



FAMILY HELD RECORD

Child & Adolescent Cancer

A collaborative publication from:

**Great Ormond Street Hospital for Children
NHS Foundation Trust**

The Royal Marsden NHS Foundation Trust

**University College London Hospitals
NHS Foundation Trust**

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Information Checklist

This is a list of the information and education you will need before being discharged home. A nurse or doctor will go through each topic with you.

Treatment plan
Treatment side effects
Blood counts
Febrile neutropenia and non-neutropenic fever
Paracetamol and pain relief
Line safety
Chicken pox and measles
What to do in an emergency
Going back to school or nursery
Dietary and travel advice
Immunisations
Explanation of the Family Held Record

Booklets and Leaflets

CCLG Parents' Guide
Information sheet or booklet about your child's condition
Drug information sheets
Treatment flowsheet

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If you have any questions about family held shared care records please call the Shared Care Co-ordinator on 020 7405 9200 ext. 8526

Child / Family Details

Child's Name:	
PTC Hospital No:	POSCU Hospital No:
If this folder is found please return to: Home Address:	
Telephone number:	
Parent(s)/ Carer(s) Names:	

Key Worker

Your key workers are:

Primary Treatment Centre:	
POSCU:	

Your key worker is a specialist nurse who will take a central role in supporting you, your child and family through treatment. They will be your main point of contact at your Primary Treatment Centre (PTC) or at your Paediatric Shared Care Oncology Unit (POSCU).

Your key worker will provide expert knowledge and co-ordination of your child's care. They will also help you to meet your emotional needs, and to access other sources of support.

Key workers often have a variety of job titles. Your key worker may be a Specialist Nurse, Clinical Nurse Specialist, Nurse Practitioner or Outreach Nurse. You will usually meet your key worker during the first four weeks of treatment.

Contact sheet - Principle Treatment Centre (PTC) / Great Ormond Street Hospital for Children

Child's name:

Consultant:	Secretary's tel. no.
24 Hour Advice at GOSH Please Call:	During working hours 9am-5pm please contact your key worker. Evenings, weekends and bank holidays please contact Lion, Elephant or Giraffe ward. See contact details below.
Key Worker:	Tel: Monday-Friday 9am-5pm If your key worker is not working you can speak to another member of their team on this number during the hours of 9am-5pm. Email:
Lion Ward:	Tel: 020 7829 8810
Elephant Ward:	Tel: 020 7829 8821
Giraffe Ward:	Tel: 020 7762 6829
To enquire about your child's next inpatient admission:	Please call Inpatient Reception: 020 7405 9200 ext. 1040 If no answer then call Lion, Elephant or Giraffe ward. Contact details above.
To enquire about outpatient or day care appointments on Safari: Such appointments for; MRI scans, lumbar punctures, day care chemotherapy or consultations	Please contact the Safari Receptions. Outpatients: 020 7405 9200 ext. 1513 Safari Day Care: 020 7829 8833

Other useful contacts:

CLIC Sargent Social Worker:	020 7405 9200 ext. 5320 or contact your key worker for a referral
Paediatric Oncology Outreach Nurse Specialist (POONS):	Direct Line: 020 7829 8678 Mon-Fri 8:00am - 6:00pm. Out of hours contact through switchboard
Safari Day Care Nurses:	020 7405 9200 ext. 1048/0046
Switchboard:	020 7405 9200
Address:	Great Ormond Street Hospital for Children NHS Foundation Trust Great Ormond Street, London, WC1N 3JH

Contact sheet - Paediatric Oncology Shared Care Unit (POSCU)

Your POSCU is the local hospital that will be providing your child's care in partnership with your PTC. **If your child is unwell this is where you need to take them.**

POSCU Hospital:		
Consultant:		Telephone:
Inpatient Ward:		Telephone:
Contact this ward if your child is unwell and needs to be admitted		
Daycare:		Telephone:
POSCU key worker:		Telephone: Bleep: Paediatric oncology mobile:
Social Worker:		Telephone:
Others:		

Some of the services provided by your POSCU:

- Emergency care if your child is unwell
- Treatment of febrile neutropenia or other infections
- Administration of blood products
- Some outpatient chemotherapy; your key worker will be able to discuss this with you
- Access to a multidisciplinary team of professionals; including a key worker, Consultant Paediatrician, dietician, physiotherapist and social worker
- Consultant Paediatrician, dietician, physiotherapist and social worker

Contact sheet - Paediatric Community Nursing Team (PCN)

Paediatric Community Nursing Team (PCN):		
Named Nurse:		
Address:	Telephone number:	Out of hours contact the inpatient ward at your child's POSCU
<p>Services provided by your CCN team:</p> <ul style="list-style-type: none"> Routine blood tests - any specialised tests may need to be taken at your PTC Care of your child's central venous line- includes dressing changes and weekly bloods Your CCN may be able to administer some medications. Please discuss with your CCN team or key worker 		

General Practitioner:		
GP Address:	GP Telephone number:	
School Nurse:	Telephone:	
Health Visitor:	Telephone:	

Who to Contact

This is some guidance on who to contact for advice, information or practical matters. These professionals should be able to help you with your queries, or direct you to the right person or team. The contact details for these teams and professionals are listed on the contact pages. **If your child is unwell contact your POSCU urgently. See page 5 for contact details.**

Topic	Who to Contact
Advice about your child's condition, treatment or side effects	<ul style="list-style-type: none"> - Key worker at PTC - Key worker at POSCU - Inpatient ward or day care ward at PTC - On-call registrar at POSCU - Community nursing team
Arranging a central line dressing change at home	<ul style="list-style-type: none"> - Community nursing team - Key worker at POSCU
To report a problem with your child's central line	<ul style="list-style-type: none"> - Community nursing team - Key worker at POSCU - Inpatient ward or day care ward at PTC - Inpatient ward or day care at POSCU
Arranging a supply of medicines	<ul style="list-style-type: none"> - Key worker at POSCU - GP - Key worker at PTC
Arranging a supply of oral chemotherapy	<ul style="list-style-type: none"> - Key worker at PTC - Out of hours: Inpatient ward at PTC
To find out about a planned admission for treatment at your PTC	<ul style="list-style-type: none"> - Inpatient administration team - Inpatient wards - Key worker at PTC
For details of an outpatient or day care appointment at your PTC	<ul style="list-style-type: none"> - Outpatient or day care reception at PTC
To arrange the flu vaccination for your child	<ul style="list-style-type: none"> - GP - Key worker at PTC - Key worker at POSCU
For information about an appointment at your POSCU	<ul style="list-style-type: none"> - Key worker at POSCU - Day care or outpatients at POSCU
To arrange for blood tests at home	<ul style="list-style-type: none"> - Community nursing team - Key worker at POSCU
To get the results of blood tests taken at home	<ul style="list-style-type: none"> - Community nursing team - Key worker at POSCU - Day care or outpatients at POSCU
To get results of blood tests taken at your POSCU	<ul style="list-style-type: none"> - Key worker at POSCU - Inpatient or day care at POSCU
For blood test results taken at your PTC	<ul style="list-style-type: none"> - Inpatient or day care ward at PTC
Advice about financial support	<ul style="list-style-type: none"> - Social worker at PTC or POSCU - Key worker at PTC - Key worker at POSCU
Planning a holiday in the UK or Abroad	<ul style="list-style-type: none"> - Outreach team at PTC - Key worker at PTC
Supporting your child to attend school or nursery	<ul style="list-style-type: none"> - Outreach team at PTC - Community nursing team
Emotional support	<ul style="list-style-type: none"> - Key worker at PTC or POSCU - Psychologist (contact Key worker for a referral)

What to do if your child is unwell during treatment

What is neutropenic sepsis / febrile neutropenia

Some chemotherapy drugs 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 are 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 blood count or Full Blood Count (FBC for short) is a blood test that gives numbers telling us whether there are normal, low or high numbers of various blood cells (including neutrophils) in the blood. Neutropenic sepsis or the older term febrile neutropenia, refers to a situation when your child is neutropenic and they become unwell with infection. This may be associated with high temperatures, although sometimes your child can be unwell without high temperatures). **Your child will be neutropenic if their neutrophils are 0.5 or below.**

What should you do if your child is unwell

The most important part of caring for a child during treatment is to seek advice immediately if they become unwell or develop a fever.

