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NERVE TUMOURS UK

"My child has been diagnosed with NF1. What does this mean, and where can I get help?"

Neurofibromatosis Type 1 (NF1)

Some helpful information and resources for parents

Contents

> **"Follow your gut feeling and don't be put off or ignored by doctors or specialists."**
>
> Michelle, mother to Daniel

Daniel and Michelle's Story

"We had known that Daniel had problems since he was three weeks old, but he was mis-diagnosed for years and it wasn't until he was in his teens that he was diagnosed with NF1.

"The most challenging thing for Daniel has been struggling with academic ability and struggling socially to make friends.

We have relied on Nerve Tumours UK when I have had queries, and a Facebook page where people can chat and discuss with each other. Both have been a lifeline as we get little support from doctors, except for the NF unit at Guy's Hospital, who have been excellent.

"My advice to the parents of children with NF1 is to follow your gut feeling and don't be put off or ignored by doctors or specialists. Be prepared for a battle and don't give up when you hit a brick wall or suffer a setback. Take each day as it comes and expect and anticipate the fight."

NF1 is a common genetic condition that causes nerve tumours to grow where they shouldn't. The 'spelling mistake' in the gene is found on chromosome 17 and occurs in 1 in 2,500 of the population. There are over 25,000 people in the UK diagnosed with NF1.

What is NF1?

NF1 varies widely in how it affects those who have the condition. Many people with the disorder will be affected very mildly and may have nothing more than skin changes. A minority of people (around a third) who have NF1 will have medical problems related to the disorder at some time in their life. Some of these problems will be mild and easily treatable and others will be more severe.

NF1 is normally easy to diagnose, but if there is doubt, a genetics department can usually help to clear up any uncertainty.

How is it diagnosed?

The way the doctor can tell if a person is affected with NF1 is to examine him or her to see if there are signs of the disorder, so it's important to keep an eye out for signs that might help a doctor diagnose Neurofibromatosis.

There are specific features that the doctor will look for. NF1 usually appears in childhood and the diagnosis is confirmed if two or more of the following signs are present:

- Six or more flat, café-au-lait patches (brown coffee-coloured skin marks), which are the size of a pencil top or bigger. These usually appear during the first year of life and can increase in size and number. Café-au-lait patches are generally harmless and there is no connection between the number or size of café-au-lait patches and the severity of the condition. They sometimes fade later in life.
- Neurofibromas (small benign pea-sized growths or lumps) on or under the skin. These are a common feature of NF1. They usually appear during adolescence and tend to increase in number throughout life.
- Freckles under the arm or in the groin. Again, these are harmless but can be another sign of NF1.
- Plexiform neurofibromas. These represent growths around large nerves and can first appear as a swelling.
- Lisch nodules – these are small pigmented areas in the iris (coloured part) of the eye. They are often not visible except during examination with an eye microscope called a slit lamp. Lisch nodules are harmless and never cause symptoms, but can help in making a diagnosis of NF1.
- Another close family member has NF1.

Epilepsy

Everyone is at risk of developing epilepsy during their lifetime. In people with NF1 that risk is slightly increased. Symptoms suggestive of epilepsy should be investigated and treated in the usual way. This will usually involve referral to a neurologist who will be able to diagnose and treat the symptoms.

Pain & Itching

Itching sometimes happens in NF1 and no one knows why this is so. Medication such as antihistamines or a simple emollient can sometimes help – ask your GP for guidance.

Learning & Behaviour Problems

Most people with NF1 have normal intelligence, but around two thirds of people who have the condition will experience some problems with learning. It is the most common 'complication' of NF1. The majority of children who have NF1 are educated in mainstream schools and do not require special education, although they may benefit from extra help.

Self Image

Most people with NF1 have some signs of the condition visible on their skin. Some individuals have more obvious signs of NF1 than others and they can find the outward signs of the condition an extremely distressing burden to live with. There is no easy way to deal with this medically. Café au lait patches may increase as a child gets older but may fade in adulthood. They can be covered with clothes or make-up.

It is important to be aware of these issues and never let your child feel insecure about their patches. If you notice signs of your child feeling embarrassed of their café-au-lait marks and trying to hide or cover them up it is important to talk to them about it.

How does it affect my child?

Olivia, NF1 patient, with parents Karen and Lee

"When Olivia was first diagnosed with NF1, we looked on the internet and scared ourselves to death!"

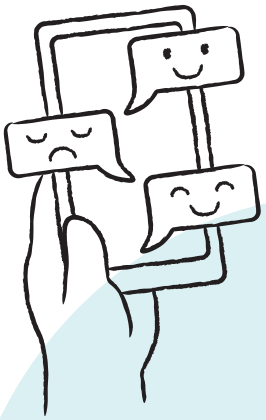
Lee, father of Olivia

Bullying

Some of the symptoms of NF, such as tumours, deafness and a different way of speaking, can often make children with NF targets of bullying.

