



# Helping your teenager through transition: information for families of young people with a neuromuscular disorder

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Transition is a planned process. It aims to:

- support teenagers in the development of skills to become more independent in their healthcare
- support parents in helping their teenager to achieve this to the best of their ability and
- prepare for transfer from child-centred healthcare to adult healthcare services.

This information sheet from Great Ormond Street Hospital (GOSH) offers you some suggestions about how you might help your teenager to move through transition.

Research has shown that when young people and their carers first make the move or transfer from children's services to adult services, they may feel nervous about the change. However, when they are prepared for the move, they may find it easier to cope in the new situation. Our Outpatient Clinic offers a safe place for your teenager to start practising talking to professionals on their own and asking the questions they need to.

## When should preparation for transition start?

Most young people will be ready to start by the age of 12. We will discuss it with you and your teenager and introduce it gradually. We recognise that this time of transition will be different for everyone. We will work with you and your teenager to respond to their individual needs as much as we can. If your teenager has a learning difficulty, it is still helpful for them to build on the skills they have and to become as independent as they can for the future.

## What are the aims of transition in the Neuromuscular Clinic?

- To provide support and information to teenagers and parents as they move through the process of transition.
- To enhance a sense of control and independence.
- To support teenagers in the development of skills needed to help them move on to adult care.

## What is the difference between transition and transfer to adult care?

Transfer is an event at the end of the transition process when your teenager moves from paediatric into adult care. Ideally, there is no fixed age for transfer as this will depend upon several factors, including:

- Age
- Maturity

- Medical status – it is best to transfer a young person with a neuromuscular condition when they are going through a more stable phase of their condition
- Level of independence
- Whether the young person feels ready.

## Taking charge – how to help your teenager become more independent at appointments

To become independent at appointments, your teenager will need to be able to start to talk to health professionals. For many teenagers, this is easier said than done.

Teenagers often know what they want to say, but do not always have the confidence or skills to do it. This may feel like a big adjustment for you and your teenager. Developing and practising useful skills to help this process along is important for all concerned so everyone can get the most out of the appointment.

Here are a few suggestions that may help you in this process:

### Preparing for a clinic visit

- Take some time before the appointment to talk to your teenager and find out what concerns they might have.
- Write a list of their concerns and your concerns to take with you.
- If your teenager is being seen alone for part of the appointment, you may like to think of any questions you might like to discuss with another team member yourself, without your teenager around. We will do our best to give you this opportunity.
- If your teenager is just getting started with this process of becoming more independent, decide on one or two questions they could ask to begin with. They will gain in confidence in asking questions with you around at first.

- Encourage your teenager in this process of gradual independence in appointments and listen to their concerns.

### During the clinic visit

The following may encourage the team to direct their conversations to your teenager rather than at you:

- Encourage your teenager to be seated in a position slightly in front of you and preferably next to the member of the team you are seeing.
- Change your eye contact – people will continue talking to you while you are looking at them. However, if you move your gaze from them and look towards your teenager, they will also shift their gaze and begin talking to them.
- If they ask you a question, redirect it to your teenager.
- Involve your teenager in all the decisions made in the management of their condition.

### Please remember...

- This is a process – it will not happen overnight but may take place over a number of clinic visits.
- Practice will help your teenager gain confidence.
- For most, if the process starts early enough, by the time they are young adults they will become independent in their own healthcare and you will feel more confident in their ability to do so. Even if your teenager has a learning difficulty you can help them become more independent.
- We recognise that teenagers vary enormously in their confidence and ability to become independent in their healthcare. We hope that we can work together with you and your teenager to develop their skills towards more independence by the time they are ready to transfer to adult services.

- Allowing them to become more independent does not mean you are less involved – it is just that you are involved in a different way.

## A pathway towards independence

### Stage 1: Introduction

- Teenager and parent both present in consultation.

### Stage 2: Preparation

- Your teenager gradually takes the lead.
  - Practice with one or two questions they might like to ask.
  - Encourage them to take the lead in appointments.

### Stage 3: Practice

- Your teenager is seen alone for part of the appointment.
  - For many parents, letting go can be difficult and understandably raises a number of questions. For example, “Will they tell the doctor everything?”, “Will they remember the names of their medications?”, “Will they make the right decisions?”
  - Talking to someone about these concerns can be very helpful and will make it much easier for you and your teenager to get the best from transition.
  - If your teenager has a learning difficulty, try to help them be involved in consultations in similar ways, accepting that they will always need some help from an adult in managing their healthcare.
  - Privacy and Confidentiality: There may be some things that your teenager talks about to the team that are private and confidential. These can only be discussed with you if your teenager agrees or if it is absolutely

necessary to keep them (and other people) safe. In nearly all cases, the team will encourage teenagers to discuss concerns with their family.

