Teacher Resource Storyboard

Understanding Neurofibromatosis Type 1 (NF1)

Supporting students in secondary schools

A teacher-focused storyboard presentation with detailed speaker notes for use in school awareness training.

Made by Students (Lauren Gowans and Ramneek Sandhu) at Manchester Metropolitan University for the Childhood Tumour Trust

NF1

Understand
Support
Include

What is NF1?

A simple explanation teachers can remember

Neurofibromatosis Type 1, or NF1, is a genetic condition a person is born with.

It can affect the skin, nerves, bones, vision, learning and emotional wellbeing.

It is highly variable: one student may have very few difficulties, while another may need regular support.

NF1 is not caused by anything the student or family did, and it is not contagious.

Teachers do not need to diagnose NF1; their role is to notice barriers, respond supportively and work with the right people.





Key message: NF1 is a lifelong condition, but the student's school experience can be made much easier through understanding and reasonable adjustments.

How NF1 may affect learning

Common classroom-related areas to be aware of

NF1 can show up in different ways

These are possible areas to notice — not a checklist every student will match.



Attention

May find it difficult to stay focused, especially during long explanations or independent tasks.

Processing speed

May understand the lesson but need longer to take in instructions, answer questions or complete work.

Executive functioning

May struggle with planning, organisation, remembering equipment, starting tasks or managing deadlines.

Visual-spatial skills

May find diagrams, copying from the board, handwriting layout, maths or maps more challenging.

Reading, writing & maths

Some students may have specific difficulties with literacy, numeracy, spelling or written expression.

Fatigue, pain & sleep

Some children with NF1 experience fatigue, headaches, pain or sleep difficulties, which may affect concentration, behaviour and learning during the school day.

Teacher Reflection

Rather than asking:
"How can this student catch up?"
Consider asking:
"What adjustments will help this student learn successfully?"

Key Message

A student with NF1 may not be behind simply because they have missed school. Many children with NF1 learn differently and benefit from teaching strategies and support that meet their individual learning needs.

What teachers might notice

Possible signs in everyday school life

The student understands verbally but produces less written work than expected.

They may need instructions repeated or written down before they can begin.

They may appear tired, overwhelmed, quiet, anxious or withdrawn on some days.

They may miss lessons due to medical appointments and then find it hard to catch up.

They may avoid PE, group work, changing rooms or presentations because of pain, confidence or visible differences.

They may be socially vulnerable, misread peer cues, or be targeted by teasing or bullying.

Some pupils may have delayed speech, language or communication skills, making it more difficult to express ideas, follow complex instructions or participate confidently in discussions.



Avoid assuming behaviour is deliberate. Ask: "What support would help this student access the same learning?"

Social and emotional impact

Why emotional safety matters as much as academic support

Students may feel different because of café-au-lait marks, visible lumps, scarring, height, pain, or needing extra support.

They may worry about classmates asking personal questions or making comments.

Missing lessons for appointments can make students feel behind, isolated or embarrassed.

Repeated difficulties with learning can affect confidence, motivation and self-esteem.

Some students may hide their needs because they do not want to stand out.

A calm, kind teacher response can reduce shame and help the student feel safe asking for help.



Inclusion is not only about access to work; it is also about feeling respected, believed and understood.

Recognising when additional support may help

When additional support may be needed

If a student with NF1 experiences any of the following, it may be helpful to discuss your observations with the school's SENCO:

- Persistent learning difficulties
- ***Significant attention or executive functioning challenges***
- Difficulties accessing the curriculum
- ***Emotional wellbeing concerns***
- Repeated absences affecting learning

Some pupils may benefit from

✓ Reasonable classroom adjustments
✓ ***Targeted learning support***
✓ SEND assessment
✓ ***Education, Health and Care Plan (EHCP), where appropriate***
✓ Referral to an Educational Psychologist (where appropriate)



Remember: Not every student with NF1 will require additional educational support or an EHCP. Decisions should always be based on the individual student's strengths, needs and experiences. Support should reflect how a student learns, not simply how much school they have missed.

Strengths-based approach

Support the student without defining them by NF1

Start with the young person's strengths, interests, goals and preferred ways of learning.

Ask what helps them feel confident, not only what they find difficult.

Give meaningful roles in group work so they are seen as capable by peers.

Use praise that is specific: effort, problem-solving, persistence, kindness or creativity.

Avoid overprotecting the student; high expectations and appropriate support should work together.

Let the student have a voice in decisions about seating, help, catch-up work and disclosure.





Remember

Many young people with NF1 go on to achieve excellent GCSEs, A Levels, university degrees and successful careers when they receive the right educational support.

Helpful question: "What do you already do well, and what would make school feel easier?"

Classroom strategies: instructions and tasks

Small changes that reduce cognitive load

Give instructions in short, clear steps rather than long sequences.

Use written instructions, checklists or task boards so the student does not rely only on memory.

Check understanding privately by asking the student to explain the first step back to you.

Provide worked examples before independent practice.

Break large assignments into mini-deadlines with reminders.

Allow extra processing time before expecting an answer, especially in whole-class questioning.



These strategies are useful for many learners, so they can be built into normal teaching practice.

Classroom strategies: access and flexibility

Supporting attendance, fatigue, pain and confidence

Plan catch-up work after appointments: identify the most important content rather than giving everything at once.

Allow rest breaks, movement breaks or a quiet space if fatigue, pain or overwhelm affects concentration.

Consider seating: good view of the board, reduced distractions and easy teacher check-ins.

Offer alternatives when needed, such as typing instead of handwriting or presenting to a smaller group.

Be flexible with PE or practical tasks if the student has pain, mobility concerns or medical guidance.

