



NEUROFIBROMATOSIS TYPE1: INFORMATION FOR TEACHERS

Neurofibromatosis is the name for a group of conditions that cause lumps to grow on the covering of nerves.

This information sheet is about NF1 only.

Neurofibromatosis Type1 (NF1) is a relatively common genetic condition affecting nerve tissue. The incidence is 1 in 2500 of the population.

Some basic facts about NF1:

- it occurs in all communities and all ethnic groups
- it affects males and females equally
- it is a condition a child is born with (though it may only be diagnosed later)
- an affected parent has a 1 in 2 chance of passing NF1 on to their child
- approximately half the cases of NF1 occur as a new event, without either parent being affected
- NF1 varies in how it affects each person

For parents, the variability and unpredictable course of NF1 is a source of anxiety as they are unsure of what the future holds.

How is the diagnosis made?

A doctor familiar with the clinical features can diagnose NF1 relatively easily. The main signs are:

- more than six brown patches (café au lait marks) on the skin
- freckles in unusual places such as armpit or groin
- lumps and bumps (neurofibromas) on or below the surface of the skin
- Lisch nodules (harmless patches of pigment) in the iris (coloured area of the eye)
- a parent with a diagnosis of NF1

Some of the more common complications in NF1 include:

- learning difficulties and some behaviour problems
- bone problems affecting the spine (scoliosis) and the long bones of the leg or arm (pseudarthrosis)
- lumps growing internally on nerves
- large disfiguring lumps that can be painful (plexiform neurofibromas)
- speech difficulties
- variation in blood pressure (hypertension)
- increased risk of epilepsy

The potential complications in NF1 are numerous. Some are very rare indeed. (The above is not a complete list). Some children will have more than one complication.

Children with NF1 will have regular routine health checks with a paediatrician. Some children will be only mildly affected whilst others can have complex medical problems which means they will be under the care of numerous hospital specialists. The resulting time off to attend hospital appointments can disrupt the school routine. Some children have to attend one of only two National Neurofibromatosis centres in the UK as their health care needs are the most complex.

What do I need to know?

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.

Not all children with NF1 need help. However, more than 65% (some research suggests a higher figure) have additional learning needs. These benefit from early identification, discussion with parents and an agreed plan to support those difficulties.

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 about the brown marks or any obvious physical difference. So the NF1 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 about their skin marks or other visible difference.

What problems can occur in school?

Most children with NF1 can join in with the normal range of school activities. The exceptions are children who are limited by a specific health problem such as a scoliosis (curve in the spine) or have tumours that bear potential risk from injury. Even this can be accommodated with planning and parental advice. For example by offering swimming instead of contact sport (if this is an agreed safe option). Offer a quieter area of the playground for protected less physically active games under supervision. Parental advice about their child's health limitations is helpful. Sometimes the paediatrician can offer specific advice and information if the safeguards needed during the school day are unclear.

Most NF1 children have an intelligence that lies within the normal range. The learning difficulties linked to NF1 are not unique: these should be identified and supported in the same way as any child presenting with those same difficulties. There have been many studies investigating cognitive impairment in NF1 but no evidence based strategies to manage learning problems. Early assessment is recommended to

ensure these are not overlooked. Children with physical or learning problems linked to their diagnosis of NF1 often need additional resources or a slightly different approach, depending on their individual difficulties, to ensure access to all parts of the school curriculum.

The learning difficulties in NF1 can cause problems in the following areas:

- concentration
- sustained attention
- coordination and movement
- working memory or short term memory
- speech clarity
- organisation and time management
- processing and sequencing
- behaviour

Please refer to the following information sheets for teachers on our website at <https://nervetumours.org.uk> for more information about the learning and behaviour patterns found in association with NF1 and suggestions about how to help.

- **Summary of learning difficulties that affect some children with NF1**
- **Additional notes for teachers: children with NF1**
- **About learning disabilities**

If you notice any worrying changes in a child's health then you should let their parents know.

