

DISCUSSING NEUROFIBROMATOSIS WITH YOUR CHILD



**Tumour
Foundation
of BC**

INTRODUCTION

Initiating a conversation with your child about neurofibromatosis (NF) can be a daunting task for many parents. Most feel unprepared to navigate this discussion successfully. There isn't a one-size-fits-all approach and there is no singular 'right' or 'wrong' way to have this conversation. This resource provides helpful tips and suggestions for exploring this discussion with your child.

WHY IS IT IMPORTANT TO DISCUSS NEUROFIBROMATOSIS WITH YOUR CHILD?

Education about NF and discussing this genetic condition openly with your child contributes to their overall well being; giving them the knowledge and skills needed to navigate life with NF effectively and confidently.

Children whose parents openly discussed a genetic diagnosis throughout their childhood exhibit better understanding and insight compared to families who did not¹. Most children, including those diagnosed with NF, express that gradual, age-appropriate disclosure is helpful, allowing them to build understanding at their own pace.

Choosing who should inform the child about NF is pivotal. Children generally prefer their own parent(s) for such important discussions, or someone they trust deeply. As children mature, information from health professionals can supplement parental explanations.

The decision of whom to inform within the family depends on personal preferences. Some families keep the diagnosis private, while others adopt a more open approach. Grandparents can provide valuable support, but it's essential to be mindful of potential negative reactions within the extended family.

While acknowledging the difficulty of discussing a genetic diagnosis, especially when it's new to

the family, it's crucial to recognize the potential positive impact on a child's coping mechanisms. Delaying the conversation can leave children feeling vulnerable and unable to openly express their concerns.

Timing is crucial in these discussions. Choosing a time when your child feels comfortable and attentive, free from distractions, is essential. It's important to manage your own emotions about the diagnosis before talking to your child. While there may be reasons to postpone the conversation temporarily, unnecessary delays should be avoided.

Research suggests that waiting until a child is more grown up is not a better idea. Children learning about their diagnosis at a young age adjust more readily than those where information is withheld. The process of understanding NF begins in childhood, continues into adolescence, and is consolidated in adulthood with the support of health professionals.

When you decide the time is right, initiate the conversation calmly. Be open, encourage questions, and allow your child to lead the discussion. Use simple language and short sentences, and be prepared for unexpected questions.

DON'T LET NF DEFINE YOUR CHILD. LET THEM BE WHO THEY ARE - A BEAUTIFUL WONDERFUL CHILD WHO JUST HAPPENS TO ALSO HAVE NF.

~TERRI

¹ Parents' and children's communication about genetic risk: a qualitative study, learning from families' experiences" Metcalfe A, Plumridge G, Coad J, Shanks A, Gill P
European Journal Human genetics 2011 (6):640-6.

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HOW DO I ADDRESS MY CHILD'S QUESTIONS?

Reassure your child that they can always ask questions and that you will provide ongoing support. Prepare yourself for your child's questions when discussing the NF diagnosis with them. If you're unsure of an answer, don't hesitate to acknowledge it as a great question and assure them that you'll find out and get back to them. As a parent, it's essential to ensure they receive accurate information. The Tumour Foundation of BC website, along with the resources listed in this document, provides comprehensive information about NF to equip you with the knowledge you need to answer your child's questions.

Talking about NF with your child is a gradual process. The initial conversation is just a starting point, and it's essential to keep the lines of communication open as your child processes and understands the information over time.

WHAT ARE THE BENEFITS OF ENCOURAGING OPEN DISCUSSION ABOUT NEUROFIBROMATOSIS (NF) WITH YOUR CHILD?

- **Empowerment through Knowledge:** Understanding their condition can empower your child. It helps them comprehend why certain things might happen to their body, making them more informed and better equipped to handle any challenges that arise.
- **Reduced Anxiety and Fear:** Not knowing or understanding a condition can lead to anxiety or fear. Discussing NF openly helps dispel myths, reduces anxiety about the unknown, and allows your child to face the condition with more confidence.
- **Emotional Well-being:** Open communication fosters trust and support between you and your child. It provides a safe space for them to share their concerns, fears, and questions, which positively impacts their emotional well-being.
- **Improved Decision Making:** Knowledge about NF enables your child to actively participate in decisions regarding their health, treatment, and lifestyle choices. It allows them to communicate effectively with healthcare providers and make informed decisions as they grow older.
- **Building a Support System:** Encouraging open discussions about NF helps your child feel comfortable discussing their condition with friends, teachers, and other trusted individuals. This builds a support network around them, fostering understanding and empathy from others.
- **Early Intervention and Management:** Understanding NF enables early recognition of symptoms or changes, leading to timely medical intervention and management. Early intervention can often prevent or lessen the severity of certain complications associated with NF.

