

Long-term follow-up (haematology/ oncology)

Information for families

Great Ormond Street Hospital
for Children NHS Foundation Trust

This leaflet explains about long-term follow-up after your child has been treated for a haematology or oncology condition at Great Ormond Street Hospital (GOSH). It explains about the need for follow-up and what will happen at clinic appointments.

What is long-term follow-up?

Long-term follow-up (LTFU) is the term used to describe the ongoing check-ups that your child will need after treatment for a haematology or oncology condition. While the treatment has been successful for treating your child's original condition, we need to monitor for any problems related to the original treatment that may develop later on.

Why does my child need long-term follow-up?

Chemotherapy, radiotherapy and surgery are important methods for treating a variety of malignant and non-malignant childhood conditions, and many children's lives are saved as

a result. However, there is a very small chance that some of the treatments your child received might cause problems in the future. The aim of long-term follow-up is to monitor your child regularly so that we can diagnose any new problems and treat them as early as possible. Sometimes it is necessary to refer your child to other specialists to treat specific problems.

Your child will be referred to the LTFU team when he or she is at least five years from the end of treatment. Some of the follow-up may be shared with your local hospital. Clinic appointments are usually annual to begin with, but as your child grows older, these appointments may become less frequent. It is important to keep coming to clinic appointments, even if your child seems completely healthy because problems can develop many years after the original treatment.

What happens during a LTFU clinic appointment?

Your child's first appointment in the LTFU clinic will be with the Clinical Nurse Specialist (CNS), six months from the date of referral. You will not see a doctor during this first appointment. Your CNS will discuss aspects of your child's care and complete a Holistic Needs Assessment (HNA). There is further information about the HNA

available. Six months after this, you will receive your child's first appointment with a LTFU Consultant.

The LTFU clinic appointment is a check-up to see how your child is progressing. While your child is young, we will measure his or her weight and height at each appointment to make sure that he or she is growing and progressing through puberty normally.

Your child will have their blood pressure checked and sometimes need blood tests or urine tests. Other tests will be arranged as necessary such as a DEXA scan to monitor bone strength, an ECHO to monitor the heart function, lung function tests, and audiology to monitor hearing.

Nurse Led Clinics

You will have an opportunity to see the LTFU Clinical Nurse Specialist. If this is your child's first LTFU appointment or they are over 13 years of age, then we will aim to give you an appointment with the Clinical Nurse Specialist as well as the Consultant when you come to clinic. Teenagers and young adults are encouraged to have part of this appointment on their own and partly with parents/carers. This gives the opportunity to have a confidential chat about issues such as relationships, fertility and their past treatment. They may not feel able to

discuss such issues in the presence of others. It is also important that they start to take responsibility for their own health. Young people need to understand about their past disease and treatment and the risk for late problems developing.

What happens when my child approaches 16 to 18 years old?

At around 16 to 18 years, young people will be invited to attend a transition appointment at GOSH with the LTFU Clinical Nurse Specialist in preparation for transfer to adult healthcare. This will happen on the same day that you come to your normal LTFU clinic with the consultant. The young person will be provided with an Aftercure booklet and treatment related factsheets and have an opportunity to discuss any concerns. The Aftercure book is also available online at www.aftercure.org.

At the age of 18 years old, young adults will either continue LTFU at University College London Hospital (UCLH) or their family doctor (GP). More information will be given about this separately at the time for transition.

What happens if my child develops a problem in between clinic appointments?

If your child has a regular childhood illness, like a cough or cold, please telephone your family doctor (GP). If you are concerned about emotional or physical problems that may be related to past treatment you can ring the LTFU team for advice.

How do I get in touch with the LTFU team?

You can ring us on the number below. The LTFU service coordinator can help with appointments and arranging investigations. The Clinical Nurse Specialist can offer health-related advice over the telephone. We also have information about LTFU on our website at www.gosh.nhs.uk/ltfu.

**If you have any questions or worries,
please call us on 020 7813 8127 or email ltfu@gosh.nhs.uk**

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Ref: 2016F0752

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in collaboration with the Child and Family Information Group

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