

Children's Tumours (Neurofibromatosis)

MISSING
SCHOOL



Neurofibromatosis (NF) refers to a group of genetic conditions that cause tumours to form on nerves, under the skin, and deep in the body. There are two variations: neurofibromatosis type 1 (NF1) and the much rarer Schwannomatosis (SWN). About 50% of cases occur without family history. Symptoms, signs and management are varied and unpredictable, making early recognition and support essential for physical, educational and social development.



Health condition

- Symptoms include café-au-lait spots, benign tumours (neurofibromas), itch, chronic pain, balance and coordination issues, fatigue, physical differences, bone abnormalities, deafness, blindness, and even cancer
- Up to 80% have learning difficulties and behavioural problems
- Up to 40% have ADHD or ASD
- 71% report an impact on mental health



Student population

Over 13,000 Australians live with NF, with a child born every three days

NF1 is the most common (~1 in 2,500 births), SWN is rarer (~1 in 40,000 children)

Approximately 2,000 school-aged children have NF out of 4 million students, though exact figures are unknown



School absence patterns

- Therapies lead to multiple days missed, exacerbated for those living in regional areas
- Physical fatigue and pain require flexible school schedules, including early finishes or late starts
- Bullying, social isolation, and anxiety contribute to school refusal
- Sensory overload in classrooms increases absences



Challenges for students

- Invisible illness can lead to misunderstandings from teachers
- Executive functioning and sensory processing issues complicate classroom learning
- Physical challenges like pain, fatigue, and coordination problems limit participation in activities
- Significant amounts of school missed, isolation and bullying from peers



Challenges for families

- Fear and uncertainty from NF1's unpredictability
- Navigating education, health, and NDIS systems can be exhausting
- Time constraints affect parents' work
- Financial strain from treatment costs
- 77% of carers report significant mental health impacts
- Isolation from community misunderstanding
- Siblings may feel overlooked



What schools should know

- Understand the complex physical and mental impacts of NF1 on students
- Implement adjustments like noise-cancelling headphones, quiet spaces, and assistive listening devices to reduce sensory overload and fatigue
- Foster understanding and acceptance among peers to prevent isolation and bullying
- Develop and regularly update Individual Learning Plans (ILPs) tailored to each student's unique needs
- Support with flexible attendance policies and adjustments for fatigue
- Maintain open communication with parents to support each child's specific requirements
- Integrate allied health services like speech pathology within the school environment for on-site support
- Allow remote classroom participation for students unable to attend physically

"Most of [the kids] have some sort of pain, whether it be general, generalised tummy pain, headaches, all kids seem to have difficulty with balance, coordination, muscle tone and fatigue. So, you put all of that together, you've got a little person in a very big, noisy, complex environment who's really struggling."



Children's Tumour Foundation

The only dedicated neurofibromatosis patient advocacy and support service in Australia for children, adults and their families.

www.ctf.org.au