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WHAT ARE SOME TIPS FOR OPENLY DISCUSSING NF WITH YOUR CHILD?

Discussing NF with your child may seem daunting and stressful, but it's a crucial conversation. Here are some tips to help you navigate it:

- **Prepare yourself:** make sure that you understand NF, it's symptoms, and how it may affect your child's life, treatment options, and prognosis. This will empower you to answer your child's questions.
- **Find a quiet and comfortable place:** this will ensure that you will not be interrupted. Choosing a time when you are both feeling calm and relaxed is crucial.
- **Use age appropriate language:** Adapting your explanations to your child's age and level of understanding will help the child more readily absorb the information.
- **Remain positive:** Be honest with your child while highlighting that the disorder does not define him or her as a person. Make sure you highlight the child's strengths, abilities, and accomplishments.
- **Provide a safe space for questions:** Encourage your child to ask questions and express feelings and be prepared to offer non-judgemental reassurance.
- **Offer support:** Reassure your child that you are there to support them on this journey. Explain to them the role of the health care team's role to help manage this condition.

EVEN WHEN YOU THINK YOUR KID DOESN'T KNOW, THEY KNOW. TELLING THEM THE TRUTH HELPS THEM NOT TO WORRY.

~ANONYMOUS

- **Offer resources:** Offer age appropriate books, websites, or support groups where your child can connect with other children that have NF.
- **Be truthful:** Be honest with your child about their NF, but also reassure them that they can live a happy and fulfilling life with NF. Explain to your child that despite the challenges, there are also many ways to manage the disorder and live a meaningful life.
- **Reach out to professionals and NF organizations:** If you are struggling to talk to your child about NF, or you notice that your child is having difficulty coping, reach out to a counsellor, support group, or therapist that specializes in pediatric health.

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WHAT ARE THE SPECIFIC AGE APPROPRIATE CONVERSATION TIPS FOR DISCUSSING NF?

Regardless of the child's age, it's important for the caregiver to initiate the NF conversation with love, acceptance, and open communication. Validate your child's feelings and assure them of your ongoing support. Listen to their questions and concerns without passing judgment. Pay attention to your child's cues and questions showing a readiness to learn about their condition, go at a comfortable pace for you and your child. Assure your child that NF is not something they caused; it's not their fault. You can let them know that the bumps and lumps grow on the body's nerves because of their genes, or something they were born with. Depending on the child's age and maturity level, you may be able to teach them simply about the different types of NF and how the various types affect the body in different ways. Highlighting treatment options and management strategies will reassure your child that there is hope for living a fulfilling life with NF. While a cure for NF is not yet available, advancements in research are bringing us closer to one, and new promising treatments are becoming increasingly accessible.

PRESCHOOL AGE (3-5 YEARS)

- Use simple words that your child can understand. Picture books, dolls, and stuffed animals can be used to create stories and teach about NF in a non-threatening way. Remind the child that they are loved and supported. Please refer to the Resource section of this document for websites and picture books about NF.
- Use simple phrases to help your preschooler understand i.e. "neurofibromatosis is a word that tells us when someone's body has bumps or spots that grow in different places". You can also show pictures of other children that have these NF spots, or you may draw them on a doll.

ELEMENTARY SCHOOL AGE (6-12 YEARS)

- Explain neurofibromatosis in simple terms while offering more details including how it might affect their health and daily life.
- Explain that NF is a condition that some people are born with, causing bumps or spots on the skin or inside the body.
- Reassure that NF it's not contagious, it isn't something they can catch from others.
- Discuss Symptoms Briefly: Mention some common signs such as skin, visual, hearing, learning, or mobility issues, but clarify that not everyone has the same symptoms.
- Briefly mention how doctors can help manage symptoms and this is the reason for more frequent visits with the doctor.
- Remind them that having NF doesn't change who they are or what they can do.
- Let them know you're there for them, always.
- Explain treatments and medical appointments ahead of time in a matter of fact and calm tone.
- Help your school age child to develop self advocacy skills, encouraging him or her to ask questions and voice any concerns that come up.
- Offer resources such as comics, books, and websites that explain NF to this age group.
- This Video provides an age appropriate explanation of NF:

ADOLESCENCE (13-18 YEARS)

At this stage your child is becoming increasingly independent, provide honest, detailed information about NF, including potential challenges short term and long term. Encourage and promote independence within safe boundaries, this will help your teen develop increased self esteem.

