



## **Talking with Children about Neurofibromatosis**

Talking with your children about Neurofibromatosis is a challenge for most parents. Many people feel ill-equipped to tackle this task successfully. Knowing what to say and when to say it needs preparation and some thought. There is no single approach that is the “right” way or the “wrong” way.

However the benefits of starting this conversation are fundamental to your child's sense of well-being. It is important to help children understand about NF and to enable them to talk openly about it: what a diagnosis of NF means for them and what it means for the rest of the family.

This factsheet points out some of the things you will need to think about.

A research project in 2011\* found that when parents had discussed a genetic diagnosis openly throughout childhood, those children had a better understanding and more insight compared to families who did not. Most children questioned in the research (including those with a diagnosis of NF) expressed the view that it was helpful to learn about their condition gradually, over an extended period of time. Children whose parents had talked about NF with them when they were very young found disclosure less of a shock, enabling them to build up their understanding gradually at a pace that matched their ability to understand. As they matured so they could gradually absorb more complex information.

### **Who should tell my child about NF?**

Children usually prefer their own parent(s) to talk to them about something as important as a medical diagnosis. If this is not possible then that person should be someone your child is close to and trusts.

In the same research project there was clear evidence that children wanted their own parent(s) to be the main source of information, at least in the first instance. Research findings showed that children believe that their parent is the person who knows them best and understands them best.

As children grow older and their knowledge increases, the information offered by their parent can be supplemented by information from health professionals. So for example, if a young person asks about genetic risk factors, this could be discussed at a clinic appointment where more specialist knowledge is on hand to support parental explanations. It can be helpful to encourage older children to think about their hospital appointments beforehand and even to prepare a list of questions for their doctor. This helps your child to use the clinic appointment constructively and to address the questions that are important to them. Their questions may be quite different to yours!

Where NF is a new diagnosis, parents can struggle to deal with the questions that their child may raise. Being honest and open, offering to find out information to tackle questions you can't answer are helpful steps in developing your child's understanding.

### **Why should we tell children about NF?**

Most parents find telling their children about a genetic diagnosis very difficult and upsetting. Where NF is a new diagnosis for a family this can be particularly challenging as there is no point of reference.

As parents we mostly want to shield our children from things that can make them unhappy or upset. For this reason some parents are reluctant to tell their child about a diagnosis of NF because they believe it will cause distress not just for their child, but the whole family. If those parents have struggled to accept the diagnosis themselves, then finding the words to talk about this becomes more and more difficult...and so it gets put off. However not telling children makes them more vulnerable as they cannot ask questions or talk openly about their fears. It creates a barrier.

Some children have found it comforting to have an explanation as to why they find some things difficult; for example if they struggle at school, if their balance is poor or if they cannot run as fast and easily as other children. Talking about NF in an open manner can help children to cope when life is not going well, so they can overcome setbacks and manage difficult situations such as health problems, uncomfortable tests, scans or surgery. Often children cope with difficult news better than parents might expect.

### **Who shall we tell?**

Your child(ren) in the first instance. Talking with your child(ren) will start their process of understanding NF, what it means...and what it doesn't mean. Being open gives them permission to ask questions, to talk about their feelings and fears, their worries for their future and offers them some reassurance.

It is also important to think about who to tell within the family. Where there are a number of children, some with NF and some not, it is important that the unaffected children are also included in discussions at some point. If this does not take place there is a risk they can feel excluded, that there is a secret that they don't know about, that something is going on that is their fault.

Some families like to keep the diagnosis a private matter limited to members of the immediate family. Others adopt a more open approach. Again it depends on personal preference. Grandparents can be a great source of support for parents in this situation. Conversely it can prompt unhelpful feelings of blame and recrimination. Some members of the extended family may deny there is any problem at all and suggest "there's nothing wrong with him/her". This can cause further difficulties within the family.

