



NHS

Great Ormond Street Hospital for Children NHS Foundation Trust: Information for young people and families

Transition for children and young people with neuromuscular disorders

This information sheet is one of a series produced for children and young people attending the Children's Neuromuscular Centre at Great Ormond Street Hospital (GOSH). It has been provided to help answer some of the questions you may have about moving on to adult services.

What is transition?

The purpose of transition is to help you to develop the skills to feel confident in talking about and taking charge of your healthcare.

Why bother?

Research has shown that when young people and their carers first make the move or 'transition' from children's to adult's services, they feel nervous about the change. However, when they are prepared for the move, they find it easier to cope in the new situation. Here in clinic it is a safe place to start practising talking to professionals on your own, asking the questions you want answered.

We asked a sample of adolescents (teenagers) who regularly come to this clinic how they felt about transition. They asked for support information and skills and also an environment which reflected that they were growing up.

How will it work?

When you arrive at clinic, we will ask you to fill in a plan that will give you an opportunity to ask for help with certain things. It is up to you what you put down, we will try to respect your choices.

- We will try to help with any advice you want – please ask us.

Do I have to go in to see the doctor on my own straight away?

No, you don't, but it is important to know that you can see the doctor on your own, whatever your age. Remember that it is a gradual process. At first, the doctor will ask you some questions. He or she may ask about your medicines, your school, what you want to do when you leave school and generally how you are feeling.

Will my parents or carers still be able to see the doctor if I go in on my own?

Yes. Sometimes they too can find it strange waiting outside for you but they still have the opportunity to see the doctor if they want to, usually at the end of the visit.

What if I want to ask the doctor something I want to keep private from my parents?

That is all right. Whatever you say to the doctor is strictly confidential and will not be passed on to your parents without your permission. The exceptions to this are if you and/or other people might be at risk of harm. If this is the case, the member of the team will discuss with you what parts of the information might need to be shared, who with, why it might be shared and how. As we work as a team in the neuromuscular services, it may be necessary for individual staff to discuss your issues with other team members. If you do not want information to be shared, please let one of the team know.

What do I need to bring?

- A list of any questions you want to ask
- Pen and paper in case you want to make notes
- A list of your medicines

Can I see a particular doctor if I want?

Certainly we will try to help with this. Sometimes seeing the same doctor helps make you feel more confident, especially if you have started to come in on your own. It may mean that you have to wait longer, so bring some things to do while you are waiting.

Contact us

We encourage young people to contact us themselves

- **To change your appointment**
– phone the Neuromuscular coordinator on 020 7405 9200 ext 1132
- **To ask a question** – phone the Neuromuscular Nurse Specialists on 020 7405 9200 ext 0517 or 1195 or bleep 2123 or 0028



Compiled by the Neuromuscular Service in collaboration with the Child and Family Information Group

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