Following your child's diagnosis of Cancer or Leukaemia

Information about Ward 2 "Lochranza"

Information for Parents and Carers

This folder has been put together for you to help provide information and advice on your child's diagnosis and treatment. We realise that this time can be overwhelming but we hope that this folder will make sure that you have all the information that you need to know to keep your child safe, with respect to their diagnosis.

We want you to feel involved in your child's treatment. We would encourage you to ask any questions you have about your child's disease and treatment and we will always answer your questions honestly and clearly.

You will be given more information as required once a diagnosis and treatment plan are confirmed. We can also let you know where to find further sources of information and support.

Useful and important contact numbers

Emergency	**999**
Lochranza	**0131 312 1334**
Ward 2 Triage Phone (The Red Phone)	**0131 312 1731**
Lochranza Daycare	**0131 312 1335**
Haematology/Oncology Nurse Specialist Team	**0131 312 1740**

Your Haematology/Oncology Nurse Specialist is:

Name: ……………………………………………………………

Mobile: ……………………………………………………………

Your Physiotherapist is: ……………………………………………………………

Your Occupational Therapist is: ……………………………………………………………

Your Dietician is: ……………………………………………………………

Your Psychologist is: ……………………………………………………………

Your Teachers are: ……………………………………………………………

Contents

Useful and important contact numbers 1
An introduction to the ward 3
Infection 3
Central lines 7
Chemotherapy 9
Surgery 10
Radiotherapy 10
Blood cells in the body 10
Giving medication 11
Toileting 12
Washing clothing 12
Vomiting 12
Dietitian 13
School/nursery 13
Mud/bark/hay 13
Pets 14
Farm visits 14
Hair loss 14
Holidays 15
Sun protection 15
Swimming/hot tubs 15
Mouth care 15
End of treatment 15
Transport 16
Useful websites for newly diagnosed patients 16

An introduction to the ward

Lochranza

When children and young people need to stay in the Royal Hospital for Children and Young People (RHCYP) overnight for investigations and treatment, they will come to the Paediatric Haematology/Oncology ward (Lochranza), where possible. Here they will be looked after by the Multi-disciplinary Health Care Team (MDT) which includes: Nurses, Doctors, Pharmacy, Physiotherapists, Dieticians, Occupational Therapists, Dentists, Teachers, and the Psychology Team.

Lochranza day-care

Children and young people attend the day-care unit for various tests and treatment which can be completed during the day time (08:00am-05:30pm).

Out-patient clinic

The out-patient clinic is in a separate area of the hospital which we will explain to you.

Infection

Children and young people with leukaemia and cancer are more at risk of infections both because of the disease itself and because of the treatment. Both of these can affect the white blood cells (the immune system) which fight infections. When the white blood cells are low after chemotherapy, your child is particularly at risk of infection. Once the blood counts rise again, the risk lessens.

Children and young people with cancer and leukaemia may be more likely to catch common infections which can affect anyone (e.g. colds), but are also at risk of more unusual infections because of a reduced immune system.

The risk of developing serious infections from contact with other people is minimal therefore your child does not need to be isolated. One of the most common reasons for a temperature is infection from bacteria within our own body. We all have millions of bacteria in our bodies and when our immune systems are lowered, we can ‘get’ an infection from our own bacteria. So, whilst keeping away from people with obvious infections (e.g. someone we know with chicken pox or flu) is very sensible, it is always possible to develop an infection without coming into contact with anyone else. It is for this reason that we would advise that your child returns to nursery, school, or college as soon as possible even though their treatment might continue for a long time.

Any temperature of 38.0^{o}c or more **must** be investigated, especially in patients with central lines. Blood stream or line infections can happen even if the white cell count is good. **If this happens, phone the red phone: 0131 312 1731**

Neutropenia is when the neutrophil count is less than 1.0- this is a condition which causes a low white blood cell count. **Febrile neutropenia** is when the neutrophil count is less than 1.0 and the patient also has a temperature of 38.0^{0}c or more. This can be life threatening and **must be treated**.

If your child has a temperature of 38.0^{0}c or more, phone the red phone: 0131 312 1731.

