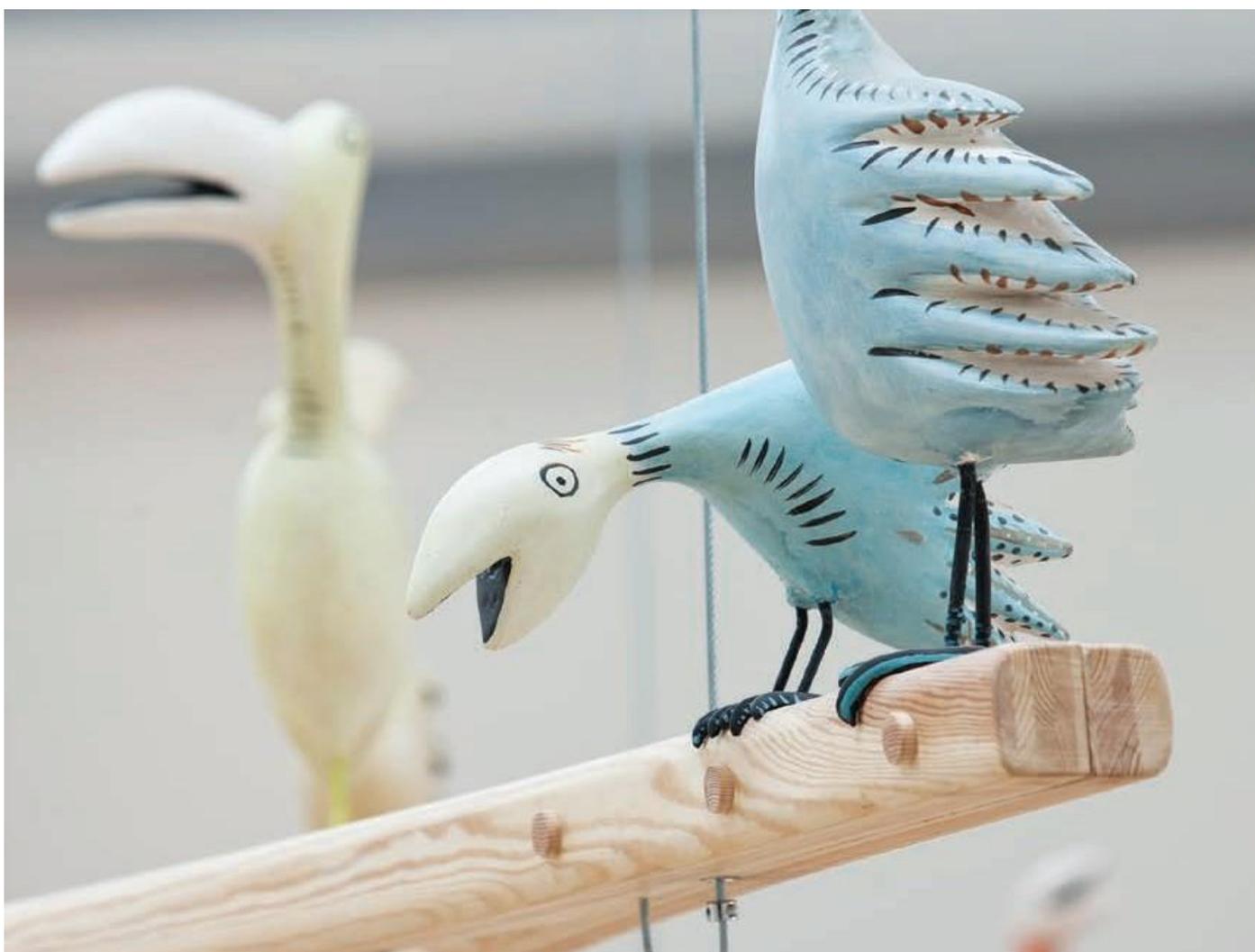


Oncology/Haematology Unit

Family Held Record

Information booklet for families



This booklet only gives general information. You must always discuss the individual treatment with the appropriate member of staff. Do not rely on this booklet alone for information about treatment.

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INTRODUCTION

We realise that this is a worrying and confusing time for you and your family. This booklet provides information about the treatment and care provided here in the Principal Treatment Centre (Alder Hey Children's NHS Foundation Trust), Shared Care Units and at home.

Our staff are here to support you through this difficult time and will always explain what will happen and be completely honest with patients and their families.

If you have any questions, worries or concerns please speak to a member of Oncology/Haematology Unit staff.

Welcome to Oncology/Haematology Unit (Ward 3B)

The Oncology/Haematology Unit at Alder Hey Hospital has a clinic, Day Care and an inpatient area for children aged under 13 years and a Teenage Unit.

In total there are 13 in-patient beds, nine of which are single cubicles with en-suite facilities; there are also ten day-case beds/chair spaces, two of which are in the Teenage Unit. There are also two stem cell Transplant Suites where patients are nursed in isolation.

The Oncology/Haematology team works together to provide family centred care that is based on the latest available evidence and research. We abide by local, regional and national guidelines to continually develop our professional practices to the highest quality.

We care for about 120 children and young people with a new diagnosis of cancer every year. Alder Hey Hospital is the Principal Treatment Centre (PTC) for Merseyside, North Wales, the Isle of Man, parts of Cheshire, parts of North Staffordshire and areas outside the North West of England for those patients requiring highly specialised care.

CONTACT NUMBERS

Please ask your nurse or team member to complete where needed.

Oncology / Haematology Contact Numbers		
Oncology/ Haematology Inpatients	If your child is unwell or you require advice Out of Hours: You must ring before bringing your child to hospital	0151 252 5212
Oncology/Haematology Day Care	If your child is unwell or you require advice; Mon-Fri 08.30 – 16.30. You must ring before bringing your child to hospital	0151 293 3684
Consultants	Dr Lisa Howell (solid tumours) Dr James Hayden (solid tumours) Professor Barry Pizer (solid tumours) Dr Kat Cooper (solid tumours) Dr Chris Howell (leukaemia) Dr Rekha Thangavelu (leukaemia) Dr Russell Keenan (leukaemia)	
Consultant Secretary & Contact	Liam Sabatina Victoria Kennedy Louise McAleavy	0151 293 3679 0151 252 5944 0151 293 3680
Key Worker Name :	Office Number	0151 252 5408
	Mobile	
Shared Care Key Worker (if applicable)		
Clinic Reception		0151 252 5804
Clinical Trials Office / Research Nurse		0151 252 5971
Lead Cancer Nurse	Kirsty Blackburn kirsty.blackburn@alderhey.nhs.uk	0151 252 5470
Lead Cancer Clinician	Dr Lisa Howell	
Ward 3B Manager	Janet Smith janet.smith@alderhey.nhs.uk	0151 252 5603
Other Members of the Multidisciplinary Team & Contacts		
Team Member	Name	Contact
Advanced Nurse Practitioners	Kevin Urdhin Sarah Doyle Ian Mason Lucy Crooks	0151 252 5799
Young Lives Vs Cancer Social Worker	Saiorse Currie – Manager Paula Dempsey Catherine Burns Lauren Pearson	07824 346136 07917 732426 07920 108502 07917 712428
Oncology Dietician	Jennifer Crowley	0151 252 5231
Physiotherapist	Helen Hartley (lead)	
Occupational Therapist	Joanne Owen (lead)	
Youth Support Coordinator	Robert Sefton	07976 208513
Clinical Psychologist	Dr Natalie Holman Dr Alice Little	0151 252 5586

MEET THE TEAM

We have a large team covering many of the needs of children, young people and families who are going through treatment. These include specialist doctors and nurses, pharmacists, physical therapists, psychologists, dieticians, teachers, chefs, play therapists, youth worker and social workers. We have detailed some of the role of these individuals below and contact details are included above. More information is given throughout this booklet.

Medical Staff

All our patients are under the care of a Consultant Paediatric Oncologist or a Consultant Paediatric Haematologist. These are doctors who specialise in the treatment of solid cancers or leukaemia. The consultants share responsibility for the daily ward rounds and our junior doctors work on the wards to support day to day patient care.

Advanced Nurse Practitioners

Advanced Nurse Practitioners (ANPs) have undertaken additional training which includes clinical assessment skills and prescribing. They carry out patient examinations, general health checks, order investigations, prescribe medications, make appointment and plans of care according to patient's treatment protocols. Patients who come to Alder Hey for cancer treatment attend the Oncology/Haematology Day Care Unit and some clinics, will see an ANP. They follow patients all the way through their treatment, so the care is consistent and tailored to a patient's needs. They help to ensure that care is of the highest possible standard and those patients and families are kept informed throughout treatment

ANP's are available to answer any questions Monday – Friday 0800-1800.

Nursing Staff

The nurses are specialised in children's nursing and Oncology/Haematology. The nursing team will include a number of student nurses who are at various stages of their training. Every patient is allocated a nurse for each shift. Each shift begins with a handover period, this is when the nurses get together to discuss the care of all the patients.

Shared Care

The term “Shared Care” is used to describe the way different hospitals and professionals work together to deliver the right treatment and support at the right time and in the right place. This means that any care that can be given closer to a patient’s home will be provided there. The Principal Treatment Centre (Alder Hey) directs the patient treatment plan and delivers the majority of the cancer treatment. Some of the supportive care around this treatment can be delivered closer to home by services delivered by the district general hospitals provided they are recognised officially as a Paediatric Oncology Shared Care Unit (POSCU). The POSCUs attached to Alder Hey include;

The Countess of Chester Hospital.
Wrexham Maelor.
Glan Clywd, Rhyl.
Ysbyty Gwynedd, Bangor.
Leighton Hospital, Crewe.
Nobles Hospital I.O.M.
Royal Stoke Hospital.

Should patients be admitted to a Shared Care Unit there is regular contact between the two teams to ensure care provided is agreed.

