



This information has been compiled to help teachers understand some of the problems that affect a proportion of children with a diagnosis of Neurofibromatosis Type 1.

Neurofibromatosis Type 1 (NF1) is a relatively common genetic condition of nerve tissue. It affects 1 in 2500 of the population.

Some basic facts about NF1:

- it occurs in all communities
- all ages can be affected and it affects males and females equally
- an affected individual has a 1 in 2 chance of passing NF on to their child
- approximately half the cases of NF1 occur as a new event, without either parent being affected
- it is a variable and unpredictable condition with a number of associated features, even within one family. For parents these factors cause great anxiety as they are unsure of what future outcomes will be.

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 of the eye
- an affected parent

Complications can develop in NF1 and include:

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

Children with NF1 are regularly checked by either a paediatrician or GP. 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.

When 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 this should also include the views of the child. It is important to find out from the parents what the child knows and understands about their NF. Other children in the class may be curious about the brown patches or lumps and in these circumstances it can help to say that they have a special name. So that the child with NF is not singled out during this discussion, you could extend the session to talk about other things that make us the same and different.

As a teacher, should I expect problems with a child with NF1?

Not necessarily. Most children with NF1 have an IQ within the normal range. However, it is estimated that 30 to 60% of these youngsters will have some difficulty at school. NF1 varies from one person to another, both in the physical effects and the impact it has on learning.

What problems can occur in school?

For children with special educational needs the provision of help is an area that frequently poses difficulties for parents and teaching resources. Help is often restricted for reasons of budget constraint to those children who are in obvious difficulty. In this situation, parents of children with NF1 can, in some cases, struggle to get help for their children. Part of the problem is that most children with NF1 have a "normal" IQ and they are not dissimilar to their peers. In the absence of formal LEA provision (either by Statement or Record of Need), children with NF1 respond well to appropriately targeted help and can reach their full potential.

Children with NF1 can often appear "normal" and "bright" and so any problems can be attributed to naughtiness, laziness or disobedience. This can be similar to the sort of behaviours that any parent or teacher might come across. However, in a child with NF1 there are some subtle differences including:

Perception and Performance

It is unclear why a relatively high proportion of youngsters with NF1 have difficulty in school. The problem seems to lie with their perception and performance, which might not reflect their innate ability. They tend to perform less well than other children of similar ability. They can be verbally competent but have difficulty expressing themselves on paper.

Concentration

Many children with NF1 find it hard to concentrate and pay attention to one stimulus for any length of time. The teacher and instruction can fade out of their attention because of some minor distraction that has equal or greater weight in their perception. Conversely, concentration can become almost obsessive — a child will persevere in a course of action and be unable to switch to a new activity or approach. Individual help is usually very effective in supporting a child with concentration problems.

Co-ordination

Problems with co-ordination are present in some children with NF1 and this affects both fine and gross motor skills. For example they can have difficulty riding a bike, kicking and catching a ball. Fine motor control can be poorly developed so handwriting might be immature or illegible.

Memory

Some children with NF1 will have difficulty with memory — remembering what they have just been told. They seem to have understood, but cannot retain the information and so are unable to retrieve it only a short time later. Verbal information needs to be explained clearly and then repeated. This includes breaking up instructions into more manageable stages, or reinforcing the facts in an alternative way.

Movement

Children with NF1 often move about in an aimless and purposeless way. They can be restless, get up and walk around during an activity or “fiddle” with things. They can also be clumsy, apparently unable to control either their own movement or visualise where they are in relation to other people and objects.

From a teaching point of view they seem to be deliberately knocking things over, bumping into things, pushing other people and generally causing irritation in the classroom.

Impulsiveness

The children can also be impulsive in their behaviour — they embark on a course of action without considering the consequences of their actions or the instruction to start. Their impulsiveness is carried over into speech and language and they may talk too quickly, gabble or be over-familiar in manner. They can also misunderstand the unwritten social rules which we all observe so they might stand too close, talk too loudly or touch inappropriately.

Social Difficulties

Children with NF1 can have difficulty making and keeping friends and so might be seen as “loners”. They often prefer to keep to the company of adults or younger children who do not judge them so harshly.

This behaviour combined with any significant physical difference, such as having brown patches on the skin, can lead to a child being bullied or feeling isolated. Often it is the child with NF1 who is regarded as the troublemaker because their behaviour is inappropriate or silly and lacks the sophistication to avoid blame.

Organisation

Problems with organisation in general is also a feature in children with NF1. This can be particularly problematic at the transition from primary to secondary school. Meeting the conflicting demands of a range of different teaching styles and expectations, or being in the right place at the right time with the right equipment, places an additional burden on a relatively immature child who has little concept of time management.

Inconsistency

From a teaching standpoint the apparent inconsistencies in a child of average ability can seem baffling and this impression can be compounded by the fact that the child’s performance can vary from day to day.

On a good day they will achieve results and do well, whilst on a bad day those same tasks seem quite beyond their grasp. Within such a short time-scale this can seem difficult to understand where the teacher is unfamiliar with NF1.

Self-esteem and confidence

Not all children with NF1 will have all or even any of these problems, however, they can influence how children learn and, more importantly, how they see themselves. Very often they are written off as lazy and low achievers. If they have any physical blemish that marks them out as "different" no matter how small, self-esteem and confidence is undermined.

They are the ones who have to try harder, who do not understand despite repetition, who cannot pay attention when they should. Increasingly they believe they are condemned to fail, become less motivated, expect to do badly and do not get opportunities to shine. Lack of effort, truancy, lying, outbursts of anger can emanate from this negative mood. For teachers trying to manage a whole class, the child with NF1 can be a disruptive presence if there is no access to appropriate support and advice.

A child with NF1 can be helped to overcome many of the challenges the condition imposes. Working with children to understand their strengths and weaknesses will equip them to develop effective strategies to achieve a degree of success. A little help, appropriately targeted, can make a significant difference to the progress and self esteem of a child with NF1. You, as their teacher, have an opportunity to contribute to that process of changing lives for the better.

For further information and practical teaching suggestions please refer to the fact sheet "Achieving In Spite Of..." which is available from the Neurofibromatosis Association. This booklet has simple ideas that work and it tackles many of the difficulties outlined in this information sheet.

If you teach a child with NF1 and need further advice please contact your local NF Specialist Advisor. These are hospital-based professionals who work with families and individuals who have NF. Details available from the Neurofibromatosis Association.

Produced
with financial
support from



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Updated 07/09