other children. When the teacher gives oral or even written instructions, this child has a hard time understanding what he or she is supposed to do and may make frequent mistakes. The child may also sit quietly, and even appear to be working, but not fully attending to or understanding the task and the instructions.

Homework can be particularly hard for children that experience this type of ADHD. They often forget to write down assignments, or leave them at school. They may forget to bring a book home, or bring the wrong one. The homework, if finished, is full of errors and corrections. Homework is often an area of much frustration for both the child and the parents.

Children with the inattentive type of ADHD don't show significant problems with impulsivity and hyperactivity. They may get along better with other children than those with the more impulsive and hyperactive types of ADHD do, and they may not have the same sorts of social problems so common with the combined type of ADHD. Their attention problems may be overlooked completely leaving the child without the help that they need to succeed in the classroom.

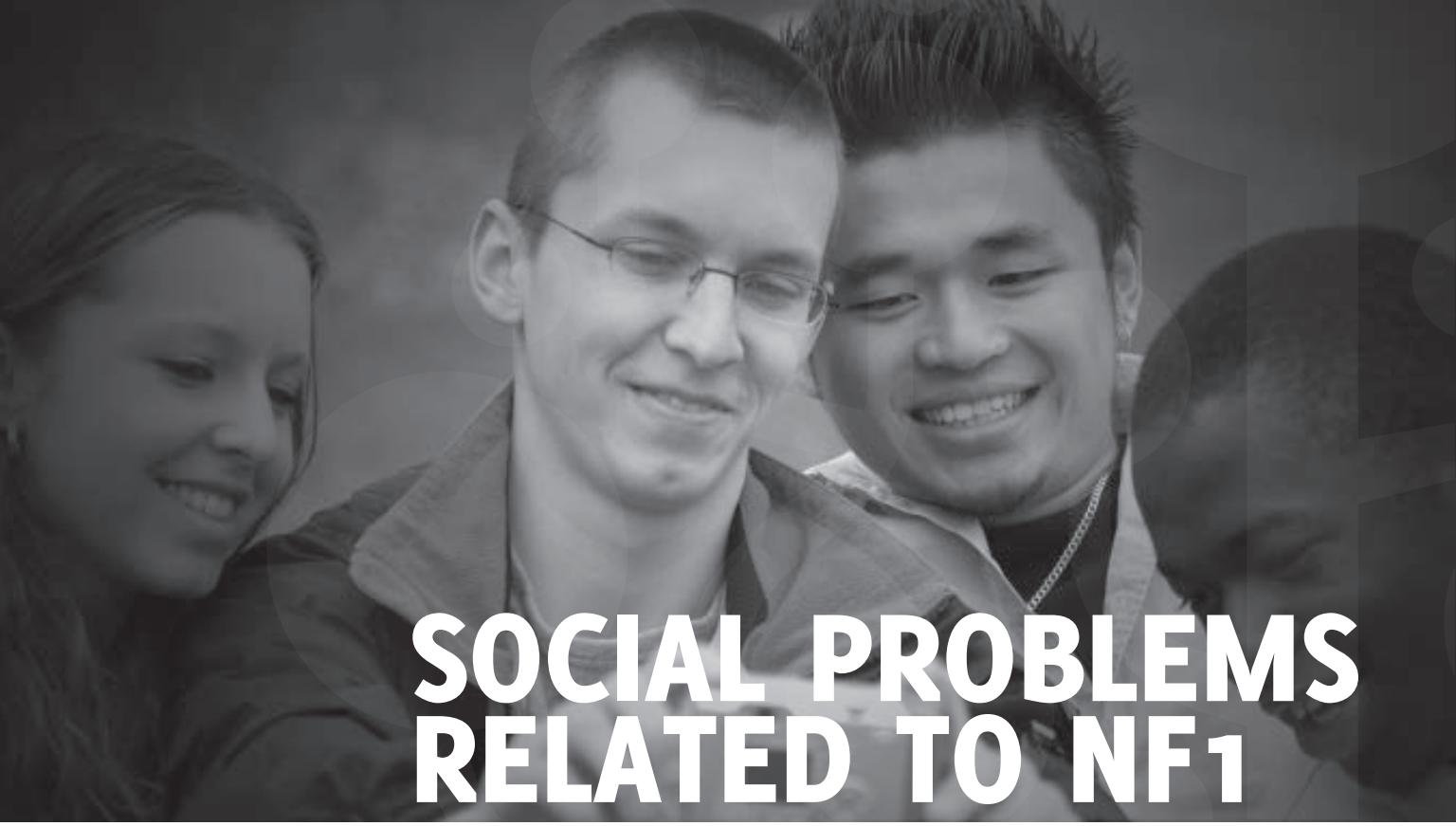
The combination hyper-activity-impulsivity and inattentive type will present with some symptoms from both types but not all. The combination and severity will differ with each child.

