

Information Leaflet for Adults from Ireland Receiving Proton Beam Therapy Abroad



Image from The Christie, with permission

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1. Introduction

Proton beam therapy (PBT) is a specialised type of radiation treatment not currently available in Ireland. If your doctor (radiation oncologist) recommends PBT, you will need to travel abroad to receive it. At present, patients from Ireland are referred for PBT to hospitals in:

- **United Kingdom:** The Christie Hospital (Manchester), the Royal Liverpool University Hospital (Liverpool) or the University College London Hospitals (London)
- **Germany:** West German Proton Therapy Centre (Essen) or Heidelberg Ion Beam Therapy Centre HIT at Heidelberg University Hospital (Heidelberg)

2. Proton Beam Therapy Explained

2.1 What is Proton Beam Therapy (PBT)?

PBT is a type of radiation treatment or radiotherapy. It uses protons rather than X-rays (photons) to treat tumours. With PBT, a dose of high-energy protons is targeted directly at the tumour, reducing the radiation given to surrounding healthy tissues and vital organs. PBT is not suitable for everyone. PBT is only suitable for a small number of people with specific types of tumours, particularly those:

- Near critical areas of the body
- Resistant to standard radiation treatments
- Where standard radiotherapy could cause severe side-effects.

Even though PBT reduces risks to healthy tissues, it can still cause side-effects. Your radiation oncologist will explain these in detail and help you decide if PBT is the right choice for you.

2.2 The PBT Referral Process

These steps outline the referral process for PBT abroad:

1. Referral to the National Proton Panel:

Your radiation oncologist will send your case to the National Proton Panel in Ireland, a team of clinical experts who review your case and decide if PBT is appropriate. This review usually takes about 1 week. If your case is not approved, your doctor will discuss alternative treatment options with you.

2. Applying for the Treatment Abroad Scheme (TAS):

The TAS is explained in section 3.1. If your case is approved by the National Proton Panel, you and your radiation oncologist will complete the TAS application form E112(IE).

- **Section A** is completed by you.
- **Section B** is completed by your consultant radiation oncologist, who will also send a referral to the PBT centre abroad and include this referral in your TAS application.
- The completed TAS application form may be sent to the TAS office by either you (the patient) or your consultant radiation oncologist.



- Please note you must await the outcome of any private health insurance application before submitting an application to TAS (see Section 3.5).

3. **TAS Decision:**

TAS typically processes applications within **15–20 working days**. A TAS coordinator will contact you directly if they need further information. You will receive their decision by letter. Most applications are approved. If declined, you have the right to appeal within 10 days and may request an extension if needed.

4. **Review by the PBT Centre:**

The PBT centre abroad will review your case to determine if you are suitable for treatment. They may request additional tests or scans. If further treatment in Ireland is recommended before PBT, your doctor will guide you.

5. **Co-ordination Between You and the PBT Centre:**

Most communication with the PBT centre happens via email. Your radiation oncologist will give your email address, or the email address of your support person, to the PBT centre. The PBT centre may contact you directly to request additional tests (for example scans, blood tests, tests for hearing and vision, CT scans etc.) or to request reports from investigations you have already had. You should work with your GP or radiation oncologist to complete these requests and ensure results are sent to the PBT centre.

6. **First Appointment at the PBT Centre:**

Once approved, the PBT centre will send you an appointment date and an information pack by email. This pack typically includes:

- Details about the PBT process at their hospital
- Directions, local transport options, and local amenities
- Accommodation recommendations

This first appointment will be to meet the doctor in person. The radiation oncology doctors in the UK are called clinical oncologists. Depending on your treatment plan, you may also be scheduled to have a CT scan or other procedure(s) during this first trip abroad (see Section 5).

7. **Treatment Start Date:**

Once you receive your treatment date from the PBT centre, inform the TAS office so they can issue an S2 form, which confirms payment arrangements. Bring a **printed copy of this S2 form** (not an e-mail or soft copy) when you travel to the PBT centre for treatment, as it is required by the PBT centre for billing and payment.

Timeline Overview

- **Steps 1–3 (up to TAS decision):** Typically takes around 3-6 weeks, though it may be longer if awaiting private health insurance approval.
- **Steps 1–6 (up to your first appointment abroad):** This depends on your case and any additional procedures required, but typically takes 6-8 weeks.