It is therefore important to have a suitable thermometer available at home, so if your child seems unwell and / or feels hot you can check their temperature. Mercury thermometers are no longer recommended for use with children.

We advise that when your child is neutropenic and develops a temperature at home, they should NOT be given paracetamol (including Calpol®) until they are reviewed at the POSCU (local hospital). Once your child has been reviewed at the POSCU and it is clear what action is needed, it will be fine to give your child paracetamol. We do not advise giving ibuprofen (including Nurofen®) to your child while they are receiving chemotherapy / radiotherapy, unless discussed and agreed with your child's Consultant at the PTC (Primary Treating Centre).

When paracetamol can be given at home:

- If your child's neutrophil count is above 0.5 (they are not neutropenic)
- Only if their temperature is below 38°C
- Only for mild or moderate pain
- Only if they are not unwell

If your child is an inpatient (that is, staying overnight in hospital), the hospital medical team may give paracetamol for pain relief under medical supervision. (This is the case for inpatients, even if child is neutropenic, without fevers or with fevers).

When to seek further advice

- **If your child has a temperature of 38°C or above. Telephone your POSCU and take your child there immediately.**
- **Whether or not your child is neutropenic - if you are concerned that they are unwell seek an urgent review at your POSCU.**

Sometimes children can be unwell without having a high temperature, it could be low your child may be drowsy or more tired than usual or have abdominal pain, vomiting or diarrhoea. You may just have the sense of them 'not being right'. If this happens, telephone your POSCU as your child may need a medical review.

Be aware:

Steroids (such as dexamethasone, prednisolone or hydrocortisone) can mask a temperature, so if your child is taking steroids and seems generally unwell with or without a temperature please telephone your POSCU or community nurse for advice.

Treatment of Neutropenic Sepsis

Once your child has been admitted to hospital, he or she will be examined, and have some blood tests taken including blood cultures. In accordance with the POSCU's supportive care protocol, which has been written by the PTC's, a course of intravenous antibiotics will be started. The length of stay in your local hospital can vary, depending on the type of infection. It is fairly common that during the episode of neutropenia the source of infection may not be found. However, the antibiotics that we use treat the most common bugs that can cause infection. The doctors will be able to tell you what tests they have done and the results.

Chicken Pox and Measles

Chicken pox is caused by the varicella zoster virus (VZV), and is a contagious disease. While on treatment and for six months afterwards, your child may be at risk of becoming unwell if they develop chicken pox. Chicken pox is infectious 48 hours before the first spot appears. The rash generally breaks out one to three weeks after exposure and remains infectious until all spots have scabbed over.

Symptoms of chicken pox

Flu-like symptoms, such as; fever, runny nose, watery eyes and tiredness. Appearance of an itchy rash, characterised by small red spots, raised red areas or fluid filled blisters like sores that break out and scab. The rash usually starts on the stomach, chest, back or scalp and new spots will develop for up to three to five days or sometimes longer.

Chicken pox is caught from close contact with someone who has either chicken pox or shingles. **Close contact is defined as being face-to-face with or in the same room** as an affected person for 15 minutes or longer. Touching a person is considered close contact. Someone who does not have chickenpox cannot pass it on.

At the start of your child's treatment, they will have a blood test carried out to see if they have antibodies to chickenpox. If your child has antibodies, this means they are likely to be immune to catching chicken pox. However, if you think your child may have been exposed to chicken pox, always contact your POSCU/PTC for advice.

Shingles

Shingles is a reactivation of the varicella-zoster virus, the same virus that causes chicken pox. Shingles results in clusters of burning, itching blisters, typically on one side of the chest or back but may affect the face and more rarely the eye.

Children who do not have immunity to chicken pox are at risk of catching chicken pox from contact with someone who has shingles. Contact means being in close contact with someone who has exposed blisters for 15 minutes or longer. If you are worried that your child may have shingles contact your POSCU urgently.

If your child has a direct contact with someone with either chicken pox or shingles then you need to do the following:

- Contact your POSCU or PTC as soon as possible after **every** contact for advice.
- If your child has antibodies (positive immunity) to chickenpox then your child **will not** require VZIG.
- If your child does not have immunity (negative antibodies) to chickenpox then they **will** require VZIG.

VZIG (Varicella Zoster immunoglobulin)

The risk of serious infection can be reduced or avoided by an injection of VZIG which should be given as soon as possible, ideally within 72 hours of contact. However it may be given up to 10 days after contact with the

infected individual. This needs to be given as an injection into the muscle (usually the leg). Once VZIG has been given the child can return to school.

VZIG is only effective for three to four weeks, after which time they will need to have the injection repeated if there is another contact. This will be for any contact with chicken pox that occurs during their treatment and for six months after the end of treatment. Your child can attend school following the VZIG injection.

If your child develops the symptoms of chickenpox, they will receive treatment with a medication called aciclovir; this is given intravenously at first.

If your child has been exposed to or has chicken pox, measles or shingles, do not bring them to the ward or clinic without telephoning first. Also, if your child has had VZIG, please inform us before coming to the hospital or clinic.

Isolation period for chickenpox

All children who have had a chickenpox contact and have negative antibodies need to be isolated from day 8 after the chickenpox contact when **visiting clinic or an inpatient on the wards.**

If your child has **not had VZIG** and they do not have antibodies, they will need to be isolated up to **21 days** from the day of contact.

If your child has **had VZIG**, they will need to be isolated up to **28 days** from the day of contact.

If your child develops chicken pox they will be infectious from two days before their spots appear until their spots have completely crusted over.

Please note: your child only needs to be isolated from other children or adults who have a low immune system. They can attend school as usual.

Measles

Measles can be a very serious infection in children receiving chemotherapy treatment or within six months of completing treatment. Children on chemotherapy can catch measles even if they have been previously immunised.

A significant contact with measles is defined as close contact for more than 15 minutes with an individual who has confirmed measles during the infectious period (which is for four days before –to four days after the rash develops).

If your child has a direct contact with someone with measles then you need to do the following:

- Contact your POSCU or PTC as soon as possible for advice.
- Your child will need to receive an injection of immunoglobulin. This is called HIG (human immunoglobulin), and it needs to be given as an injection into the muscle within 48 hours of contact with measles if possible, but it can be given after this period if necessary.

You can help lower the risk to your child by getting your other children immunised (if they have not already been so) and by encouraging school friends to do the same. There is no risk to your child of transmission of the virus from other children who have recently been immunised.

