



# General information for patients having proton therapy

**Rutherford**  
Cancer Centres

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# What is proton therapy?

## Introduction

**You have been given this leaflet as you are going to be treated with proton therapy. We hope it will go some way towards explaining your treatment: how it works, how it will be planned, what the benefits are, and detail any side effects you may have.**

We appreciate it is not the same as speaking to someone in person, so our team of consultant oncologists and radiographers, along with our planning team and other staff at the Rutherford Cancer Centre will be available to provide information and address any questions or concerns you may have. They will know your full medical history so feel free to ask them anything. It is important to us that you feel involved and supported throughout your treatment and beyond.

Your consultant will have given you some information about proton therapy and you may already have some knowledge about what it involves from the news or from someone you know who has had the treatment. While it is useful to gain an understanding from someone with first-hand experience, it is important to remember that their information and experience may not always apply to you, as everybody is different.

Proton therapy is planned differently depending on your type of cancer. In addition, patients with the same cancers don't have identical treatment, as this is individual to you and your body.

When you come to the centre you will be given further information explaining the possible side effects of your treatment in more detail.

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# What is proton therapy?

It can be useful to understand what proton therapy is so you know what to expect.

Proton therapy uses beams of protons to shrink tumours. Protons are small particles of an atom and a "particle accelerator" (cyclotron) is used to speed up the protons to produce the beam. The latest form of proton therapy, which is the type of treatment you will receive, is called intensity-modulated proton therapy (IMPT) with pencil beam scanning. This uses spot scanning to deposit streams of protons back and forth through the area being treated. Carefully measured doses of protons are given to the precise area needing treatment.

This usually takes place over a period of days or weeks and you may hear people call these "fractions of treatment". This is because the full dose of your treatment is divided into separate smaller doses called fractions.

A team of highly skilled professionals called therapy radiographers will deliver your treatment. They are there to help you, so if you have any questions or concerns, they will be able to address them.

## How does proton therapy work?

To understand how your proton therapy will work, it can help to know how it will affect your body. The organs and tissues of your body are made up of tiny building blocks, which are called cells. Proton therapy causes physical and chemical damage to the cancer cells in the treated area. Although normal cells are also affected, they can repair themselves and recover over time. When radiation damages the genes of cancer cells they stop growing and are unable to divide any more. Over time, these cells die.

Proton therapy itself is painless, the same as having an x-ray. Like an x-ray, it is invisible to the human eye. It does not make you radioactive and it is perfectly safe for you to be with other people, including children, throughout your treatment course.

Proton therapy may be used as your main treatment, or combined with other treatments such as radiotherapy, surgery and chemotherapy.

If you are a woman of childbearing age, it is advisable that you do not become pregnant during your treatment as proton therapy may seriously affect the growth of your unborn baby. If you suspect you may be pregnant you must speak to a member of staff, who will be able to advise you.

## What are the benefits of treatment?

There can be many benefits of proton therapy, and these will vary from person to person. The aims of treatment may be:

- To kill the cancer cells
- To reduce the likelihood of the cancer coming back
- To shrink the tumour and slow its growth, providing relief from your symptoms

Your consultant will discuss the expected benefits of your treatment with you, so please take the opportunity to ask any questions you may have, as they will have access to your medical history. Your radiographers will also be able to address any concerns.

The benefits of proton therapy over conventional radiotherapy are:

- Fewer side effects
- More accurate targeting of the area to be treated
- Lower radiation exposure to normal tissue beyond the treatment area



## Good to know:

During your first visit, some tests and scans – for example a CT planning scan – may be needed as part of the planning process.

# Planning your treatment

**Before your treatment begins, you will probably need to attend the Rutherford Cancer Centre for a planning appointment. Careful and accurate planning is necessary to make sure you receive the maximum benefit from your proton therapy. It will also be helpful for you to know how your treatment will proceed.**

At your planning appointment, you will be given information about your treatment and asked to complete a consent form if you have not done so already. We know there is a lot of information to take in, so it can sometimes be useful to bring someone with you to your first appointment. It is also an ideal opportunity for you to ask questions. It is a good idea to write down a list of any questions you may have.

