



INTRODUCTION

INTRODUCTION TO THE PROTON BEAM THERAPY SERVICE

AN INTRODUCTION TO THE PROTON BEAM THERAPY SERVICE

Welcome to The Christie!

We are the largest single site cancer centre in Europe, treating more than 44,000 patients a year. We provide radiotherapy through one of the largest radiotherapy departments in the world, chemotherapy on site and through 10 other hospitals, highly specialist surgery for complex and rare cancer, and a wide range of support and diagnostic services.

We are also an international leader in research, with world first breakthroughs for over 100 years. We run a large, high quality, dedicated clinical research environment where our patients can participate in complex and early phase clinical trials, with around 400 trials taking place at any one time.

In December 2018, The Christie became home to one of only two high energy NHS proton beam therapy (PBT) centres in the UK. The other is being built at University College London Hospitals NHS Foundation Trust (UCLH) ready in 2020. We provide specialised treatment for UK patients with complex and hard-to-treat cancers who would otherwise be required to have this treatment abroad at centres in either Europe or in the USA.

The Christie proton team will offer you as much support as possible, whether you are receiving treatment as an inpatient or outpatient.

This folder provides you with all the information you need to know throughout your treatment. As well as this folder you will be given other information more specific to your illness and treatment.

You will be assigned a key worker who will be more than happy to answer any questions you have throughout your treatment. There is space at the back of this folder for you to make notes and we encourage you to do so.

The background consists of several overlapping circles in various shades of blue, creating a layered, abstract effect. The circles are semi-transparent, allowing the colors of the circles behind them to show through.

PHILOSOPHY OF CARE

CARING FOR TEENAGERS AND YOUNG ADULTS WITH CANCER

We believe that every teenager and young adult we care for is a unique individual with their own physical, psychological, social, spiritual and cultural needs.

These needs will be individually assessed and your care will be tailored to meet your needs. You will be cared for by the multidisciplinary team who have expertise and experience in working specifically with young people. Our aim is to provide holistic care and support to you, your family and your loved ones.

As you are supported through our service we will endeavour to always be sensitive to the individual needs of young people at all times and will act in such a way to respect and promote privacy, dignity and independence. The need for confidentiality will be respected at all times.

We believe that the young person is central to all our care and services and will endeavour at all times to meet all individuals' best interests.

The background features a solid blue color with several large, overlapping, semi-transparent circles of varying shades of blue. The text 'BEHAVIOUR POLICY' is positioned in the lower-left area, rendered in a white, bold, sans-serif font with a thin white outline.

BEHAVIOUR POLICY

BEHAVIOUR POLICY

The care of patients is always the priority of the staff. In order to ensure there is a safe and pleasant environment for patients, families, carers and staff we request that all people accessing the proton beam therapy centre and its services be mindful of the following:

- Please respect the privacy of other patients and their families/carers at all times.
- The Christie is a no smoking site. Smoking is not permitted either on or around the ward or hospital.
- The consumption of alcohol is strictly prohibited at all times.
- Anyone found to be in possession of or partaking in illegal substances will be reported to the police.
- Verbal or physical abuse directed at other patients or their carers will not be tolerated at any time and will be dealt with severely.
- Any form of abuse towards staff, verbal or physical, will not be tolerated and will be dealt with severely.
- Any actions that could be deemed to be bullying towards patients, their families and carers or staff will be dealt with accordingly.
- The theft or deliberate damage of any equipment from the ward will be reported to the police.
- Please do not take any photographs/films of other patients or staff without permission.
- The Christie NHS Foundation Trust operates an e-safety system. This prohibits anyone accessing the guest Wi-Fi for inappropriate websites e.g. websites containing sexual images, terrorism, racism, gambling etc. Anyone attempting to gain access to such material will be reported to necessary third parties and may be prohibited from using the guest Wi-Fi in future.

LGBTQ+

LGBTQ+

The Christie recognises different ways that people describe and identify with their gender and sexuality.

Please let us know what your preferred name is, how you want to be referred to, which pronoun(s) you use to describe yourself and anything else you think we might need to know to ensure you are well looked after and comfortable at The Christie.

If you wish to, please write down your preferred name and hand it to your key worker, nurse, social worker or youth support coordinator. If you feel comfortable, this can then prompt us to have a conversation with you about your preferences.

Gender: the internal sense of self.

Sexuality: who a person may or may not be attracted to.

CONTACT NUMBERS

CONTACT NUMBERS

THE PROTON BEAM THERAPY CENTRE AT THE CHRISTIE:

Ground floor main reception
0161 918 7577

First floor treatment reception
0161 918 2300

Second floor clinic reception
0161 918 3600

Scheduling team
0161 918 7170

Key workers
0161 918 7235 or 7239

**Ambulance hospital
transport service**
0161 446 8114 or 8143

Shuttle bus queries
0161 918 7270

ROYAL MANCHESTER CHILDREN'S HOSPITAL (RMCH):

Proton beam therapy nurse
0161 701 8430

Ward 84
0161 701 8400 or 8401 or 8404

Ward 84 day case unit
0161 701 8411 or 8412

RMCH Hotline
0161 701 7489

The Christie Hotline
0161 446 3658

Open 24 hours a day,
7 days a week



MEET YOUR TEAM

Your Team

The background is a solid green color. Two large, overlapping circles are present. The circle on the left is a darker shade of green, while the circle on the right is a lighter shade. They overlap in the center of the frame.

MEET YOUR TEAM

MEET YOUR TEAM

KEY WORKERS

This team consists of specialist radiographers and nurses.

Every patient having proton beam therapy at The Christie will have a named key worker. They are there to provide you with support and advice and are important in co-ordinating your care. The key worker is likely to be the first point of contact for patients even before they visit The Christie.

CLINICAL SUPPORT WORKERS

This team will be one of the first points of contact for patients when they arrive at the centre.

Our friendly and helpful clinical support team will check you in and direct you to the appropriate department for your clinic, or other, appointments or treatment. Clinical support workers also help with clinical duties such as taking blood, weighing patients and applying dressings etc.



RADIOGRAPHERS

One of the largest teams that patients and carers will meet during their treatment.

Both diagnostic and therapeutic radiographers have various roles in the preparation for treatment and treatment delivery. Patients and carers will also meet some of the radiographers before starting treatment at the assessment visits.

Radiographers acquire CT and MRI scans which are used to plan a treatment, and they make the casts or masks that may be required for treatment. The radiographers will also position you on the treatment couch daily and use X-rays to ensure you are in the correct position before starting treatment.

The team works alongside the clinical oncologists, treatment planners, dosimetrists and physicists to deliver treatment.

ONCOLOGISTS

Clinical oncologists are doctors who treat and manage patients with cancer.

Your named clinical oncologist will discuss your treatment plan with you and plan your proton beam therapy, as well as monitor you whilst on treatment.

You may see other specialist oncologists as part of your treatment.

Your oncologists are supported by a team of junior doctors (fellows, specialist trainees and registrars). They are also supported by nurse/radiographer practitioners, nurse clinicians and other skilled specialist staff.





**YOUR KEY
WORKER**

YOUR KEY WORKER

As soon as you are approved for proton beam therapy you will be allocated a key worker. This person is either a specialist nurse or a specialist radiographer.

This person is your key point of contact and will support you and your family through your treatment.

They can:

- Provide you with information and support about your treatment and side effects
- Speak to doctors on your behalf
- Provide emotional and psychological support

My key worker is:

and they can be contacted on:

The background features a green-to-teal gradient. Two large, semi-transparent circles are overlaid: a larger teal circle on the left and a smaller green circle on the right, both partially overlapping each other and the text.

PROTON YOUTH
SUPPORT
COORDINATOR

PROTON YOUTH SUPPORT COORDINATOR

While you are having proton beam therapy you will meet the Teenage Cancer Trust youth support coordinator (YSC), who works with young people having proton beam therapy.

You may have worked with a YSC in your local hospital in which case you will have a good idea about what a YSC does and how they can help you. YSCs are non-medical members of staff who are available to help you through your proton treatment. Here is a summary of the YSC role based within the proton service:

- They can offer practical and emotional support (alongside other proton team members) to you and your family/carers.
- They encourage you to use the TYA lounge while you are waiting for your treatment. The lounge has TVs, music, gaming etc for you to use.
- They will provide workshops and activities for you to do within the proton beam therapy centre at The Christie.
- They will organise nights out and events for you to take part in with other young people. These will take place in the local community and the Manchester area.
- They will be able to give you lots of ideas about places to go locally and a list of local facilities and amenities.
- The YSC welcomes thoughts, ideas and feedback from young people with regards to things that would be beneficial whilst having proton beam therapy.

