



**ADDRESSING EXECUTIVE
FUNCTION: A GUIDE
FOR PARENTS OF CHILDREN
WITH NEUROFIBROMATOSIS-1**

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HOSPITAL • ST. LOUIS
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WHAT IS NEUROFIBROMATOSIS?

Neurofibromatosis Type 1 (NF1) is a common condition. It affects approximately one in every 3000 people. This makes NF1 more common than cystic fibrosis and hereditary muscular dystrophy combined.

A diagnosis of NF1 is made following an extensive physical exam. Your NF doctors are looking for birthmarks (café-au-lait macules) and freckling in the armpits or groin area. Other signs of NF1 include neurofibromas (benign tumors affecting nerves throughout the body), optic gliomas (brain tumors involving the optic nerve), and specific bone abnormalities.

Once a child or adult is diagnosed with NF1, your NF medical team closely monitors for the appearance of specific signs and symptoms. Importantly, NF1 affects people differently during infancy, school-age years, and adulthood. For this reason, young children and adolescents require yearly visits with an NF specialist. In adulthood, visits may become less frequent.

Although NF1 increases the risk of tumor growth, individuals are expected to have generally full and active lives. However, due to the complicated nature of NF1, you/your child should be cared for by a team of specialists, each an expert in the management of NF1. Every member of the team has a particular role. Together, your NF team aims to help you/your child obtain the highest level of health, function and quality of life.

Learning problems are common in children with NF1. In addition to these difficulties, children with NF1 frequently have problems with executive functioning, which can dramatically affect their daily lives.



What is Executive Functioning?

Executive Functioning (EF) is a set of complex brain activities that help control emotion, achieve goals, and manage our daily routines. Children with NF1 are much more likely to have difficulties with EF than children who do not have NF1. Problems in EF may cause difficulties at school and at home.

Normal EF allows us to create a picture of a specific goal in our minds, develop a plan to achieve that goal, and identify the resources we will need to accomplish this successfully. Doing this requires several aspects of EF, including planning, organizing, time management, holding information in our minds while performing complex tasks (working memory), and the ability to examine and evaluate our own behaviors and thoughts (self-monitoring).

Additional EF skills are critical to the successful execution and completion of our goals. For example, we must be able to:

- (1) resist the urge to do other things (response inhibition)
- (2) manage our emotions, frustrations or fears
- (3) start projects in a timely manner (initiation)
- (4) change and adapt as new information arises or mistakes are made (mental flexibility)
- (5) follow through and complete tasks

Children with NF1 have problems with some or all of these skills.





What is the relationship between EF and NF1?

Children with NF1 have difficulties with many EF skills. Their parents and teachers may report that children with NF1 have difficulties with planning ahead, organization, time management, mental flexibility, keeping multiple things in mind at the same time, and response inhibition. In addition, some children have significant problems with sustained attention, another EF skill, leading to the diagnosis of Attention Deficit/Hyperactivity Disorder (ADHD). Because of this, children with NF1 have a higher risk of ADHD than children who do not have NF1.

How do I know if my child has EF problems?

Problems with EF can lead to a wide variety of difficulties that affect development and achievement. Some of these difficulties can be found in all children at some time during their development. While EF doesn't fully develop until young adulthood, children with NF1 may have delays in their development, and may not reach the same level of function as their peers or siblings without NF1.

Signs that children with NF1 might be struggling with EF include the following problems:

- Keeping their room or school supplies organized
- Sitting still for a period of time
- Starting projects (procrastinating)
- Finishing projects, such as homework or cleaning their room, without constant reminders
- Planning tasks on their own
- Following morning or evening routines
- Controlling behaviors when they are frustrated, stressed or disappointed
- Talking out in class, interrupting or saying things without thinking
- Performing math in their heads
- Forgetting to bring home materials needed to complete homework assignments and/or leaving homework at home
- Giving up in the face of challenges or obstacles
- Failing to finish work on time
- Arranging things according to a system
- Estimating the time it will take to complete tasks
- Controlling their frustration or anger when unexpected changes to plans or schedules arise
- Catching or correcting mistakes





What can I do if I suspect my child has problems with EF?

Children with weak EF skills often need to be taught how to improve their performance. Here are a few things to consider when teaching your child EF skills:

- Identify the problem by keeping a record of the difficulties you are having at home.
- Select one or two skills at a time that you would like to work on. It is best to work on one item at a time to build confidence, provide a model for learning, accomplish things in a step-by-step process, and prevent you and your child from becoming overwhelmed.
- Use one of the resources below to help you select a specific strategy that is most appropriate for the type of problem your child is having. Encourage your child to be involved in helping themselves. Encourage them to come up with solutions - often their own suggestions will turn out to be the most successful ones. Allowing your child to help generate the solutions to the problem will also help your child feel invested in a successful outcome.
- Focus on the desired outcome rather than the “problem” behavior. For example, you may choose to say, “You may want to write the assignment down in your daily planner,” rather than blaming them by saying “why are you so disorganized?”

