

Ward 3B Oncology/Haematology

Family Held Record



Information booklet for families

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 booklet alone for information about your child's 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 Centres and at home.

Our staff 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 Ward 3B staff.

Our Philosophy

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 of the highest quality.

Welcome to Oncology/Haematology Ward 3B

Ward 3B Oncology/Haematology at Alder Hey Hospital has a Clinic and Daycare Department, an In-patient area for children aged less than 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.

We currently care for over 120 children and young people with cancer every year. Patients are referred from the Merseyside and Cheshire Cancer Network (MCCN); Alder Hey Hospital is the Principle Treatment Centre for Merseyside, Cheshire Mid Staffordshire, the Isle of Man, and areas outside the North West of England for those patients requiring highly specialised care.

We have a strong commitment to research and excellent record of participation in national and international clinical trials.



Principal Treatment Centre Details

Alder Hey Children's NHS Foundation Trust Oncology/Haematology Ward 3B Contact Numbers

Inpatients/Teenage Cancer Trust :	0151 252 5212
Day Care	0151 293 3694
Clinic Reception	0151 252 5804
Clinical Trials Office	0151 252 5971
Consultant Oncologist/Haematologist	Name:
Consultant Secretary and contact details	Name: Contact Number:
Key Worker	Name: Contact Number:
Unit Manager	Jeanette White 0151-252 5470 Jeanette.White@alderhey.nhs.uk
Ward 3B Manager	Janet Smith 0151-252 5603 Janet.Smith@alderhey.nhs.uk

Other Members of Multidisciplinary team and contact details

Member of Team	Name	Contact Details
Children and Young Person's Oncology Outreach Nurse Specialists (CYPOON)		
CLIC Sargent Social Worker		
Dietitian		
Play Specialist		
Advanced Nurse Practitioner		0151 252 5799
Research Nurses		0151 282 4646 0151 282 4670
Social Worker (other)		
Physiotherapist		
Occupational Therapist		
Youth Support Worker		

Meet the Team

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.

Junior doctors will join and leave the medical team as part of their training.

Nursing Staff

The nurses are specialised in children's nursing and oncology/haematology. The Nursing Team will have number of student nurses who are at various stages of their training.

Every patient is allocated a nurse for each shift who will work several different shifts. Each shift begins with a handover period, this is when the nurses get together to discuss the care of all the patients

Key Workers

All patients are allocated a Key Worker at a multidisciplinary meeting (MDT). A MDT meeting is when staff come together to agree diagnosis and a treatment plan. The Key Worker is a senior nurse or other healthcare professional. The Key Worker will introduce themselves to the patient and their family and will provide their contact details. They stay in regular contact with their patients throughout treatment and arrange additional support nearer to home if it is needed.

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 appointments and plans of care. Patients who come to Alder Hey for chemotherapy attend Day Care or 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 work Monday to Friday and are available to answer queries from patients, families, local hospitals or community staff. Their contact number is 0151 252 5799 they work Monday to Friday 09:00am to 5:00pm.

Children and Young Person's Oncology Outreach Nurse Specialists

The Children and Young Person's Oncology Outreach Nurse Specialists (CYPOONS) are a team of nurses with specialist knowledge and experience in children and young person's cancer. . Every child or young person is allocated a CYPOON who will work closely with them and their family to provide specialist care, advice and support.

There are two CYPOONS teams based at Alder Hey caring for children being treated here.

One team covers the Merseyside and Cheshire area and Isle of Man. The other team works in partnership with local services for patients living outside of the above areas.

CYPOONS contact details

Alder Hey: 0151 252 5408 Monday to Friday 9am – 5pm.
(Answer phone out of normal office hours.)

North Wales Families will be given contact details by their CLIC Nurse.

Dietitians

Dietitians provide expert advice and information about diet and growth. Chemotherapy can alter sense of taste and appetite and Dietitians can recommend the best choice of food or alternative nutrition. **Please ask your child's nurse to contact the Dietitian if you have any questions or worries.**

Ward Chefs

Ward 3B has its own kitchen and two chefs to support patients during their stay.

Our Chefs will:

- take orders for food for patients between 11.30am and 6.00pm. The last order for Day Care patients is 3.30pm.
- prepare a meal for one parent or carer on the In-patient Ward. There is a charge for this service.



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

Each day there are snack rounds for patients on the ward. Patients on supplements can receive a feed or supplement and other patients are offered a drink (juice, milkshake) and fruit or a biscuit.

There is fruit and vegetable stall located outside of the entrance by the W.H. Smith shop and is available Monday - Friday until around 3pm.

