



Introduction

The diagnosis of a disorder like neurofibromatosis (NF) can be a great shock and cause a lot of emotional stress. This will mean that when you see any health professional (Doctor, GP, Nurse etc) you are so anxious that you forget to ask the important questions. There are many reasons why you might feel anxious and it can be difficult to get the information and support you need. Whether you are the parent of a child with NF or have the condition yourself this fact sheet will guide you on how to avoid this.

You will probably be referred to a consultant at some stage. This may be before or after diagnosis to confirm what your GP has suspected. You may also have to see more than one consultant. For whatever reason you have to see a health professional, it is wise to prepare yourself for the appointment so that you get the most out of it. This preparation can include taking steps to overcome the effects of your worry or stress.

Preparation

Find out a little about NF. Too much information can be confusing, especially if you have not had a confirmed diagnosis. You can get information by contacting the Neurofibromatosis Association or your local NF Specialist Adviser (information from head office). The NF Specialist Adviser will also be able to answer any specific queries you might have.

Try to sort out in your own mind what it is that is bothering you most or what you want to know. Then put these needs into the form of questions and write them down. Talk it over with someone you feel comfortable with. If necessary you should consider taking someone with you to the appointment to act as a listener and perhaps a prompter if you forget something.

At the consultation

There are different types of consultants with differing approaches to patients. Depending on the nature of the NF you can end up seeing more than one consultant in different specialities. For example: if you are asking to have neurofibromas removed, you may see a dermatologist or surgeon. Each consultant will know a lot about their particular speciality, but not know all the things that can happen in NF. To discuss the condition 'as a whole' you are better to ask to see a specialist or clinical geneticist. In some areas of the country there are consultants with a particular interest in NF and the Neurofibromatosis Association can give you information.

Whatever speciality they are in, consultants are only human and they may be as nervous as you are. Appointments are a two way process and it is important that you co-operate as fully as you can. Some of your queries might get answered during the consultation but there should be time for questions. Sometimes the professional can appear distant and unapproachable but do say if you feel uncomfortable at any stage. They may appear to be struggling with how to manage aspects of the condition or talk using words you do not understand. If this is the case, try not to worry about it. Try to concentrate on listening to what is being said to you and ask if you do not understand something. Check your list of questions—have they been answered? If not, ask again and listen carefully to the answers. However do be realistic about how much time you have for the appointment.

Try not to take in only the information which suits your preconceived ideas—that is, perhaps, the answers you want to hear, or indeed, the “possibilities” you fear. Listen to what the consultant is trying to tell you. If the consultant sees that you are upset he/she may reduce the amount of information. This is when you should check your list of questions.

Even after all this you might still not be taking in what you are being told. This is probably because of your close involvement and not because it is necessarily bad news (very often it will not be). This is when having someone else with you at the appointment may be helpful. They can often listen in a more detached way to what is being said and compare notes with you afterwards.

Conclusion

There are often many calls on a professional’s time. They will try to give you as much time as they can and not rush the consultation. It will help you to get the most out of the time available if you prepare yourself as well as you can, with a list of questions that you want to discuss. If you still have questions or queries you should note them for your next appointment or contact your local NF Specialist Adviser.

Checklist

- **Aim** to work with the professional. Try to develop a positive relationship so that you feel confident and comfortable about asking questions
- **Ask** where further help can be sought but be wary of involving too many professionals
- **Remember** the meeting is a two-way thing. You will expect the professional to listen to what you have to say but listen carefully to what they say to you. Check that you have understood properly by repeating, or asking for further explanation of, your questions if you are at all unsure.
- **Keep it simple!** Write things down but try to be concise. If you have lots of questions prioritise: which are the most important ones you would like answered?

Produced
with financial
support from



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Updated 07/09