There are certain infections that are always dangerous for cancer and leukaemia patients. These are chickenpox and measles. If there is a possibility that your child has been in contact with either, then you should telephone us to discuss it as soon as possible as they may need treatment.

Important signs of infection

If you see **any** of these signs, especially if you know that your child's white blood cell count is low, then you should contact us **as soon as possible**:

- Fever – if their temperature is 38°C (or 100°F) or more
- If their temperature is low, e.g. 35°C or below
- Shivering and feeling cold with a high temperature
- Cough and fast breathing
- Severe diarrhoea
- Stomach pains, nausea, vomiting
- Headaches, stiffness, changes in behaviour
- Rashes, blisters, ulcers, mouth sores
- Earache, sore throat
- Pain with pooing and peeing
- Infections around the fingers or toenails
- If your child looks unwell and feels ill, even though there is no fever.

If your child has a fever, or is unwell, **phone the red phone first on 0131 312 1731-** then we will ask you to bring them to hospital. Out of normal working hours (08.30am-04.30pm Monday to Friday) you must take your child to the Accident and Emergency (A&E) department- the ward will let A&E know to expect you. This is very important as there are no regular doctors on the ward out of hours.

We continue to work very hard to smooth the pathway through A&E. It is the safest place to go to out of hours. Your child will be examined and samples of blood, urine and throat swabs will be taken. Your child will need intravenous (IV) antibiotics (where the medicine is given directly into a vein) as soon as possible, ideally within one hour of coming to hospital. IV antibiotics will normally continue until 48 hours (2 days) after we record the last temperature of 38.0°c.

Viral infection

Over a long period of time, particularly during continuing therapy for leukaemia, the drugs can interfere with the body's ability to cope with certain viruses.

Most common viral infections are not prolonged or serious in children on treatment and you do not need to worry about them unless your child has a temperature of 38.0°c or above.

The Following are the exceptions:

- Measles
- Chickenpox
- Shingles.

Measles

Measles can be a very serious infection in children receiving continuing treatment. Fortunately most children in Britain have now been immunised with the MMR (measles, mumps and rubella) vaccine. If your child has been immunised with MMR they are very unlikely to get measles.

If your child comes in direct contact with another child with measles, and they have not had measles or the MMR vaccine, they need to get an injection of immune globulin to help strengthen their body's defence system. This is called HIG (human immune globulin) and it has to be given as an injection into the muscle. It should be given within 48 hours of contact with measles but it can be given after this time if necessary.

You can help lower the risk to your child by getting the other children in your family immunised. There is no risk of transmission of the virus from other children who have recently been immunised.

Chickenpox

Chickenpox is a common childhood illness, but for children who are immunocompromised, (have low immunity to infection) it can make them very unwell.

Chicken pox is caught from contact with another person with chickenpox, up to 48 hours before they develop the rash or during the first few days of the rash appearing. The contact person can be infectious for 48 hours before they know that they have chicken pox. In most cases it cannot be passed on to someone who has previously had chicken pox. A contact means being in the same room as the affected person for 15 minutes or more.

Your child will be checked to see if they have antibodies to chicken pox by a blood test. If they have had chicken pox previously they will probably have immunity and will be at low risk of re-infection. However, sometimes the chemotherapy treatment can reduce a child's immunity. We will check your child's antibodies at various time points throughout their treatment.

You should always phone your **nurse specialist team on 0131 312 1740** to report a chicken pox contact so we can check their most recent level.

In the event that your child does not have immunity and they come into close contact with chicken pox, serious infection can be reduced or avoided by taking a course of anti-viral medication called Acyclovir. Ideally this should be started within 7 days after your child has come in to contact with the person who has chickenpox.

Contact the ward (**0131 312 1334**) or your Haematology/Oncology Nurse Specialist as soon as possible after exposure to chicken pox so that previous antibody results can be checked. A positive immunity result within the last 6 months means that no treatment is needed. A negative immunity result or no information means that a prescription for oral Acyclovir is needed.

Children who develop chickenpox should receive prompt treatment with intravenous (IV) Acyclovir. Your child will need to stay in hospital for at least 7 days to receive treatment.

