

Talking to Your Child About **NF1**

A Guidebook for Parents





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It can be hard to know how to talk to your child about their diagnosis of neurofibromatosis type 1 (NF1). Many parents and caregivers have questions and concerns or may not know where to start. This resource was created to provide support to parents and caregivers. The information in this guide was gathered from studies that explored how caregivers talk to their children about genetic conditions, including NF1. This resource can be used independently or along with the accompanying children’s resource, “Super Emerson,” which is available at ctf.org/education.

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References for this resource and for “Super Emerson” can be found at ctf.org/superemerson

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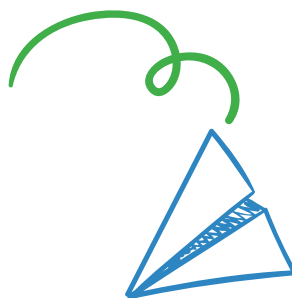
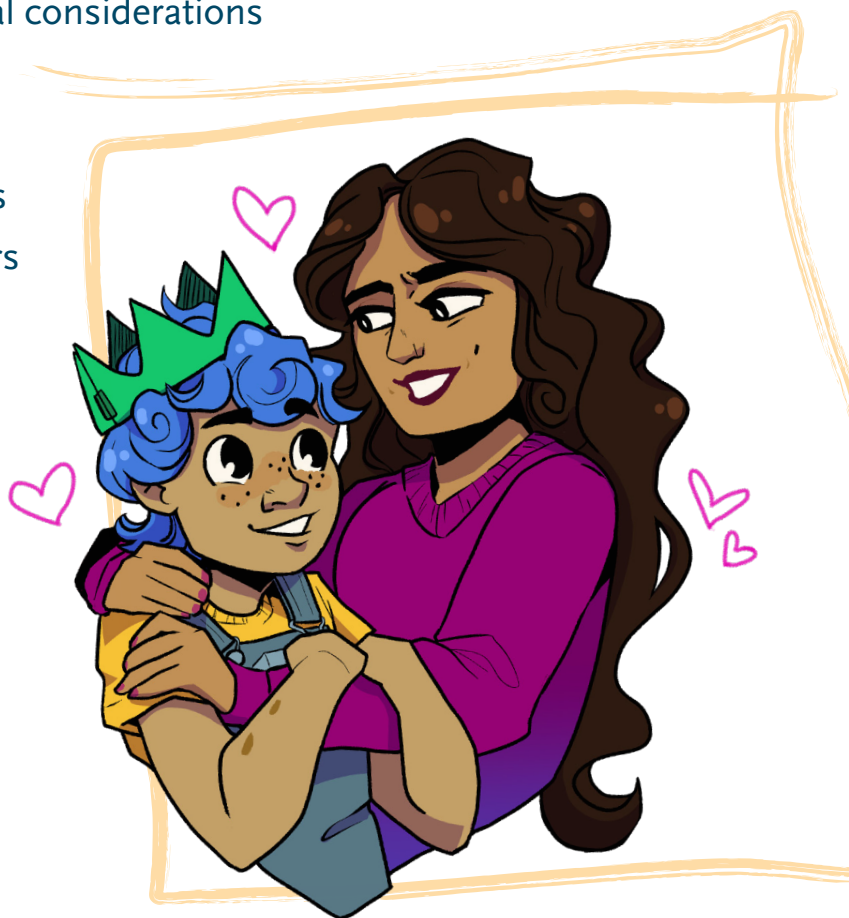


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Reasons to talk to your child about NF1

It is important to talk with children about their diagnosis. Studies have found that children with NF1 have some idea about their condition by age 8, even without being told, and most children want to learn and know more about having NF1. Parents and caregivers can create a safe, age-appropriate, and honest space for these conversations. Talking with your child about NF1 may:

- Strengthen family relationships and trust
- Increase the independence of your child
- Reduce your child's anxiety
- Enable your child to take an active role in their medical care
- Help your child cope with and accept the diagnosis
- Clarify misunderstandings or misconceptions
- Explain the reasons for medical appointments and tests
- Allow your child to understand how the diagnosis impacts themselves and others



Prepare to talk to your child

- Take time to learn about NF1
- Prepare yourself so that you can calmly talk to your child without your own fears and emotions impacting the conversation
- Reach out to your child's healthcare provider for guidance and questions
- Plan who will be present, where the conversation will be, and the best time to discuss NF1 with your child
- Consider practicing what you'll say to your child – either on your own or with another person (e.g., another caregiver, friend, or counselor)
- Remember that you don't have to get everything right the first time; it is okay to make mistakes and not have all the answers
- Recognize that they may have a variety of feelings and reactions, and that is okay
- Be ready to modify the discussion based on your child's understanding, questions, and reactions



What is NF1?

