

Radiotherapy treatment for

Total Body Irradiation

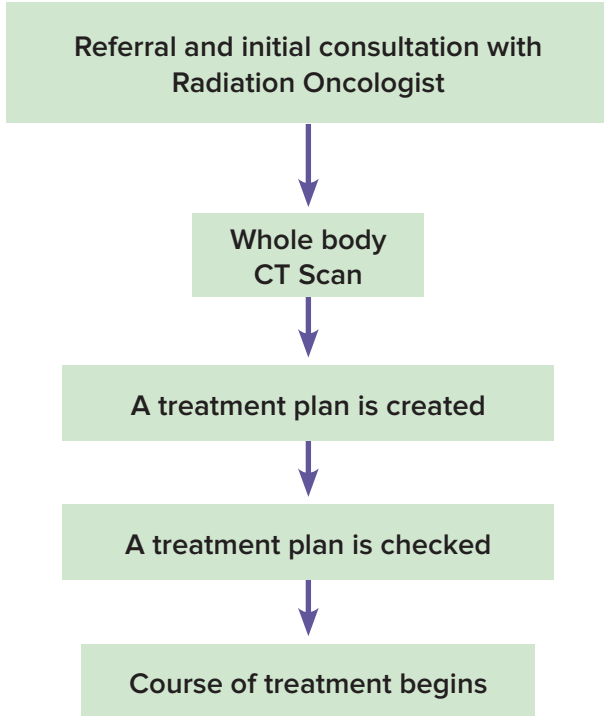
A guide for patients

QUIT

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Patient journey for radiotherapy for total body irradiation



About this guide

The information in this guide has been written to give you a better understanding about **radiotherapy**. It contains general information about radiotherapy, as well as more specific detail about total body irradiation (TBI). It has been prepared with input from doctors, radiation therapists, nurses and patients.

Please share this guide with your family and friends – they have an important role in helping you. It is important that they feel well informed and understand what is happening. There are also DVDs on radiotherapy which you can take home to watch.

It is impossible to include everything you may need to know in this guide. However, your medical team (doctors (radiation oncologists), nurses and radiation therapists) will give you more precise information about your specific treatment.

We hope you find this guide helpful and we welcome your comments so that the next edition can be improved.

**You will receive your treatment at the
St. Luke's Radiation Oncology Centre at
St James's Hospital, Dublin 8.**

What is radiotherapy and why is it given?

Radiotherapy uses carefully measured doses of radiation to treat many conditions, most of which are cancers. Radiotherapy beams damage cancer cells and stop them from dividing and growing. The beams can be directed very accurately to any area of the body using sophisticated machines. These machines are called 'linear accelerators' (or linacs).

How does radiotherapy work?

A high dose of radiation damages cells and stops them from growing and dividing. Cancer cells, which are abnormal cells, tend not to recover. Normal cells usually recover or repair themselves quite quickly. Any side effects which occur during treatment are usually temporary.

How is it given?

TBI is, as the name implies - given to the whole body. **It does not hurt.** The machine does not touch you and it is very much like having an ordinary X-ray. When receiving radiotherapy you lie on your back. Any variation from this is explained later in the guide or will be discussed with you by your medical team.

Radiotherapy is given while you are an in-patient in St Jame's Hospital. Radiotherapy may sometimes be given as a single treatment. However, usually treatment is delivered twice a day (with 6 hours between each treatment) for 4 consecutive days. Your medical team will talk to you about which treatment is best for you.

What are the benefits of radiotherapy?

Total body irradiation is given because it destroys your immune system and diseased bone marrow. This will then be replaced by bone marrow stem cells from your donor or your own cells.

What are the side effects of radiotherapy?

Radiotherapy can damage or destroy normal cells and cause treatment side effects. These are discussed in more detail later in this guide.

The side effects of radiotherapy can generally be split into two categories:

- **Early or acute side effects** develop during or shortly after treatment. These are usually temporary.
- **Late side effects** are those which can develop months or even years after your radiotherapy is finished. The risk of these side effects occurring is small but, whilst they are rarely severe, they may be permanent.

Your doctor will not advise you to have any treatment unless the benefits are greater than the side effects.

Women: If you are a woman of childbearing age you **should not become pregnant** before or during radiotherapy because the treatment may harm the foetus, especially in the first three months of a pregnancy. **Please discuss with your doctor, nurse or radiation therapist if you think you may be pregnant.**

Receiving external radiotherapy does not make you radioactive or dangerous to be around. Once you have left the treatment room each day it is completely safe for you to mix with children and pregnant women.

Men: Treatment will permanently damage the testis ability to make sperm. Your doctor will talk to you about sperm donation or freezing and it is very important that this happens **before** your treatment starts.