CLIC Sargent

CLIC Sargent is the UK's leading cancer charity for children, young people, and their families. They provide practical and emotional support to help them 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. CLIC Sargent Social workers do not meet with families until a definite diagnosis has been made. CLIC Sargent Social Workers tailor their support 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 provided by CLIC Sargent and other partner organisations.
- 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.

Teenage Cancer Trust Youth Support Co-ordinator

The Youth Support Co-ordinator works with patients who are aged 13 and over when diagnosed or whilst on treatment - and for up to two years off-treatment.

The Youth Support co-ordinator will:

- provide activities and one-to-one support on Ward 3B,
- support the monthly peer support group,

- organise and assist with many residential opportunities,
- offer opportunities for teenagers and young adults to get involved in shaping our services.

Young People's Social Work Team – Merseyside & Cheshire

This service provides an outreach service for young people diagnosed with cancer who are aged 16 to 24 and are treated in Liverpool and Merseyside adult's hospitals. They provide support to young people who are aged 18 at diagnosis and treated at Alder Hey as part of the Teenage and Young Adult's Merseyside & Cheshire Multi-disciplinary team.

Ward 3B 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 effect 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 multi-disciplinary team 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 -5:00pm 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 a new concept being introduced in Alder Hey and other hospitals in 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.



Further Support

Clinical Psychologists

Clinical Psychologists are trained in various forms of therapy for adults and children. They do not use medication but use talking and play to try to understand and work with children and their families. When someone faces a very serious illness and lengthy, difficult treatment, brothers and sisters, parents, family and friends all experience very powerful emotions. This, of course, is normal in the circumstances.

Sometimes it can be particularly difficult and stressful for family members and our nurses may suggest they see one of our Clinical Psychologists. Clinical Psychologists are prepared to answer any questions and can support other members of the medical team in their work. Please ask a member of the team if you would like a referral to this service.

Physiotherapist

Physiotherapists work closely with other members of the units teams and help and advise on treatment. They can provide a specially designed exercise activity programme and, when appropriate, refer onto the Community Physiotherapy Team.

Why research is Important

Many medical improvements in the treatment of children's cancers happen because families were willing to take part in research. Without research we cannot develop better cures and better ways of caring.

We may ask families if they would be willing to take part in a clinical trial as part of our research. Patients and families are under no obligation to take part in a clinical trial if they do not wish to.

Some staff work specifically in clinical trials:

- **Clinical Trial Pharmacist**

Treatments given as part of a clinical trial are carefully controlled. Pharmacists' responsibilities include making sure clinical trial medicine is stored and dispensed correctly and in line with strict policies and guidelines. Pharmacists advise other health professionals on the correct use and storage of medication.

- **Research Nurses**

Research nurses work closely with doctors and other members of the team to ensure the smooth running of the clinical trial. Please ask our Research Nurses any questions you may have about clinical trials.

The need for accurate recording and processing of patient data is fundamental to any clinical trial. We have a team of Data Managers and Clinical Trial Co-ordinators who ensure all information collected is accurate.

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.

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, the Oncology/Haematology Doctors, Radiologists, Surgeons, Pathologists, Radiotherapists, Specialist Nurses and Pharmacists.

A "Multidisciplinary Team" meeting (MDT) takes place to discuss all the relevant results. There are different MDT meetings depending on what the patient's diagnosis is. These meetings take place every week to ensure the team are in agreement regarding the diagnosis and treatment plan for each patient.

Before any patient has chemotherapy treatment, it's important that we check their blood count. A sample of the patient's blood is taken and sent to the laboratory. These bloods are then checked to make sure that they are at a level high enough for treatment to go ahead. If the blood count is too low, having more treatment could make it lower and could cause further sickness to be experienced.

If chemotherapy treatment has been agreed and the blood count is OK, there may be a delay whilst chemotherapy is prepared. This is because chemotherapy drugs are made especially for each patient and this takes time. You may find it helpful to bring something with you to help pass the time. If the blood count is not OK, treatment will have to be delayed and patients will be given another appointment to have another blood test.

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 drug 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 Ward 3B.

Oncology/Haematology Day Care Ward and Outpatient Clinics

Our Oncology/Haematology Day Care Ward and Clinics are based on the third floor of the hospital (Ward 3B)

- **Day Care Ward**

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.

As well as a small number of beds, Day Care also has chairs for children who do not need a bed, such as those who are having a kidney test or blood transfusion. Day Case treatment for teenagers is given in the Teenage Cancer Trust (TCT) Unit.

Chemotherapy in Day Care

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, as other patients who have arrived on time may be seen first. If you are running late please ring Day Care to advise of the delay.