The Christie has a well-established service for teenagers and young adults (TYA) and the YSC based within the proton service will be working as part of and alongside this service.

The proton service YSC looks forward to meeting you!

Please ask your key worker if you have not met the proton YSC.

The background is a solid green color. Two large, overlapping circles are positioned in the upper half of the frame. The circle on the left is a darker shade of green, while the circle on the right is a lighter shade. They overlap in the center, creating a darker green area.

HEALTH PLAY SPECIALIST TEAM

HEALTH PLAY SPECIALIST TEAM

We have a team of qualified health play specialists who are dedicated to proton beam therapy preparation, education and support for children and young people. The health play specialists will help your child to understand the treatment process during preparation sessions. These will take place during the single assessment visit.

Play preparation enables your child to experience aspects of the treatment through play and visits to the department which will help your child to become familiar with staff and the hospital surroundings. For older children and young people they will tailor this to be more of an educational session and adapt it to their needs so they feel involved in

their care. Health play specialists can also help with siblings and family members so they feel supported too.

Play is a valuable tool to enable understanding and awareness and will help your child to feel comfortable with the proton beam therapy treatment. A health play specialist can attend treatment appointments with your child to offer full support and guidance. They will also facilitate activities to keep them engaged during their time in the hospital.





ABOUT YOUR TREATMENT

Treatment



WHAT HAPPENS
DURING TREATMENT?

WHAT HAPPENS DURING TREATMENT?

Proton beam therapy is given on an outpatient basis – with treatment delivered once a day for 5 out of the 7 days a week. Usually this translates to treatment Monday to Friday with the weekend off. However, we may ask you on occasions to attend for treatment on a weekend. A course of treatment can last up to 7 weeks.

On the day of your first treatment, you will come to the reception of the proton beam therapy centre. You will meet one of the proton beam therapy support team on arrival where we will check we have your contact details correct on the system and you can discuss your future appointment schedule.

You will be collected by a radiographer who will explain the treatment processes. They will also ensure you are aware of the possible side effects of treatment and give advice on minimising these side effects. They will check you are happy to proceed with treatment. Please use this as an opportunity to ask any additional questions you may still have.

The radiographers will take you into the treatment room and ask you to remove or loosen clothing that covers the area being treated. There are cubicles for changing and gowns if necessary. They will assist you onto the treatment bed. If you have had a mask or cast made this will be placed on and you will be positioned as you were for the planning scan. They will make adjustments so that you are in the correct position for treatment and make you as comfortable as possible. All you need to do is stay still once you are in the right position.

The Christie is a training hospital, so you may meet students in the department who may be involved in the delivery of your treatment. If you have any objections to students being present please let the radiographers know.

The machines are quite large, but please don't worry – the treatment is painless and the machine won't touch you. Each session may take between 20-40 minutes to complete, depending on the area being treated. The radiographers will be with you until you are ready for the treatment to commence. There may be a delay before the treatment starts, because there may be a wait for the proton beam. This is common and nothing to worry about. The radiographers will talk to you while you wait and inform you when the treatment is about to start. There is nothing to see or feel when the machine is delivering the treatment; however, you may hear a buzzing noise.

Cameras inside the room give the radiographers a clear view of you from the control desk. They are watching you all the time and if required can stop the machine and come in immediately. Once treatment is finished radiographers will assist you off the treatment couch.

You will be scheduled to see a doctor once a week. Before this appointment, please think of any questions you have and check you have enough Christie medication, if applicable, for the following week of treatment. Any prescriptions will need to be collected from the pharmacy in the main hospital. If you need to be seen outside this appointment please contact a member of the team.



MRI

WHAT TO WEAR FOR YOUR MRI SCAN

An MRI is a type of scan that uses very strong magnetic forces and radiowaves to create detailed pictures of the human body. This scan is used to help plan your treatment and it is therefore extremely important that we obtain the best possible images.

Some clothing and makeup may contain small amounts of metal that can interact with the magnet and affect the images and can also create a heating effect during the scan.

Patients may be asked to change into a hospital gown before their scan.

When attending for your scan we ask that you refrain from wearing the following items:

- Hairspray, clips, grips and hair accessories
- Mascara and other eye makeup
- Magnetic eyelashes
- Anti-microbial clothing such as sportswear, as this can contain small amounts of silver or copper within the fabric
- Any clothing which contains copper (such as specialist underwear or socks etc. or radio frequency shielding clothing)
- Any specialist magnetic clothing

- Jewellery (including facial and body piercings)

If you have any issue removing piercings then please discuss this with your radiographer.

If you have any questions or concerns please do not hesitate to ask your radiographer before the scan or contact your named key worker.



SIDE EFFECTS

MANAGING YOUR SIDE EFFECTS

Side effects from your proton beam therapy will vary depending on where on the body you are being treated. Even people who have had very similar treatments can have different side effects. These potential side effects should have been discussed with you during the consent process. Please ask a member of staff if you feel unsure about this.

Most people notice the side effects during the second half of their course of treatment. These may well continue after you have finished your treatment, but they should gradually fade by 4-6 weeks after treatment.

You will be supported throughout your treatment by your proton team. If you are experiencing any side effects, please mention this to the team as in most cases these can be managed with medication.

The Christie Hotline is available 24 hours a day for urgent support and specialist advice if you need support when you aren't at the hospital.

The Christie Hotline
0161 446 3658

Open 24 hours a day,
7 days a week

CALL 999 should you experience any chest pain, difficulty in breathing or severe breathing.



END OF
TREATMENT

END OF TREATMENT INFORMATION

LOCAL PATIENTS

When you have completed your proton beam therapy, a letter with details of your treatment and any side effects that you may have experienced will be sent to your GP (and a copy sent to yourself). You will be followed up regularly. Your first appointment after the completion of your treatment should be approximately 6 weeks from the last day of treatment and annually thereafter for 5 years. Your doctor will go through the details of your individual long term follow-up at this appointment, including when you will have scans. This will be determined by the type (and site) of cancer that was treated. We will make arrangements for your appointment and send you an appointment letter.

Attending your follow-up appointments is very important as it allows us to look for problems that might arise from treatment. This helps us identify your problems early and direct any on-going care that you may need relating to any long-term treatment side effects you may have. Also, this is an opportunity for us to gather a great amount of information that will help us improve the treatments we give to patients in the future. This allows us to continue to deliver high quality, safe and effective treatment.

If follow-up here has been arranged please make every effort to attend. If you wish to cancel your follow-up, please contact us first. If your follow-up has been arranged elsewhere, please remind your doctor to send any letters and results to us.

If you have not received a proton follow-up appointment within 4 weeks after completing proton beam therapy, please contact the secretary of your Christie consultant.

If you have any problems or concerns after treatment, please contact your key worker, the secretary of your Christie consultant or your GP. So we can keep track of any side effects of treatment, please inform your key worker if you are admitted to hospital or receive any other (unplanned) care within the 6 weeks following the end of proton beam therapy and your follow-up visit.

However, if you feel unwell and need urgent medical attention, please contact your GP, out-of-hours GP

or in an emergency the Accident and Emergency Department (999). For the first month following proton beam therapy you can also contact The Christie Hotline (24 hours) on **0161 446 3658**.

We would also be happy to hear from you. You can let us know how you are doing or request a call back by email **patientoutcomes@christie.nhs.uk**. (Please note that personal information sent by email is not secure).

OUT OF AREA PATIENTS

When you have completed your proton beam therapy, a letter with details of your treatment and any side effects that you may have experienced will be sent to your GP and referring consultant (and a copy sent to yourself). You will be followed up regularly. Your first appointment after the completion of your treatment should be approximately 6 weeks from the last

day of treatment. This will be done at your original hospital. Your doctor will go through the details of your individual long term follow-up at this appointment, including when you will have scans and when you will need to travel back to The Christie. This will be determined by the type (and site) of cancer that was treated.

If you have not received an oncology follow-up appointment within four weeks after completing proton beam therapy, please contact the secretary of your Christie proton therapy consultant or alternatively via The Christie switchboard on **0161 446 3000**.

Attending your follow-up appointments is very important as it allows us to look for problems that might arise from treatment. This helps us identify your problems early and direct any on-going care that you may need relating to any long-term treatment side-effects you may have. Also, this is an opportunity

for us to gather a great amount of information that will help us improve the treatments we give to patients in the future. This allows us to continue to deliver high quality, safe and effective treatment.

