

section

1

The Impact of Neurofibromatosis
on the Family

The Impact of Neurofibromatosis on the Family

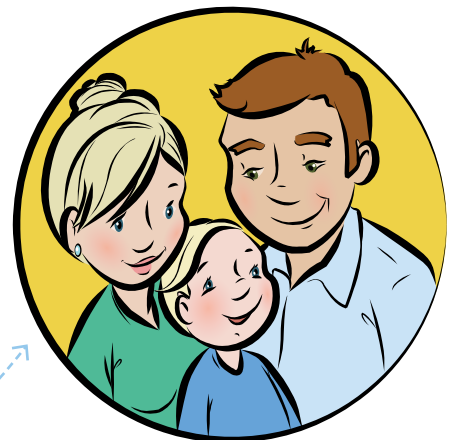
A diagnosis of neurofibromatosis (NF) in a child impacts the entire family. It may heighten emotions that can add to the usual challenges of daily living. In addition to the stress that a diagnosis of NF brings to families, associated conditions, such as attention deficits, behavioral problems, and difficulties with social interactions, can add more stress and further impact quality of life for the family.

You Are Not Alone: Support and Information to Help You and Your Family

The NF Parent Guidebook: How to Help Children With Learning Challenges Associated With Neurofibromatosis Type 1

It is important that families with NF know that they are not alone. Many families experience these difficulties both immediately and long after the diagnosis. The *NF Parent Guidebook* is a home-based resource designed to provide support and education to families throughout their NF journey. The information the program provides is based on surveys and studies completed by other parents just like you.

The *NF Parent Guidebook* can be completed at your own pace and convenience, and it can be repeated as many times as you would like. The *NF Parent Guidebook* contains useful information and resources to help guide you through your journey with NF and associated learning, behavioral, or social deficits. It is important to understand that The *NF Parent Guidebook* is *not* a tool for diagnosis or a replacement for medical or developmental evaluations. It is a place to find ideas, strategies, and suggestions that will help you understand and meet the needs of your family and child.



family

strategies

Parenting Strategies

After a child has been diagnosed with NF, it is common for the family to feel overwhelmed with stress and emotion. Parents may find it challenging to keep normalcy at home while adjusting to meet their child's needs, such as a schedule filled with doctor's appointments. The affected child's siblings will likely also be impacted and may find it difficult to understand situation.

Here are a few parenting strategies that may help keep you from becoming overwhelmed:

- Learn about your child's diagnosis—knowledge is power!
- Be consistent
 - When possible, share the parenting duties
 - Try to choose your battles and not “sweat the small stuff”
- Understand your children and their individual needs and strengths
- Encourage your family to work as a team
- Develop a routine, as structure can be comforting
- Remember that you are not alone; consider attending support groups
- Above all, try to maintain a sense of humor

Remember that
you are not alone.



strategies

Taking Care of Yourself and Your Relationships

Often, caring for your children seems to leave little time for anything else. It is important to remember that taking care of yourself and your relationship with your significant other are two of the most important things that you can do, for both yourself and your family.

Before getting started, keep in mind the following suggestions:

Learn as much as you can about your child's diagnosis and the issues that you will face together as a family

Try not to take your child's issues personally

Practice compassion, for yourself, for your child, and for your close friends and family

Keep a "disability perspective," to help shape your responses to your children; this perspective means being sensitive to the needs and abilities of your child

Try to remember that parenting is not the cause of your child's difficulties, but it can help lessen the impact of the symptoms

compassion



activity to share with your child

1



Print this page for your child!

color me in

Moxie and Sparx are here for you!

Print this page and color it in. When you're done, hang it in a place where you will see it, such as on your refrigerator.



Moxie

Sparx