3. Cost of Proton Beam Therapy

3.1 Treatment Abroad Scheme (TAS)



Image from <https://www2.hse.ie/services/schemes-allowances/treatment-abroad-scheme/>

PBT is funded by the HSE's TAS, so you don't need to pay for the therapy/treatment itself. You and your radiation oncologist must complete the TAS application form E112(IE), also known as the S2 form (see Section 2.2). The form and more information about TAS are available on the HSE website. The TAS accepts applications for PBT from public hospital consultants only. The TAS will only fund public healthcare services abroad. Applications for funding of treatment in a private hospital abroad are automatically declined by TAS.

3.2 Travel and Living Expenses

The TAS does not cover expenses for travel, accommodation, food or other living expenses while you are abroad. You will most likely receive your PBT as an out-patient i.e. you are unlikely to be admitted to hospital while you receive your PBT abroad. You may need to budget for up to 8 weeks abroad, depending on your treatment plan. Please be aware that travel and living expenses abroad can amount to several thousand euro.

Some centres provide accommodation advice, but it's best to ask the PBT centre directly for assistance with arranging accommodation. Most patients and their families arrange their own accommodation, typically renting an apartment or using Airbnb near the treatment centre. The TAS may provide reimbursement for air/sea travel costs, but this is subject to available funding and is not guaranteed. The TAS will not cover travel costs to/from airports/ports/PBT centre.

The Irish Cancer Society's Welfare and Supports Team can advise on benefits, social welfare entitlements, public services, medical card applications, community support, legal entitlements, housing and mortgages, childcare or talking to your workplace about your diagnosis. The Irish Cancer Society's Support Line Freephone number is 1800 200 700.

The Gavin Glynn Foundation assists families of children and young adults with cancer who need to travel abroad for specialist treatment not available in Ireland. They can help with both the logistical and financial challenges of overseas care. Support may include covering the cost of flights, accommodation, and essential living expenses such as groceries and local transport. For more information, visit www.tggf.ie The Gavin Glynn Foundation is available to provide advice on logistics for adults travelling overseas for treatment by emailing info@thegavinglynnfoundation.ie



3.3 Other Medical Treatments Related to Your PBT

Costs for other related treatments while you are abroad, such as chemotherapy, are covered by TAS if included in your original TAS application.

You should ask your consultant radiation oncologist in Ireland if you are likely to need any prescription medications or skin creams while receiving your PBT e.g. patients receiving PBT to the face/neck region may require a specific mouth wash and/or toothpaste during treatment. These items can be very expensive abroad. However, you may be able to get these medications in Ireland through your medical card or the drugs payment card. It might be more convenient for you to have any creams or toothpaste etc. with you, rather than having to purchase these/similar items abroad.

3.4 Other Medical Treatments Unrelated to Your PBT

Unrelated medical treatments abroad are not covered by TAS. Medical costs for travelling companions are not covered by TAS. All travellers should have a valid European Health Insurance Card (see Section 4.4).

3.5 Private Health Insurance

Health insurance policies might cover, might not cover or might only cover part of the cost of the PBT. You are not obliged to apply to your health insurance company to fund your PBT. If you have private health insurance, you can choose to contact your insurance company to see if they might cover your PBT abroad. However, you must do this prior to applying to the TAS. If your private health insurance company declines funding your PBT, you may apply to TAS. Include the official letter from your private health insurance company evidencing the decline of funding along with your completed TAS application form and copy of the referral letter from your consultant radiation oncologist in Ireland to the PBT centre. If your private health insurance company agrees to fund part of the cost of your PBT, you may apply to the TAS for balance funding and such applications are reviewed on a strictly discretionary basis.

4. Travel advice

4.1 Organising Travel and Accommodation

You'll need to arrange your own travel and accommodation. Once you have been accepted for PBT abroad, a co-ordinator from the PBT centre will email you an information pack that may include information regarding accommodation and local transport options.

Travel:

When you receive the date for your first appointment – to meet the doctor at the PBT centre and possibly undergo additional scans/procedures - you should then make your travel arrangements. The PBT centre will give you as much notice as possible to make these travel arrangements and will tell you how long you need to stay for this first trip. However, this notice may be one week or less. Therefore, please be aware that flights/ferries may be expensive when booked at short notice.



It is likely that you will be able to return home after your first appointment. The coordinator will contact you again regarding your treatment start date and will give you as much notice as possible. Again, this notice may be a week or less and travel costs may be expensive. You will have to arrange local transport abroad yourself i.e. to/from the airport abroad, the PBT centre and your accommodation. The information pack may provide you with helpful information about local transport options e.g. bus/rail/tram/taxi, routes, where to depart/arrive etc. However, if you need additional information, you should contact the local co-ordinator and ask them for assistance.