Unfortunately we are unable to provide accommodation for these infrequent visits, so if you are unable to attend The Christie for your planned follow-up appointments, please inform your key worker so that we can arrange this at your local hospital.

If follow-up here has been arranged please make every effort to attend. If you wish to cancel your follow-up, please contact us first. If your follow-up has been arranged elsewhere, please remind your doctor to send any letters and results to us.

If you have any problems or concerns after treatment, please contact your key worker, the secretary of your Christie consultant

or your GP. So we can keep track of any side effects of treatment, please inform your key worker if you are admitted to hospital or receive any other (unplanned) care within the 6 weeks following the end of proton beam therapy and your follow-up visit.

However, if you feel unwell and need urgent medical attention, please contact your GP, out-of-hours GP or in an emergency the Accident and Emergency Department (**999**).

We would also be happy to hear from you. You can let us know how you are doing or request a call back by email **patientoutcomes@christie.nhs.uk**.

(Please note that personal information sent by email is not secure).




**MACHINE
UNAVAILABILITY**

MACHINE UNAVAILABILITY

During the course of your treatment there may be times when it is not possible to have proton beam therapy. This is usually due to equipment breakdown.

Depending on your treatment plan you may miss some treatments. This is nothing to worry about and has been carefully considered with your doctor and the proton team. You may also have another plan produced which is for conventional X-ray therapy. This is referred to as a back-up plan. It may be necessary for you to have some photon treatments in the radiotherapy department using the back-up plan. This is something that will have been carefully considered by your doctor and the proton team prior to you starting treatment and will have been discussed with you during the consent process.

If you feel like you need more information regarding this please speak to the radiographers who are delivering your treatment.



HEALTH AND
WELL-BEING

HEALTH AND WELL-BEING

It is important to look after your general health as much as possible during your treatment. This can minimise the side effects of your treatment and allow you to continue doing the things you enjoy.

HEALTHY EATING

Eating a balanced diet can help you to maintain muscle strength, keep energy levels high and reduce the risk of other illnesses such as diabetes.

For most people, a balanced diet consists of:

- Lots of fruit and vegetables.
- Plenty of starchy foods (carbohydrate) such as bread, rice, pasta, potatoes, noodles.
- Some protein-rich foods such as meat, fish, nuts, eggs, lentils, beans.

- Some milk and dairy foods such as cheese, yogurts.
- Small amounts of food that are high in fat, salt and sugar.
- Drinks should be mainly those with no added sugar or that are sugar-free.

If you have questions about your diet please ask your GP, oncologist, specialist nurse or key worker.

KEEPING ACTIVE

Keeping active during cancer treatment helps maintain strength, fitness, physical function and well-being. Physical activity is also the best way to manage cancer-related fatigue.

The level and type of physical activity you can manage is individual to you, and will likely vary from day to day during your treatment. Everyday activities such as going for a walk, climbing the stairs and doing basic stretches can all help to keep you fit and healthy.

If your treatment involves being an inpatient on the ward, try to minimise the amount of time you spend in bed where possible, for example by participating in the activities on the ward, or even just sitting out in the armchair. Going for a daily walk is a good habit to get into, as long as you check with the nurses looking after you that this is okay.

If your cancer or symptoms prevent you from carrying out the above activities, or you have any questions or concerns about being physically active, please contact the physiotherapist for further advice (either directly or through your oncologist, key worker or nursing staff).



UNDERSTANDING YOUR TREATMENT

INFORMATION TO HELP YOU UNDERSTAND YOUR TREATMENT

The Christie has a wide range of information booklets on various topics. You will find most of these in leaflet racks around the unit or in the cancer information centre located on the glass corridor. If there is a specific topic that you wish to know about, please ask your key worker or nursing team.

AGREEING TO TREATMENT AND INFORMED CONSENT

The doctors and nurses will discuss the treatment that is recommended for you, and explain how it will affect you. It is important that you understand the meaning of any treatment, test or operation that you are having. The team will then ask you to sign a consent form once you have had all your queries and concerns about your treatment answered to your satisfaction.

TESTS AND INVESTIGATIONS

Chemotherapy and radiotherapy can affect the function of various organs in the body. You will have tests before you start treatment, and on a regular basis throughout the course of your treatment.

The tests you need depend on the particular course of treatment you are having. The nursing and medical staff will tell you in detail about the tests you need. Listed below are some of the tests that you may need. It is unlikely that you will need all of these. If you have any questions or concerns about any of these then please ask either your doctor or any of the nursing team.

BLOOD TESTS

Blood samples are taken before, during and after your treatment. These help us to assess how your bone marrow, liver and kidneys are working and how your treatments are affecting you. The nursing staff will explain your 'blood counts' to you in more detail.

GFR TEST (GLOMERULAR FILTRATION RATE)

This test is used to assess your kidney function. You will have the test in the radioisotopes department at The Christie. An isotope is injected which goes to the kidney and is then cleared by the body. This is a simple test that involves taking some blood samples at various intervals. The test will be fully explained by the staff. This test takes up to 4 hours so please feel free to use the teenage and young adult facilities while you are waiting.

ECHOCARDIOGRAM (ECHO)

This test assesses your heart function and is performed at The Christie in Department 37. This simple test is a scan/ultrasound of the heart.

AUDIOMETRY

This is a simple hearing test usually performed at the nearby Withington Hospital (Nell Lane, Manchester, M20 2LR). You will be placed in a room and will be asked to listen to a series of tones via headphones.

LUNG FUNCTION TEST

This test assesses how your lungs function. It is carried out at The Christie. The test involves blowing into a machine that then measures the capability of the lungs.

BONE MARROW ASPIRATE

This test involves taking a sample of bone marrow, usually from the hip bone. Local anaesthetic is used to 'freeze' the area (this may sting). A needle is then passed through the skin into the bone. A small sample of bone marrow is drawn into a syringe and can cause some discomfort. You can ask the doctors for sedation (to be drowsy and therefore not remember) for this procedure and you will be given pain killers afterwards if needed.

LUMBAR PUNCTURE

This test involves a needle being inserted into the spine and a small amount of fluid taken for sampling. A local anaesthetic is used, but the procedure may be a little uncomfortable. Some people have headaches after this procedure. To help reduce the potential for headaches you should lie flat for 2-3 hours afterwards and drink plenty of fluids.

SCANS

You may need a scan. There are various scan options. Your consultant will discuss with you which is the most appropriate, for example: CT scan, MRI scan, PET scan, bone scan, or a combination of multiple scans. Scans are carried out before treatment to help the medical staff assess your disease and/or to enable them to plan your treatment. Other scans may be carried out during treatment as a way of monitoring your body's response to treatment. Some people also have a scan when they finish their treatment.



THE DAY UNIT

THE YOUNG ONCOLOGY DAY UNIT

The young oncology day unit (department 30) has 2 beds and 3 chairs for patients who do not require an inpatient stay.

The day unit is open 8.00am – 6.00pm, Monday to Friday.

The day unit will see patients who require day case chemotherapy, injections and transfusions. These will be by appointment only and your key worker will arrange them for you.

Emergency admissions can be seen in the day unit between 8.30am and 3.00pm when arranged via The Christie Hotline only.

The day unit staff will try to ensure you receive treatment as quickly as possible but please note that for some treatments you should expect to be here for most of the day.

Day unit patients are encouraged, where possible, to use the social hubs on the first and second floors of Palatine ward. There you will be able to join in with activities and events to help pass your day. Don't worry, the staff on the day unit will let you know when they need you or you have to go back to the day unit, you will not miss your appointment.



AFTER YOUR CHEMOTHERAPY

AFTER YOUR CHEMOTHERAPY AT THE CHRISTIE

Before you are discharged from the hospital someone will talk to you about some of the things to look out for when you get home. This may include signs and symptoms of an infection, nausea and vomiting, tiredness or a lack of appetite. The discussion you have before you leave will let you know what you need to be worried about and at what point you should ring.

The Christie Hotline
0161 446 3658

Open 24 hours a day,
7 days a week

You may have more than one cycle of chemotherapy during your proton beam therapy. If you need any further appointments your key worker will discuss this with you. If you have transferred your care temporarily to Manchester in order to have proton beam therapy, we will contact your local treatment centre to ensure your care continues as planned when you return home.

Every young person should have the contact details for at least one person from the teenage and young adult team (as well as the hotline number), this may be one of the specialist nurses, specialist radiographer, a social worker or one of the youth support coordinators (YSCs). This person can be contacted should you have

any questions, concerns or worries. Please do ring this person as often there can be easy explanations to questions and concerns and we will do everything possible to reduce worries and anxieties.

