

The ROYAL MARSDEN

NHS Foundation Trust

The long-term follow up service
(LTFU) for children and young
people at The Royal Marsden

Oak Centre for Children and Young People

Information for patients and their families



NHS

Introduction

This leaflet tells you about the long-term follow up (LTFU) service for children and young people who have been treated for cancer at The Royal Marsden. This leaflet explains why follow up is important and what will happen in the LTFU clinic.

Why does my child need to come to the long-term follow up clinic?

We know the treatment children with cancer receive can sometimes cause problems as they get older.

The aim of LTFU is to provide regular review so any problems can be discovered and treated as early as possible. Sometimes this might mean seeing a doctor specialising in cardiology (heart), endocrine (hormone), orthopaedics (bone) or dermatology (skin) for example, either at The Royal Marsden or another hospital. For some children, LTFU can take place at the Royal Alexandra Children's Hospital, Brighton.

When does my child transfer to the long-term follow up clinic?

Children are usually transferred from the acute oncology or haematology clinics into the LTFU clinic five years after their treatment for cancer has finished. Children who have had a brain tumour or a bone marrow transplant usually transfer to the LTFU service one to two years after the end of treatment, as they may need to see the consultant paediatric endocrinologist sooner.

What happens in the long-term follow up clinic?

Children have their height and weight checked at each appointment to make sure they are growing and going through puberty as expected.

Your child will have their blood pressure checked and may sometimes need to have blood and urine tests. These and any other tests such as a cardiac echocardiogram (echo, heart scan), lung function tests or audiology (hearing tests) will be done as needed depending on the type of treatment your child had.

If your child requires any of these tests and is having an appointment via telephone or video link, we may ask that you arrange this via your GP surgery. The plan for what tests your child needs and how often they take place will be explained by the team in the LTFU clinic.

Your child will see a doctor or specialist nurse in clinic who will ask questions about your child's health, their time at school or college and their general well being. As younger children get older, the questions will be directed at them so they are involved in their care. During each appointment with the LTFU team, you and your child will have the chance to ask any questions you may have.

You and your child will be given a treatment summary and long-term follow up care plan. The treatment summary gives details of the cancer treatment your child received and any possible health complications during or after treatment. The long-term follow up care plan is designed to help your child understand his or her health care needs now and in the future.

Children's clinic

Long-term follow up clinics for children take place every Tuesday morning either via telephone, video appointment or face to face in the Children's Outpatient Clinic at The Royal Marsden. Patients with endocrine problems are seen on the second and third Tuesdays, and bone marrow transplant patients are seen on the fourth Tuesday of each month.

Clinic appointments are more frequent during childhood growth and development, for example, every six months but may become less frequent in time, such as every one or two years.

Most young people transition to the Teenage and Young Adult LTFU Clinic following their 16th birthday. In healthcare we use the term 'transition' to describe how we prepare patients and their families for transfer to a new clinic or service. Transition is a gradual process which aims to give everyone time to feel prepared and ready to make the move. The change will be discussed at least a year in advance with you and your child; you will meet members of the new team and we will tell you how the teenage and young adult LTFU clinic works.

Teenage and young adult clinic

This clinic is for young people aged between 16 to 25 years and aims to give young people more independence in managing their health and care needs. The young person will be encouraged to attend some or all of the clinic appointments on their own with the emphasis on developing the knowledge and skills to take responsibility for their ongoing healthcare needs as an adult. The clinic is held on a Wednesday in the Children's and Young People's Outpatient Clinic at The Royal Marsden.

Long-term follow up as an adult

In the teenage and young adult clinic, your child will have an opportunity to discuss what kind of long-term follow up is recommended for them in the future and how this is best achieved. Following discussion, some young people will choose to be discharged from regular clinic visits to supported self-management. Others will decide to transfer to regular clinic appointments at an adult long-term follow up service often at University College London Hospital or the Royal Sussex County Hospital in Brighton.

Supported self-management is when the young person has developed the skills and knowledge to be responsible for their own health and wellbeing. The young person is discharged from regular hospital follow up visits and continues their follow up in the community with the support of their GP.

All adults treated for cancer as children at The Royal Marsden are offered life long access to phone support from the long-term follow up team. Contact details are on page 4.

The LTFU team

- Child LTFU Consultant
- Teenage and Young Adult LTFU Consultant
- Child Endocrinologist
- Teenage and Young Adult Endocrinologist
- Academic Clinical Fellow for LTFU

- Child, Teenage and Young Adult LTFU Clinical Nurse Specialists
- Endocrine Clinical Nurse Specialist

Contact details for the long-term follow up team

Email: longterm.followup@nhs.net

Telephone: 020 8915 6475 (direct line)

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

Useful websites and leaflets

The NHS website

General health and wellbeing information can be found on the NHS website.

www.nhs.uk/Livewell

Children's Cancer and Leukaemia Group

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

www.cclg.org.uk

The Ellen MacArthur Trust

The Ellen MacArthur Trust takes young people aged eight to 24 on sailing trips to help inspire them in rebuilding confidence after treatment for cancer and leukaemia.

www.ellenmacarthurcancertrust.org

The Princes Trust

The Princes Trust supports 13 to 30 year olds who are unemployed or seeking training.

www.princes-trust.org.uk

Trekstock

Empowering young adults in their 20s and 30s to thrive through and beyond the challenges of cancer.

www.trekstock.com

Email: health@trekstock.com

References

This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

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

The Royal Marsden Help Centre
Freephone: 0800 783 7176
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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