Accommodation:

The accommodation assistance offered by individual PBT centres varies. You or your support person are advised to contact the co-ordinator yourself and ask them for assistance with finding suitable accommodation. As stated earlier, in section 3.2, The Gavin Glynn Foundation is available to provide advice on logistics, including finding (but not funding) accommodation, for adults travelling overseas for treatment.

4.2 Airline and Security Requirements

If you need to carry medication or fluids, your radiation oncologist can provide a letter for airport security. Some airlines may also require a “fit to fly” certificate. Your doctor can provide you with this certificate if required. This is usually not necessary.

4.3 Visas



EU citizens do not need a visa for Germany or the UK. Non-EU residents should check with the authorities of the country abroad to confirm visa requirements before travelling.

4.4 European Health Insurance Card (EHIC)



The EHIC provides access to emergency public healthcare in a European country you are visiting. The EHIC does not cover travel or repatriation costs e.g. via air ambulance. You can apply for a EHIC at the HSE website <https://www2.hse.ie/services/schemes-allowances/ehic/>. Irish citizens travelling in the UK are entitled to access healthcare through the Common Travel Area. However, other EU citizens should use the EHIC, which is still accepted in the UK. Any person travelling with you or visiting you should also have a EHIC in case they need to avail of emergency public health services while abroad.

4.5 Travel Insurance

Travel insurance is highly recommended to cover unexpected costs. Having travel insurance may offer you peace of mind if unforeseen circumstances occur for example flight cancellations, lost luggage or repatriation costs e.g. via air ambulance. The EHIC gives you access to medically necessary, state-provided healthcare during a temporary stay in another EU/EEA country, it does not cover travel or repatriation costs.

4.6 Foreign Currency and Cash



Bring euros for Germany and sterling for the UK. Many hospitals do not accept cards and may not have an ATM on the campus, so carry some cash e.g. if you wish to buy a coffee/lunch in the hospital or if you need to pay for parking.

4.7 Travel Checklist

Here is a list of items that you should check prior to travelling abroad for PBT:

- ✓ Confirm travel arrangements.
- ✓ Confirm accommodation arrangements.
- ✓ Bring an up-to-date passport with 6 months' travel time remaining.
- ✓ If needed, arrange visas or residency permits.
- ✓ If needed, bring a travel letter for airport security from your consultant.
- ✓ Bring an EHIC for everyone travelling.
- ✓ Travel insurance – optional but recommended. Bring contact details and policy number in case of an emergency (e.g. lost luggage, flight cancellation).
- ✓ Mobile phone cover abroad – contact your provider to ensure cover and be aware of costs.
- ✓ Bring your Driving license if intending to drive while abroad.
- ✓ When travelling for your treatment (not your first appointment) – bring your printed S2 form confirming TAS's approval of funding for your treatment abroad.
- ✓ Pack prescribed medications, skin-creams, and a 3-month supply of regular medicines.
- ✓ Bring appropriate travel adapters for electrical items.
- ✓ Bring a small amount of cash (euro for Germany, sterling for UK).
- ✓ Download Google Translate app or alternative app (for Germany) to your mobile.
- ✓ Inform your bank of your travel plans to avoid issues with card transactions while abroad.

5. Appointments and Treatment at the PBT Centre



Image from Heidelberg, with permission

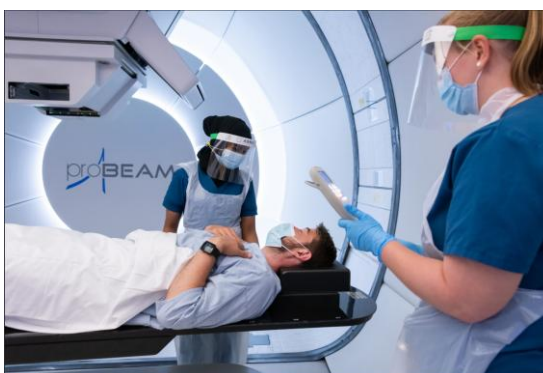


Image from UCHL website, with permission

5.1 First Appointment

Your first visit to the PBT centre will be to meet with your radiation oncologist (a PBT specialist) and their team. During this appointment, they will discuss the following:

- The aims of PBT.
- The steps involved in the planning and preparation for your treatment.
- Information about your treatment course, including the number of sessions and the expected start date.
- What to expect during the treatment, including the duration of each session, your positioning during treatment and you won't feel any pain. You will also be informed about the sounds you may hear in the treatment room.
- Potential side-effects of the treatment and how to manage them.

You will have the opportunity to ask any questions regarding the treatment and its side-effects before giving your informed consent. Informed consent means signing a form acknowledging that you understand the treatment and agree to proceed.