### Stage 4: Independence/ Interdependence

- Your teenager is seen alone for the majority of the consultation.
  - Progressing from stage 1 to 4 may take a little time and may not be completed. That’s fine. Help your teenager progress to a point that is comfortable for them.
  - Let your teenager set the pace.
  - Sometimes, for example during consultations about scoliosis surgery or other more difficult discussions, your teenager may need greater support from you. When things are settled again, help them to return to the stage they are comfortable with and continue the process.

## Decision making

Part of the process of your teenager becoming more involved in appointments is also becoming more involved in making decisions about their health. It is helpful for children (whatever their age) to feel involved in the decision making about things that affect them. This becomes more important during teenage years. Remember that both you and your teenager can always ask questions if you don’t understand or feel you want to know more. For instance, you might want to find out about:

- what sort of things it will involve
- what benefits they hope will result
- how good the chances are of your teenager getting such benefits
- whether there are any alternatives
- whether there are any risks
- whether the risks are small or large

- what may happen if your son or daughter does not have the treatment.

Remember – if you need more time to make the decision, it is okay to ask for it.

## Other issues that may arise for teenagers as they progress through adolescence

### Teenagers and their bodies – how to help your teenager talk about sexual health issues

One of the stages of adolescent development is for teenagers to find their own identity, including their sexual identity. There are obviously important cultural, religious and legal aspects to sexual health issues during adolescence.

However, there are several very important reasons why sexual health issues should be addressed during teenage years. For instance,

- they can be a concern for young people.
- they can be difficult for young people to express.
- research shows that young people acquire most of their sexual health information (and misinformation) from their peers. Most of them want more accurate information, as well as opportunities to discuss their concerns, feelings and opinions.
- young people with chronic illnesses and disabilities are often denied the right to express their sexuality and may have limited access to information.
- all young people have the right to protect themselves from potentially harmful situations and to establish positive and healthy relationships.
- children are subjected to sexual imagery every day on TV, films, song lyrics and magazines, yet have few opportunities to participate in serious discussions about sex or to receive information presented in the right context.

These issues are important for you as parents and you may wish to consider how you might approach them. If you can, let your teenager know that they can talk to you about sexual health issues whenever they need to. This will provide them with the space and the opportunity if they wish to do so.

You could try saying something like “Some teenagers worry about whether they will be able to have sex when they are older. If you are ever worried about this, know that you can talk to me about it any time.”

If you find it difficult to talk with your teenager about sexual health issues, one of the team may be able to help you find appropriate advice and support.

Here are some useful resources for parents and teenagers:

- ‘Growing up, sex and relationships: a booklet to support parents of young disabled people’ – produced by Contact (previously Contact A Family) available online at [www.contact.org.uk/advice-and-support/your-child-your-family/growing-up-sex-and-relationships/](http://www.contact.org.uk/advice-and-support/your-child-your-family/growing-up-sex-and-relationships/) or by calling 0808 808 3555). This booklet not only has lots of useful information, but also has a resource section where you can look for further information.
- There is also a booklet written by the same organization for teenagers with disabilities – ‘Growing up, sex and relationships: a booklet for young disabled people’.

### Teenagers and their mental health – how they feel about themselves

Teenagers are often moody and uncommunicative, but it is helpful to know the difference between teenage ‘blues’ and the onset of depression. The following can be signs that a teenager is depressed:

- Being extremely moody and irritable

- Giving up interests or hobbies but not finding new ones
- Losing interest or not doing well

Teenagers with impairments sometimes find adolescence a challenge and need some help and support with feeling good about themselves. Here are some suggestions about where you might find support for you and for your teenager:

- The YoungMinds Information Service (0800 018 2138 or [www.youngminds.org.uk](http://www.youngminds.org.uk))

provides information and support for parents and some very useful booklets for teenagers on subjects such as depression, anger and school issues. Some of these booklets are available in clinic.

- Family Lives (previously known as Parentline Plus) (Helpline: 0808 800 2222 or [www.familylives.org.uk/](http://www.familylives.org.uk/)) is a UK registered charity that offers support to anyone parenting a child.

## Further information and support

If you have any questions, please ring Clinical Nurse Specialists in the Dubowitz Neuromuscular Centre – 020 7405 9200 only ext 1195 and email [neuromuscular.cns@gosh.nhs.uk](mailto:neuromuscular.cns@gosh.nhs.uk).