

## Doctors – a prescription for good service

Have you just had a diagnosis for your child? Are you still doing the rounds, trying to get an answer as to why your child is different to other children? Perhaps you are about to start meeting a number of doctors, consultants or specialists. A little preparation beforehand will help to make this process much less traumatic for you and your child. These are a few simple tips to guide you.

### **G.P. Appointments**

- If your child needs to be dressed or undressed for an examination, or you know it will take some time to settle them, try to get a **double appointment** booking. The usual time allocated for an appointment is about 5 to 10 minutes so extra time will mean you and the doctor won't feel so rushed.
- Doctors are there to help you but you can help them to do their job. Some parents find visits to the surgery a complete nightmare and so they 'save up' their child's ailments and then visit the doctor. While this certainly saves time, it may create the impression that you are an overanxious mother looking for trouble. So it helps to limit the problems to one or two (or three!) that are most urgent.
- Have some idea about what you want to say to the doctor. In many cases it will be very obvious; your child has a sore throat or chesty cough. But there will be occasions when you have a number of concerns relating to your child's chromosome disorder. It will help you and the doctor if you can spend some time before the appointment preparing a list of the most important points you want to discuss. Leave some space between questions so that you can write down any answers. Make a copy for the doctor as well.
- Perhaps you are clear in your own mind that you want the doctor to do something specific like refer your child to a specialist, arrange for a blood test or see a therapist. You can give your G.P. details about your child and reasons for your concern first, it then gives him a chance to make suggestions. It may be tempting to say that you read about a particular treatment or test on the Internet but doctors are very cautious about the reliability of medical information found on some internet sites. You can introduce this information by saying "that reminds me Doctor, I recently read that XYZ had been used successfully to treat ABC. Have you come across XYZ at all?". If he hasn't then you could offer to give him a copy of the relevant information.
- If you are not sure what the doctor has said to you, a useful tip is to repeat the answer back to him. "Let me make sure I understand you correctly Doctor. You are saying .....etc ". This will make sure that there are no misunderstandings. Ask him to write down any particular medical terms that are unfamiliar to you.
- If the doctor's room is on an upper floor and it is difficult for your child to get there ask to be seen on the ground floor. There is often a nurses' room available there (Practice nurses see more elderly frail people who can't get up the stairs). Sometimes it is very difficult to actually get your child to the surgery. Not everyone has access to a car or good transport links. Under the Disability Discrimination Act (DDA) a doctor's surgery must make 'reasonable adjustments' to allow disabled people to have access to their services. A home visit would be a 'reasonable adjustment' if it is very difficult for your child to attend the surgery. You might also check if the surgery has a disabled toilet and easy access for wheelchair users.
- If your child has difficulty waiting when appointments run late, explain this to the reception desk and see if they will give you the first appointment of the morning or afternoon. My own experience is that if my son has to wait too long he will dismantle the notice boards, make lots of noise and become very active! A few visits like that and it's amazing how quickly the doctor will see you.
- A cheery smile and a few words of greeting at the reception desk will work wonders sometimes. Don't be afraid to start off by saying, "My child has a very rare chromosome disorder and because he is not well. It is important that we see a doctor today in case it's something serious". It avoids you having to give your entire family history before they will let you see a doctor!
- Some G.P. practices have more than one doctor. If possible try to see the same doctor each time you visit. It helps to build up a relationship where the doctor can get to know you, your child and the family and will save you having to explain each time about your child's rare condition. In emergencies you will have to take pot luck and see whoever is available.
- If afterwards you discover that you forgot to ask a question you can ring the surgery when you get home and request that the doctor gives you a call back at home.
- If you feel that your doctor just does not listen to you or won't help then you are entitled to ask for a second opinion. This can be done without causing any ill feeling or questioning the doctor's ability. You could say, "Doctor, I would feel more reassured if I could speak to a specialist about my child", or "Would you mind if I spoke to another doctor about my child as I feel it would help me to get a better picture of how my child is doing?".
- Keep a diary that records your appointments. If you can't get to an appointment do ring and cancel it or re-arrange it.

### **Hospital Appointments**

Some of the points above will apply when you have a hospital appointment. If you are seeing a consultant for the first time they will usually see new patients in the morning at the Out Patients clinics. Some consultants have ward rounds before their clinics and this can delay them. Be prepared for this and have some toys, drinks or food available. Ask how long the waiting time is and if you can take your child for a stroll while you are waiting.

