



Great Ormond Street Hospital for Children NHS Foundation Trust

## Long term follow up in the joint Haematology and Endocrinology Clinic: Information for young people

This information sheet from Great Ormond Street Hospital (GOSH) tells you about long term follow up in the joint Haematology and Endocrinology Clinic at GOSH. It explains why you might need to come to the clinic, what is involved and what to expect at your appointment. If you have any questions or worries, please call the Clinical Nurse Specialists on 020 7813 8127 or email [ltfu@gosh.nhs.uk](mailto:ltfu@gosh.nhs.uk)

Long term follow up is the way we describe the important ongoing check-up appointments you will need if you have had treatment for a haematology (blood) or oncology (cancer) condition.

### Why do I need long term follow up?

While the treatments you had for your original condition have worked, there is a chance they might cause you problems in the future, particularly with the hormones involved in growth, puberty and your general well-being. Even if you are feeling well it is very important that we see you regularly so that we can discover and treat any problems that you might develop related to the treatment you received.

This is because treatments such as chemotherapy or radiotherapy can affect the glands that release hormones in your body. Hormones are chemical messengers that switch on and off important processes within your body. The release of hormones is managed by the endocrine system.

### What is the joint Haematology and Endocrinology Clinic?

The Haematology and Endocrinology Clinic is a special, joint clinic run by the Haematology-

Oncology and Endocrinology teams and provides your long term follow up by regularly checking your blood and hormone systems and your growth. The two teams work closely together to make sure that they have all the information about your previous diagnosis and treatments and are aware of any of the problems that might affect your blood or hormone systems as you grow up.

The aim of the clinic appointments is to:

- check the hormones that might be affected by your previous treatments
- make sure you and your parents understand the treatments you have had
- give you opportunities to ask any questions you might have
- see if you need any new treatments
- decide when you next need a check-up appointment

Examples of the hormones that we will talk about with you in clinic include:

- Growth Hormone-this makes you grow and can be affected by the treatment you received and your family's growth history
- Thyroid hormone-this helps to make you feel well and gives you energy by controlling chemical processes in your body

- Sex Hormone-this helps you go through puberty
- Adrenal Hormones- these help your body cope with stressful situations.

There are other hormones that we will talk about in more detail in clinic.

## **Who will I see in the joint Haematology and Endocrinology Clinic?**

As it is a specialised joint clinic between two services you will probably meet lots of new people. You will meet consultants from the Haematology-Oncology and the Endocrinology teams, and a Clinical Nurse Specialist. Sometimes trainee doctors or student nurses might be there as well. Everyone in the room should introduce themselves to you and tell you why they are there. If the room feels too crowded you can ask if some of the people could leave, especially if you want to talk or ask a question about something private. You can also ask to see someone on your own after your appointment.

## **What happens in the joint Haematology and Endocrinology Clinic?**

The first part of the appointment will be your chance to talk about how you are feeling and what has happened since your previous visits to GOSH. The doctors will ask you questions to make sure they understand what you have said. Sometimes young people may want to discuss things without their parents in the clinic room. If you would like to see a doctor or nurse without your parent please tell us. What you talk will be confidential (kept private). We would only share something you have said if we were very worried about you. We would always tell you if we thought we needed to share anything you have said. We do encourage young people to share any information with their parents and can help you with this if you find it difficult.

You will need to have a physical examination and will need to go behind some curtains and get undressed for this. The examination couch is behind the curtains too, and just one person at a time will check you. You can ask for a chaperone or one of your parents to stay with you for this if you feel uncomfortable or embarrassed.

The doctors will want to assess the hormones involved in puberty. If you are a girl a doctor will ask to check that your breasts and pubic hair are growing as expected. For boys, the doctor will want examine your penis, testes and pubic hair. There is no 'internal' examination for boys or girls. The doctors are very experienced and they are only looking to see whether they are developing properly not your general appearance.

Once you have had your physical examination, you can get dressed again. You may have some accurate measurements taken of how tall you are and what you weigh. You might need to have some blood samples taken – you can ask for cold spray or local anaesthetic cream if you like. You may need to go somewhere else in the hospital for a scan, such as an x-ray- we will tell you where you need to go for this.

The specialist nurse will make sure you know what needs doing and how you can get there. They can also talk you about what the doctors said to make sure you understand. Again, if you would like to talk to the nurse in private, this is fine.

We always aim to be honest and open and to answer all of your questions. Sometimes the issues we discuss may be sensitive. Please contact the Long Term Follow Up (LTFU) team [ltfu@gosh.nhs.uk](mailto:ltfu@gosh.nhs.uk) if you would like to discuss specific concerns before your appointment. If you forget to ask a question in clinic you can contact them afterwards. You could contact the team using MyGOSH if you have signed up to it. To find out more about My GOSH visit [MyGOSH | Great Ormond Street Hospital](#)

## How often will I have clinic appointments?

This will vary from person to person and can depend on:

- the type of treatment you had when you were younger
- the results of the tests and scans at each appointment
- whether you are on any hormone replacement treatment

The team will let you know how often and when they want to see you.

## What happens if I have a problem in between appointments?

If you become ill with a cough or cold you should talk to your local pharmacist or family doctor (GP).

If you are worried it might be linked to your previous treatment, you can contact the LTFU team for advice. Their details are at the end of this information sheet-make sure you keep their number and email address in your phone.

## How long will I have to come to clinic?

The joint clinic is for young people aged 11 to 18 years old. When you are 18 you will need to carry on having clinic appointments, but these will be at University College London Hospital (UCLH). Sometimes people only need regular check-ups with their family doctor (GP). We will tell you if you need to go to UCLH for your follow up, or whether you should go to your GP instead. We will do our best to help you get you ready to move on to your adult health services.

## Access to Psychological Services

We recognise the reasons you are coming to hospital and some of the conversations we have within clinic appointments can be difficult. The Psychology team work closely with us and are able to meet with young people and their families to support coping.

If you think this would be helpful, please ask your medical team to refer you.

## Growing Up, Gaining Independence

As you grow older you will be expected to start to take more responsibility for your health. Your specialist nurse and other people at GOSH are here to help you get more confident and independent. We have developed the *Growing Up Gaining Independence (GUGI)* programme to help you learn the skills you will need to manage your healthcare on your own.

There is more information about GUGI at [www.gosh.nhs.uk/your-hospital-visit/growing-gaining-independence](http://www.gosh.nhs.uk/your-hospital-visit/growing-gaining-independence) or you could ask the nurse for a leaflet for you and your parents.

## Any questions?

If you have any questions Long Term Follow Up please call the nursing team on 020 7813 8127 or email [lfu@gosh.nhs.uk](mailto:lfu@gosh.nhs.uk).

Further information about the team is online at [www.gosh.nhs.uk/medical-information/clinical-specialties/long-term-follow-care-childhood-cancer-information-parents-and-visitors](http://www.gosh.nhs.uk/medical-information/clinical-specialties/long-term-follow-care-childhood-cancer-information-parents-and-visitors)

As you grow older The Aftercure booklet will be your main source of information— we will give you a copy but it is also available online at [www.aftercure.org](http://www.aftercure.org) Information sheets on specific topics are also available from this website.

There is more information available at

[www.cclg.org.uk/publications/Aftercure-factsheets](http://www.cclg.org.uk/publications/Aftercure-factsheets).