Shingles

Shingles is caused by the same virus as chickenpox (the varicella zoster virus). Shingles can only occur if you have had chickenpox and it is caused by reactivation of the virus which has been lying dormant in the body. This can happen when immunity is low. The virus travels along a nerve path and will appear as a rash on the skin supplied by that nerve.

As for chicken pox, shingles must be treated promptly with IV Acyclovir and your child will need to stay in hospital for at least 7 days for treatment.

If your child has been exposed to chickenpox or measles or has shingles, **do not** bring them to the ward or clinic without **phoning the red phone first: 0131 312 1731**.

Inpatient treatment for these infections will take place in a different area to reduce risks for other immunocompromised patients on the Oncology/Haematology ward.

Cold sores

These are caused by the herpes simplex virus, and some children get recurrent problems. If they are persistent or troublesome the doctor will treat them with oral Acyclovir. They rarely cause major problems but can be uncomfortable and can delay bone marrow recovery after heavy drug treatment.

Pneumocystis (Carinii) jiroveci Pneumonia (PCP)

Children who are receiving long-term therapy may be at risk of an unusual type of pneumonia called pneumocystis. This infection is due to an organism (bug) which may be present in most people’s lungs. In patients who are on long-term drugs which interfere with the body’s ability to cope with infections, the infection may be activated.

The symptoms of this infection include: fever, rapid breathing and a dry cough.

Some chemotherapy regimens may increase the risk of developing PCP. In these circumstances your child will be on a low dose oral medication called co-trimoxazole (septrin) two days a week to help prevent this infection.

Vaccinations/immunisations

Whilst on treatment, children **should not have** live vaccinations/immunisations.

The only exception to this is the flu vaccine which should be given in the injection form rather than the nasal vaccine.

When your child has finished treatment, the need for repeat vaccinations will be discussed. Children should be re-immunised or given boosters 6–12 months after stopping therapy. If your child has had a bone marrow transplant, specific advice will be given from the transplant hospital.

Immunisation of brothers/sisters

Full immunisation is recommended for brothers and sisters. Immunisation against measles is especially important. We recommend that all household members also receive the annual flu vaccine while your child is on treatment. Siblings are still eligible for the nasal flu vaccine. Speak to your family GP about having this.

Central lines

A central line is a large, hollow tube, (catheter) which is used to give medication, including chemotherapy and is used to take any necessary blood tests.

The use of central venous lines for children undergoing treatment for cancer has greatly improved their quality of life. These lines enable us to give the chemotherapy safely, take blood samples and perform other procedures with minimum trauma.

The central line means that needles are not being continually inserted into the small veins in the hand.

As the tube which enters the skin is located in a larger vein than those in the hand, a central line makes giving chemotherapy safer as it reduces the risk of ‘extravasation’ (when medicine leaks from the vein into surrounding tissues).

The central line is inserted while your child is under a general anaesthetic (they are ‘asleep’ for the procedure).

In Edinburgh we use different types of central lines, which include

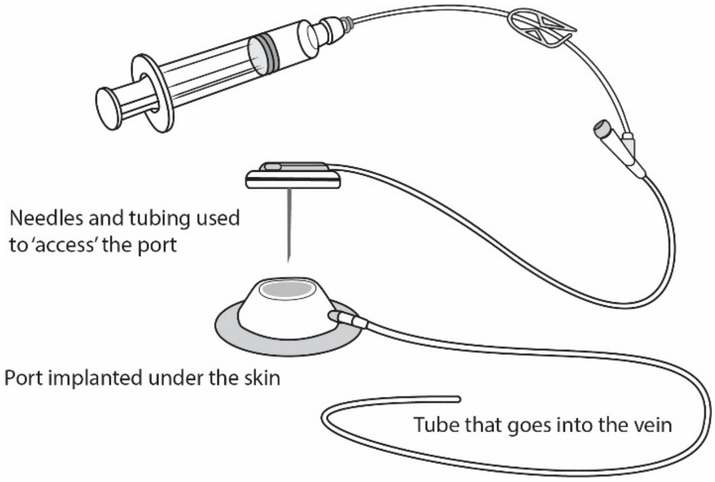
- **Portacath** (Single or double lumen)
- **Hickman Line** (Single or double lumen)