There is a lot to learn and understand about NF1, and the unpredictability of the condition can be a challenge. Learning about NF1 first will help you talk about it with your child. Here are a few helpful tips for your conversation. There are also resources at the end of this guide where you can find more information.

- NF1 is caused by a genetic change in the *NF1* gene. (When we speak of the *NF1* gene it is in italics to differentiate it from the diagnosis, or condition, of NF1.)
- Half of the time (50%) a child inherits NF1 from a parent, while the other half (50%) of children are born with a new change in the *NF1* gene.

TAKING IT ONE DAY AT A TIME

With NF1, there are a lot of unknowns, such as what features your child will develop. It is important to support your child through the uncertainty.

NF1 is Variable

Some individuals have very few characteristics, while others have many. Here are some common physical features:

- Café-au-lait spots (brown skin spots often referred to as birthmarks)
- Freckling, especially around the armpit or groin regions
- Neurofibromas (benign tumors that grow on nerves)
- Optic glioma (tumors of the optic pathway that sometimes cause vision issues)
- Learning disabilities or behavior problems
- Short stature
- Softening and curving of bones

Clinic visits and monitoring are needed for the care of an individual with NF1.

CLINICAL DIAGNOSIS

Genetic testing is not required for a diagnosis of NF1. Some people are diagnosed with NF1 in a doctor's office without genetic testing. This is referred to as a clinical diagnosis.



Approaches to tell your child

- Tell your child in a calm and patient way
- Take your time
- Talk to them in private
- Be honest
- Start broadly and remember the discussion does not have to take place all at once
- Encourage questions and comments
- Stay positive and make sure your child knows you are there to support them
- If you have multiple children affected, each may benefit from their own disclosure conversations

KEEP COMMUNICATING

Open and honest communication is important. It can lead to mutual trust and reduce anxiety. Encourage your child to tell you or a trusted adult about changes they may notice in their body such as lumps, bumps, pain, itching, vision changes, dizziness, or stomach problems.

Learning and attention difficulties

Some children with NF1 have difficulty with learning and attention. These challenges might affect life in school or at home. Additional support at school or help at home may be needed. But remember, a diagnosis of NF1 does not mean that your child will not have many accomplishments or be independent. Many individuals with NF1 are highly successful.

We all must celebrate our successes and not compare ourselves to others. Children need to accept all parts of themselves. They can benefit from open and supportive conversations about their challenges with caregivers, teachers, and other trusted individuals.



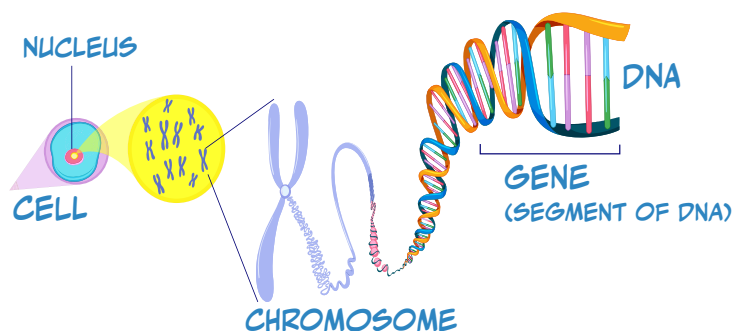
When to begin the conversation

In a study focused on collecting caregiver advice and experiences, the average age at which discussion about NF1 began was around five years old. While most caregivers found it helpful to tell their child in stages as they grew up, this may not be the right approach for you. Here are some things to consider when determining the right time to talk to your child about their NF1:

- Because the diagnosis of NF1 is often made in early childhood and screening begins shortly after the diagnosis is made, children may be curious and benefit from a general understanding of why they go to the doctor more frequently than their siblings or friends.
- Your child may start to ask questions first and initiate the conversation. This is a good, natural prompt for discussion.