During your first visit, some tests and scans – for example a computerised tomography (CT) planning scan – may be needed as part of the planning process. If so, the radiographers will tell you about this. With your permission, your photograph will be taken for identification purposes. This photograph will only be used by the staff in the centre and will not be used for any other purpose.

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# The CT Scan

As part of your planning for treatment, you will have a computerised tomography (CT) planning scan. This will be done using a CT machine, which is a special x-ray machine that helps your consultant oncologist and radiographers plan your proton therapy.

For this scan you will be asked to lie flat on a CT bed, which is the position in which you will have your treatment at every appointment. If you find it uncomfortable or painful to lie flat, let the radiographers know so they can help make the experience as comfortable for you as possible. You may wish to take some pain relief before your scan as CT beds can be very hard. It is a good idea to bring your regular painkillers with you for your planning and treatment appointments, just in case you need them.

Having a CT scan may require you to remove items of clothing. There are changing areas available for this purpose, as well as gowns for you to wear if you wish. Alternatively, you may prefer to bring your own dressing gown, although this may still have to be removed for the scan so that the radiographers can access the area that needs to be treated. Staff will do their best to make sure you remain as covered as possible, so please let them know if you have any concerns.

Temporary pen marks may be drawn on your skin during the treatment planning, the radiographers may ask your permission to permanently mark a point (or points) on your skin. This involves using the tip of a sterile needle to place a tiny dot of black ink just under your skin. It is a permanent mark but it is as small as a freckle, and will mean we will be able to accurately position you for your treatment every day. It also means you will be able to continue with normal day-to-day activities, such as washing, without worrying about removing any marks.

If you need treatment to your head, neck or spine it will be necessary to make a special mask. More details about this will be given to you before you come for your planning appointment.

When your treatment planning is completed, you will be able to start your treatment. This may be a few days later, or in 1 – 2 weeks' time, depending on the area you are having treated. The radiographers will talk to you about any further appointments you have.

If you have a pacemaker, you must inform the staff at your computerised tomography (CT) planning appointment and before you start treatment. Pacemakers can be affected by radiography, so your treatment planning needs to take this into account.

# Having your treatment

**Your treatment will usually be given daily, Monday to Friday, at around the same time each day. Whenever possible, you will be seen at the time of day that suits you. The number of treatments you have will be confirmed by staff on the first day.**

When you arrive for your first treatment you should go to the reception at the main entrance of the centre, where you will be given directions to the waiting room. A member of the treatment team will take you through to the treatment room. Your first time in a treatment room can be disorientating and it's normal to feel anxious at the start of your treatment course. The staff members involved in your care will be able to reassure you about any concerns you may have.

You can expect to spend 20-30 minutes each day in the treatment room, but this may be longer on the first day. The radiographers will carefully place you and the machine in the correct position for your treatment. The machine does not actually touch you and it is only switched on for a fraction of this time.

When you are in the correct position the radiographers will leave the room and take a quick imaging scan using the treatment machine to confirm your treatment position. The machine will move around you taking a series of images, which the radiographers can then compare with your planning scan. Not all treatments need a scan before treatment is delivered, but you will have an image taken to ensure accuracy of treatment. This is known as image guided proton therapy (IGPT).

Once you are in the correct position and the radiographers are satisfied that your treatment is going to be delivered correctly, they will leave the room to switch the machine on. When this happens, you will not feel any pain or heat. Some treatment machines do, however, make a buzzing sound and the radiographers will explain before leaving the room what sounds you may hear during treatment.

You will only be alone for a few minutes at a time and the radiographers will be watching you carefully on closed-circuit TV monitors (CCTV). There is also a two-way intercom system, so they can talk to you and you can talk to them if needed.

