

# TALKING WITH CHILDREN ABOUT NEUROFIBROMATOSIS

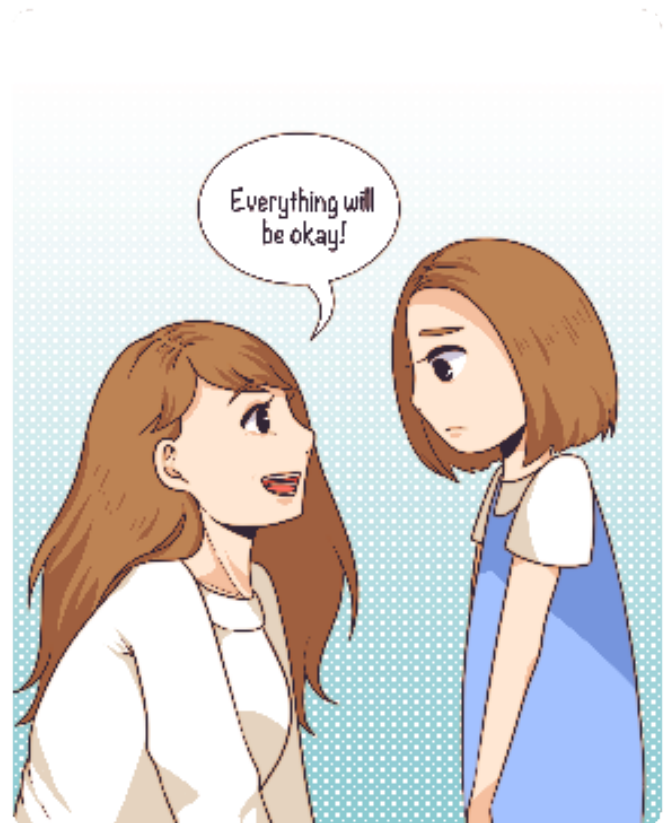
Talking with your child or children about *Neurofibromatosis* (NF) is a challenge for most parents. *However*, many feel better about it with a little preparation.

**There is no single approach that is the “right” way or the “wrong” way.**

Where NF is a new diagnosis, parents can struggle to deal with the questions that their child may raise. Being honest, open and offering to find out information to tackle questions you can't answer are helpful steps in developing your child's understanding of NF and will also enhance your own knowledge.

Most parents find telling their child/children about a genetic diagnosis very difficult and upsetting. Where NF is a new diagnosis for a family, this can be particularly challenging as there is no point of reference.

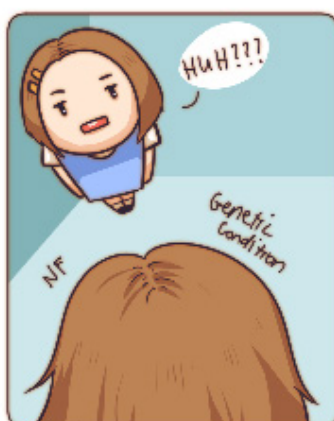
As parents, we want to shield our children from things that can make them unhappy or upset. For this reason, some parents are reluctant to tell their child about a diagnosis of NF because they believe it will cause distress not just for their child, but the whole family.



The benefits of starting this conversation are fundamental to your child's sense of well-being. It is important to help children understand about NF and to enable them to talk openly about it, what it means for them and the rest of the family.

Research shows that when parents discussed a genetic diagnosis openly with their child regularly, those children had a **better understanding**, were more well-adjusted, and had more insight compared to families who did not. Most children expressed the view that it was helpful to learn about their condition gradually, over an extended period of time.

**Children whose parents talked about NF with them when they were very young found disclosure less of a shock, enabling them to build up their understanding gradually. As they matured they could progressively absorb more complex information, but at their own pace.**





As children grow older, the information offered by their parent can be supplemented by information from health professionals. It can be helpful to encourage older children to think about their hospital appointments beforehand and even to prepare a list of questions for their doctor. This helps your child to use the clinic appointment constructively and to address the questions that are important to them. Their questions may be quite different to yours!



It is also important to think about who to tell within the family. Where there are a number of children, some with NF and some not, it is important that the unaffected children are also included in discussions at some point



Some families like to keep the diagnosis private and confined only to members of the immediate family. Others adopt a more open approach. This entirely depends on personal preference and family relationships.

Grandparents can be a great source of support for parents in this situation. Be prepared that some family members will need time to adjust to the news and may also need your support and guidance. They too will have questions and will benefit from your knowledge and reassurance.

It may help to talk to your children, if they are old enough, about who they think needs to know. Some children have strong views about this and don't want to be seen as "different" to their peers.