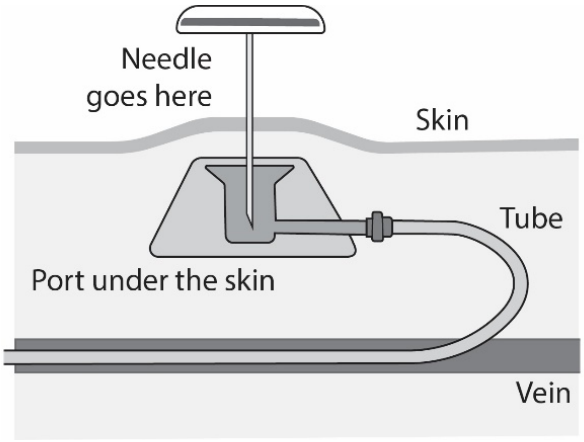
There are a number of different factors involved when choosing a line. They can be ‘single’ or ‘double lumen’. Some chemotherapy treatments are more complex than others and will require a double lumen central line (double lumen means you can have medicines running at the same time as fluids). Many cancer treatments can be managed with a portacath which is the type of line we use most commonly at RHCYP.

All lines have individual advantages and disadvantages and these will be discussed with you and with your child as appropriate.

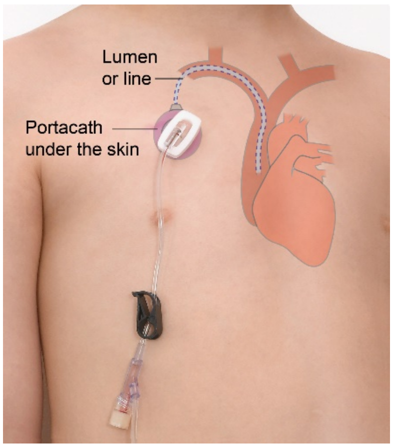
Portacath

There will be a small incision in the neck to place the catheter, or tube, into the vein. From there, it will be fed down inside the vein to just above the heart. The rounded end or ‘box’ or ‘port’ is fed down under the skin to its position on the chest wall above or to the side of the breast area. It is totally covered by skin.





To use the portacath, a needle is inserted through the skin into the port. Before inserting the ‘Gripper needle’, ‘magic cream’ (Emla anaesthetic cream) can be placed over the port site and it will be held in place with a clear dressing film. Numbing “freeze spray” can also be used to numb the area before the gripper needle is placed.

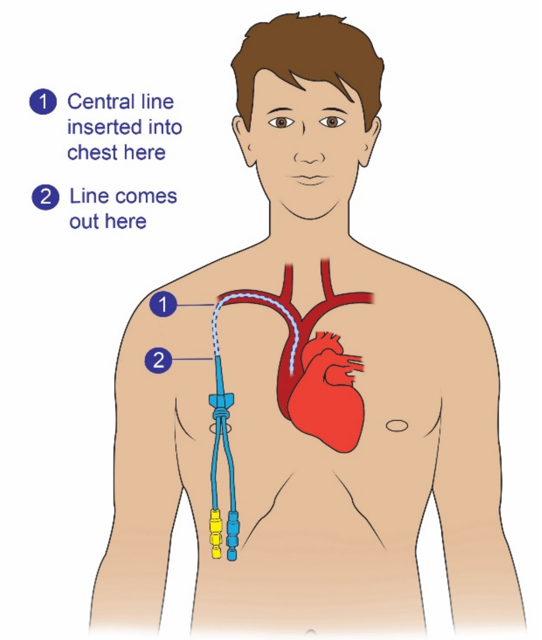


Although this process can frighten children at first they soon get used to it. The needle can stay in place for one week before being changed and a dressing is used to cover and support the needle.

When the portacath is not in use, no particular care is required and they only need to be flushed monthly. When there is no gripper needle in the portacath, your child can go swimming and bathe although contact sports should be avoided.

Hickman Line

A small incision is made on the side of the neck and the tip of the line is inserted into a large vein leading into the heart. The other end is tunnelled down under the skin and comes out on the chest wall above or to the side of the breast area. There is a Dacron cuff around the line, which helps to hold the line in place. There is also a stitch, supporting the line at the exit site, which may be removed at a later stage. Hickman lines come in either single or double lumen.