Central Venous Access Devices

There are several types of long term central venous access devices that are commonly used. Your child's treatment plan will often determine the type of device they will need. In some cases, there will be a choice of more than one type of device. A member of the team will discuss the options with you and your child.

There are two types of device we use most commonly. The first is called an Implantable Port. The other line is a Central Venous Catheter (CVC) commonly referred to by its brand name 'Hickman®'.

Why we use central venous access devices

Your child may require a central venous access device to help us give them their treatment in the safest, least painful and most convenient way. We can use it to give your child their chemotherapy as well as any other necessary medications, fluids or blood products.

The central venous access device can also be used for the majority of routine blood samples that your child will need during their treatment. However, some circumstances we may ask to take blood samples from your child's finger (for example antibiotic levels) or from a vein in their hand or arm. This would be for specific tests and the reasons will be explained if this becomes necessary.

Central Venous Access Device Care

Although there are many benefits to using central venous access devices, they can be a source of infection. In some cases, bacteria can grow in the line. This is called a line infection. There are also infections that can develop at the central venous line exit site.

Implantable Ports are accessed using a special type of needle which is inserted through the skin into the device. When the device is not accessed in this way, the risk of infection is minimal.

In order to prevent infection, there are principles that should **always** be followed in caring for a child with central venous line:

Hand Hygiene	Everyone who touches a central venous access device (CVAD) must wash their hands with soap and water	
Daily checks	<p>Single/double lumen tunnelled line Check the site for redness, swelling, oozing or discomfort</p> <p>Check line is looped, curved or in an 'S' shape under dressing</p> <p>Check clamp(s) are closed</p> <p>Check there is a "bung" on the end of the line</p>	<p>Implantable Port Check skin over the Port site for redness, swelling, oozing or discomfort</p> <p>If port needle is in situ: Check line is looped, curved or in an 'S' shape under dressing</p> <p>Check the clamp is closed</p> <p>Check there is a "bung" on the end of the line</p>
Dressing	<p>All central venous access devices should have an intact, dry, transparent dressing that sticks to the skin.</p> <p>For Single/double lumen tunneled lines the dressing should be changed at least every seven days.</p> <p>For Implantable Ports the needle should not remain in place for longer than seven day without being changed.</p>	
CVAD Access	<p>Nurses or doctors will follow ANTT (Aseptic non-touch technique). The basic principle of this is that the end of the line, or "bung" or any other key part should not come into contact with any item that is not sterile. For example, this means they will not touch the end of the line or the syringe tip, even if they are wearing gloves.</p> <p>At GOSH, to clean the line directly before use, we firmly wipe the hub/bung using friction with a 2% chlorhexidine gluconate and alcohol based wipe for 30 seconds and allow to dry.</p>	

If you have any questions or concerns about your child's central line please contact your PTC, POSCU or your community nurse for advice.

Extravasation

- Some medicines we give can cause tissue damage if they leak outside of the vein into the surrounding tissues. This is called extravasation.
- Prior to giving any medicine that could cause this; the nurses will always make sure the catheter bleeds back.
- If you notice any of the following then you **must** tell a nurse as soon as possible:
 - the line is pulled accidentally
 - leaking on the dressing
 - CVC or port needle is not secured by a dressing
 - the loop has come out from under the dressing

CVC and Implantable Port Pack

This pack contains everything you will need in the event of a line related problem. You should always carry this with you.

Central Venous Access Device Record

Child's Name:

Device information

Type of venous access

Size of device

Date of insertion

Manufacturer

Dressing

IV3000

Mepitel film

Other

Please note: Port needle size may need to be changed with weight gain or weight loss.

Effects of chemotherapy and radiotherapy on blood cells in the bone marrow

The drugs and radiotherapy given for treatment have the inevitable effect of depressing the normal blood cells and bone marrow. The effects of this are shown in the table below:

Blood Count	Normal level	Low level	Symptoms/effects of low level	Treatment for low level
Red blood cell count (Hb)	Varies with age, but around 110 – 130	70 or lower except during radiotherapy Low count also known as anaemia	<ul style="list-style-type: none"> • Tiredness and lack of energy • Pallor • Breathlessness • Feeling cold • Dizziness/headaches • Poor feeding/lack of appetite 	Blood transfusion
White blood cell count (WBC)	5 – 10		<ul style="list-style-type: none"> • Increased risk of infection 	
Neutrophil count (N)	1.5 - 6	0.5 or lower = neutropenia	<ul style="list-style-type: none"> • Increased risk of bacterial infections 	When your child is neutropenic, they will need antibiotics if they have a temperature above 38.0c (see page 8)
Platelet count	150 – 400	10 or lower For children with brain tumours: 30 or lower For patients due a lumbar puncture: 50 or lower For patients undergoing spinal irradiation: 50 or lower Low count also known as thrombocytopenia	<ul style="list-style-type: none"> • Bruise more easily • Bleeding gums or nose bleeds • Small bleeds under the skin (petechiae) 	Platelet transfusion NB: In all brain tumour protocols, a platelet transfusion is given if the count is less than 30 or there is evidence of active bleeding Children due a lumbar puncture will be transfused if platelets are 50 or lower

During the course of your child's treatment they will have many blood tests. The results of these tests will often be telephoned to you. We encourage you to use pages in this book to record your child's blood test results.

Blood Counts

Normal cells most affected by chemotherapy include 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 70 or below, but will also be based on their clinical condition.

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**.

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. Generally, children will be transfused if their platelet count is 10 or lower. If your child has a brain tumour platelets are transfused if 30 or below.

Blood Count Record

Name:

PTC Hospital No:

POSCU Hospital No:

Useful Phone No:

Date																				
Full Blood Count																				
Hb																				
WBC																				
Neutrophils																				
Platelets																				
Other bloods																				
Weight																				
Height																				

Date																				
Full Blood Count																				
Hb																				
WBC																				
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Blood Count Record

Name:

PTC Hospital No:

POSCU Hospital No:

Useful Phone No:

Date																												
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Hb																												
WBC																												
Neutrophils																												
Platelets																												
Other bloods																												
Weight																												
Height																												

Notes

Some parents find it useful to keep notes.
This section is for you to use as you please.

Cancer Treatment

We have provided some information about treatment and an overview of some of the side effects that your child is likely to experience. Your Keyworker will also talk this through with you and will be able to give you additional information/booklets to help build your understanding.

Chemotherapy: what is it?

Chemotherapy is the use of anti cancer (cytotoxic) drugs to destroy cancer cells; they can reach the cancer cells all over the body. These drugs 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. The side effects caused by destroying some of these normal cells are almost always temporary.

Chemotherapy Treatment Plan

- Chemotherapy may be given by different routes. Most commonly chemotherapy drugs are given by mouth or intravenously via your child's central line or a cannula. Some patients will also have chemotherapy given into their spinal fluid via a lumbar puncture.
- Chemotherapy may sometimes be given as a series of sessions of treatment known as a cycle of chemotherapy or it may be given continually. This depends on your child's individual treatment plan (protocol).
- Individual chemotherapy drugs 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 you can do to help manage these.