Disability, special educational needs and NF1

The Equality Act 2010 means it is unlawful to discriminate against pupils who have a disability. The Act defines disability as someone who has a physical or mental impairment that has "a substantial and long term adverse effect on the ability to carry out day to day activities". This definition therefore includes not only obvious physical problems such as impaired mobility, hearing and eyesight but also impairments of speech, memory, concentration difficulties or the perception of risk. Specifically the Equality Act also includes people with severe disfigurements, impairment controlled by medication, and progressive symptomatic conditions.

Not all children with NF1 are "disabled" nor will they necessarily have Special Needs. Special Needs are defined as "having learning difficulties ...which make it harder for (the child) to learn or access education than most other children of the same age".

A child with NF1 will be said to have a learning difficulty if they have greater difficulty in learning than the majority of their peers or they have a disability that is a barrier to accessing the educational facilities offered by their chosen school. A high proportion of children with NF1 (research suggests between 65% - 85%) have learning difficulties. Severe learning difficulties (ie an IQ assessed as less than 70) are unusual in NF1 but do occur more frequently than in children who don't have NF1.

Children who have a diagnosis of NF1 and ADHD or NF1 and autistic spectrum difficulties will also be included in this definition.

How can I manage this effectively in the classroom?

In the first instance discuss any concerns with parents at an early opportunity. Ensure medical information is shared, respecting confidentiality. Most parents want

the best outcome for their children. Ensure plans are in place that are effective and reviewed regularly. Wherever possible include parents' views and opinions.

Some strategies effective in NF1 children require few resources: for example positioning a child to minimise distraction (with their back to the window, seating nearest the teacher). Others may need enhanced support including the expertise of the Educational Psychologist and a full educational assessment. A smaller but significant proportion of NF1 children will have an additional diagnosis of ADD/ADHD and/or Autistic Spectrum Disorder which occur more frequently in association with NF1 compared to non NF1 children. This needs specialist assessment usually involving referral to the CAMHS team (Child Adolescent Mental Health service) or a community paediatrician. If you have concerns about a child, discuss this with their parents at an early opportunity. The paediatrician may ask for your contribution to the assessment process where this type of problem is suspected. This will usually be by an individual questionnaire about the child to determine the degree of difficulty their behaviour presents in school.

Consider the resources of your special needs co-ordinator (SENCo) and whether it is appropriate to include the child on the SEN register. This step needs discussion with parents and an explanation. Many parents will be unfamiliar with this process and it needs sensitive explanation and reassurance.

Refer to the literature specifically written for teachers listed above for ideas.

Some examples of how to help

When any child first starts school they face challenges. When a child with NF1 starts school these challenges can be greater if they have learning difficulties or are comparatively young for their years. Their social skills may be adrift.

Example: Jalil is described as a messy eater and struggles to manage cutlery; he clearly has difficulty with fine motor skills. Other children have refused to sit near him. His mother is upset and his attendance is patchy. Involvement with the Occupational Therapist has enabled school to provide the correct equipment to support Jalil whose attendance has consequently improved. Jalil follows an OT programme that works to improve his coordination skills. He still needs support to dress himself but his efforts are slowly showing progress.

Example: Tia tends to interrupt at circle time. She seems to ignore the convention of responding only when her name is called. Her teacher introduces a karaoke style microphone and explains the only person who can speak is the one holding the microphone. This visual prompt helps to reinforce when it is appropriate for Tia to have her turn...and when to stay quiet.

Example: Owain finds it difficult to share communal table space. He sprawls himself and his possessions across the workspace of 5 other children. This creates arguments. His teacher uses coloured tape to delineate each child's personal space. She does this for all the tables and this helps reduce conflict whilst not singling out Owain.