KEY WORKER

Key Worker / Paediatric Oncology Outreach Nurses (POON)

You will be allocated a named keyworker / POON on diagnosis. Keyworkers / POONs are specialist nurses with experience of caring for children and families with a cancer diagnosis. The keyworker will provide support, information and consistency from the point of diagnosis, throughout treatment and beyond and where possible will be present for important discussions around diagnosis and treatment plans. They will signpost you to other services where required and will link in with services and teams within the hospital and closer to home. They will complete holistic needs assessments at various points during the treatment to ensure the needs of both your child and wider family are being met in the most appropriate way.

Your key worker will visit you on the ward when your child is an inpatient or in day-care and will undertake home visits as required. They will provide information, training and support to your child's school, college or nursery placement to enable your child to attend as soon as they are able to.

You will be given contact details for your named keyworker/ POON and are encouraged to contact them via phone call, text message or by email. If you need an urgent reply it is important you speak to the ward as your keyworker may be on holiday or on a day off.

Of course, other staff members are also there to support you and can provide answers to many questions you may have.

You may also be supported by a key worker closer to home, your Alder Hey team will discuss this with you in more detail.

Contact details

Office: 0151 252 5408, Monday – Friday 9am-5pm with an answer phone if no one is available to take your call.

TREATMENT PLAN

Treatment Plan

Over the first few days to weeks the results of any tests carried out are discussed by the team involved in caring for children and young people with a possible diagnosis of cancer. This includes, Oncology/Haematology Doctors, Radiologists, Surgeons, Pathologists, Radiotherapists, Specialist Nurses and Pharmacists. Treatment plans are often nationally or internationally agreed depending on the disease being treated.

Your Oncology/Haematology Consultant and your Key worker will talk through the planned treatment with you and will give you additional information/booklets to help build your understanding. More detailed information can be found in the CCLG (Children's Cancer and Leukaemia Group) booklet. A Parent's Guide for Childhood Cancers which is also on their website (www.CCLG.org.uk)

Clinical Trials

Clinical Trials often form the basis of a treatment plan. One of the reasons there are such good cure rates for children and young people is because treating teams, both across the UK and elsewhere, have worked together to learn the best treatment plans and the best way to give these. Some clinical trials test the introduction of a new and promising treatment; however, many are testing different ways of giving recognised treatments to improve outcomes even further and reduce side effects. Some clinical trials aim to improve outcomes by sharing treatment and outcome information with Oncology/Haematology community experts as valuable lessons can be learned this way. We have to have your permission to share this information, which is why this is viewed as a clinical trial.

It is likely that your child will be invited to participate in some research at some point during treatment. This might be as simple as an extra blood sample or agreeing to send some tissue away to be stored or being enrolled onto a trial using new treatments. You are under no obligation to take part in clinical trials and can withdraw at any time should you agree and then change your mind.

The Alder Hey Oncology Clinical Trials Unit is recognised as one of the UK's eleven specialist phase I/II centres, which are able to deliver more experimental treatments to certain groups of patients. We are part of a wider network known as The Experimental Cancer Medicine Centre (ECMC) Network and a member of the European Innovative Therapies in Childhood Cancer (ITCC) Network.

Our team works very closely with doctors and other members of the care team to ensure smooth running of our trials. We accurately record all results and data and this is sent to the main trial team for them to collate results of the trial treatments and draw conclusions which may be relevant for future treatments.

Our team consists of:

- A trial coordinator: Involved in the set-up of trials and then coordinating all aspects of the trials. It is their job to ensure that trials are set up and run in accordance with regulations.
- Two data managers: Responsible for data entry, queries and supporting and monitoring visits and inspections. They also lead some of the trials which require less nursing involvement. They also manage files and generally support the team with anything they can.
- Three research nurses: Responsible for screening patients, arranging patient appointments and timetables, completing any reports of symptoms, data entry, attending consent, having knowledge of trials to enable them to advise patients and families, management of files, liaising with other teams, giving trial treatments, sample handling and arranging.
- A trials pharmacist: Responsible for maintaining clinical trial specific pharmacy records and storage of the trial medications. They are also responsible for ordering/dispensing the trial medications. They monitor medication compliance and can advise on adverse reactions and medication interactions. All prescriptions are checked by a pharmacist specifically trained to undertake this role.
- Consultant Doctors who have expertise in the safe delivery of clinical trials and help to lead clinical trials both nationally and internationally.

Multidisciplinary Team Meetings (MDT)

The team of professionals who help make individual diagnoses and subsequent treatment plans is called a diagnostic and treatment multidisciplinary team. This team may consist of a range of professionals, including Oncology and Haematology consultants, surgeons, radiologists, radiation oncologists, pathologists, specialist nurses and pharmacists. This team of specialists meets every week to discuss all appropriate investigations and relevant findings important for making a final diagnosis and treatment plan for an individual patient. All professionals are experts in their own field and many have national and international roles in the diagnosis and management of cancers of childhood and young people. There are different MDT meetings depending on the disease type and site. These include; Solid Tumour (chaired by Dr Lisa Howell), Neuro Oncology or brain and spinal tumours (chaired by Professor Pizer) and Leukaemia (chaired by Dr Thangavelu).

There are other MDT meetings with a different focus, such as care around stem cell or bone marrow transplant, after treatment (or late effects service), rehabilitation and holistic needs.

CANCER TREATMENT

Depending on your child's diagnosis and treatment plan they will have different types of treatment. Your consultant will discuss this information with you as part of the treatment plan.

Systemic anti-cancer therapy (SACT)

Systemic anti-cancer therapy (SACT) is used to describe all types of medicines used to treat cancer. This includes chemotherapy, immunotherapy and targeted therapies.

SACT may be given by different routes, most commonly these medications are given by mouth or intravenously via your child's central line or a cannula. Some patients will also have SACT given into their spinal fluid via a lumbar puncture. SACT may sometimes be given as a series of sessions of treatment known as a cycle or it may be given continually. This depends on your child's individual treatment plan (protocol). Individual SACT agents have specific side effects, the medical and nursing team will tell you about the side effects that your child may experience during their treatment and what we can do to try to prevent or support your child through these side effects.

- **Chemotherapy**

Chemotherapy is the use of cytotoxic drugs to destroy cancer cells; they can reach the cancer cells all over the body. These medications do not distinguish between cancer cells and normal cells, as a result they affect other dividing cells such as the bone marrow (which makes blood cells), lining of the mouth, hair follicles, and the digestive system (lining of the stomach). This is why it is not uncommon for patients to have a sore mouth, upset stomach and hair loss.

- **Immunotherapy**

Immunotherapy acts on the immune system to target particular cancer cells. Immunotherapy is only suitable for certain types of cancer. It is usually given with chemotherapy.

- **Targeted therapy**

Targeted therapy involves medicines that target and block a specific gene or protein that cancer cells may have. Tumours are analysed for relevant 'targets' and targeted therapy is only suitable for certain types of cancer. It is usually given with chemotherapy. Many are experimental and given at times of relapse or resistant disease.

NB: The word Chemotherapy may be used by the team to describe all types of anti-cancer medicines.

Surgery

The decision regarding an operation and how important this may be in a patient's treatment plan is discussed between the different members of the team. Often these discussions occur in the Alder Hey team meetings (as described above) but can at times be discussed with experts elsewhere. The actual operation may also take place in other hospitals, if this is felt to be the best place for the surgery. This of course would be fully discussed with you and your family.

Radiotherapy

This is more targeted treatment given in a similar way to taking an x-ray or scan. Active particles (similar to x-ray) are directed towards the area requiring treatment. Not all tumours are sensitive to this type of treatment and therefore it is reserved for those where it is felt to be most useful. This treatment is not given at Alder Hey, but we work very closely with the teams at Clatterbridge Hospital and The Christie Hospital in Manchester where radiotherapy is given. Both hospitals have expertise in treating and looking after children and young people.

CANCER TREATMENT SIDE EFFECTS

All treatment causes side effects; those discussed below are some of the most common. Specific side effects will be discussed in more detail with you by the team.

Blood count

Normal cells most affected by chemotherapy including those in the **Bone marrow, where blood cells are produced**. There are several types of blood cells affected:

Red blood cells contain an iron rich protein called haemoglobin. The haemoglobin (Hb) picks up oxygen from the lungs and carries it to all organs of the body. If your haemoglobin level is low, your child is **anaemic** and they may feel more tired and look pale. If the Hb drops below a certain level your child will need a blood transfusion. The level at which a transfusion is given is usually 70g/l or below but will also be based on their clinical condition. When your child starts treatment you will be given a transfusion information pack which has more information relevant to the use of blood products. Should your child have a specific blood product requirement we will discuss this with you.

White blood cells are cells needed to fight infection. When the white blood cell count is low your child may be more likely to get sick from infections (bacterial and viral). There are different types of white blood cells; each one has a different role in fighting infections. In children receiving chemotherapy we are most concerned with a white blood cell called a neutrophil, as neutrophils are very important in fighting bacterial infections. Children with a low neutrophil count are said to be **neutropenic**. There is more information later in this booklet and this will be discussed with you in more detail, to ensure you are comfortable with knowing how we will monitor for this and when to bring your child back to hospital.

Platelets are cells that are needed for the blood to clot. When your child's platelet count is low they may be at more risk of bleeding/bruising. This is called **thrombocytopenia**. If the platelet count drops below a certain level they will require a platelet transfusion. The level at which a transfusion is given is determined by your child's diagnosis and their clinical condition. Platelets are given in a similar way to a blood transfusion and the transfusion information pack will detail more about this.

Your child's planned treatment may be delayed should the blood counts not be sufficiently recovered from the previous cycle. This will be discussed with you in more detail, however short delays will not have a significant effect on the effectiveness of the treatment.