Talk about genetics

- Talking about the genetics of NF1 is often a discussion later in childhood. However, it is important to emphasize that having NF1 cannot be controlled; they need to know that it is not their fault that they have NF1.
- For older children: Explaining genetics can be complicated because it is not something that the child can see. Applying something tangible to genetics can be beneficial. For example, explain that all 46 chromosomes make up an “instruction manual” or “a book,” where each chromosome is a “chapter,” and the genes are “sentences” that are the instructions.



GENES

Genes can be explained as the instructions for the body that we receive from our mother and father. Genes determine what we look like, such as our height and eye color, as well as if we have a genetic condition, such as NF1.

Advice from Caregivers of Children with NF1



There is no single approach to talking to your child about NF1.

Below are some suggestions from other parents, and you can decide which may be right for your family:

- Take care of yourself and calm your own emotions before the conversation.
- Instead of creating an event around the discussion, use a casual and calm approach, which might be less overwhelming for the child.
- Observe when your child starts to pay more attention to clinic visits or notice differences between themselves and others. This can lead to a natural conversation.
- Be open and honest with your child.
- Have conversations with a positive approach and help your child see all the things they can do.
- Tell your child small amounts of information at a time to avoid overwhelming them.
- Normalize your child's condition and explain that your child is not alone and there are many other people with NF1. It may help to find other families who have children with NF1.
- Give your child time to process the information.
- Remind them that no matter what happens, you will be there to support them.
- Remember that internet searches may not be accurate or might show only the most severe cases of NF1. Support your child in their own research by providing reliable resources and links.
- Try not to tell your child to feel a certain way. Let them feel what they feel and encourage them to share.

Possible responses

There are different ways that your child might respond to these discussions, all of which are normal. Your child's age, cognitive abilities, maturity level, or stage in their life may affect their understanding and reaction to the information. Although variable, some possible age-related responses are broadly outlined below.



Developmental considerations

The following pages offer guidance for discussing NF1 with your child and are organized based on a child's age. These timelines are flexible and are provided as a general approach to talking to each age group. Remember to:

- Keep in mind that every child is different, and these are suggestions to consider as you talk with your child. Children may not be ready for some information. Children with NF1 may also have learning difficulties and need additional time to process the information and recognize what having NF1 means.
- Trust your own judgment about what stage your child is in and what information is appropriate for them.
- Be prepared to modify your approach based on your child's response.

Birth-2 years

At this age, children...



- **May make simple connections between things.**

“I go to the doctor, and they look at the spots on my skin.”

- Use simple statements to help your child understand why they are going to the doctor and what will happen. For example:

“You are going to the doctor to check your eyes.”

- **Tend to be very focused on themselves and things they can do.**

- Use this to show and normalize features of NF1. For example:

“Look, you have a spot that is a different color.” (Point to spot)

- Use this to point out strengths.

“You are very good at hopping.”



When I see someone in a white coat, something uncomfortable may happen.

When we get in the car, I get to see my sister because we will pick her up from school.



Ages 2-7



At this age, children...

- **Think very factually, and they may have trouble seeing different perspectives.** For example, they may think: “I get a shot every time I go to the doctor.” Even though that is not the case, the connection between the two can be confusing.
 - Remind your child gently that while it may feel like one outcome is always true, there are other things that could happen. For example:
“Remember last time we went to the doctor, she only looked in your eyes.”
- **Can start to understand that their features come from their parents.**
 - Explain common features in their family to help them start to understand inheritance. They may make the connection that mom has brown hair, and they have brown hair.
 - Educate that you both have the same condition if you are a parent with NF1 and point out the features you both might share. For example:
“Dad has bumps on his skin, and you have bumps on your skin.”
- **May start school around this time.**
 - Talk with your child about their experiences in school and watch for any learning difficulties. Keep in close contact with your child’s teacher to hear about their progress and raise any concerns you may have.
 - If your child does have learning challenges, normalize them and provide support. For example:
“Everyone learns differently; we will find a way that works for you!”
- **Could experience other children pointing out physical differences caused by NF1.**
 - Encourage your child by reminding them that everyone looks different. Teach your child the basics of how to explain their physical features to others. For example: “I have something called NF1 that causes bumps on my legs.”
 - Practice different phrases your child can say to their peers so they can educate their new friends about NF1.
 - Emphasize that they cannot spread NF1 to their friends.