Multidisciplinary Team Meetings (MDT)

The team of professionals who will be caring for your child and supporting you through his/her treatment is called a multidisciplinary team. This team may consist of a range of staff members, including Oncology and Haematology consultants, surgeons, radiologists, radiation oncologists, pathologists, nurses, psychologists, physiotherapists and many other professionals. This team of specialists meets every week to discuss the diagnosis and treatment of individual patients. They make sure that each patient is given the same high standard of care and has the most appropriate investigations and treatment. There are several separate MDT meetings: Oncology, Haematology and Neuro-oncology MDT. Your child might also be discussed in other MDT forums if needed (Urology, Neurosurgery, Cardiothoracic MDT).

Common Side Effects

All treatment causes side effects; those discussed below are not an exhaustive list but are some of the most common. Specific side effects will be discussed in more detail with you by the team at the PTC. **For information on the effects of treatment on blood counts see page 16.**

Nausea and vomiting (feeling and being sick)

Nausea and vomiting is a side effect of many chemotherapy drugs. Anti-sickness drugs can be given to reduce these symptoms. **If the nausea and sickness is not controlled or persists, please inform your key worker or Doctor.** It may be that a different combination of anti-sickness drugs may help. Depending on the treatment protocol, on discharge from hospital you will be sent home with one or two days of oral anti-sickness drugs. If your child continues to be sick or has diarrhoea for longer than 24 hours or you are worried about them contact your local shared care hospital (POSCU).

Diarrhoea

Some of the chemotherapy drugs we use can cause diarrhoea. As a result of the increased loss of fluid, diarrhoea can lead to dehydration, and should therefore be discussed with your doctor. 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, if not effective seek advice about what else to use from your POSCU.

Constipation

Constipation is also associated with some chemotherapy drugs, 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). Your doctor may also give your child a laxative at the same time as starting some drugs, e.g. codeine/ morphine, as they are known to cause constipation.

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. The following are some general principles: in some situations, paracetamol can be used for pain relief. However, if your child's neutrophil count is 0.5 or below, we do not recommend the use of paracetamol for pain relief at home as this may mask the fever of febrile neutropenia. Ibuprofen can affect the function of platelets and increase the risk of bleeding; we do not recommend the use of ibuprofen for children on chemotherapy treatment. There are also other

medications that can be used safely and effectively. If your child has pain please discuss it with your medical team who will be able to advise and prescribe appropriate medicines.

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. Try to keep their mouth clean, moist and free from infection. This is best achieved by brushing with a soft toothbrush and fluoride toothpaste after meals and before bedtime, or at least twice a day. Sometimes a child may not say they are in pain but you might notice a change in how they speak, husky voice or they may seem to have difficulty in chewing, swallowing food and even at times their own saliva. If your child's mouth becomes sore, please let your doctor or nurse know as there are medicines we can use to help them feel better.

Practical Tips:

- Soft, non-spicy foods cut into small pieces will be easier to chew and swallow.
- Avoid food and drinks with a high acid content such as tomatoes & pure orange juice which will irritate the mouth and may cause increased pain.

Please refer to Mouth care Leaflet enclosed at the front of the folder or via www.gosh.nhs.uk.

Weight loss

Your child's weight and height will be regularly measured. For some it can be very difficult to eat enough food during treatment. If your child is losing weight or has a poor appetite ask to speak to one of the dieticians. They can suggest food and drinks that may be helpful in maintaining weight. Artificial feeding is often recommended for children who are still losing weight. This is usually given through a thin, plastic tube called a nasogastric (NG) tube. This type of feeding is very common with younger children and during certain types of treatment. For more information on helping your child to eat, see page 25.

Weight gain

If your child is on steroids they may experience 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. These effects are temporary, and their appetite will usually decrease when the steroids stop. Some children may also put on weight due to a lack of physical

activity during treatment. If your child is well, enough it is important to encourage regular exercise.

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, 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. 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 weird and wonderful 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 your child has developed an unusual rash similar to chicken pox for example, please contact your POSCU promptly.

Infections

The treatment used to treat cancer reduces the immune system's ability to fight infection. Therefore your child will be at increased risk of developing infection, particularly if they are neutropenic as previously mentioned. This section discusses some of the infections we are most concerned with.

Bacterial Infections

Bacteria can cause serious infections in children who are immunocompromised (at greater risk of infection). Some bacteria that normally live in or on our bodies and would normally not do us any harm can cause severe infection in children receiving treatment for cancer, particularly if they are neutropenic or have a central line (CVC). Bacterial infections will be treated with antibiotics often given intravenously, see the pink section for information treatment of febrile neutropenia.

Opportunistic Infections

There are germs around us that do not cause infections in healthy children, but can be harmful to children who are immunocompromised. These infections known as opportunistic infections include, fungal infections such as thrush, and pneumocystis pneumonia.

Pneumocystis Jiroveci Pneumonia (formerly known as PCP)

This infection is due to an organism (bug) that is probably present in most people's lungs. Children who are receiving long term drugs 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. You may hear the doctors and nurses referring to this as 'PCP' as it was previously called Pneumocystis Carinii pneumonia.

To help reduce the risk of children developing Pneumocystis Jiroveci Pneumonia some protocols advise that whilst receiving chemotherapy we give children an antibiotic called co-trimoxazole (Septrin). Co-trimoxazole is usually taken twice a day for two consecutive days each week and it is important that if prescribed your child does take it regularly (unless your doctor / nurse advise you to stop taking for a short time).

Viral Infections

Most of the common viral infections are not prolonged or serious in children on chemotherapy and you do not need to worry about them. Chicken Pox and Measles are the exceptions. There is more information on these conditions on page 9-12.

Cold sores

The herpes simplex virus causes cold sores, and some children can get recurrent cold sores. If they are persistent or troublesome the doctor will usually treat them with Aciclovir given orally. They rarely cause major problems but can be uncomfortable. Please contact your POSCU or PTC for advice.

Life at Home

This section discusses information which you may find useful on a daily basis. If you are worried or concerned about any of the things mentioned here please contact your key worker for further advice and support. It is important for your child to try and maintain as normal a family life as possible during treatment; support is available to help you do this.

Diet

Persuading your child to eat a balanced diet can be difficult when they are feeling unwell. It is quite normal for your child's appetite to decrease while having treatment. Chemotherapy can cause foods to taste differently, for example, some children find that red meat has a 'metallic' taste. Your child may also go off food if their mouth is sore or they are feeling sick.

There is an information sheet available that you may find helpful:
Coping with children's eating problems during chemotherapy – online at <http://www.gosh.nhs.uk/medical-information-0/procedures-and-treatments/coping-eating-problems-when-your-child-having-chemotherapy>

If you are concerned about your child's diet, please ask your key worker to refer your child to a dietician.

Food hygiene advice

When your child is ill or having treatment they are more at risk of getting food poisoning. To reduce this risk, all foods should be heated thoroughly and stored at the right temperature. Cooked food should be eaten immediately. Food can only be reheated once and must be cooked until piping hot. Do not reheat cooked rice. Salad, vegetables and fruit should be washed and dried before eating. Do not use food that has passed the 'sell-by' or 'best before' date.

