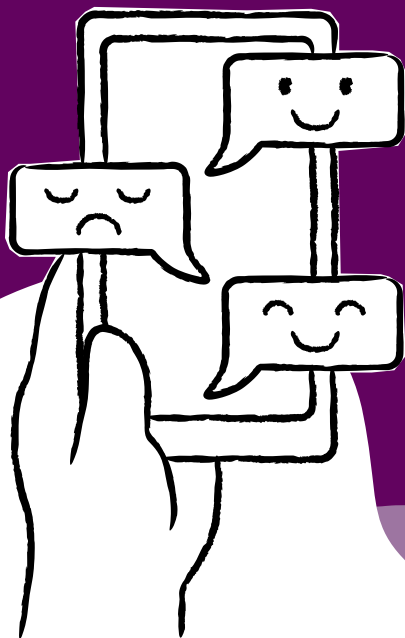




**"Don't let people
put you down
because you are
'sick'. Live your
best life."**

Nicola, NF2 patient



NF2-related Schwannomatosis (NF2)

Some helpful information and
resources for teenagers

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My brother was tested - it felt like we had to pick a straw and I got the short straw because he did not get NF2!

Ben, NF2 patient



Ben, NF2 patient

What is NF2?

NF2-related Schwannomatosis (NF2) is a rare genetic condition caused by a 'misspelling' on chromosome 22. NF2 occurs in 1 in 30,000 of the population.

Like NF1 it can be passed on from parents or it can start in a family by chance.

NF2 patients will need operations or other treatments for brain or spinal cord tumours. Also, people will develop tumours typically in the brain and spine.

The hallmark of NF2 is the development of benign tumours called vestibular schwannomas which grow on both hearing nerves.

These tumours can cause hearing loss, deafness, and mobility problems due to the pressure exerted on key nerves. Benign tumours may also develop on the nerve roots as they leave the spine and on the coverings of the brain. Some people with NF2 have a few benign tumours on the skin nerves.

NF1 and NF2 are very different conditions.

NF1 can not become NF2, and likewise, NF2 cannot turn into NF1.

How is it diagnosed & how does it affect me?

The doctor or GP who first talks to you about NF2 may not be a specialist in the condition itself. They may suggest that you should have an appointment with other specialist doctors to confirm if you do have NF2-related Schwannomatosis.

Specialist doctors will explain what the diagnosis means for you, they will answer questions about how the condition has occurred, what are the possible problems that can arise, and how best to manage these problems.

Most NF2 tumours are slow growing and may cause minimal problems for years. Although they are not malignant (not cancerous) their position may produce significant symptoms. For the majority of people, the most common first symptoms of NF2 are:

- **Gradual hearing Loss**
- **Tinnitus (ringing or roaring in the ears)**
- **Unsteadiness, particularly when walking on uneven ground or in the dark.**

These symptoms are caused by tumours on the hearing nerves (vestibular schwannomas). Other symptoms may relate directly to the pressure caused by tumours on the spine or on the lining of the brain. For example:

- **Headaches**
- **Change in vision**
- **Change in sensation, pain or weakness of an arm or leg.**

Hearing Loss

Hearing loss in NF2 can be gradual or sudden and each brings its own difficulties. Adjustment to this loss is never easy and takes time. Friends and family are there to help with this big change in your and their lives. Professionals can supply the information and support to make the change more manageable. Learning to lipread is important. For some, learning sign language opens up new opportunities.

Facial nerve damage

Ask a close friend or family member to assess how difficult it is to understand you – you may be very surprised to find it's not as bad as you fear. Try to look

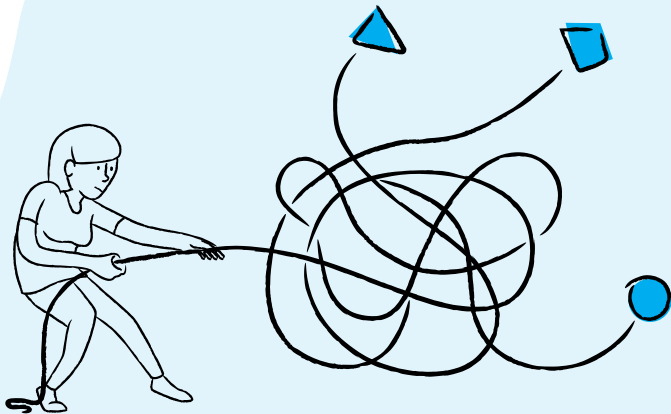
positively at people when you meet them as this makes it easier for them to respond to you and see beyond the facial nerve damage. Try to remember that even the most beautiful models usually have some part of their body they don't like – we're all the same under the skin! Don't try to cover the facial nerve damage with your hand or hair as this only distances you further from people and makes it harder to communicate.

