Supporting children, young people and their families affected by Neurofibromatosis type 1 (NF1)

Dear Sir / Madam

Childhood Tumour Trust is a Charity which supports children, young people and their families and carers who are affected by the condition Neurofibromatosis Type 1 (NF1).

Whilst we cannot comment on individual children personally, we would like to explain a little more about Neurofibromatosis, (NF1).

What is NF1?
NF1 is a lifelong genetic condition that is incurable and progressive. It affects each person differently, but it often comes with a range of medical, social, and developmental challenges.

How NF1 Impacts A Child

- **Learning and Development**: Around 70% of children with NF1 have some level of learning difficulty. Nearly half also experience autism spectrum traits or sensory processing challenges, for example they may struggle with sensory overload in noisy environments, or require extra support with reading and concentration.
- **Medical Challenges**: NF1 causes tumours to grow on nerves anywhere in the body. These tumours can be extremely painful, and the pain can occur unexpectedly, like an electric shock. Although the tumours may not always be visible, they can significantly impact a child's daily life.
- **Energy Levels**: NF1 can cause fluctuations in energy. Some days a child may seem full of energy, while on other days, they might struggle to keep up physically or mentally. This unpredictability is a common feature of NF1.

What This Means for School
Because NF1 varies from day to day a child may need extra understanding and flexibility. Small adjustments, such as a quiet space for sensory breaks, extra time for tasks, or allowances for days when their energy is low, can make a huge difference.

Support and resources

Childhood Tumour Trust (CTT) provides information and resources to help families and school staff understand NF1 and support children and young people in education.

Our School and Education webpage includes presentations for early years, primary and secondary schools, downloadable PowerPoint versions, guidance on additional support, and a letter about attendance and hospital appointments.

These resources can help staff understand individual needs and promote inclusion. Any plans to explain a child or young person's NF1 to classmates should be agreed with them and their family first.

Explore our resources at:
www.childhoodtumourtrust.org.uk/school-and-education/

Thank you for taking the time to read this. I appreciate your support in helping them thrive at school despite the challenges of NF1.

Yours faithfully

Childhood Tumour Trust