A patient guide to treatment for rectal cancer

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This leaflet is for patients who have been recommended to receive radiotherapy to the pelvis. It will highlight the important details that you will have already discussed with your doctor. This leaflet is intended to be a guide as details and side effects of treatment will vary from one patient to another.

**What is radiotherapy?**

Radiotherapy uses high energy X–rays. The aim of radiotherapy is to slow down or stop tumour growth. Radiotherapy is similar to having a scan, it is painless, and you will not see or feel anything. You do have to lie still for a few minutes.

Radiotherapy treatment is sometimes called external beam radiotherapy and is carried out on a machine called a linear accelerator.

Treatment is normally given in short daily treatment sessions, Monday to Friday. The number of treatment sessions you will be having will depend on your condition. Your doctor will discuss this with you in more detail. We are a teaching hospital and have student radiographers in the department everyday who are supervised by trained staff. Your radiotherapy is delivered by radiographers, both male and female.

Unfortunately some normal healthy cells within the treated area can also be affected, resulting in some side effects. The side effects will be discussed at a later point in this leaflet. The treatment will not make you radioactive so it is safe to be around children and other people after your treatment.

*It is extremely important that you are not pregnant or become pregnant during your course of radiotherapy. Even a small amount of radiation can harm an unborn foetus (baby) so it is very important to let the radiographers know at once if you think there is even a small possibility that you may be pregnant before being exposed to any radiation on the CT scanner or treatment machine.*

**Why do I need radiotherapy?**

Radiotherapy can be used as the main treatment for cancer or it can be used after surgery, just in case any cancer cells that were too small to see were left behind.
What are the benefits of radiotherapy?
For most patients the benefit of radiotherapy will be to potentially cure or improve the control or the symptoms of your cancer. Your doctor will discuss this with you in more detail at your first appointment in clinic.

Are there any alternative treatments to radiotherapy?
Cancer may also be treated with surgery and/or chemotherapy. It may be that you receive a combination of these treatments and your doctor will discuss this with you.

Please see the table below for potential treatment options when treating rectal cancer, to be discussed with your cancer doctor.

<table>
<thead>
<tr>
<th></th>
<th>Short course of radiotherapy BEFORE surgery</th>
<th>Long course of radiotherapy BEFORE surgery</th>
<th>Radiotherapy AFTER surgery (if you did not receive radiotherapy before)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Aim</strong></td>
<td>Reduces the chance of the cancer coming back after surgery</td>
<td>Shrinks the cancer before the operation and reduces the chance of the cancer coming back</td>
<td>Reduces the chance of the cancer coming back after surgery</td>
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<tr>
<td><strong>Chemotherapy</strong></td>
<td>Not during radiotherapy</td>
<td>Some patients receive capecitabine (chemotherapy drug) depending on their overall health</td>
<td>Some patients receive capecitabine depending on their overall health</td>
</tr>
<tr>
<td><strong>Duration of radiotherapy</strong></td>
<td>5 days</td>
<td>4 – 5 weeks</td>
<td>4 – 5 weeks</td>
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</table>
What will happen if I do not have treatment?
Without treatment, the cancer will continue to grow, which may mean the symptoms get worse. The cancer may then spread away from the area and become incurable.

Pacemakers
It is important that you inform your doctor or a radiographer if you have a pacemaker. Radiation may affect your pacemaker so checks will need to be organised through your treatment.

What happens before my radiotherapy begins?
Radiotherapy treatment has to be carefully planned and your first appointment will be for a computed tomography planning scan (CT scan). You will be sent an appointment to attend the CT scanner in Radiotherapy, The Cancer Centre, Queen Elizabeth Hospital.
The CT scan of your pelvis enables your radiotherapy treatment to be planned and the scan needs to be carried out regardless of any other scans you may have had recently.
When you arrive for your appointment the radiographers will ask you to drink 4 cups of water, 30 minutes before they are expecting to scan you to ensure you have a full bladder for your CT scan. For each treatment session you will be required to have a full bladder as this helps reduce side effects from radiotherapy treatment. There is a water machine available in the radiotherapy department but you are welcome to bring your own preferred drink with you if you wish.
Some patients will have an injection of dye (contrast) into a vein in the arm and / or have contrast in your drink before the CT scan. A radiographer will ask you some questions before giving you any contrast and if you have ever had a reaction to contrast before then please let them know. The contrast is used to make it easier for the doctor to plan your radiotherapy.
For your scan you will need to take off all of your clothes below the waist apart from your underwear. Ladies may find it easier to wear a skirt or trousers rather than a dress to the appointment. You will be covered with a paper sheet to maintain your dignity and modesty during this procedure.
During the CT scan some marks will be drawn on your skin to plan your radiotherapy treatment. The marks can be washed off when you get home. After the scan the radiographers will ask permission to make 3 – 4 tiny permanent dots, called tattoos which are the size of a small freckle. The tattoos do not indicate where you need treatment or the position of the tumour but are used to ensure you lie in the correct position each day. If you decide that you really don’t want these tattoos, please discuss what alternatives are available with the radiographers at the time of your CT scan.