Please ring Day Care on 0151 293 3684 if you think you will be late for your appointment.

Children having chemotherapy or going to theatre for Lumbar Puncture and Bone Marrow must have blood tests 48 hours before admission.

For blood tests (finger pricks) at Alder Hey Hospital please ring 0151 293 3684 for an appointment.

Blood tests at a Shared Care Centre are arranged in agreement with your child's Consultant. Please check with a member of our team if you are unsure if a blood test is needed.

Blood tests needed before chemotherapy are:

- Full Blood Count.
- Oncology Profile

Test results will then be phoned through to Ward 3B and our Pharmacist will prepare the chemotherapy in time for your child's appointment.

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.

Unwell Patients and out of hours access to Ward 3B

Between the hours of 8:30am and 5:00pm Monday to Friday all patients will be assessed in Ward 3B Day Care. Please phone Day Care for advice on: 0151 293 3684 first before bringing your child to the hospital, the nurses can then advise you on what you need to do.

All patients who are unwell between the hours of 5:00pm and 8:30am will be assessed and reviewed by the Emergency Department staff before being admitted to the inpatient wards. **Please ring Ward 3B if your child is unwell on 0151 252 5212.** The nursing staff will then advise and make an assessment over the phone of your child by asking specific questions, they will advise you whether you need to attend Alder Hey or your Shared Care Hospital. They will also inform the Accident & Emergency Department and that you are coming in. If you have been advised to attend Alder Hey please report to the Accident & Emergency Department Reception on the ground floor of the hospital.

Please note there is drop off car parking outside the Accident & Emergency Department. Please show the Receptionist your child's **ALERT CARD** which informs them of your child's name, hospital number and that they are an Oncology/Haematology patient. You will then be directed to a cubicle where your child will be assessed by the Triage Nurse. If you do not have an Alert Card please ask nursing staff on the inpatient or Day Care Ward to give you one.

Transport

If transport 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.

Sharps Bins

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

Outpatient (Clinic)

We ask that you always report to our Receptionist when arriving for an appointment.

All patients going to theatre on Wednesday or Thursday should be booked in at reception at their allocated time slot. Patients who are going to theatre will be seen first. Occasionally, clinics will run late and we will try our best to keep patients and their families informed if there are delays.

Patients attending the Tuesday Bone Marrow Transplant Clinics should report to reception before having any bloods taken. A doctor or nurse will advise if blood tests are needed.

Oncology/Haematology Clinics

Monday Morning

- **Advanced Nurse Practitioner**
After Cure Clinic. This clinic is for patients who have completed treatment.
9:00am-1:00pm

Monday Afternoon

- **Consultant Paediatric Oncologists**
This clinic is for patients who have undergone or who are having treatment for a solid tumour. It may be necessary for them to have blood tests an X-ray or scan. If this is the case, patients should attend the Radiography Department before coming to Ward 3B.
Clinic Time: 1:30pm-4:30pm

Alternate Tuesday Mornings

- **Consultant Haematologist /Specialist Registrar in Haematology/Bone Marrow Transplant (BMT) Nurse**
This clinic is for patients who have had, or who are going to have, a Bone Marrow Transplant.
Clinic Time: 9:00am -12.00 midday

Tuesday Morning

- **Consultants/Associate Specialists/ Advanced Nurse Practitioners/Specialist Registrar in Oncology/Haematology**
This is for patients who are having or have finished treatment. There is no theatre schedule for this day.

There is also an After Cure Clinic once a month on a Tuesday morning
Clinic Time: 9:00am -12:00 midday

Tuesday Afternoon

- **Consultant Paediatric Oncologists**

This clinic is for patients with brain tumours. Patients should attend any booked scans before coming to Ward 3B. The Neuro (Brain) Surgeon, Radiotherapist and a Macmillan Nurse will be in this clinic.

Clinic Time: 1.30pm –4:30pm

Tuesday afternoon

- **Consultant Endocrinologists**

This clinic is for patients needing endocrine (hormone treatment) follow-up.

Clinic Time: 2:00pm –4:30pm

Wednesday and Thursday Morning

- **Consultants/Associate Specialists/Advanced Nurse Practitioners/Specialist Registrar in Oncology**

These Leukaemia Clinics are usually very busy so please arrive promptly for your appointment. Patients who need to go to theatre for a Lumbar Puncture (LP) or a Bone Marrow Test will be seen on these days.

Patients going to theatre must have nothing to eat or drink beforehand ('nil by mouth') See below for further information.

Clinic Time: 8:30am -12:00midday

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.