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- Encourage your teen to actively participate in discussions with healthcare providers.
- Discuss social and emotional implications of NF recognizing that socialization with friends is a critical developmental focus of this stage.
- Adolescents may have a range of emotions about their diagnosis, including fear, anger, or sadness. Let them know that it's normal to have these feelings and that you're there to support them. Encourage them to talk about how they're feeling and listen to what they have to say without judgment.
- Teens with NF may be self-conscious about their appearance due to the visible symptoms of the disorder. Talk to them about body image and self-esteem and reassure them that they are valuable and worthy. Be supportive of your teen's clothing and style choices when these foster increased self esteem. Continue to celebrate strengths and accomplishments to promote the teen's confidence.
- Offer support, encouragement, coping strategies, opportunities to meet other adolescents living with NF.
- Encourage conversations about the future, giving your teen a safe space to voice concerns and fears. Talk about their dreams and goals for the future, consistently offering encouragement and support.
- Provide resources such as websites and support groups for your teen to explore.

PROMOTING SELF-CONFIDENCE IN YOUR CHILD WITH VISIBLE PHYSICAL MANIFESTATIONS OF NF

Children with NF can have a wide range of visible physical characteristics depending on the type and severity of the NF. These physical characteristics can range from mild and undetectable to more pronounced and noticeable. Some children have cafe-au-lait spots, cutaneous neurofibromas, freckling, bone abnormalities, learning disabilities, short stature or mobility challenges, learning disabilities, visual or hearing disabilities, depending on the type and severity of their disorder.

Your child will look to you for acceptance and unconditional love, having these needs met will promote a positive body image and self esteem. Recognizing and celebrating your child's unique strengths and qualities in their daily life can greatly enhance their sense of self-worth. Does your child possess artistic talents, a special connection with animals, an ease with gardening, musical talents, culinary skills, or any other unique qualities? Embracing these qualities can enhance their self-esteem and sense of belonging.

Infuse positivity into your conversations with your child. Instead of focusing on others' physical appearance, highlight their personal strengths such as kindness, positivity, or perseverance. Encourage your child to see the best in people and appreciate their inner qualities.

Finally, your own actions and attitudes serve as a role model for your child. By showing acceptance and empathy towards those who are different, you teach your child to follow your example. This promotes compassion and inclusivity, guiding your child in social interactions with others.

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HOW IMPLEMENTING REGULAR FAMILY MEETINGS CAN ENHANCE COMMUNICATION IN THE HOME

Family meetings are regularly planned sessions where family members gather to share their feelings, discuss concerns, and collaborate on problem-solving. These meetings foster cooperation and trust among all members. According to HealthLinkBC Health-wise authors, the benefits of family meetings are significant, including giving children a voice in decision making, helping them learn social skills, problem-solving techniques, and allowing them to express their thoughts and opinions. Consider holding regular family meetings where neurofibromatosis is openly discussed, challenges are communicated, and all family members have the opportunity to offer and receive support. For more parenting resources visit the HealthLinkBC website:

WHERE CAN I SEEK PROFESSIONAL SUPPORT TO ASSIST ME IN NAVIGATING THIS CONVERSATION ABOUT NEUROFIBROMATOSIS (NF) WITH MY CHILD?

Pediatrician: Your child's Pediatrician is equipped with the knowledge and tools to assist you in breaking down the complexities of NF in an age appropriate way for your child to understand. Voice your concerns and fears in discussing the NF diagnosis with your child's Pediatrician and seek guidance and support.

Psychologist: A child psychologist can be an invaluable resource if you feel overwhelmed by the prospect of having this conversation with your child. These professionals are trained to communicate difficult news to children in an age-appropriate and sensitive manner. They can provide guidance not only on how to deliver the diagnosis but also on how to support the child's emotional needs and help them understand and cope with the diagnosis. Additionally, they can offer strategies for parents who may feel overwhelmed or afraid to discuss NF with their child. One resource is the Psychology Department at BCCH:

You will need a referral from the pediatrician or your general practitioner i.e family doctor to access this specialist service. Alternatively, you may contact your family doctor to request a referral to a Psychologist in your geographical area.