Balance difficulties

Explain to people (if necessary) about the balance difficulty so that you feel safe and confident. Take a friend along with you for support as well as helping you to have a good time! You may prefer to use a walking stick which also alerts others to your needs without you needing to spell it out. If possible, check out new venues before visiting e.g. steps, parking, lighting, noise levels.

Tiredness

Recognise and accept your limitations. Plan ahead for important events. Explain to others so that they understand the issue. Make sure you get enough rest. Don't be unduly hard on yourself when you think you should be able to do more!



Hi, my name is Ben and I'm 13 years old. I was tested at the age of five for NF2-related Schwannomatosis (NF2), as my mum has NF2. My brother was tested too – it felt like we had to pick a straw and I got the short straw, because he did not get NF2!

I currently go to secondary school and my hearing has been great. Then, in June 2018, my acoustic tumours showed a sudden growth very quickly. It has been a hard few months, though it was as if a superhero had arrived, Avastin was called out to us!

On Thursday 11th October it was my first time taking the treatment and I couldn't be happier, it felt like the luckiest day of my life and everything went smoothly! I am to continue having treatment every two weeks and I am going to have my first MRI scan since I started taking Avastin around New Year's. My family and friends are so proud and supportive, I'm so lucky to have them around me!

Ben's Story

“Look after yourself, do what you can and push yourself to be the best you can.”



Nicola's Story

Life before NF2-related Schwannomatosis (NF2) is very hard to remember since I was diagnosed at six years old.

I have faced many problems since being diagnosed with NF2. I lost my hearing completely in my right ear, I have facial weakness and body weakness, as well as heat loss and partial hearing in my left ear. I also have a wobble when I walk due to the removal of a tumour wrapped around my balance nerve.

I'm currently a student at Edge Hill University, aiming to further my career as a producer in Film and

TV Production. I enjoy photography, reading, shopping and visiting new places and I am obsessed with nature. I love being out in the rain.

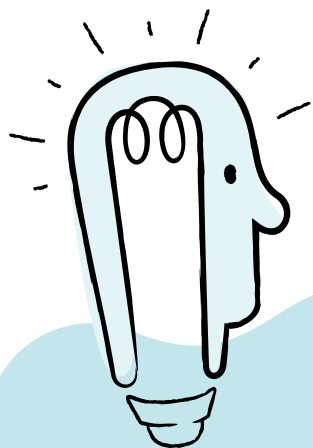
My advice to anyone with NF2 is to look after yourself, do what you can and push yourself to be the best you can. Also, remember self-love and self-support is also resting and resetting yourself. Go and do things you are scared of, like holding a spider or swimming. Don't let people put you down because you are 'sick' – being sick doesn't have to be lonely and isolating. Live your best life.

Who can I talk to?

Speak to a friend, relative or your doctor if you feel unwell, notice any new or unusual symptoms at any time or are at all worried. Tell them you have NF2 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



NF2 Service Centre

The NF2 service is coordinated through the NF2 clinics in Manchester, Cambridge, Guy's and St Thomas' in London, and Oxford.

Each designated centre is supported by experts in facial nerve reconstruction, audiologists and hearing therapists, physiotherapists and psychologists – all professionals who understand NF2. There is also a team of NF2 nurse specialists, who will coordinate patient care and act as the link between the centres and the local services. Some of the Nurses will be based in the other centres with existing NF2 clinics. They also perform NF2 surgeries funded through the service: vestibular schwannoma removal, brain stem and cochlear implants. The other key service is for radiation based treatments for NF2.

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 NF, the medical group name for Neurofibromatosis Type 1 (NF1), NF2-related-Schwannomatosis (NF2) and Schwannomatosis (SWN), and provide crucial support to patients and families.

National Helpline

The Nerve Tumours UK national helpline offers advice and support. **Open Monday, Wednesday and Friday 9am–5pm. Call 07939 046 030/ Freephone 0300 102 17 22 or email helpline@nervetumours.org.uk**

Nerve Tumours UK Website

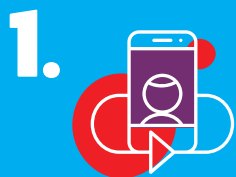
Visit **nervetumours.org.uk** for in-depth information about NF2-related Schwannomatosis (NF2) and the charity's support services.



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.



Photos

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



Games

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



Videos

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



Information

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



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 NF2, 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. And people with NF2 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.



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

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

f /NerveTumoursUK **in @NerveTumoursUK** **@NerveTumoursUK**

Our Nerve Tumours UK Specialists are available to offer support to anyone living with NF, the medical group name for NF1, NF2 and SWN, all of which cause tumours to grow on nerve endings.

Call our Helpline on 07939 046 030/ Freephone 0300 102 17 22 or email helpline@nervetumours.org.uk

Monday, Wednesday and Friday 9am-5pm

Nerve Tumours UK

First Floor, 44 Coombe Lane, London SW20 0LA

Never Tumours UK is the trading name of the Neurofibromatosis Association.
Registered Charity Number: 1078790 and SC045051