



The Christie **NHS**
NHS Foundation Trust

Welcome to The Palatine ward

We care, we discover, we teach



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Welcome to the Haematology and Teenage and young adult service (TYA)

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The Palatine ward

Welcome to Haematology and Teenage and young adult service (TYA)

Our ward, opened in 2014, was purpose built to merge two units – the haematology and transplant unit and the young oncology unit. This ward specialises in offering care to people with differing blood disorders - haematology is the discipline that investigates disorders of the blood. The ward is also designated for young people with cancer, and is the primary treatment centre for teenagers and young adults with cancer in the North West region.

We have given you this booklet to provide you with information about all aspects of your illness and treatment. There is a different booklet for patients accessing services for young people with cancer. Please ask if this is applicable to you.

Please do not be put off by the size of this booklet. You don't have to read it all at once. Use the contents page to find your way around it, and dip into it when you need particular information.

As well as this booklet you will be given other information about your specific illness and treatment.

1. About the Haematology and Teenage and young adult service

Introduction

From the moment you arrive on the ward or from the moment you are diagnosed, you and your family will have many questions to ask about your illness and your treatment.

The doctors, nurses and other staff will do everything they can to answer your questions, but it can be difficult to think of the right questions or perhaps remember the answers. There is a space at the back for you to make notes.

This booklet is designed for you to keep and may be used as a reference and a source of information.

All staff are here to help you, so please do not hesitate to ask any questions you may have.

The unit cares for patients with newly diagnosed leukaemia and patients with other cancers such as multiple myeloma and lymphoma having high dose treatments and transplants.

The unit has 31 beds, all of which are single rooms with en-suite facilities. Special precautions apply to these rooms and to the unit as a whole. These will be explained later in the booklet.

We aim for you to have most of your treatment on the Palatine Ward but on occasion it may be necessary for you to be moved or to start treatment on another ward. Although it may feel strange to be cared for in a different environment, there is no need to worry. The care and treatment will be of the same high standard.

Information about the unit

Telephone numbers

The Christie: 0161 446 3000

The Palatine ward: 0161 446 3926/3960
(seven days a week)

Haematology & transplant day unit

Outpatients: 0161 446 3924

If you need to phone the ward for information -
please call between the following times. **8am to 1:30pm**
2pm to 7:30pm
In an emergency or if you are unwell, worried or
concerned, please ring the emergency/out of
hours advice hotline: **0161 446 3658**

Address: The Palatine Ward
The Christie NHS Foundation Trust
Wilmslow Road
Withington
Manchester M20 4BX

Entering the unit

Anyone visiting you on the unit **MUST** wash their hands with soap and water at the entrance of the unit

Rooms on the unit

There are 31 single rooms on the unit.

Anyone who enters your room must put on a plastic apron first, then re-wash their hands or apply the alcohol gel located throughout the unit.

When leaving the room, all visitors must remove their apron in the room and wash or gel their hands outside of the room.

Isolation rooms

There are twelve specific isolation rooms. The air in these rooms is filtered under high pressure (sometimes called HEPA filtered rooms). This produces cleaner air that has less airborne bacteria and spores.

- Isolation rooms are generally used for donor bone marrow transplants and for patients who are especially vulnerable to infection.
- Entry to the isolation rooms is through a small separate room with hand-washing facilities.
- Please wait for the internal door to close before opening the outer door. This prevents differences in air pressure and balance in the rooms.

- The windows are sealed and the temperature is controlled inside all the ward rooms. This is to prevent any external organisms entering the ward. Please ask if you need help or assistance adjusting the temperature.

All rooms

- It is important to stay in your room at certain times during your treatment to reduce the risk of infection.
- The windows in all rooms are sealed.
- All rooms have en-suite showers and toilet. Your visitors must not use your bathroom. There is a visitor toilet near the main reception.
- No flowers, fresh or silk are allowed as they may carry micro-organisms.
- There is a handset plugged into the wall where you can call the nurse by pressing the orange button, or for house-keeping by pressing the “tea” symbol button. A light will shine outside your room and a tone will sound indicating which service you require.
- Please help us to answer calls quickly by using the house-keeping button for all non-urgent tasks that do not require a member of the nursing team, such as extra urine bottles, drinks or snacks. This allows the nursing staff to prioritise nurse calls, and our housekeeping and hostess team can assist with other calls.
- All rooms are cleaned on a daily basis. The domestic staff will clean the floor and the bathroom and all other items in your room including the bed, table and other equipment will be damp dusted by the housekeepers, healthcare assistants or nurses. Your bed linen will be changed daily.
- Mobile phones are allowed in the unit.
- All televisions have freeview, and digital radio.
- Patients may use their own laptops whilst on the unit or we have a limited number available for patient use. Please ask your nurse how to access the network.

Information for relatives/visitors

If you would like information about a friend or relative, you can telephone the ward on the numbers at the beginning of this booklet. But please note specific details can only be given to the next of kin over the telephone with the patient’s permission.

If you want to talk to a doctor or nurse while you are visiting, please ask.

You can also arrange to see a consultant, but you need to make an appointment. Please ask the nurse, who will arrange this for you. The consultant team work on a rota system on the ward and cover a month at a time.

Visitors are normally welcome between the hours of 9.30am and 10pm. Visiting outside of these hours must be at the discretion of the nurse in charge but it is possible. Although patients appreciate visitors, they can feel tired and exhausted because of their treatment.

