



Proton Beam Therapy – Adult /Young Adult (TYA)

A guide for patients and their carers



Contents

Welcome to The Christie	3
What happens during treatment?	3
Your treatment.	4
Side effects	5
Machine unavailability	6
Health and wellbeing	7
Sexual health	7
End of treatment	8
Useful contact numbers	9
Support services.	10
Hospital Facilities	12
The Christie charitable fund	12
Will you help us tell the story?	13
Comments and feedback	13
PALS (Patient Advice and Liaison Service)	14
Formal Complaints	14

The Christie website

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

Welcome to The Christie

Since 2018, The Christie has been treating patients in the first of only two high energy NHS proton beam therapy (PBT) centres in the UK. 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.

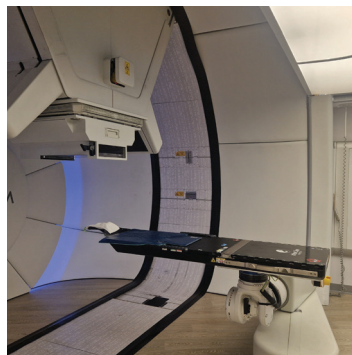
The Christie proton team will offer you as much support as possible. You have been assigned a specialist nurse or a specialist radiographer who will be your main point of contact and who will also provide help and support throughout your proton therapy planning and treatment. Teenage and young adults will also be assigned a youth support coordinator who can offer practical and emotional support tailored to this age group. They also provide workshops, activities and organise social events for you to take part in with other young people.

Please let us know how you would like to be known, 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.

What happens during treatment?

Proton beam therapy is given on an outpatient basis – 5 days a week over the course of several weeks. This may include weekends or bank holidays. Your doctor will discuss how long your treatment will be with you.

On the day of your first treatment, you will need to check in at the ground floor reception and one of the proton therapy



support team will confirm your contact details and you will receive your appointment schedule.

You will be collected by a radiographer who will explain the treatment process and possible side effects again and confirm you are still happy to proceed with treatment. Please use this as an opportunity to ask any additional questions you may still have.

Your treatment

Before entering the treatment room, you will be taken to a cubicle to change into a gown if required. You will be asked to select some music/ radio station which will be played during your treatment. You may also bring your own playlist/ audiobook if you wish.



You'll be taken to the treatment room and assisted onto the treatment bed. The radiographers will make you as comfortable as possible, whilst ensuring that you are in the correct position for treatment. If you have had a mask or cast made, this will be positioned as it was when you were scanned. All you need to do is remain as still as you can throughout the session.

Each session may take between 20 – 90 minutes to complete, depending on the area being treated. Most of this time is used to confirm you are in a suitable position for treatment using X-Rays. The radiographers will remain in the treatment room with you until they are ready to deliver treatment. They will then move to the control area and monitor you on a series of cameras. There can be a delay before the treatment starts because the beam is shared

between 3 treatment rooms, but the radiographers will update you over the intercom 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 at 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, the radiographers will help you off the treatment couch.

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.

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. During the consent process, your doctor will explain the potential side effects of your treatment and ask you to sign a consent form. This consent form will contain all potential side effects discussed, and you will receive a copy to take home. Please contact your specialist nurse or radiographer if, at any point, you have more questions.

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 reduce 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/7 days a week for urgent support and specialist advice.

The Christie Hotline 0161 446 3658

CALL 999 immediately if you experience chest pain or difficulty in breathing.

Machine unavailability

During your treatment, there may be occasions where the machine is not available to deliver your treatment. This can be due to several reasons:

- Machine breakdown
- Planned machine service
- Bank Holiday

Machine breakdowns

Machine breakdowns are unexpected and unavoidable. When this happens, we will always try to deliver your treatment that day with protons, but due to the complexity of the machine this is not always possible.

Your consultant will be informed and kept up to date with the situation. A plan of action, specific to each individual patient, will be made to account for the missed treatment. This may include:

- Adding the missed treatment/s to the end of your treatment schedule.