Foods to avoid

While your child is on treatment, he or she should avoid certain high-risk foods:

- Raw or lightly cooked eggs
- Shellfish (like mussels and prawns)
- Pate
- Soft unpasteurised cheeses, for example brie, camembert
- 'Blue' cheeses such as stilton or Roquefort
- Live yogurts

Practical tips:

- If your child's tastes have changed try foods with strong flavours, such as spicy sausages, Marmite™ or crisps.
- It is common for children to want to eat the same thing every day while on treatment. This improves over time.
- If your child has a reduced appetite, try smaller meals, and have snack foods ready for when they feel like eating. Avoid overfilling plates or presenting your child with too much food.
- If your child is losing weight buy full-fat products, offer high calorie snacks such as cake, and add extra butter, margarine or cheese to meals and snacks.
- CCLG has published a booklet of useful advice entitled 'Helping your child to eat'. This is available from www.cclg.org.uk

Vitamins / Probiotics

We do not advise the use of vitamin and mineral supplements or probiotics during treatment, as they have the potential to interact with the chemotherapy drugs. Please discuss any additional supplements you may wish to use with your child's medical team including homeopathic remedies and herbal preparations

Building Work

If you are or intend to do any significant building work at home, please discuss with your Consultant or key worker, as your child may be at risk of developing a fungal infection from dust, which can be disturbed during building work.

Travel

It is safe for your child to travel on public transport whilst on treatment, even if neutropenic.

There are some situations where you may be entitled to help with congestion charges or travel. This will be based on individual hospital's transport policy and be assessed on a case by case basis.

Some parents find it helpful to prepare an Overnight bag for any unplanned hospital admissions
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Coming in to your PTC

There may be occasions when your child's expected admission date is changed or delayed. This can be based on your child's condition, for example if they have had a recent infection. In other instances delays can be due to bed availability on the inpatient wards or on day care. In the event

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of any changes to your child's plan of admission you will be contacted by a member of the team. However, on the day of admission please ring one of the inpatient wards to confirm which ward your child is going to and what time the room will be ready. In some cases, your child may be admitted to a ward that does not specialise in Haematology/Oncology. If this occurs, the medical and nursing team will ensure that your child receives the care and expertise that they need.

When coming to hospital for an outpatient appointment or for an inpatient stay please bring all your child's medicines with you.

Disposal of nappies and body fluids after a course of chemotherapy

Your child will still be excreting chemotherapy in their urine and faeces up to seven days after the chemotherapy has finished.

If your child is wearing nappies or needs assistance with toileting, we suggest that you wear gloves (household rubber gloves are ideal) to change the nappy to protect yourself. Place the nappies, wipes or cotton wool, gloves if you are using disposable, in a plastic carrier bag and dispose of in your dustbin as usual.

School / Nursery

Children can attend school or nursery during treatment, even if neutropenic. Going to school and maintaining contacts with friends can help them cope with treatment better and boost their self-confidence. There may be times when they are not well enough to go to school, or times when hospital admissions make it difficult to go attend. Your key worker will be able to discuss with you when this is more likely to happen. Often schools can send out school work for your child.

Whilst going to school there is a risk of catching chicken pox or measles. It is important that the school or nursery inform you immediately if there is a case of chicken pox or measles in your child's class. If your child has been in close contact with someone who has developed chicken pox or measles contact your POSCU as soon as possible.

You may also be concerned about how other children will react to your child especially regarding his or her hair loss. We have found that if the other children understand your child's illness, then the possibility of teasing may be reduced, although there are no guarantees unfortunately. This is not to say that everyone needs to know, but we can liaise with your child's school and share information with the head teacher or class teacher if appropriate. You should encourage the continuation of your child's friendships, even when he or she is not at school. This provides opportunity for play, an escape from their illness and boosts their self-esteem.

There are a number of helpful publications for schools and nurseries including:

Welcome Back available via www.cancerresearchuk.org

Pupils with cancer – a guide for teachers

Returning to school – a teachers guide for pupils with brain tumours

Both of which are downloadable from www.royalmarsden.nhs.uk

When your child is ready to return to school / nursery your key worker, outreach nurse (POON's) or children's community nurse can arrange to visit the school. They will discuss any issues and concerns the school may have and help facilitate a smooth transition back to school for your child. You are welcome to be involved in this discussion and visit.

Pets

If you have a pet or pets there is no reason why your child needs to stay away from them. As always, hand washing is extremely important after handling animals and particularly before meals. Cats and dogs should be treated regularly for worms, and vaccinated as recommended by your vet. Avoid contact with excreta or litter trays and with mucking out horses as fungus lives in the straw. A leaflet with further information, *Children with cancer and pets* is downloadable from www.cclg.org.uk

Swimming

If your child has a tunnelled central line ("Hickman line") inserted for chemotherapy then they should not go swimming. Your child is allowed to go swimming if he or she has a port, unless the port needle is in place.

Sun protection

While your child is having treatment and after treatment is completed, his or her skin may burn more easily than usual. You should avoid your child being exposed to sunlight and other forms of ultraviolet light. If your child does go out in the sun always use a good sun block of SPF 25 or higher and ensure they wear a sun hat.

Transition to Teenage Services

Being a teenager can be a difficult time without the added difficulty of receiving treatment for your illness. That is why specialist Teenage and Young Peoples Units have been developed all over the country. Patients and relatives report benefits from being in an environment where they have

contact with other teenagers, young people and relatives going through a similar journey. For these reasons young people from the age of 13 years receiving treatment at Great Ormond Street Hospital will have their care or follow-up at University College London Hospital.

This transition process can be likened to the move from primary school to secondary school. It may make the teenager or young person and their family feel excited if they are ready for the change, or worried and scared about leaving especially if they know the doctors, nurses and team at GOSH really well. It may be reassuring to know that GOSH and UCLH work in partnership and the medical and nursing teams attend many meetings together and discuss patient care and treatment together.

We aim to ensure that the transition from GOSH to UCLH goes well but if you have any concerns or are finding transition difficult please do not hesitate to discuss these worries with a nurse or your Consultant so we can try to make things better.

All teenagers, young people and their families are invited to attend family support days run by the Teenage Cancer Trust in conjunction with UCLH. These days give teenagers, young people and their families an opportunity to meet and share with others of their own age who have experienced similar experiences to themselves. They are open to any teenager and their family who has ever received treatment for cancer. Their treatment may have been years ago, they may be currently on treatment or many find the days especially useful if they have recently completed treatment as it provides additional support at a time of change. If you would like additional information, or to be added to the mailing list email familysupportnetwork@teenagecancertrust.org

Coping as a family – who can help

We know that coping with the diagnosis of cancer, coming to hospital, and treatment itself can be stressful and can leave you and your child with a range of different feelings. These feelings can include worry, confusion and anger and are all perfectly normal.

These are the people who can help:

Clinical Psychologist

Work with children, young people and their parents at any time during treatment to help them cope. This includes helping people to cope with change, anxiety, low mood, loss, worries about having procedures, changes in body image and managing pain. They can also offer advice about behaviour especially if this interferes with treatment.

CLIC Sargent Social Worker

Offer practical and emotional support, information and advice. This includes helping you find ways to deal with the practical issues, such as financial concerns, employment, referrals for housing, DLA, blue badge and charity applications. As well as bereavement support, 'Home from Home', CLIC Sargent holidays and respite breaks. For more information see page 36-37.

Play Specialist

Provides play support to your child and their siblings. They can help your child gain confidence having procedures and a better understanding of treatment, as well as providing play activities and distraction during procedures.

