

Yorkshire Regional Centre for
Paediatric & Adolescent Oncology and Haematology

Meet the team

Information for patients
and parents



Nurse



Doctor



Physio



Play Team



Leeds children's
hospital

caring about children

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



We care for a large group of patients from 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 many other qualified doctors working both on the ward and in clinic. They have different levels of expertise and experience. Some of them change every 6 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 and 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 inpatient 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 inpatient 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.

We have a small team of 'Advanced Nurse Practitioners' (ANPs) who work across our department and you may meet them in both our Day Care Unit and on the inpatient wards.



They are very experienced nurses who have had additional training to take on some of the roles that in the past were undertaken by medical staff. They can examine and assess children before chemotherapy or if they come in unwell. They take part in the daily 'ward rounds' and can prescribe medication. They work very closely with both the nursing and the medical team in providing continuity of care.

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:

The Children's Haematology and Oncology Outreach Team

In the Children's Haematology and Oncology Outreach Team there are Outreach Nurse Specialists (Key Workers), an Oncology Outreach Administrator and Outreach Play Specialists. Working alongside the multi-disciplinary team, they provide specialist help, advice, support, education and care to children and young people with cancer, and their families.

They have specialist experience and knowledge of children's cancer care and use this to co-ordinate the care needed by children, young people and their families, both in hospital and at home. They frequently link with other services and settings of care to co-ordinate the treatment and care needed by children and their families.

What do they do

Children's Haematology and Oncology Outreach Nurse Specialists

Every child or young person aged 0 - 16 diagnosed with cancer is offered the support of a nurse specialist key worker. As Key Workers for children, young people and families, they try to help in the following ways:

- providing information, 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 you any skills that you might need to care for your child 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 GP's;
- working with colleagues in district general hospitals so that children and young people can have hospital care that is closer to home - shared care;
- maintaining and promoting school attendance and 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;



- being a point of contact for telephone advice and support, and to help coordinate your child's care; and
- unfortunately, for a small number of children, treatment is not successful. The Nurse Specialists provide a dedicated service for children who need palliative care and support their families in this situation.

Oncology and Haematology Outreach Administrator

The Outreach Administrator works alongside the nurse specialists. This is providing telephone advice and responding to families concerns, answering the phone in the nurses absence, relaying messages and providing administrative support to the team.

Candlelighters Outreach Play Specialists

The Candlelighters Outreach Play Specialists works with children and young people who are identified as needing extra therapeutic play support during their treatment. These sessions can be carried out within the child's own home where they feel most comfortable and safe or during hospital visits. They are able to provide help and support to children who may be struggling with going back to nursery / school to help make the transition back easier. For children and young people receiving palliative care, they can help create valuable memories through play support and activities to both patients and siblings.

Some local communities nursing teams have Play Specialist within their teams. The Outreach Play Specialist can also liaise with these teams to ensure the right support is provided.

How to contact the team

The service is available Monday to Friday, 8.00 am - 6.00 pm.

The Oncology and Haematology Administrator will help with your query or take a message for your key worker. A member of the team is hospital based Monday to Friday 8.00 am - 6.00 pm. If you need to speak to a nurse specialist urgently, the Oncology and Haematology Administrator can ask them to contact you.

If no one is available to take your call, you can leave a message or contact either the Day Care Unit / Clinic or the Inpatient Wards and ask them to contact the nurse of the day.

Telephone: 0113 3922323

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.

The TYA team is made up of Specialist Nurses, Youth Support Co-ordinators (YSCs), a Learning Mentor, Psychologists and Social Workers. They have expertise in both looking after teenagers and in cancer care. They offer supportive services to all members of the family as well as help and advice with educational and vocational issues.



If a young person is 16 or over (or in their GCSE year), the Clinical Nurse Specialists in this team will be their key worker and support them and their family in the same way Children's Outreach Nurse Specialists do with those under 16.

Through the YSCs, they 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 is 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 University Hospital, where young adults aged 19 - 24 years are cared for. Once a young person has been referred, the team would aim to contact / meet them and their families, within 48 hours.

Team Leader Mobile: 07876 475053

Research team

To investigate treatment improvement, the research team co-ordinate studies involving childhood cancer and non-malignant blood disorders. Our Unit is involved in many national and international trials, and local studies. These investigate many aspects of cancer care and blood disorders 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 or blood disorders, 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 or blood disorders; and
- Improvement of services for children, teenagers and young adults with cancer or blood disorders.

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 and Haematology.

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 and support workers and data managers for the Paediatric and TYA Oncology Unit, who have wide and varied experience in oncology and research. Between them, they co-ordinate and run the research and clinical trials on the Unit, and 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.

We have a dedicated clinical research facility that provides a specialist environment for the safe delivery of complex treatments.