BLAME

Sometimes, children may worry they caused NF1 or that NF1 is a punishment. Remind your child that NF1 is not their fault and is one of the many things that makes them unique.

“Sometimes I have to take extra time.”

“Mommy gave me my curly hair!”

Ages 7-11



At this age, children...

- **Are better able to think about the future.**
 - Starting to talk about the possible features of NF1 they could see as they get older is beneficial at this age.
- **Can see that some things are inherited in a family.**
 - If family members also have NF1, pointing out the other members with the condition can be helpful.
 - Talk about how people in the same family can have different NF1 characteristics. For example:

“Mom and Uncle Max both have NF1. Mom has dots on her eyes and lots of freckles, but Uncle Max doesn’t.”
- **Could understand a clinical diagnosis.**
 - Educate them that a combination of their features led to being diagnosed with NF1.

“Remember how Dr. Bob looks at your entire body when you visit the doctor? Because mom has NF1 and you have lots of freckles in your armpit, which is common with NF1, you can also be diagnosed with NF1.”
- **May understand genetic testing**
 - Explain that a test was done or will be done to tell if they have NF1.

“Remember that cheek swab at the doctor? They were looking to see if you have NF1.”
- **Could experience precocious puberty, also known as early puberty.** (before 8 in girls and 9 in boys)
 - Explain to your child that everyone’s bodies go through changes at different times.

“Even though it takes me longer to read a book, I can still enjoy reading or listening to audio books.”

“So, in the future, I could have a bump on my leg like dad?!”

SELF WORTH

This time is important for developing a child’s sense of worth.

- *Make sure that they know that they are more than NF1*
- *Remind them of all the things they can do well and the wonderful things about them*
- *Emphasize that they cannot spread NF1 to their friends*

Ages 11-17



At this age, adolescents...

- **Start to have more independence and friends become more important than other relationships. This is a normal part of growing up as is a big adjustment for everyone.**
- **Experience an “imaginary audience,” meaning they feel constantly watched and judged by their peers. This leads to increased vulnerability.**
 - These feelings may intensify if your child has visible features of NF1, such as café au lait spots or neurofibromas.
 - Support your child and remind them that everyone is different. It may be helpful to connect them to groups where people have NF1 and similar life experiences.
 - They may begin to feel self-conscious about needing extra support in school or being pulled out of class for therapies.
 - Talk to your child about learning disabilities with NF1 and how everyone learns differently. Emphasize that having extra help doesn't mean they aren't smart, it just puts them on a level playing field with their peers.
 - Teens can be sensitive to criticism at this stage, especially from their peers.
 - Encouraging them to be around people who support everything about them can help.
- **Start figuring out their own identity and who they are as a person.**
 - Adolescents may interpret NF1 as a large part of their identity, while others may not. Support your child however strongly they connect to their diagnosis.
 - Teens will want more independence and begin separating themselves from their caregivers.
 - Providing other safe contacts for your adolescent, such as a mental health counselor and genetic counselor, can help.
 - Empowering them to be involved in their care management, such as participating in and scheduling doctor's appointments, may give them a greater feeling of control.



- **Can be more influenced by peer pressure and social media.**

- Talk to your child about avoiding activities that may pose a risk of injury specific to their features of NF1 and foster activities that help them thrive.
- Monitor your child's use of the internet and social media by engaging them in conversation about what they are seeing.
- If your child has intellectual or developmental differences, provide more education and supervision regarding safety on the internet and in social situations.

- **May struggle during times of change such as transitions to middle school, high school, or adulthood especially if they have intellectual or developmental differences.**

- Learning differences may become more apparent expectations increase both at home and school. Make sure your child is getting the support they need in all settings.
- Explore community resources for your child.

Special Considerations for Puberty

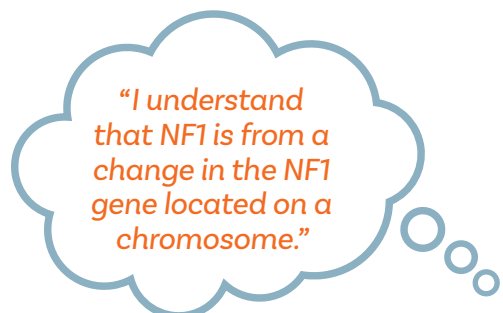
Puberty is a time of dramatic physical and hormonal changes.

