

The Paediatric Oncology and Haematology  
**Long term follow up  
clinic**

Information for patients  
aged 11-15 years



leeds children's  
hospital

caring about children

The Children's Oncology Long Term Follow Up Clinic provides support and advice for you and your family about late effects of the treatment you have received and also advice on maintaining a healthy lifestyle.

*This clinic is specifically for you if you finished your treatment five years ago and have had:*

- cancer or any other condition treated by a doctor specialising in cancer treatments.
- a blood disorder which required a bone marrow transplant.

### Why should I attend Long Term Follow Up clinic?

At your clinic visit we will discuss your previous illness and treatment. You and your family will have the chance to ask questions. You will be offered a summary of your treatment and details of your Key Worker. A Key Worker is a nurse specialist who you can contact if you have any questions or worries about your previous diagnosis or treatments received.

### Who are the Long Term Follow Up Team?

#### Doctors

The doctors are experienced in looking after children who have had cancer, bone marrow transplant or any other condition treated by a doctor specialising in cancer treatments. The doctor will be aware of any possible late effects you may experience.

#### The Doctor is:

Prof Adam Glaser

There may also be other doctors in clinic who you may see you during your visit.

#### Specialist Nurses

The specialist nurses offer support, information and advice to you during your clinic visit. You can also contact the nurse between visits if you have any questions.

#### Your specialist nurse is:

Naseem Sarwar

#### Social Worker

The Social Workers are available to offer you and your family support and advice about issues about your previous cancer diagnosis.

#### Psychologist

The psychologists are available to offer support and advice if you have any worries about your previous cancer diagnosis.

## When and where are the face to face clinics are held?

All clinics are held in the Children's Haematology/Oncology Day Unit. This clinic can be found on C Floor, Clarendon Wing, Leeds General Infirmary. For telephone and video clinics you are not required to attend in person. The consultation takes place virtually.

Please note that you will be discharged if you do not attend an appointment on two consecutive occasions.

### Medical (face-to-face, video, telephone) Clinics

Takes place on a Monday afternoon.

### Nurse-Led (face-to-face, video) Clinics

Takes place on a Thursday afternoon.

### Nurse Telephone Clinic

Takes place on a Monday and Tuesday lunchtime.

## What will happen at your face-to-face clinic??

- Your clinic visit may take up to two hours.
- At each visit you will be seen by a doctor, or a nurse or both.
- We will record your height, weight and blood pressure.
- You will be asked to complete a form that asks about any worries you may have and any medications you are taking.
- Your doctor or nurse will discuss your previous illness and treatment you had.

- The doctor may examine you.
- We may request other tests such as blood tests or scans.

You will be given the opportunity to speak to the Doctor or Nurse without your Parents or Carer. This is part of preparing you for moving onto the adult services at the age of 18.

## Monitoring Late Effects

Some of the treatment you received may put you at risk of having other problems. These are known as 'late effects'. Late effects may cause problems many years after your treatment.

At your clinic visit we will discuss the possible late effects of the treatment you have received. It is important you tell us about any problems you have in order that we can arrange for you to have some tests if needed. Some late effects may mean we need to refer you to other specialist doctors.

*Here are some examples of late effects, please note they do not apply to everyone:*

- Some of the treatments may affect your growth and development. We will monitor this and refer you to a specialist should there be any concerns.
- Some of the treatments may affect your heart. If you have had these treatments we will offer you heart scans to check for problems.
- Some treatments may affect your ability to have children. If this worries you we can discuss this and refer you to a specialist for assessment when you are older.

## Life Style Advice

We offer you information and advice to help you lead a healthier lifestyle.

### *This includes information on:*

- eating healthily
- exercising regularly
- sun awareness
- importance of avoiding drinking alcohol
- importance of safe sex
- importance of avoiding illegal drugs
- importance of avoiding smoking
- any other issues you are worried about.



Please ask the nurse or doctor you see in clinic if you would like to discuss any of these issues or anything else that is worrying you.

## Transition

Transition is the planned and coordinated move from Children's Oncology Long Term Follow Up to the Adult Oncology Long Term Follow Up service.

At around the age of 12 you and your Parents/Carer will be invited to a Transition Event where you will meet other young people of your age. The event will provide you with further information about Transition in Healthcare. From the age of 13 you will be enrolled on the Transition Programme as you begin your journey preparing you for independent adult healthcare when you are 18 years old.

You and your Parents/Carer will all be asked to complete some extra paperwork (Ready, Steady, Go) at certain time points when you come to clinic. This will help the staff focus on the areas you may need more support in order to aid a smoother transition when moving to adult healthcare services.

## Who can I contact between my visits?

If you have any questions or worries between your clinic visits about your previous cancer diagnosis or treatments received, you can contact your key worker who will be happy to help.

### *Your Key Worker is:*

**Naseem Sarwar, Clinical Nurse Specialist**

Telephone Number: **0113 392 8853**

Email: [n.sarwar@nhs.net](mailto:n.sarwar@nhs.net)

## Useful Contact Numbers

For queries or to change your appointment, please ring the Long Term Follow Up Administration team: **0113 392 2121**

If you need to speak to a Social Worker, please ring:  
**0113 392 2446**

If you need to speak to a Religious Leader, please ring:  
**0113 206 4365**

## Further Information

- [www.leedsth.nhs.uk/LTFU](http://www.leedsth.nhs.uk/LTFU)
- [www.cclg.co.uk](http://www.cclg.co.uk)
- [www.macmillan.org.uk](http://www.macmillan.org.uk)
- [www.cruk.co.uk](http://www.cruk.co.uk)
- [www.ycn.nhs.uk](http://www.ycn.nhs.uk)
- [www.candlelighters.org.uk](http://www.candlelighters.org.uk)

or ask in your Treatment Centre.



**What did you think of your care?**

Scan the QR code or visit [bit.ly/nhsleedsfft](https://bit.ly/nhsleedsfft)

***Your views matter***



© The Leeds Teaching Hospitals NHS Trust • 4th edition Ver 1

Developed by: Naseem Sarwar, Paediatric Oncology Services

Produced by: Medical Illustration Services • MID code: 20211019\_003/JG

LN002809  
Publication date  
06/2022  
Review date  
06/2025