



My child has Neurofibromatosis type 1. What should I tell the teacher?

NF1 is a complicated condition. It is difficult to explain the health effects of this diagnosis. It is particularly difficult to explain how it affects learning and behaviour. Not all children with NF1 have problems in school, but a majority do. This sheet offers some suggestions.

Where to start

A diagnosis of NF1 can mean a child may need extra help or a slightly different approach to learning. If your child has any physical problem affecting their health then this information should be shared with the school. If there are things that your child cannot do because of their health difficulties, then staff need to know so they can offer an alternative activity, or support to enable your child to be included.

For example if your child has a scoliosis (curve in the spine) that limits movement, they may be unable to do contact sports, but can join in swimming. If your child needs to take medication during the school day this needs to be discussed with teachers.

The person to talk to at school will be one of several staff members:

- the class teacher
- Headteacher or head of year
- Special Needs co-ordinator (SENCo). This person may be called something else in some schools

Most teachers will not know about NF1. However they will know what your child is good at and the areas where they struggle. Discussing this can help to identify the help your child needs. It can also clarify whether there are other professionals who could help (eg. occupational therapist, physiotherapist, educational psychologist etc).

Sources of information

You can suggest that the teachers download information from Nerve Tumours UK website – www.nervetumours.org.uk We have factsheets written specifically for teachers. These include:

1. Information for teachers
2. Summary of the Learning Difficulties that affect some children with NF1
3. About learning disabilities (courtesy of the Children's Tumor Foundation - www.ctf.org)

What to say

Many parents are unsure whether to tell teachers about the diagnosis. This decision is important and needs thought. Having a diagnosis of NF1 can be a factor if your child is

making slower progress compared to the rest of the class. With additional help their progress may improve and this will certainly increase confidence and encourage them.

If you decide to discuss NF1, the key person to talk with will be the Special Needs Co-ordinator. Every school has someone whose job it is to identify children who need extra help in school. Children have “special needs” for all sorts of reasons. NF1 will be just one of those reasons. Helping staff in school to understand about NF1 is an important step in making school a happier place for your child to learn.

The steps involved in getting the help your child needs, if they have difficulties, is explained in a booklet published by the Department for Children, Schools and Families. The booklet is called “Special Needs - a guide for parents and carers” and can be downloaded from the site <https://www.gov.uk/government/publications/send-guide-for-parents-and-carers>.

A useful source of support for parents of children with special needs is the Parent Partnership service. For contact details of your nearest local service look at www.parentpartnership.org.uk . Other useful sites to guide you include: www.network81.org and www.ipsea.org.uk.

Rosemary Ashton

updated July 2013

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