The play specialist also:

- Provides appropriate support to all family members including siblings.
- Help's your child to gain confidence and a better understanding of their treatment through role play.
- Prepares your child for procedures and familiarizes them with medical equipment, visits to theatres, MRI and X-ray.
- Provides effective distraction during procedures (blood tests, MRI, etc.).
- Provides a safe place to play by organising daily play and art activities in the playroom or at a patient's bedside.
-

Chaplaincy

Provide spiritual support to families of any faith or no faith background. The hospital has a team of chaplains from a variety of faiths and denominations who are available. The chapel and prayer room are always open and available for prayer or as a quiet space.

Nurse Consultant for learning disabilities

Provides support to children with learning disabilities and their families. He will work with you and the team to make the necessary adaptations to the environment or process so that your child's individual needs are met.

Complimentary therapy nurse specialist

If your child is an inpatient on Lion, Elephant or Giraffe ward they will have access to the complimentary therapy nurse specialist at Great Ormond Street Hospital. This is an experienced oncology nurse who specialises in massage therapy.

Research has shown that massage can help to improve mood and coping and help to alleviate pain and the side effects of cancer treatment.

If your child wants to have a massage and they are well enough and infection free then they can come to the Complementary Therapy Suite, situated on Lion Ward. If they are feeling unwell, have an infection, or simply do not want to, they can be given a massage in their own cubicle.

Please speak to your key worker to get in touch with any of these people.

Coping as a family

Your child

Knowing what and how much to tell your child about their illness or treatment is a common concern. It can be useful to discuss such worries. Some parents also notice a change in the way their child behaves, either in hospital or when they get home. This often only lasts for a short time but it can still be very upsetting. Introducing a regular routine and a gradual return to normal activities is important as your child's health improves.

Brothers and Sisters

When your child has been diagnosed with cancer the impact of the news and the treatment affects the whole family. It is important to recognise that this can be a difficult time for brothers and sisters. They are often faced with the absence of one or both parents as well as coping with worries about their ill brother or sister. Brothers and sisters can sometimes feel ignored and rejected. They may feel worried about their brother/sister but are too afraid to ask questions. Sometimes you may notice changes in their behaviour. They may become clingier and have difficulty being away from you. They may have problems concentrating at school. Sometimes siblings can act in a jealous way and become more demanding of your attention. They may become angrier and argue more frequently, this is normal and understandable. *How to help brothers and sisters* is a leaflet downloadable from www.cclg.org.uk/ with further information.

Grandparents / Wider Family

Grandparents and other close family members may also experience a lot of stress and anxiety. They often worry about you and how you are coping, as well as worrying about the ill child. Some friends/relatives appreciate being able to assist in practical ways (e.g. looking after other children in the family).

-Further Information and suggestions downloadable from www.cclg.org.uk/
Grandparents – A guide for grandparents of children and young people with cancer.

Top Tips for Parents

- It is not uncommon for you to need information to be repeated – you will be told lots of new information and you will meet lots of new people, particularly in the first few weeks. Don't be afraid to ask if you are unsure about something or can't remember what you have been told previously.
- Helping your child to understand – we know that children cope better with their treatment and adjust more easily to new situations when they understand what is happening and why. We can help you talk to your child. Please feel free to discuss this with your key worker
- You may find your child's behaviour changes – children and young people express their feelings through their behaviour. Your child may become withdrawn or angry and aggressive. A clinical psychologist may be able to help. Please speak to your key worker if you would like to be referred.
- Maintaining consistency and discipline is difficult when your child is ill. Your style of discipline and 'rules' are important for your child so that things are familiar for them. Giving lots of praise and encouragement for times when they have coped well is really valuable. The play specialists at your PTC and POSCU may be able to help with strategies.

CLIC Sargent Social Worker

CLIC Sargent social workers have one simple aim: to ease the burden of childhood cancer on children, young people and their families.

Expert help for every child and family from the moment of diagnosis.

They help with the trauma of diagnosis, the often long journey through treatment, and continue to support them afterwards.

CLIC Sargent recognises that children, young people and their families need specialist support, information and advice from diagnosis and throughout treatment. Social workers are there for all the family members. CLIC Sargent social workers tailor their support to suit the individual needs of children, young people and families.

For example, they can:

- Provide emotional support to all members of the child or young person's family. This includes siblings who may feel confused and detached.
- A CLIC Sargent social worker co-leads a weekly group on the ward called Parent's Tea.
- They can also help families deal with the demands of daily life, work and financial commitments.

- Advise you about the benefits or grants you may be entitled to, and where else you might be able to apply for financial help. They can also help with the paperwork and applications
- Help you deal with people or organisations like your employers or your child's school.
- Referrals to charities and sign-posting to other sources of support
- For those who live beyond the M25; referrals to "Home from Home" and "Paul's House" who may be able to help with accommodation

They can also introduce you to other families and parents who have children with cancer. Then you can talk about the experience and share useful tips on coping with the effects of cancer on your family.

Immunisations

Chemotherapy can reduce immunity to infections that your child has already been on treatment should not receive their childhood immunisation from diagnosis until six months after the end of treatment.

The exception to this is children who are under one year of age. Babies who have not completed their immunisations at two, three and four months of age can receive these during chemotherapy if they are well. Please discuss with your PTC when it is appropriate to start vaccinations as this will differ according to each protocol.

Seasonal Influenza vaccine is recommended every year in autumn for all patients over six months old receiving chemotherapy. However children during treatment should not receive the "live" vaccine given to other children.

The only exception to this advice is for those with a severe egg allergy. Currently, the flu vaccine is developed using eggs. If your child has an egg allergy please contact your PTC for advice.

Re-immunisation is needed after finishing treatment.

It is very important that your child is revaccinated six months following completion of treatment. This is because they will have lost of some of the immunity they had before treatment, meaning previous vaccines will not keep them protected. We recommend that you contact your GP arrange this when your child finishes treatment.

Please note: patients who have received a bone marrow transplant will receive different guidance on when to be re-immunised after treatment.

Immunisation of siblings / parents / carers

We advise that siblings are fully immunised, as this protects them and the child with cancer. There is no risk of a child with cancer catching measles from a vaccinated sibling. Seasonal Influenza vaccine is also recommended for all household contacts (parents, siblings, close family members aged six months or older) during treatment and for six months afterwards.

If your child does not have antibodies to chicken pox, siblings and parents/carers who have not had chicken pox should be vaccinated against it. This is to protect the child receiving treatment. You can obtain this vaccination from your GP, but if there are any difficulties in obtaining the vaccine please discuss with your key worker.

Holidays and Holiday Insurance

If you are planning any holidays in the near future, then we advise you to seek advice from the doctors and nurses well before you book anything, especially if you are going abroad. There are some destinations which we would not recommend you travel to while receiving treatment.

Your (POONS) outreach nurse, or local team will be able to provide letters if required to help you take medical supplies abroad and arrange a local contact should medical help be required for the child receiving treatment – however they will need at **least two weeks** notice to arrange this for you.

Travelling Abroad

We recommend that you do not travel without appropriate travel insurance which is likely to be more expensive. A list of insurance companies who may undertake to provide appropriate medical travel insurance is listed below; in addition useful travel advice is available from: www.macmillan.org.uk

If you are travelling abroad during or soon after chemotherapy, discuss immunisation requirements with your medical team.

If you are considering taking a holiday abroad it is important to arrange appropriate insurance cover.

Listed below are some insurance companies who will undertake to provide medical insurance – provided that your child is travelling with the permission of their doctor. You are still able to approach other companies who provide travel insurance. Most companies will require either a letter from the doctor or medical report form to be completed before a decision about cover can be made.

