



Being a parent is one of the most difficult jobs. If your child has neurofibromatosis (NF) you might find that, depending on their age and stage of development, coping with their behaviour, will at times be even more challenging. No one knows why this should happen but as parents you need to find ways of coping with this. Sometimes the way they behave will make you feel angry and exhausted, or isolated with no one to turn to for help. This factsheet highlights some ideas from parents who have first hand experienced of caring for a child with NF1 and challenging behaviour.

**Remember you are not alone.** Talk to someone about the difficulties you are having. Do not try to cope on your own. Talk to a friend, NF Specialist Advisor, teacher, parents' helpline, health visitor, social worker or doctor.

**Safety is important.** Children with NF often behave impulsively so make sure your child cannot harm himself or anyone else. We recommend that you do not have locks on your bathroom (flooding risk) or bedroom doors. Children have a particular interest in water and fire, so keep matches under lock and key. Ensure windows, especially upstairs, are locked. Ensure your garden is secure. Children with NF have a tendency to wander so you will need to supervise closely where they go and with whom. Peanuts and other small objects such as boiled sweets, lollipops and small toys can be dangerous as they can cause choking.

**What is the worst behaviour you are facing?** Ignore the things that do not really matter even though it is difficult. Concentrate on dealing with one or two problems at a time. If you try to sort out everything in one go you might be left frustrated when you do not get results.

**All children push the limits.** This is especially true with those they are closest to and in their home where they feel most secure. You need to be able to discuss issues without your child being present. It is important to reach an agreement about what is acceptable behaviour and what is not. This will include establishing ground rules at home. All children need love, discipline, good food and lots of sleep and they do respond to discipline. It makes them feel secure when they know they have to live within boundaries, even though they try to push them. Children also respond to structure and routine in their lives, such as doing the same things at the same time each day. However, children with NF often get upset when their routine is disturbed.

**Do not make a promise or threat that you cannot keep.** We have all done it! You need lots of patience and sometimes this can be tested. Try to keep your word — this is how children learn about consequences.

**Shouting does no good.** At times you will feel so frustrated you cannot help yourself and will feel better for shouting although the situation will not have changed. There are other things you can try, for example, distracting younger children often helps: "Oh, look at that big dog over there." For older children: "Let's tidy up together."

**How do your children know when they have misbehaved?** Do you raise your voice or have a cross expression on your face? Children with NF do not always read these non-verbal signs very well, which makes it harder for them to understand that an adult does not like the way they are behaving. If you do need to intervene when your child misbehaves, try to keep calm and matter of fact. It can help to put some distance between your child and the problem so that everyone can calm down. Try different ideas to work out what helps and what does not.

**NF children are often impulsive.** The behaviour of children with NF can often be more impulsive and unpredictable than those without NF. Most children seem to have a 'mad time' each day and according to some parents, NF children can 'run riot'. at a time when they seem to be harder to manage than others, which is often early evening. Try to find somewhere safe either inside or outside where they can run about. This might help to tire them out so they sleep better.

**Concentration can be a problem for children with NF.** Parents tell us you can work with this problem and sometimes achieve results. Use your kitchen timer and set it for maybe two minutes at first. Try doing an activity with your child for this length of time, gradually increasing the time.

**Avoid confrontation.** If you know the supermarket is where their behaviour is worst, if at all possible leave them at home when you go shopping

**Food is an important area in your child's life.** If you know certain foods trigger behaviour problems, avoid them where possible. Drinks containing caffeine, crisps and brightly coloured sweets are known to have a bad effect. Birthday parties can be a nightmare! Remember, routine is important to your child so establish boundaries at mealtimes and have a set mealtime. Preferably eat at the table with the television off. Try to encourage them to eat the food that you as a family are eating.

**Time alone is essential.** This way you feel you are getting a break for a while, even if it is just for an hour. Dealing with challenging behaviour can put a strain on relationships and parents do not always agree on how to deal with the problems. You can also feel more tired than usual. Parents tell us the worst feeling is that sense of losing control of the situation. In difficult times, remember you are the parent, you are in charge, even though it does not always feel like this!

**Brothers and sisters.** Try to make sure the children who do not have NF do not feel left out. It is hard to get the balance right when one child is more demanding of your time but try to do things with them that everyone can enjoy.

**Remember: not all difficult behaviour is due to Neurofibromatosis. If you need further information or advice please contact your local NF Specialist Advisor.**

The Neurofibromatosis Association has taken reasonable care to ensure that the information contained in its publications is accurate. The Neurofibromatosis Association cannot accept liability for any errors or omissions or for information becoming out of date. The information given is not a substitute for getting medical advice from your own GP or other healthcare professional.

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