- Treating you twice in one day with a minimum 6-hour gap between treatments .
- Treating you on our monthly Saturday catch up session.

If the breakdown lasts for longer than one day, or there is more than one breakdown during treatment, we may consider treating you with photon (X-ray) therapy in the radiotherapy department. If this treatment option is deemed appropriate for your tumour type, this will have been discussed with you during your initial proton consultation, and you will have signed an additional consent form specifying this.

This decision is made by your consultant and is decided on an individual basis, taking in to account your tumour type and any treatments missed so far.

Planned maintenance

For planned machine maintenance, and some bank holidays, we will treat you on a Saturday or Sunday to make up for the missed treatment. You will be informed of these dates in advance.

Please do not book public transport to return home immediately following treatment, as any of the delays detailed above could have an impact on when you finish your treatment.

Health and wellbeing

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.



Eating a balanced diet and keeping active can help you to maintain muscle strength, keep energy levels high and aid your recovery. Please keep in mind that your proton beam therapy plan has been tailored to your current weight/ shape. It is important that you do not intentionally attempt to gain or lose significant weight during your treatment.

Smoking and alcohol consumption during treatment can negatively impact any side effects experienced and may affect the outcome of cancer treatment itself. Smoking and alcohol cessation and alcohol advice services are available to help you stop or reduce your intake.

Please contact your specialist nurse / radiographer should you need any more information.

Sexual health

You must not be/ become pregnant during proton beam therapy as this could result in significant harm to an unborn child and cause delays to your treatment that could potentially impact its effectiveness. If you suspect you could be pregnant, you should notify your treatment team immediately.

- If you are receiving chemotherapy, you must use a barrier method of contraception (condoms and dams) as chemotherapy can be passed from one individual to another via bodily fluids.
- Some cancer treatments can leave you susceptible to bleeding and infections. It is important to speak to a member of staff about any 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 your specialist nurse/ radiographer 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 staff.

For general contraceptive advice, please call The Hathersage Centre in Manchester on **0161 701 1555** or via their website www.thenorthernsexualhealth.co.uk. If you choose to speak to them directly, please tell them if you are on active treatment as their advice may differ.

End of treatment

Once your course of treatment has been completed, a letter will be sent to you, your GP and your local team with treatment details including side effects.

Follow up is at 6 weeks, 6 months and then annually for 5 years. The Christie team will be following up on the effects specifically of the proton beam therapy. Your local team will be responsible for organising routine follow up appointments, scans and any further treatment if required.

If you have not received an oncology follow-up appointment within 4 weeks of completing proton beam therapy, please contact the secretary of your Christie proton therapy consultant or alternatively via The Christie switchboard on **0161 446 3000**.

If you have any problems or concerns after treatment, please contact your specialist nurse / radiographer; 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**.

Useful contact numbers

Ground floor main reception	0161 918 7577
Second floor clinic reception	0161 918 3600
Scheduling team	0161 918 7170
Specialist nurse/radiographer – head and neck/sarcoma/others	0161 918 7232
Specialist nurse/radiographer – neuro/base of skull	0161 918 7235
Youth support coordinator	0777 4332 560
The Christie pharmacy	0161 446 3433
Ambulance hospital transport service for in-area patients	0161 446 8114 or 8143
The Christie Hotline 0161 446 3658 Available 24 hours a day, 7 days a week	

Support services

The following support services will be offered to you if needed;

- **Speech and language therapy** – provides support for disorders of swallowing and communication.
- **Physiotherapy** – supports patients to maintain physical activity and function.
- **Occupational Therapy** – provides practical support to help essential day-to-day tasks that will increase independence and quality of life.
- **Dietetics** – specialise in assessing, managing and treating nutritional problems and giving dietary advice, including help with using feeding tubes.
- **Robs Day Unit (Palatine outpatients)** – For patients aged 16-24 who require day case chemotherapy,

injections and transfusions. This is by appointment only and your specialist nurse / radiographer will arrange this for you. Patients are encouraged to use the social hubs on the first and second floors of Palatine outpatients where they can join in with activities and events to help pass the day.