JD Consultants

Website: www.jdtravelinsurance.co.uk
Tel: 01689 859 102/3/4
01689 856 984
Fax: 01689 856 808
44 High Street, Farnborough, Kent, BR6 7BA

Orbis Insurance Services

Website: www.orbisinsurance.co.uk
Email: cover@orbisinsurance.co.uk
Tel: 01424 215 315
49-51 St. Leonards Road, Bexhill-on-Sea, East Sussex, TN40
1JA

Medi travel cover Ltd

Website: www.insurecancer.com
Tel: 01252 780 190 / 0845 649 0190
76 Crooksbury Road, Farnham, Surrey, GU10 1QD

It's So Easy Travel Insurance

Website: www.itssoeasytravelinsurance.com
Tel: 0330 6061422
27 Old Gloucester Street, London, WC1N 3XX

Allclear Insurance

Website: www.allcleartravel.co.uk
Email: info@allcleartravel.co.uk
Tel: 01708 339295 (9am to 7pm Monday to Friday, 9am to 4pm
Sat, 10am to 4pm Sun)
AllClear House, 1 Redwing Court, Ashton Road, Romford,
Essex, RM3 8QQ

Free Spirit

Website: www.freespirittravelinsurance.com
Email: contact@freespirittravelinsurance.com
Tel: 0845 230 5000 (8am to 6pm Monday to Friday)
Stansted House, Rowlands Castle, Hampshire, PO9 6DX

Further Sources of Information and Support

There are many organisations that may be able to help. Some are listed below.

Children's Cancer & Leukaemia Group

Website: www.cclg.org.uk

A charity which provides reliable written information for families. CCLG also produce a magazine for families which you can access through the CCLG website.

Cancer & Leukaemia in Childhood (CLIC)

Website: www.clicsargent.org.uk

Email: helpline@clicsargent.org.uk

Tel: 0300 330 0803 (Helpline)

Aims to improve treatment and support for children with cancer and leukaemia. Provides free accommodation adjacent to paediatric oncology units in certain areas. Funds home care nurses and crisis breaks via Social Workers.

Kids Cancer Charity

(Formerly Christian Lewis Trust)

Website: www.christianlewis trust.org

Email: enquiries@kidscancercharity.org

Tel: 01792 480 500

Aims to improve the quality of life for children and provide support to their families. They provide information about support groups and a national network of approved complementary therapies.

Macmillan Cancer Support

Website: www.macmillan.org.uk

Email: cancerline@macmillan.org.uk

Tel: 080 8808 0000 (Cancerline – Mon to Fri, from 9am to 6pm)

This is a National Charity, working to help improve the quality of life for people with cancer and their families.

Children's Cancer Web

Website: www.cancerindex.org/ccw

Website indexing lots of children's cancer websites.

CancerHelp UK

Website: www.cancerhelp.org.uk

Tel: 080 8800 4040 to speak to a nurse

A free information service about cancer and cancer care for people with cancer and their families brought to you by [Cancer Research UK](http://www.cancerresearchuk.org). They believe that information about cancer should be freely available to all and written in a way that people can easily understand.

Lennox Children's Cancer Fund

Website: www.lennoxccf.org.uk

Tel: 01708 734 366

Offer practical, financial and emotional support to the whole family through our range of projects.

Starlight Children's Foundation

Website: www.starlight.org.uk

Email: wish@starlight.org.uk

E-newsletter: enews@starlight.org.uk

Tel: 020 7262 2881

Grants wishes and provides entertainment facilities in UK hospitals.

REACT

Website: www.reactcharity.org

Email: react@reactcharity.org

Tel: 020 8940 2575

Gives specific help to children who suffer from a potentially life-limiting illness, and their families such as grants for equipment, heating, clothing, and toys.

Rainbow Trust

Website: www.rainbowtrust.org.uk

Email: enquiries@rainbowtrust.org.uk

Tel: 01372 363438

Provide practical help and emotional support to the whole family. For example, help attending hospital appointments, providing respite and care for siblings, and support in talking to your child about their illness.

Charities for children with specific conditions

Bloodwise

Website: www.bloodwise.org.uk

Tel: 020 75042200

UK research charity devoted to research into the causes, treatment and prevention of leukaemia and related diseases.

Contact a Family

Website: www.cafamily.org.uk

Email: helpline@cafamily.org.uk

Helpline: 080 8808 3555 (Mon to Fri from 9:30am to 5pm)

Contact a Family provides a network of support groups for parents whose children have special needs and disabilities.

Leukaemia CARE

Website: www.leukaemiacare.org.uk

Email: info@leukaemiaCARE.org.uk

care@leukaemiaCARE.org.uk

Tel: 08088 010444 (freephone helpline)

Provide support to families and to patients with leukaemia and allied blood disorders. Provide information, holidays, discretionary financial assistance, and support by volunteers (many with personal experience of the illness).

Neuroblastoma Society

Website: www.neuroblastoma.org.uk

Email: secretary@neuroblastoma.org.uk

Tel: 020 8940 4353

Charity, which aims to fund research into the illness and support families of children who have been affected by the disease.

The Childhood Eye Cancer Trust

Website: www.chect.org.uk

Email: info@chect.org.uk

Tel: 020 7377 5578

Offers support and information to families. Publishes a newsletter and puts families in touch with each other.

The Dancing Eye Syndrome Support Trust

Website: www.dancingeyes.org.uk

Email: support@dancingeyes.org.uk

Tel: 01793 493131 / 07434304291

Supplies information about Dancing Eye Syndrome and neuroblastoma and offers support by putting families in touch with each other. There is a newsletter and an annual meeting.

The Histiocytosis Research Trust

Website: www.hrtrust.org

Email: info@hrtrust.org

Tel: 07850 740241

An organisation devoted to raising funds for and commissioning research into histiocytosis.

Parent Council of the North Thames Children's Cancer Network

Are you a parent or carer of a child under 16 years of age being treated or previously treated for a childhood cancer or tumour (including leukaemia) at Great Ormond Street Hospital or University College Hospital London? Would you like to help improve children's cancer services?

We are looking for parent representatives to join the North Thames Cancer Children's Parent Council. The Parent Council aim to provide experience and act as the child's voice to help improve services and patient experience for children treated with cancer or tumours from the North Thames area. We send representation to the Children's Cancer Network Coordinating Group, which is made up of primary care representatives and cancer professionals. We also act as a resource for one off projects where professionals are looking for parent representation, examples include a junior doctor training day/testing computer package for children.

We are an engaging and diverse group and want to get more parents or carers involved. We anticipate a time commitment of approximately four hours per month maximum, with meetings being held centrally every couple of months. You can get involved as little or much as you would like.

If you are interested and would like to know more, or would like to put yourself forward to join the Parent Council, please email Claire Gallon at claire@gallonmail.co.uk with your name and a few sentences about what you feel you would bring to the group.

Holidays for children and families and wish granting charities

There are a number of different charities that provide free holidays for the families of children and young people on treatment. You can contact these charities directly, or ask your CLIC Sargent social worker for a referral.

Barretstown

Website: www.barretstown.org

An international summer camp in Ireland for children with cancer and serious blood diseases. Provides holidays for all the family.

Calum's Cabin

Website: www.calumscabin.com/

Named after Calum Speirs, this holiday cabin on the Isle of Bute is available to families with a child with cancer to have a wonderful holiday.