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

<https://tinyurl.com/CCLG-Clinical-Trials>

<https://tinyurl.com/CCLG-TYA-Research>

Young Lives vs Cancer Social Work team

The charity Young Lives vs Cancer employs a team of social workers to support children, young people (aged 0 - 25) and those around them, following a cancer diagnosis. The social workers at Leeds are experts in helping individuals and families handle the day-to-day challenges that come with a cancer diagnosis. Support may include emotional support to navigate the cancer journey, benefits and financial advice, assisting with work or education arrangements, housing and advocacy. Support can be provided at hospital, home or in the community.

The team work closely with the medical professionals and are an integral part of the Oncology Team. They're there to help because of a child or young person's cancer and to make sure families get the support they need throughout treatment.

To be referred, ask your CNS or consultant to get in touch with us or self-refer by: **0300 303 5220 (Monday to Friday, 9.00 am - 5.00 pm)**; **GetSupport@younglivesvcancer.org.uk** or directly through the **Chat To Us function** on the website: **<https://www.younglivesvcancer.org.uk/>**

The Play team

Play is at the very centre of a healthy child's life. Through play, children learn about themselves and the world around them. 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 to develop a child's mental and physical well-being, whilst in hospital.



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;

- distraction and support during treatment or procedures;
- post procedural play and support;
- anxiety management;
- support around phobias or non-compliance;
- liaise with Outreach Play Specialists;
- support families and siblings;
- contribute to clinical judgments through their play-based observations;
- teach the value of play for the sick child; and
- encourage peer group friendships to develop.

Play staff are based on the ward, in Day Care 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 all 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 lady' - 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, offering support around education and doing bespoke engagement sessions with the young person.

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 reintegration 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

The Clinical Psychology team offers psychological assessment and therapeutic interventions to children and young people and / or their parents, or caregivers during or after their treatment.

A Clinical Psychologist is trained in the assessment and treatment of psychological difficulties. They work together with the child / young person and / or their parents / caregivers to develop an understanding of the difficulties and to develop a supportive treatment plan to reduce psychological distress. Sometimes, this involves the Psychologist advising the team rather than working directly with the patient.

It is very normal for children, young people and parents to experience emotional distress through treatment. The Clinical Psychologists become involved where more severe psychological distress is impacting on the ability to tolerate treatment or on the child or family's quality of life.

The Clinical Psychology team work very closely with the wider Oncology and Haematology team, and other specialist services within the hospital or external to the organisation (e.g. schools, social care, children's mental health services) to ensure that children and young people's psychological needs are being met during their treatment and beyond. We have close links to Child Psychiatry and Neuropsychology and can signpost or work jointly with these services, where appropriate.

Services provided by the Clinical Psychologists include:

- offering full psychological assessments before major surgery or treatments such as Bone Marrow Transplant;
- advice to parents in relation to their child's behaviour or mental health;
- advice to parents about their own mental health during their child's treatment;
- working jointly or alongside other team members (i.e. Play Specialists, Physiotherapists, Dieticians, Consultants) to minimise distress caused by illness, procedures and treatments.

Providing psychological interventions to children and young people during their treatment or up to 5 years off treatment for difficulties including:

- anxiety / phobias;
- feeding / eating issues;
- body image concerns;
- trauma;
- behavioural difficulties;
- adjusting to life off treatment; and
- low mood.

Referrals and appointments

We accept referrals from members of the wider team who know the child / young person well. Appointments with the psychologist can be over the telephone, by video call or face-to-face. Children or parents can be seen on the ward if they are an inpatient, or in the Psychologist's consultation room near the Paediatric Oncology Day Unit. Occasionally, the Psychologist will call parents to ask some questions before the initial assessment.

The psychologist may suggest a referral to local community-based services if the difficulties are not related to the diagnosis or treatment. It is sometimes appropriate for the psychologist to offer a brief assessment to support this type of referral.

Pharmacists

We have a team of specialist pharmacists who 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; and
- 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 dietitians are available to support all children and young people who are struggling with any aspect of nutrition. All families should receive a copy of the CCLG Nutrition booklet and can find it online at:

<https://www.cclg.org.uk/publications/Everyday-life/Helping-your-child-to-eat-well-during-cancer-treatment/HELPEAT>.

The dietetic team also give advice about certain foods to avoid during treatment because they carry a higher risk of infection. You should receive a leaflet called 'Safe Eating for Immunocompromised Patients'.

It is also online within the Leeds Children's Hospital website - A to Z of Hospital Leaflets - under D for Dietetics [<https://flipbooks.leedsth.nhs.uk/LN004564.pdf>].



The better nourished your child is, the better chance they have to tolerate treatment, fight infections and grow and develop throughout treatment. If your child is struggling to maintain an adequate food intake and weight, the Dietetic team can talk you through special dietary supplements, tube feeding and / or how to replace vitamins and minerals.

