



Supporting a student who has Neurofibromatosis Type 2 (NF2).



Supporting children who have Neurofibromatosis (Nerve Tumours)

Teachers have a duty of care to their charges, and it can be daunting when one of those children has a condition you have never heard of before. It is important to understand that Neurofibromatosis - which translates to mean "nerve tumour increase", can cause a variety of complications in an individual's life. In the case of Neurofibromatosis Type 2, the individual usually shows signs of the condition during puberty, and their hearing is also usually impacted.

Nerve Tumours UK is the national charity providing support for those living with Neurofibromatosis Type 1, Neurofibromatosis Type 2, Schwannomatosis and Legius Syndrome. Three of the four conditions cause nerve tumours, and all involve health complications.

What is NF2?

Neurofibromatosis Type 2 (NF2) a rare genetic condition caused by a "misspelling" on chromosome 22. NF2 occurs in 1 in 30,000 of the population.

It is most often identified in the teenage years or early twenties, however on rare occasions it is picked up during early school years. Problems associated with NF2 are hearing loss and deafness. Some people may have reduced vision. Others may have weakness in one of their limbs that may limit mobility or strength or may have balance difficulties.

NF2 does not come with associated learning difficulties in the same way as NF1. Whilst we know that up to 80% of people with NF1 will have some degree of learning difficulty, NF2 is usually limited to problems relating to their balance and hearing, pain and eyesight problems.

What problems can occur in school?

The vast majority of individuals will be able to learn and progress with the right support. However, Neurofibromatosis Type 2 can also involve associated learning difficulties, often related to their hearing. They can also suffer from social issues and exclusion. 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.

Please remember that Neurofibromatosis is variable, and affects most people differently. Many people will experience only some of these issues.

Most children with NF2 can join in with the normal range of school activities. The exceptions are children who are limited by a specific health problem such as tumours that bear potential risk from injury. Even this can be accommodated with planning and parental advice.

Other problems that may arise include:

- Bullying
- Difficulties e.g. loneliness and lack of confidence
- Social communications problems because of their loss of hearing and speech difficulties.

General information

- Performance may vary from day to day for no apparent reason.
- Individuals with NF2 will miss some schooling because they have to attend hospital appointments. Absences compound their difficulties. Physical health may be affected.
- Individuals with NF2 often have low self-confidence.
- Some children will have a parent who also has a diagnosis of NF2. They may share their child's difficulties, remembering school as an unhappy experience.



Should I talk to the class about NF2?

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 NF2. 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 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 NF2. It can help the child with NF2 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 neurofibromatosis, such as tumours, deafness and a different way of speaking, can often make children with NF2 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.

Where to get support

When a child with NF2 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 all of this information below will ensure that this is possible.

Nerve Tumours UK Specialist Support

Nerve Tumour UK helps to fund a team of specialist advisors 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 Specialist Advisor 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 2 (NF2) and where you can find more help.
www.nervetumours.org.uk





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

nervetumours.org.uk
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
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Never Tumours UK is the trading name of the Neurofibromatosis Association.
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