

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

Information for parents and  
patients aged over 16 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.



### ***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. If you would like to speak to someone please ask your nurse specialist or doctor.

### **Psychologist**

The psychologists are available to offer support and advice if you have any worries about your previous cancer diagnosis. If you would like further information please ask your nurse specialist or doctor.

## When and where the clinics are held?

All face-to-face clinics are held in the Children's Haematology/Oncology Day Unit. This clinic can be found on C Floor, Clarendon Wing, Leeds General Infirmary. All telephone and video clinics are held virtually. You are not required to physically attend the hospital.

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

### Medical Clinic (face-to-face and video)

Takes place on a Monday afternoon.

### Nurse-Led Clinic (face-to-face and video)

Takes place on a Tuesday and Thursday afternoon.

### Telephone Clinic

Takes place on a Monday and Tuesday lunchtime.

## What will happen at 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 urine tests, blood tests or scans.

You will have the opportunity to speak to the Dr or Nurse without your parents or carer.

## 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.

The late effects you may be at risk of will depend on your cancer or blood disorder and the treatment you received. Your doctor will have discussed the late effects your treatment may cause, with your parents or carer, when you had your treatment.

*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. From the age of 18 years your Long Term Follow Up care will be transferred to the adult Long Term Follow Up service. This clinic is based in Bexley Wing at St James's University Hospital.

You will be allocated a new Nurse Specialist at this time. Some of the doctors who have looked after you in the children's clinic will also see you in the adult clinic however there will be other doctors and nurse specialists who you may also see when you come to clinic.

Before you move to the adult clinic this will be discussed with you. You will be given the opportunity to ask any questions you may have. You may benefit from coming into clinic to discuss the move to adult service face-to-face.

## 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 Nurse Specialist/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

If you need 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 • 2nd edition Ver 1

Developed by: Naseem Sarwar, Paediatric Oncology Services

Produced by: Medical Illustration Services • MID code: 20211019\_010/JG

LN004450  
Publication date  
06/2022  
Review date  
06/2025