

Great Ormond Street Hospital for Children NHS Trust: Information for Families

Transition: getting ready to move on to adult health services

This information sheet explains about transition and the process we follow at Great Ormond Street Hospital. The aim of the transition at GOSH is to make sure that your child's move to adult services is as smooth as possible.

What is transition?

As your son or daughter is getting older, you will be thinking more about their future. You may have heard people talking about 'transition'. In health care, we use the term 'transition' to describe the process of planning, preparing and moving from children's health care to adolescent or adult health care. Transition is a gradual process of change, which should give everyone time to ensure that young people and their families are prepared and feel ready to make the move to adult health care. This process should start at around 12 years of age but will depend on individual circumstances.

When should transition happen?

The exact timing of the move from children's to adolescent or adult services varies from person to person. It also depends to a certain extent on which adult services are available. Some young people move to a specialist adolescent unit at around 13 or 14 years old, but the

majority move directly from children's to adult services when they are aged between 16 and 18 years. Often young people will also be experiencing other transitions at a similar time, such as moving from secondary school to sixth form college or starting work.

Who organises transition?

At GOSH, we want to make the transition as easy as possible for you and your teenager. Every teenage patient should have an allocated member of staff who is responsible for organising their transition. They will also be responsible for ensuring that both you and your teenager are supported throughout the process and receive all the preparation needed to feel ready to move to adult services. Usually clinical nurse specialists or consultants take the 'transition coordinator' role although other members of staff may be involved in the process. You can discuss any queries or concerns with any member of your teenager's health care team or the Adolescent Nurse Specialist at GOSH.

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Understanding transition

Patients should have a written 'transition plan', which outlines the timing of key phases of the transition process, the expected time for the eventual transfer and details of any specific concerns, queries or requirements that you and your teenager have in relation to the move to adult services.

You and your teenager should receive information about the adult service, contact details for staff there, how the service is organised and how the adult services differs from our services. It is important that both you and your teenager are comfortable with the transition and the new service. There may be a choice of which adolescent or adult service your teenager can transfer to, but this depends very much on their illness or condition.

It might be possible for your team at GOSH to arrange an informal visit to the adult service or organise other ways for you and your teenager to meet the new team and start to get to know them. A visit to the new service can help all of you get used to travelling to the new hospital and find out where appointments are held or the location for tests and scans.

Preparing for transition

We know that approaching a move to adult care can be a scary time in a young person's life. As they get older, they will start to take more responsibility for things like medicines and treatments, just as they take on more responsibility in other areas of life. As a parent, this can be a difficult time for you as well. It can take time for you to get used to handing over some of the responsibility.

Young people in adult services are generally seen as being independent. The transition process should involve ensuring that your teenager has all the skills necessary to feel comfortable and safe in the adult health care service. In children's services, parents are given the responsibility for managing young people's health care, communicating with health care professionals and making important decisions. This is different to adult services, where the responsibility is usually given to the patient rather than the family. However, you will still be able to give your teenager advice and be there to provide support.

Talking about transition

At GOSH, we value the role that families have in the health of children and young people. Because of this, we feel that parents have a great deal of valuable experience to offer young people who are in the transition process. Families will often be able to give young people tips on how to organise appointments, find out information, remember medicines and treatments and which questions to ask during admission, ward rounds and clinics. Families can also support young people in gradually developing independence and becoming more involved in their health care. Topics for you and your teenager to think over and discuss might include:

- learning the names of regular medicines, why they need them, how much to take and how often
- asking and answering questions about their health and treatments
- seeing their doctor or nurse on their own, for part of clinic appointments or

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consultations

- staying overnight in hospital without you sometimes
- keeping track of hospital appointments
- the ways that his or her GOSH team can help your teenager feel ready to move to adult services.

There might be some aspects of growing up with a medical condition or disability that have not been discussed with you and your teenager. For example, you may have questions about how your teenager's condition might affect his or her adult life, in relation to things like career choices, benefits, relationships or family planning. It is a good idea for you to discuss these things with your GOSH team, who will be able to advise you or put you in contact with appropriate organisations that can help. Support

groups and charities can sometimes offer valuable support to young people and their families who are going through the transition process. It may also be useful to speak with other families of teenagers who are getting ready for adult services.

After transition

The most difficult thing for some families is to break contact with the children's service once the move to adult services has happened. It is important for your teenager's continuing health that any questions or concerns are discussed with the adult team. While you can stay in touch with the team at GOSH, the new team should be the first point of contact in all matters related to your teenager's health.

If you have any questions or concerns about transition, please talk to your clinical nurse specialist or consultant or call the Adolescent Medicine service on 020 7813 8541.

Notes		

Compiled by the Adolescent Medicine team in collaboration with the Child and Family Information Group

Great Ormond Street Hospital for Children NHS Trust Great Ormond Street London WC1N 3JH

www.gosh.nhs.uk

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