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If you have any problems when you are in the room on your own, just call for the radiographers or wave your hand slightly. However, please avoid putting your hand in the way of the treatment beam. Try to stay as still as possible during your treatment so that the beam is in the right place.

You will need to lie still on the treatment couch for about 10 - 15 minutes. You can of course breathe normally during your treatment, unless you are having special breath-holding treatment (this will be explained by the radiographers during your planning scan before your first treatment).

Once your prescribed dose of treatment has been given, the machine will stop (the machine can also be stopped at any time during treatment if required). You will need to remain still when the machine stops until the radiographers say you can move. If you wish, music may be played in the room to help you relax while your treatment is under way. If you'd like to bring your own music, ask the radiographers to see if it is possible to play it.



## Good to know:

You can expect to spend 20-30 mins each day in the treatment room, if you wish music may be played in the room to help you relax.



# What are the side effects?

**Your treatment will be unique to you, which means that so too will any side effects you may have. They will therefore be difficult to predict. Your consultant oncologist and radiographers will advise you about the side effects that may occur during your specific treatment, and you will be given more detailed information in a format that meets your needs before you start treatment.**

As proton therapy is a localised treatment, only the area you are having treated will be affected by it, so any side effects you have will depend on the area of your body being targeted. For example, hair loss will not occur unless there is hair in the treated area.

The side effects of proton therapy do not tend to appear suddenly, but instead develop over time. This delayed effect means that they may get worse seven to ten days after finishing treatment, depending on how much treatment you have had. However, the side effects will slowly settle in the weeks following treatment.

It is important you tell the radiographers how you are feeling throughout your treatment, as help is available for many symptoms. If you take any regular medication, it is important to continue. Speak to your consultant oncologist or radiographers if you are unsure.

## Skin reaction

Around 10 to 12 days after starting your treatment, the skin where you are having your treatment may change. For example it might become sore or itchy. The nature and severity of any skin reactions will depend on the area of your body being treated, as well as the amount of treatment you are being given.

If a skin reaction is causing you concern, your treatment team will be able to give you advice on how best to manage it. If needed, you will be given detailed information on how to care for your skin during and after proton therapy.

## Fatigue

Some people find their energy levels are unaffected by proton therapy, while others experience more tiredness than usual. This may especially be the case if you are travelling a long way for treatment each day. If tiredness is affecting your everyday routines, try to 'pace' yourself. Listen to what your body is telling you and rest whenever you need to.

Your energy levels may take weeks or months to return to normal. Macmillan Cancer Support has created a guide – 'Coping with fatigue' – which contains lots of good advice. Please ask a member of staff for a copy.

## Loss of appetite

During your treatment course, your eating habits may change. For example, your appetite may vary or there may be times when you don't feel like eating at all. Eating well will help you manage your energy levels and will help give your body the best chance of recovery, so try to eat well and keep hydrated during your treatment. You should try to drink about two litres (approximately eight glasses) of fluid each day. The radiographers will discuss this with you in more detail if you have any concerns.

For more information about maintaining a healthy, balanced diet, please ask your radiographer for advice. There is also a range of information available on the Macmillan Cancer Support website ([www.macmillan.org.uk](http://www.macmillan.org.uk)) or, if you'd prefer a paper version, please ask a member of staff for a copy of the 'Healthy eating and cancer' leaflet.

## Smoking

If you are a smoker, it is important that you try to stop. Research shows that not only can proton therapy be less effective if you continue to smoke, but smoking will also make any side effects much worse. In addition, smoking can slow down the healing process when your treatment has finished.

Your tissues need a good oxygen supply to help them respond to treatment in the best possible way. Smoking can restrict the supply of oxygen to your tissues, making your treatment less effective than it could be.

To give your body the best chance of recovering from cancer, you are advised to give up smoking as soon as possible. Your treatment team will be able to put you in touch with resources that will help you to do this.