- **Adolescents may experience strong emotional reactions, especially to some of their NF1 features.**

- Address these and encourage positive ways for your child to balance their feelings.
- Stay calm, connect them to groups, and remind them of the things they are good at.
- Connect them to mental health support if you think that would be beneficial. You can use the “Find a Mental Health Provider” section at the end of this resource.

- **Start to realize how NF1 can impact future children.**

- Talk about them possibly having a child with the condition. It is important that they know they have a 50% chance of having a child with NF1.





A closing note

As a caregiver, you are not alone while trying to navigate talking to your child about NF1. It's important to support yourself by connecting to others with similar experiences while supporting your child. There are many other families in your same situation. Please use this guide however it best helps you, and remember there is not one "right" way to talk about NF1. Additional resources and support can be found on the following page.



Make it a priority to take care of yourself.

- It's important to take care of yourself too! Having a child with NF1 brings up a variety of emotions. There is no one way or right way to feel.
- Some parents feel guilty about their child having NF1, but it's no one's fault. Genetic changes occur by chance, and we have no control over which genes are passed to our children.
- Feelings of isolation are not uncommon. Joining online support groups, meeting other families in similar situations, and participating in community events can help.
- If you feel overwhelmed, mental health and genetic counseling services are available to support you. Trusted websites to find these services are located at the end of this resource.

Resources

LEARN MORE INFORMATION

- **Children’s Tumor Foundation (CTF)** is a nonprofit organization with a mission to drive research, expand knowledge, and advance care for the NF community. CTF has many resources for parents and children available in multiple languages at ctf.org/education, including:
 - The NF Parent Guidebook
 - Learning with NF1
 - NF1 for Educators
 - Café Au Lait: A Story of NF1 and My Special Spots
 - Moxie & Sparx Explain NF1
 - Coloring Pages and Flashcards featuring Moxie & Sparx

CONNECT WITH THE NF COMMUNITY

- **Children’s Tumor Foundation** – It is so important to get involved and meet others in the NF community. CTF sponsors Shine A Light Walks, clinic symposia, NF Endurance events, an annual NF Summit, and a fun event called Cupids Undie Run. You can also find support and friendship on our many social media channels. ctf.org
- **NF Collective** – Many additional organizations around the world offer support for patients with NF, and many of them have joined together as the NF Collective. We encourage you to reach out for information and support to an organization that is the right fit for you. NFcollective.org

GET INVOLVED IN RESEARCH

- **NF Registry** – The NF Registry is a secure website that allows people living with all forms of NF to take an active role in the search for better treatments. Joining the Registry is as simple as filling out a survey once each year about your symptoms and experiences and NF. nfregistry.org

FIND A GENETIC COUNSELOR

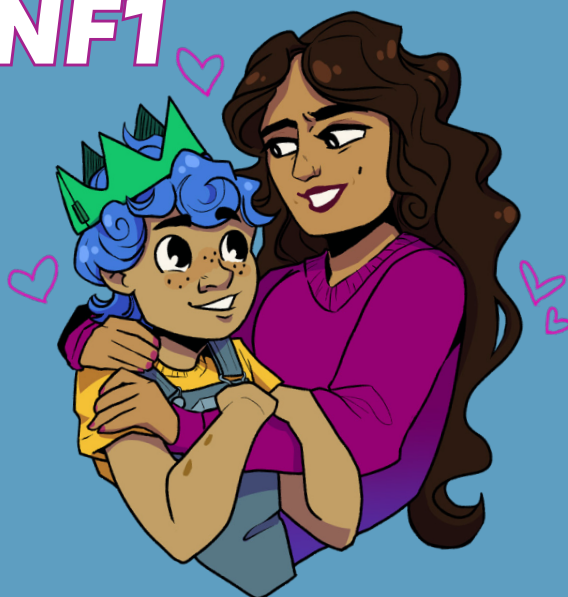
- **NSGC Find a Counselor Tool** – A resource created by The National Society of Genetic Counselors to help find a genetic counselor. findageneticcounselor.nsgc.org

FIND A MENTAL HEALTH PROVIDER

- **Psychology Today** – A tool where you can apply filters to help you find a mental health provider. psychologytoday.com



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CHILDREN'S
TUMOR
FOUNDATION
ENDING NF
THROUGH RESEARCH

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