

Transition of craniofacial patients from paediatric to adult services

Information for young people
and families

Great Ormond Street Hospital
for Children NHS Foundation Trust

What is transition?

Transition is a planned process. It aims to:

- Prepare the young person for adult services
- Ensure that when that transfer happens it is a smooth and staged process
- Involving the young person in decisions about their care and move to adult services

This booklet aims to offer some suggestions for parents and young people about how you as a family might be helped through this process.

Why bother with help for 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.

When should preparation for transition start?

Most young people will be ready to start talking about it by the age of 12, although we would not aim to move you over to adult services until you are 16 to 18 years old. We will discuss it with you and introduce it gradually. We recognise that this time of transition will be different for everyone. We will work with you to respond to your individual needs as much as we can.

If there are some specific issues, for example, learning difficulties, we can work with you to ensure that you are well supported both in the hospital and in the community in moving on to adult services.

What are the aims of transition in the Craniofacial Clinic?

- To introduce the idea of transition and let you know how it will work for you
- To enhance a sense of control and independence.
- To support you as a young person in the development of skills needed to help you 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 you as a young person will move from paediatric into adult care. Ideally, there is no fixed age for transfer as this will depend upon several factors, including:

- Age
- Maturity
- Level of independence
- Whether the young person feels ready.

Having said that, we would not aim to transfer you over to adult services before your 16th birthday, sometimes not until your 18th.

Taking charge – how to help you become more independent at appointments

To become independent at appointments, you will need to be able to start to talk to health professionals. For many young people, this is easier said than done. You as a young person often know what you 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 family. 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 as a family and find out what concerns you might have.
- Write a list of your concerns to take with you.
- It is a good idea for a young person to be seen alone for part of the appointment, you may like to think of any questions you might like to discuss. As a parent you may wish to discuss questions with another team member yourself, without your young person around. We will do our best to

give you this opportunity.

- If you are just getting started with this process of becoming more independent, it may be helpful to decide on one or two questions you could ask to begin with and bring these with you written down. You will gain in confidence in asking questions with your family around at first.
- Your family should encourage you in this process of gradual independence in appointments.

During the clinic visit

The following may encourage the team to direct their conversations to you as a young person rather than at your family:

- 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 whilst 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 you 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 young people 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 a young person 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

Young person and parent both present in clinic consultation.



Stage 2: Preparation

Young person 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

Young person 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

Young person is seen alone for the majority of the consultation.

- Progressing from stages 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 major midface surgery, your teenager may need greater support from you. That’s fine. When things are settled again, help them to return to the stage they are comfortable with and continue the process.

A pathway towards independence

Decision making

Part of the process of you as a young person becoming more involved in appointments is also becoming more involved in making decisions about your 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 your adolescent years.

Remember that both of you 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 you getting such benefits
- whether there are any alternatives
- whether there are any risks
- whether the risks are small or large
- what may happen if you don't have the treatment/surgery.

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

Occasionally, decisions are more complicated. We can help you both with this in our clinic consultations

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

Young people and their bodies – how to talk about sexual health issues

One of the stages of adolescent development is for young people 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 medical conditions and disabilities are often denied the right to express their sexuality and may have limited access to information.

Young people with a facial difference – how to talk about your feelings

Largely as a result of other people's attitudes, living with looking different can be a challenge. You may feel many emotions about this like anger, sadness, anxiety. You may on the other hand feel ok about your appearance and have good support to help you deal with this.

If you do have worries or concerns about your facial appearance there are three important factors that can enable you to adjust to this:

- getting realistic information about what treatment is available to you – this can be done by talking to your nurse specialist and consultant
- learning how to manage other people's reactions in social situations of all kinds. Our psychologists in the team, who you will already know are there to help you with this, as are your nurse specialists.
- getting good support from family and friends or an appropriate professional as above or a support group like Changing Faces (details in the next section)

For young people like yourself with a facial difference, there will be a stage when you may have more questions about your medical

condition and what happens if you decide to have children of your own. We will ensure that you see someone from our genetics team who can tell you all about this and answer your questions.

Here are some useful resources for parents and young people regarding transition:

■ Changing Faces

The Squire Centre
33-37 University street
London WC1A 6JN
Tel: 0845 4500 275
email: info@changingfaces.org.uk
Website: www.changingfaces.org.uk
Young persons website:
www.iface.org.uk

■ Contact A Family

209 – 211 City Road
London EC1V 1JN
Freephone helpline: 0808 808 3555
(Monday – Friday, 10.00am – 4.00pm)
Website: www.cafamily.org.uk

■ The Young Minds Information Service

Provides information and support for parents and some very useful booklets for teenagers on subjects such as depression, anger and school issues.
Helpline: 0800 018 2138
Website: www.youngminds.org.uk

■ **Parentline Plus** is a UK registered charity that offers support to anyone parenting a child.
Helpline: 0808 800 2222

■ **Trans-active**
A project managed by Mencap for teenagers with and without learning disability
Website: www.trans-active.org.uk

■ **Moving on up**
A website designed to be used by young people. It includes advice around learning and working, health and well being as well as money, housing culture and news events.
Website: www.movingonup.info

■ **Learn Direct**
Help with courses and career skills, interviewing skills and getting work.
Helpline: 0800 101 901
Website: www.learnndirect.co.uk

■ **Transition Information Network**
This is an alliance of organization and individuals who come together to improve the experience of disabled young people's transition to adulthood.
Website:
www.transitioninfonetwork.org.uk

If you need help in getting any information or booklets then please ask your nurse specialist.

© GOSH NHS Foundation Trust April 2015
Ref: 2015F1018

Compiled by the National Paediatric Craniofacial Benchmarking Group in collaboration with the Child and Family Information Group at GOSH. Adapted with permission from the Transition booklet produced by the Children's Neuromuscular Centre at GOSH.

To contact the Craniofacial Clinical Nurse Specialists, telephone 07768 526 449 or email andrea.white@gosh.nhs.uk or kathy.truscott@gosh.nhs.uk