

GUIDE FOR
FAMILIES OF
CHILDREN
RECEIVING
PROTON BEAM
THERAPY
ABROAD



**Irish
Cancer
Society**



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INTRODUCTION

If the doctors looking after your child recommend a type of radiotherapy known as proton beam therapy, you must travel abroad for it as the treatment is not currently available in Ireland. At present, children are referred to the **West German Proton Therapy Centre in Essen (WPE)**, known as 'the Proton Centre'.

We know that travelling overseas for treatment can be a worrying time for families so this leaflet hopes to answer some of the questions you and your family may have about proton beam therapy. It explains how proton beam therapy works, the benefits and the possible side-effects. You will also find lots of practical information to help you to organise overseas travel for you and your child.

PROTON BEAM THERAPY EXPLAINED

What is radiotherapy?

Radiotherapy is the use of high energy X-rays (photons) and other types of radiation to treat diseases – usually cancer but sometimes non-cancer or benign diseases. Patients can have radiotherapy on its own, or when having another form of treatment, such as chemotherapy.

Radiotherapy is often given after surgery because it can help to get rid of any tumour cells that may have been left behind. This reduces the risk of the disease coming back and it is successful for many patients.

Radiotherapy has to be planned with great care as it can cause side-effects, especially in areas of the body where the tumour lies very close to important normal healthy structures and developing tissue.



What is proton beam therapy?

Proton beam therapy is a type of radiotherapy. It uses protons, which are small parts of atoms, rather than **high-energy X-rays**. With this type of radiotherapy, a dose of high-energy protons is targeted directly at the tumour.

Despite this, patients may still have side-effects and risks similar to those experienced with the other forms of radiotherapy.

It is extremely important that you discuss the treatment options available for your child with your radiation oncologist. This will help you and your child to make an informed decision about whether proton beam therapy is the most suitable option for your child.

How is my child referred for proton beam therapy?

Your child's radiation oncologist will refer their case (with your agreement) to the Proton Centre. The specialist team at the Proton Centre will then discuss and review your child's case in their multidisciplinary team meeting. They will then decide if your child's case is suitable for treatment.

The Proton Centre may request more investigations (for example, scans, blood tests, tests for hearing and vision) prior to planning or starting radiotherapy. Sometimes, the centre may recommend further surgery in Ireland before proton beam therapy, to achieve the best possible outcomes. Planning for your child's investigations, treatment and medical supplies will be done in conjunction with the team in Essen.

Do I have to pay for proton beam therapy?

Proton beam therapy is funded under the HSE Treatment Abroad Scheme. You and your radiation oncologist must complete the E112 application form. Your medical social worker can help you to complete the application.

Do I have to pay for any other medical treatment costs related to proton beam therapy?

If your child needs any other treatment related to their proton beam therapy (eg chemotherapy) while you are abroad, these costs will be covered by the HSE Treatment Abroad Scheme, provided that the required treatment has been requested in the original application by the Irish-based consultant and approved by the HSE.

Any other medical treatments your child receives abroad that are related to your child's proton beam therapy treatment will **not** be covered by the HSE. No medical costs for parents or carers will be covered. Each person travelling should have a valid European Health Insurance Card (EHIC).

Do we have to pay for our travel costs?

The HSE will fund economy travel costs for “the [paediatric] patient and one parent/carer accompanying the patient”.

Important: Any claimed travel, costs for patients, parent(s) or carer (s), are subject to specific conditions outlined in the EU Regulation 574/72 in accordance with Department of Health and Children Guidelines (<http://Europa.eu>).

Please note that some charities provide support to families travelling for treatment abroad. This may include arranging and covering the cost of travel, accommodation and subsistence.

Do I have to pay for accommodation?

Yes. The Treatment Abroad Scheme does not cover the cost of accommodation. However, there is a Ronald Mc Donald house in Essen. Accommodation for the initial two-day assessment visit is usually arranged by the Proton Centre.

Is there any financial support provided for meals?

No. The HSE will not fund the cost of meals or refreshments.

TRAVEL ADVICE

How will the Proton Centre contact me?

The proton beam therapy teams work hard to ensure that you and your child are supported as much as possible. A member of the proton beam therapy care team at the Proton Centre will contact you after your referral has been accepted. Most communication is done by email and we suggest you provide the HSE and the Proton Centre with your email address at the earliest opportunity.

Do I have to organise travel and accommodation?

Once your child has been accepted for treatment at the Proton Centre, your social worker will contact you to discuss travel arrangements. Families must book the flights themselves and apply to the HSE later for a refund.

Who will help me with my travel and accommodation arrangements?