The Hickman Line requires a dressing, which needs to be changed weekly, and the exit site cleaned. The line requires flushing once a week when not in use. Hickman lines are often used when more intensive therapy is required, or if a child has needle phobia. Children with Hickman Lines are unable to go swimming and have to bathe with care.

When the line is not in use it is secured in a special bag or with tape to prevent pulling and discomfort.

The ward nurses and Haematology/Oncology Nurse Specialist team will ensure that you are taught how to care for the Hickman line and additional information is available if you wish to learn how to change the dressing.

Chemotherapy

It is possible that your child will require chemotherapy (chemo) as part of the treatment plan for their cancer/leukaemia.

There are many different chemotherapy drugs. They all look different, are given differently, and have their own individual side effects. You will be given written information about each of the chemotherapy drugs your child will receive and the doctors will discuss them all with you.

- **Oral Chemotherapy**

  Some chemo drugs can be given by mouth or down a feeding tube. **Please wear gloves when administering oral chemotherapy.**

  If your child's treatment plan includes oral chemo you will be taught how to do this at home.

- **Intrathecal Chemotherapy**

  This is chemotherapy which is given into the cerebral spinal fluid (CSF). This is done using a lumbar puncture (where the medicine is injected between the bones in the lower back) and requires a general anaesthetic.

- **Intravenous Chemotherapy**

  Most chemo is given into the vein, (intravenously/IV). In most cases this will be done using your child's central line.

  Some IV chemo is given quickly, over a few minutes as a 'bolus' or 'push'. Others are given as an 'infusion' using an infusion pump to give over a longer period, (usually several hours).

  Some IV chemo is given alongside IV fluids, (through a drip).

You will be given separate information sheets about each of the chemo drugs your child will receive which will explain how they are given and specific side effects. Your doctor will discuss all of these side effects with you in more detail. Please ask questions if you do not understand something or need some clarification.

You will be asked to sign a consent form before we begin any chemotherapy treatment.

It is our policy to ask all female patients who have reached puberty to provide a urine sample for a pregnancy test before each cycle of chemotherapy. This is to confirm whether there is any possibility that they may be pregnant before commencing chemotherapy. If a patient is going to be treated on a clinical trial they may require a negative pregnancy test. Please do not be offended if we discuss this with you as it is a requirement for all relevant patients under our care.

Surgery

Some types of cancers will require your child to have an operation to have their tumour/cancer removed.

This depends on what the diagnosis is. Some operations are at the beginning of treatment but sometimes chemotherapy is given first to shrink the tumour before taking it out. The doctors will discuss with you if your child needs an operation.

If surgery is necessary then it is unlikely that this will happen on the haematology/oncology ward. Usually the patients are looked after on one of the surgical wards in the days after their operation where the staff have specialist knowledge.

In some circumstances it may be necessary for your child to have their surgery in another hospital which has particular expertise in performing operations for rarer cancers.

Each child under our care is discussed at a national meeting with children and young people cancer specialists to ensure the best course of action is taken for each individual patient.

Radiotherapy

Some types of cancer require treatment with radiotherapy. This can be the only treatment received in some cases but more commonly it is given as well as chemotherapy and/or surgery.

Radiotherapy uses high energy rays to treat the disease. It is not a painful procedure but does require a patient to be absolutely still throughout the session.

This type of treatment is planned very carefully to avoid treating healthy tissue as much as possible. Normal cells can be damaged by radiotherapy although they often can repair themselves. Radiotherapy has certain side effects which will depend on where in the body the tumour is.

Where possible, radiotherapy is avoided in young children as it can affect growth. It may be necessary for younger children to have a short general anaesthetic during the session if they are unable to lie still.

At NHS Lothian we give radiotherapy at the Western General Hospital. We will arrange all the appointments for you and your Haematology/Oncology Nurse Specialist will try to go with you for your first appointment.

Proton therapy

Proton therapy is a specialised form of radiotherapy which is recommended for certain tumours. If this treatment is required for your child, you will receive more information about what is involved. We currently do not offer proton therapy in Scotland so there will be a need to travel to receive this.