Communicate changes early because uncertainty can increase anxiety and organisation difficulties.



Flexibility does not mean lowering standards; it means removing unnecessary barriers.

Responding to questions and comments

How to protect privacy while building understanding

Do not share a student's diagnosis with the class unless the student and family have agreed.

If classmates ask questions, use general language: "Everyone's body and health needs are different."

Challenge unkind comments immediately and calmly.

Avoid making the student explain their condition unless they choose to.

If the student wants to share, help them plan what they are comfortable saying.

Use PSHE, tutor time or inclusion lessons to teach empathy without identifying one student.

With the agreement of the student and if their family are comfortable, consider providing age-appropriate information about NF1 through tutor time, PSHE lessons or assemblies. Increasing awareness can reduce misconceptions, encourage empathy and help create a more inclusive school environment.



Privacy first: the student should have control over what others know about their condition.

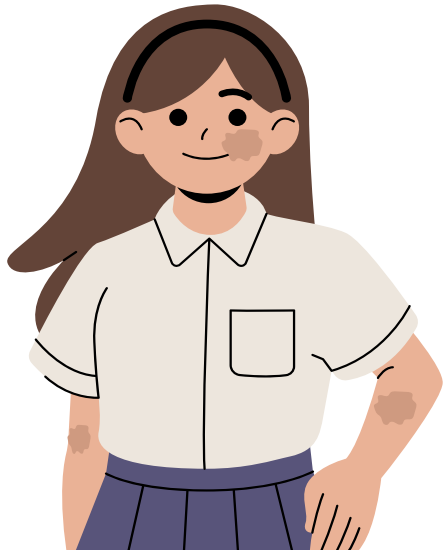
Example students with NF1

Olivia, aged 13

Olivia struggles with self-confidence and anxiety due to her café-au-lait marks and tumours. She has dealt with bullying in the past due to this.

She can find school daunting and often has anxiety surrounding her checkup appointments, which are to check for any changes in her condition.

Despite this, Olivia loves to create art and often finds it is a good distraction from worries that she is facing.



Characters created based on different lived experiences of NF1

Example students with NF1

Jack, aged 15

Jack has also missed school for appointments but is sitting his GCSEs at the end of the year so is worried about his grades.

He loves playing football and can find it a welcome distraction to any worries he is facing with NF1

He can find it difficult to concentrate in lessons which he can find frustrating and tiring, adapting learning for him is vital to keep him engaged and focused.

With additional support Jack will be able to thrive in his GCSEs and finds learning easier.



Characters created based on different lived experiences of NF1

Working with parents, carers and SENCO

A joined-up approach prevents support from becoming inconsistent

Ask parents/carers what has helped before and what current concerns they have.

***Work collaboratively with the SENCO, parents/carers and other professionals involved in the child's care, such as speech and language therapists, educational psychologists and healthcare professionals*.**

Keep communication practical: attendance, workload, fatigue, peer issues, homework and exam arrangements.

Review support regularly because NF1-related needs can change over time.

Include the student in age-appropriate discussions so support feels collaborative rather than imposed.

Record agreed strategies so all teachers respond consistently.



Visual idea:
Use a calm classroom, teacher, student or simple icon illustration here.

Canva-style visual space

Consistency matters: support works best when all staff understand the same plan.

Example teacher response

Turning awareness into everyday practice

Instead of: “You need to try harder to finish.”

Try: “I can see you understand this. Let’s choose the first two questions and build from there.”

Instead of: “You were absent, so catch up everything tonight.”

Try: “Here are the key points you missed. We’ll prioritise these first.”

Instead of: “Why are you not joining in?”

Try: “Would it help to take a smaller role today or work with one trusted partner?”

Instead of : "You just need to catch up.„

Try: "Let's work together to identify what support will help you access the learning."



Supportive language reduces shame and keeps expectations realistic.

Key takeaways for teachers

What to remember after the session

NF1 affects students differently, so individualised support is essential.

Learning, attention, organisation, fatigue and emotional wellbeing can all be affected.

Behaviour may be communication: look for the barrier before assuming the student is not trying.

Small classroom adjustments can make a major difference.

Protect the student's privacy and respond firmly to teasing or bullying.

Work with the student, family, SENCO and wider school team.

Keep expectations high, but make the route to success accessible.



The goal is not to make NF1 the centre of the student's identity. The goal is to make school feel safe, fair and achievable.

What every Teacher should remember

Students with NF1 are capable of achieving extraordinary things.

Our role is not to expect them to overcome unnecessary barriers alone.

Our role is to provide the understanding, adjustments, and encouragement that allow them to reach their potential.



Support today → Success tomorrow

Every student deserves the opportunity to feel understood, included and able to thrive.

They were all told they would not achieve academically









Support their potential instead of limiting it

Further information

Resources and next steps

Childhood Tumour Trust: support for children, young people and families affected by NF1.

NHS: overview of NF1 symptoms, diagnosis and support.

Nerve Tumours UK: school guidance and information for teachers.

School SENCO: first point of contact for learning support and reasonable adjustments.

Parents/carers and the student: key experts on how NF1 affects daily school life.



www.childhoodtumourtrust.org.uk

Thank you for Listening!

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Evidence base used for content

NHS. Neurofibromatosis Type 1 overview: symptoms, diagnosis and school support.

Childhood Tumour Trust. NF1 information and support for children, young people and families.

Nerve Tumours UK. Support for teachers and iNForm your School guidance.

Children’s Tumor Foundation. NF1 guide for educators and learning resources.

GeneReviews / NCBI. Neurofibromatosis 1 clinical overview.