If your child has food or drink before going to theatre it is vital that you inform either a nurse or doctor.

If you are unable to keep an appointment please contact the Oncology/Haematology Clinic as soon as possible on 0151 252 5804

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 a firm lump and no other symptoms. We realise it can be embarrassing but it is very important that the doctors and 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 men 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.

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 by using the right resources at the right time. This means that any care that can be given closer to a patient’s home will be provided there. Shared care will usually involve the Principal Treatment Centre (Alder Hey), the Paediatric Oncology Shared Care Unit (POSCU) based at a District General Hospital, Children’s Community Team and the family GP.

Many Oncology Centres across the UK are developing shared care as there are many benefits for the centres and their patients.

Swabs

Why we need to take swabs?

We all have bacteria (bugs or germs) living harmlessly on our skin and in our intestines (gut). Patients on chemotherapy are particularly prone to develop overgrowth of certain bugs in their throat and gut. These bugs can cross over from the gut into the blood stream and cause an infection (septicaemia). Some of these bugs can cause life threatening infections. It is very important to know what bugs are being carried by patients, which is why we sometimes need to take swabs.

What is involved?

We may take a stool (poo) sample or a swab from the rectum (also called a bottom swab). By identifying the bad bacteria in the gut we can start to give medicines and antibiotics to get rid of them.

How We Take Samples and Swabs

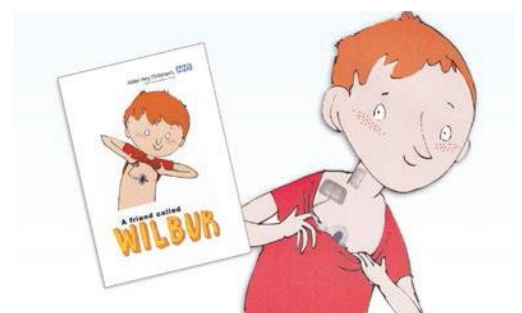
- **Stool sample**
Patients are given a specimen pot and - using a little spade which is provided in the pot – they can put a sample of poo into the pot and then secure the lid back on the pot.
- **Rectal/Bottom Swab**
Using a cotton swab, patients may be asked to gently put the tip of swab in their bottom. A little bit of poo staining on the swab is all we need. The cotton swab then goes back into the plastic tube and the lid is replaced.

What Happens to the Swabs?

Swabs are sent to our Microbiology Laboratory to see if anything grows on them. Microbiology staff and doctors will meet up to discuss any swabs where bugs have been identified. If needed patients will then be prescribed treatment.

Central Venous Lines

Before a central venous line 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 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.

The tip or end of the central venous line 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.

The other end of the central line comes out of the skin on the chest. The line has a "cuff" which lies under the skin and forms scar tissue around it, holding it in place.

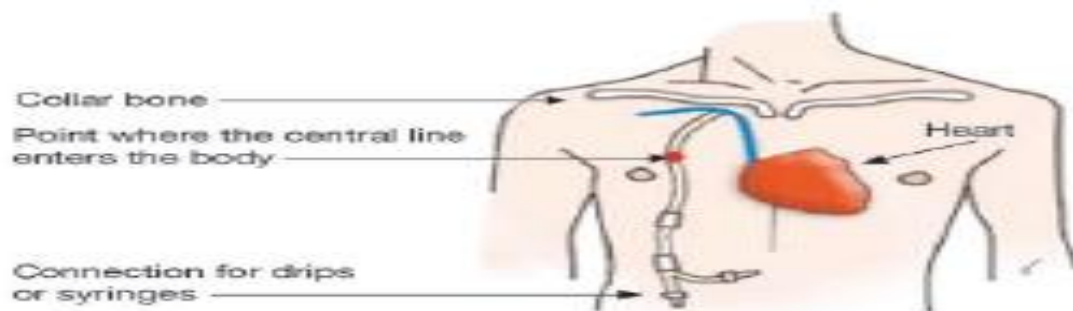


Illustration showing a central line

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 central venous lines which may have one, two or even three tubes (Bungs) 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 Centre 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.

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.

Bathing and showering guidelines

If the central venous line dressing gets wet, please follow the guidelines below. If you are worried at all about the line please contact Ward 3B or your Shared Care Centre.

- **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. Central venous line 'bungs' must be taped up to prevent them dangling in the water.

Remove the dressing after bathing.

The exit site should be dried with clean gauze (not a bath towel or flannel) and a new dressing put on. The central venous line exit site should be cleaned weekly with 2% Chlorhexidine spirit and the dressing should be changed at **least once a week**.