A parent knows their child best and will know if something is wrong. Some behaviours to look out for if you suspect your child may be being bullied include:

- reluctance to go to school
- being mysteriously 'ill' each morning, or skipping school
- belongings getting "lost" or damaged
- being nervous, losing confidence, or becoming distressed and withdrawn



Social Media & Cyber Bullying

Social Media, and the Internet have become an integral part of modern life, although these tools can be useful and fun, it can be difficult to protect your children online.

Signs of cyber bullying include:

- being withdrawn or upset after texting or being online
- being unwilling to talk about what they're doing online or on their phone
- spending much more or much less time texting or online
- many new phone numbers, texts or email addresses show up on their phone, laptop or tablet

How to Help

Knowing or suspecting that your child is being bullied can be very upsetting, but there's lots you can do to help tackle the problem.

After talking to your child about the issues they are facing, it is important to notify your child's school. All schools are required by law to have an anti-bullying policy, and you should discuss the best plan of action to tackle the bullying with your child's teachers.

"A parent knows their child best and will know if something is wrong."

Why does my child have NF1?

NF1 is a genetic condition. This means there is a problem that is caused by a change in a particular gene. Our body is made up of cells. Genes contain the instructions within the cells that tell the body how to work. Genes determine things like eye colour or hair colour.

NF1 is caused by a change or miscopy in the structure of the gene.

The genetic miscopy can be passed from a parent with NF1 to their child. A parent with NF1 has an equal chance (or 50% risk) of passing on the NF1 gene fault to each child they have. If a child is born with an NF1 gene fault, when they decide to have children, there is the same equal chance (50% risk) of passing on the condition.

> **Nerve Tumours UK has been a lifeline.**
>
> Michelle, mother of Daniel

Where no-one else in the family has NF1, then the miscopy in the gene that has caused a child to have NF1 has most likely occurred by chance. There is no known reason why it has happened. It is not something that could have been prevented by, for example, diet or environmental factors.

Michelle, NF1 patient and parent of Daniel with NF1

What should I tell my child?

Talking with your children about neurofibromatosis is a challenge for most parents. Many people feel ill-equipped to tackle this task successfully. Knowing what to say and when to say it needs preparation and some thought. There is no single approach that is the "right" way or the "wrong" way.

However, 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 a diagnosis of NF means for them and what it means for the rest of the family.

What to say...

Once you think the time is right, 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 as your child may ask questions that take you by surprise and so throw you off track.

Allow your child to ask questions...these 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.

Examples of how you can start the conversation are as follows:

"Tomorrow we're going to see the doctor to make sure you're doing well, do you know why we have these check ups?"

"The doctor sees a lot of little kids with brown patches on their skin. Doctors have a special name for these too, they're called café-au-lait marks"

"Next week we're going to have your hearing tested at the hospital. This is to check to see if your hearing nerve is working properly."

Encourage 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 does ask you a question make sure you answer the question they ask and don't go off at a tangent. 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. That having NF does not change the person that they are. NF is just a part of who they are.

If you notice that your child looks unwell, if you see any new or unusual symptoms at any time or you're at all worried, you should always talk to your Paediatrician. And remember to remind him or her that your child has NF1 and ask if the symptoms could be anything to do with that.

What support can we get?

Some examples of unusual symptoms could be:

- **Passing out or fainting.**
- **Getting more headaches that last longer.**
- **Lumps that quickly get bigger or harder, or look different to the way they did.**
- **Pain for no reason.**
- **Changes in your eyesight.**
- **And anything else that's worrying you.**

These are some of the other organisations that can help you:

National Neurofibromatosis Centres at Guy's Hospital, London and St Mary's Hospital, Manchester.

Nerve Tumours UK Support Specialists who can speak to you on the phone and sometimes visit your home or school.

Nerve Tumours UK Specialist Support

Nerve Tumours UK helps fund a team of Support Specialists in a number of regions across the United Kingdom. These Specialists work to improve the lives of those affected by Neurofibromatosis and provide crucial support to patients and families.

National Helpline

Another service we work to maintain is our national helpline. **Open Mondays and Wednesdays 9am – 5pm**, if you need someone to talk to or some help getting to the right place. Call **07939 046 030** or email **helpline@nervetumours.org.uk**

Nerve Tumours UK Website

Head over to our website site to find out more information on Neurofibromatosis Type 1 (NF1) and where you can find more help.

nervetumours.org.uk

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Do you have nerve tumours? We're here to help.

nervetumours.org.uk
info@nervetumours.org.uk
020 8439 1234

/NerveTumoursUK **@NerveTumoursUK** **@NerveTumoursUK**

Our Nerve Tumours UK Specialists are available to offer support to anyone living with nerve tumours.

Call our helpline on 07939 046 030
Monday and Wednesday 9am-5pm

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Never Tumours UK is the trading name of the Neurofibromatosis Association.
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