The Proton Centre’s care team (normally a nurse case manager or a social worker assigned to your child’s case) will discuss accommodation with you and help organise you and your child’s accommodation and transportation needs during your stay.

Please note that certain charities may offer help with arranging flights, transfers and accommodation.

The Proton Centre will provide a provisional schedule of dates and times for your child’s first set of appointments. (During treatment, a schedule of dates and times will be provided to you twice a week.)



Do we need a visa to travel?

No. You do not require a visa to travel to Essen, if you are an EU citizen.

Do we need a European Health Insurance Card (EHIC)?

A EHIC is needed for each member of the travelling party. The EHIC entitles the holder to state-provided medical treatment within the country you are visiting. You and your child can apply for a card at **EHIC.ie**.

Do we have to make any special arrangements with the airline before travelling to the destination?

Your child's clinical nurse specialist or consultant should give you a letter confirming that your child needs to carry medicines or fluids, which you should show to airport security. Some airlines also require your child's doctor to complete a 'fit to fly' certificate.

What happens once we get to our destination?

Once you arrive at the Proton Centre there will be a number of appointments you must attend prior to starting proton beam therapy treatment.

The Proton Centre team will also provide contact details in case you have any other queries.

It is important that the medical team can reach you at all times during your stay abroad. (For example, in the case of equipment malfunction, treatment will be cancelled on the day and parents will be contacted by phone.)

TRAVEL CHECKLIST

CHECKLIST OF ITEMS:

- Up-to-date passport with 6 months' travel time remaining for everyone travelling.
- A copy of your two E112 documents confirming approval for treatment in Essen.
- Valid European Health Insurance Card for everyone travelling.
- Flight arrangements confirmed.
- Travel insurance confirmed.
- 3-month supply of all regularly prescribed medicines.
- Travel letter for airport security and airline staff from your clinical nurse specialist (CNS) or consultant.
- Driving licence (photo card and paper counterpart) if intending to drive.
- Copies of any documentation or correspondence that contains information about your proton treatment and accommodation details (these may be required by Customs and Immigration/Passport Control).
- If planning to drive we advise you take your own child seat with you so you have it as soon as you pick up your car from the airport.
- Appropriate travel adaptors for electrical items.
- Tell your bank that you are staying abroad.

When you arrive

What will happen at the first appointment?

Note: The reception area of the WPE is comfortable: it has couches and a large play area with games and toys for young children

Your first visit to the Proton Centre will be to meet your child's radiation oncologist (a specialist in proton beam therapy) and their team. They will discuss:

- The planning and preparation process
- What your child can expect in the room when they are having treatment
- The aims of proton beam therapy treatment
- Any side-effects that may occur.

There will be many opportunities to ask any questions about the treatment and the side-effects before giving informed consent on behalf of your child.

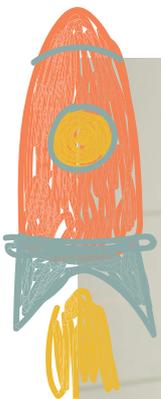
How do we prepare for my child's treatment?

It is very important that your child is as still as possible during the treatments to allow accurate delivery of the proton beam therapy.

To help your child lie still for the treatment they may need an anaesthetic and might be fitted with some type of immobilisation device during the preparation stage. For example, when treating the head, a face-mask or a device with a bite-block might be used. The Proton Centre may put temporary or permanent marks (tattoos) on your child's skin as a guide for subsequent therapy.

To plan your child's treatment they will need to have a CT scan whilst immobilised. A further MRI scan may also be required to help doctors target the proton beam therapy accurately.

Your child will also need to see a paediatric oncology specialist regularly. This will be at a separate site to the Proton Centre.



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How often is proton therapy delivered?

A treatment course is usually delivered daily (Monday to Friday) and may last up to 7 or 8 weeks. Your child will be given a provisional start date for their treatment, but due to the highly individual and complex planning required, this date may change. For this reason, you must take a three-month supply of your child's regularly prescribed medicines with you to the Proton Centre.

How long does each treatment take?

Each day your child may spend up to 1 hour in the treatment room. During this time, your child will be fitted into their immobilisation device and correctly positioned. Daily positioning checks are taken before treatment is given.