- **Showers**

For the first four weeks after insertion the central line exit site should be kept dry.

If the site is well healed and shows no sign 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 from the shower will be adequate. Dry the site with clean gauze (please do not use a bath towel or flannel). Put on a new dressing.

The central line exit site should be cleaned weekly with Chlorhexidine spirit 2% and the dressing changed at least once a week.

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. It 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.

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 portacath can be felt, before the needle is inserted. The Gripper needle goes into the portacath 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.

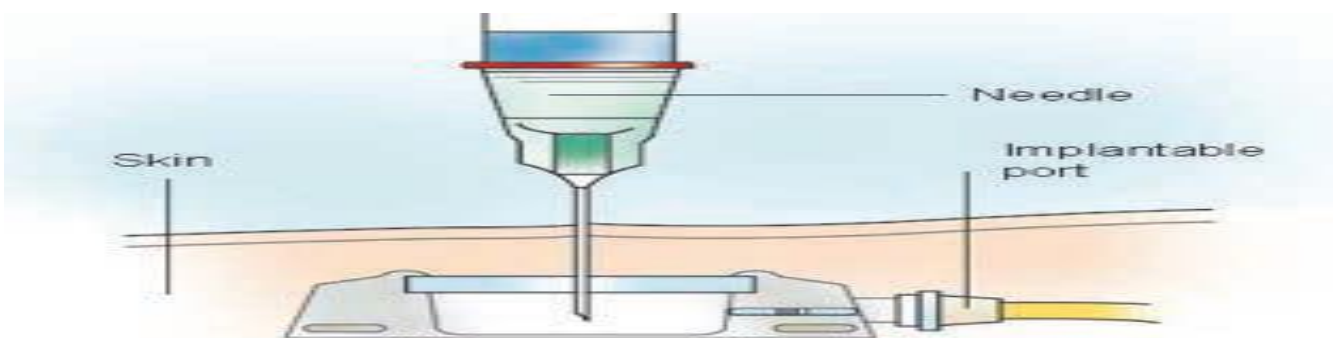


Illustration showing a portacath

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.

What is the Port-a-Cath Used For?

The port-a-cath is used to take blood samples and to give fluids, blood products and chemotherapy.

Extra information

Immunisations and Childhood Diseases

Children who are having chemotherapy treatment have low immunity. This means they are not able to fight infection in the same way as those who have not had chemotherapy.

Vaccinations are made from live bacteria and live viruses. For this reason patients should not receive routine immunisations whilst on treatment. The only exception to this is the Flu vaccine. It is recommended that anyone receiving chemotherapy, as well as any family members living in the same house, should receive the Flu vaccine annually in the autumn. Please discuss this with your child's Consultant before arranging it with your GP.

After Treatment

Any immunisations that are missed during chemotherapy can be given by your GP once your child has finished treatment. This will be discussed with you during a clinic appointment and we will send a schedule of the vaccinations required to your GP practice.

Following a bone marrow transplant, patients may need to wait longer before having their immunisations. Your child's Consultant will discuss which immunisations are required and when they should be given.

Brothers and Sisters

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

Chickenpox

Chickenpox is caused by a virus (Herpes Zoster) which also causes shingles. Chickenpox is spread by droplet infection e.g. breathing, coughing and sneezing. Shingles is spread by touch contact.

Signs and Symptoms of Chickenpox

- **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 or shrivel up to form crusts.

The incubation period can last up to 21 days after contact as chickenpox is infectious until no new blisters appear and the last one dries. The illness usually lasts between five and ten days.

Chickenpox Contact

Any patient who has no immunity to the virus and has had **close contact** with someone who has chickenpox will need medicine to prevent it from developing. Close contact means play or direct contact for more than 15 minutes during the infectious period.

Ward 3B and the Shared Care Centre should be contacted immediately if any patient experiences chickenpox symptoms.

Treatment

The medicine used for treating chickenpox contact is called Aciclovir and may be obtained from your G.P. It can be given as tablets or in liquid form. Patients will need to take Aciclovir medicine for seven days following significant contact with an infected person at school,

playgroup or on holiday. If a sibling or other household member has symptoms, there is a risk of exposure and the medicine will need to be taken for 21 days.

Measles

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

- **Signs and Symptoms of Measles**

Symptoms include:

Fever, runny nose, red eyes (conjunctivitis), cough and later a red rash.

The incubation period lasts until seven to ten days after contact and measles is infectious in the period five days before to four days after a rash appears. The illness usually lasts between five and ten days. A protective medicine to prevent measles from developing may be needed.