Counsellor: A pediatric or family counsellor can be a tremendous resource in providing support and coping strategies for both the child and the caregiver. The BC Association of Clinical Counsellors can help you connect with a registered counsellor or psychotherapist in your area. This connection can provide the safe space you need to have the difficult conversations with your child.

Urgent Mental Health Support in British Columbia: If you or your child are experiencing feelings of distress, despair, or hopelessness, please call the **BC Mental Health Support Line at 310-6789**. Trained mental health professionals are available to provide immediate support and connect you with valuable resources.

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HERE ARE SOME WORDS OF WISDOM
AND ENCOURAGEMENT SHARED BY OUR
NF COMMUNITY MEMBERS::

*“Don’t let anyone tell [your child] what they can
and can not do.” ~Tammy*

*“It is YOUR strength and resiliency to the
diagnosis that guides your child through their
NF journey.” ~Anonymous*

“One day at a time!” ~Lisa

*“Everyone has their own gifts. You bring yours
as well and use them to the best of your ability.”
~Colette*

YOU ARE NOT ALONE!
~ANONYMOUS

CONCLUSION

Navigating neurofibromatosis with your child is a significant step in successfully managing the disorder. Having open and honest conversations with your child will facilitate a positive relationship built on trust and mutual respect. You will empower your young person to understand their NF, recognize crucial changes in their health, and self advocate in the healthcare system. Your unconditional positive regard for your child will foster self confidence and hopefulness. Children often fear the unknown, giving them accurate and timely information about NF will give them the tools to manage the disorder.

The Tumour Foundation of BC is eager to join forces with you on this journey. We offer education, support, and a multitude of resources to ensure you are not alone in navigating NF. Reach out to us – we’re just a phone call away at **1-800-385-2263** (toll-free). For further resources, visit our website:

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REFERENCES AND RESOURCES

CHILDREN'S TUMOR FOUNDATION

The Children's Tumor Foundation offers a range of online resources tailored for children to expand their knowledge about NF. Explore these resources to find engaging comics and additional educational materials designed specifically for children.

PARENT GUIDEBOOK

The Tumour Foundation of BC provides a complimentary downloadable resource for parents of children with NF. Visit our website to access this invaluable tool, where you'll discover insights into the distinctive developmental challenges faced by children with NF, strategies to help your child, and practical tips for educating your child's teachers about the disorder.

NF BUDDIES

A beautifully illustrated children's book explaining neurofibromatosis in a positive and affirming way. Children can browse through pictures of other children that have similar manifestations of NF.

NF STORIES LIVE

The Tumour Foundation of BC's *NF Stories Live* is an online video collection resource. Watch the videos with your child to get introduced to other individual with NF and to hear their stories. These real stories can encourage you and your child and avoid feelings of isolation in living with neurofibromatosis.

ONLINE COMMUNITY

The Tumour Foundation of BC's *Online Community* offers the NF Families Facebook group and the Foundation's online monthly support group meetings on Zoom. These resources are a powerful way to stay connected with other families living with NF, to bounce off ideas and questions and find valuable recommendations and support related to your child's NF care.

The Children's Tumor Foundation's *NF Parent Guidebook* provides helpful support and education to families affected by NF. Visit the website for a downloadable version of the handbook.

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THE BC ASSOCIATION OF CLINICAL COUNSELORS

Use the website to find registered counselors or psychotherapists in your geographical area.

RELATIONSHIPS AND EMOTIONAL HEALTH

This website contains a wealth of resources regarding family relationships and parenting.

BC CHILDREN'S HOSPITAL (BCCH) PSYCHOLOGY SERVICES

The Psychology department at BCCH supports children and families experiencing acute and chronic health conditions and mental health disorders. Psychological services include assessments, diagnosis, therapy, and consultation. This service can be accessed through a referral sent by the child's pediatrician.

MAYO CLINIC HEALTH SYSTEM

Promoting Healthy Body Image in Children, Teens

– this article discusses how parents can interact with their children in a way that fosters confidence and a positive body image.