Infections

The treatment used to treat cancer reduces the immune system's ability to fight infection (as mentioned in blood count section), therefore your child will be at increased risk of developing infection, particularly if they are neutropenic. **Please refer to 'What to do if your child is unwell' section.**

Nausea and vomiting (feeling and being sick)

Nausea and vomiting are a side effect of many chemotherapy agents. Anti-sickness medications can be given to reduce these symptoms and mostly we are able to effectively manage this. Some patients, however, may feel sick and vomit for several days after the chemotherapy has finished, on discharge from hospital you will be sent home with one or two days of oral anti-sickness medications. **If vomiting continues at home and patients are unable to keep down fluids or if urine is not passed in a 12 hour period, please contact the Oncology/Haematology Day Care Unit (in working hours), the Oncology/Haematology Inpatient ward (out of hours) or your local Shared Care Unit immediately.**

Diarrhoea

Some of the chemotherapy agents we use can cause diarrhoea. As a result of the increased loss of fluid, diarrhoea can lead to dehydration, and attempts to ensure adequate fluid intake are important. The hospital team should discuss with you how to manage this at home and when hospital admission may be necessary. Diarrhoea can also cause abdominal pain and an excoriated (sore) bottom, similar to severe nappy rash. It is advisable to use a good barrier cream to try and prevent this. Any blood seen in the diarrhoea should be reported to the hospital immediately.

Constipation

Constipation is also associated with some chemotherapy agents, depending on the combination and dose given. Please tell the doctor or nurse if your child seems constipated as they may prescribe a laxative (medicine to help). It can help to drink plenty of fluids and to eat more high fibre foods this includes wholemeal bread or pasta, fruit and vegetables or baked beans.

Pain

Your child can have pain as a result of the disease he/she is being treated for, or as a side-effect to treatment. **We do not recommend the routine use of paracetamol or ibuprofen for pain relief at home** as this may mask the temperature at a time when it is important to detect infection as early as possible. If your child has pain please discuss it with your medical team who will be able to advise and prescribe appropriate medicines. A form of morphine is often used and can be very effective.

Mucositis / sore mouth

Chemotherapy can cause ulcers and pain in your child's mouth. This can be managed and minimised by good mouth care. When your child starts treatment, one of the nurses will explain how to care for your child's mouth. Please see going home section for information on mouthcare. Sometimes a child may not say that they are in pain, but you may notice and increase in drooling, a change in how they speak or they may seem to have difficulty in chewing or swallowing food. If your child's mouth becomes sore please let your doctor or nurse know or please contact the ward for advice.

Weight loss/gain

Your child's weight and height will be regularly measured. For some it can be very difficult to eat enough food during treatment. Weight loss and poor nutrition can affect your child's general wellbeing and ability to tolerate the treatment being given. We therefore take this seriously. If your child is losing weight or has a poor appetite, please ask to speak to one of the dieticians (see dietician section on page 26). They can suggest food and drinks that may be helpful in maintaining weight. Some children and young people require other ways of receiving adequate nutrition. This will be fully discussed with you as appropriate.

If your child is on steroids they may experience an increased appetite. This can cause them to gain weight. In some cases, this can be significant, and you may find that you are having to feed them a lot more than usual. This weight gain may also cause a difference in their appearance. If your child is well enough, it is important to encourage regular exercise. These effects are temporary, and their appetite will usually decrease when the steroids stop.

Body image changes

Children and young people undergoing treatment for cancer may experience changes in physical appearance as a result of the treatment. This is often the most upsetting side effect of treatment for your child who will need a lot of reassurance and support at this time. Hair loss, weight loss, weight gain and skin changes are all physical changes that may occur at some stage during their treatment. Based on your child's protocol the medical nursing team can advise you about the possible changes in appearance to expect. There is support available to help cope with the impact of body image changes, please discuss this with your Key Worker or other member of staff, who can arrange for you or your child to meet with one of our clinical psychologists.

Hair loss/Alopecia

This affects different children in different ways. The older children are more aware of it and may find it an embarrassing problem, particularly where their friends are concerned. Not all chemotherapy causes complete hair loss, your Doctor or key worker can advise what is likely to happen for your child based on the treatment they will be receiving. If your child is receiving radiotherapy to their head, this will also cause hair loss.

Hair tends to thin and fall out gradually, but often around 10 days from the start of treatment. Long hair may be best cut before it falls out. If you think your child might want to wear a wig it is worth discussing this before their hair falls out to allow time for the wig to be made and to match their own hair colour. Please ask your key worker or Outreach Nurse (POONS) about arranging a wig as there are a number of options available. The contacts for these nurses are in the front of the folder.

Otherwise there are many hats and bandanas available in the shops. Hair will grow back following completion of treatment, although it may not grow back completely in the area where your child had radiotherapy.

Skin changes

Children sometimes develop rashes or changes in skin pigmentation (colour) as a result of chemotherapy. Rashes can also be a side effect or allergic reaction to certain medications. Reassure your child that skin colour often returns to normal after treatment has stopped. If you suspect that your child has developed an unusual rash similar to Chicken pox for example, please contact the ward/shared care unit immediately (refer to page 18).

Extravasation

Some chemotherapy medicines that we give can cause tissue damage if they leak outside of the vein into the surrounding tissues, this is called extravasation. This problem is much more unlikely with a central line or port-a-cath. Prior to giving any medication that could cause this, the nurse will always make sure that the venous access device bleeds back. If nursing staff are concerned about the safety of a cannula or long line, we may insert a new one to give the treatment safely. Please inform the nurse immediately if your child complains of burning, stinging or any other changes at the site of injection such as redness or swelling. If the line is pulled accidentally or any leakage is noted please let the nurse know.

WHAT TO DO IF YOUR CHILD IS UNWELL

What is neutropenic sepsis or febrile neutropenia?

Some anti-cancer treatment agents can reduce the production of white blood cells by the bone marrow. This lowers your child's immunity and makes them more prone to infection. There are many types of white blood cells, one type is called neutrophils. When the neutrophil level in the blood is low, this is often referred to as neutropenia. The risk of infection varies depending on the type of treatment your child is having; how low their blood counts are and the length of time they are low. A full blood count (FBC for short) is a blood test that gives the levels of different cells (including neutrophils) in the blood. Febrile neutropenia is a term for fever (a temperature of 38°C or above) in the context of severe neutropenia (≤ 0.5). Evidence of severe infection in the context of neutropenia is termed neutropenic sepsis. This may be associated with high temperatures, although sometimes your child can be unwell without high temperatures.

Taking temperatures

Make sure you have a centigrade thermometer at home. Usually small digital thermometers are easy to use and can be placed safely under the armpit. These thermometers are available from our Ward but some families prefer to buy their own ear thermometer. If you choose to do this, please bring it to our Ward so we can check you know how to use it and it is working correctly.

Patients who complain of being unwell or hot must have their temperature checked immediately. A high temperature may be a sign of infection. Since cancer treatment reduces the ability of the body to fight infections, it is important to respond quickly to high temperatures. Antibiotic treatment in hospital may be needed. Some children may be unwell without a high temperature or even a very low temperature.

If a patient has a temperature of 38°C or higher please telephone Oncology/Haematology Day Care (in working hours), Oncology/Haematology inpatients (out of hours) or the local Shared Care Unit immediately. Patients must not take paracetamol or ibuprofen of any brand. Examples of these are Calpol, Disprol or Calprofen as these can hide temperatures. Calprofen also contains ibuprofen which can lower platelets.

Always call the Oncology/Haematology Unit first so that the nursing staff can triage and give advice. Please be aware that out of hours in Alder Hey you will be advised to take your child to the accident and emergency department. You will need to inform the triage nurse of your child's diagnosis and treatment. If you attend your Shared Care Unit, please contact them and they will advise on the route of admission. **Please ensure you bring all medications with you to the hospital and oral treatment record if you have one.**

Infections

The treatment used to treat cancer reduces the immune system's ability to fight infection as discussed previously. In general, infections fall into different types which require different treatments.

Bacterial

Bacteria can cause serious infections in children who are at greater risk of infection. Some bacteria that normally live in or on our bodies and would not normally do any harm can cause severe infection in children receiving treatment for cancer. Bacterial infections will be treated with antibiotics, often given intravenously.

Routine swabs

We ask for regular 'poo' swabs and swabs from other body areas, from patients so we may monitor these 'carried' bacteria and obtain information which may be very relevant for treatment should your child become unwell. This helps us to know if your child carries a bacteria which is resistant to our usual antibiotics and we would therefore plan to give an alternative. You will be provided with these swabs.

What is involved?

Swabs are taken from the nose and the groin area for routine admission MRSA swabs. As part of oncology surveillance we will take a stool sample or a swab from the rectum. Stool sample; Patients are given a specimen pot and taken using a little spade which is provided in the pot. Rectal/Bottom Swab; On the occasions when we can't obtain a stool sample, we can use a cotton swab to obtain a small sample of poo staining.

Fungal

There are germs around us that do not cause infections in healthy children but can be harmful to those who are a greater risk of infection. These infections include thrush caused by candida and other infections which most commonly affect the lungs. Should a child or young person have a prolonged fever whilst in hospital, we often add in antifungal medicines and actively look for these, which may not give any obvious symptoms.

Pneumocystis Pneumonia (PCP or PJP)

This infection is due to an organism that is probably present in most people's lungs. Children who are receiving long term medications which interfere with the body's ability to cope with infections may be more at risk from this type of pneumonia. The symptoms of this infection include a raised temperature, rapid breathing and a dry cough. To help reduce the risk of children developing this, some protocols advise giving an oral antibiotic called co-trimoxazole (Septrin), this will be discussed with you if required as part of the treatment.

Viral

Most of the common viral infections are not prolonged or serious in children on anti-cancer therapy apart from the exceptions of chicken pox and measles.

Chicken pox

Chicken pox is caused by a virus (Herpes Zoster) which also causes shingles. Chicken pox is spread by droplet infection e.g. breathing, coughing and sneezing. Shingles is a reactivation of a previous chickenpox infection, but chickenpox can be caught by direct contact with a shingle lesion in a person who is not immune to chicken pox.

Chicken pox can cause severe infection in people who have a suppressed immune system.

Signs and symptoms include; fever, runny nose and a rash of red itchy fluid filled blisters mostly on the upper body. Within a few days the blisters burst and form crusts. The incubation period can last up to 21 days after contact as chicken pox is infectious until no new blisters appear and the last one dries. The illness usually lasts between 5-10 days.