## Alcohol

We strongly recommend that you do not drink alcohol during your proton therapy course. This is because alcohol, especially spirits, may irritate the areas affected by your treatment, especially your mouth, throat, digestive system, bladder and kidneys. If you are having treatment to the head and neck region, it is best to avoid mouthwash containing alcohol, unless these have been recommended by your treatment team.

Drinking alcohol during your course of treatment will make side effects much worse, as well as slow down the healing process when your treatment has finished. You deserve the best chance of recovery, so if you think you will find it difficult to stop drinking, your treatment team will be able to connect you with advice and support. Please do not hesitate to ask them.

# When treatment ends

**It is important that you feel supported, not only during your treatment, but also afterwards, to give your body the best possible chance to heal.**

After your treatment has finished your recovery will be supported by regular follow-up checks with your consultant. These will vary depending on the area of the body you have had treated, and the amount of treatment you have had. Follow up appointments are to help keep track of your recovery, so if you have any concerns or notice any new symptoms, you will be able to discuss them with your consultant.

## Planning a return to work

We know how much of an upheaval a course of treatment can be for some people, so if you find that you are tired after your treatment has ended, you may wish to consider taking a break from work, or working part time. It can be useful to talk to your employer about returning to work gradually, for example working shorter or fewer days at first. Most employers will be understanding and will want to accommodate your needs to help ease your possible full return to work in the long term.

## Holidays

If you feel a holiday may help with your wellbeing and recovery after treatment, Macmillan Cancer Support has produced information booklets on travel and insurance. These can be requested from the Macmillan Cancer Support website ([www.macmillan.org.uk](http://www.macmillan.org.uk)), or your radiographers will be able to obtain copies for you.

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## Vaccinations

If you find yourself needing vaccinations or a flu jab it is best to seek guidance, as information on these is subject to change. Please ask your consultant or any member of your treatment team for the latest advice.

## Leisure and physical activities

If energy has been an issue for you, gentle exercise can help, as well as play a part in your recovery.

Whatever physical activities you wish to take part in, remember to start slowly and build up the amount of exercise gradually. It is a good idea to choose something you enjoy, as the more you enjoy the exercise, the more beneficial it will be.

You will be given more information about health and wellbeing, including physical exercise, when you complete your treatment.



### **Good to know:**

It can be useful to talk to your employer about returning to work gradually, for example, working fewer or shorter days at first.

# Support and wellbeing

## Talking to children

If you have children or grandchildren, you may need to talk to them about your treatment. This can be upsetting for them so it can be hard to know where to begin. In addition, how you choose to talk about your cancer will depend on the ages of your children.

Older children may want to know if the cancer is hereditary. The answer is almost always 'no'. If you need help explaining this or any aspect of your cancer, your consultant will be able to provide clarification.

Macmillan Cancer Support has produced a booklet – 'Talking to Children when an Adult has Cancer' – which will help you to explain what cancer is to them and how it may be treated. If you would like a copy, please ask your radiographers.

## Emotional wellbeing

The diagnosis of cancer combined with the side effects of treatment can affect how you feel. Your treatment team are here to support you and we encourage you to tell us if you feel overwhelmed, unable to cope or just 'not yourself'. Sometimes just talking about your emotions can be of great help and if necessary we can arrange for further advice and support.

## We are here for you

If, at any time, you have concerns or worries, you can speak to a member of the treatment team in confidence.

All discussions are treated in line with our policies on patient confidentiality, dignity and respect, which can be found on our website.

We endeavour to provide patient information that is informative and supportive to those using our services. We welcome feedback on our patient information.

Please talk to a member of the treatment team or write to us if you have any suggestions or feedback on the information you have received.

## Useful contacts

Macmillan Cancer Support offer a wide range of information and support, as well as help with your practical, emotional, and financial needs. All telephone help lines are free and confidential, and interpreting services are also available.

**Freephone: 0808 808 00 00** (7 days a week, 8.00am – 8.00pm)

**[www.macmillan.org.uk](http://www.macmillan.org.uk)**

# Rutherford Cancer Centres

**Rutherford Cancer Care Limited**

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