Blood cells in the body

The bone marrow (the spongy component found inside the hollow of the bones), is the blood factory of the body. Blood is essentially made up of the following three cells:

- Red blood cells
- White blood cells
- Platelets.

One side effect which is common to many of the chemotherapy drugs is a low blood count (Pancytopenia). This is caused by the drugs having an effect on the healthy blood and bone marrow cells as well as the cancerous cells.

When on chemotherapy your child's blood count will be monitored carefully. The following may occur:

Low	Possible Signs & Symptoms include	Possible Treatment
Red Cell Count (Haemoglobin/Hb) *Anaemia*	• Pale • Tired/increasing lethargy • Shortness of breath • Headaches.	Red Cell Transfusion
Platelet Count *Thrombocytopenia*	• Bruises • Bleeding from nose or gums • A rash of tiny, red, pin-prick spots.	Platelet Transfusion
White cell count (Includes neutrophils) *Neutropenia*	Often difficult to detect without testing but often goes alongside low red cells or platelets. **Patients are at significantly greater risk of infection during periods of neutropenia.**	Waiting for counts to recover. Sometimes a drug called GCSF (Granulocyte colony-stimulating factor) can be given for **some** patients at certain time points.

When blood counts are low, your child is at a greater risk of infection and we will monitor them for any signs. We keep a close watch on your child's temperature during this time.

Any temperature of 38.0^{o}c or more **must** be investigated (phone the red phone: **0131 312 1731**), especially in patients with central lines. Blood stream or line infections can happen even if the white cell count is good.

Giving medication

You will be responsible for giving your child their oral medication when they are at home.

If your child has a NG (nasogastric) tube you will be given appropriate training until you are confident in using this.

If the medication you are given is oral chemotherapy, there are a few specific precautions to take.

Safety precautions when handling oral chemotherapy:

1. Avoid direct contact with tablets/capsules/liquids
2. Wear gloves when handling tablets/capsules/liquids; cleaning any spills; or cleaning oral/enteral syringes
3. Do **not** halve or crush tablets; do **not** open capsules
4. If opening capsules is unavoidable, pharmacy staff will inform you of the best way to do this
5. If there is any spillage, wipe clean with water and kitchen paper and dispose in a plastic bag before putting in household waste
6. Wash oral/enteral syringes with washing up liquid and rinse with water before leaving to dry. Syringes may be sterilised if required
7. Dispose of plastic gloves in a plastic bag after each administration.

Paracetamol and Ibuprofen

Please do not give Paracetamol or Ibuprofen to your child unless confirmed with medical staff. Paracetamol and Ibuprofen can mask a temperature, which is often a sign of an infection. Ibuprofen can cause your child's platelets in the blood to not work as effectively as they should.

Toileting

You will notice the nurses on the ward wearing protective items when giving chemotherapy. This includes gloves, an apron, eye protection and sleeves. This is because chemo can irritate the skin if it comes into contact.

Likewise, for up to 7 days after your child has had their chemo, they will excrete some of this in any bodily fluids. For this reason we recommend the following:

- Double flush the toilet after they have used it
- Boys should sit down rather than stand when passing urine
- Gloves should be used if handling waste (e.g. changing nappies or wet/soiled beds). Any used nappies should be double bagged before being disposed of in the household waste
- If your child does have an accident or vomits on their clothes/bedding, these should be washed in a hot wash setting in your washing machine separately from other items. Following this it is advisable to run the washing machine through an empty cycle
- Always wash your hands thoroughly with soap and water.

Sometimes patients experience either constipation or diarrhoea because of their treatment. Both can be treated with additional medicines.

Washing clothing

If your child has had chemotherapy within the last seven days, we recommend washing any soiled clothing/bedding in its own separate wash on a hot wash (60 degree wash). Following this, you should then run your washing machine on an empty cycle. Remember to wash your hands thoroughly with soap and water.

Vomiting

Sometimes chemotherapy can make your child feel and/or be sick. There are many different medications we can give to help this and it is important you let us know if this is a problem for your child so we can add in different medicines if necessary.