Chicken pox contact

All patients who start a chemotherapy treatment plan will be asked if they have had chicken pox and will have their immunity checked using a blood test to see if they have antibodies. Any patient who has no immunity to the virus and has had direct close contact with someone who has Chicken pox will need medication to prevent it from developing. Direct close contact means play or direct contact for more than 15 minutes during the infectious period. Children may be infectious from 2 days before a rash appears and until crusting of the vesicles. For certain treatment plans we recommend preventative medication even if there is evidence of immunity, in case the cancer treatment has reduced the antibodies which were present before treatment.

Please contact Oncology/Haematology Day Care (in working hours), Oncology/Haematology inpatient ward (out of hours) or your local Shared Care Unit immediately if your child experiences Chicken pox symptoms or has had direct close contact.

The medication used for treating Chicken pox is called aciclovir. This can be given as tablets or liquid form and patients will need to take it for 7 days following direct contact with an infected person at school, play group or on holiday. If a sibling or household member has symptoms there is a risk of ongoing exposure and the medication will need to be taken for 21 days.

Measles

Similarly measles is a serious disease in patients having treatment for cancer. Any patient who has received the MMR vaccine will usually be immune to measles. However immunity can sometimes be lost if a patient has had chemotherapy.

Signs and symptoms include; fever, runny nose, red eyes (conjunctivitis), cough and later a red rash. Incubation period lasts until 7-10 days after contact and measles is infectious in the period 5 days before to 4 days after rash appears. The illness usually lasts between 5-10 days. A protective medication to prevent measles from developing may be needed. **Please contact Oncology/Haematology Day Care (in working hours), Oncology/Haematology in-patients (out of hours) or your local Shared Care Unit immediately if your child has been in direct contact with someone who develops measles.**

WHERE WILL THE TREATMENT BE GIVEN?

Where will my child have their treatment?

Your child will receive chemotherapy treatment on the Oncology/Haematology Inpatient ward, Day Care or in theatre. The Oncology/Haematology ward is situated on the third floor of the hospital. Some aspects of treatment may be delivered at home or in a Shared Care Unit. Please be aware these are very limited and will be made clear to you if this is proposed for part of your child's treatment.

If your child is admitted as an unplanned admission and there are no beds available on the Oncology/Haematology ward, they may need admission to a different medical ward within the trust. These patients remain under the care of the Oncology/Haematology team and will be seen at least daily.

Should your child be attending hospital for a routine appointment or visit but have symptoms suggestive of an infection (even without a fever), please contact the unit ahead of your arrival to discuss this. We may need to take special precaution to protect other patients and staff.

Oncology/Haematology Day Care

Day Care is the area where we give any treatment that does not require an overnight stay. This can include:

- Emergency (unplanned) reviews.
- Day case chemotherapy.
- Blood and platelet transfusions.
- Theatre recovery.

Oncology/Haematology Day Care has 10 spaces; 4 bedded bay area, 2 cubicles, 2 Teenage Cancer Trust (TCT) beds and 2 treatment chairs.

Treatment in Day Care is given by timed appointments and you will be given a time to arrive. Please make sure you arrive on time as lateness will mean you may have to wait longer for treatment. **Please ring Oncology/Haematology Day Care on 0151 293 3684 if you think you will be late for your appointment.**

Children having anti-cancer therapy or going to theatre usually have blood tests 48 hours before admission. For blood tests (finger pricks) at Alder Hey Hospital please ring 0151 293 3684 for an appointment. These bloods are then checked to make sure that they are at a level high enough for treatment to go ahead.

Blood tests can be arranged at your Shared Care Unit, but these must be arranged in agreement with your child's Consultant. Please check with a member of our team if a blood test has been requested.

Any medicines or equipment needed at home will be given on discharge. Before leaving Day Care, please check that you have everything you need, including the date of your next appointment.

Theatre

Some aspects of leukaemia treatments are given into the spinal fluid and are given in theatre under anaesthetic. We have specific theatre lists for these procedures, as well as some routine tests which are given under anaesthetic. These take place most often on Wednesday and Thursday mornings. All patients going to theatre on these days should be booked in at reception at their allocated time slot. Patients who are going to theatre will be seen first. Occasionally delays do occur, but we will try our best to keep patients and their families informed in these instances.

Eating and drinking guidelines before going to theatre.

- Patients must not have any solid food in the six hours before theatre.
- Babies and infants may be fed with formula milk/cow's milk up to four hours before going to theatre.
- Babies and infants may be breast fed up to three hours before going to theatre.
- All patients may be given clear fluids up until one hour before theatre.
- No chewing gum should be given to patients going to theatre.

On theatre days we ask all our patients and families to not eat food in clinic and waiting room. **If your child has food or drink before going to theatre it is vital that you inform either a nurse or doctor.**

Oncology/Haematology Inpatient Ward (3B)

Depending on your child's diagnosis and treatment plan, admission to the inpatient ward for treatment may be required. A member of the medical team or the ANP's will discuss this with you throughout your treatment journey.

Oncology/Haematology Outpatient clinics

Also situated on the third floor is the Oncology/Haematology outpatient clinic. We ask that you always report to our receptionists when arriving for an outpatient appointment. The timetable for clinics can be seen below. Oral anti-cancer medication will be prescribed and dispensed from this clinic and the associated satellite pharmacy.

The Schedule for Alder Hey Paediatric Oncology/Haematology Outpatient Department (OPD)		
Day	Morning Session (08.30 – 13.00)	Afternoon Session (14:00 – 16:30)
Monday	Leukaemia OPD (Patients off treatment)	Solid Tumour OPD
Tuesday	Bone Marrow Transplant OPD After Cure Clinic (Patients 3-5 years post treatment)	Brain Tumour OPD Endocrine OPD
Wednesday	Leukaemia OPD	
Thursday	Leukaemia OPD	
Friday		

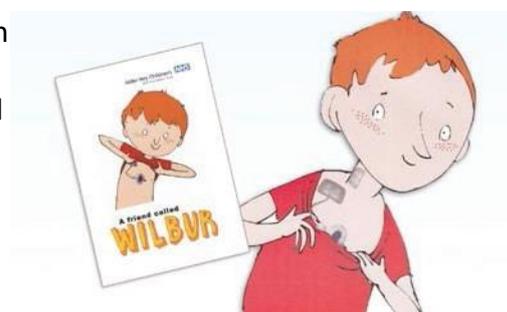
If you are unable to keep an appointment please contact the Oncology/Haematology Clinic as soon as possible on 0151 252 5804. Please also contact your consultant secretary if other investigations/tests have been arranged to coincide with your appointment.

HOW WILL THE TREATMENT BE GIVEN?

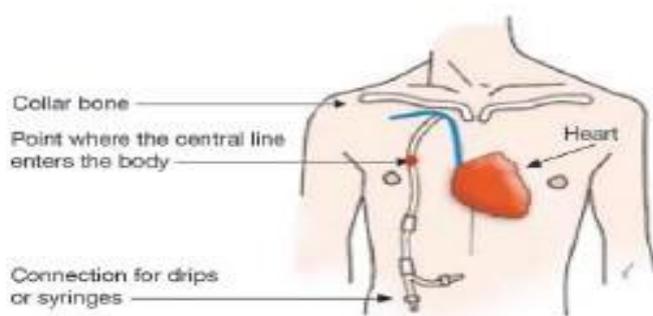
Most treatments are given into a vein using a long-term device. There are several types of long term central venous access devices that are commonly used to administer chemotherapy. Your child's treatment plan will often determine the type of device needed and when it is needed. This will be discussed with you by a member of the medical team. There are two devices commonly used, a central venous line (CVL) and a port-a-cath. Some treatments are given via mouth or a temporary device (cannula or a long line).

Central Venous Line (CVL)

A central venous line is a tube which is tunnelled under the skin on the chest and into one of the large veins leading to the heart. It enables treatment to be given safely and allows blood samples to be taken. Before a CVL is inserted your child's nurse, doctor or play specialist will take time to explain to you what it is and what it will do. There is also a booklet available called "A Friend Called Wilbur" which will help.



A thin tube is tunnelled under the skin on the chest, where a small amount of tubing is visible, and a 'cuff' lies under the skin to hold the line in place. The tubing ends in one of the large veins leading to the heart. A central line can stay in place for the entirety of treatment for months or even years.



Lines should always be clamped when not in use. A screw on cap (bung) is attached to the end of the line through which injections may be given. This must not be removed when the line is not in use. There are different types of CVL's which may have one, two or even three tubes fixed together. Although they may look slightly different they all work in the

same way.

What is the central venous line used for?

The central venous line is used for taking blood samples and giving fluids, blood products and medicines. However there may still be occasions when injections (finger pricks) will be needed.

How long does the central venous line stay in for?

The central line can stay in place throughout treatment. This may be months or can be for years depending on the length of each treatment.

Who takes care of the central venous line?

At first our nurses will take care of the line, but we will arrange training sessions to teach patients and their families on how to care for the line. We will make sure that you feel confident in this before taking on the responsibility. The Community Nurse and the Shared Care Unit are also available to help you. The most important thing is to keep the line free from infection by ensuring the entry site remains clean and, if an infection does develop, make sure it is treated quickly. Lines need flushing once per week if not being used.

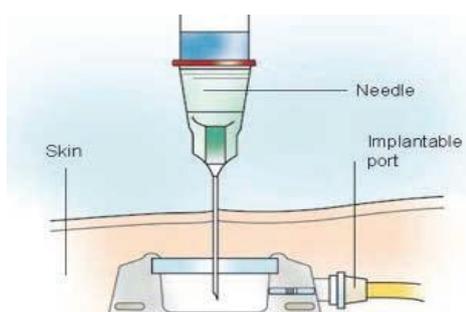
When is the central venous line removed?

When treatment has finished, arrangements will be made for the central venous line to be removed. This may involve your child having another trip to theatre.