STRATEGIES FOR COPING AND COMPENSATING FOR THE CHILD WITH ADHD

You are encouraged to share any of these suggestions that make sense to you with your child's learning team.

- A student with ADHD may need breaks where he/she can move around a bit.
- Try to prepare student ahead of time for times of change, such as planned field trips, assemblies, or when the regular teacher will be away.
- Respect the child - treat the student as you would any other student - especially in front of his/her peers.
- Consistency with directions and discipline is very important when dealing with a student with ADHD. It is imperative that the student understands both the rules and the consequences for breaking them.
- Raising your voice can be completely ineffective with the child with ADHD, as he/she may not understand the meaning, or may not even hear the raised tone.
- The use of positive language with a student with ADHD 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 for the child.
- The child with ADHD 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, as he/she can get confused or distracted and then feel frustrated.
- 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 two to three tasks per request 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 with ADHD to 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 other students understand the reasons for this child's behavior, they often become more accepting of this individual - both in the school and play setting.
- Children with ADHD have a lot to handle in just fitting into the institutional environment and the 'norm'. This can be very stressful for them and they may have problems monitoring appropriate behaviours at times with the weight of this extra stress. Thus, having a 'time out' process set up before hand 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. It may serve you better to be informative to the teacher and not prescriptive.



SOCIAL PROBLEMS RELATED TO NF1

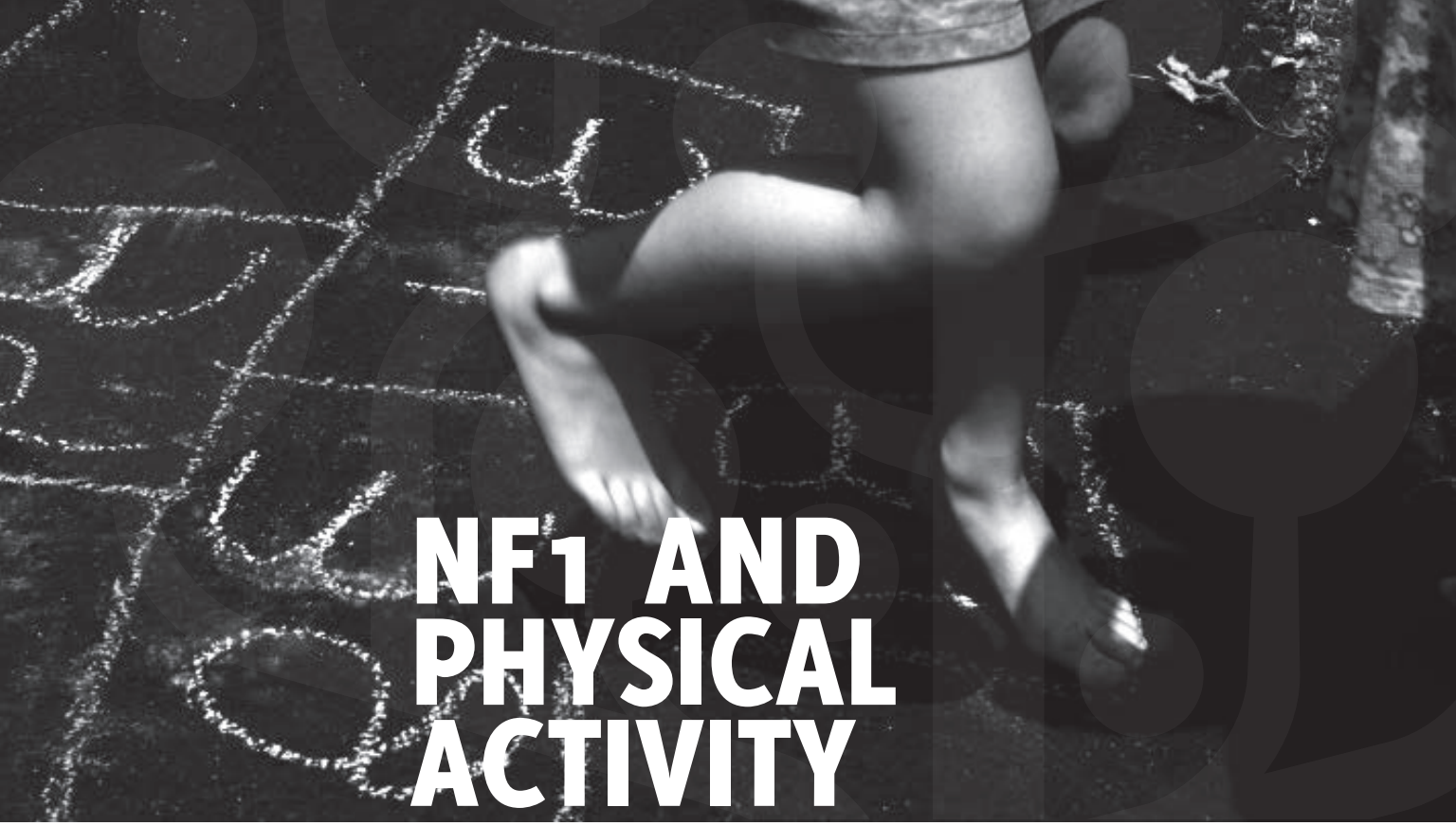
Children with NF1 often have significantly poorer social outcomes than their unaffected siblings. Almost 40% of children with NF1 experience social problems in the borderline/clinical range. It appears that social problems often are combined with attention problems in NF1, with almost one third of NF1 children having borderline/clinical problems in both areas.