GOING
HOME

GOING HOME

GOING HOME CHECKLIST

- Do I need any X-rays or other tests before I go home?
 - Have I got my medications to take home?
 - Have I got the appropriate equipment such as bungs or syringes?
 - When do I need to come back?
 - Have I made my next appointment?
 - Do I have The Christie Hotline number (0161 446 3658)?
 - Do I need to speak to a nurse about arranging for a district nurse to flush my line at home?
- Have I arranged my transport?
 - Have I packed all my belongings?
 - Have my carers returned any keys for the relatives' accommodation?

IF YOU NEED A PRESCRIPTION

Please allow plenty of time if you need a prescription before you go home. There can be a couple of hours wait at The Christie pharmacy, so if you know you are going home and need a prescription, let a nurse know as soon as possible.

Please ensure the staff know which medications you do not need if you already have a supply at home.

GLOSSARY

GLOSSARY

Below are some of the terms used by nursing and medical staff:

Alopecia

Hair loss.

Analgesia

Pain killer.

Anti-emetic

Anti-sickness drug.

Audiometry

Simple hearing test.

Beam line

The link between the cyclotron and each treatment gantry.

Blood count

Levels of specific cells produced by your bone marrow.

Blood cultures

Blood taken to test if infection is present in your blood.

BP

Blood pressure.

Bone marrow transplant

Donation of bone marrow to the patient.

Cannula

Small plastic tube into a vein (to receive drugs, etc).

Central line

Usually inserted in the chest, a central line is used to give chemotherapy and take bloods without the need for needles or cannulas.

Central venous catheter (CVC)

A long fine tube which provides access directly into the blood stream.

Clotting screen blood

Specimen usually taken from the arm to test if the blood is clotting normally.

Couch/bed

A carbon-fibre table top that you lie on during treatment.

Creatinine clearance test

To assess kidney function by collecting all urine over a 24 hour period.

Cerebrospinal fluid (CSF)

Fluid in brain and spine.

Cyclotron

An accelerating device; the proton beam therapy machine.

Dinamap machine

Used to measure your blood pressure and pulse.

Diuretic drug

Given to help you pass urine.

Drug levels blood

Test taken to check correct dose of certain drugs.

Electrolytes

Chemicals in body vital to normal function of all organs, essentially potassium and sodium.

Fluid balance

An essential part of monitoring fluid intake and output.

Gantry

The treatment delivery system for proton beam therapy; able to rotate 360 degrees around the treatment couch.

Glomerular filtration rate (GFR)

Test that measures how well your kidneys are able to filter blood.

Haemoglobin (Hb)

Amount of iron carried by the red cells in your blood.

Hickman

Type of central line.

Immunosuppression

Suppression of body's ability to fight infection.

Immobilisation mask (mould)

A piece of plastic mesh used to hold your head in the same position during each treatment episode over a course of radiotherapy.

Isotope

A radioactive substance.

Intravenous (IV)

Into a vein.

Liver function tests (LFTs)

To assess organ function.

Lumbar puncture test

Taking samples of spinal fluid from your back.

Lung function test

To assess how well your lungs are working.

Mid-stream urine (MSU)

Urine sample to test for infection.

Mouthcare

Use of various mouthwashes to help prevent infection.

Neutropenic

Low white cell count of the cells that protect you against bacteria. When the Neutrophils are less than 1.0 you are at greater risk of infection.

Observations/obs

Usually temperature, pulse and blood pressure. Taken every 4 hours when on treatment.

Oedema

Visible swelling in face, ankles and hands caused by retention of fluid.

Peripheral bloods

Blood samples taken from a vein, usually in the arm.

Phlebitis

Inflammation of veins.

Photons

High energy X-rays.

Platelets

Cells responsible for blood clotting. If platelets are low you could bleed or bruise more easily.

Prosthesis

An artificial replacement of, for example, a bone.

Protons

Small particles found in the middle of atoms that can be used to give carefully calculated doses of radiation.

Pyrexia

Above normal temperature.

Remission

No evidence of disease by routine investigation.

Septicaemia

Infection in the blood.

Shingles

Painful virus (same virus as chicken pox).

Stomatitis

Mouth ulceration.

Sub-cutaneous

Under skin surface.

Sub-lingual

Under the tongue.

Thrombocytopaenia

Low platelet count.

TTOs

Medication to go home with.

Urea and electrolytes (U&Es)

Sugars and salts in the body.

UTI

Urinary tract infection.



SEXUAL
HEALTH

SEXUAL HEALTH

Staff members may ask you about your sex life, relationships and whether you could be pregnant at different points during your treatment.

Here is some very important information that you need to know about having sex while you are having treatment.

- If you are having sex with a partner(s) you will need to use barrier methods (condoms and dams) to protect you and your partner. This includes condoms and dental dams for vaginal, oral and anal sex. Chemotherapy can be passed from one individual to another via bodily fluids, and this could cause harm to your partner.
- You will be given a sexual health pack (including condoms) when you start your treatment. Should you want any more condoms, lube etc please ask your Youth Support Coordinator.
- We strongly advise that whilst on treatment you take precautions during sex to prevent a pregnancy. We advise this because a pregnancy during treatment is potentially harmful to an unborn child, potentially harmful to yourself and could impact on your treatment.
- Some cancer treatments can leave you susceptible to bleeding and infections. Therefore it is important to speak to a member of staff with regards to appropriate precautions to follow if you want to have sex while you are on treatment.

- If you suspect that you may have contracted a sexually transmitted infection (STI) please speak to a member of staff so that you can be supported to access the appropriate advice and treatment. **Do not start treatment for an STI without speaking to a member of the teenage and young adult team or treating hospital team.**
- For advice about contraception related to your cancer treatment please ask a nurse/doctor/your key worker.
- For general contraceptive advice, please call The Hathersage Centre in Manchester on **0161 701 1555**, or speak to your local sexual health centre (for example Brook). If you choose to speak to them directly, please tell them if you are on active treatment as their advice may differ depending on where you are up to with your treatment and what treatment you are having.



GENERAL ANAESTHESIA

GENERAL ANAESTHESIA

If your child is unlikely to cope with treatment awake, even after support from the health play specialists, they may be offered general anaesthesia for their planning scans and proton beam therapy. This is performed by our anaesthetic team.

Once this has been agreed, your child will need to follow strict fasting guidelines when they require an anaesthetic. These instructions **MUST** be followed **EVERY** time your child comes for proton beam therapy otherwise a general anaesthetic will be unable to be performed for safety reasons, and your child will have their treatment cancelled for that day.

FASTING INSTRUCTIONS

- No food/milk/juice at least 6 hours prior to your child's anaesthetic
- Your child can continue to drink water only up to 2 hours before the anaesthetic
- No food/fluid at all for 2 hours before the anaesthetic

The consultant anaesthetist will visit you and your child at the proton beam therapy centre and perform an assessment. You will then accompany your child, with a member of the nursing team to the anaesthetic room.

Your child will then be given a general anaesthetic, either via their line/port, cannula or mask. You will be able to stay with them until they are asleep and then you will be escorted back to the waiting area to allow the team to attend to your child quickly and safely.

Once your child is awake, the nurse will escort you to the recovery ward.

Your child will be discharged from the recovery ward when they are fully awake and have had something to eat and drink.

ROYAL MANCHESTER
CHILDREN'S HOSPITAL
(RMCH)

PLANNED ADMISSION TO RMCH

If your child is to have chemotherapy which will require an overnight stay, they will be admitted to Ward 84 at RMCH. Ward 84 is the regional oncology and haematology unit for the North West of England and is based in the centre of Manchester.

Ward 84:
0161 701 8400 or 8401 or 8404

This will be arranged once your child's proton beam therapy schedule has been agreed. Your child will attend the outpatient clinic on a Friday where the go ahead for chemotherapy will be given by your allocated paediatric consultant. They will then be admitted to Ward 84 for delivery of their medications.

If your child requires a hospital to hospital transfer prior to proton beam therapy commencing then this will be arranged and they will be transferred directly to the inpatient ward. We will then ensure your child is transported the short distance to the proton beam therapy centre at The Christie on a daily basis for their treatment.

If your child does not require an overnight stay, their chemotherapy will be delivered on the day case unit.