If your child is vomiting a lot and not managing to keep fluids down you will need to bring them into hospital so we can give them IV fluids while we adjust the anti-sickness medications until this is under control. You should **phone the red phone on 0131 312 1731 first**.

If the problem is more to do with uncontrolled nausea (feeling sick), telephone the nurse specialist team (**0131 312 1740**) who may be able to organise getting extra medication to you at home to avoid a hospital visit.

Dietitian

Many children receiving cancer treatment will experience problems with eating and drinking at some stage throughout their therapy. This can be due to the cancer itself and to the side effects of the treatment and of the medication.

During your child's treatment course it is important that a good nutritional status is maintained. Being well nourished throughout treatment allows:

- The body to fight infection and reduce the risk of additional complications
- The chemotherapy and/or radiotherapy to be better tolerated
- The body to build and repair healthy tissues that have been damaged during treatment
- Continued growth and development.

Every child reacts differently to cancer treatment. Some experience no difficulties with their appetite and maintenance of their nutritional status. More commonly appetite and taste can be affected and it is during these periods when your child may need to be referred to a dietician.

The role of a dietician is to provide advice and support to make sure your child maintains their nutritional status throughout treatment. There are different approaches to achieve this (e.g. providing information on ways to increase the nutritional content of meals using supplements and extra snacks).

Sometimes it will not be possible to maintain nutritional status with diet and nutritional supplements alone and a feeding tube may be needed. This may be either via the nose (nasogastric tube) or directly into the stomach (gastrostomy). Very occasionally nutrition will need to be provided directly into a vein. This is called parental nutrition (PN). Before this type of feeding is agreed upon, there are discussions with you, the doctors and pharmacists. If you have any concerns about your child's nutritional status, please ask to be seen by a dietician.

School/nursery

Nursery and school is an essential part of any child's life, so we hope as far as possible that your child will still be able to attend nursery or school, even if on a part time basis. Your child may still be able to attend school even if they are neutropenic, and can participate in most activities. However, contact sports must be avoided.

When your child is ready to return to school, your Nurse Specialist will arrange a visit to the school to meet the class teacher and discuss any specific requirements that your child may have, alongside any concerns staff may have about caring for your child. You are welcome to attend this visit alongside your Nurse Specialist. Some special precautions will be put in place to allow your child to attend school safely and your Nurse Specialist will help educate the school about these.

For children who have a prolonged hospital stay, there are hospital teachers who can visit you on the ward and provide appropriate school work.

Mud/bark/hay

Due to the risk of introducing a fungal infection we recommend that children receiving chemotherapy avoid playing in mud, bark, and hay. This is useful to remember when children go back to school/nursery.

Pets

If you have any pets there is no reason why your child needs to stay away from them. However hand washing is extremely important after handling the animals and particularly before meals. It may be worth treating your pets for worms, as recommended by your vet. It is also important for your child to avoid contact with your pet's poo, wee or litter tray.

Puppies and kittens should be immunised before coming into the house.

Please advise your doctor or Nurse Specialist if you have exotic pets as extra precaution may be needed.

Farm visits

There is growing evidence of a link between farm visits and infection in young children. This means that some simple and sensible precautions should be taken.

Families should enjoy their farm visit but parents (and other adults accompanying children) must be vigilant. To avoid infection children should do the following:

- Wash and dry your hands thoroughly after touching animals
- Do not eat or drink anything at all while going round the farm and only eat when well away from the animals after thoroughly washing your hands
- Do not put your face against an animal and do not put your hands in your mouth after touching an animal
- Do not touch animal droppings - but wash and dry your hands immediately if you do
- Avoid climbing on or playing in hay bales which are sometimes a source of significant fungal infections
- Clean your shoes when you leave the farm, or when you get home, and then wash your hands thoroughly.

This repeats the advice given already to parents, teachers and others. It reminds them all that farm visits should be both fun and educational but that sensible precautions should be taken to reduce the risk of infection.

"For all visitors, farmers have responsibility to ensure that hand washing and drying facilities are available and are suitably located, picnic areas are separate and clean, and that all other Health and Safety law is fully observed." *(Department of Health)*

Hair loss

Your child's appearance will change throughout treatment and hair loss can be a challenging time. The Little Princess Trust provides real hair wigs, free of charge for children and young people with childhood cancer.

