

Transition:

getting ready to move on to adolescent and adult gastroenterology services for inflammatory bowel disease



This information sheet explains a little about the transition process and what it will mean for you. Remember that if you have any questions about transition, please talk to your clinical nurse specialist, your consultant and/or your local Paediatrician.

Information for young people and families

What is transition?

In health care, we use the word “transition” to describe the gradual process of planning, preparing and moving from children’s health care to adolescent and then adult health care. Transition allows time to talk about issues related to this exciting but also challenging time of becoming a young person and to make sure you are ready to make that move.

When will I move on?

This depends on your readiness to move on, some patients move on from the age of 13 to 14 years, the latest you should move on to adolescent/ adult services should be between 16 and 17 years old. Your consultant, clinical nurse specialist and your parents/carers will discuss with you about when to make this move. Whatever you plan, you will have time to make sure you feel ready, nothing will be rushed and as nothing will be done without your consent.

Can I choose where I move on to?

Paediatric Gastroenterology patients at Great Ormond Street Hospital (GOSH) are usually transitioned into the Adolescent Gastroenterology Services at University College London Hospital (UCLH) – a unique model in the United Kingdom. Alternatively you might choose to be transitioned into your local adult services or choose a half-way house, where you attend the Adolescent Services at UCLH and then get transferred into local Adult services. We can talk about all the available options when we either see you in clinic or when you contact your clinical nurse specialist. We can then decide together which is the right option for you.



Why do I need to move on?

As you are now becoming a young adult, you may start feeling that you have outgrown the Paediatric Gastroenterology Services at GOSH and that you will be ready to move on to a more grown-up setting without having to share facilities with babies, toddlers and children.

The thought of moving to a new hospital and leaving staff that in some cases you have known from when you were a baby yourself, can be difficult and frightening. However, we know from research and experience that you should see this transition as a natural step in growing up and that you are entering a new chapter in your life. You might have felt the same when you moved from primary to secondary school, again a natural step of your life. Our experience again tells us that you should settle into your routine within your chosen service as many young persons before you have done so.

What will be the same?

Both Paediatric and Adolescent services are there to care for you and your health. The Adult services at UCLH are staffed by one Paediatric and two Adult Gastroenterologists as well as a clinical nurse specialist (CNS) and a dietitian. A senior adult registrar completes the medical team. You may have already met Dr McCartney, Dr Kiparissi, CNS Lisa Whitley and the dietitian Katie Keetarut in the transition clinic at GOSH, so the faces will be familiar to you. Medicine practiced at UCLH will follow the same guidelines as at GOSH, as both follow the same national and international guidelines.



Will the adult services be different?

One of the main differences between children's and adolescent services is that being in charge of your health will gradually move from your parents/carers to you. This process will start at GOSH and will continue at UCLH.

This means that you will need to learn about your condition, the treatment you are on, the complications that can arise from your condition and how to manage it.

You will learn to ask for help if and when needed independently, by communicating with the CNS. Although being in charge can be scary, it is also a great opportunity to have more control and independence over your health and the care you are given and is a natural part of growing up.

When you are asked to make decisions about your health, you will be given all the information you need to make an informed choice. We encourage you to ask questions and let us know if you are unsure about things. We will make sure that you understand everything before making a decision. Although you, rather than your parents/carers, will be asked to make decisions, you can still talk with your parents/carers and get their advice before making your choice.

Within the adolescent services, the doctors, nurses and dieticians will primarily address you rather than your

parents/carers, for example in clinic or during admissions. You can take your parents/carers with you to clinic, but you might choose to spend some time without them in clinic, talking about issues that you feel more comfortable not having them around. It might be helpful to think about what questions you would like to ask and writing them down before coming to clinic.

Quite often young people come to clinic with their friends or siblings rather than their parents/carers once they got used to the new environment, this does not mean though that you cannot speak to your parents afterwards.

You need to know that once you reach your 18th birthday, your parents/carers will not be allowed to contact the hospital to request information about your appointments, medical history, test results and so on. You will need to learn to make those arrangements yourself.