**WARD 84
DAY UNIT AND
OUTPATIENT CLINIC**

WARD 84 DAY CASE UNIT AND OUTPATIENT CLINIC

The oncology and haematology outpatients department consists of two areas: the outpatient clinic and the day case unit. The outpatient clinic is where your child will be assessed, which will include taking a small amount of blood for testing and will also be seen by a doctor. The day case unit is where treatments will be given.

WHERE IS IT?

The department is on the second floor of the Royal Manchester Children's Hospital.

You can gain access via the lift on the right hand side of the hospital main entrance. Take this lift to the second floor and then turn left. You'll find the entrance to the department on your left hand side.

WHEN IS IT OPEN?

The outpatient clinic is open Monday to Friday, 8.00am - 4.30pm

The day case unit is open Monday to Friday, 8.00am - 7.00pm

WHAT HAPPENS IN THE CLINIC?

When you come to the department you will book in at reception, your child will have their height and weight measured and will be given a finger prick test. This involves taking a small amount of blood for testing prior to starting chemotherapy.

WHAT HAPPENS IN THE DAY CASE UNIT?

The day case unit is where your child will receive their chemotherapy or any required blood/platelet transfusions.

For chemotherapy, once they have seen the doctor, their treatment will be made up by pharmacists. This may take some time, but the nurse looking after you will let you know how long. For chemotherapy requiring an overnight stay, admission will be organised to the inpatient facilities on Ward 84.

If your child also needs blood or platelets, a nurse will need to take a blood sample so that your child's blood/platelets can be prepared safely in the laboratory. Again, this can take some time, but your nurse will keep you informed.

FACILITIES ON WARD 84 (RMCH)

FACILITIES ON WARD 84 (RMCH)

Parent facilities - a parents' room with basic food preparation facilities and fridges for food storage, shower/toilet facilities and a housekeeper who can orientate you to the ward and hospital and offer drinks to parents at regular times. They also host a parents' support group fortnightly. There are parent beds available so you can stay with your child if you wish.

Car parking - the main patient/visitor car park is Hathersage Road car park. This is the nearest to the Children's Hospital entrance and to the Paediatric Emergency Department. When you attend the department you are eligible for a reduction in car parking prices, depending the expected length of your child's admission.

Play room - on Ward 84 there are dedicated play staff who will see your child at the bedside or will provide activities in the play room. There are many activities available on the ward and an outdoor play area in the hospital if your child is well enough.

Hospital school - Ward 84 has a school room on site and teachers and teaching assistants for all levels. They will do their best to support your child's on-going education whilst an inpatient and also involve them in all activities in the school room.

Allied health professionals - RMCH work with a wide team of health professionals including physiotherapists, occupational therapists, dietitians, specialist nurses, pain management teams and psychologists and will support your child's individual needs whilst in Manchester if required.

Around the hospital there are many facilities such as:

- WH Smith (within the children's and adult hospitals)
- Costa Coffee and Starbucks cafes throughout the hospital
- Hospital canteen with a Subway
- Out of hours hospital canteen (in the Royal Eye Hospital)
- Cash point in the Children's Hospital main entrance
- Fruit and veg stalls on week days
- Marks and Spencer Foodhall within the hospital grounds

It is minutes away from Oxford Road, Manchester which has numerous shops and food outlets. There are two large supermarkets, a park and art gallery within the local area and excellent transport links to the city centre.

POST DISCHARGE INSTRUCTIONS

POST DISCHARGE INSTRUCTIONS

If you have any concerns about your child whilst at your accommodation/home, please phone Ward 84 at Royal Manchester Children's Hospital on 0161 701 8400.

Do not bring your child back to the proton beam therapy centre at The Christie. If your child needs to return to hospital, you will be advised to take them to Royal Manchester Children's Hospital.

IF YOUR CHILD
BECOMES UNWELL
IN MANCHESTER

IF YOUR CHILD IS UNWELL DURING THEIR STAY IN MANCHESTER

Please contact the team at Royal Manchester Children's Hospital (number below) if you need any advice or if your child is experiencing any of the following:

Paediatric emergency department:
Ground Floor
Royal Manchester Children's Hospital
Oxford Road
Manchester
M13 9WL

24 hour triage nurse:
0161 701 7489

- A temperature over 38.0°C
- Lethargy with reduced activity
- Vomiting, diarrhoea and not responding to anti-sickness medication
- Not eating or drinking or passing urine
- Develops any rashes, bruising or bleeding
- Any unexplained or unmanageable pain
- Has a cough, shortness of breath or difficulty breathing
- If the Hickman line site becomes reddened
- Any other physical symptoms you are concerned about

Your call will be answered by an oncology/haematology nurse, who will assess your child over the phone, get advice from a doctor if needed and then let you know what to do next.

If your child requires review or admission you will be asked to either attend the day case unit or the children's emergency department.



SUPPORT SERVICES

Support Services

SPEECH AND LANGUAGE THERAPY

Speech and language therapists specialise in disorders of swallowing and communication. As a result of your illness or treatment you may find that eating and drinking or communicating is more difficult than before. The department will assess your swallowing or communication problem and provide treatment, advice and support. You may be referred to speech and language therapy before, during or after your treatment.

HOW CAN I ARRANGE TO SEE A SPEECH AND LANGUAGE THERAPIST?

If you would like to see a speech and language therapist whilst you are in hospital, please ask your doctor or nurse to refer you.

They may be able to put you in touch with a speech and language service closer to your home.

WHAT CAN THE THERAPISTS DO TO HELP?

- Advise how your swallow function is likely to change due to the treatment you will be undergoing and how you can be supported through this. Swallowing exercises will be given to all patients having proton beam therapy to the head and neck. This is to help reduce the effects of the treatment on your ability to eat and drink, and to achieve the best possible long-term swallow function.
- Provide strategies and techniques to make swallowing food and drink easier and safer.

Your cancer treatment can make you more at risk of food and drink 'going down the wrong way'.

- They can carry out instrumental swallow assessments if necessary. For example, carrying out an X-ray examination of your swallow (a video fluoroscopy) or observing your swallow function via a thin scope that is passed through your nose.
- Advise on strategies to help make communication easier and more effective.
- Advise on ways of looking after and getting the best from your voice.
- Provide communication aids when speech is difficult.

PHYSIOTHERAPY SERVICE

Being active and exercising during and after treatment can be very beneficial.

The role of the physiotherapy service is to help you maintain physical activity and function throughout all stages of your treatment.

The physiotherapy service is available to inpatients and outpatients aged 16 and over, both during and after treatment. Please ask a member of staff if you would like to be referred.

This may include:

- Specific rehabilitation to maximise function during and after treatment
- Individualised exercise programmes to maintain or regain strength, flexibility or improve balance and coordination
- Supervised use of the gym in the main hospital including exercise classes
- Addressing any mobility problems and providing equipment as necessary
- Providing advice on maintaining a healthy lifestyle during treatment
- Helping you to continue your activity when you are at home, e.g. going to local gyms, attending local sports groups and referrals to local services

WHAT IS OCCUPATIONAL THERAPY?

Occupational therapy provides practical support to help people to overcome barriers stopping them from doing the things that matter to them. This could be essential day-to-day tasks such as self-care, work or hobbies. The aim of the occupational therapist is to increase people's independence and quality of life.

The occupational therapy service is available to patients aged 16 and over, with a diagnosis of a brain or sarcoma tumour.

WHAT SUPPORT CAN AN OCCUPATIONAL THERAPIST PROVIDE?

An occupational therapist can offer several services to help you with your independence which may involve:

- Completing an initial assessment to establish your needs and any potential difficulties with daily activities and function
- Developing a programme of support and interventions to enable you to maintain your function throughout treatment
- Providing advice and coping strategies to help with managing physical symptoms such as fatigue, pain, weakness etc. This could be on your own or in a group
- Providing advice and coping strategies to help with psychological and cognitive difficulties such as anxiety, body image, low mood, changes in confidence levels or memory difficulties
- Offering advice on equipment provision or adaptation of activities/environment to make it easier for you to take part in daily activities, for example, wheelchairs, bathing equipment, feeding aids etc
- Completing referrals and liaising with your local services at the end of treatment for further support.



NUTRITION AND DIETETIC SERVICE (ADULT)

NUTRITION AND DIETETIC SERVICE

It is important to keep well-nourished during your treatment, this helps to minimise any weight loss and support you during and after your treatment. There are diet information booklets available to give you general advice if you are experiencing any side effects from the treatment, which you can ask your key worker for. If you are struggling with your eating or weight please speak to your doctor or key worker for further advice.