Please be sensitive to the patient's need for adequate rest to help their recovery. Because of this, the nurse may advise you not to visit on a particular occasion, or may not put your telephone call through. But it is important to keep in touch.

If you have any queries **please ask us** - we will be pleased to help. Please note, there may be times when visitors will have to wait in the reception or the relatives' rest room located on the ward.

Patients on the unit are very prone to infection. Please do not visit if you feel unwell, have an infection (including diarrhoea) or have been in close contact with someone who is unwell.

You can also send a greeting via The Christie website: www.christie.nhs.uk or by using the following link: www.christie.nhs.uk/egreeting.

Other important information:

1. If you are visiting with gifts, please note - no fresh flowers, plants, or fruit which can't be peeled, are permitted.
2. Cuddly toys and soft furnishings such as bed covers, cushions should not be brought onto the unit.
3. All books, magazines and newspapers must be new – no library or second hand books can be brought in.
4. Food brought into the unit for patients should always follow the recommendations of the 'clean diet'. Please check with nursing staff first. No patient food should be stored in their room.
5. Only **2 visitors** are allowed inside ANY patient room at any time. However, other visitors may wait in the lounge, if available, or visit the Oak Road coffee bar or other areas at The Christie.
6. No children under the age of 12 year can visit the unit unless they are the patient's own children or siblings. Children under 5 years of age can only visit patients at the discretion of the ward manager or nurse co-ordinator. Children must be restricted to the patient's bedroom. This is to prevent any disruption to the rest of the ward environment.
7. Please do not sit on the patient's bed. Each room has additional chairs for visitors please use these chairs provided.
8. Visitors are allowed to take drinks into the rooms.
9. Please help to keep the room clutter-free by taking away suitcases and all other non-essentials. This helps our staff to keep the rooms dust free and the environment safe.
10. Relatives are NOT allowed to stay in a patient's room overnight unless under exceptional circumstances. Limited accommodation is available within the unit. Please see the nurse in charge or ward manager for more information.
11. Please note smoking or the use of e-cigarettes is not allowed within The Christie or its grounds.

Facilities for visitors on the unit

- There is a visitors' toilet – please do not use the patients' toilet because there may be a risk of infection to the patient.
- Please do not enter the ward kitchen area.
- TYA patient visitors can use the TYA lounge. Access to the TYA social spaces are reserved for TYA patients and their visitors only.
- Haematology visitors can use the designated lounge adjacent to the main entrance of the unit. Access to the day room in the centre of the ward is reserved for patients over 25 years of age who are not in isolation and their visitors.
- Those visitors staying in the accommodation will have access to a lounge within the accommodation on the second floor.

Hospital facilities

Visitors can get a snack, salad or a hot meal from the dining room on the main corridor, open Monday to Friday 7.15am to 3pm. Cooked breakfast is served from 8.30am to 11am, hot lunches between 11.45 and 2pm, and hot drinks until 3pm.

Drinks, cakes and sandwiches are available at the coffee shop in the Oak Road reception. Opening times vary: Monday to Thursday 9.00am to 6pm; Friday 9am to 4.30pm and Saturday and Sunday 9am to 4pm.

The tea bar in main outpatients is open Monday to Thursday 9.30am to 5pm and Friday 9.30am to 3.30pm for drinks and snacks.

There is a small shop in Oak Road reception area selling gifts and basic toiletries.

Visitors are welcome to use the conservatory or gardens within the hospital grounds.

Local facilities, getting to The Christie and car parking

The Christie is situated a short walk from Withington village and a bus ride from Didsbury. Both places have a selection of pubs, cafes, shops and banks.

There are many buses which travel into Manchester and these are very frequent during the day time. For further information about bus times telephone **0161 228 7811**, or timetables are available at the Oak Road entrance. There is also a Metro station located at the corner of Palatine Road and Lapwing Lane which allows easy access to Manchester city centre.

Staff on the unit

Consultants/medical team

All the consultants on the unit specialise in the treatment of haematological cancers and stem cell transplantation. They are supported by a team of registrars and junior doctors in training. You are likely to meet all the consultants at some time during your treatment. Your main consultant will normally see you in outpatients. The consultants work on a monthly rota system. All the consultants are fully informed about the current treatment and future plans of every individual patient.

The ward doctors undertake a daily ward round with a consultant-led ward round on a Monday and Thursday. Each consultant spends one month managing inpatient care, in rotation. There is a grand round on a Thursday and a multi-disciplinary team meeting on a Wednesday, when both inpatient and outpatient care is discussed by all members of the multidisciplinary team. If you should ever wish to talk to a consultant, please ask the ward staff or contact their secretary and an appointment can be made for you.

Nurse clinicians

Nurse clinicians are advanced nurse practitioners and experienced cancer nurses who work both independently and as part of the medical team. They assess and manage patients often instead of a doctor. They also offer support and information throughout your treatment and follow-up care. They can be contacted on 0161 446 8010/8036.

Matron

The matron oversees the management of several areas including Palatine ward. If you have any queries she can be contacted via the nurses on the unit, or alternatively on **0161 446 3000 and ask for bleep 12837. Please ask to speak with her if you have any concerns regarding your care, (or the care of your relative).**

Senior sister/Unit manager

The unit manager is in charge of the Palatine ward including nursing/support staff and daily management of the unit. If you have any problems she can be contacted via the nurses on the unit or alternatively on **0161 918 2111**.