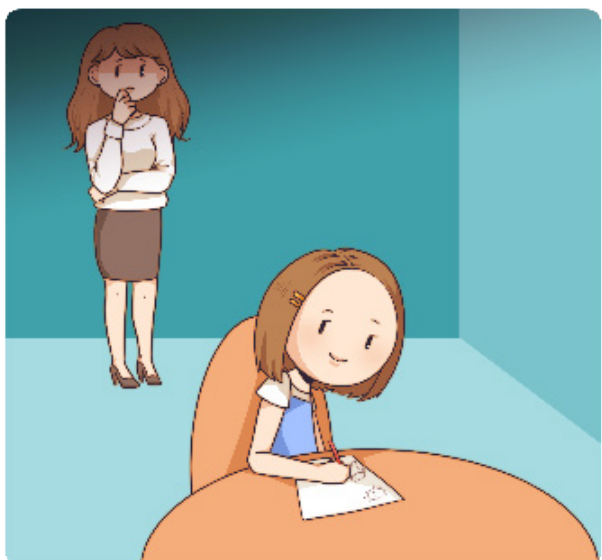
They may want to tell only a few friends or other adults they are close to and can confide in. It is usually helpful to talk to your child's teachers (class teacher, head teacher or Special Education teacher) about the diagnosis.

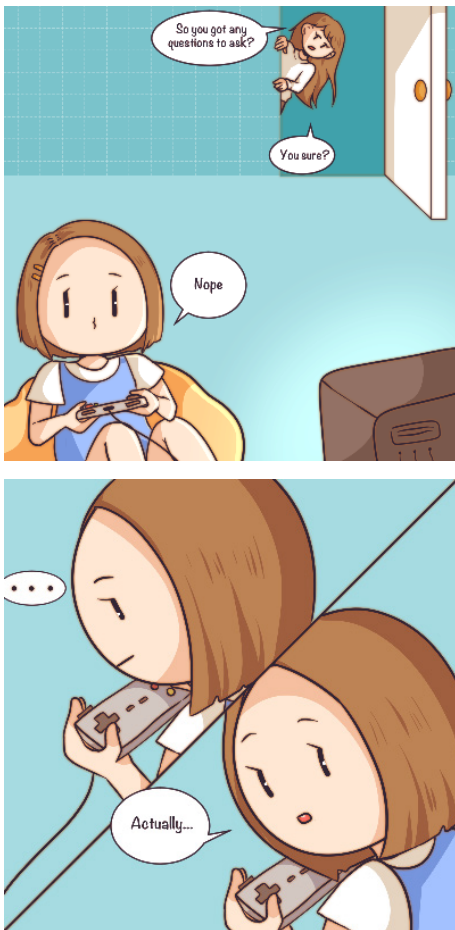
If there are any emerging problems evident within the school setting these should be addressed promptly and support made available. The CTF can help with advocacy and provide resources for you to give to schools and teachers. We also have an "NF Hero" Storybook which can be used to assist children to feel that they are not alone.

Choosing the right time to talk to your child/children is important. You need to think about a time when your child feels comfortable and able to listen without distractions. If this is a new diagnosis you may find it difficult to talk because you feel upset and are still coming to terms with having a child with NF. It is important therefore to allow yourself some time to manage your own feelings about the diagnosis and to feel ready before talking to your child or family.

Once you think the time is right, when you are comfortable and calm, you can start the conversation. You know the words your child will understand.

The first conversation is just a starting point, a bit like the first step on a ladder. Don't plan too much and let your child ask questions. Some questions may be immediate or come some days later. Let your child take the lead in where the conversation goes. Don't try to cram too much into the first session or overload your child with too much information. Keep language simple with short sentences.





If your child has problems with understanding or learning difficulties it is important to ensure your language is simple and clear, that your sentences are quite short and that you don't offer too much information at once.

Reassure them that they can always ask you questions if they forget or don't understand sometimes, that you will talk with them again later.

Keep encouraging your child to ask questions. Keep your comments open so that you can encourage your child to express what they are thinking to help you share their feelings.

It helps if you ask open questions that don't just lead to a yes or no reply. For example, you might say: "... tell me about" ... or "what do you think about..."

If your child asks you a question make sure you answer the question they ask. If you don't know the answer then say so, but offer to try to find out.

Finally, it is important to reassure your child that there will always be people who love them and will care for them.

**Having NF does not change the person that they are; NF is just one part of who they are.**

## This is a true story of how knowing about your condition can help break down barriers and be empowering for your child.

This is Bella. She is 5 years old and when she started a new school, one of the first things she did was ask her teacher to read the NF Hero Book and talk about Neurofibromatosis (NF).

Bella stood in front of her class to show her peers her "NF spots". She used the knowledge she had been given to show others what makes her a NF Hero.

In a single, uncomplicated moment Bella was able to do what many fail to achieve even as adults - she showed others what made her special. She understood that talking about her NF was the first step in building understanding and acceptance amongst her peers, and that our differences do not have to divide us.

Sharing something that makes you "different" can be daunting. So, it is admirable to see someone so young recognise that this doesn't have to be the case.



**Remember the CTF Support Service Coordinators are available for you to talk to prior to having a conversation with your child or other family members.**

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