FOR PATIENTS WITH A FEEDING TUBE

If you have a feeding tube, your key worker will let you know what needs to be done.

If you are coming from home with a feeding tube in place please bring with you your supplies (pump, giving sets, syringes and any other equipment you may require). You will need to bring enough feed and equipment with you for the duration of your treatment.

If you are set up with a feed company (Abbott/Nutricia or Fresenius), a 'holiday service' can be arranged. This will mean that your feed and equipment can be delivered directly to you. You will need to contact them to organise this if you wish.

If you receive your feed and equipment from a local chemist/district nurse team, you will need to bring enough with you for your stay.

Please speak to your key worker for more details and what steps need to be taken.

TUBE PROBLEMS DURING YOUR STAY

If you have a gastrostomy tube, you can access our 'gastrostomy drop in' service located within the IPU (department 2). This service is available Monday to Friday, 9.00am – 5.00pm.

For any other type of feeding tube problem speak to your key worker or doctor.

For any tube related problems out of hours, please call The Christie Hotline on **0161 446 3658**.

FOR PATIENTS HAVING TREATMENT TO THE HEAD AND NECK AREA

If you are under the care of the head and neck team, you will be seen by the proton dietitian.

Dietitians are core members of the head and neck team and have an essential role in assessing, managing and treating the nutritional problems that these cancers and their treatment cause.

Whilst you are under the care of the proton beam therapy centre, you will be assessed by a dietitian, who will monitor your nutritional progress over the course of your treatment. You will be assessed before your treatment starts and as your treatment progresses.

If you are already on a feed, you will be advised what you will need to bring with you. See above for more details.

Your dietitian will:

- Advise the team on the best course of nutritional management along your treatment journey
- Provide you and your family/ carers with practical dietary information, including suitable foods and the best textures for you to choose, portion sizes and meal patterns as your treatment progresses
- Provide you and your family/ carers with support and guidance regarding nutrition support. This will include the use of special nutritional supplement drinks and tube feeding, if this is felt to be in your best interest
- Arrange local follow-up upon treatment completion

The head and neck dietitian will be available Tuesday, Wednesday and Thursday and you will automatically be booked into clinic.

If you are not under the care of the head and neck team, please liaise with your key worker/specialist team if you have any concerns regarding your weight, appetite or dietary intake.



NUTRITION AND
DIETETIC SERVICE
(PAEDIATRIC)

NUTRITION AND DIETETIC SERVICE

It is important to keep your child well-nourished during their treatment, this helps to minimise any weight loss and avoid delays in treatment. If your child is not tolerating oral feeds please seek advice from nursing staff. We can arrange a referral to a dietitian at Royal Manchester Children's Hospital if necessary.

FOR CHILDREN WHO EAT AND DRINK

Refreshments will be provided. We will have cold drinks available, cereal, and sandwiches. If you think your child would prefer to eat something else you may bring this with you on the day.

FOR CHILDREN WHO ARE BREAST FED OR DRINK FORMULA MILK

We have breast feeding facilities on the unit. If your child has formula milk, please bring this with you on the day.

FOR CHILDREN WITH FEEDING TUBES

It is vital you bring all equipment with you. You will need to bring a pump, giving sets, and enough feed to last the duration of your child's treatment. Alternatively you can contact your named dietitian to arrange a 'holiday service' delivery. This will mean that your feed and equipment can be delivered to you. If you have any problems with your child's feeding tube whilst having treatment please speak to one of the nursing team.

SIDE EFFECTS

Your child may have side effects from their radiotherapy treatment. However, depending on where your child is having treatment they may not experience all the side effects listed. Please inform the nursing team if your child is experiencing any side effects.

Feeling sick

Occasionally your child may have feelings of sickness which is a common side effect of radiotherapy. This can usually be effectively treated by anti-sickness drugs.

Change in appetite

Your child may find their food tastes differently and therefore their appetite may be affected. It is important to encourage them to eat little and often. If you feel your child has a reduced intake please seek advice from one of the nursing team.

Sore throat

Your child may develop a sore throat and discomfort on swallowing. All of these can usually be treated with medication.

Bowel disturbances

Depending on the location of the tumour, your child may develop diarrhoea or constipation. It is important to maintain your child's hydration during this time. If you are concerned about your child's bowel functions, please speak to one of the nursing team.



PSYCHO-ONCOLOGY
SERVICE

PSYCHO-ONCOLOGY SERVICE

Receiving a cancer diagnosis and having treatment is a difficult thing for young people and their families to go through. The proton team at The Christie includes highly skilled professionals who will help and support you but sometimes you may need the help of the psycho-oncology team.

The psycho-oncology team at The Christie provides a wide range of emotional and psychological support services. You will be assessed as to which type of service you would most benefit from.

Available services include:

- Counselling
- Clinical psychology
- Psychiatry
- Sexual counselling
- Cognitive behavioural therapy

These therapies and techniques are available to any patient over the age of 18. They can be used to help deal with anxiety, depression and other psychological conditions. Before any referral into the psycho-oncology service, there will be discussion between you and your key worker.

Alternatively, you can self-refer through the Maggie's Centre, located on Kinnaird Road.
Call **0161 641 4848**

SMOKING CESSATION AND ALCOHOL ADVICE SERVICES

For further advice and support contact our health advisors on: 0161 446 8236 or 0161 918 7175 or call 0161 446 3000 and ask for bleep 12565.

Electronic cigarettes are not permitted within the hospital or close to entrances.

The Christie and its grounds is a non-smoking site.

WHY IS IT IMPORTANT TO STOP SMOKING?

Smoking during cancer treatment increases the risk of infection, nausea and anxiety. Becoming smoke-free is the most important step you can take to reduce ill health and early death from many cancers and other lung and heart diseases. We strongly advise you not to smoke.

WHY DO WE ASK ABOUT ALCOHOL USE?

We will ask you about alcohol use as a normal part of taking your medical history. It is not unusual for patients to increase its use on diagnosis, adding to insomnia, low mood and anxiety. Drinking alcohol during cancer treatment can increase side effects, and may affect the outcome of cancer treatment itself.

Our health advisors can provide information about safer alcohol usage and withdrawal from alcohol during cancer treatment.

HOW CAN WE HELP YOU TO GO SMOKE-FREE?

We can help you by arranging a nicotine replacement therapies (NRT) prescription and showing

you how to use NRT products and by providing:

- Information about medically approved nicotine replacement therapies
- Coping strategies for managing cravings
- Rapid relaxation, breathing and hypnotherapy techniques
- Information about where to get help and support locally
- Advice about switching/ withdrawing from using electronic cigarettes
- Ear acupuncture – temporary acu-seeds placed on the earlobes

WIGS AND BANDANAS

There are many cancer treatments that lead to a degree of hair loss. Please speak to your doctor or key worker to find out whether your treatment will lead to any hair loss.

If it is expected that there will be hair loss as a result of your treatment then you will be offered a wig. You will be able to obtain a synthetic wig on prescription through the hospital. You will need to collect the voucher from the cancer information centre and take it to the wig room which can be found in the Oak Road reception area, department 3.

Real hair wigs are also available through various charities. Please ask your key worker for more information and a referral. These are also free of charge.

You can have a synthetic wig and a real hair wig.

There are a wide range of hats, bandanas and scarves that can be obtained from shops or the internet. The cancer information centre has a list of websites who supply scarves/bandanas. Some funding may be available to help with the costs of these items, please ask your key worker.

The Maggie's Centre offers a head care workshop to support people who are experiencing hair loss. They also provide complimentary cotton hats on request. Please contact the Maggie's Centre directly or the cancer information centre for more information.

Maggie's Centre:
0161 641 4848

CHAPLAINCY AND SPIRITUAL CARE

The chaplaincy and spiritual care team are available to help people of any faith or of no faith with their religious, spiritual or pastoral needs. Illness and treatment can raise big questions about spirituality, meaning and hope, whether you are religious or not, and they are always ready to listen.

The chaplaincy team includes Christian, Jewish and Muslim faith representatives. The team also has links with many other faith and belief communities, including Buddhists and Humanists. Facilities include a chapel, a prayer room (equipped for Muslim prayers) and a multi faith room in department 57. Just follow the signs to 'chapel and prayer room' situated near the entrance to the main hospital from the proton beam therapy centre. The facilities are open 24/7 for prayer, worship, meditation or quiet time.

Regular Christian and Muslim worship times include weekly Roman Catholic Mass, monthly Church of England Holy Communion and weekly Muslim Friday prayers. A list of worship times are advertised in the department. If you would like to make a specific request for prayer, there is a dedicated book in the chapel. The team will include these requests in their daily prayers (around 12 noon), which are also open to the public.