Children with NF1 and ADHD have significantly more social problems than children who only have NF1. This result is not surprising, since ADHD is a disorder that is characterized by impaired social functioning, inattentiveness, impulsiveness and hyperactivity. It appears to be the ADHD, which creates roadblocks to social performance, rather than the NF1 itself, thus it is an area, which needs to be addressed in any NF1 children who also deal with ADHD.

They are also a number of characteristics that are often seen in children with learning disabilities that contributes to awkward social interaction. Children with learning disabilities may:

- appear to be disinterested in the opinions of others or inpatient with them as they speak
- have difficulty in that back-and-fourth of a conversation, resulting in the child interrupting or talking out of turn
- misinterpret the feelings of others
- be unaware off when his or her behaviours are annoying
- 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

More information on the social challenges related to learning disabilities can be found on the Learning Disabilities Society's website at *ldsociety.ca* ↗



NF1 AND PHYSICAL ACTIVITY

In general, children with NF1 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. Your child's physician or pediatrician will point out any restrictions on his/her physical activity. Include copies of any restrictions or recommendations from your child's doctor in their IEP and share this information with the learning team.

MOTOR DEFICITS

It is clear that children with NF1 have an increased challenge in the development of skills in both the fine and gross motor areas.

Motor coordination is the result of a complex set of cognitive and physical processes. Smooth, targeted, and exact movements, gross and fine, involve the exact functioning of sensory input, central processing of this information in the brain and coordination with the higher executive cerebral functions, and finally carrying out of a certain motor pattern. These elements must work in unison and in a rapid way to ensure the execution of complex movements with the different parts of the body.

GROSS MOTOR SKILLS

Gross motor skills are the skills that allow your child to carry out activities that require the coordination of large muscles and large groups of muscles. Examples of gross motor skills are running, jumping and hopping. Gross motor skills require balance and coordination.

FINE MOTOR SKILLS

Fine motor skills consist of movements of small muscles that act in an organized and subtle fashion. Fine motor skills are those skills that allow your child to develop the ability to do such things as write and manipulate small objects. Some examples of fine motor activities are painting, sewing, drawing, imitating facial gestures and/or whistling. Many children who have difficulties in their fine motor skills also have difficulties in the articulation of sounds or words.