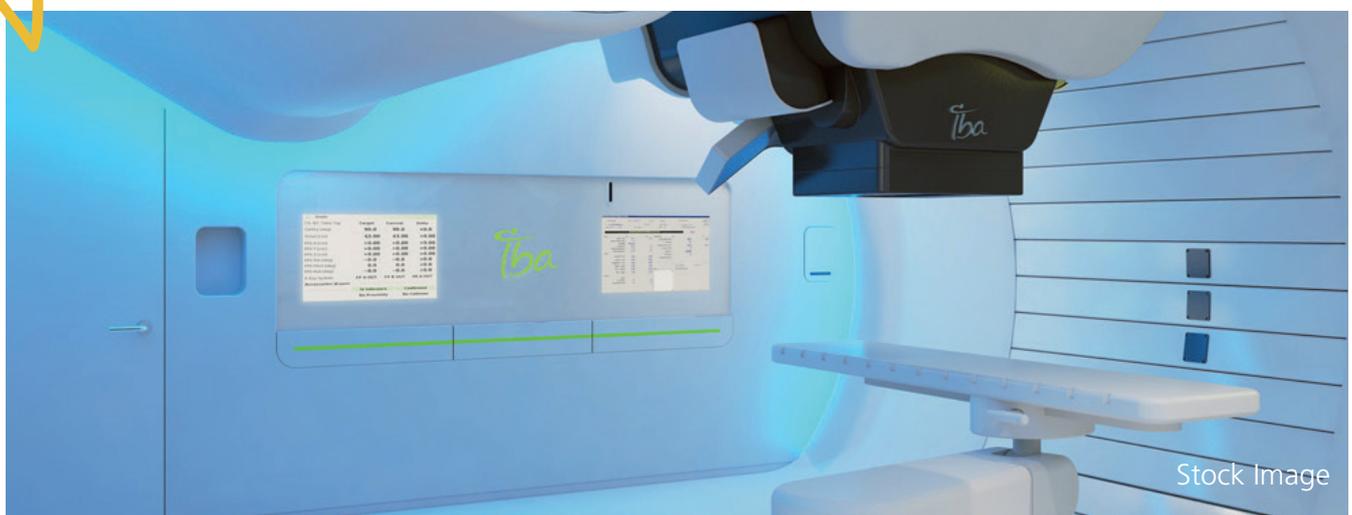
For those children who require an anaesthetic daily, total time spent at the Proton Centre is typically 3 to 3.5 hours. It is important to remember that your child will need to fast (not eat) for a time before being anaesthetised, which may require stopping overnight feeds by the appointed time. For children who do not require an anaesthetic, the total average time spent at the Proton Centre is approximately 1 to 1.5 hours.

Can I stay with my child whilst they are having their treatment?

Since radiation is used for the treatment, your child must be alone in the proton beam therapy room but they will be monitored closely at all times by a specialist team through closed circuit TV monitors.

Some patients have reported that the treatment machine can be noisy, but your child will not feel anything during treatment. Music can be played during treatment and there is also an intercom so that your child can speak to the medical team looking after them.

For those children who require an anaesthetic daily, you will typically accompany your child while they are being anaesthetised and will be reunited with your child in a recovery room before they wake up. You should bring some food and drink to the recovery room.



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What are the side-effects of proton beam therapy?

Possible side-effects vary according to which part of the body is being treated. However, in general proton treatment gives fewer side-effects compared to high-energy X-ray (photon) treatments, (ie the more usual radiotherapy) because it is a more precise form of treatment and therefore affects fewer of the healthy cells away from the tumour. Side-effects vary from person to person and can be affected by factors such as the total dose and duration of treatment and other existing conditions.

Side-effects can occur during treatment, immediately after treatment or months to years afterwards. The doctors at CHI Crumlin and at the Proton Centre will give information regarding specific side-effects on an individual basis before your child's referral and treatment. During treatment there will be regular reviews by the medical team who will ask about any side-effects your child might be experiencing and will be available if you or your child have any concerns.

When can we fly home?

Most patients are able to fly home immediately after completing their treatment.