Consent to treatment

You will be asked to sign a consent form but only when you are happy that you have all the information you need and your questions are answered. This is a written record stating that you have agreed to the planned radiotherapy. **There is a copy of the consent form in the back of this guide for your reference.**

Your medical team

Over the course of your treatment at the radiotherapy centre you will meet various members of the medical team. The team is often referred to as the 'multidisciplinary team'. The team will have a consultant radiation oncologist, specialist registrars, radiotherapy or clinical nurse specialists, planners, physicists and radiation therapists. The radiation therapists operate the treatment machines and give you your radiotherapy. You will not meet the planning and physics staff but they are part of the team that plan your radiotherapy treatment.

All members of your multidisciplinary team work closely together. They can give you help and advice about any aspect of your treatment. Don't be embarrassed or afraid to ask them anything you are concerned or anxious about.

Planning your treatment

We have to make sure that the area of your body to be treated includes all of the cancer cells and any areas that might be hiding cancer cells.

When you arrive at the treatment centre you should report to the reception desk.

Planning takes place in the **CT scanner** which is a special X-ray machine that takes a scan of your body. The scan helps the team carefully plan your treatment. The CT scan will be taken with you lying on your back. Sometimes we use additional devices to help keep you comfortable and still.

Once all the scans have been taken, the rest of the treatment planning will happen behind the scenes over the next few weeks with the help of a **physicist** or **planner**. They assist the doctors in deciding the best way of giving you the amount of radiotherapy you need.

When will treatment begin?

Your treatment will usually start 2 weeks after your radiotherapy planning appointment. If you are given a different timeframe the reason for this will be explained by one of the team at your consultation.

During the treatment

At each treatment the radiation therapists will take you into the treatment room and make sure you are in the right position. When they are satisfied with the position, they will leave the room for a short while so that the treatment can be delivered. You will not feel anything but you may hear a bleeping sound. This is quite normal and means that the treatment is happening. During the treatment, the radiation therapists will watch you on a television screen and can talk to you over an intercom. **They can also hear you.** You are welcome to bring a favourite CD to listen to while you are being treated. Each treatment may take 40 minutes.

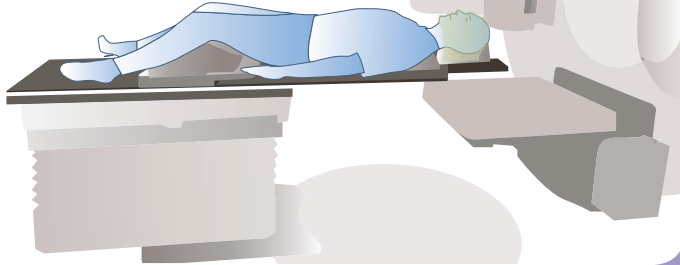
It is very important that you lie still in exactly the same position for each treatment.

Some days you might notice some changes in the way the radiation therapists give you your treatment. For example, they might take a scan, a measurement or change the angles of the machine. Every effort will be made to make sure that changes are explained to you beforehand but if you are concerned about anything please just ask.

You will probably meet many other patients in the waiting area each day. Even though you might think your treatment is similar to someone else's, each patient's treatment is often very different. Therefore, if you are comparing stories and hear something that worries you, please just ask one of the professional staff.

Illustration A

Undergoing radiotherapy treatment on a linear accelerator.



Although your treatment only takes about 40 minutes each day you may be delayed longer on the days that you see the doctor, nurse or any other health care professional.

Please be assured that we make every effort to keep your waiting times to a minimum.

Side effects

In general, the body can handle radiotherapy well. It can destroy cancer cells and it may affect normal cells within the treatment area. Side effects are generally limited to the area being treated. Radiotherapy affects people in different ways and not all the side effects mentioned below will occur. Your medical team will discuss these with you on an individual basis. Side effects are described as 'early' or 'late'.

Early – side effects which occur during or shortly after treatment.

Late – side effects which occur months to years after treatment.

You will be fully informed about what to expect and about potential side effects when you sign your consent form.

Remember: your medical team are all available to answer any questions that you may have during your course of radiotherapy.

Early side effects (during and shortly after radiotherapy)

Fever

It is very common to have a slight fever in the first few hours after treatment and this is a direct effect of the radiation.

Nausea and vomiting

Prior to commencing TBI you will be given strong anti-sickness medication. Some patients require additional anti-sickness therapy and therefore if you feel sick at any time don't hesitate to tell the nurse caring for you. The majority of patients complete their TBI with tolerable symptoms

Parotitis

This is swelling and inflammation of the parotid glands in the upper neck, just under the angle of your jaw bone, which can cause some discomfort. It occurs within 24 hours of treatment and can be controlled with mild painkillers. The symptoms disappear after a couple of days.