- **Ambulatory Care** – some patients aged 16-24 who require chemotherapy over a few days are eligible for ambulatory treatment. This means you will be able to go home or to your accommodation with a small electronic pump rather than staying on an inpatient ward. Your specialist nurse/ radiographer will arrange this for you.

The following support services are available at the Proton Beam Therapy Centre upon request, please discuss with your named specialist nurse/radiographer.

- **Complementary Health and Wellbeing** – uses a holistic approach to support emotional, psychological and physical wellbeing. Support is available for a variety of conditions such as: anxiety, panic attacks, insomnia, claustrophobia and alcohol and smoking cessation.
- **Chaplaincy** – The chaplaincy and spiritual care team help people of any faith, or no faith, with their religious, spiritual or pastoral needs. This includes holding regular Christian and Muslim worship.

Maggie's Centre

Maggie's provides free practical, emotional and social support to people with cancer, their families and friends. Staff are on hand to offer the support you need to find your way through cancer, including information about treatment, financial advice, psychological support, relaxation and exercise classes and nutritional advice. Or simply to sit quietly with a cup of tea.

No appointment needed. Support is free. Drop-in, Monday to Friday between 9.00am and 5.00pm.

Maggie's Manchester, The Robert Parfett Building, 15 Kinnaird Road, M20 4QL

Maggie's is the pavilion style building at the bottom of Kinnaird Road. Cross Wilmslow Road, turn left and then right onto Kinnaird Road.

Email: manchester@maggies.org

Tel: **0161 641 4848**

maggies.org

Hospital Facilities

The Christie Pharmacy (department 36)

All prescriptions for medications from 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. You can contact the pharmacy directly on **0161 446 3433**.

Opening hours are Mon to Fri 9:00am – 6:00pm and Sat 10:00am – 1:00pm. Bank Holiday opening times vary but will be advertised at the pharmacy.

The following facilities can be found at the main hospital entrance;

- Marks and Spencer café
- WHSmith
- Cancer information centre (also available in Outpatients Department 22).
- The Christie charity centre
- Cash machines

- Taxi point
- Post Box
- Restaurant located on the main hospital corridor (Dept 19).

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.

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. Alternatively, call **0161 446 3988** or visit www.christies.org

Registered charity no. 1049751

Will you help us tell the story?

Since the proton beam therapy centre at The Christie started to treat patients in December 2018, there has been a high level of media interest in the work we do here.

Our communications team is looking for patients and their families who are willing to discuss their experiences of proton beam therapy with the media and to support other publicity and marketing activities, such as writing a blog, keeping a video diary or featuring in a Christie film. Your named specialist nurse/radiographer will discuss this with you and if you decide you would be willing to share your story, they will pass your details to a member of our communications team, who will contact you to discuss this further.

For further information please contact: **0161 446 3706** or **0161 918 2059**. You can also email the-christie.press.office@nhs.net

Comments and feedback

We are always interested to receive any feedback you have about your experiences, both positive and negative.

If you have any concerns about your care or any services at The Christie, 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.

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 give on the spot assistance and information and aim to resolve any concerns as quickly as possible.

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**.



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

Visit the Cancer Information Centre

The Christie at Withington **0161 446 8100**

The Christie at Oldham **0161 918 7745**

The Christie at Salford **0161 918 7804**

The Christie at Macclesfield **0161 956 1704**

Open Monday to Friday, 10am – 4pm.

Opening times can vary, please ring to check
before making a special journey.

The Christie NHS Foundation Trust

Wilmslow Road

Manchester M20 4BX

0161 446 3000

www.christie.nhs.uk



The Christie Patient Information Service
August 2023 - Review August 2026

CHR/PBT/1501/02.08.2023 Version 1