Port-a-cath

A port-a-cath is a central venous catheter system, it is different to a central line in that there is no part exposed outside the skin. A port-a-cath consists of a stainless steel chamber with a silicone membrane which is placed under the skin on the chest. It has a tube attached that sits in one of the large veins leading to the heart. This allows treatment to be given safely and blood samples to be taken. The tip or end of the port-a-cath sits in one of the heart's chambers it is quite safe for it to be in this position as it does not cause blockage and the veins and heart continue to work normally. Unlike the central venous line which has to be flushed weekly, the port-a-cath only needs flushing once a month to prevent it from becoming blocked. The port-a-cath is used to take blood samples and to give chemotherapy, fluids and blood products.

To use the port-a-cath, our staff will need to put in a special needle called a Gripper Needle. Anaesthetic cream is placed on the skin where the port-a-cath can be felt, before the needle is inserted. The Gripper needle goes into the port-a-cath and has a short extension tube at the other end from where bloods can be taken. The tube also has a screw on cap (Bung) attached through which injections may be given. When the Gripper Needle is in place but not in use, the tube must be clamped and the screw cap (bung) must not be removed.



When not in use, the needle is removed and the port-a-cath just looks like a bump under the skin. A new Gripper needle will need to be put in the next time treatment is required.

Please see going home section for advice and guidance on the care of CVL/Port-a-cath at home.

MEET THE REST OF THE TEAM

Clinical Oncology/Haematology Pharmacy Service

The Oncology/Haematology Unit has a dedicated pharmacy service provided by pharmacy staff based on the Unit and within the satellite pharmacy.

The pharmacists have specialised knowledge of the medicines used in the treatment of children and young people with cancer. The pharmacist role is to ensure that medicines are used in the most effective and appropriate way. This involves checking prescriptions to ensure that the right medication is being used at the right dose for the right condition and providing information about medicines to staff and patients.

Pharmacy technicians and assistants play a vital role working alongside the pharmacists preparing and dispensing medicines.

The Oncology/Haematology pharmacy team can help you/your child understand what medicines they need to take, when and how to take them, what they are being used for and what possible side effects may occur.

Oncology/Haematology Satellite Pharmacy

The Satellite Pharmacy is responsible for preparing and providing medicines for patients attending the Oncology/Haematology Unit (day case, in-patients and some out-patient clinics). It does not provide medicines that need to be made in extremely clean conditions e.g. intravenous chemotherapy are provided by the Pharmacy Aseptic Services based in the main pharmacy.

Oncology/Haematology Outpatient Clinic

Opening times: 8.45am - 1.15pm, Wednesday and Thursday mornings only.

When we receive your prescription, we will start to prepare (dispense) the medication. The pharmacist checks that the dosage of medicine prescribed is correct for your child's age and cancer treatment protocol. The dispensing of medicines for patients with cancer can be a complex process. A call back system is available so that families can leave the unit whilst dispensing takes place.

Day case and Inpatients

Opening times: 8.45am – 5pm (closed 1.15pm to 2pm), Monday to Friday.

Clinical Psychologists

A Clinical Psychologist is trained to understand how people think, feel and behave. The Clinical Health Psychology team at Alder Hey aims to help children, young people and their families to cope with some of the challenges that can come from living with a medical condition and its treatment. We have two dedicated Clinical Psychologists who provide support for those under the care of the oncology service.

It is really normal for families to experience a range of difficult emotions following a cancer diagnosis. For some families, these emotions settle with time and with support from family, friends and the medical team, however, for some families these difficult emotions may persist and impact on daily life. In these situations, a referral to the Clinical Health Psychology team may be helpful. We use talking, play, and creative activities to help children, young people and their families. We can meet with families on the ward as an inpatient, in Day Care, or in our separate outpatient department. We can also offer support over the phone or through the use of video calls.

Some of the common reasons for referrals to our service include support with:

- Adjusting to a diagnosis.
- Coping with treatments and hospital procedures.
- Managing symptoms such as pain, tiredness and bodily changes.
- Dealing with feelings related to the health condition, such as feeling different, sad or worried.
- Coping with how a health condition affects daily life, including school and friendships.

We are able to provide support at any point following a child's diagnosis, whether this is at the time of diagnosis, later on during treatment, or even months or years following the end of treatment. This support is available for anyone in the family who is affected by the child's diagnosis. If you would like a referral to the Clinical Health Psychology team at any point then you can speak to any member of the oncology team or contact our department directly.

Dieticians

Our Oncology unit has a dedicated dietetic service which specialises in the nutritional management of children and young people who have cancer. They offer both inpatient and outpatient support and are available throughout your child's treatment journey.

Most children and young people with cancer will experience problems with eating and drinking at some stage. Eating well during treatment is really important as this helps children cope better with treatment, fight infection and maintain normal growth and development.

A dietician can provide advice regarding;

- Managing common side effects of treatment such as nausea, taste changes, constipation, diarrhoea and sore mouth.
- Managing fussy eating or a poor appetite.
- Use of prescription high calorie drinks when your child's appetite is poor.
- Managing tube feeding in hospital and at home.
- Minimising excessive weight gain during steroid treatment.
- Transitioning back to healthy eating once intense treatment has finished.
- Any other nutritional concerns.

If you would like to see the dietician, please ask your nurse or doctor to make a referral.

Hospital Volunteers

Volunteers are an important part of hospital life. They work alongside hospital staff and contribute to the care and wellbeing of patients and their families. They do this by offering a range of services and activities to children and their families to improve their patient experience of Alder Hey Hospital.

Occupational Therapist

Occupational Therapists can help children and young people to achieve essential everyday activities which they may find difficult as a result of their cancer diagnosis and treatment.

They assess for difficulty in functional activities - self-care, play, leisure, fine motor activities and access to home and school. They can provide advice and strategies on how to modify activities to help children achieve their goals. Occupational Therapists are involved also in discharge planning to ensure children can return home safely following any prolonged hospital stay.

Physiotherapist

Physiotherapists use physical approaches to promote, maintain and restore physical, psychological and social well-being. A physiotherapist may see your child during their treatment. This is because they might experience side effects from their illness or from their treatment which can sometimes affect their mobility.

The physiotherapist may monitor and offer advice on activities / exercises to help. Keeping active is important during treatment. Whilst on treatment it is better for them to do regular short bursts of activity rather than a lot in one go.

They work closely with other members of the team and help and advise on treatment. Physiotherapists can provide a specially designed exercise activity programme to carry out whilst an inpatient or at home. If your child requires ongoing outpatient physiotherapy input they will be referred to their local community team.

Play Service

Play is a physical and mental activity which gives emotional satisfaction and develops communication skills. Play is extremely important for children of all ages but sometimes our patients may lack the will or ability to create suitable play activities for themselves.

Some children develop changes in their behaviour during treatment. Play provided by specialists is important to patients and their families in preparing, supporting, recognising and understanding their needs during and after treatment.

Play specialists can provide therapeutic play activities for children of all ages and abilities. Activity and play programmes are structured to allow children and young adults to talk about their feelings and express any fears that they may have. Therapies such as relaxation techniques can be used with great affect alongside pain therapy to maximise relief and reduce anxiety. These are all useful techniques which may be appropriate during painful or unpleasant procedures.

Play specialists work in partnership with other members of the MDT to bridge the gap between hospital and home. Ward 3B has two Play Specialists and one Play Assistant who provide and supervise play activities for all patients Monday - Friday 8.30am -4:00pm. Please note when they are available, Play Specialists from Ward 3B can provide therapeutic input to our patients on other wards but cannot provide play activities.

Beads of Courage

The Beads of Courage Programme is run throughout the UK. It is designed to support children going through their treatment. It allows them to tell their story using colourful beads. The beads are used as meaningful symbols of courage that commemorate different milestones such as blood transfusions, bone marrow transplants, hospital stays, chemotherapy and radiotherapy treatments. Their beads build up over time into a unique record of what they have experienced. On diagnosis, one of our Play Specialists will explain the programme and give out the first beads. After this other staff trained on the programme can give out beads.



Spiritual Care – The Sanctuary

The Spiritual Care Department is centred in The Sanctuary which is located in the lower floor of the Tree house in the Atrium. As well as the main Sanctuary prayer space, we have a quiet room where families may reflect or pray in peace. Members of the team are available to speak to anybody and they are not just available for those who go to church. They can also assist those of other faiths whom have differing worship needs and can be contacted via the main hospital switchboard.

Teenage Cancer Trust Youth Support Co-ordinator

Having cancer can be an isolating experience, where you may miss out on school, seeing friends and other normal stuff. Youth Support Coordinators are there to support you and make the hospital ward a less scary place, providing an informal and relaxed atmosphere.

Making up less than 1% of the cancer population – Teenage and Young Adult (TYA) cancer patients often experience isolation and can feel like they are the only people their age dealing with their diagnosis and treatment. The Youth Support Coordinator is there to make sure there are plenty of chances for TYA cancer patients to socialise and stay connected with other people their own age, with similar experiences to them.

They'll arrange activities and give practical help and support around specific treatment-related issues, as well as adolescence generally. All this support can make a huge difference to coping during treatment and beyond.

To access the Youth Support Co-ordinator service young people must be aged 13 or over on diagnosis or whilst still on active treatment, and support continues up to two years post-treatment.

The Youth Support Co-ordinator will:

- Provide group activities and one-to-one support to TYA cancer patients on Ward 3B.
- Provide a tailored service suited to the individual.
- Support young people in coping with both issues around treatment/diagnosis as well as general adolescence.
- Link in with educational providers and employers to ensure young people are receiving the best support available to them.
- Assist young people in keeping up with current workload as well as offering further learning opportunities such as music tuition/recording, art and more.
- Facilitate the online and face-to-face TYA Peer Support Group, enabling young people to socialise with their peers in activities and projects they shape themselves organise and facilitate various residential opportunities through Teenage Cancer Trust and other charities.
- Offer opportunities for teenagers and young adults to get involved in shaping our service.

Unit Chef

The Oncology/Haematology Unit has its own kitchen and chef to support patients during their stay. Our chef will:

Take orders for food for patients between 11.30am and 5.30pm. The last order for Day Care patients is 3.30pm.

