



Leeds Children's  
Hospital

# Yorkshire Regional Centre for Paediatric & Adolescent Oncology and Haematology

## Meet the team

Information for patients & parents



Nurse



Doctor



Physio



Play Team

# The Paediatric and Adolescent Oncology and Haematology Unit is a specialist service in Leeds treating children from the Yorkshire region who either have cancer or a blood or clotting disorder.

As a regional specialist centre we care for a large group of patients from all across the region. To help in managing the care of children and families referred to us we have a large team of professionals working in the department, all with different roles and jobs to do in looking after you and your child.

This leaflet will help to tell you about the various people you may meet during your child's care and what they say about their service.

## Medical Staff

Your child will have been referred to one of the departments' consultants. Your Consultant, along with other members of the team, will lead the planning and management of your child's treatment and care with you. The Consultants are experts in your child's condition and have overall responsibility for their treatment.

There are a number of other doctors working both on the ward and in clinic. They have different levels of expertise and experience, and some of them change every six months or so as they are learning about all aspects of working with sick children and teenagers. You will see some of these doctors more frequently than your child's consultant, but they keep

your child's consultant informed of their progress. Your child's consultant will be involved in any of the big decisions about your child's treatment, and will discuss them with you. One of the consultants is always on-call (day & night) for any problems which may arise.

## Nurses

In the department there are many nurses working both on the ward and in clinic, all of whom have different jobs and roles in looking after you and your child.

When you are on the in-patient ward you will always have a nurse looking after you and your child. There is a senior nurse who is responsible for the running of our in-patient wards, and each day there is an experienced Nurse in charge on the ward. If you have any worries or concerns that 'your' nurse cannot help with, please ask to speak to the Nurse in charge.

When you are in clinic, or day care, there will be an experienced nurse responsible for each clinic. There is a Senior nurse who is responsible for running the unit. If you have any worries or concerns, please ask to speak to the Nurse in charge.

Being part of a specialist unit and within a university hospital, the team is involved in the training and development of doctors, nurses and other health professionals.

This can mean that, at times, students may be present or involved in your child's care. They will always be supervised by a member of the team.

Here is some information about other nursing teams and individuals that you may meet:-

## Children's Macmillan Nurse Specialist Key Workers

The Children's Macmillan Nursing Team consists of experienced nurses who provide specialist help, advice, support, education and care to children and young people with cancer, and their families.

Every child or young person diagnosed with cancer will be allocated a nurse specialist key worker based upon the area in which they live or their diagnosis.

The allocated nurse, or another member of the team in their absence, will aim to meet families within two weeks of a confirmed diagnosis

### What do we do

As Key Workers for children, young people and families we try to help in the following ways:

- Working with you to look at what support you might need during treatment, and coordinating a 'holistic needs assessment' to do this. We then work with you on a plan to meet those needs.
- Education and advice about diagnosis, treatment plans and any associated side effects. We aim to make sure that you have the information (including written information) you need to look after your child at home.
- Teaching families new skills to care for children at home.
- Working with colleagues in the community and other agencies to provide care for children in their own home. This might include other professionals such as children's community nursing services, district nurses, health visitors, physiotherapists, occupational therapists and general practitioners.

- Working with colleagues in district general hospitals enabling children and young people to receive 'shared care' that is closer to home.
- Maintaining and promoting education. When the time is right we will contact your child's schools to provide specialist medical and nursing advice and support so that they can safely return to school.
- Unfortunately for a small number of children treatment is not successful. The Macmillan Nurse Specialists provide a dedicated service to support and care for children and their families in this situation.

## Working hours

The service operates Monday to Friday 08:00 – 18:00. At times, our office is unmanned, but messages can be left on an answer phone. If a call is urgent you should contact the ward or clinic. If you need to speak to your Macmillan Nurse urgently please ask a member of staff to page them.

**Telephone: (0113) 392 2323**

## Teenage and Young Adult (TYA) team

This service, which spans both paediatric and adult cancer services, consists of a team of people who have the expertise to provide holistic services to young people with cancer, aged 13 - 24 years, and their families.

We are a team of Specialist Nurses, Youth Support Co-ordinators (YSCs), a Learning Mentor, Psychologists and Social Workers. We have expertise in both looking after teenagers, and in cancer care. We can therefore offer supportive services to

all members of the family, as well as help and advice with educational and vocational issues. Through our YSCs we also offer many activities, both on and off the ward, where the teenagers and young adults can meet up with each other and gain support from their peers.

The TYA Service are based in two areas ~ the Teenage Cancer Trust Unit, on Ward L33, at the LGI where we look after teenagers aged 13 - 18 years, and the Young Adult Ward J94, in Bexley Wing at St James's, where young adults aged 19 - 24 years are cared for. Once we have been referred a young person within this age range, we would aim to contact/meet them, and their families, within 48 hours.

**Team Leader Mobile: 07876 475 053**

## Research Team

In order to improve the treatment for childhood cancer and its side effects, it is necessary to carry out research. Our unit is involved in many national and international trials as well as studies we conduct locally that investigate many aspects of cancer care including:

- Improvement of current standard treatments for different types of cancer.
- New anti cancer drugs (often referred to as early phase clinical trials).
- Studies looking more closely at the biology of cancer and its treatment (biological studies).
- Studies looking more closely at the way drugs are used by the body (Pharmacokinetic or PK studies).

- Improving the quality of life of people who have been treated for cancer.
- Improvement of services for children, teenagers and young adults with cancer.

Most investigations into new procedures and drugs start in the laboratory and are then well tested on adults before being introduced into the ward or clinic. Some trials are looking at new drugs and whether they may have any benefits in paediatric oncology. Other trials involve the use of drugs that are well established in the treatment of cancer but examine their benefits when they are compared to other standard treatment or are administered in a slightly different regimen.

All trials are submitted to a research ethics committee for approval before they can be conducted.

There is a research team comprising of nurses, trial assistant & support workers and data managers for the paediatric/ TYA oncology unit, who have wide and varied experience in oncology and research. Between them they coordinate and run the research and clinical trials on the unit & they visit the clinical areas every day. They may come and see you when you are on the ward or in the clinic to talk to you about a study or trial that may be relevant to your child's treatment and will be happy to answer any questions you may have.

If you are approached and asked if you would like your child to take part in one or more of the trials, you will be given all the necessary information and your consent would be entirely voluntary. You are free to refuse to take part, and this will not affect your child's care in anyway.

If you participate in a trial you will be spoken to in detail before you make a decision. You will be kept up to date

during the study and your child will be monitored closely both during and afterwards.

The following links will give you some more information on research and clinical trials.

[http://www.cclg.org.uk/products\\_files/CCLG-A-Guide-To-Clinical-Trials.pdf](http://www.cclg.org.uk/products_files/CCLG-A-Guide-To-Clinical-Trials.pdf)

<http://www.cclg.org.uk/our-publications/parents-and-carers/biological-studies-and-tissue-banking>

<http://www.cclg.org.uk/treatment-research/clinical-trials/published-trial-summaries>

<http://www.cclg.org.uk/treatment-research/biological-studies>

## **Regional Specialist Social Work Team- Oncology and Haematology**

The Regional Specialist Social Work Team are a group of social workers who support children and young people diagnosed with cancer and haematological conditions, and their families. The team are mostly employed by Leeds Children and Young People's Social Care. However, their posts are predominantly funded by charities such as Candlelighters and CLIC Sargent. We work with children, young people and families who attend the specialist centre in Leeds from across the region.

Social workers are able to meet families where a child has been diagnosed with cancer or a blood disorder and discuss individual support for the patient and their wider family. A social worker is able to meet with families in the hospital setting as well as at home as appropriate.