- Model the desired behavior and demonstrate how you talk yourself through the specific task or challenge at hand. For example, if you are trying to teach your child organizational skills at home, you might say, “Oh, I just walked in the house. It’s time to hang up my coat. Where does it go? On the hook. I’m tired. I don’t want to put my shoes away, but I can do it. I just put them in the cubby. That wasn’t so bad”. Eventually, your child may perform this self-talk exercise aloud before proceeding to silently reminding themselves.
- Praise and reward your child for each small step in the right direction! Improving EF skills is hard work for everyone involved, and it is extremely important to celebrate each small success. Rewards include providing your child with an extra privilege such as staying up 15 minutes past their usual bedtime or playing a game with your child for an extra 15 to 20 minutes. It might be helpful to keep track of your child’s progress with a chart, so that he or she can see how much improvement is being made. For example, each week you might document the number of assignments your child turned in on time.

Here is an example of a step-by-step plan for teaching an EF skill:

Many children have trouble keeping a clean bedroom. To tackle this specific problem, you should develop a plan with your child for organizing their room. Help your child feel invested in the plan by explaining how keeping the room organized will benefit them. For example, you will bother the child less about picking up, and he or she will have more free time, because everything will be easier to find!

- **Step 1:** Reduce the amount of stuff in the room! It is always easier to organize belongings when there is a manageable amount of items.
- **Step 2:** Select an organizational scheme that makes sense to your child. Here are some examples:
 - Use colored boxes or bins for each type of your child's belongings. For example, use a blue bin for sports gear, a red bin for art supplies, and a yellow bin for blocks and building items.
 - Label shelves and drawers in the room so it is clear where everything belongs.
 - It may be helpful to take a picture of each part of the room when it is well organized. This will provide a reference for your child of what the room should look like when everything is in its place.
- **Step 3:** Create a "drop off space" for your child to put their school bag and a specific bin/space to store things that need to be put away later.
- **Step 4:** Work through the plan step by step with your child
- **Step 5:** Create a simple reward system to reward your child for maintaining the organizational system. For example, if your child is successful during the week, he or she might get to choose a later bedtime or have a friend come over to play during the weekend.
- **Step 6:** Revise the plan as needed.



If you think that the problems you are seeing are more severe than what you can manage at home, your child might benefit from a formal evaluation of his or her EF skills. He or she also may benefit from support from a psychologist or an executive function coach. Talk to your pediatrician about a referral. After assessment, your child might qualify for extra support at school. More information about your child's rights for these educational services can be found in the Washington University/St. Louis Children's Hospital NF Center brochure, entitled "Addressing Academic Concerns: A Guide For Parents Of Children With Neurofibromatosis 1". This can be found on our website at <http://nfcenter.wustl.edu>.



Where can I get more information?

Additional information about EF skills can be found in the following resources:

Books on Executive Function

Late, Lost, and Unprepared: A Parents' Guide to Helping Children with Executive Functioning by Joyce Cooper-Kahn, Ph.D. and Laurie Dietzel, Ph.D. (Woodbine House, 2008)

Smart But Scattered by Peg Dawson, Ed.D. and Richard Guare, Ph.D. (The Guilford Press, 2009)

Executive Functioning Skills in Children and Adolescents, Second Edition: A Practical Guide to Assessment and Intervention by Peg Dawson, Ed.D. and Richard Guare, Ph.D. (The Guilford Press, 2010)

Where's My Stuff? The Ultimate Teen Organizing Guide by Samantha Moss (Zest Books, 2007)

The Organized Student: Teaching children the skills for success in school and beyond by Donna Goldberg (Fireside Books, 2005)

Super study skills: The ultimate guide to tests and studying by Laurie Rozakis, Ph.D. (Scholastic Inc., 2002)

Websites for Local and National Resources

Washington University Neurofibromatosis Center
<http://nfccenter.wustl.edu>

St. Louis Children's Hospital
www.StLouisChildrens.org

Missouri Special Education
www.dese.mo.gov/divspeced

Illinois Special Education
www.isbe.state.il.us/spec-ed

National Research Center on Learning Disabilities
www.nrcld.org

Neurofibromatosis, Inc.
www.nfnetwork.org

Children's Tumor Foundation
www.ctf.org

Parent Advocacy Groups

State Learning Disabilities Association
http://ldaamerica.org/state_chapters/index.asp

State Parent Training and Information Center
<http://www.taalliance.org/centers/>

Missouri Protection and Advocacy Services
573.659.0678 or 800.392.8667

MPACT (Missouri)
816.531.7070 or 800.995.3160 or 877.876.2831

Family Matters (Illinois)
217.347.5428 or 866.436.7842



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One Children's Place
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314.454.KIDS (5437)
<http://nfcenter.wustl.edu>

*This brochure is provided through the generosity of the
Doris and Donald Schnuck Fund for Children in Need
and the St. Louis Children's Hospital Foundation.*

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