Prepare a meal for one parent or carer on the inpatient ward, there is a charge for this service.

Our Chefs **cannot** prepare food that has been brought to the ward by parents or carers.



Young Lives vs Cancer

Young Lives vs Cancer (formally CLIC Sargent) is the UK's leading cancer charity for children, young people, and their families. They provide practical and emotional support to help patients and families cope with cancer and get the most out of life. They are there from diagnosis and aim to help the whole family deal with the impact of cancer. Support is tailored to suit the needs of families including:

- Providing emotional and listening support.
- Helping you to understand and find ways to deal with practical issues.
- Giving financial support including grants and help you access benefits support and advice.
- Provide a wide range of information on childhood cancer and its impact.
- Helping children, young people and their families access short breaks or holidays.
- Helping children and young people keep up with school, college, university, training or work.
- Supporting parents and young people to liaise with schools, colleges and employers.

GOING HOME

Going home during treatment can be a worrying time for patients and their families. The keyworker and all members of the unit staff are here to support in preparation for going home and once at home. We will provide patients and their families with all the information needed to feel confident to be at home. In addition, you will be given the numbers to access advice and support 24 hours per day. Community nurses and other healthcare professionals (where necessary), may also provide services and support once at home.

Our patients will return to hospital regularly for further treatment or for check-ups as an inpatient, an outpatient or Day Care. **Please be sure you have your next appointment date before you leave.**

Some advice for managing issues at home is also included in this booklet. See page 16 for advice re taking temperatures/monitoring for infection, page 13 for vomiting and diarrhoea management and below for care of the central line and mouth care (important for preventing infection).

Central Venous Line (CVL) Care

Bathing and showering guidelines; if the CVL dressing gets wet please follow the guidelines below. **If you are worried at all about the line please contact the Oncology/Haematology Day Care (in working hours), Oncology/Haematology inpatients (out of hours) or your local Shared Care Unit.**

Showers

- For the first 4 weeks after insertion the CVL site should be kept dry.
- If the site is well healed and shows no signs of redness or oozing, showers are then allowed.
- Remove the dressing but do not use soap or shower gel around the exit site, fresh running water will be adequate.
- Dry the site with clean gauze (not a bath towel or flannel) and put a clean dressing on.
- The CVL exit site should be cleaned weekly with 2% chlorhexidine spirit and the dressing should be changed at least once a week.

Baths

- Do not remove the dressing before bathing.
- Patients should sit in a shallow (waist deep) bath and not submerge or soak in the bath as the water will not remain clean for long.
- CVL bungs must be taped up to prevent them dangling in the water.
- Remove the dressing after bathing
- Exit site should be dried with clean gauze (not a bath towel or flannel) and a new dressing put on.
- The CVL exit site should be cleaned weekly with 2% chlorhexidine spirit and the dressing

should be changed at least once a week.

Important CVL information

It is very important to prevent infection of the central venous line as this may mean it needs to be removed. **If you notice any redness, discharge or swelling around the central line exit site, the route of the line under the skin, or if the line appears to have moved, please contact the Oncology/Haematology Day Care Unit (in working hours), the Oncology/Haematology inpatient unit (out of hours) or your Shared Care Unit because there may be an infection.**

How to prevent Infection

- Never leave the dressing wet as this can encourage the growth of bacteria.
- Ensure the bung is well secured. If the needleless device (bung) falls off, wash your hands well, clean the end of the central venous line with a sterile alcohol swab for 30 seconds and screw on a new bung.
- Don't allow the ends of the central venous line to dangle down by the nappy/groin area.
- Make sure the clamps are always closed.

Accidental removal

If the central venous line should accidentally fall out or be pulled out:

- Do not panic. Bleeding is unlikely to occur as the hole seals up quickly so there is no immediate danger.
- Cover the site immediately with sterile gauze and press firmly for a few minutes.
- **Contact Oncology/Haematology Day Care (in working hours), Oncology/Haematology inpatient unit (out of hours) or your Shared Care Unit** who will advise if you need to come to the hospital to check that the site is alright. A stitch or a new line may be required.

How to prevent accidental removal

To prevent accidental removal, always ensure that the central venous line is fully secured and taped to the chest using a 'Wilbur holder'. The line should also be tucked up when not in use.

Breakage

If the central venous line should accidentally get cut or split:

- Immediately clamp the part of the line going into the chest above the cut.
- Wrap the open end in sterile gauze.
- **Contact Oncology/Haematology Day Care (in working hours), Oncology/Haematology inpatient unit (out of hours) or your Shared Care Unit** who will advise if you need to come to hospital.

How to prevent breakage

- Never use scissors anywhere near the central venous line.
- Young patients should be discouraged from biting and pulling at the line.
- If your child is wearing a vest it will help to prevent too much fiddling with the line.
- Do not let pets that nibble near the central venous line.

Blockage

Occasionally a central venous line can become blocked and cannot be used. If a blockage does occur, please contact our Ward or Shared Care Unit for advice. We may advise you to come to the hospital.

A nurse or doctor can inject a medication into the line which will usually dissolve the clot causing the blockage. If the line is completely blocked X-rays and/or scans will be taken if the line is completely blocked.

How to prevent blockages

- Make sure that the central venous line is flushed weekly.
- Always check that the clamp is closed after the line has been flushed and when not in use.

Oral hygiene

Oral health can be affected by treatment so it is necessary that our patients and their families understand the importance of caring for their mouth and teeth.

The effect of cancer treatments on the mouth

Some chemotherapy can cause neutropenia, (when the body's immune system is unable to fight infection.) This will happen seven to fourteen days following treatment when white blood cells, made in the bone marrow, are temporarily reduced in numbers.

During this time, the mouth will be more susceptible to infections as there are fewer cells able to protect the body. When the blood count is low, there is a possibility of bleeding from the mouth and gums.

Some medications directly affect the lining of the mouth by interrupting the growth of healthy cells. This usually happens around seven days following treatment when new cells are not available to replace the cells damaged or killed by the treatment. This may cause the lining of the mouth to become fragile, tender, and ulcerated.

Radiotherapy to the head and neck region will always cause soreness of the mouth. This usually occurs five to ten days after the start of treatment. The areas particularly affected

are the soft palate (roof of the mouth), sides of the tongue and the floor of the mouth.

Saliva helps to keep the mouth clean by washing food particles off the teeth, this then helps to reduce the amount of bacteria in the mouth, saliva also helps to neutralise the acids that cause tooth decay. There may be a reduction or absence of saliva (spit) especially if radiotherapy is directed at the parotid gland in the cheek.

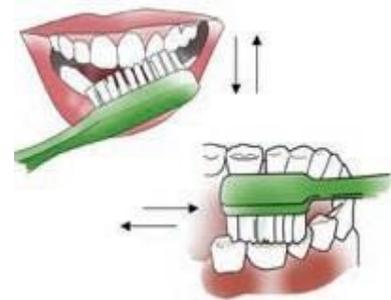
These side effects depend on which particular treatment agent is used and which areas of the body receive irradiation; our staff will advise you when mucositis (sore mouth) is a risk.

Mouth care will not always prevent these side effects but will reduce problems such as; pain and discomfort, insufficient food and fluid in-take, omission of oral medication and an increased risk of secondary infection.

Dental hygiene

Regular brushing of the teeth helps to prevent inflammation of the gums (gingivitis), infection and tooth decay. It is really important that patients (and their families) brush and clean their mouth effectively.

All patients will have their teeth assessed by our dentist on diagnosis. Any urgent dental treatment will take place in Alder Hey's Dental Department, either before or early on into treatment. During chemotherapy, any dental treatment that is needed will also be carried out by the Hospital Dentist. Any orthodontic work is usually postponed until the end of treatment. Any possible long-term effect on the teeth can be discussed with the Dental Team.



Remember to tell your local dentist of your child's diagnosis and cancel any outstanding appointments.

Assessing the mouth

Most deterioration of the mouth occurs while patients are at home. It is important that patients assess their mouth daily to check that it's pink, moist, clean and free from infection.

The mouth should also be assessed daily using the **B.R.U.S.H.I.N.G** technique;

Bleeding	From gum and teeth margins or infected areas
Redness	Around gum and tongue areas
Ulcers	Inside the mouth or on the lips (cold sores)
Saliva	Too much or too little saliva
Halitosis	Bad breath
Infection	White patches on the roof of the mouth or inner cheek

None Unable or refuses to clean teeth

Gingivitis Swollen and shiny gums

If any of these problems occur **please contact Oncology/Haematology Day Care (in working hours), Oncology/Haematology inpatients (out of hours) or your local Shared Care Unit.**

Common oral problems encountered at home

- Vomiting – if vomiting occurs it is important to rinse the mouth as soon as possible using ordinary tap water. This will remove any debris and will help freshen the mouth.
- Bleeding – mostly occurs around the teeth or gum margins and in any ulcerated areas especially if the platelet count is low. This bleeding may occur spontaneously, during brushing of the teeth or after the loss of a tooth. **Please contact Oncology/Haematology Day Care (in working hours), Oncology/Haematology inpatient unit (out of hours) or your local Shared Care Unit** for advice if any bleeding occurs.
- Infection – Infection can occur when white blood cell count is low (neutropenia). Sometimes oral thrush (creamy white raised areas) can be found on the inner cheeks, tongue or the soft palate. **Please contact Oncology/Haematology Day Care (in working hours), Oncology/Haematology inpatient unit (out of hours) or your local Shared Care Unit** if you suspect thrush in the mouth.
- Mouth ulcers – can occur as early as 5 days after chemotherapy or radiotherapy. If your child is in pain or is unable to eat and drink **please contact Oncology/Haematology Day Care (in working hours), Oncology/Haematology inpatients (out of hours) or your local Shared Care Unit** for advice.
- Cold sores – caused by a virus which may appear during a neutropenic episode. **Please contact Oncology/Haematology Day Care (in working hours), Oncology/Haematology inpatients (out of hours) or your local Shared Care Unit** for advice if needed.