Sisters

The senior staff nurses/sisters on the unit are the point of contact in the absence of the unit manager and will be more than happy to answer your questions. The sisters will also work on the ward looking after you whilst you are an inpatient - **0161 446 3925/6**.

Nurses

Ward nurses will be responsible for your care whilst you are an inpatient on the unit. They will help you with the daily care and support that you need.

Health care assistants

Health care assistants will assist the nurses on duty with your care. They also support the hostess service and housekeepers with their roles.

Ward hostess

The ward hostess is responsible for ordering and delivering your meals to you. They will also provide you with drinks and snacks at your request.

Housekeepers

Our housekeeping team have many roles within the unit, all working to support the day-to-day running and cleaning/maintenance of the ward environment. They work closely with the nursing and domestic team to ensure your environment is maintained and cleaned to a high standard. Each day they will damp dust your room and provide clean linen and towels.

Domestic staff

Our domestic team are responsible for cleaning the ward and will ensure your bathroom and floors are cleaned to a high standard. They also dispose of any waste from your room.

Ward clerk

The ward clerk will order newspapers, deliver post, arrange any clinic appointments, sick notes and also arrange transport for you if you should need it. **Please allow 48 hours notice if you need transport.**

Myeloma nurse

The role of the myeloma nurse specialist is to support both patients and families who have myeloma or associated conditions.

If you would like to speak to the myeloma nurse, please ask the ward staff who will refer you. The contact telephone number is **0161 446 8167** or via the switchboard on **0161 446 3000** bleep **12599**.

Transplant nurse specialist/co-ordinators

The role of the transplant co-ordinator is to provide support for patients and their relatives regarding bone marrow transplant. The pre-transplant investigations are arranged by the co-ordinators and their aim is to ensure that your transplant admission is as straightforward and stress-free as possible. They can be contacted on **0161 446 7219** or via switchboard on 0161 446 3000 and ask for bleep 12723.

Outpatient nurses

The outpatient nurses will be responsible for your care when you are discharged from the unit and attend the day unit as an outpatient. They also liaise with ward and medical staff as necessary. They may be contacted on **0161 446 3924**.

Research nurses

The research nurses co-ordinate the clinical trials. Your doctor will tell you if there is a clinical trial available for you. The research nurses are available to give information on the trials and standard treatment and co-ordinate your care through this. You can contact them on **0161 446 8093/8298** or **0161 918 7899/7222**, or via switchboard on **0161 446 3000** and ask for bleep **12312/12643**.

Aromatherapists

There are several trained aromatherapists on the ward who can provide massage and a number of complementary therapies for you and your carer. They are available on Mondays, Tuesdays and Thursdays and will discuss your requirements. If you wish to see them please let the nursing staff know.

Physiotherapist

The physiotherapists are available if you are having problems with breathing or mobility. Some helpful exercises are listed on pages 21 to 24 for you. Please ask the nurses if you wish to be referred.

Occupational therapist

Occupational therapy can maximise your abilities in everyday aspects of life, and maintain your quality of life. They can advise on techniques to reduce fatigue and increase independence, equipment and home alterations and individual programmes to enable you to improve your function in specific areas. Please ask your nurse to contact the occupational therapist if required.

Dietitian

The role of the dietitian is to make sure that you are receiving optimum nutrition. Some patients are at risk of being malnourished or having malnutrition because of their disease or treatment. Nursing staff will complete an assessment weekly and refer you to the dietitians if necessary. Please talk to your nurse if you think a referral would be helpful.

Pharmacist

The pharmacist is likely to visit you during your stay on the unit and before you go home to arrange tablets for you to take home with you.

Counsellor

Patients and relatives from the unit can refer themselves or be referred for counselling and support from the psycho-oncology team. The staff on the unit can also refer patients to the team for psychiatric and psychological assessment and/or advice.

Secretaries

Each consultant has a secretary who works with them. If you have any concerns regarding appointments or wish to see a consultant, please contact the secretaries via The Christie switchboard on **0161 446 3000**.

Volunteers

We have volunteers on the ward who help deliver your newspapers and help to provide refreshments.

2. Your illness and treatment

Most illnesses treated on the unit are related to blood. The following information explains about blood.

Blood

There are three main types of blood cell and these are found in the bone marrow. The bone marrow is the spongy tissue found within the hollow spaces of the bones. Bone marrow contains stem cells from which all blood cells are made. The main types are:

Red blood cells

White blood cells

Platelets

Red blood cells	<p>The red blood cells contain haemoglobin (Hb). This gives the blood its colour and carries oxygen from the lungs around the body. When the Hb levels are reduced, this results in anaemia, making you weak, tired, dizzy, possibly breathless on exertion and nauseated.</p> <p>Hb normal range = 11.5 – 16.5 If your Hb drops below 8 you may need a blood transfusion.</p>
White blood cells	<p>The white blood cells are made up of several types of cell. They are responsible for fighting infection. The main type of white blood cells you will hear about are the neutrophils. These are important for the body to fight infection.</p> <p>White blood cells: normal range = 4.0 – 11.0 Neutrophils: normal range = 2.0 – 7.5 (Note: when your neutrophils are below 1.0 you are most vulnerable to infection. This is called neutropenia.)</p>
Platelets	<p>Platelets help to clot your blood and when these are low, bruising and some bleeding may occur.</p> <p>Platelets: normal range = 150 – 400 You may need a platelet transfusion if your platelets drop below 10.</p>

The treatment will usually lower your platelet count and you should therefore only use an electric razor when shaving to minimise the risk of bleeding.