Telephone: 0113 3920635 or 0113 3920634

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

Your child may experience physical difficulties due to their type of cancer or side-effects of treatment. If they do, they will be referred to the Physiotherapy team.

Physiotherapists help with mobility, loss of function, musculo-skeletal problems, respiratory infections, fatigue and delayed development. They also advise on how to maintain an appropriate level of physical activity and exercise throughout, and following treatment. Physical activity is an important part of your child's treatment and has many benefits. For further information and guidance on physical activity, please read Children's Cancer and Leukaemia Group '**Keeping active during and after treatment**' leaflet -

<https://www.cclg.org.uk/write/MediaUploads/Publications/PDFs/keeping-active-during-and-after-treatment-2022-web.pdf>.

Physiotherapy services are provided on Wards L31, L32, L33 and in outpatient clinics Monday to Friday, 8.30 am - 4.30 pm. If your child needs long-term physiotherapy input, then we will refer to the local Physiotherapy team to continue your child's care closer to home. If your child needs to be seen urgently for respiratory physiotherapy, then there is a 24 hour on call service that the medical team can access.

If you feel that your child may benefit from having the input of a physiotherapist, please inform any member of staff or contact the team directly on **07785 475374**.

Occupational Therapists

During your child's treatment, carrying out everyday activities can be challenging. The Occupational Therapists work with children and young people to reach their optimum level of performance in self-care, leisure and education looking at the different skills needed. They provide a regional inpatient and outpatient intervention to children across the Oncology, Teenage Oncology and Haematology services.

The service is provided Monday - Friday, 8.00 am - 4.30pm. Children can be seen on the ward, in clinic, at home and in school.

Areas of intervention we may provide:

- self-care assessments e.g. washing, dressing, bathing and toileting;
- developmental delay assessments;
- specialist seating;
- equipment provision e.g. wheelchair / major buggy and other assistive equipment;

- home environment assessment to enable children to access all areas of home safely for discharge;
- reintegration into school where the child / young person is experiencing on-going functional difficulties;
- upper limb assessment and rehabilitation for children experiencing decreased functional ability i.e. neuropathy, brain / spinal tumours; and
- difficulties with memory concentration and understanding visual information.

Please inform a member of staff if you feel your child would benefit from Occupational Therapy.



Candlelighters is a local charity which provides lifelong support to children and their families who are affected by childhood cancer, across Yorkshire.

Our support varies from providing immediate financial support, through to practical support on the wards at the hospital and through the Candlelighters Cottage, a place where families can stay when children are receiving treatment at the Leeds General Infirmary. We also provide additional well-being support for the whole family, either on the wards or at our Family Support Centre, The Square.

What we provide:

- financial support upon diagnosis and throughout treatment, which can be accessed through your social worker;
- practical support on the hospital wards such as sitting with children and signposting to other charities;
- extra facilities for families throughout the Oncology and Haematology departments;
- funding of additional staff roles throughout the Oncology and Haematology departments;
- a family holiday to Center Parcs (Whinfell or Sherwood Forest) or Cayton Bay, plus a holiday grant;
- emotional and well-being support for families through therapies that can be accessed at The Square and out in the community.

The Square is Candlelighters Family Support Centre which is just a couple of minutes' walk from the Leeds Children's Hospital. It is a relaxing space to take a break from the hospital environment and all the family are welcome here.

Families can access many of Candlelighters' support service at The Square, including well-being therapies, talking therapies for children and adults, support groups for mums, dads, siblings and grandparents, hairdressing, family fun days and much more!

The support Candlelighters offers lasts a lifetime so whenever you are ready to visit, please just pop in. If you would like one of the Candlelighters staff to meet you at the hospital and bring you to The Square to show you around, either look out for our Family Support Workers on the wards or feel free to ask one of the hospital staff to give us a ring on: **0113 887 8333**.

Opening Hours:

10.00 am - 4.00 pm (Mon, Tues, Wed, Fri) and 10.00 am - 8.00 pm (Thurs)

8 Woodhouse Square, Leeds, LS3 1AD

Tel: **0113 8878333**

Email: thesquare@candlelighters.org.uk

Website: www.candlelighters.org.uk

Facebook: www.facebook.com/candlelightersthesquare
(All family events listed here)

www.facebook.com/CandlelightersTrust

Further information

Further information about the department and some of the tests and investigations that your child may have can be found on the Leeds children's Hospital TV website:

Leeds Children's Hospital TV: <http://www.lchtv.com/>



Useful telephone numbers

Ward L31: 0113 3927431

Ward L32: 0113 3927432

Ward L33: 0113 3927433

Children's Haematology and Oncology Team: 0113 3922323

Children's Oncology and Haematology Day Unit: 0113 3927379

Teenage and Young Adult Team: 07876 475053

Social Workers: 0113 3922446

Candlelighters: 0113 8878333



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter

