



association
of Ireland



Neurofibromatosis –
Talking to Your Child

NF1



Disclaimer

Every care has been taken to ensure the accuracy of the information contained in this brochure. The NF association cannot however accept responsibility for errors or omissions, but where such are brought to our attention the information will be amended accordingly. The author and publisher accept no responsibility for any loss, damage, injury or inconvenience sustained or caused as a result of information supplied in this brochure. It is recommended that anyone who has concerns about Neurofibromatosis first speak to their doctor.



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PREAMBLE

Parents regularly ask when and how to explain the disorder to their child, is there a specific time or way to approach the topic, at what age and who should be involved, how does one prepare to explain about Neurofibromatosis to a child. This brochure has been compiled as a guide to assist parents but much will depend on one's understanding of the disorder, the child's maturity and how the child is affected.

As children mature they are bound to ask questions, why do I have to see a Doctor, attend Hospital, why am I different from other children? They may even pick up information from the TV or overhear a parent discussing their NF with a friend.

Ultimately it is up to the parent to decide at what time it is best to speak about NF to their child, generally, the advice is, don't leave it too late. Keep information at a level the child understands, be honest, if one is unsure seek advice beforehand from a Doctor who is knowledgeable about the condition or a Genetic counsellor, in this way one can be sure the information you impart is accurate and proportionate to the child's age and ability to understand.

NF1 BROCHURES

- OVERVIEW OF NEUROFIBROMATOSIS TYPE 1
- A GUIDE FOR EDUCATORS
- LEARNING & COGNITIVE DIFFICULTIES
- NEUROFIBROMATOSIS TYPE 1 FOR TEENS
- THE CHILD WITH NEUROFIBROMATOSIS TYPE 1
- TALKING TO YOUR CHILD
- INFORMATION HELP & SUPPORT FOR THOSE WHO NEED IT

LEAFLETS

- NF1 REVIEW CHECKLIST FOR CHILDREN & ADULTS
- SCHWANNOMATOSIS

INFORMATION FOR HEALTHCARE PROFESSIONALS

- CLINICAL GUIDELINES FOR THE MANAGEMENT OF INDIVIDUALS WITH NEUROFIBROMATOSIS TYPE 1

NEUROFIBROMATOSIS TYPE 2 BROCHURES

- FOR FAMILIES
- FOR HEALTH PROFESSIONALS

Helpline + 353 85 702 0024

INTRODUCTION – SPEAKING TO YOUR CHILD ABOUT NF

There is never a single right way to approach this and different families will go about it in different ways. Some children learn at a very young age that they have a diagnosis of Neurofibromatosis (NF) and it becomes a familiar word which is referred to easily and often. It is part of their make-up and absorbed by the family.

Other parents, who have perhaps struggled to accept the diagnosis themselves, may often think about the time when it will be right to 'tell' but, somehow, this time never seems to come and the moment gets put off. Talking to your child about NF can then become more and more difficult: a subject to be avoided, a secret.



BELOW ARE SOME OF THE COMMON QUESTIONS PARENTS ASK.

WHO SHOULD TELL MY CHILD?

Usually a parent or someone your child is close to and trusts. It is important that the information you give is accurate and can be understood by your child.

Try to answer any questions as simply and truthfully as you can. If you do not know the answer it is better to say so, but offer to find out more.

- Make sure what you say is correct
- If you are not certain of the facts say so and then find out
- Use simple language
- Don't offer too much information at once
- Answer the question that is asked
- Start with simple facts and add more as your child grows up and can grasp more complex information
- If relevant, use pictures or drawings to explain

WHEN SHOULD WE TALK ABOUT IT?

It is a good idea to grasp opportunities when they are presented. This may come from occasions such as:

- your child's question
- preparing for a hospital appointment
- an article in a magazine or a television programme
- any other time that feels right – often bed time or bath time

CAN I HELP MY CHILD TO UNDERSTAND WHEN I HARDLY UNDERSTAND IT ALL MYSELF? I DON'T KNOW WHERE TO START!

It might help you to go over basic facts about NF with a genetic counsellor or a doctor who is familiar with NF.

Start to think about a simple answer to questions such as:

What is NF? What are these birthmarks?

And then think about what you might say.

There are some suggestions at the end of this fact sheet to help you.

CAN'T I WAIT UNTIL MY CHILD HAS GROWN UP AND CAN UNDERSTAND BETTER?

Yes, of course, you could choose to do this. However, if your child has tried to talk with you about NF but feels you are unable to do this, she/he may feel that they have no-one else to turn to express their confusion and worries.

Keeping the channels of communication open throughout childhood and adolescence is one of the most important, and sometimes very difficult, roles of parents. It is parents, not children, who are most able to make this process work.

Research has shown that people who were not given information can feel angry as adults that important facts were withheld from them.

Remember – you are your child's first teacher and all their learning, including about NF, starts at home.

DO YOU THINK I NEED TO TELL ANYONE ELSE?

Again there are no rights or wrongs to this question, it very much depends on how you feel. There may be very good reasons to choose not to tell some people, who you decide to share the information with and when can depend on so many different factors, for example: a brother or sister may not yet be old enough to understand, or a grandparent may be unwell and you may decide to delay telling them until you feel they are better able to cope with the news. Go with what feels right at the time.

SHOULD I TELL HIS/HER TEACHER?

Talking with teachers

Parents often ask whether a child's teachers and school should be informed that a child has – or may have – NF1. Almost half the children with NF1 have learning problems; parents are often concerned that telling the school could result in the child being labelled as learning disabled, setting up a self-fulfilling prophecy in the child's educational and social development at school.

Deciding to tell a child's teacher is an individual family decision. However, harm is often done if school personnel aren't informed. Without knowing about a child's NF1, the school could easily mislabel a learning problem as a behavioural problem. A frank discussion with a child's teachers can often correct common misconceptions about NF1, leading to earlier detection and treatment of learning problems.

Some parents decide not to tell their child's teacher unless difficulties arise in school, believing that they risk special treatment if the diagnosis of NF is disclosed. Many parents prefer their child to be treated just like

all other children in the class and not marked out as potentially different. Most schools try to be as helpful as they can in supporting parents' wishes. However, if problems do crop up, then it may be important to explain about the diagnosis of NF because this can affect how your child learns and behaves.

Your genetic counsellor can help and support you with this, particularly when talking with teachers. Brochures "a guide for educators" or "about learning difficulties" are available from the association.

IT MAY BE HELPFUL TO THINK ABOUT THE SORTS OF QUESTIONS A CHILD MAY ASK – HERE ARE SOME SUGGESTIONS ABOUT HOW TO ANSWER THEM:

What is NF?

NF is a short way of saying neuro-fibro-ma-tosis. It is something you were born with. It may be helpful here to add 'like mom/dad/gran' if other members of the family are affected.

Why have I got brown patches?

The brown patches are called café-au-lait (caffey-olay) marks. Nearly all people with NF have them. They won't harm you.

Can a doctor make it go away?

No. NF is part of you.

Why do I have to go to the hospital?

Because you have NF you need to see a doctor for a regular check up to make sure you are keeping well. With older children, you could add more information at different stages to help them increase their knowledge and understanding.

You can encourage your child to ask questions by being open and confident. If you need help to prepare for this, talk to your Genetic Counsellor. Sometimes they can put you in touch with other parents so that you can benefit from shared experience.

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A photograph of a young man's back, showing several light brown, irregular patches known as café-au-lait patches. The background is a bright blue sky with white clouds and a green field. A black text box with white text is positioned over the upper back, and three pink arrows point from it to the patches. A pink text box is at the bottom of the image.

CAFÉ-AU-LAIT PATCHES

NEUROFIBROMATOSIS: Tell-Tale Signs
*Café-au-lait patches,
6 or more consult your Doctor*

Phone: + 353 85 702 0024

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