Ward 3B must be notified immediately if any patient has had direct contact with someone who develops measles.

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 drugs can cause neutropaenia, (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 drugs 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 chemotherapy drugs.

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 chemotherapy drugs are 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 medications.
- 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.

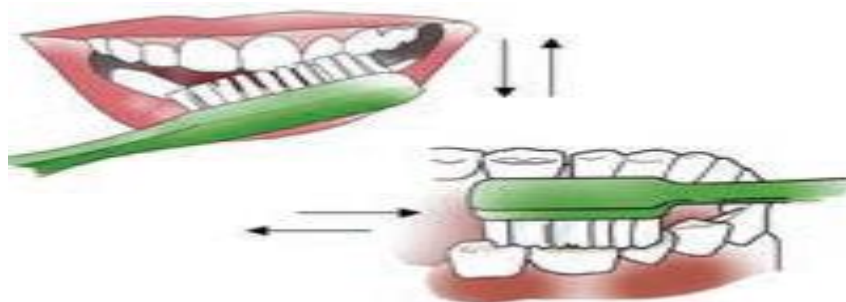


Illustration showing method for brushing teeth

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, which will help to highlight problems:

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, inner cheek.
Non	Unable or refuses to clean teeth.
Gingivitis	Swollen and shiny gums.

If any of the above problems occur, please contact Ward 3B or the Shared Care Centre for advice. It may still be possible for treatment to take place at home.

Oral Hygiene: common 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 to freshen the mouth.
- **Bleeding**
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 Ward 3B or the Shared

Care Centre for advice if any bleeding occurs. Sometimes it may be necessary for patients to be admitted for a platelet transfusion.

- **Infection**

Infection can occur when the white blood cell count is low (neutropaenia). Sometimes oral thrush, (creamy white raised areas) can be found on the inner cheeks, tongue or the soft palate. Please seek advice from Ward 3B or the Shared Care Centre if you suspect thrush in the mouth.

- **Mouth Ulcers**

Mouth ulcers can occur as early as five days after chemotherapy or radiotherapy. Staff on Ward 3B and the Shared Care Centre can offer advice if patients are in pain or are unable to eat and drink.

- **Cold Sores**

Cold sores, which are caused by a virus, may appear during a neutropaenic episode. Please contact Ward 3B or the Shared Care Centre for advice.

Nutrition

A sore mouth will make eating and drinking difficult but it is essential that patients have a good nutritional intake during treatment. If there is a problem with eating or drinking, our Ward dietitian can provide help and support.

Some useful tips include:

- Make meals softer to eat by adding extra gravy or sauce.
- Avoid rough, dry foods like toast or dry biscuits.
- Have plenty of nourishing drinks such as milkshakes.
- Have soft puddings on standby such as egg custard, yogurts and milk jellies.
- Avoid foods that may sting the mouth such as citrus fruit juices.
- Avoid very hot or very cold food and drinks as they may aggravate any soreness.
- A smaller spoon should be used for eating and a straw for drinking.

This will help to avoid contact with the sore part of the mouth.

Sometimes it may be necessary for us to give fluids and nutrition differently. This may be through a tube put into the stomach via the nose, known as naso-gastric feeding. With this method patients can often return home when their parents feel confident giving the feeds.

Alternatively, the central venous line can be used for feeding but this will mean staying for several days in hospital. The Dietitian regularly visits Ward 3B and will be able to advise you further.

Dental Treatment

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.

From hospital to home

Returning home

Going home during treatment can be a worrying time for patients and their families. We will contact Community nurses and other healthcare professionals so there is support once at home. We will provide patients and their families with lots of information to prepare them for the big day. Including details of the staff they should contact in the Shared Care Centre

Our patients will return to hospital regularly for further treatment or for check-ups as an inpatient, an outpatient to clinic or Day care.

Please be sure you have your next appointment date before you leave.

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 aural (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 chemotherapy drugs will have reduced the ability to fight infections, it is important to respond quickly to high temperatures. Antibiotic treatment in hospital may be needed.

If a patient has a temperature of 38°C or higher please telephone Ward 3B (or the local Shared Care Centre) **immediately.**

It is very important to contact Ward 3B so please don't think you are making a fuss – even when there are no obvious differences in appearance.

Patients must not take Paracetamol, Calpol, Disprol or Calprofen as these can hide temperatures. Calprofen also contains Ibuprofen which can lower platelets.

Vomiting

Some patients may feel sick and vomit for several days after chemotherapy has finished. It may be necessary for them to continue taking anti sickness medicines at home.

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 Ward 3B or the Shared Care Centre.