Children with NF1 have tested significantly lower in tests of both fine motor coordination and motor speed tested, with almost 30% of them having received some form of occupational therapy. The results of the current study clearly showed that these motor deficits are the sole contributor to a slowing of information processing. Slowed information processing is highly problematic in the classroom as difficulties maintaining the pace of the general class are likely to negatively impact learning. 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 with fine motor challenges. Children with NF1 who experience difficulties in fine and gross movement quite often express frustration with certain challenging activities.

Statements such as "I hate to draw", "I hate writing", or, "I hate P.E.," 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.

Motor control is something that can be greatly improved when the child is exposed to exercises that help to develop these areas. While the classroom may not be the appropriate place for extended development, both home exercises, non-competitive, extracurricular activities such as occupational therapy, martial arts and swimming can improve not only the child's skills, but also self-esteem in relationship to the use of these skills. Children with developmental coordination disorders often end up feeling isolated, angry, frustrated and sad, thus it is imperative that they are given the skills to overcome some of these problems.

OCCUPATIONAL THERAPY

Ideally occupational therapy will be provided for the student with motor skill challenges by a trained therapist and will be supported by the entire learning team.

Activities to develop fine motor skills in primary years:

- 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.

- Beading, building blocks (such as Lego or Tinker Toys), peg boards, wooden puzzles, are all good fine motor control exercises.
- 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 presentation 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 the child with 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.

SPECIAL CONCERNS REGARDING MOTOR DEFICITS

Some controversy exists regarding how much accommodation should be implemented in school for a child with a motor coordination difficulty (such as a child who has severe problems writing). Opinions differ regarding the extent to which school personnel should intervene. Some think that the child should be expected to practice extensively, with the expectation that handwriting, for example, will improve over time. Others believe that a child with severe writing problems should be allowed to exclusively use a word processing keyboard. In some cases, a child with a writing problem may even dictate his or her thoughts to others rather than doing any writing him/herself.In the end, decisions regarding the creation of the most responsible and efficacious school intervention for any given child can only be decided on a case-by-case basis, after individual evaluations by experienced professionals have been obtained, and in consultation with you, the parent.

THE PSYCHOLOGICAL IMPLICATIONS OF LEARNING PROBLEMS

General lowering of cognitive ability and academic problems at school are likely to negatively impact the self-concept of the NF1 child. Poor self-image may also occur due to the physical features of NF1, which may be cosmetically disfiguring. The psychological effects of NF1 are quite poorly understood. Given the broad range of difficulties of the NF1 child, it becomes difficult for parents and caregivers to minimize the negativity of their disabilities. 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. Consequently they minimize the practice and therefore do not develop the skill. Their continued failure leads to further loss of confidence, self-esteem, and motivation. 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 affects 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. This may be due to the child not completing work within the allocated time or due to disruptive behaviour. It is vital not to "punish" children for behaviour they cannot control (such as impulsivity, distractibility). Unrealistic expectations on behalf of the parent or teacher can lead to extreme frustration for the child with NF1. You cannot force a child with an organic attention problem to sit and pay attention for as long as their peers, or force a child with motor slowing to complete a written assignment in the same time as other children. 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. Children with NF1 often have good strengths and can excel in some (or even all) subjects and areas.

AND LAST BUT NOT LEAST...

Get the support you need – get connected – you're not alone!

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. You can also try your local library - it can usually prove to be a wealthy source of information.

There are numerous associations that are dedicated to improving the lives of the people that are living with NF, learning disabilities, and ADHD. These organizations can often help you find answers to your questions through posted FAQs, or chat rooms, message boards, or even with staff counselors, available by phone or drop-in.

They often offer suggestions for reading material, support group meetings, seminars and workshops, or just a little friendly advice when you need it. Many have resources for both the child afflicted with these disorders, and for their family and support team. Use these resources; they are out there for you. You are not alone with these challenges.

We need your feedback

Now that you've gone through the guide, tell us what you like, didn't like, need to know more about, or would like to see included in a future printing. Our hope is that this guide will evolve as research involves. Please drop us a note

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