Tests, investigations and procedures

There are several tests and procedures which you may need before starting and during treatment; some people will have had these already. This can be a very busy and intense time. If you don't understand what is happening, do ask the nursing or medical staff for more information.

- **Blood tests**

These will be taken daily to assess your general health and assess how your organs are functioning such as your kidneys, liver and bone marrow.

Once you have a central venous catheter or PICC line inserted, the majority of these blood samples can be taken from your line.

- **Central venous catheter/PICC line**

Most patients will require a central line to be inserted before treatment. This will not only enable blood tests to be taken more easily, but also drugs and transfusions can be given without daily injections. There are separate booklets explaining lines in more detail. Please ask.

- **Blood product support**

During your treatment you may require regular blood and platelet transfusions. You will receive separate patient information leaflets providing further information on this.

Some patients due to undergo transplants or receiving certain types of chemotherapy may need irradiated blood products. A member of the unit team will discuss this with you and provide you with a patient information leaflet. This contains an alert card which you are advised to carry with you at all times.

- **Swabs**

All patients are swabbed on admission. Swabs will be taken from your nose and throat and perineum/groin. A sample of faeces will also be needed. These will be sent to the laboratories to find out if they grow any particular infections.

- **Chest X-ray**

A chest x-ray gives the doctors the opportunity to see what your heart and lungs look like and to check that they are healthy.

- **Heart function test (MUGA or an Echocardiogram)**

A heart test will be performed routinely before chemotherapy is given. A MUGA scan is a painless procedure where a small amount of radioactive x-ray dye is inserted into the vein and x-rays are taken to assess the function of your heart. NB: The amount of radioactivity you will receive in the dye is not harmful and you will quickly excrete it.

An Echocardiogram is an ultrasound-like procedure which will allow the technicians to gain a 'picture' of the heart through images and assess the function.

- **Bone marrow test**

You will need to have this test at intervals throughout your treatment to assess your bone marrow function more closely and to see if you are in remission. It involves taking a sample of bone marrow, usually from the back of the hip. Local anaesthetic is used to numb the area first. The procedure lasts approximately 15 to 20 minutes, and can cause some discomfort. To help ease any discomfort gas and air can be offered. If you require a sedative, please discuss this with the ward staff. Please ask for a separate leaflet explaining this procedure.

- **Lumbar puncture**

At some point in your treatment you may require a lumbar puncture to give treatment and/or to assess whether there is leukaemia in your central nervous system. This test is done using local anaesthetic, and involves inserting a small needle into your back/spine. Please ask for a separate leaflet explaining this procedure.

Daily routine

- Your temperature, pulse and blood pressure will be recorded approximately every four hours during the day.
- Anything you drink needs to be measured, so please try to keep a record of what you have drunk.
- Your urine also needs to be measured, so please use the containers/bedpans provided.
- You will be weighed daily – twice if you are having a transplant.
- You will be asked daily if you have any new problems: bruises, sores, rashes etc. It is very important to inform the doctors and nurses if you have any new problems immediately so appropriate action can be taken to help you.
- We suggest that, if you feel well, during the day you wear comfortable clothes, and change into your night clothes in the evening.
- We encourage you to have regular, gentle exercise.
- Try to eat regularly and to have plenty of fluids.
- Each week we will collect a stool sample from you and should you experience diarrhoea, we will need to measure this, so please use the bedpans provided. **It is important that you let the nursing or medical staff know promptly if you start to have diarrhoea.**
- On admission and weekly, we will also collect swabs for routine screening for infections.

Your treatment

What is chemotherapy?

Chemotherapy means using drugs to treat cancer. Many types of drugs are used in chemotherapy, all of which attack cancer cells in different ways. For this reason, we often give several drugs in combination to increase the effectiveness of treatment. Chemotherapy can be used alone or with radiotherapy and surgery.

How does chemotherapy work?

The drugs are carried by the bloodstream to all parts of the body where they act by interfering with the growth of rapidly growing cells such as cancer cells. The cells of some normal tissues also grow rapidly, for example, the cells of the hair roots, mouth, bone marrow and lining of the bowel. These may be temporarily affected by the chemotherapy.

How is it given?

Chemotherapy can be given orally, in tablet form, intravenously (via a vein), through a central venous catheter/Picc line or intrathecally via a lumbar puncture.

How often is it given?

This depends on the type of treatment you are having. In most cases, there will be a cycle of chemotherapy followed by a rest period of approximately four weeks, three of which may be spent in hospital. This does vary for each person. There are information leaflets on each specific treatment.

Agreeing to treatment: consent

We will ask you to sign a consent form agreeing to accept the treatment that you are being offered. The basis of the agreement is that you have had The Christie's written description of the proposed treatment and that you have been given an opportunity to discuss any concerns. You are entitled to request a second opinion from another doctor who specialises in treating this cancer. You can ask your own consultant or your GP to refer you. Your consent may be withdrawn at any time before or during this treatment. Should you decide to withdraw your consent then a member of your treating team will discuss the possible consequences with you.

What are the benefits of chemotherapy?

The benefits of treatment will depend on the type of cancer you have and how advanced it is. The aims include:

- to put the cancer into remission; this is when chemotherapy is given to destroy all of the cancer cells
- or to slow down/control the progress of the cancer
- or to relieve the symptoms.

What are the risks of treatment?

The potential side effects of chemotherapy are explained in the specific chemotherapy information leaflets. You will also be given a separate booklet on chemotherapy, please ask if you have not yet received one.

