

#### ADDITIONAL NOTES FOR TEACHERS: CHILDREN WITH NF1

NF1 is a variable and unpredictable genetic condition. For some people it follows a relatively mild course; for others it may cause serious health problems that limit everyday life. (For more information about the physical problems linked to NF1 please see our factsheet "NF1 Information for teachers").

## **Learning and NF1**

Most children with NF1 have an intelligence that lies within the normal range.

Their performance (i.e. the work they produce) may not reflect their true ability because of the cluster of difficulties they have.

Not all children with NF1 will have problems in school. However a high proportion (upwards of 65%) will. Identifying potential learning difficulties in the child, developing strategies to support them in school is essential to ensure their educational needs are met and that they can fully participate in all your school has to offer.

The learning problems linked to NF1 are not unique. Once identified, the difficulties should be supported using the same strategies as any other child with those same difficulties. It is helpful to enlist the support of your SENCo and the resources of an Education Psychologist.

#### **General information**

- Performance may vary from day to day for no apparent reason.
- Children with NF1 will miss some schooling because they have to attend hospital appointments. Absences compound their difficulties. Physical health may be affected.
- Children with NF1 often have low self confidence
- Some children will have a parent who also has a diagnosis of NF1. They may share their child's difficulties, remembering school as an unhappy experience.

#### **CONCENTRATION**

Ensure you seat the child near the front in the line of sight of the teacher. Minimise distraction and model with a group of children who are quiet and focussed.

Gain attention...by naming, eye contact. Offer short simple instructions, step by step. Repeat or offer in a visual form. Avoid multiple commands – ensure one task is completed before giving next instruction.

Check understanding. Ensure they are listening and not distracted.

Show what you want the child to do (example, demonstrate, visual prompt)

Highlight important information.

If concentration is a severe problem discuss with parents at an early opportunity. ADD (Attention Deficit Disorder) and ADHD (Attention Deficit Hyperactivity Disorder) occur more frequently in NF1 compared to the general population. This needs specialist assessment and referral. Parents can discuss this initially with their GP or paediatrician and request referral to the Child Adolescent Mental Health service (CAMHS).

If child is restless allow a short period when they can wander/fidget before bringing them back to the task.

Praise freely. Offer positive reinforcement recognising progress and rewarding effort.

#### **CO-ORDINATION AND MOVEMENT**

Can affect gross (large) and/or fine (small) motor skills. Child will often find team sports difficult. Self help skills including dressing can be a problem: can't do up buttons, zips, laces and gets things back to front and inside out. May need additional support with changing for games, manipulating equipment, eating and cutting up food. Slow and can't be hurried. No concept of time.

Bumps into things and other people. Misjudgement (visuo-motor skills impaired) knocks things over.

When seated tends to slump in a heap. Seems not to be attentive and has not learned teacher pleasing posture...but may be listening...so check and praise.

Handwriting poor and illegible. Deteriorates as speed and volume of work increases. The first paragraph will be the best. If this is the case try to avoid criticism of poor handwriting...offer practice...and alternative recording methods. May benefit from intervention of Occupational Therapist (OT) and/or Physiotherapist. Discuss with parent if appropriate.

If handwriting difficulties persist in spite of interventions, consider enhanced typing skills with access to computer or laptop. This is a realistic alternative for some children and will help them to produce better quality work.

Copies inaccurately and if problematic suggest minimise or avoid.

Messy eater. Difficulty using cutlery. (OT can offer advice)

Tires easily and can't sustain effort. Lacks stamina. (Check for health factors. Tailor activities child can manage) Take account of any physical health problems that may impair movement skills. Discuss with parent.

Important to value work child produces well even if limited. Child will feel frustrated and lose motivation.

Restless and fidgets. Contain this constructively...allow brief periods of movement before bringing back to the task. Occupy hands with "tangle toy" or similar to avoid disruption to others.

If sharing table/desk space leads to arguments, mark out all shared space with coloured tape. Do this for all the class so NF1 child is not singled out.

#### **MEMORY**

May have poor short term memory but good long term memory.

Inconsistent memory. Something that has been mastered one day is lost the following day so it is difficult to build on foundations.

Benefits from visual aids, alternative recording methods such as tape recorder, goal cards, computer.

Teach child to recognise main points of task. Repeat and reinforce. Give prompts. Consider repetitive "daily drill" approach. Offer rules, lists, schedules.

Introduce home to school diary or planner to ensure understanding of homework task. As a routine, check this at the beginning and end of the day.

Record a brief message on a tape.ask child to tell you what it said...increase the length of the message as their skill increases. If child is able, ask them to be give messages/directions to others and then praise.