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. 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 of children, preferably in a locked cupboard. If you have any questions about medicines, please telephone Ward 3B or Shared Care Centre. 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. A label is also attached to prescriptions and we will write on the prescription which medications are IMPs. IMPs are dispensed specially for patients and Ward 3B does not keep stocks of these medications. The Shared Care Centre will not be able to obtain the IMPs for you.

Please make sure you bring all medicines into hospital with you.

How to give oral cytotoxic medicines

A cytotoxic medicine is a drug that is toxic to cells. Cytotoxic drugs are often used to treat cancer and other conditions which respond to suppression of the immune **system**.

How should oral cytotoxic medicines be taken?

These medicines are taken by mouth as tablets or syrup. Instructions will be on the label. If you are not sure what the label means please ask the doctor, pharmacist or nurse.

What if a dose is missed?

It is very important that cytotoxic drugs are taken regularly on the days specified. **If a dose is missed for any reason, please contact the Ward 3B or clinic for advice.**

If there is any vomiting immediately after a dose and the medicine or tablet is visible in the vomit repeat the dose one hour later. If vomiting continues please contact Ward 3B or Shared Care Centre for advice.

What if an extra dose is given?

It is unlikely that an extra dose will cause any problems but please inform Ward 3B if this happens. If you notice any unusual symptoms, contact Ward 3B or Shared Care Centre for advice.

Storage of Medication

Keep all medication out of reach of children. If storage in a fridge is indicated 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.

What precautions should be taken when handling cytotoxics?

- It is recommended that any woman, who is breast-feeding or pregnant or thinks she may be pregnant, does not handle cytotoxic drugs.
- Always handle cytotoxic medication with care.
- If the cytotoxic medicine looks different from your usual prescription do not use. Contact Ward 3B or the Shared Care Centre for advice
- Avoid touching cytotoxic tablets, capsules or medicines when giving a dose.
- Anyone who is likely to come into contact with the cytotoxic medicine should wear disposable gloves.
- Do not crush or open capsules. If tablet segments are required these will be prepared in the Pharmacy Department.
- Always wash your hands thoroughly before and after giving treatment or handling any spillage.

Spillages

Spillage on the skin

The affected area should be washed with plenty of soap and water. Contact Ward 3B or the Shared Care Centre for advice if you experience any adverse effects.

Spillage in the eye(s)

The eyes should be washed with plenty of water. Contact the Ward or the Shared Care Centre for advice if you experience any adverse effects.

Spillage on work surfaces/floors

The spillage should be covered using absorbent paper. Wipe the area clean with water then with soap and water.

Spillage onto clothing

Put on a pair of disposable gloves and blot dry the spillages with paper towel. Clothing should be changed and washed separately to other items.

How should the administration equipment be disposed?

Sharps (needles, ampoules and vials), syringes and other dry waste (including gloves) used for injectable cytotoxic drug 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 drugs for injection should be placed in the plastic bag provided and returned to the clinic or ward of issue for disposal. Syringes of cytotoxic drugs 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. 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.

How should bodily fluids be disposed of?

Cytotoxic drugs are passed out of the body in urine, stools (poo) and vomit. The time period for drug excretion varies with individual drugs but can be as long as seven days. Disposable gloves, cytotoxic sharps bins and vomit bowls are all available from Ward3B or the Shared Care Centre. Extra care should be taken if pregnant or breast feeding.

When disposing of these fluids, please follow the guidance below:

- Wear disposable gloves when handling urine, stools, (poo) 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 must be flushed down the toilet.

- Contaminated bed linen and clothes 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. If you need further Information about good toilet hygiene please speak to a member of Ward 3B staff
- Wash your hands with soap and water after handling cytotoxic medicines and waste.

Central Lines – some important 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 Ward 3B 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 falls off, wash your hands well, clean the end of the central venous line with a sterile alcohol swab 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 Ward 3B or the Shared Care Centre 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 Ward 3B or the Shared Care Centre 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 Centre for advice. We may advise you to come to the hospital.

A nurse or doctor can inject a drug 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.

Later effects of treatment

When patients have completed all of their treatment and require no more they will continue to still be seen in clinic. At these clinics children and young adults will be seen regularly to monitor any health related or lifestyle issues following ending their treatment some investigations maybe carried out, your Consultant will inform you in clinic what investigations are required.

Children and young adults will be seen in clinic at Alder Hey until point of transfer to adult services. Patients are transferred to the late effects clinic usually held at the Clatterbridge Satellite Centre at Aintree Hospital. Some potential problems or late effects may include:

Fertility and Puberty

Certain treatments for cancer can affect puberty and the chances of having children in later life. In the follow up clinics, our staff will carefully monitor for signs of puberty in children. Your child's doctor will explain more about any potential problems in their follow up appointment.