Social workers will support families with the emotional and practical aspects of dealing with your child's illness and support children and their families throughout their treatment journey.

The social work team regularly attend clinic and the wards to meet with families.

### **Volunteer Support**

Social Workers can refer you to the CLIC Sargent volunteer. Volunteers can visit your home to assist with household tasks; make regular visits to play or spend time with a child or young adult at home or in hospital; and provide sibling support by taking brothers and sisters on regular outings. Ask your social worker or Macmillan nurse for more information and they will make an assessment to see if your family could benefit from a volunteer.

You may also find our volunteers supporting the play specialists on the wards, in clinic and day care, or welcoming families at Children's Radiotherapy Room at St James's.

### **Specialist Support for Siblings**

The team run a sibling support group along with the Macmillan Nurse Specialists. This is for 5-15 year old brothers and sisters of patients who attend the unit. The group meets every 2 months on a Saturday from 10.30-2.30.

## A Dedicated Service for Teenagers and Young Adults

The social work team understand that teenagers and young people have very different needs to younger children with cancer or a life limiting blood disorder, and require specialist support and advice. Our social workers offer a dedicated service to support teenagers and young adults as part of the Teenage and Young Adult Service (TYA), specifically working with patients between the ages of 13 and 25 years.

## The Play Team

Play is at the very centre of a healthy child's life. From the earliest age, playing helps children to learn, to relate to other people and to have fun. When children or teenagers are admitted to hospital, they are at their most vulnerable. They are not only ill, but are also separated from their friends and familiar surroundings. Play can really make a difference.

## What do we do?

Working closely as part of the multi-disciplinary team, hospital play specialists and play leaders:

- Organise daily play and art activities in the playroom or at the bedside provide play to achieve developmental goals
- Help children master and cope with anxieties and feelings
- Use play to prepare children for hospital procedures
- Support families and siblings
- Contribute to clinical judgements through their play-based observations
- Teach the value of play for the sick child
- Encourage peer group friendships to develop

- Organise parties and special events

Play staff are based on the ward, Day Care, Clinic and in radiotherapy.

## Family Support Workers

These members of the team are here to help look after parents and families staying on the ward. They are funded by the 'Candlelighters'; our local charity.

They aim to support parents in any way they need. They provide practical help - for example in sitting with your child whilst you take a break; making sure you get something to eat and drink, or just a bit of 'time out'. They help to look after the bed space and the parents' kitchen - ask them if we run out of tea or coffee or washing up liquid! They can tell you about the facilities we have for parents who are resident on the ward - and make sure you know your way around.

They also provide an 'ever ready ear' - and like all the team, are ready to listen to your concerns and provide support at difficult times.

They work closely with our 'dinner ladies' - also funded by Candlelighters, and you will recognise them all by their bright pink T-shirts!

## Learning Mentors and Hospital School Teachers

The Learning Mentors provide pastoral support to the young person or child and their families with regard to educational issues. They liaise with school or college whilst children or young people are in hospital, and keep the home school

updated as to their progress. The Learning Mentors attend a weekly update meeting with the medical, nursing and therapy staff to share information with other outside agencies if appropriate. They help support re-integration back into school.

The hospital teachers deliver the teaching either on the ward or in the purpose built schoolroom. There are specialist primary and secondary teachers who can support the child or young person whether they are just starting school or they need to revise for GCSEs. They aim to devise a personal education plan for each long term patient so that the education that they receive in hospital is both relevant and appropriate.

Should the child or young person require home teaching at the end of their hospital admission the Learning Mentors can arrange that with the Local Authority.

## Clinical Psychology

Clinical Psychologists make up part of the Psychosocial team alongside Social workers, Play specialists and Macmillan nurses. We offer a confidential service offering psychological therapeutic interventions to inpatients, outpatients and young people from diagnosis through to up to five years off treatment.