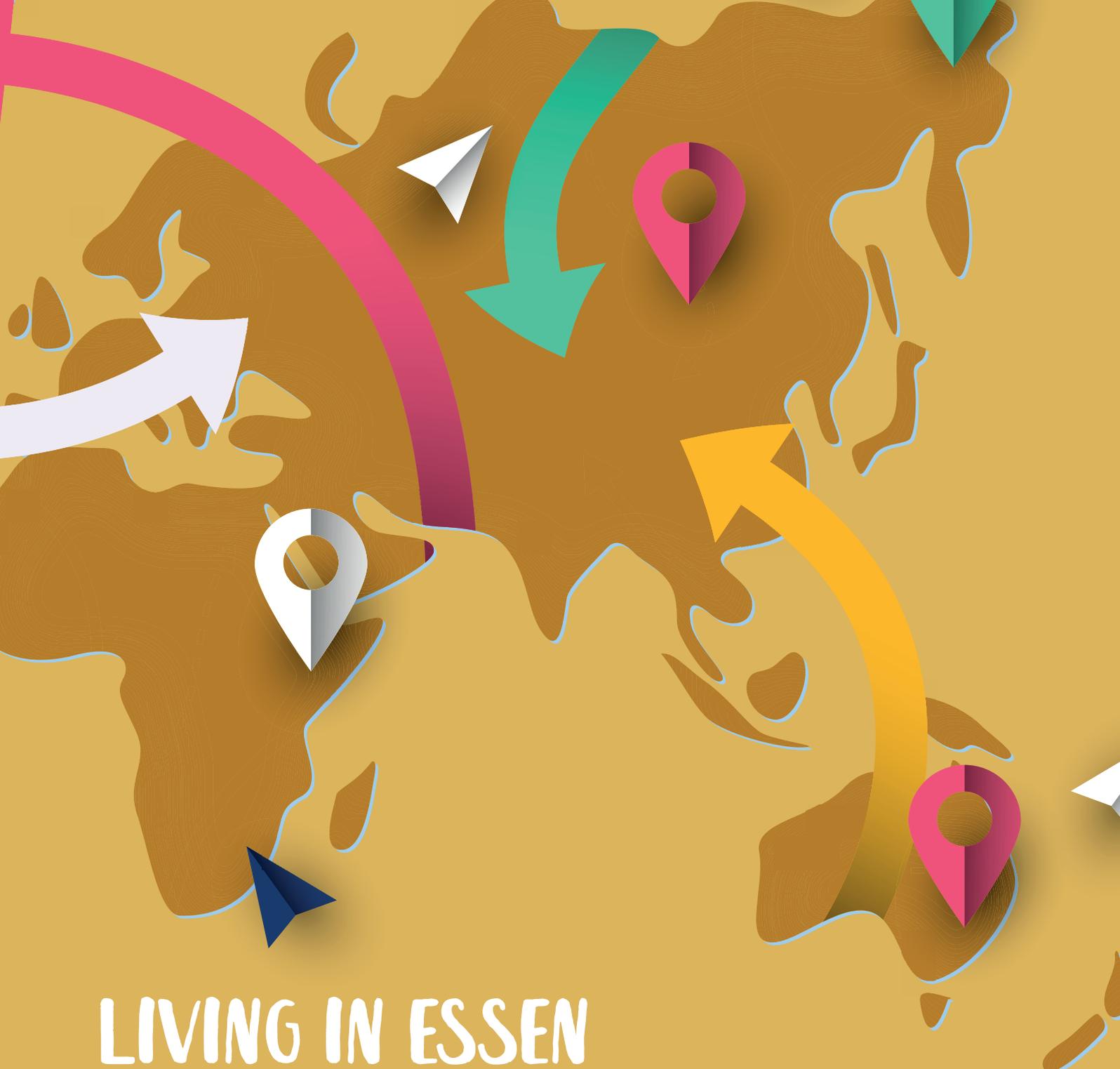
Families must book the return flight when medically advised to do so. A claim may then be made to the HSE for a refund.

Will my child have follow-up appointments in Ireland?

Your child will require regular detailed assessments following their proton beam therapy. These are likely to continue for many years. After treatment your child will be reviewed by the local oncology team who will work closely with the Proton Centre to share your child's clinical information and ensure that your child receives the best care possible

Note about samples: Patients who have been abroad (including to the UK and Northern Ireland) must have 4 negative stool (poo) samples obtained one week apart. The last sample must be obtained 28 days (or more) after your child's last visit abroad. This is to allow testing for carbapenemase-producing/resistant enterobacterials (CRE). Patients will be in isolation until these 4 samples have been obtained and are all negative for CRE.





LIVING IN ESSEN

GETTING AROUND

- Apps:** Google Maps will identify routes around Essen, using public transport. The "FreeNow" taxi app works in Essen.
- Buses and trams:** Essen has a good tram and bus network, with a ticket kiosk at every station. Tickets must be validated on board the tram.
- Trains:** The main train station (Hauptbahnhof / "HBF") is in the centre of Essen, with trains to places outside of Essen.

GRUGA PARK

There is a large park, called Gruga Park, in Essen. It has a small train, a petting zoo, swimming pool and multiple playgrounds. The Proton Centre can provide free passes to Gruga Park. The centre backs onto the park.

Getting around

Note that all shops close on Sundays, so plan accordingly.

There are large shopping centres in Essen (Limbecker Platz) and nearby Oberhausen (the Cenro).

For groceries, there are branches of Edeka, DM, Aldi, Lidl throughout the city.

Day trips

It is likely that you will not have medical appointments at the weekend so it is possible to plan longer day trips away from Essen. For example, you could go to: Cologne; Dortmund; SeaLife and Lego Discovery Centre, Oberhausen; Duisburg Zoo; Westflaenstadion football stadium.

Useful contacts:
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