The chaplaincy team is happy to meet with you and/or your loved one in the proton beam therapy centre. Just ask a staff member or call direct on **0161 446 3097**.

MAGGIE'S CENTRE

Drop into Maggie's for practical, emotional and social support from our professional staff at any time from 9.00am - 5.00pm, Monday to Friday.

Find us:

The Robert Parfett Building
The Christie NHS Foundation Trust
15 Kinnaird Road
M20 4QL

0161 641 4848
manchester@maggiescentres.org

Some of the support available:

- Cancer support drop-in
- Benefits advice
- Job advice and support
- Exercise classes
- Talking Heads (advice on hair loss, head wear)
- Living with less stress
- Where now? Support beyond treatment
- Clinical trials support group
- The rhythm of life choir
- Creative writing
- Shared reading
- CALM sessions

SCHOOLING

Daily attendance for proton beam therapy may interfere with your child's ability to attend school on a regular basis. A team of specialist teachers and teaching assistants, based on the ground floor of the proton beam therapy centre at The Christie, ensure that when they are well enough, children and young people can access this facility and make progress with their education.

Look out for their green ID badge lanyards.

For more information contact:

Kerri O'Brien

0161 225 2199

k.obrien@hospitalschool.
manchester.sch.uk

www.manchesterhospitalschool.com

All children of school age who are receiving proton beam therapy at The Christie will be offered teaching in the classroom. With children's treatment schedules in mind, Christie staff will liaise with teachers to arrange times to attend daily classroom sessions.

WHEN IS SCHOOL AVAILABLE?

Classroom based teaching sessions will be held Monday to Friday, 9.30am - 12.00pm and 1.00pm - 3.30pm.

Pupils can generally expect to be in a mixed age class group, but learning will be personalised to suit the needs of each learner and will include a mix of one to one and small group sessions.

CAN CHILDREN DO THEIR OWN SCHOOL WORK?

Yes, of course. We will help with any school work children have from their own school.

HOW ARE CHILDREN KEPT SAFE IN THE CLASSROOMS?

Christie staff will complete a risk assessment before children attend the classroom, so that we know they are well enough to attend. Children will be supervised at all times during the sessions.

CAN SCHOOL STAFF GIVE MEDICAL SUPPORT DURING LESSONS?

No. If a child requires medical support, clinical staff will always provide this support.

Cancer
Information
Centre



USEFUL INFORMATION

CANCER INFORMATION CENTRE

CANCER INFORMATION CENTRE

The cancer information centre is located in the main hospital entrance at Oak Road, in department 3. It is staffed Monday to Friday 9:00am - 4:00pm, however, it is open 24 hours a day so you can help yourself to any booklets or leaflets you find useful.

There is also a patient information kiosk located on the ground floor of the proton beam therapy centre.

Contact:
0161 446 8100/8107

The information centre offers advice on a wide variety of topics including:

- Information on different types of cancer, diet, exercise, complementary therapies and much more
- Support on coping with hair loss and signposting to other services
- Wig vouchers (for NHS patients) are available from the information centre and further information about the wig room
- Support groups local to The Christie or in areas near where patients live
- Activities timetabled at The Christie and at the Maggie's Centre - art classes, Tai Chi, yoga, choir, creative writing and much more

BENEFITS AND FINANCE

BENEFITS AND FINANCE

You may have had to stop work and had a reduction in your income. You may be able to get benefits or other financial help.

Personal Independence Payment (PIP) is a social security benefit and has replaced Disability Living Allowance (DLA) for new claimants. It's for people who need help either because of their disability or their illness. You can apply if you are aged 16-64.

People aged 65 or over who need help with personal care or supervision could be entitled to Attendance Allowance.

Your carer could get Carer's Allowance if you have substantial caring needs.

Find out more today:

- To get a claim pack for Attendance Allowance, call **0345 605 6055** and for PIP call **0800 917 2222**.
- For DLA: if you were born on or before 8 April 1948 call **0345 605 6055**, if you were born after 8 April 1948 call **0345 712 3456**.
- For Carer's Allowance call **0345 608 4321**
- For benefits advice, contact Maggie's Centre on **0161 641 4848** or email **manchester@maggiescentre.org**

- Contact your local social services department for help with equipment and adaptations, or for an assessment of care needs. Visit **www.gov.uk** for further information
- Macmillan Cancer Support can give advice on helping with the cost of cancer on **0808 808 0000** or **www.macmillan.org.uk**
- The Cancer Research UK website offers information regarding financial support that is offered by both the government and charities **www.cancerresearchuk.org**

ONLINE RESOURCES

ONLINE RESOURCES

THE CHRISTIE

www.christie.nhs.uk

The Christie has a fully accessible website with news and information, as well as practical information about travel and facilities for patients and visitors.

CANCER RESEARCH UK

www.cancerresearchuk.org

Cancer Research UK provides a wide range of reliable and easy to understand information for people affected by or worried about cancer.

MACMILLAN CANCER SUPPORT

www.macmillan.org.uk

Macmillan Cancer Support provide practical, emotional and financial support for people diagnosed with cancer, their families, carers and communities.

THE BRAIN TUMOUR CHARITY

www.thebraintumourcharity.org

The Brain Tumour Charity provides support and information for anyone affected to improve quality of life.

TEENAGE CANCER TRUST

www.teenagecancertrust.org

Teenage Cancer Trust keeps you up to date with their events and also allows you to post messages to other patients from around the world.

JTV CANCER SUPPORT

www.jtvcancersupport.co.uk

This website has a collection of other patients' video diaries, experiences and animations. There are also message rooms where you can contact other young people with cancer.

CLICK 4 TIC

www.click4tic.org.uk

Provides cancer information written specifically for young people. Offers clinical and support information. You can also email qualified staff with questions you may have.

TEENS UNITE

www.teensunitefightingcancer.org

Teens Unite is dedicated to providing long term, on-going support to 13 to 24-year-olds with cancer. Regular fun days out to bring teens together and help build their self-esteem and self-confidence.

CLIC SARGENT

www.clicsargent.org

CLIC Sargent is a children's cancer charity providing practical and emotional support to patients and families.

HOSPITAL TRANSPORT

HOSPITAL TRANSPORT

Hospital transport is provided by North West Ambulance Service and West Midlands Ambulance Service.

Contact the transport liaison office at The Christie directly on **0161 446 8114** or **8143** for advice and bookings (Monday to Friday, 8.00am – 6.00pm)

Ambulance transport can be arranged subject to eligibility criteria based on medical need. There also needs to be a medical need for you to bring an escort on hospital transport.

Please note:

The ambulance service offers transport to many hospitals in this region and delays often take place due to the high volume of patients they are delivering on a daily basis. Please keep this in mind before considering using the service.

TRANSPORT LINKS

TRAVELLING TO THE CHRISTIE BY PUBLIC TRANSPORT

Patients and patient's visitors are encouraged to consider using public transport for travel to and from The Christie.

For further information call Transport for Greater Manchester on **0871 200 2233** or visit **www.tfgm.com**

BY BUS

Buses are very frequent and routes are displayed at the three main entrances and nearby bus stops.

For further information visit:

Stagecoach Manchester
www.stagecoachbus.com

or

First Bus
www.firstgroup.com

BY TRAIN

Most main line trains arrive at Manchester Piccadilly and some of these also stop at Oxford Road Station. Some trains arrive at Manchester Victoria. You can take a bus or taxi to The Christie.

The three local train stations are Mauldeth Road, Burnage and East Didsbury and they are linked to The Christie by bus.

For further information call National Rail Enquiries on **08457 484 950** or visit **www.nationalrail.co.uk**

BY METROLINK (TRAM)

Metrolink is a light rail network operating throughout Greater Manchester. There is a tram stop at West Didsbury, 5-10 minutes' walk to The Christie. There are footpath signs giving directions to The Christie.

BY CAR

The closest motorway junction is junction 5 of the M60. For detailed directions and information on car parks, visit our website www.christie.nhs.uk.

In addition to our car parks, there are also 14 car parking spaces available directly outside the proton beam therapy centre. The Trust cannot guarantee you an on-site car parking space. Parking is permitted for up to 3 hours on some local streets.

Pay stations are located in the car parks, please pay for your parking before returning to your vehicle when you are leaving. Please check the pay station in the car park you are using to see how you are able to pay.

