



## **The child with NF1: behaviour difficulties**

Being a parent is one of the most difficult jobs: rewarding and a source of joy, but at times it can feel overwhelming, both physically and emotionally draining. As parents we are expected to cope with our children regardless of the resources and skills we possess; it is a job like no other, requires no training or qualifications. Most of us just get on with it...most of the time. Managing difficult behaviour in your child is always a challenge. If your child has additional needs because of a health or learning disability even the most competent parent can feel inadequate, exhausted or not up to the job. This Information Sheet offers some suggestions we hope will help.

### **Can Neurofibromatosis Type 1 affect behaviour?**

Having a diagnosis of NF1 does not mean that your child will necessarily have problems with behaviour. Misbehaviour can arise for a number of different reasons that have nothing to do with NF1: for example bullying at school, problems with friends, illness or family difficulties such as divorce or bereavement. Children often cannot explain their distress in words but rather act it out in their behaviour. In a sense the difficult behaviour is their signal that something is wrong.

Children with NF1 can demonstrate some behaviour patterns that other children also share, but they occur more frequently in NF1. For example children with NF1 are more likely to have problems paying attention and listening to what is said. They may have memory difficulties, be impulsive and immature for their age. (*see our Information Sheet "Summary of the Learning Difficulties that affect some children"*) Each of these problems makes life more difficult for your child.

Recent research has shown that there is an increased incidence of Attention Deficit Disorder (ADD) and Attention Deficit Hyperactivity Disorder (ADHD) linked to NF1. Some children are natural "live wires" and very active; this is different to ADHD. Careful assessment is needed by experienced professionals when considering this diagnosis. Between 30-50% of all children with NF1 meet the criteria for a diagnosis of ADD/ADHD (*Pride, Payne and North 2012*). This is a much higher incidence compared to the non-NF1 population where this figure is estimated to be about 5%. However sometimes ADD/ADHD may not be formally diagnosed, but dismissed as being "just part of having NF1".

Furthermore recent research evidence shows an increased incidence of behaviours associated with autism in NF1 (*Garg et al 2012; Walsh et al 2012*). Autism is a developmental disorder that creates problems in several areas: social communication, social interaction and social imagination. It is a spectrum disorder, in other words some people are mildly affected whereas others have more severe problems. Aspergers syndrome is a form of autism diagnosed in a child (or adult) of average or above average intelligence. It is often described as a hidden disability because people look "normal" with no obvious indication that they are struggling to make sense of language or unwritten social rules.

The combination of these difficulties means that children can have noticeable problems within several areas of their development. No single area is dramatically different from their peers; however the difficulties they have within several skill areas can have a cumulative effect on their functioning. In other words, children with NF1 can have a lot of small problems that impact on one another, making daily life more difficult.

### What does this mean in practice?

Activities we undertake each day may be more difficult for a child with NF1. Although there is no magic wand to change this, the way those difficulties are managed by you can help. For example make sure you reduce distractions to help your child concentrate (tv off, choose a quiet place) especially if they are undertaking a task such as homework. Make sure you have their full attention before you ask your child to do something. Keep instructions brief and to the point. Avoid asking your child to “be good” or “go and tidy your room” as these are too vague; rather be specific about what you want and how to go about it.

For example if you want your child to tidy their room, show them and work with them to achieve this. Make a reminder chart about what they need to do to arrive at the tidy state. If reading is difficult for them make it a series of pictures and pin it to the wall. Often parents say everything falls out of a cupboard or is pushed under the bed after they have asked their child to tidy up! *(For more hints and ideas look at the Information Sheet “Additional notes for teachers”).*

When things go wrong your child may have a short fuse which means they can over react. Your child may not be able to tell you what has happened because they cannot recall the sequence of events. Their account may be inaccurate or even dismissed as a pack of lies. Where several children are involved the child with NF1 is more likely to be the one who gets into trouble because they cannot anticipate the consequences of what they are doing. They are not astute enough to recognise that a situation is causing risk either to themselves or others. They may be the one left behind when the rest of those involved have run off: they are an easy target to be the scapegoat or the one who gets encouraged to do wrong in the first place by their more sophisticated peers.

### What are the first steps I can take?

Trying to understand the cause of poor behaviour is a first step in helping to manage the situation. It is often helpful to try to **focus on how your child is feeling rather than the problem itself**. You could start by saying “I think you are feeling very upset and cross just now....and maybe that's why you have ....”. This acknowledgement of how your child is feeling suggests that you understand and are sensitive to their feelings. If you ask your child to explain why they are so angry they probably cannot or will not tell you. It needs a step by step approach...although you might be feeling pretty wound up yourself.

