



# Supporting a student who has Neurofibromatosis Type 1 (NF1).



# Supporting children who have Neurofibromatosis (Nerve Tumours)

**It can be daunting when one of the children in your class has a condition you have not heard of. It is important to understand that Neurofibromatosis - which translates as 'nerve tumour increase' - can cause a variety of complications in an individual's life. No two cases are the same, and each child's situation will need to be approached on a case by case basis.**

Nerve Tumours UK is the national charity providing support for those living with the group of conditions known as "the neurofibromatoses" these include, Neurofibromatosis Type 1, Type 2, and their significantly rarer variants, Schwannomatosis and Legius Syndrome.

## What is NF1?

**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 approximately 25,000 people in the UK diagnosed with 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.

# What problems can occur in school?

**The vast majority of children and individuals will be able to learn and progress with the right support. However, Neurofibromatosis can also involve associated learning difficulties and complications. Most of the time, these can be approached with small adjustments or the same techniques that your school would normally engage with to provide support.**

## Learning & NF1

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.

The learning problems linked to NF1 are not unique. Once identified, the difficulties should be supported using the same strategies as any other child with those same difficulties. It is helpful to enlist the support of your SENCo and the resources of an Educational Psychologist.

## General information

- Performance may vary from day to day for no apparent reason.
- Children with NF1 will miss some schooling because they have to attend hospital appointments. Absences compound their difficulties. Physical health may be affected.
- Children with NF1 often have low self confidence.
- Some children will have a parent who also has a diagnosis of NF1. They may share their child’s difficulties, remembering school as an unhappy experience.

## Concentration

- Ensure you seat the child near the front in the line of sight of the teacher. Minimise distraction and model with a group of children who are quiet and focussed.
- Check understanding. Ensure they are listening and not distracted.
- Show what you want the child to do (example, demonstrate, visual prompt).
- Highlight important information.

## Memory

The child could have various issues with their memory and maintaining information. They could have poor short term memory but good long term memory or they could have an inconsistent memory. Something that has been mastered one day is lost the following day, so it is difficult to build on foundations.

There are various ways you can counteract this:

- Visual aids.
- Teach the child to recognise main points of task.
- Introduce a home to school diary or planner to ensure an understanding of the homework tasks.
- Record a brief message on a tape and ask the child to tell you what it said...increase the length of the message as their skill increases.
- Think of memory games.
- Offer instructions simply, clearly, one step at a time. Reinforce. Repeat.
- Has the child’s hearing has been checked? Consider discussion with parent. It can be a “listening” problem rather than a hearing problem.

## Reading, Writing and Calculating

- Avoid the need for too much copying; check for accuracy. Copying from a whiteboard, a blackboard or screen may be particularly difficult. Substitute with an alternative e.g. notes with gaps.
- Adjust the volume of written work and/or allow extra time.
- Allow technology support, such as tablet computers. Consider a scribe. Apply for extra time in exams. Consider dyslexia strategies to support the student.
- Offer support unobtrusively where possible to avoid the child being seen as “different”.
- Ensure some tasks can be achieved successfully to avoid disaffection/loss of motivation.

# Should I talk to the class about NF1?

**It is important to discuss this first with the child's parents and be guided by them. Where appropriate, dependent on age/maturity this should also include the views of the child. It is important to find out from parents what their child knows and understands about their NF1. Parents will expect this information to remain confidential unless their permission is given to share it.**

Other children in the class may be curious. So that the child is not singled out, think about a general discussion at circle time around the things that make us the same and the things that make us different. This will provide an opportunity to explore general themes without specific reference to NF1. It can help the child with NF1 if they have a simple ready answer (such as "it's just something I was born with") to questions to do with their hearing or speech.

## Bullying

**Neurofibromatosis, as with any disability, can provoke bullying and anti-social behaviour in others. This is especially true with visual disfigurements or obvious learning difficulties. This is something to be aware of when providing support to a child, as they have an increased vulnerability to different forms of bullying and insecurity.**

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, so it's always important to talk to the child's parents if you are worried about them. Some behaviours to look out for if you suspect one of your students are 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.



# JO AND LILLY'S STORY

by Jo Clements, SENCO

**For Lilly, in school, living and learning with NF1 means that she does need extra nurture and times when we can enable her to feel that she can honestly talk about how she feels.**

Lilly is now in year 5 and is finding that sometimes the pace of the curriculum and the learning demands can make her feel overwhelmed. She also worries about things that can appear seemingly trivial to her peers and she can display behaviours that appear immature to them. She then gets upset if she feels that she has made social blunders or can't keep up with the social conversations among her group. She is always mortified about the effect she sometimes has and we, together as a team, can always find a way to sort out any upsets.

We do give Lilly extra pre and post teaching opportunities so that she feels a lot more confident to put forward her ideas based on knowledge and practised skills and through this we are trying to instil in her strategies and build her confidence.

For Jeans for Genes day, Lilly decided that she wanted to make a presentation about her neurofibromatosis and to share it with the school. She went from class to class, and the rest of the children were genuinely interested. Lilly did an amazing job and I think that she was genuinely moved by the natural and instinctive positive interest she felt from the other children and adults. We all learnt a lot of new things and it made the Jeans for Genes day even more relevant.

Lilly is an amazing young girl who is an absolute joy to teach and spend time with and we are SO fortunate to have her as a member of our school. We are also fortunate with how supportive her parents are and how much of a team approach we have forged between home and school.

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**The information that we have received from Nerve Tumours UK has enabled us to get more of an idea of NF1.**

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# Where to get support

**When a child with NF1 joins your class, it will be helpful to talk with their parents at an early stage about what the diagnosis means for their child and to understand if there are any significant health problems that will impact on the school day. This will enable you to be clear about what support, if any, the child needs and to have a plan in place. Children with Neurofibromatosis do face challenges on a day to day basis. Helping them to develop the skills to deal with these confidently is a challenge but brings great rewards both for the child and their teachers. It is a real investment for their future.**

At Nerve Tumours UK we want to make sure you receive the best support to ensure that this is possible:

## **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. They frequently attend schools to provide guidance to teachers who wish to support a child in their class with Neurofibromatosis. Check with us whether there is a Support Specialist who covers your area.

## **National Helpline**

Our **National Helpline is open Mondays and Wednesdays 9am – 5pm**, if you need information or support. 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.  
**[www.nervetumours.org.uk](http://www.nervetumours.org.uk)**





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

[nervetumours.org.uk](http://nervetumours.org.uk)  
[info@nervetumours.org.uk](mailto:info@nervetumours.org.uk)  
020 8439 1234

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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**  
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