Blue Badge holders are exempt from car parking charges. Please leave your clock visible on the dashboard and take your Blue Badge with you. Before you return to your vehicle, please take your ticket and blue badge for validation to the information point in Oak Road entrance.

There are drop-off points at the Oak Road, Wilmslow Road and Palatine Road entrances.

BY PLANE

The Christie is located 30 minutes away from Manchester International Airport.

For further information visit www.manchesterairport.co.uk

HELP WITH TRAVEL AND CAR PARKING COSTS

Patient travel expenses can be reimbursed for patients who qualify under the 'Healthcare Travel cost scheme'.

To claim costs, please take your car park receipts and proof of eligibility to the cashier's office (department 16), just off the main corridor near the restaurant (open 9.30am – 1.00pm and 2.00pm – 4.00pm, Monday to Friday).

HOSPITAL FACILITIES

HOSPITAL FACILITIES

MAIN HOSPITAL ENTRANCE

The main hospital entrance is off Oak Road. There is a large seating area together with the following facilities:

CASH MACHINES

There are two cash machines in the hospital. One is located at the main entrance of the hospital; the other is located along the main hospital corridor. There is no charge to use these machines.

TAXI POINT

There is a telephone in the main entrance and in Wilmslow Road entrance, which is free to call a taxi.

POST BOX

The post box is located next to WHSmith.

PLACES TO EAT

Marks & Spencer

There is a Marks & Spencer café in the Oak Road reception area. Snacks and sandwiches are available to eat in or take away.

It is open Monday to Friday, 7:00am - 9:00pm and on Saturday and Sunday, 8:00am - 5:00pm.

WHSmith

There is a WHSmith shop based at the main entrance of the hospital selling newspapers, cards and small gifts. You can also buy snacks, drinks, books, games and toiletries.

It is open Monday to Friday 7:00am - 6:00pm and on Saturday and Sunday 10:00am - 4:00pm.

Hospital restaurant

Located on the main hospital corridor and open Monday to Friday, 7:00am -7:00pm.

Snacks, salads and hot meals are available to eat in or take away.

Cooked breakfast is served from 8:30am - 11:00am, hot lunch from 11:45am - 2:00pm.



THE CHRISTIE PHARMACY

THE CHRISTIE PHARMACY

The Christie Pharmacy is located in department 36.

All prescriptions for medications made by doctors at The Christie during your treatment can only be collected from The Christie Pharmacy.

Any prescriptions relating to your cancer diagnosis will be free of charge.

Contact Number:
0161 446 3433/2465

OPENING TIMES

Monday: 8.45am - 6.00pm

Tuesday: 8.45am - 6.00pm

Wednesday: 8.45am - 6.00pm

Thursday: 8.45am - 6.30pm

Friday: 8.45am - 6.00pm

Saturday: 10.00am - 1.00pm

Sunday: CLOSED

Bank Holidays:

Opening times vary but will be advertised at the pharmacy.

Note to patients staying in The Christie accommodation Staycity Aparthotel:

If you have other medical conditions requiring medication on a repeat prescription (this includes feeds) you will need to organise delivery to your Staycity accommodation or to a local pharmacy) for the duration of your stay in Manchester. You will find the address of your accommodation, including postcode, in the Staycity accommodation guide.

LOCAL AMENITIES TO THE CHRISTIE

LOCAL AMENITIES TO THE CHRISTIE

The Christie proton beam therapy centre is positioned between Withington and Didsbury Village where you can find many shops, cafes, leisure centres, eateries and supermarkets within walking distance.

For more information visit the patient information area situated on the ground floor of the proton beam therapy centre or the cancer information centre in the main entrance of the hospital.



THE CHRISTIE CHARITABLE FUND

THE CHRISTIE CHARITABLE FUND

The Christie charity helps to provide enhanced services over and above what the NHS funds. Gifts from the public make a huge difference to the care and treatment that The Christie is able to provide to our patients and their families.

Whilst we have achieved a phenomenal amount thanks to the backing of our donors, this doesn't mean we can be complacent with our achievement and we always have plans to further improve our services. We have big goals and ambitions for the future, and all of these require your support.

We are one of the largest hospital charities in the UK with 83p in every pound raised going directly to the patients.

THE CHRISTIE CHARITY AND PROTON RESEARCH

Unique to the proton beam therapy centre at The Christie, is the addition of a research space – paid for by The Christie charity through a funding appeal which raised the £5.6 million needed to build and equip the research room.

The state-of-the-art equipment will enable the actual proton beam to be switched through to the research room after treatment has finished for the day.

The research is headed up by Professor Karen Kirkby and her team and their aim is to further improve the accuracy of the proton beam to minimise side effects and late effects of treatment in young patients. Also they will be looking at

whether proton beam therapy can be combined with other drugs to make treatment even more effective in future.

Because proton beam therapy is a new type of radiotherapy in the UK the research team will play a key role in training the next generation of clinicians, scientists and engineers.

Should you wish to know more about the work of The Christie charity you can visit our charity centre in the foyer area of the Oak Road entrance of the hospital, open Monday to Friday 9.30am - 4.00pm. Alternatively, call 0161 446 3988 or visit www.christies.org

Registered charity no. 1049751

COMMENTS, FEEDBACK AND FORMS



COMMENTS
AND FEEDBACK

COMMENTS AND FEEDBACK

We are always keen to know what your thoughts are about our department and any feedback you have about your experiences. You can speak to any member of the proton beam therapy team to let us know what you think about what we do. In addition there are separate procedures within the hospital should you wish to speak to someone outside of this department.

PALS (PATIENT ADVICE AND LIAISON SERVICE)

PALS provides a confidential listening, advice, information and support service for any patient, relative or carer who has a problem using The Christie services. PALS gives on the spot assistance and

information, and aims to resolve any concerns as quickly as possible.

If you have any worries about the care or services at The Christie or if you need advice or information, please speak to the staff involved or your consultant. They will make every effort to resolve your concerns. If, after this, you remain dissatisfied or you need further help, please contact PALS. The PALS coordinator is normally available 10am to 4pm, Monday to Friday on **0161 446 8217**.

FORMAL COMPLAINTS

If you wish to make a formal complaint, you can write to:

**The Chief Executive
The Christie NHS Foundation Trust
Wilmslow Road
Withington
Manchester
M20 4BX**

Or contact us on:
0161 446 3701

The leaflet 'Telling us what you think: How to make a comment or complaint' explains in detail what to do. The Health Service Commissioner (Ombudsman) may investigate certain complaints, but the usual procedure is to contact the hospital first. The Independent Complaints Advocacy Service (ICAS) can provide independent advice about complaints. You can phone them on **0808 802 3000**.

The background features a solid red field with two large, overlapping circles. The circle on the left is a lighter shade of red, while the one on the right is a darker, more vibrant red. They overlap in the center, creating a gradient effect.

BLOOD TESTS AND MEDICATION

BLOOD TESTS AND MEDICATION

Your child will have twice weekly blood tests during their proton beam therapy. If you would like you can keep a record of them [here](#).

	Date/ Treatment Number	Date/ Treatment Number	Date/ Treatment Number	Date/ Treatment Number	Date/ Treatment Number	Date/ Treatment Number
White Cell Count						
HB						
Platelets						
Neutrophils						
Lymphocytes						
Weight						

	Date/ Treatment Number	Date/ Treatment Number	Date/ Treatment Number	Date/ Treatment Number	Date/ Treatment Number	Date/ Treatment Number
White Cell Count						
HB						
Platelets						
Neutrophils						
Lymphocytes						
Weight						

Please bring your child's medication with you and use the table below to keep a record of your child's regular medications:

Medication	Dose	Frequency

NOTES

THE CHRISTIE INFORMATION

For more information about The Christie and our services, please visit www.christie.nhs.uk or visit the cancer information centre at Withington, Oldham or Salford.

© 2019 The Christie NHS Foundation Trust. This document may be copied for use within the NHS only on the condition that The Christie NHS Foundation Trust is acknowledged as the creator.

We try to ensure that all our information given to patients is accurate, balanced and based on the most up-to-date scientific evidence. If you would like to have details about the sources used please contact patient.information@christie.nhs.uk

The Christie NHS Foundation Trust
Wilmslow Road
Manchester
M20 4BX
0161 446 3000
www.christie.nhs.uk

The Christie Patient
Information Service

January 2019 –
Review January 2022
CHR/PBT/1325/16.01.19 Version 1

**Contact The Christie Hotline
for urgent support and
specialist advice**

The Christie Hotline
0161 446 3658

Open 24 hours a day,
7 days a week