Try to keep calm. Shouting won't help, although we have all done that! Be open to what your child tells you and try to listen even if the explanation does not reflect what has actually happened. Children with NF1 have problems with processing information and their version of events may have significant misunderstandings in it. But it is important that you listen carefully so they feel you are in sympathy with their feelings.

Children who are behaving in a defiant or aggressive way can feel very frightened by the strength of their feelings. When they have lost control, the restraints that they usually have are swept away. They want to get better control and will look to you as their parent to help them to regain that control. Children out of control feel unsafe and helpless.

Many children have outbursts that can challenge parental authority. From your point of view it is important in a two parent family that you agree together how to handle your child so that you can support one another and have a united approach. If you don't have a partner, enlist some support from a relative or a good friend who you trust. If this option is not available then ask for help from a professional such as your Health Visitor, your GP or specialist doctor or your child's teacher.

**Try not to disagree with your partner (or other adult) in front of your child** and avoid criticising each other's management. Differences are best resolved separately (eg. when your children are asleep) and you have time to discuss and agree a compromise on different parenting styles.

### **What behaviour do you want to change?**

Think about the behaviours that cause you most worry and concern. You won't be able to tackle everything at once. It may be better to focus on one or two things that you consider important and work on those. For example you might tell all your children that running off in the supermarket is not allowed.

Once you decide to tackle this then talk to your child(ren) and introduce the new "rule". You need to be consistent in your approach. Parents must agree on how to tackle a situation and what consequences you will introduce for this to be effective. Keep things simple. Don't get drawn into arguments.

What you are trying to do is to enable your child to develop greater self-control and to learn how to behave in a way that is acceptable and appropriate. It is really important therefore, to acknowledge when your child is behaving well by **praise and positive encouragement**. For example if your child holds your hand while shopping or helps you by fetching the things you need, praise them and thus reinforce that "good" behaviour. You want your child to learn that good behaviour is the best way to get your attention.

If your child does break the family rule then it is important that you quickly remind them of the rule and the agreed consequence. The consequence will help your child learn a valuable lesson. It may not change things immediately but in time hopefully your child will learn that if they do act in a certain way, a consequence will follow.

Keep your language simple. Get their attention. Remind your child **briefly** about what just happened. State the rule. State the consequence...and implement it.

For example you might say "I can see you are getting very angry. I think that if you don't calm down we will end up getting very cross with each other. This makes me feel sad. I want you to stop being angry now. If you don't I will....(the agreed consequence).

Try to keep calm.

If your child is so upset that they cannot listen, you may need to remind them later when they have calmed down about what has happened and why you have had to introduce the consequence.

If your child later says they don't care about your consequence, tell yourself that you decide the rules; you are in charge as parent. There is no room for a democracy in family life at this time!

If after a while the chosen consequence no longer works, you can decide to change it. Your child may continue to test you out to see if you will stick to the rule. It is important that you do this because if you give in, it will only give the wrong message to your child...and make it harder next time.

### **Reinforce good behaviour**

Rewarding good behaviour doesn't mean a bribe! It means acknowledging when your child has done something appropriate. This can be by a hug or doing something special together like going to the park or playing a game together. It doesn't have to be money or sweets or expensive things. **Your time spent together** is often the most important to a child.

So you could say "When you put your toys away for me that made me feel really good. You are so helpful when you do that. Thank you...now we can go to the playground".

### **Bedtime routine and sleep problems**

Many children have difficulty settling to sleep and staying asleep. If this is a problem for your child with NF1 the starting point is to seek advice. Firstly establish there is no physical cause such as pain or discomfort. Your paediatrician, GP or Health Visitor may be a source of advice and support if your child is having significant problems sleeping.

It helps to have a planned "winding down" routine before bedtime itself. Fizzy drinks are best avoided as these can stimulate rather than promote relaxation. Introducing quieter games about half an hour before bedtime helps reinforce preparation for bed. Avoid having tv, ipad or other technology in the bedroom. Ensure the bedroom is a calm place. Offer a warm bath and for younger children a bedtime story. Be consistent in your approach to the bedtime routine.

Children with a diagnosis of ADHD or other behaviour difficulty can find it very hard to "switch off" at night. Again your paediatrician can offer advice and occasionally a hormone based medication may be prescribed short term to establish a better sleeping pattern. This will only be successful in conjunction with other strategies.

If problems continue then seek more advice. For example Cerebra have information and a sleep service at [www.cerebra.org.uk](http://www.cerebra.org.uk).