Dry mouth

This usually occurs two to three days into treatment and can last up to three months following its completion. You can help to alleviate the discomfort by taking drinks regularly and performing mouth care two hourly, as instructed by the ward nurses. If you are distressed by this side effect report it to the doctor, who may then prescribe some artificial saliva spray. After radiation you may experience an alteration in your sense of taste. This will gradually return to normal over several months.

Skin rash

Radiotherapy can make your skin dry, itchy and red. This is usually only mild and temporary but to try and prevent this you should follow a strict hygiene programme.

For 6 weeks after treatment:

- Only wash in a lukewarm shower and pat your skin dry very gently with a soft towel.
- Do not use any perfumed soaps / shower gels or shampoos.
- Use aqueous or E45 cream to prevent dryness and itching.
- Use un-perfumed baby powder to freshen your skin.

Diarrhoea

This may occur as early as 2-3 hrs after TBI is performed. Inform the nurse immediately if this occurs. A specimen will be taken to look for infection but radiotherapy is the most common cause.

Unfortunately it can take up to three days to check for infection which may be distressing if you have profuse diarrhoea. During this time you must perform strict standards of hygiene and may apply aqueous/E45 cream to the anal area to prevent the development of soreness and ulceration (always use gloves).

What about sun exposure?

The skin that has been exposed to radiation therapy might be more sensitive to the sun than it was in the past. You can go out in the sun, but be sure to use a sunblock that is rated SPF 50 or higher on the area that has been treated. Also, try to wear a hat and clothing that will cover the skin.

Fatigue (tiredness)

You might feel more tired than usual after your radiotherapy. This is at its worst immediately after treatment is finished. It is important that you get enough rest.

The fatigue you will feel with radiation therapy is not the same kind of tiredness that comes after 'overdoing it' which goes away after a good night's sleep. This treatment-related fatigue might feel like an overall lack of energy and might persist for many weeks or even months.

You might become fatigued during radiation treatment because of a combination of factors, including:

- > the effect of radiation on your body
- > the emotional toll of the months since your diagnosis
- > lingering physical effects from chemotherapy

Alopecia (hair loss) and bone marrow suppression

Both of the above are discussed in detail in the Bone Marrow Transplant information you have been given.

Somnolence (sleepiness)

This may occur four to six weeks following TBI. Usually it is just a feeling of tiredness but sometimes results in the constant desire to sleep. This can be distressing as it may develop after discharge from hospital in the period when you expect to feel better. It affects 70% of patients and varies from mild to severe tiredness, which will resolve spontaneously. Don't worry it will pass.

Late side effects (months to years after radiotherapy)

Pneumonitis

This is inflammation of the lung tissue due to radiation. Special shielding of your lung is used to prevent this side effect. The risk of this happening with the radiation dose you will receive is about 1% and will occur six weeks to six months following TBI. The symptoms are shortness of breath and cough. If this occurs it must be reported immediately to the BMT team. The symptoms are similar to the symptoms of a chest infection, and if tests fail to reveal an infection, your doctors may prescribe steroids to alleviate the symptoms. The symptoms usually resolve quickly.

Cataracts

This is clouding of the lens of the eye, which may occur three to four years after TBI treatment. If your eyesight is affected, the lens can be replaced by a relatively simple day case surgical procedure. This is a relatively common occurrence in up to 30 - 40 % of patients.

Pituitary gland

The pituitary gland is a small but very important gland, which produces hormones, such as growth hormone. This controls growth in children and affects muscle and bone strength in adults. It also “fine tunes” other hormones in the body. It lies in the middle of the brain, behind the eyes. Adults who have finished growing need much smaller amounts of growth hormone, but it continues to maintain muscle and bone strength. It is unlikely that the TBI dose administered is sufficiently high to affect growth hormone production in an adult. It will be monitored by a once yearly blood test

to ensure that hormone levels are adequate and whether replacement therapy is required.

Thyroid gland

The thyroid gland is situated in the centre of the low neck and produces a hormone called thyroxine. The thyroid gland may become underactive, even many years after TBI. Low levels of thyroxine can result in reduced metabolism and lead to weight gain, a feeling of sluggishness, feeling cold and a slow pulse. The levels of thyroxine in the blood will also be monitored by an annual blood test. Lack of thyroxine can be easily replaced by simple daily medication.

Effects on the Ovaries and Testis

Pre-menopausal women may experience premature menopause. The doctors will take blood tests to assess hormone function and will offer hormone replacement therapy after BMT, if appropriate. Women may also experience problems with sexual intercourse, usually due to dryness of the vagina. If this does occur please discuss it with either a doctor, nurse or the BMT coordinator as it may be easily remedied or other professional help sought. The BMT information discusses fertility in greater detail. All these hormones can be replaced and deficiencies are detected by a single annual blood test, done in your followup clinic.

Infertility

Radiation affects the production of sperm from the testis, and eggs from the ovary. They may already have been affected by chemotherapy, but the addition of radiotherapy will cause sterility in almost all patients. Discuss this with your doctor, nurse or radiotherapist if you have any concerns.