Are there any alternatives to chemotherapy?

Your doctor will discuss alternative treatments with you. All treatments carry risks as well as benefits and thinking about possible options can help you decide what to do. There are intensive and less intensive chemotherapy options which will be discussed with you in detail.

What happens if you decide not to have chemotherapy?

There is a high risk that your cancer will continue to grow and your symptoms will get worse. You can discuss what to do next with your doctor. We will continue to support you in whatever way we can, and liaise with community staff to help you if required.

Clinical trials/research studies on the unit

The Christie is an international leader in cancer research and development and the largest cancer treatment centre of its kind in Europe. Research is fundamental in the development of cancer treatments and therefore each disease group has a dedicated team of research staff to enable this work to continue.

Clinical trials are carefully designed research studies involving patients and look to compare different types of standard treatments/regimens and may include new drugs. The doctor responsible for your treatment and care may discuss with you about treatment as part of a clinical trial. It is usually necessary to decide about a clinical trial soon after diagnosis. This may seem hurried, but many trials depend on you not having any other treatment beforehand.

You will not be involved in a clinical trial without your knowledge and consent. Your doctors and the research nurses will give you all the appropriate information you need to help you understand the implications of the trial and decide whether you want to take part or not.

Should you decide not to participate, your care on the unit will not be affected.

If you would like to know what the current trials on the unit are or any information related to trials, please contact the research nurse team on 0161 446 8093/8298 or 0161 918 7899/7222 (bleep 12312/12643).

3. Coping with treatment

Diet

It is important to try to eat well while you are in hospital and having treatment. Eating well helps to ensure that your body has the energy and nutrients needed to rebuild damaged tissue, fight infection and cope with any treatment side effects. Your treatments are likely to increase your risk of infection and certain foods can carry germs which may be harmful to you at this time. As a precaution, we advise you to **avoid the following higher risk foods** during your stay in hospital.

Item	Avoid
Milk & dairy produce	All unpasteurised dairy products e.g. milk sold on local farms
Cheese	Soft cheeses made with unpasteurised milk e.g. feta, parmesan Homemade/deli paneer and labnah Mould-ripened cheeses e.g. Camembert, Brie, goat's cheese Blue veined cheeses e.g. Danish blue and Stilton
Shellfish	Raw or lightly cooked shellfish
Meat, fish & poultry	Raw/undercooked meat, poultry or fish e.g. meat which is still pink, sushi, caviar and oysters Smoked meats e.g. salami Avoid smoked salmon unless eaten directly from a freshly opened packet
Eggs	Raw eggs or undercooked eggs e.g. homemade mayonnaise, homemade ice cream, mousse, egg-nog, meringue, hollandaise sauce, and béarnaise. Any dressing containing raw eggs e.g. home/restaurant-made Caesar salad dressing
Probiotic drinks and yogurts	Probiotic or "bio" foods, drinks or supplements eg Yakult, Actimel, ProViva Yogurt which is described on the label as bio or probiotic
Pate	Meat paté, vegetable paté

Points to note:

- Foods that are prepared at home must be cooked from fresh and rapidly refrigerated afterwards (ideally within one hour), **NOT** kept at room temperature. Such foods may be reheated in the unit kitchen by the ward hostess or HCA **only once** – reheated cooked foods must be piping hot all the way through and have a core temperature above 70°C on serving. Foods must be consumed within 24 hours of cooking or defrosting.

The unit is only able to store shop-bought food in the refrigerator, and not food prepared at home. Therefore food must be reheated on immediate arrival to the unit. NB The unit is unable to guarantee the safety of food that is prepared at home and reheated.

- Take-away food should be from a reputable establishment and cannot be kept or reheated.
- Shop-bought frozen or chilled (sealed) microwaveable convenience meals may be brought in from home for patients and cooked thoroughly in the unit kitchen according to manufacturer's instructions.

- Good hygiene practice is essential when preparing food e.g. thorough handwashing, using clean utensils, and separate utensils for raw and cooked foods.
- All cooked food from the hospital kitchen should be served piping hot, i.e. at a core temperature of 70°C or above.
- All permitted foods brought in by patients or relatives should be labelled and dated before being stored in the ward fridge/freezer/cupboard. All items should be checked for expiry dates daily.
- Fresh fruit should **not** be kept in patients' rooms.
- All food and drink opened should be discarded within 24 hours.
- Food/drinks in smaller packs e.g. individual drink cartons/bottles or packets of biscuits/cereals/cakes are useful to minimise contamination and avoid wastage.
- You may drink small amounts of alcohol but this is not advisable during chemotherapy treatment or if you are taking certain antibiotics. Please ask the staff for advice.

General advice:

Your treatments can change the way food tastes to you and dampen your appetite – if this happens there are several ways we can help you to supplement your dietary intake. The nurses looking after you will regularly assess how well you are eating, so help can be offered if you do lose your appetite and/or begin to struggle to eat. Discuss with your nurse if you are worried about your nutritional intake. He/she can provide you with a booklet called 'Eating – Help yourself'. Keeping a diary of what you are managing to eat can be useful.

There are snacks available 24 hours per day on the unit (see menu folder located in your room for a full list of items). These are especially useful as eating small but frequent nourishing meals and snacks (up to 6 times a day) can be easier to manage than 3 normal-sized meals when your appetite is reduced and/or you are feeling unwell.

