

The ROYAL MARSDEN

NHS Foundation Trust

Transition: moving from children's to teenage and young adult long- term follow up

Oak Centre for Children and Young People

Information for patients and their families



NHS

What is transition?

In healthcare, we use the term ‘transition’ to describe how we prepare patients for the transfer of their care to a new clinic or service. In this case it is how we help you to move from the children’s long term follow up (LTFU) team to the teenage and young adult long-term follow up team and then on to adult care. Transition is a gradual change, which gives everyone time to feel prepared and ready to make the move. The change will be discussed at least a year in advance; you will meet members of the new team and we will tell you (and your family) how the teenage and young adult long-term follow up clinic works.

When do I move to the teenage and young adult long-term follow up clinic?

The exact timing of transition varies from person to person, but most young people move to the teenage and young adult clinic at The Royal Marsden after their 16th birthday.

In this clinic you may meet an Endocrinologist, Oncologist or Clinical Nurse Specialist in Late Effects. You can be seen in this clinic up to your 25th birthday.

What happens in the teenage and young adult long-term follow up clinic?

The aim of this clinic is to help meet your needs as a teenager or young adult. The team will help you to understand the treatment you have had as a child, address your current healthcare needs and work with you on planning how to meet these needs. You will have an opportunity to discuss the plan for your future care and how you can manage your health and wellbeing. In the teenage and young adult long-term follow up clinic, you will also get to know the team who will work with you as an adult.

As a young adult, you are encouraged to start attending some or all of the clinic appointments on your own. Your family will still be involved in your care but attending some of your appointments on your own enables you to have confidential chats with us about issues such as your past treatment, general health, relationships and fertility. You will have the opportunity to develop your knowledge about your past disease and treatment and any possible risks of problems developing later on. In this way you will develop the confidence to be able to manage your own health needs and be able to explain your past history to a new GP or hospital doctor in the future.

Will I always need to come?

This is an individual decision made between you and your follow up team as you move into adulthood. It will depend on the treatment you received and other factors such as your general health and social circumstances.

With information, education and availability of phone access with the long-term follow up team, many people eventually no longer need to attend regular hospital follow up appointments but instead manage their own health needs with the support of their GP. We call this **supported self management**.

If the decision is made that you will continue regular hospital visits as an adult, your care will be transferred to one of the specialist adult long-term follow up clinics within the UK. Most of our patients choose to be transferred to University College London Hospital or the Royal Sussex County Hospital, Brighton. Many of the regular surveillance investigations and adult specialists you may need are based at these hospitals. Wherever possible, attempts will be made to bring your appointments together on the same day there by reducing the number of times you need to visit hospital.

What happens if I develop problems in between appointments?

If the problem is an unrelated common illness such as a cough or a cold, please contact your GP. If you are worried about emotional or physical problems that might be related to your past treatment for cancer you can contact the LTFU team by phone or email (contact details below).

What happens if I can't attend my appointment?

Please telephone or email us at the earliest opportunity and let us know so that someone else can be booked in your place. We understand that when you are not being seen frequently it is easy to forget your appointment. We will endeavour to text, phone or send you a letter reminding you of your appointment. It is important that you ensure we have your correct contact details.

Our clinics are very busy. If you fail to attend two or more appointments we will consider that you no longer wish to attend long-term follow up and will discharge you from our service. Your GP will need to refer you again if you need to be seen.

Who do I ask if I have any questions?

If you have any questions about transition, please do not hesitate to contact the long-term follow up team.

Contact details for the long-term follow up team

Email: longterm.followup@nhs.net
Telephone: 020 8915 6475
Address: Long-Term Follow Up Team
Children and Young People's Unit
The Royal Marsden Hospital
Downs Road
Surrey SM2 5PT

Please note: If you have an acute health concern, please contact your GP or 111 the NHS emergency and urgent care phone line.

Useful numbers and websites

NHS Live Well

Information on mental wellbeing, sleep, exercise and sexual health.

www.nhs.uk/live-well/

Children's Cancer and Leukaemia Group

Children's Cancer and Leukaemia Group provide information leaflets on diagnosis, treatment and post-treatment care.

www.cclg.org.uk

Trekstock

Provides social and practical support for those in their 20s and 30s, living with cancer or its effects.

www.trekstock.com

Teens Unite

Charity devoted to helping young people build on their self esteem, self confidence and to reduce the feeling of isolation, realising that others are facing similar challenges.

www.teensunite.org

Ellen MacArthur Cancer Trust

Charity that takes young people aged eight – 24 from all over the UK on sailing trips to help inspire them in rebuilding confidence after treatment for cancer and leukaemia.

www.ellenmacarthurcancertrust.org

Pan Care

European network of professionals, survivors and their families that aims to reduce the frequency, severity and impact of late side effects of the treatment of children and adolescents with cancer.

www.pancare.eu

The Prince's Trust

The Prince's Trust supports 11 to 30 year olds in gaining skills and confidence to take their next steps in education, training and employment.

www.princes-trust.org.uk

FRANK

FRANK helps you find out everything you might want to know about drugs (and some stuff you don't). For friendly, confidential advice.

www.talktofrank.com

References

This booklet is evidence based wherever the appropriate evidence is available.

Details of the references used in writing this booklet are available on request from:

The Royal Marsden Help Centre

Telephone: Chelsea 020 7811 8438 / 020 7808 2083

Sutton 020 8661 3759 / 3951

Email: patientcentre@rmh.nhs.uk

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Should you require information in an alternative format, please contact The Royal Marsden Help Centre.

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