### Where are we based?

We are based in the Department of Clinical & Health Psychology, Fielding House, St James's University Hospital.

We work with inpatients on the Children's, Teenage and Young Adult wards. We sometimes also work in clinic and

in Bexley Wing Radiotherapy Service. We offer Psychology Outpatient appointments in Fielding House, at St James's.

We work with children, teenagers, young adults and/ or family members (including siblings). We also work with the rest of the team to offer consultation, teaching and training on psychosocial aspects of care for young people with cancer.

Some of the ways that Clinical Psychologists can help include:

- Contributing to the team, helping children and young people to access normal activities including playing, learning and socialising with other young people to encourage their continuing development
- Offering support and advice to parents and staff to help young people express their feelings, either through playing, talking or other creative activities
- Offering psychological support and advice to parents in relation to their child's illness where required
- We sometimes work jointly or alongside other team members and with families to minimise distress cause by illness, procedures and treatments
- We offer assessment of behaviour, emotions and family functioning where families experience difficulties and need specific psychological input and support.
- We offer a variety of psychological interventions/ therapies to young people and their families, including siblings

### **How can you access the Clinical Psychology Service?**

You can ask any member of the Paediatric/ TYA team if you want to speak with a Clinical Psychologist. They will then contact us to make a referral. Sometimes team members talk

with families about referring them to our Psychology Service too. We ask all team members to seek your permission and consent to being referred, before they contact us about a referral.

You may see us on the wards, in the outpatient department or in the Radiotherapy Children's Room, so please feel free to come and introduce yourself and ask any questions any time that you see us!

## Pharmacists

We are a team of specialist pharmacists and provide a daily clinical service to patients treated within the Paediatric and Adolescent Oncology and Haematology Unit. A clinical pharmacist visits Wards L31, L32 and L33 on a daily basis from Monday to Friday. There is also a pharmacist in the Children's Haematology and Oncology Day Unit each morning.

Our responsibilities include:

- Planning chemotherapy along with nursing and medical staff to ensure monitoring and blood tests are performed in advance of treatment
- Producing chemotherapy prescriptions on 'Chemocare'; an electronic prescribing system and checking chemotherapy doses against protocols to ensure the correct treatment is given
- Ensuring chemotherapy is ready when it is needed by close liaison with the pharmacy aseptic unit. The aseptic unit prepares all intravenous chemotherapy and is released to the wards and clinic by specially trained pharmacists.
- Ensuring supportive care such as anti-sickness and antibiotic medications are prescribed appropriately

- Validating all inpatient drug charts on a daily basis to ensure all drugs, doses and administration details are prescribed correctly
- Advising medical staff on dose modifications or drug interactions where necessary
- Discharge planning - to ensure where possible that all medication is ready in advance of discharge to avoid delays
- We are involved with prescribing medicines, as most pharmacists in the team are independent prescribers
- We are closely involved with Clinical Trials to ensure treatment is given and monitoring carried as per the trial protocol and that trial regulations are followed
- Introduction of new medication into the trust by working with the Drugs and Therapeutics Committee
- Providing specialist advice about medication to any members of the paediatric oncology team and to patients, parents or carers

## Dietitians

During your child's treatment they may experience problems with eating due to the side effects of treatment such as nausea, vomiting, sore mouth, loss of appetite, taste changes, diarrhoea and constipation. The dietitian aims to see all newly diagnosed children and parents, to give them a general information booklet 'Eat' which gives nutritional advice on some of the side effects of treatment. They also advise on certain foods to avoid during treatment because they carry a high risk of infection.

The better nourished your child is the better they will tolerate treatment, fight infections and grow and develop throughout

treatment. If your child is struggling to maintain an adequate food intake and weight the dietitian will recommend the use of special dietary supplements or tube feeding.

## Dentists

The paediatric dental team, who are based at the Leeds Dental Hospital, see children and young people in our outpatient and day care department, and on the wards. They aim to see every child who requires treatment for their cancer. If you feel that your child already has dental problems please ask your doctor or nurse to arrange for them to be seen by the dental team.