Nutrition

Eating well during treatment is really important as this helps children cope better with their treatment, fight infection and maintain normal growth and development. A sore mouth can make it difficult for your child to eat enough to maintain their weight and to drink enough fluid.

If there is a problem with eating or drinking our dietician can provide help and support as per information on page 24.

Some useful tips include;

- Ask your doctor or nurse about mouth sprays or mouthwashes.
- Rough or sticky foods like crisps, crispbread, peanut butter may be hard to eat. Choose soft food like shepherd's pie or creamy pasta.
- Add extra sauces and gravy on to food.
- If the mouth is very sore you may need to blend foods or soups.

- Avoid very hot food or drinks. Warm, cool or frozen may be easier to manage.
- Try to have yoghurts, mousses and milky puddings as snacks.
- Avoid salty, acidic and spicy foods such as citrus fruits, vinegar and chillies as these will sting the mouth.
- Try using a smaller spoon when eating and a straw when drinking, this will help reduce contact with the sore part of the mouth.
- Ask to see the dietician about suitable high calorie supplement drinks.

Additional nutritional support

Patients who are going to have treatment which is likely to cause severe mucositis may be offered a gastrostomy tube before their treatment starts. A gastrostomy tube is a feeding tube which is surgically placed directly into your child's stomach. It is used to give extra fluids and special feed which contains the right amount of calories, protein, vitamins and minerals for your child.

Some children who do not have a gastrostomy tube may need nasogastric tube feeding if they are not able to eat or drink enough. A nasogastric tube is a thin, soft tube that goes down the nose and into the stomach.

Occasionally it is necessary to give intravenous nutrition. This is a specialist form of nutrition which is given via a central line and requires an inpatient stay.

Medication

Medication may need to be taken at home. Please make sure that you understand all the information about the medicine e.g. correct dosage, the time of day and number of days it should be taken, expiry date. Instructions will be on the labels of any medication containers we give to you.

Please check whether the medicine needs to be kept in the fridge or in a cupboard at room temperature. All medicines should be kept out of the reach and sight of children, preferably in a locked cupboard if stored at room temperature.

If the medicine looks different from the usual prescription do not use and contact the ward for advice.

If you have any questions about medicines, please telephone **Oncology/Haematology Day Care (in working hours), Oncology/Haematology inpatients (out of hours)** or your Shared Care Unit. It is very important that the course of prescribed medicine is given correctly.

Clinical trial medication

Some medications are known as Investigational Medicinal Products (IMPs) and have to be easily identified. Our pharmacy staff will attach clinical trial labels to all bottles of IMPs.

IMPs are dispensed specially for patients and the Oncology/Haematology Unit does not keep stocks of these medications. The Shared Care Unit will not be able to obtain the IMPs for you. **Please make sure you bring all medicines into hospital with you.**

Safe handling and administration of systemic anti- cancer medication

Some anti-cancer medicines can be taken by mouth as tablets or liquids. Instructions will be on the label. If you are not sure what the label means please ask the doctor, pharmacist or nurse.

Where available you will be provided with a patient information leaflet for the medication.

The medication may have a short expiry so please check on the label.

If the medicine looks different from the usual prescription do not use and contact the ward for advice.

You will also be given an **oral chemotherapy record**. The record contains contact details for specialist information and advice and the name of the patient's consultant. The record will also indicate the treatment plan: the name of the treatment regimen, stage of protocol, blood count results, oral chemotherapy and any other anti-cancer medications prescribed including duration of treatment. The oral chemotherapy record must be brought to each hospital visit and shown to any doctor, nurse, pharmacist or health professional who is giving care or advice.

It is very important that anti-cancer medications are taken regularly on the days specified. **If a dose is missed for any reason, do not give a double dose, please contact Oncology/Haematology Day Care (in working hours) or Oncology/Haematology inpatients (out of hours) for advice.** Do not give them another dose without informing the doctor or nurse

If your child vomits after taking the dose, **please contact Oncology/Haematology Day Care (in working hours) or Oncology/Haematology inpatient unit (out of hours) for advice.** Do not give them another dose without informing the doctor or nurse.

Storage

Keep all medication out of reach and sight of children. If storage in a fridge is recommended on the label, place the medicine bottle upright on the bottom shelf or where it will not easily be knocked over. It should preferably be kept in a plastic storage box away from food. Medicines that need to be stored at room temperature should be kept in a cupboard that cannot be easily reached by young children.

Precautions handling cytotoxic medication

Cytotoxic chemotherapy medication is toxic to cells. Cytotoxic medications are used to kill or damage abnormal cancer cells. They can also damage healthy cells so safe handling is required in order to minimise the risk.

NB: Other anti-cancer medicines used to treat cancer may not require all the safe handling requirements required for cytotoxic chemotherapy but where information is limited you may be advised to handle the medication in the same way.

1. It is recommended that any woman who is pregnant, thinks she is pregnant or is breast feeding does not handle cytotoxic medication.
2. Always handle cytotoxic medication with care.
3. Avoid touching cytotoxic tablets, capsules or medicines when giving a dose.
4. An oral syringe will be provided by pharmacy to measure each liquid dose.
5. Anyone who is likely to come into contact with the cytotoxic medicine should wear disposable gloves.
6. Do not crush or open capsules.
7. Always wash your hands thoroughly before and after giving treatment or handling any spillage.

Spillages

Clean up any spillage immediately following the details below. **Always wear a pair of disposable gloves.**

Skin – Put on gloves. The affected area should be washed immediately with plenty of soap and water. If there are any adverse effects to the skin, please contact the ward for advice.

Eyes – Put on gloves. The eyes should immediately be washed with plenty of water. If the patient experiences any adverse effects to the eyes please contact the ward for advice.

Work surface/floor – Put on gloves. The spillage should be covered using absorbent paper towel. Wipe the area clean then wash with soap and water. Used paper towel, gloves and other items used to clean the spillage should be double bagged and disposed of with the household waste

Clothing – Put on disposable gloves and blot dry the spillages with paper towel. Clothing should be changed. The soiled items should be put through the machine wash cycle twice, without removing the items from the drum after the first wash. Soiled clothing should be washed separately to other items. Used paper towel, gloves and other items used to clean the spillage should be double bagged and disposed of with the household waste.

Disposal of equipment/bodily fluids

Equipment

- Sharps (needles, ampoules and vials), syringes and other dry waste (including gloves) used for injectable cytotoxic medication preparation and administration must be discarded in a cytotoxic 'sharps bin'. When not in use, the 'sharps bin' must be closed (but not sealed) and stored out of the reach of children.
- When the cytotoxic sharps bin is two thirds full, it should be sealed and returned to the clinic or ward that provided it at the next hospital visit.
- Unused cytotoxic medications for injection should be placed in the plastic bag provided and returned to the clinic or ward of issue for disposal. Syringes of cytotoxic medications for injection, which have been only partially used but not given for some reason, should be discarded in the cytotoxic sharps bin immediately.
- Empty cytotoxic tablet bottles can be discarded in the household waste. If on a clinical trial the empty container may need to be returned to the hospital - you will be told if this is required. Empty medicine bottles, medicine pots, syringes/medicine spoons used for oral cytotoxic drug administration should be discarded in the cytotoxic sharps bin. Cytotoxic tablets and medicine bottles which have not been given should be returned to the hospital pharmacy for disposal.

Sharps Bins

- Sharps bins must be locked when bringing them back to the Oncology/Haematology Unit or your Shared Care Unit. If you are unsure how to do this, please ask a member of staff for assistance.

Bodily fluids

- Cytotoxic medications are passed out of the body in urine, stools (poo) and vomit. The time period for medication excretion varies with individual medications but can be as long as seven days. Disposable gloves, cytotoxic sharps bins and vomit bowls are all available from the Oncology/Haematology Unit or the Shared Care Unit. Extra care should be taken if pregnant or breast feeding.
- Wear disposable gloves when handling urine, stools, vomit, contaminated bed linen and nappies for seven days following cytotoxic treatment.
- Gloves should be changed immediately if torn or contaminated.

- Nappies, empty vomit bowls and gloves should be double bagged and disposed of in the household waste. The contents of the vomit bowl should be flushed down the toilet.
- Any soiled bedding should be put through the machine wash cycle twice, without removing the items from the drum after the first wash. Soiled bedding should be washed separately to other items.
- Barrier creams should be applied liberally to children in nappies to protect their skin from contaminated urine and stools.
- Children out of nappies should be taught good toilet hygiene.
- Wash your hands with soap and water after handling cytotoxic medicines and waste.

Education (Nursery/school/college)

Education is very important for all children and young people as it represents a “normal life” and provides an opportunity to socialise with peers. Attending nursery/school/college will help reduce the sense of isolation which can sometimes become part of illness and hospitalisation. There may be concerns about how others react to a patient’s illness and treatment. Helping school friends understand what is wrong with the patient can encourage them to become more supportive.

With parents’ permission our Paediatric Oncology Outreach Nurses will be happy to share any necessary information with your child’s teachers and classmates shortly after diagnosis.

We encourage patients to attend nursery/school/college as much as possible during treatment, however there may be times when attendance is not possible. This will be discussed with you in detail by your Paediatric Oncology Outreach Nurse.

Nursery/schools/college will need to inform you immediately if either chickenpox or measles is reported.

All in-patients will be able to access ward schooling daily during term time.

Immunisations

Vaccinations may be problematic during (and shortly after) treatment for 2 different reasons;

- Live vaccine may be harmful (MMR, rotavirus and the live intranasal flu vaccine). These should be avoided during treatment and for up to 6 months afterwards (1 year from bone marrow or stem cell transplant).

- Vaccines may be ineffective if the immune system is sufficiently suppressed. Routine non-live vaccines can be administered when due during chemotherapy treatment provided the patient is not on steroids or neutropenic (or about to be) at the time.

Please discuss this with the treating team.