Second malignancies

Very rarely, patients who have been successfully treated may develop a second cancer some years later. All of the above can be discussed with a doctor, the BMT co-ordinator or ward staff. Please ask if you have any queries before treatment commences.

Prior to commencing TBI you will be asked to sign a consent form verifying that all issues have been discussed with you.

During your follow-up care your team will be looking out for all of these problems. Please feel free to talk to us about any concerns you have when you return for your follow-up appointments.

Your feelings

After your cancer diagnosis and treatment, it's normal for you to have a range of very mixed feelings including anger, anxiety, fear and sadness. These are all normal reactions that many patients go through. Everyone has their own way of coping. Some find it helpful to talk things over with other people who have been through similar experiences as themselves. Other patients prefer to keep their feelings to themselves.

There is no right or wrong way to cope, but help is there if you need it. Please feel free to talk to a team member about getting support if you feel it would help you. You might find it helpful to contact another **support group** or **organisation**.

The Irish Cancer Society

43/45 Northumberland Road,
Dublin 4

Tel: 01 231 0500

National Cancer Helpline

1800 200 700

www.cancer.ie

The Irish Cancer Society Information Service offers free, confidential advice, support and information on cancer and related issues to anyone worried about any aspect of cancer prevention, early detection, diagnosis, treatment or follow-on care. Through the Cancer Information Service, people can also access patient support groups and counselling services.

ARC House

65 Eccles Street,
Dublin 7

Tel: 01 8307333

www.arccancersupport.ie

559 South Circular Road,
Dublin 8

Tel: 01 7078880

ARC is a registered charity offering professional support to people affected by cancer and those who care for them. They are based in Eccles Street and the South Circular Road in Dublin.

Who you'll meet

Consultant and their team

Your consultant is a Radiation Oncologist who will decide on the type and amount of treatment you will have. In general, you will have been referred to them by one of the Consultant Haematologists in St James' Hospital.

Radiation Therapist

Radiation therapists are specialists who are trained to give you your radiotherapy treatment and to operate the machines that are used to give you your treatment. They are completely involved with your treatment from helping to plan it right through to monitoring all aspects of your daily treatment. They work closely with the doctors and other staff within the department. As they see you every day while you're having treatment they can answer any questions you have about any aspect of your radiotherapy treatment.

Clinical Nurse Specialist

A Clinical Nurse Specialist is a nurse in clinical practice who has undertaken additional education relevant to their area of specialist practice. Clinical Nurse Specialists provide support for the patient and their family throughout treatment and after discharge from the hospital. They have up-to-date information about treatment, possible side effects and any other problems or issues that may arise.

Radiotherapy Nurse

Each consultant has a radiotherapy nurse attached to their team. These are nurses who are specially trained in caring for people with cancer. You may meet one of them when you first attend your treatment centre. They are available throughout the working day if you have any concerns.

Physicist and Planner

These people are highly trained scientific specialists in the subject of radiotherapy planning. They help the doctors to decide the best way of delivering the radiotherapy you need.

Useful contacts

Consultant Radiation Oncologist

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Consultant's Secretary

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Clinical Nurse Specialist

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Other

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**Contact information for
St Luke's Radiation Oncology Network
is listed on back cover**

St Luke's Radiation Oncology Network would like to acknowledge the assistance of our patients and staff in producing this guide.

Edited by Dr Catriona O'Sullivan and Dr Charles Gillham

St Luke's Radiation Oncology Network

St Luke's, Beaumont and St James's Centres

Patient or Guardian Consent to Radiotherapy

Patient Name:

Patient D.O.B.:

ID Number:

Type of Treatment:

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Statement of Patient or Guardian

I agree to the above treatment. I understand what is involved in radiotherapy planning and treatment and I have been given enough time to ask questions.

For females only: I have no reason to think I am pregnant now. I understand there is a risk to the foetus if I become pregnant during treatment.

Signed: Date:

Name (PRINT): Relationship to patient (if applicable):

Statement of Interpreter (where appropriate)

I have communicated the above information to the patient or their guardian to the best of my ability and in a way in which I believe they can understand.

Signed: Date: Name (PRINT):

Statement of Health Professional

(to be completed by a health professional with appropriate knowledge of the proposed treatment)

I have explained the treatment to the patient or their guardian or their interpreter. I have outlined the potential benefits as well as the potential acute and late side effects of treatment. I have discussed the procedures involved in radiotherapy treatment planning and delivery and have provided appropriate written information.

Signed: Date:

Irish Medical Council No:

Data Protections Acts 1988 apply

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St Luke's Radiation Oncology Network at

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Dublin

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Email: radiotherapy.stlukes@slh.ie

St Luke's Radiation Oncology Centre at

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