### **"Fussy" eating**

Some children with NF1 are reported by parents to eat only a limited range of foods and have a restricted diet, unwilling to try new foods or viewing vegetables with suspicion. Some children with NF1 seem to choke easily or have difficulty chewing and swallowing; they may be very slow to eat their meal.

If you are concerned about your child's diet you should seek advice from professionals in the first instance: your Health Visitor, GP or paediatrician. If your child is well and gaining weight this is reassuring that there is not an underlying health problem.

If you are reassured that there is no clear health problem, then it is a matter of trying to introduce new foods gradually. If the family can eat together this is helpful. Ensure you offer the same meal to all family members. Praise your reluctant child if they eat even a small amount of a food previously refused. If your child does refuse food, take it away without fuss. Don't offer alternatives. Try to keep calm.

Some children eat better at nursery where the experience of eating communally with other children prompts them to try out new foods. If you are concerned about your child's diet speak to staff to see if there is a pattern developing.

### Resources that can help

If you are concerned about your child's behaviour discuss this with your **Health Visitor, GP or specialist doctor** in the first instance. If your child is of school age it may be helpful to talk to their teachers to consider whether this is a similar problem in school. Because the rules are very clear in the classroom and most children understand the expectations of that setting, your child is more likely to behave appropriately in class time. This may be different at break time when the rules are less clear. So it is useful to understand how your child copes at different times of the day as well as different settings.

School can access the **Educational Psychology** service of the Local Education Authority (LEA). The role of an Educational Psychologist (EP) varies but their expertise is often used when a statement of Special Educational Need is being considered. The EP can undertake a general IQ test together with other tests to assess specific strengths and weaknesses of a child. They can also be a useful source of expertise and offer ideas for how to manage difficulties within the classroom.

Assessments of children with NF1 mostly indicate an IQ within the "normal" range. However, the average ability tends to cluster around 90 (compared to the non NF1 population where it clusters around 100). This can mislead and disguise evidence of other learning problems that can contribute to underachievement in an otherwise able child.

If behaviour difficulties persist you could discuss with your GP or NF1 doctor whether referral to the **CAMHS** team (Child Adolescent Mental Health service) for assessment is an appropriate step. Making a diagnosis of ADD/ADHD and ASD requires assessment by child psychologists or by a community paediatrician with expertise in this specialty. Medication may be offered but this is strictly monitored with the necessary health safeguards.

Medication is not offered in isolation. Other resources such as **parenting classes** can help parents to develop strategies that are more likely to be successful with children whose behaviour is challenging. Some competent experienced parents feel inadequate and overwhelmed by relentless difficult behaviour in their child. Parenting classes can be very helpful in that they act as an additional support and encourage struggling parents to be consistent with boundaries. It can also be a safe place to exchange good ideas: sharing with other parents who have discovered things that work and things that don't.

Young people in High School can independently access the service of a **school based counsellor**. This has the advantage of being readily accessible and on school premises. It is a confidential service and the counsellor will be a professional experienced in working with young people in a therapeutic setting.

### Looking after yourself

Managing difficult behaviour is hard work: it is time consuming, requires a lot of patience and effort, is tiring and emotionally draining. So it is important to get the help you need. Support may be from your partner, a family member or friend.

Try to have some time when you can have a break from child care responsibilities, even if only a couple of hours a week. This will enable you to re-charge your batteries.

If as a parent you have your own physical or emotional health problems it is important to seek help. In the first instance your GP may be a starting point for help and advice. Most GP practices can refer their patients to counselling services linked to their surgery.

Social Services can offer support for children with learning disabilities and this may include the offer of respite breaks. Depending on the policy in your area the criteria varies as to who may be eligible for their help. Crossroads (a voluntary organisation) also offers support for families caring for disabled children.

Rosemary Ashton  
Neurofibromatosis Specialist Advisor  
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Further sources of useful information:

#### Reading resources:

The Incredible Years by Carolyn Webster-Strachan  
1-2-3 Magic series by Thomas Phelan  
Understanding ADHD by Christopher Green  
Toddler Taming by Christopher Green  
Helping The Child Who Doesn't Fit In by Stephen Nowicki and Marshall Duke

### Helpline Team

#### Nerve Tumours UK Helpline

[helpline@nervetumours.org.uk](mailto:helpline@nervetumours.org.uk)  
07939 046 030

**Nerve Tumours UK**  
44 Coombe Lane, London SW20 0LA

[nervetumours.org.uk](http://nervetumours.org.uk)



**Please seek further information from [www.nervetumours.org.uk](http://www.nervetumours.org.uk), or contact our helpline on the details above.**

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