It may help to talk to your children, if they are old enough, about who they think needs to know. Some children have strong views about this and don't want to be seen as "different" to their peers. They may want to tell close friends or other adults they are close to and can confide in. It is usually helpful to talk to your child's teachers (headteacher, classteacher, SENCo or Head of Year) about the diagnosis. If there are any emerging problems evident within the school setting these should not be overlooked but supported constructively and resources made available as necessary.

### **When to talk about NF**

Choosing the right time can be tricky! You need to think about a time when your child feels comfortable and able to listen without distractions. If this is a new diagnosis you may find it

difficult to talk because you feel upset yourself. It is important therefore to allow yourself some time to manage your own feelings about the diagnosis and to gain some sense of perspective before talking to your family.

If there is no pressing urgency then talking about NF can be delayed until you feel better able to manage the situation. Other reasons to postpone telling may be important exams or serious illness in the family. But it is important to do this at an early opportunity and not delay unnecessarily.

Sometimes the timing of a discussion about NF can be prompted by a forthcoming hospital appointment, a magazine item or tv programme, or your child's question. This gives you the opportunity to start the conversation. Some children find it easier to hold this conversation when they are with you doing some routine task such as washing up together or during a walk or a car journey.

If your child has problems with understanding or learning difficulties it is important to ensure your language is simple and clear, that your sentences are quite short and that you don't offer too much information at once. Reassure them that they can always ask you questions, that if they forget or don't understand you will talk with them again.

### **Is it not a better idea to wait until my child is more grown up?**

Research into the experiences of children talking about their genetic diagnosis suggests that this is not the case. Children learning about their diagnosis at a young age adjust and accept their status more readily than those where that is withheld.

A proportion of adults with NF1 will be transferred to the care of their GP after discharge from the paediatric service. It is important that young people leaving paediatric care understand their health needs and know when to seek medical advice.

Most patients with NF2 will have their health monitored in one of several specialist centres so continuity is assured. The process of learning about NF is one that begins in childhood, continues into adolescence and, supported by health professionals, is consolidated in adulthood.

If parents delay this process until their child reaches adulthood, there is the risk of anger and recrimination that this, their personal health information has been withheld... even when the underlying motive has been to protect. There is also the real risk that children will make their own enquiries without your knowledge on the internet. They will then have no-one to share their fears and worries with. Some parents find they have never been able to talk to their child about the diagnosis, and then face the very difficult situation all over again when grandchildren are born to their affected son or daughter who is oblivious of the risk their child may inherit NF.

### **What to say...**

Once you think the time is right, when you are comfortable and calm, you can start the conversation. You know the words your child will understand. The first conversation is just a starting point, a bit like the first step on a ladder. Don't plan too much as your child may ask questions that take you by surprise and so throw you off track.

Allow your child to ask questions...these may be immediate or come some days later. Let your child take the lead in where the conversation goes. Don't try to cram too much into the first session or overload your child with too much information. Keep language simple with short sentences.

Some examples of what you could say to start the conversation about NF:

*"We are going to see the doctor at the hospital tomorrow. She will be checking you over to make sure you are keeping well...."*

*"This doctor sees lots of children with brown patches on their skin. Doctors call these a special name: cafe au lait patches..."*

*"Next week you will be having your hearing test at the hospital. This is to check to see if your hearing nerve is working properly..."*

Encourage your child to ask questions. Keep your comments open so that you can encourage your child to express what they are thinking to help you share their feelings. It helps if you ask open questions that don't just lead to a yes or no reply. For example you might say: ...*"tell me about"...* or *"what do you think about...."*

If your child does ask you a question make sure you answer the question they ask and don't go off at a tangent. If you don't know the answer then say so but offer to try to find out.

Finally it is important to reassure your child that there will always be people who love them and will care for them. That having NF does not change the person that they are. NF is just a part of who they are. But they are still "Jack" or "Maryam" who is good at cooking or who is brilliant at helping Mum.

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January 2013

\* "Parents' and children's communication about genetic risk: a qualitative study, learning from families' experiences" Metcalfe A, Plumridge G, Coad J, Shanks A, Gill P European Journal Human genetics 2011 (6):640-6. For a summary of this paper see The Neuro Foundation newsletter Spring 2012

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