If you need to be admitted to the Adolescent Unit at UCLH, you will need to check with the ward T12 if your mum, dad or carer can stay with you.

If you need an upper and lower endoscopy you will still have this under a short acting anaesthetic with an Anaesthetist present, like at GOSH.

Once you are older you will be given the option to have the procedures under sedation, like in adult practice.

Who can help me to get ready?

Your parents/carers have played an important part in your life in looking after your health and will continue to do so. They can teach you from their experience, for example, how to make outpatient appointments, how to re-order medication before you run out, how to monitor your health and how to liaise with school. You should make plans as a family on how you can practise getting more involved in looking after your health and taking responsibility.

You are probably very technology savvy, so sending the CNS an email about an issue you have would be a good first step, making sure that you do not run out of medication and knowing whom to call when and if you need help.

You will come across other young people with similar or the same conditions as yours, so it might be useful to share ideas with them. GOSH and UCLH will be organising work shops where you will be able to meet young people of your age going through the same process.

Linking up with national organisations for example Crohn's and Colitis UK and CICRA for patients with IBD can give you more information and the possibility to chat with people your

age via their websites – see below for details. At UCLH you will be able to talk to young adults who have already finished their transition and ask them about their experience and any tips they can give you.



What can I do to get ready?

1. Learn about my condition
2. Start asking questions and answering questions rather than sitting quietly in clinic
3. Try to learn the names of my medication, why I am taking them, how often, what dose, what side effects they have and how to get a follow up prescription before I run out of them
4. Practice making my own outpatient appointments, know how to cancel and try not to miss one. Requesting a specific time, for example at the end of the list, so that I do not miss too much school.
5. Keep my own record of the contact details of my CNS in my smart phone, so that I have it when I need it
6. Start to take responsibility for agreeing to treatment changes
7. Know when my condition needs emergency treatment and whom to contact as well as knowing whom to contact if my problem can wait for 24 hours or so.

Who can I talk to at GOSH about transition?

As a GOSH patient, you have a named health care professional who is responsible for your transition - this is usually your consultant. Please feel free to ask your consultant about anything that is either bothering you or you are not clear about. Your CNS will be another person to talk to, as they have been your port of call so far. Your local Paediatrician, although not at GOSH, can also help with answering your questions.



Further information and support

Crohn's and Colitis UK (formerly the National Association for Crohn's and Colitis) have an information line on 0845 130 2233 or you can visit their website at www.crohnsandcolitis.org.uk.

You can also call **Crohn's in Childhood Research Association (CICRA)** on 020 8949 6209 or visit their website at www.cicra.org



Questions I can ask?

1. What is the plan for my transition and will I be moving?
2. Who is organising my transition?
3. When is my workshop?
4. Can I choose which services I will be attending?
5. What is different in the adolescent services?
6. Can I meet the staff from UCLH before I leave GOSH?
7. Can I visit UCLH to have a look around before I leave GOSH?
8. Can I talk to other young people who are going through or have finished their transition?
9. How can my family help me to get ready?
10. Will my condition affect my schooling/education or career choices?

Useful numbers

GOSH switchboard: 020 7405 9200

Division of Mucosal Immunology

Clinical Nurse Specialists:
Tel: 020 7762 6982 or bleep
0020 or 0673 through
switchboard
Email: gastroenterology.
IBD@gosh.nhs.uk

Dietitian: ext 0143

Service Co-ordinator:
ext 1339 or email
gastro@gosh.nhs.uk

Division of Nutrition and Intestinal Rehabilitation

Clinical Nurse Specialists:
Tel: 020 7762 8304, or bleep
0921, 0360 or 1027 through
switchboard
Email: cns.intestinalcare@
gosh.nhs.uk

Dietitian: ext 5163

Service Co-ordinator:
ext 5175 or email
gastro@gosh.nhs.uk

Division of Motility and Neurogastroenterology

Clinical Nurse Specialist:
ext 1644

Dietitian: ext 5032

Service Co-ordinator:
ext 1449 or email
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