Also available is the Appetito menu offering hot meals 24 hours a day. A menu is provided in each room; please ask the ward staff for your selection.

There are special supplements available that contain extra energy and nutrients. These include milkshakes, juices, yoghurt drinks and soups. They are kept on the ward and are available at any time – please ask.

Occasionally you may not be able to manage sufficient food or drink orally to meet your needs due to treatment side effects, e.g. your mouth may be too sore to eat. If this happens, there are other feeding options that will be discussed with you. Short term enteral feeding (tube feeding) is a method of giving nutrition into your stomach or small bowel via a tube that can be passed from your nose. In some cases parenteral feeding is used. This method of feeding uses a line directly into your veins.

We have a team of dietitians within the hospital who can offer further advice if you have ongoing difficulties with eating and drinking. If you have any special dietary requirements, are worried about any aspect of your diet or have queries about specific foods or complaints, please tell the nursing staff. The catering manager is also happy to visit to discuss any catering concerns.

Personal hygiene

When your white cell count is low you will be at greater risk of infection, so tell the staff immediately of any new cuts, sores, rashes or obvious infections. You can help to minimise infections by noting the following advice:

Mouth

Your mouth and throat are vulnerable to soreness and infection because of:

Low white cell count
Soft skin inside your mouth
Dry mouth
Dental problems

- It is important that you keep your mouth clean by brushing your teeth twice daily with a soft/children's toothbrush. Gently brush your tongue if you can. If your gums bleed, please let a nurse know.
- Use the mouthwash provided 4 times a day.
- Drink plenty to keep your mouth moist. If you can't drink at least take sips regularly. Drinking with a straw may be easier. If your mouth becomes very sore, painkillers can be given to cope with this.
- Eat soft, moist foods such as stews and soups. Add extra gravy, salad dressing, sauces or butter to make foods, moister. Avoid food that will hurt or irritate such as salty, spicy or acidic foods. If you are unable to eat enough, you will be assessed by a dietitian who can advise on nourishing drinks and other nutritional supplements to help you. If you are unable to tolerate this, other options may be considered such as a soft tube placed into your stomach through your nose, or fluids (and nutrition if required) can be given through a drip.
- Artificial saliva or mouth gels can be useful for persistent dry mouths – please ask your doctor. For more information, please ask for the unit's mouthcare guidelines.

Skin

Many types of germs are present on the skin, especially the hands, so please follow this advice carefully.

- Wash your hands regularly, particularly after using the toilet and before meals.
- Shower daily using the soap provided (Aquasept) while you are in hospital.
- Do not use flannels or body buffers. Only use the disposable cloths provided.
- Change your nightwear on a regular basis. Towels will be provided daily.
- If you notice any bruises, rashes, lumps, spots or bleeding, please tell your nurse.
- Avoid using perfumed products as this may irritate your skin. If your skin becomes very dry, you can use gentle un-perfumed moisturiser and the staff can provide creams which are helpful. Please ask.

Anal area

- This area is made up of soft skin and is more likely to become infected and sore. Daily washing of this area is essential. If you have diarrhoea you may need to wash this area more often.
- Please let your nurse know if you have diarrhoea or any soreness, and you will be given a cream to use.

Central venous catheter or PICC line

- **Your line is a possible source of infection so it is important that it is taken care of.**

The staff will give you an information booklet when your line is put in.

- If you notice any pain, swelling or redness around the line or dressing, please tell your nurse.

a) Anxiety and depression

The diagnosis of leukaemia and other forms of cancer, along with sudden admission to hospital can cause people to feel anxious. There are many factors that can affect people's anxiety. Some of these include:

- Isolation.
- Loss of independence.
- Strain on relationships.
- Financial and work worries.
- Change in how you look and feel about yourself.
- Fear of treatment and the future.

The degree of anxiety depends on the individual. It is important to remember that there is no right or wrong way to feel or act.

It is not unusual for people to feel depressed, often for the first time in their life. Try to share your feelings with your relatives and loved ones, to gain support and to prevent unfortunate misunderstandings between yourself and those closest to you.

The nurses and doctors are willing to help you through your worries and anxieties, and are happy to talk to you. However, at the same time, we do not want to intrude on your privacy.

Other ways you can help yourself through this difficult time:

- Keep up with recreational activities such as reading and games.
- Ask to see the art worker who may have some ideas about crafts and activities.
- Take regular rest periods.
- Ask to talk to previous patients and relatives.
- Ask to see the aromatherapists
- Ask to see the occupational therapist who can advise on anxiety management techniques and how to cope with fatigue.
- Ask to see the social worker and/or nurse specialists, if you would like someone to talk to.
- Read the Macmillan booklets. The cancer information centre will have these.
- Set yourself a daily routine, and small daily goals.
- Bring in photographs from home and change them daily.

There are trained counsellors who will be willing to assist you through listening and talking to you. Please ask the nurse specialists or ward staff if you wish to be referred for counselling.

Hospital chaplains

The chaplaincy team is committed to accompanying you through the changes and challenges that come with being ill, or being close to someone who is ill. They will listen to your concerns with total respect. They can help with any religious needs you may have, or contact one of your own religious leaders if you wish.

If you wish to see a member of the chaplaincy team, just ask the ward staff who will contact them.

Our facilities include a chapel, a quiet room, and a prayer room equipped for Muslim prayers. There are regular services in the chapel: these are advertised around the hospital, or you can ask a member of staff.