For further information and to arrange your free real hair wig, please contact:

- Phone: 01432 760 060
- Email: wigs@littleprincesses.org.uk
- Website: www.littleprincesses.org.uk

Holidays

It is advised that you do not travel abroad whilst your child is on treatment and for up to six months after treatment is completed. However, as long as it is discussed with your consultant or Nurse Specialist, you may able to travel within the UK. If you are planning any holidays, please contact your Nurse Specialist as soon as possible so that they can inform the local hospital that you will be in the area, arrange any blood tests and also provide you with a hospital letter before you travel.

Sun protection

Whilst your child is receiving treatment, their skin will be very sensitive and more susceptible to sunburn. Please ensure your child wears SPF 50 sun screen (UVA 5*) as well as a hat when out in the sun. Remember to do this even on cloudy days.

Swimming/hot tubs

If your child has a hickman line inserted, they must not go swimming or use a hot tub.

If your child has a portacath inserted, they can swim as long as the needle is not inserted.

If your child is neutropenic, please avoid swimming and hot tubs.

Mouth care

Dental hygiene is very important, especially in immuno-suppressed patients. Chemotherapy and radiotherapy can cause problems in the mouth such as; infections, sore bleeding gums, ulcers, dry mouth/lips and tooth decay. Any patient who wears braces may need to have these removed before starting chemotherapy. We recommend a strict dental routine to help minimise the risk of infection spreading from the mouth to the blood stream:

- Your child should use a fluoride toothpaste and brush carefully in small circular movements on all surfaces of their teeth and gums. They should not rinse their mouth after brushing. Rinse their toothbrush thoroughly after every use. This should be done at least twice a day
- Your child can use mouthwash or oral gels if prescribed by the Consultant or Dentist
- Keep a close eye for any sore areas in the mouth and let your Consultant or Nurse Specialist know if you have any concerns
- Regular use of lip balm will help to prevent dry/sore lips.

There is a hospital Dentist who will assess your child’s teeth and can help with any issues which may arise.

End of treatment

At the end of your child’s treatment, they will be regularly followed up in clinic with their Consultant. Your Haematology/Oncology Nurse Specialist will continue to look after your child for around 6-12 months after the end of their treatment when you will be introduced to your Aftercare Nurse Specialist.

Transport

Car Parking

There are a number of visitor car parks on site – please follow the signs on campus to find the closest car park.

The RHCYP has three close-proximity car parks for certain eligible patients and their families. Car parks 1A, 1D and 1E are barrier-controlled with number plate recognition and can be pre-booked under certain circumstances for families with a clinical need (for example patients with severe mobility problems, or children dependent on medical equipment). Please discuss these spaces with your clinical team, who can pre-book these for you if you are eligible to use them.

Travelling costs

Travelling from home to the hospital can be expensive. There may be some help available to cover these costs. If you are caring for a child with a long-term hospital admission or frequent visits, help with your transport costs (including parking) might be available. Please ask on your ward, or visit the Family Support Hub on the ground floor.

Other help with the cost of transport

The many journeys to the hospital can become very expensive, especially over a long period of time. CLIC Sargent Cancer Care for Children has recognised the problems that these costs can bring, and may be able to help with the cost of bringing your child to hospital for treatment. Speak to a CLIC Sargent Social Worker for more information.

Where no suitable transport is available

If your child is not well enough to travel by public transport, an ambulance may be arranged to bring your child to hospital. The clinic or the ward clerk, with the permission of the medical staff, will arrange this.

You can also ask us about the CCLASP bus. CCLASP (Childhood Cancer – Advice and Support for Parents) is a local charity who can offer, among other things, help with transport to hospital.

Useful websites for newly diagnosed patients

Types of blood cancer:

- https://bloodcancer.org.uk/understanding-blood-cancer

Keeping active:

- https://bloodcancer.org.uk/support-for-you/living-well/keeping-active/

Eating well:

- https://bloodcancer.org.uk/support-for-you/living-well/eating-well/

Useful Publications PDF able to be downloaded

- https://bloodcancer.org.uk/understanding-blood-cancer/patient-information-publications/