We do recommend your child receive the inactivated flu vaccine (intra muscular) from your GP during treatment and in the winter following treatment. School age brothers and sisters may receive the intra nasal vaccine, other household members should also receive the intra muscular inactivated vaccine. We suggest any immunisations that are missed during chemotherapy and boosters of previous immunisations can be given by your GP or practice nurse around 6 months from the end of your child's treatment. This will be discussed with you during a clinic appointment and we will send a schedule of the vaccinations required to you and your GP practice.

Siblings should continue to have all of their routine childhood immunisations, it is safe for patients to stay in contact with them.

ADDITIONAL INFORMATION

Important – Pregnancy testing before cancer treatment

Cancer treatments which may include chemotherapy, radiotherapy, surgery, scans and x-rays may harm an unborn baby. The treatment prescribed is very important for the management of cancer. It is very important that we know, before treatment is given, if there is any chance of pregnancy in our patients.

We understand that many girls/young women are not having sex, so it is not possible for them to be pregnant. We do not know who is and who isn't sexually active, and many girls may not want to tell us if they are. By doing a pregnancy test we hope to prevent harm to any unborn baby.

Some pharmaceutical manufacturers now state that a pregnancy test must be performed before giving treatment to any female of childbearing age.

All female patients aged 12 years or over (who have started their periods) attending Alder Hey for chemotherapy will be asked to provide a sample of urine for a pregnancy test. Testing will be repeated each month until the chemotherapy treatment has been completed. For further information, leaflets (for parents/carers and patients) are available on the unit.

Similarly, if a mother/carer is pregnant please discuss this with the ward staff. We can be generally reassuring, however there may be some situations to avoid.

Important - Testicle examination and self-examining

In children and young men some types of leukaemia or lymphoma can present or relapse in the testicles. This is because the testicles are protected by a natural barrier and most chemotherapy medicines don't get to this part of the body. It is important to pick up any testicular disease early as it can be harder to treat if diagnosed late. If leukaemia or lymphoma is in the testicle it presents usually with an enlarged testis or a firm lump and no other symptoms. We realise it can be embarrassing but it is very important that the doctors/ANP's caring for your child examine their testicles.

Young boy's parents are encouraged to be present during the examination and to learn what to look for. Teenagers and young men may prefer their parents not to be there and a chaperone will be provided. The examination is quick and lasts around one minute.

Doctors and ANP's will focus this examination at times of diagnosis, the maintenance part of treatment and the first two years off treatment to check for any suspicion of a relapse. Self-checking should continue after this time.

All teenagers and young adults are recommended to check their testicles once a month. It is important for patients and parents of younger boys to learn how to check the testicles. This is something that can be learnt when being examined in clinic.

Transport

If transport to hospital is needed for medical reasons Ward Clerks can arrange this. If you require transport, please tell our Ward Clerks 48 hours in advance of when it is needed so they have time to arrange transport. If you need help with travel expenses, please ask the nursing staff for details.

Holidays

We all look forward to holidays, but it is very important not to book any holidays without first speaking to your child's Consultant. Holidays overseas are not generally advised whilst your child is on treatment. Holidays taken in the UK are generally possible, but we ask that you discuss possible plans. If the Consultant agrees it is safe to go on holiday whilst still on treatment, a member of the team will need to liaise with the hospital local to the area you are visiting. You will need to have a letter to take with you in case of any medical issues whilst you are away. Please speak to your Alder Hey/Shared Care Unit key worker, as this letter will be required if you need to visit a hospital whilst on holiday.

Holiday insurance cover

Your Paediatric Oncology Outreach Nurse or Young Lives vs. Cancer social worker will be able to advise you on holiday insurance which includes medical cover. As part of this you may need to telephone a medical screening line and give details of medicines your child is on. (It will be useful to list all medicines before you ring). Information is also available on www.cancerbackup.org.uk.

The NHS website has information on the new Global Health Insurance Card (GHIC), which replaces the existing European Health Insurance Card (EHIC) www.nhs.uk/travel/insurance.

Swimming

If your child has a CVL inserted then they should not go swimming. Your child is allowed to go swimming if they have a port-a-cath unless the gripper needle is in place.

Building work

If you are or intend to do any significant building work at home, please discuss with your consultant or key worker. The dust created during building work increases the risk of your child developing a potentially serious fungal infection.

Skin care and sun

It is important to have some exposure to sunlight to ensure an adequate level of Vitamin D. Vitamin D is often called the 'sunshine' vitamin, because your body makes it when you spend time in the sun. Vitamin D has a role in bone health, energy, wellbeing and likely has a role in immunity. Deficiency of this vitamin is common and vitamin D levels are analysed on all new patients starting treatment, with replacement being offered if required.

It is however, very important to remain covered or wear sun block in strong sunlight. Some chemotherapy agents (and anti-fungal medicines) can make skin more sensitive to sunlight, during and after treatment. They may also cause skin to become dry or slightly discoloured. Any rashes should be reported to the doctor/nurse. You may notice nails grow more slowly and notice white lines appearing across them. Sun cream with a high protection factor should be used when the patient is out in the warm weather/sun.

Sun beds should not be used at any time as they have been shown to cause cancer.

Body piercing & tattoos

There is a risk that any new body piercing (ears, belly button etc.) could become infected whilst the blood count is low. Therefore we advise not to have any new piercings or tattoos whilst on treatment. Please speak to your doctor in clinic if you have any questions.

Pets

Owning a pet is a very rewarding and can help you feel much happier. For many people pets are a part of the family. Most children with cancer can and should keep their pets. However, it is important to be aware of the risks of owning and caring for a pet. It is recommended that you do not get any new pets until after treatment has finished. However if you choose to have a new pet we advise you not to get a young pet (puppy, kitten) but an older pet.

If you are thinking of getting a new pet please discuss with your child's Consultant. There is a fact sheet available called Children with Cancer and Pets. Please ask a member of staff for a copy.

END OF TREATMENT & LATE EFFECTS

When patients have completed all their treatment, they will continue to have clinic appointments and any necessary surveillance test. We recognise this is a period of uncertainty and anxiety for many patients and families. Our psychologists are able to provide support during this time period. Patients will receive an end of treatment summary. This provides details of the diagnosis, treatment and on-going management care plan. It includes information on the symptoms to be aware of, the potential late effects, and who to contact. Your GP will also receive a copy of this summary.

Once patients have finished the surveillance period following treatment, they will be transferred to the After Cure Service within Alder Hey or Aintree depending on their age. The clinical lead for this service is Dr Hayden and this service is led by Associate Nurse Specialists Susan Otten and Antonia Derbyshire.

The late effects following treatment for cancer can be varied and your treatment summary will outline any that you will be at risk of. Health promotion forms an important part of after cure, helping children and young people make healthy decisions regarding diet and exercise as well as not smoking, being careful with alcohol and taking precautions to avoid sun damage, boys are also encouraged to get into the habit of checking their testicles for any lumps or swellings.

SUPPORT GROUPS

Children's Cancer and Leukaemia Group (CCLG)

www.cclg.org.uk



The CCLG supplies lots of useful and in depth information available in printed form on ward 3B and also on their website. The website also has links to other useful organisations. They publish a magazine called CONTACT, for families of children and young people with cancer. Copies of this magazine are available from our Ward also

Children Cancer Support Group (CHICS)

www.chicsonline.org

CHICS is our local support group attached to the Oncology/Haematology unit and has been since 1986. This comprises of 3 branches, Liverpool, Wirral and North Wales and it is run solely by parents that have had a child treated on the unit.

They can provide;

- Support for patients and families.
- Holiday/outings for children and families.
- Caravans for hire.
- Treats and parties.
- Monthly newsletter.



Regular CHICS meetings are held at Alder Hey with a drop in session every Wednesday and Thursday in our Oncology/Haematology outpatients clinic. There are also Teenage Groups which meet every month. To join CHICS please complete the membership form which is available on our Alder Hey Oncology/Haematology website. For more information please call CHICS office 0151 523 8886.

Teenage Cancer Trust

Provides support and activities for 13-24 year olds

www.teenagecancertrust.org

Owen McVeigh Foundation

A charity funded foundation to support children and their families who are suffering from cancer in Merseyside. They work alongside CHICS and aim to provide those special occasions creating life memories for children suffering from cancer.

<https://www.owenmcveighfoundation.co.uk/>



Joshua Tree

A children's cancer support charity founded in 2006 by parents after their son was diagnosed with leukaemia. The team recognise that every family's cancer journey is unique and tailor the service to suit the specific needs of the family by means of emotional and practical support. The support is offered to the whole family to ensure that life remains as normal as possible.

<https://thejoshuatree.org.uk/>



Teens Unite

Provide those aged 13-24 with the social, emotional, and physical support that is vital to their recovery. They can come together with others their age who understand what they're going through, and remember who they are as a person, not just a cancer patient.

<https://www.teensunite.org/>



Maggie's

Provide cancer support and information to those with cancer and to those who care about someone with cancer. Includes Support Specialists, Psychologists and Benefits Advisors. Can be accessed at the Wirral Maggie's Centre and online.



<https://www.maggies.org/our-centres/maggies-wirral/>

INFORMATION CHECKLIST

This is a list of the information and education you will need before discharge. Please confirm by signing that your nurse has explained the information to you. This will be copied and a record kept in the hospital patient notes.

	Date	Staff Signature	Parent Signature
Treatment Plan			
Key Worker Leaflet & Contact Details			
Treatment Side Effects			
Blood Counts			
Temperatures/Febrile Neutropenia			
Thermometer Given			
Paracetamol and Pain Relief			
Line Safety			
Chicken Pox & Measles			
What to do in an Emergency			
Chemotherapy Spillage			
Going Back to Nursery/School/College			
Dietary Advice			
Immunisations			
Travel Advice			
Copy of this Checklist taken by Nurse			

Booklets / Leaflets Given (Please Complete Table Below)
CCLG ; Children and Young People with Cancer: A Parent's Guide
Transfusion Information Pack
If on oral SACT a patient information leaflet

NOTES

Please use this section to write any information you feel relevant to your child's care.

This booklet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this leaflet alone for information about your child's treatment.

This information can be made available in other languages and formats if requested.

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