Boredom

There will be times when you feel tired and unwell. You may simply want to sleep and rest, but when you are feeling well, you may notice the boredom more. You may feel isolated and lack concentration. The following ideas may help you.

- There are televisions in all rooms. There is also Freeview and digital radio in most rooms.
- You can have new books and newspapers. Please ask the ward clerk to order a newspaper (free) for you.
- You can try to continue with some work or a hobby. But you will need a lot of rest, so don't overload yourself with work.
- There are some laptop computers available to use on the unit – please ask.
- Games machines (e.g. X-box) are available on request.

Please remember that any electrical equipment brought from home needs to be checked by the ward staff and maintenance department.

Sexuality

How we express ourselves is important. The effects of chemotherapy and radiotherapy can cause sexual problems, and change the way we feel about ourselves and others.

When you are in hospital, you may feel that your privacy is invaded. Don't be afraid to ask for time for yourself, and for the blinds to be pulled down. If it is your partner who is unwell, you may be afraid to touch and hold them; their appearance will change and perhaps even their behaviour. Don't be afraid to touch, kiss or hug. It is important to be close and feel loved at this difficult time.

At home, between your treatments, it is usually safe to have sex (unless your platelets or white cell counts are very low), although your sex drive is often temporarily affected. However, it is strongly advised that you use a condom, as pregnancy should be avoided, and condoms also reduce the risk of infection.

The chemotherapy drugs that you will be given may affect your fertility, particularly if you have a bone marrow transplant. It is important that any concerns regarding this are discussed as soon as possible. Please ask your doctor or nurse specialist about this.

Sperm storage is available. It is very important that this is collected immediately following diagnosis, as the treatment you have can affect the quality of your sperm. The sperm is stored at St. Mary's Hospital, Manchester. Please ask for the information leaflet and a referral for donation, if you feel this is appropriate and even if you currently have no partner.

For women, there are some new developments which may help to maintain your fertility although these cannot be guaranteed. Your doctor will discuss these with you and refer you to St Mary's if this is possible.

You may experience loss of sexual desire, satisfaction, and changes in hormone levels. For women treatment may cause vaginal dryness and painful intercourse. Lubricating gel (KY jelly) may be helpful. An early menopause can also occur particularly if you have a bone marrow transplant. Men can suffer with impotence problems. Usually problems are temporary and improve as you recover when your treatment is over.

Please do not be embarrassed to discuss any concerns you may have with your nurse or doctor. It is important to remember that not everyone will encounter problems.

Keeping fit

It is important that during your stay in hospital, you try and keep as fit as possible, as muscles can waste quite quickly. Research has shown that exercise intervention during and following cancer treatments can reduce fatigue and therefore improve quality of life. We have enclosed an exercise sheet to work the main muscle groups. (See Exercises I). If possible try to walk around your room and ask for the exercise equipment which is available on the ward.

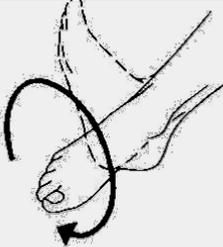
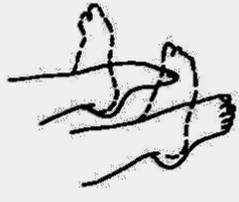
It is also important to maintain lung function and to help you with this there is a sheet of diaphragmatic breathing exercises that need to be practised several times a day. (See Exercises II).

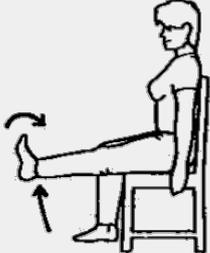
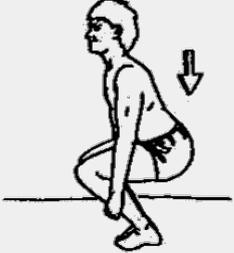
An exercise DVD produced by our physiotherapists is also available just ask your nurse for a copy.

If you need any further advice or are unsure of what to do, ask your nurse to refer you to the physiotherapist and she will help you.

**We aim to make your stay on the unit as comfortable as possible.
At any point in your treatment if you or your family have any questions or concerns, please ask the staff.**

Exercises I

	<p>Sitting or lying.</p> <p>Rotate your ankle. Change directions.</p> <p>Repeat _____ times.</p>
	<p>Lying on your back or sitting.</p> <p>Bend and straighten your ankles briskly.</p> <p>If you keep your knees straight during the exercise you will stretch your calf muscles.</p> <p>Repeat _____ times.</p>
	<p>Lying on your back with legs straight.</p> <p>Bend your ankles and push your knees down firmly against the bed. Hold 5 seconds – then relax.</p> <p>Repeat _____ times.</p>
	<p>Lying on your back with one leg straight and the other leg bent. (You can vary the exercise by having your foot pointing either upwards, inwards or outwards).</p> <p>Exercise your straight leg by pulling the toes up, straightening the knee and lifting the leg 20cm off the bed. Hold approx 5 seconds – slowly relax.</p>
	<p>Lying on your back.</p> <p>Bend and straighten your leg.</p> <p>Repeat _____ times.</p>
	<p>Lying on your back with knees bent.</p> <p>Squeeze your buttocks together and lift your bottom off the floor.</p> <p>Return to starting position.</p> <p>Repeat _____ times.</p>

	<p>Lying on your back.</p> <p>Bring your leg out to the side and then back to mid position.</p> <p>Repeat _____times.</p>
	<p>Sit on a chair.</p> <p>Pull your toes up, tighten your thigh muscle and straighten your knee. Hold approximately 5 seconds and slowly relax your leg.</p> <p>Repeat _____times.</p>
	<p>Stand straight with feet apart and pointing forward.</p> <p>Slowly bend your knees and then return to starting position.</p> <p>Repeat _____times.</p>
	<p>Stand.</p> <p>Push up on your toes.</p> <p>Repeat _____times.</p>

Diaphragmatic breathing exercises

Breathing exercises will help you to

- Breathe with minimal effort
- Relax your breathing pattern
- Clear secretions
- Re-expand your lungs

Your diaphragm is a large sheet of muscle attached to the bottom of your ribs. It is the most important muscle for breathing IN. The diaphragm can only work if your tummy is relaxed.