Growth and Development

All patients are weighed and measured regularly at follow up clinic. This is because some treatments such as radiotherapy can affect their growth and development. Radiotherapy to growing bones may prevent or reduce growth and patients may be smaller in height. If radiotherapy has been applied to the brain the production of certain hormones, including those for growth in the pituitary gland, can be affected. If not enough of the hormone responsible for normal growth is produced the patient may not grow normally and could need additional treatments. We hold an endocrine clinic to monitor patients who have received such treatment to check on their growth and development.

Heart

Certain chemotherapy drugs can affect the heart, although this is rare. Anyone who has received these drugs will be monitored with an echocardiogram (heart scan).

Kidney Problems

Some chemotherapy drugs may affect the kidneys and blood tests may be required after treatment to monitor any potential problems.

Second Cancers

A very small number of patients may go on to develop another different type of cancer later in life. Although rare, some families have an inherited risk factor for cancer and some chemotherapy drugs may increase the risk of other cancers.

These are some of the long term side effects that patients may experience as a result of certain treatments. It is important to remember that not all children and young adults have long term problems and it is an individual matter, relating to treatment, cancer type and individual health issues. Please contact your Consultant or an ANP for any further help or advice.

Educational issues

Throughout treatment, most patients are able to continue with their education normally and their learning abilities are not affected. However some younger children, particularly those treated for brain tumours, may develop some learning difficulties and require extra help at school. Your child's doctor will discuss this with you if necessary in your follow up appointment.

Education

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 school 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 school or college as much as possible during treatment. However there may be times when attendance is not possible. For example following chemotherapy, patients have an increased risk of catching infections from others. Schools/college should inform you immediately if either chickenpox or measles is reported.

All in-patients are encouraged to attend the Ward School daily during term time, unless their Consultant advises otherwise. **The hospital teacher works Monday-Friday from 10am-12:00pm and 1:00pm -3:00pm (term time only)**. If a child is going to be in hospital for more than a few days the hospital teacher will contact their school so the child can continue with their work.

If you have any concerns about your child returning to school or feel worried, please let us know and we will help with any problems.

Additional Information

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. The general advice is not to travel whilst in the first year of treatment for leukaemia or still on treatment for a solid/brain tumour. This includes holidays in the UK country well as abroad. If the Consultant agrees to your child going on holiday whilst still on treatment, you may need to have a letter from the Alder Hey. The letter will be useful if you need to visit a hospital whilst on holiday.

Holiday Insurance Cover

Tell the Paediatric Oncology Outreach Nurse or CLIC Sargent Social Worker if you will be going on holiday. You should have holiday insurance that includes medical cover. You may need to telephone a medical screening line and give details of medicines. It will be useful to list all medicines before you ring. Social Workers have a list of medical insurance companies and information is available on www.cancerbackup.org.uk.

The EHIC entitles you to reduced cost and sometimes free medical treatment that may be needed while you are in Europe (list of countries on the internet). You need to apply in advance for the EHIC. You can apply by telephone on **0845 606 2030**, internet www.Dh.gov.uk or at the Post Office. You will need each applicants name, date of birth and NHS or National Insurance number.

Skincare 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.

It is very important to take extra care in strong sunlight. Some chemotherapy drugs 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 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.

Most skin problems are not serious, but a few demand immediate attention. For example, certain chemotherapy drugs given directly into the vein (intravenously, IV) can cause serious and permanent tissue damage if they leak out of the vein.

Body piercing and tattoos

There is a risk that any new body piercing (ears, belly button etc.) could become infected while 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 etc.) 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

Support Groups

Children's Cancer and Leukaemia Group (CCLG)

Website: www.cclg.org.uk



The CCLG website offers in depth information about children's cancer and leukaemia, along with links to other useful sites. The group also publish a magazine for families of children and young people with cancer. Copies of this magazine are available from our Ward.



CHICS is our local support group who provide:

- support for patients and families.
- holidays/outings for children and families.
- caravan for hire.
- treats and parties.
- a monthly newsletter.

Regular CHIC 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 – your local group can give you details of these groups. 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 on **0151 523 8886**

Declaration

Please sign below to confirm that our staff has discussed this booklet with you and have explained the information within it.

I confirm that Alder Hey staff has explained the contents of this booklet to me and I understand the content within it.

Parent/carer Signatory:

Date:

.....

.....

Trust Signatory:

Date:

.....

.....

Notes

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