Planning CT scan

To plan your treatment, you will have a “planning CT scan” at the PBT centre. This planning CT scan is like previous CT scans you may have had. However, for this planning scan you will be lying in the same position you will be in for your actual treatment. You may need a specific immobilisation device that helps you keep still during your scanning and treatment procedures. For example, patients undergoing treatment to their head area might need to wear a specific type of mask for both their planning CT scan and the treatment itself. You may also need an MRI scan to help doctors and specialists plan your PBT accurately.

Your PBT care team will explain your treatment and planning procedures to you. They will book all necessary appointments for you. Your planning CT scan usually happens within a few days after your first appointment with the doctor, but it may take longer. Your contact person at the PBT centre will advise you how long you need to stay for your first trip abroad.

It will take about 3 weeks (though it may take longer) from your planning CT scan, until the start of your PBT. This is because the treatment plan is specifically tailored for you and is a complex, time-consuming process. It is usually possible for you to return home after the

planning scan and come back to the centre when your treatment is ready to begin. While you will be given a provisional start date, this may change due to the complexity of the planning process. The PBT care team will keep you updated and provide as much notice as possible of your treatment start date (usually a week's notice, though it may be shorter).

5.2 Having Treatment



Images from UCHL website, with permission

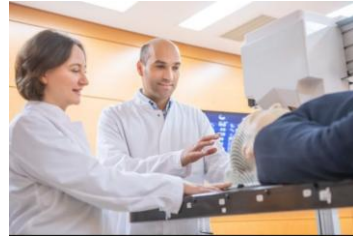


Image from Heidelberg, with permission

Your PBT care team will contact you regarding your treatment start date and time. Treatment is typically delivered daily (Monday to Friday) and may last between 3 weeks to 8 weeks. In some cases, treatments may be scheduled over the weekend or during a bank holiday. The bank holiday dates abroad may differ from those in Ireland. Your care team will inform you of the exact duration of your treatment course, including the number of daily sessions and the total number of weeks. You should bring a 3-month supply of your regularly prescribed medicines with you when you travel abroad for your PBT.

During treatment, specialists known as radiation therapists (in Ireland), therapy radiographers (in the UK), or radiotherapy technologists (in most centres in mainland Europe) will explain the procedure, any additional appointments, and waiting times to you. Each treatment session lasts 20 to 90 minutes, depending on the area being treated. Most of this time is spent ensuring that you are in the correct position for treatment. The treatment specialists will stay in the room while preparing to deliver the treatment, but they will move to a control area to monitor you through cameras during the actual procedure. While you won't feel anything during the treatment, you may hear a buzzing noise.

Although each session can take 20 to 90 minutes, your time at the PBT centre may be longer due to waiting for your treatment slot or additional appointments with doctors or other healthcare professionals. Occasionally, treatment delays may occur due to equipment breakdowns or scheduled maintenance. The PBT centre will make every effort to provide treatment as scheduled but will adjust if necessary, ensuring that any missed sessions are rescheduled.

5.3 Side-Effects of PBT

The side-effects of PBT vary, depending on the area being treated. People receiving similar treatments can experience different side-effects. Generally, PBT causes fewer side-effects compared to standard X-ray radiotherapy because it affects fewer healthy cells surrounding the tumour. Side-effects can develop during treatment, immediately after, or even months to years later. The nature of these side-effects depends on factors such as total radiation dose, number of sessions, and any pre-existing health conditions. The doctor will discuss potential side-effects with you during the informed consent process.

Some side-effects may appear in the second half of your treatment course, but they generally improve within 4 to 6 weeks after completing treatment. You will receive support throughout your treatment from the PBT care team. If you experience any side-effect or have any concern, don't hesitate to inform the team, and they will assist you in managing any issues. As your treatment progresses, particularly towards the later stages, you may experience increased fatigue or general tiredness and lower energy levels. This fatigue can be caused by the treatment itself, the hospital setting, and time away from home and your usual routine. To help manage fatigue, try to rest when you can and get light exercise and fresh air, such as by taking a daily walk. Fatigue can make everyday tasks — such as shopping for groceries or preparing meals — more difficult. Many people also find that being away from home and their familiar surroundings for several weeks can feel lonely. If possible, consider arranging for a support person to accompany you during the final weeks of treatment, or plan for family or friends to visit on weekends.

Maintaining your overall health and well-being during treatment is important. Eating a balanced diet and staying active can help maintain muscle strength, energy levels and support recovery. Some patients feel pressure to keep busy while they are abroad. However, it's important to prioritise self-care and rest whenever you can. Many patients find it helpful to engage in gentle, screen-free activities that support relaxation. Examples include taking a daily walk, sitting on a park bench to read, or spending time drawing or doing other creative hobbies.