Example: John is 9 years old and after a complaint from another child's parents about inappropriate touching, school is considering suspension. John has NF1 and is young for his age. There is a deteriorating relationship between school and home. It is clear he does not recognise when, where and who it is appropriate to touch. The SENCo and John's mother work together to teach John who he can touch or cuddle

safely. They are guided by other professionals involved with the family. They make a body chart to show those areas it is safe...and those it is unsafe. The whole class are involved in the discussion of stranger danger which benefits everyone. John is included in a nurture group to build on the work he has done to help him to recognise facial expression and body language. This makes school a better place for John to be.

Example: Aysha has started High School. She is bright and able but she struggles with organisation and her handwriting is illegible. Access to a dedicated laptop has improved the presentation of her work. However she needs some support with organising her homework which a TA is able to give. The TA introduces a home to school diary and checks daily that the correct task is noted. She emails Aysha a similar schedule of tasks and helps her prioritise her project work. Aysha takes instruction in typing and her speed on the keyboard improves. She is awarded additional time in exams.

Should we consider applying for an Education, Health and Care Plan (EHCP)?

This should be decided on an individual case by case basis, depending on the level of need and additional support required.

Having a diagnosis of NF1 does not mean a child will automatically require an EHCP, however some children with NF1 will have significant needs that can only be met with the support of an EHCP. The school or the parent/carer can make a request for an EHC needs assessment.

If a local authority is requested to carry out an EHC needs assessment by a parent, young person, school, or college, they must consider:

- whether the child or young person **has or may have** special educational needs; and
- whether they **may** need special educational provision to be made through an EHC plan.

If the answer to both of these questions is yes, they **must** carry out an EHC needs assessment.

Parents may need support to understand that this process involves a detailed investigation into the child's learning needs and will involve seeking the opinions of all professionals involved in the care of the child and the parent/carer and child view.

Actively promoting co-ordinated educational support can make a difference.

In Wales and Northern Ireland, an EHC plan is equivalent to a 'statement'.

In Scotland, there is Additional Support for Learning (ASL).

Common Assessment Framework (CAF)

The Common Assessment Framework is a process whereby people from different agencies who are working with children can determine a child's needs holistically. The CAF is a key part of delivering integrated services that focus around the needs of children and young people in England and Wales.

The purpose of the CAF is to help early identification of additional needs which are not being met by the current universal services in place. The CAF enables different agencies working with the same child (or young person) to work together in a "joined up" approach, promoting coordinated service provision. This provides the opportunity

for a multi agency plan designed to meet the child's identified needs. A lead professional assumes responsibility for the coordination of actions identified and also acts as the single point of contact for the family.

Self Esteem and Confidence

Children with NF1 have a cluster of difficulties that can cause problems at school. They are often vulnerable children and can be a target for bullying. Their social skills may be adrift and they are often described as isolated or loners.

It is important that these difficulties are acknowledged and supported appropriately. Helping the child with NF1 to develop their strengths and capitalise on those, understand their weaknesses and develop strategies to compensate for them will increase their confidence and reduce social isolation.

Building resilience, encouraging children to try new experiences, enabling them to participate in all the opportunities your school offers is an investment that will benefit that child in the future.

Children with NF1 may encounter numerous challenges in their lives. School years can lay positive foundations, influencing how those young people go on to face life as an adult and equipping them with the tools to manage what their uncertain future holds.

Rosemary Ashton
Neurofibromatosis Specialist Advisor

Date reviewed March 2022

Helpline Team Nerve Tumours UK Helpline

helpline@nervetumours.org.uk
07939 046 030

Nerve Tumours UK
44 Coombe Lane, London SW20 0LA

nervetumours.org.uk



Please seek further information from www.nervetumours.org.uk, or contact our helpline on the details above.

Nerve Tumours UK has taken reasonable care to ensure that the information contained in its publications is accurate. Nerve Tumours UK cannot accept liability for any errors or omissions or for information becoming out of date. The information given is not a substitute for getting medical advice from your own GP or other healthcare professional.

Nerve Tumours UK is the working name of the Neurofibromatosis Association, a Registered Charity No. 1078790 and SC045051 and a Company Limited by Guarantee registered in England and Wales, No. 03798407