You can continue to see your own dentist for checkups; however, any treatment must be discussed with either the dental team or your doctor before it takes place.

## Physiotherapists

Throughout the course of your child's treatment there may be times when they require the intervention of one of our physiotherapists. Physiotherapy services are provided during the week Monday to Friday 8.30 - 4.30 by the paediatric physiotherapy team on the wards and in clinic. Children and Teenagers can be seen for acute chest physiotherapy at night or over the weekend by a member of the paediatric physiotherapy staff.

The Physiotherapists see children and teenagers to help with mobility, loss of function, musculo-skeletal problems, chest infections, fatigue and delayed development. We also advise on how to maintain an appropriate level of physical fitness and exercise throughout and following treatment. If you feel that your child may benefit from having the input



of a physiotherapist please inform a physiotherapist or any member of staff as we are happy to see parents and children for advice at any time.

## The Robert Ogden Macmillan Centre

The Robert Ogden Macmillan Centre is at St James's Hospital and offers a range of different types of support including;

Complementary therapies, one to one support, counselling, beauty therapies, hair loss support services, support groups and self help programmes.

Services are available to you and your family free of charge.

Therapy appointments are based at The Robert Ogden Macmillan Centre. Appointments can be made by contacting the Centre directly or by dropping into one of the manned Bexley Wing information lounges on Level 1 and Level 2, at St James's Hospital

Open Monday to Friday 10.00 a.m. to 4.00 p.m.

**Telephone 0113 20 66498**

**Email [cancersupport@leedsth.nhs.uk](mailto:cancersupport@leedsth.nhs.uk)**

The Centre is based directly behind the Thackray Medical Museum, with limited parking available.

## Candlelighters

'Candlelighters' is the registered charity started in 1976 by parents and medical staff to support the work of the Regional Paediatric and Adolescent Oncology and Haematology Unit here in Leeds. The Trustees of the charity are still parents whose children have been treated at the Unit and the consultants responsible for their treatment.

The dedicated help that Candlelighters give in supporting children and their families in Yorkshire is seen in many ways. Financial assistance is provided for families upon initial diagnosis and throughout their journey. Help is offered by encouraging support groups for parents, siblings and teenagers. Candlelighters also provide a break away from home whilst a child is on treatment. Packs are sent to families at the beginning of each year.

Some of the money raised is used to fund additional staff for the unit and to purchase medical equipment for the ward, outpatient's clinic, bone marrow transplant unit and for use in the home. Many of the books, toys and games available on the ward have been bought by Candlelighters.

One area of Candlelighters funding is their support for research into various aspects of childhood cancers. In 1992 following a major fundraising initiative, the Candlelighters' Children's Cancer Research Laboratory was opened on the St. James's site. In 2011 Candlelighters provided funding to open the first Brain Tumour Laboratory in Leeds.

The parents of all new patients are added to the mailing list and should automatically receive details of the charity and a regular Newsletter. If you would like to know more about their activities they are based on C Floor Clarendon Wing in clinic.

**Opening hours are Monday to Friday, 10.00 a.m. and 4.30 p.m.**

Telephone: **0113 247 0372 / 392 6741**

Website: **[www.candlelighters.org.uk](http://www.candlelighters.org.uk)**

Email: **[info@candlelighters.org.uk](mailto:info@candlelighters.org.uk)**

Twitter: **CandlelightersT**

Facebook: **CandlelightersTrust**

### **Useful Telephone Numbers**

Ward L31 **0113 3927431**

Ward L32 **0113 3927432**

Ward L33 **0113 3927433**

Children's Haematology  
and Oncology Day Care Unit: **0113 3927179**

### **Children's Macmillan Nurse Specialist**

Key Workers **0113 3922323**

Social Workers **0113 3922425**

**0113 3922446**



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