5.4 Culture and Language Differences

The staff at the proton centres are very experienced in caring for patients from abroad and you will have regular appointments with the doctor and nurses in your treatment centre. Do not hesitate to mention any concerns you may have to a member of your treatment team. If you have any concerns or symptoms outside of your scheduled appointments, you should proactively request to see a doctor. The hospital staff will gladly arrange this for you, but you will need to ask.



In Germany, many hospital staff may not speak English. While there may be an English-speaking person available to meet you on your first day, they may not be a health care professional (e.g. they may be working in administration). It is highly recommended to download a translation app like Google Translate before travelling. This will help with everyday situations, such as reading signs or explaining symptoms to healthcare professionals. It may

also be useful if you have a question/concern that seems complex or if you have a strong dialect/accent. Patient information leaflets at German hospitals are often only available in German, so having a translation app can help if you wish to understand the content in English. As mentioned, the staff at the proton centres are very experienced in caring for patients from abroad and are familiar with using translation apps.

5.5 Living Abroad/Getting Around

Each PBT centre offers information on their location, public transport access and accommodation options. These centres are well-connected by public transport. If you require additional information, don't hesitate to contact your co-ordinator at the PBT centre.

5.6 Travel Home

Most patients can return home soon after completing their treatment. However, it is important to book your return trip only after receiving medical advice from your PBT care team. Any delays, such as equipment breakdowns or bank holidays, could affect your finish date.

Although travelling home for a weekend during treatment might seem tempting, it is usually not recommended due to the fatigue associated with travel. The journey—getting to the airport, flying, travelling home from airport, and then repeating the process on your return—can be exhausting. Additionally, if you get sick while at home for a weekend, you may not be well enough to travel back for your PBT and would therefore cause a delay in your treatment course. Flights may also be subject to last-minute changes or cancellations. If possible, it may be more beneficial for a family member or friend to visit you while you're abroad to provide you with support.

Once your treatment is complete and you return home, your care will be transferred back to your referring radiation oncologist in Ireland. In some cases, the PBT centre may also want to follow up with you in the months following treatment, either through an in-person visit or an online consultation. They will let you know if this is necessary.

We wish you all of the best with your PBT.

6. Useful Contacts:

6.1 Your Main Contact Person in Ireland e.g. Consultant/Secretary/Coordinator:

Name: _____

Role: _____

Telephone: _____

Email: _____

6.2 Your Main Contact Person Abroad E.g. Consultant/Secretary/Coordinator at the Proton Centre

Name: _____

Role: _____

Telephone: _____



Email: _____



6.3 Here are the Contact Details of Some PBT Centres Abroad:

The Christie, Manchester, UK

The Christie NHS Foundation Trust

Wilmslow Road

Manchester

M20 4BX

Tel: + 44 (0) 161 918 7577

<https://www.christie.nhs.uk/patients-and-visitors/services/proton-beam-therapy>

The Christie Hotline – Available 24 hours a day, 7 days a week: +44 (0) 161 446 3658

The Christie Scheduling team: +44 (0) 161 918 7170

The Clatterbridge Cancer Centre, Wirral, Liverpool, the UK national centre for eye PBT:

The Proton Patient Coordinator

The National Centre for Eye Proton Therapy

The Clatterbridge Cancer Centre NHS Foundation Trust

Clatterbridge Road

Bebington

Wirral

CH63 4JY

www.clatterbridgecc.nhs.uk

Proton Patient Coordinator: + 44 (0) 151 556 5301 / + 44 (0) 151 556 5529

Email: ccf-tr.Cyclotron@nhs.net

The National Centre for Eye Proton Therapy at Clatterbridge Cancer Centre – Wirral: Tel: + 44 (0) 151 556 5596 / + 44 (0) 151 556 5584. Their information booklet “Proton beam therapy to the eye” Issue 5.2 can be found at [Proton beam therapy to the eye :: The Clatterbridge Cancer Centre](#)

University College London Hospitals, London

Proton Beam Therapy

Basement (B3 & B4)

Grafton Way Building

1 Grafton Way

London WC1E 6AS

<https://www.uclh.nhs.uk/our-services/find-service/cancer-services/proton-beam-therapy-pbt>

Tel: + 44 (0) 20 3456 8000 / + 44 (0) 20 3456 8287

Email: uclh.pbtadmin@nhs.net

Essen - West German Proton Therapy

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<https://www.heidelberg-university-hospital.com/diseases-treatments/cancer-and-tumor-diseases/proton-therapy-and-carbon-ion-therapy>

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Building a
Better Health
Service

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