

There is never a single right way to approach this and different families will go about it in different ways. Some children learn at a very young age that they have a diagnosis of neurofibromatosis (NF) and it becomes a familiar word which is referred to easily and often. It is part of their make-up and absorbed by the family. Other parents, who have perhaps struggled to accept the diagnosis themselves, may often think about the time when it will be right to 'tell' but, somehow, this time never seems to come and the moment gets put off. Talking to your child about NF can then become more and more difficult: a subject to be avoided, a secret. Below are some of the common questions parents ask.

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

Usually a parent or someone your child is close to and trusts. It is important that the information you give is accurate and can be understood by your child. Try to answer any questions as simply and truthfully as you can. If you do not know the answer it is better to say so, but offer to find out more.

- Make sure what you say is correct
- If you are not certain of the facts say so and then find out
- Use simple language
- Don't offer too much information at once
- Answer the question that is asked
- Start with simple facts and add more as your child grows up and can grasp more complex information
- If relevant , use pictures or drawings to explain

### **When should we talk about it?**

It is a good idea to grasp opportunities when they are presented. This may come from occasions such as:

- Your child's question
- Preparing for a hospital appointment
- An article in a magazine or a television programme
- Any other time that feels right — often bed time or bath time

### **How can I help my child to understand when I hardly understand it all myself? I don't know where to start!**

Try to prepare yourself for the time when your child will ask questions, or when you choose to introduce the subject. This can help control the anxiety you may feel. It may also encourage your child to share their worries if you approach the subject confidently and are not taken unawares. It might help you to go over basic facts about NF with your Regional NF Specialist Adviser or a doctor who is familiar with NF. Start to think about a simple answer to questions such as: **What is NF? What are these birthmarks?** and then think about what you might say. There are some suggestions at the end of this fact sheet to help you.

