

Transition: getting ready to move from Great Ormond Street Hospital long-term follow-up clinic to adult health services



This leaflet explains about long-term follow-up after you have been treated for a haematology or oncology condition at Great Ormond Street Hospital (GOSH). It also explains how you will transition from the children's hospital to adult health care.

Information for young people

What is transition?

Transition in health care describes the process of moving from children's health care to adult health care. You will be offered an appointment in the transition clinic with the clinical nurse specialist at Great Ormond Street Hospital (GOSH) about a year before you move to adult care. The appointment is to help you to prepare for long-term follow-up in adult services. You will then also be offered a transition appointment at University College London Hospital (UCLH) led by both the UCLH and GOSH clinical nurse specialists, where you will have the opportunity to discuss the plan for your future care.

Why do I need to continue long-term follow up as an adult?

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 chance that some of the treatments you received might cause problems in the future.

The aim of long-term follow-up is to monitor you, if we need to, so that we can diagnose any new issues and

act as early as possible. Sometimes it is necessary to refer you to adult specialists to treat specific issues. As a young adult, you will continue long-term follow-up at UCLH or with your GP, with your individual care plan. It is important to keep coming to clinic appointments as planned. The appointments are infrequent and often years apart.

Which adult service will my care be transitioned to?

We work in close partnership with UCLH and most young adults will have their follow up care there, unless they specifically choose to be seen closer to home and this is deemed to be appropriate. If we anticipate minimal late effects related to your treatment then we may arrange for your LTFU care to be carried out by your GP alone with access to an adult LTFU service if needed. This will all be discussed at your transition appointment and will be decided with you.

What happens during the LTFU transition clinic appointment at UCLH?

The transition clinic appointment gives you the opportunity to discuss any health concerns you might have. As a young adult you are encouraged to start attending clinic appointments on your own. This gives you the opportunity to have a confidential chat about issues such as your past treatment, relationships, and fertility.

It is also important that you start to take responsibility for your own health rather than relying on your parents or carers as you may have done when you were younger. You need to understand about your previous disease and treatment and your individual risk for late problems developing. This is important so that you will be able to explain about your past history to a new GP or hospital doctor if you move away from home. It will also help you to look after yourself and recognise if any problems are developing. The clinical nurse specialist will provide you with an individualised treatment summary and care plan for the future. The booklet and fact sheets are also available online at www.aftercure.org

Will LTFU be different in the adult hospital?

Most young people prefer to be seen in an adult hospital although it can seem difficult to separate from a familiar hospital and team. Adult specialists will carry out all your investigations and are experienced in recognising adult problems. The doctors will discuss things directly with you and encourage you to make your own decisions, which is different from the appointments at the children's hospital. Although you might be used to your parents or carers taking responsibility, this change is all part of becoming an independent and responsible adult. Of course you may choose to invite a parent, partner or friend to accompany you on your clinic visit.

Appointments will not be so flexible because adult clinics are very busy. You should reschedule appointments well in advance and only cancel your appointment at the last minute if there is an emergency. Adult outpatient departments will discharge you if you fail to attend your appointment and a new referral from your GP would have to be made. This is very different from the children's hospital where you would have been contacted and offered a new appointment.

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.

You will be continuing your follow-up appointments at the adult hospital and your point of telephone contact will be at UCLH. There is further information on the GOSH website at www.gosh.nhs.uk/teenagers/preparing-for-adult-health-services/ and www.gosh.nhs.uk/medical-conditions/clinical-specialties/long-term-follow-up-childhood-cancer-information-for-parents-and-visitors.

LTFU team at GOSH: 020 7813 8127

UCLH appointments: 020 3447 5536

Transition to discharge

Your GOSH consultant may feel that follow up into adulthood for your particular previous condition and current healthcare state is not necessary. If you had minimal treatment, and it is felt that you are not at an increased risk of developing late effects from the treatment you had, then we may feel it is appropriate to discharge you from follow up. If this is the case, we will discuss this with you and give you the opportunity to ask questions. You will also be offered a 'transition to discharge' appointment so you are fully equipped with all the knowledge you need about your diagnosis and treatment. We will also give you contact details of how to access the service again should a problem arise.

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