Step 1:

Sit comfortably in a chair with your head and back well supported and your feet on the floor.

If you are in bed bend your knees slightly.

Step 2:

Place your hands on your tummy with your fingers slightly overlapping each other.

Step 3:

Breathe in slowly and gently through your nose. Watch your fingers slide apart slightly as your tummy expands.

Step 4:

Breathe out gently. DO NOT force the air out or tighten your tummy muscles. Your fingers will slide back together.

Step 5:

Try and take deeper breaths into your tummy for 6 breaths and then breathe in and out gently for a minute. (do not worry about the exact timing of this) Then repeat 5 times.

Practise this sort of breathing regularly for 3-4 times a day or whenever you feel tense are having problems with your breathing please speak to your nurse and and out of breath. If you she can refer you to the physiotherapist.

4. More information

Useful addresses

There are many organisations who offer support and information about helpful services, activities, alternative therapies and telephone help-lines within the North-West for people affected by cancer.

There is information about local cancer care/complementary therapy centres in the information centre here at The Christie.

Below are some contact details for centres which may be helpful.

Cancer information centre at The Christie

Visit the Cancer information centre at The Christie on the glass corridor near Oak Road.

Open 8.45am to 4.30pm Monday to Thursday and 8.45am to 4pm Friday.
(Opening times can vary, please ring to check before making a special journey).

☎ 0161 446 8100

CALL (Cancer Aid and Listening Line)

Provides emotional support and practical help for people with cancer, their carers and families. Support includes respite sitting, support for hospital appointments, social activities, befriending and support for carers.

CALL also runs a listening line in office hours (9am to 4pm Monday to Friday), Saturday, Sunday and bank holidays (including Christmas and New Year) from 7.30pm to 10.30pm.

☎ 0845 123 23 29 www.canceraid.co.uk

Other local cancer care centres offering support and alternative therapies

Vine House

22 Cromwell Road
Ribbleton
Preston
PR2 6YB
☎ 01772 793344

Beechwood Cancer Care Centre

Chelford Grove
Stockport
SK3 8LS
☎ 0161 476 0384
www.beechwoodcancercare.co.uk
email: enquiries@beechwoodcancercare.co.uk

Neil Cliffe Cancer Care Centre

Wythenshawe hospital
Southmoor Road
Manchester
M23 9LT
☎ 0161 291 2912

The following national organisations offer help and support

Leukaemia Care

☎ 08088 010 444

www.leukaemiacare.org.uk

Bloodwise

☎ 020 7504 2200

www.bloodwise.org.uk

Lymphoma Association

☎ 0808 808 5555

www.lymphomas.org.uk

Macmillan Cancer Support

☎ Freephone 0808 808 0000

www.macmillan.org.uk

Myeloma UK

☎ 0800 980 3332

www.myeloma.org.uk

Institute for Complementary and Natural Medicine

☎ 0207 922 7980

www.i-c-m.org.uk

Patient information for the Haematology and Transplant Service

The unit staff will give you information as your treatment progresses, but if you would like to see any of the items listed below, please ask the staff and they will give you a copy.

There are other Christie booklets on treatment and coping with side effects – just ask the ward staff if you would like specific information..

155	Welcome to The Palatine ward
163	Total body irradiation
164	Bone marrow harvest
284	Methotrexate
382	MidAC chemotherapy
383	MACE chemotherapy
384	High dose Ara-C chemotherapy
385	FLAG chemotherapy
386	DA chemotherapy
387	FLAG-Ida chemotherapy
395	Low dose Ara-C chemotherapy
417	Alemtuzumab (Mabcampath [®])
420	Gemtuzumab ozogamicin (Mylotarg [®])
503	ALL 2003 maintenance
524	Idarubicin and ATRA (Tretinoin)
525	Daunorubicin and Clofarabine
538	CODOX-M
619	Donating bone marrow or peripheral blood stem cells – information for the donor family
664	Azacitidine
700	ALL cycle 1 Daunorubicin and vincristine
701	ALL cycle 2 Cyclophosphamide and cytarabine
761	Going home and the future following an allogeneic transplant
763	Going home and the future following an autologous transplant
766	Hyper CVAD
800	Mitoxantrone and ATRA (Tretinoin)
802	Ofatumumab
846	ALL Consolidation (Cycles 1-4)
852	Late side effects following chemotherapy for acute myeloid leukaemia
904	Chronic lymphocytic leukaemia (CLL) service at The Christie
908	LEAM conditioning
960	High dose Melphalan for autologous transplant for inpatients
908	LEAM conditioning
960	High dose melphalan for autologous transplant for inpatients on HTU
	Long term sperm storage (Department of Reproductive Medicine - Central Manchester University Hospitals)

List updated March 2016