Camp Quality UK

Website: www.campquality.org.uk

A non-profit organisation providing a holiday experience for children with cancer or other life limiting conditions.

CLIC Sargent

Website: MSH@clicsargent.org.uk

Tel: 01292 671 233

Offers holidays at [Malcolm Sargent House](#), located on Ayrshire's stunning coast. Holidays for families during and after treatment, as well as short breaks during the weekends or low season. Accommodation and all meals provided free of charge, with medical support nearby should you need it. Contact CLIC Sargent Administrator at Malcolm Sargent House.

Donna's Dream House

Website: www.donnasdreamhouse.co.uk

Blackpool based charity providing free sponsored holidays of a lifetime in Blackpool for children and teenagers with life limiting illnesses and their families.

Dreamflight

Website: www.dreamflight.org

Dreamflight is a registered UK charity whose purpose is to take seriously ill and disabled children on their 'Holiday of a Lifetime' to the theme parks of Central Florida.

Dreams Come True

Website: www.dctc.org.uk

Charity helping terminally and seriously ill children by fulfilling their most treasured dream.

Ellen Macarthur Cancer Trust

Website: www.ellenmacarthurcancertrust.org/

gosailing@emcancertrust.org

Tel: 01983 2977750

Takes young people aged 8–24 in recovery from cancer on four-day sailing trips on board 38-48ft yachts at Cowes on the Isle of Wight or Largs in Scotland. Three days spent on the water, staying at a different port each night. Organised activities onshore in the evenings. The emphasis is on having fun – sailing, crabbing, fishing, games, flying kites, eating ice cream, making friends and epic water fights!

Hannah's Appeal

Website: www.hannahsappeal.org

Email: pam@hannahsappeal.org

Tel: 023 9257 0810

Mobile: 07790 349876 and 07518 026172

Holiday home in the New Forest for families of children who have cancer.

Kids Cancer Charity

Contact Details

Judith May, judith.may@kidscancercharity.org Tel: 01792 480500

3 day breaks in Disneyland Paris

Sharon Gosney, sharon.gosney@kidscancercharity.org Tel: 01792 480500

Free holidays in a luxury caravan in a holiday park near the Welsh coastline, close to the local amenities and tourist attractions.

Katie's Ski Tracks

Website: www.katiesskitracks.org

Provides skiing holidays for children and young people with an illness or disability.

Make A Wish Foundation

Website: www.make-a-wish.org.uk/

Make-A-Wish grants magical wishes to children and young people fighting life-threatening illnesses.

Over the Wall

Website: <http://www.otw.org.uk>

A charity that provides residential camps for children and young people who are affected by cancer and other serious illnesses.

Rays of Sunshine Children's Charity

Website: www.raysofsunshine.org.uk

Charity which grants wishes for terminally and seriously ill children (age 3-18).

Round Table Children's Wish

Website: <http://www.rtcw.org>

A registered charity granting wishes to children under 18 with life-threatening illnesses in Great Britain and Ireland.

Starlight Foundation

Website: <http://www.starlight.org.uk>

Grants wishes and provides hospital entertainment for seriously and terminally ill children.

The Happy shack (beach hut)

Website: www.unlockalifeforlockey.co.uk/the-happy-shack-beach-hut/

A beach hut that can be used for family day trips. Priority given to families living in Essex, Suffolk and Norfolk.

The Oliver Curd Trust

Website: www.theolivercurdtrust.co.uk/

The Oliver Curd Trust was set up by Richard and Sarah Curd, in memory of their son Oliver who was diagnosed with Ewings Sarcoma in April 2006 but sadly lost his long brave fight with the disease in November 2007. Caravan holiday in Crowhurst Park, Battle and Combe Haven Holiday Park, St. Leonards

When you wish upon a star

Website: www.whenyouwishuponastar.org.uk

Aims to fulfill the wishes of children with life threatening and terminal illnesses.

Willow Foundation

Website: www.willowfoundation.org.uk

A charity dedicated to improving the quality of life of seriously ill adults aged 16 to 40 by organising and funding a special day of their choice.

Youth Cancer Trust

Website: www.yct.org.uk (Region: National, Northern Ireland)

The Youth Cancer Trust provides free holidays to young people between the ages of 14-30 suffering from, or in remission from cancer or any other malignant disease.

Fasting guidelines before general anaesthesia or sedation

If your child needs to have a general anaesthetic or sedation, special preparation is necessary for the procedure to be performed safely.

This involves stopping your child eating and drinking before the anaesthetic or sedation. More specific information is available from the doctors and nurses on the ward where your child is admitted.

General anaesthetic

Children over 1 year:

- No food or milk 6 hours before the general anaesthetic time.
- Clear fluids like water or diluted juice, but not milk, up to 2 hours before the anaesthetic time.

Children under 1 year on regular milk feeds:

- No formula or milk feeds for 6 hours before the anaesthetic time.
- No breast milk for 4 hours before the anaesthetic time.
- Clear fluids like water or diluted juice, but not milk, up to 2 hours before the anaesthetic time.

If your baby is having 2 to 3 hourly feeds, please ask your doctor or nurse for further advice.

Sedation

No food or milk 4 hours before the sedation time.

Clear fluids like water or diluted juice, but not milk, up to 2 hours before the sedation time.

It is important you check the time of the scan with the ward or day care so your child is correctly starved.

Please ask your doctor or nurse for further advice if your child is under 1 year old, or if they have other problems like kidney disease, low blood sugar or sickle cell anaemia.

Useful Words

Unfortunately, we sometimes use certain words and abbreviations that you may not understand. Please ask for an explanation, but here are a few of the very common ones you may hear.

Afebrile	Normal temperature
ALL	Acute Lymphoblastic Leukaemia
AML	Acute Myeloid Leukaemia
Anti-emetics	Medicines to control nausea (feeling sick) and vomiting
Apyrexial	Normal temperature
BMA	Bone marrow aspiration - test to take a small sample of bone marrow (see our leaflet for more details)
BMT	Bone marrow transplantation
BP	Blood pressure
CVC or CVAD	Central venous catheter/Central venous access device – usually a Hickman line® or Port
FBC	Full blood count - the test that checks the levels of Haemoglobin (Hb), platelets and white blood cells in your child's blood
Febrile	Raised temperature or a 'spike' in temperature
GCSF	Granulocyte Colony Stimulating Factor
GvHD	Graft versus Host Disease
Hb	Haemoglobin - substance in red blood cells that carries oxygen
Intrathecal	Drugs given into the spinal fluid during a LP
LFT	Liver function test – test to check how the liver is working
LP	Lumbar puncture - test where a needle is inserted into the spinal fluid (see our leaflet for more details)
Mucositis	Inflammation of the lining of the mouth and gut
Nil by mouth	The times when your child should not eat or drink before having sedation or a general anaesthetic
Obs	Temperature, pulse, respirations and blood pressure monitoring
PBSCT	Peripheral blood stem cell transplant
PTC	Principle Treatment Centre
POSCU	Paediatric oncology shared care unit
Pyrexia	Raised temperature or a 'spike' in temperature
TPN	Total Parenteral Nutrition - Food supplement given into your child's bloodstream via a vein
TTO's	Medicines you are given before going home 'to take out' with you
U&E	Urea and electrolytes - the blood tests that checks the levels of chemicals in your child's blood