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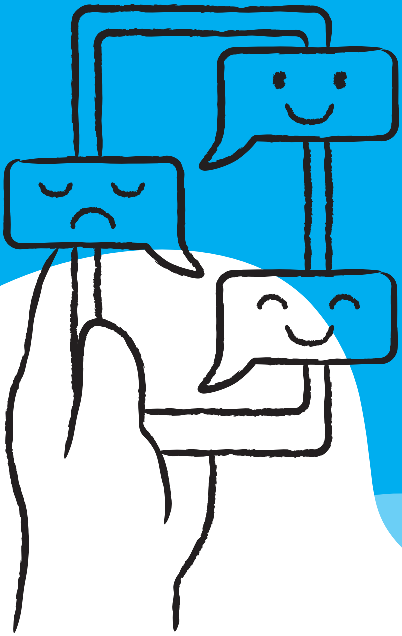
NERVE TUMOURS UK

"Try to be positive. There is always light at the end of the tunnel."

Olivia, NF1 patient



Neurofibromatosis Type 1 (NF1)

Some helpful information and
resources for teenagers

Contents

> "NF1 is a part of you which you have to embrace."
>
> Olivia, NF1 patient

Introduction

Neurofibromatosis Type 1 is indiscriminate; it affects all races, age and genders equally. It is a dominant genetic condition, which means that it can be passed on in families from one generation to the next through genetic inheritance. About half of NF1 cases recorded have no previous family history of the condition. This is called a "spontaneous gene mutation".

NF1 is an incredibly variable condition, and might vary from one person to another even within the same family.

Some people may be affected very mildly and have very few health complications. Others may have many more complications that can seriously impact daily life, and restrict what they can do.

With a condition that varies so much, it is important to learn some basic facts about NF1, and to understand when you need to seek help from your doctor.

This is a large part of why Nerve Tumours UK exists; to support people with Nerve Tumours, and to help you manage your condition and live your best life.

Olivia, NF1 patient

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.

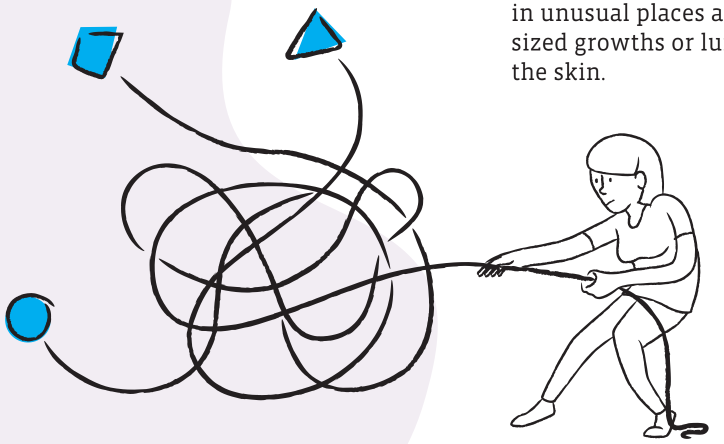
NF1 is normally easy to diagnose, but if there is doubt, a genetics department can usually help to clear up any uncertainty.

If one of your parents has NF1 then it's usually pretty straightforward for a doctor to tell whether you have NF1. But around half of children will be the first person in the family to have NF1 and this means it takes longer to be sure you definitely have it. You may also need to have a genetic test.

How is it diagnosed & how does it affect me?

Your doctor will take a good look at you, particularly your skin, to see if you have two of the signs that can be symptoms of NF1. Some of these signs take a while to appear so doctors can take some time to tell if you definitely have NF1, especially if no-one else in your family has it.

The early signs of NF1 are flat, milky brown marks on your skin, freckles in unusual places and small pea-sized growths or lumps on or under the skin.



Olivia's Story

"I'm 17. I find things that come along with NF1 hard. I am dyspraxic and that makes lots of everyday things tricky. For example, using a normal knife and fork is hard, opening jars or bottles is really difficult and general things that mean me using both my hands together are challenging and sometimes impossible. I also find the unpredictability of NF1 scary – I don't know what will happen next with it, and whatever does happen next will be my next challenge.

"I don't know how I'd cope without the people I have around me... family, friends and medical people and of course my dog! Nerve Tumours UK helped my Mum and Dad a lot when I was younger, so I know I can go to them as well if I need to. I think support is very important.

"At this point in life I am quite scared for the future. I don't know what I'm going to do after college or where I'll end up. Life is definitely like a rollercoaster, there are ups and downs and you just have to go along with the ride. I enjoy life even with NF1. It is part of me – without it I don't know who I'd be and I am happy with the person I am."

> "Try to be positive, even though at times it can be hard. There is always light at the end of the tunnel."
>
> Olivia, NF1 patient

Who can I talk to?

If you feel unwell, notice any new or unusual symptoms at any time or you're at all worried, you should always talk to your parents and see your doctor. Remember to remind him or her that you have NF1 and ask if the symptoms could be anything to do with that.

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

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**

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.

Social Media

How to use Social Media

Social Media can be a big part of everyday life. However, especially amongst people who are still at school, it can lead to bullying and in extreme cases, dangerous situations. Follow these basic rules, inspired by our friends at O2 NSPCC, to keep your use of social media enjoyable.

1.

Photos

Don't share photos of yourself just because someone else asks, especially of your body, even if you have feelings for them.

2.

Videos

Don't video chat with people you don't know, and don't send video of yourself to strangers.

3.

Games

Enjoy them! But remember the people you are playing with online might be strangers – so don't give out personal details.

4.

Information

Don't ever share your home address, phone number, financial details or real-life contact details with someone you don't know, especially in an email or chat.

5.

Most importantly

Think about what you post online, and **never agree to meet a stranger** without talking to your parents, and bring them along if you do meet.

Bullying

Bullies often pick on what they don't understand. Some of the symptoms of NF1, such as tumours, deafness and a different way of speaking, sometimes means people with the condition can experience bullying.

Bullying can make people feel very low and have an effect on their confidence and self esteem. People with nerve tumours may already experience a sense of worthlessness, so bullying can make this worse. If you think anyone you know is being bullied, it's very important to speak to an adult. This could be a parent or relative, a teacher you trust, or your GP. They can then take action to stop the bullying.

NF1

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NERVE TUMOURS UK

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

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