Think of memory games, word games and memory aids to support at appropriate level of ability.

Offer instructions simply, clearly, one step at a time. Reinforce. Repeat.

Has child's hearing has been checked? Consider discussion with parent. It can be a "listening" problem rather than a hearing problem... so ensure attention is focussed.

#### **SPEECH**

Can be unclear, poorly articulated, rapid, breathy and nasal. Lacks modulation.

May benefit from Speech and Language Therapy intervention. Some children can have persistent problems in spite of therapy and need access to a specialist setting for some of their education.

Fails to understand language. The meaning of words is unclear to them. Humour, irony, sarcasm are lost on them. Fails to understand jokes. This is socially isolating.

May need to check the meaning of words and that child has understood what you are asking them to do.

Conversely some children with NF1 are able to express their ideas much better verbally than in writing.

### **READING, WRITING AND CALCULATING**

Avoid the need for too much copying; check for accuracy. Copying from a whiteboard, a blackboard or screen may be particularly difficult. Substitute with an alternative eg notes with gaps.

Adjust the volume of written work and/or allow extra time.

Allow technology support, recording work on tape etc. Consider a scribe. Apply for extra time in exams. Consider dyslexia strategies to support student.

Offer support unobtrusively where possible to avoid "being different".

Ensure some tasks can be achieved successfully to avoid disaffection/loss of motivation.

#### PROCESSING AND SEQUENCING

May find it very difficult to identify the beginning, middle and end of the task. Highlight the starting point.

Can't recall what was asked and the order the of the task. Offer step by step instruction with visual prompt card if reading is difficult.

Cannot identify the salient point(s) so ask child to identify the main points in material they have just read. Encourage them to re-read. Underline or highlight main points.

Tape record student to enhance comprehension or ask them to make notes.

With older children, ask student to tutor another student to teach a concept they have mastered.

#### **ORGANISATION**

Disorganised and can be chaotic.

Frequently loses things...pieces of work, clothing and their belongings. May need support to acquire these skills. May need frequent reminders during the day.

Establish a routine that enables checking of materials needed at beginning and end of day. Allow time for the check to be effective. Offer notes home or email to support this.

Ensure materials are put away in locker/drawer etc at end of session. Help child with keeping their store place tidy

Use coloured folders/paper, visual diary.

#### **BEHAVIOUR PATTERNS**

Focus on child's strengths to increase self-confidence. Praise freely. Positive reinforcement to encourage appropriate behaviour. Catch them "being good" and praise.

Encourage child to try different activities, both competitive and non competitive eg drama, photography, baking, art, singing etc.

Impulsive: acts first without thought of consequences. May need high level of supervision as neither recognises nor anticipates danger. Fails to understand the links in a chain of events.

Teach appropriate behaviour. Show, demonstrate and use role play.

Teach child to recognise facial expression, body language, tone of voice. These are important clues that ease friendship and social interaction. NF1 child can find they are in trouble or being ostracised...but have no idea why. Can be described as a loner but are desperate for friendship.

Consider including in nurture group if social skills are adrift of their peers.

Cannot prioritise the most important task. May focus on the detail rather than the whole.

Prepare child for change in normal routine. May be upset when things are different to "normal". Seems inflexible. Struggles to switch to new approach. Needs early warning and reminders of change with lots of reassurance.

There is an increased incidence of ASD (Autistic Spectrum Disorder) in NF1. Discuss with parent if you have concerns. Parents can discuss with GP or paediatrician and request referral to the CAMHS team for assessment.

Prepare for change such as having a different teacher, a change in planned lesson routine or changing schools. As the child matures discuss with them what approach they think works best and ask them to identify what support the prefer.

Finds it difficult to be flexible, to share ideas and different approaches. Has difficulty in prioritising and identifying the most important task. Struggles to manage time effectively. (Try an old fashioned egg timer as visual prompt).

#### **IMPORTANT REMINDERS**

The learning difficulties that children with NF1 have are not unique: they will therefore respond to the strategies you would use for any child experiencing similar learning difficulties.

If you have concerns about a child's health, talk to their parents at an early opportunity.

Offer a safe place such as the library or Special Needs room to a child who struggles socially.

Identify a mentor who the child can turn to when life is difficult for them and they need to confide in a trusted adult.

Consider a peer support network.

When the NF1 child does well do let parents know of their success. It can be very disheartening for parents who feel their child is always in trouble and never gets things right.

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# Please seek further information from www.nervetumours.org.uk, or contact our helpline on the details above.

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