

# Transition:

getting ready to move on to adolescent and adult gastroenterology services for intestinal rehabilitation



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 an adult specialist intestinal rehabilitation centre closest to your home. Alternatively you might choose to be transitioned into your 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.

## 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.

Linking up with national organisations for example PINNT for people requiring artificial nutrition can give you more information and the possibility to chat with people your age via their websites – see below for details.

## 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

### **PINNT (Patients on Intravenous and Naso-gastric Nutrition Therapy)**

PO Box 3126, Christchurch,  
Dorset BH23 2XS

Tel: 01202 481 625 (9.30am – 4.30pm,  
answerphone at other times).

Fax: 01202 481 625

Web: [www.pinnt.com](http://www.pinnt.com)



## 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 my new centre before I leave GOSH?
7. Can I visit the new hospital 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  
gastro@gosh.nhs.uk

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