The appointment will take approximately 30 minutes and once completed you will be given an appointment for your first radiotherapy treatment. There will be a time delay between your CT planning scan and the start of your radiotherapy treatment because your treatment now needs to be planned and this can be a complex process involving your doctor and a team of other professionals.

You will be asked if you have a preference for morning or afternoon appointments. The routine hours of the radiotherapy department are from 8am to 6.30pm. If you have a need for a certain appointment on a specific day it is best to ask at the earliest available opportunity once you have started radiotherapy to avoid disappointment. It may not always be possible to accommodate all patient requests as we are a very busy department, with approximately 250 – 300 patients on treatment each day. If you require hospital transport for your radiotherapy treatment please discuss this with the radiographers at your CT scan.

**Bladder filling**

Each time you attend for treatment it is important to have a full bladder. This will ensure your bladder is pushed away from the area we are treating which will help reduce side effects you experience and ensure your treatment is accurate.

Each time you have treatment please empty your bladder and then drink 4 cups or 500 millilitres of fluid, 30 minutes before your appointment. There is a water machine available in the radiotherapy department, but you are welcome to bring your own drink if you prefer.
What happens when I come for my first treatment?

Your treatment will be carried out on a machine called a linear accelerator. These are located on the ground floor of the Radiotherapy department. You will be shown where to find your treatment room at the end of your CT planning session. On your first day of treatment you can go directly to your allocated room. If you cannot remember where it is, please ask at the reception desk in the Cancer Centre, or any member of staff. Place your appointment card in the box outside the room so that the radiographers know that you have arrived.

Please arrive 30 minutes before your appointment to give yourself enough time to fill your bladder. Each time you have treatment please empty your bladder and then drink 4 cups or 500 millilitres of fluid, 30 minutes before your treatment appointment.

When the radiographers are ready to start your treatment they will come and talk to you and explain the procedure. Please feel free to ask any questions that you may have.

When you go into the treatment room, you will be asked to lie down on the couch, in the same position you were in the CT scanner. You will be asked to remove your clothes below the waste as it is important that the radiographers can see your tattoos and that there is no clothing in the treatment area to help reduce any side effects. You will be covered with a sheet of paper. The treatment couch will be moved closer to the radiotherapy treatment machine. The radiographers will dim the room lights so that they can see the machine lights. They will then move you to line up your tattoos and get you into the correct position and put some pen marks on your skin. The marks are used to check your position during treatment and monitor if you have moved.

The treatment machine will move around you but does not touch you at any point. The radiographers will inform you when they are leaving the room to commence treatment and you will hear an alarm sound which is part of the safety procedure. The radiographers will operate the machine from the control area and they can hear and see you at all times. If you need assistance just call out or raise your hand. For your own safety, please do not try to get off the bed as it is raised up off the floor.

For some treatments the radiographers may move the machine around you to perform a short scan of your pelvis before treating you. This
allows us to look at more images to ensure you are in the correct position. These images cannot be used to assess your response to radiotherapy. If this scan is part of your procedure it will be explained to you at your first treatment.

When the machine switches on you may hear some noises such as buzzing and bleeping. This is normal and they are the noises that the machine makes whilst delivering the treatment. When the treatment has finished please remain in position until the radiographers enter the treatment room and tell you that everything is finished. This is for your safety. Your first treatment appointment normally takes around 20 minutes.

**What happens at my other treatment appointments?**

After your first treatment the process is very similar for each appointment. Please put your appointment card in the box outside your treatment room. Please make sure that you have a full bladder for each of these appointments. If you are finding this difficult, please discuss this with your radiographers.

Appointments may take around 15–20 minutes. These appointments are normally quicker because on the first day additional checks and measurements are performed.

**What if there is a delay?**

If you are kept waiting and are unable to hold your bladder full please tell the radiographers. You may need to empty your bladder, drink and fill again with approximately half the amount of fluid (1–2 cups). Please discuss this with the radiographers if you are unsure of what to do.

**Is there anything that I need to do whilst receiving my radiotherapy treatment course?**

Whilst receiving radiotherapy treatment it is important to make sure that you keep hydrated and drink plenty of fluids, especially if you are also receiving chemotherapy.
It is important to keep your skin clean and maintain good levels of hygiene as this can help reduce skin soreness.

If you are diabetic please ensure you bring your insulin and some food each time you attend in case there are any delays.

We also recommend you bring any medication you are required to take regularly for example pain killers.

**Will I see a doctor during my treatment course?**

During the course of your treatment you will be monitored by your treatment radiographers and you will be seen by your doctor or one of their team. The radiographers will let you know when this is. Please be aware that your treatment appointment time will be made to coincide with the doctors’ clinic so that you do not have to make two visits in one day. Occasionally clinics may be cancelled but your radiographers will keep you informed when this happens.

Please make sure you tell your doctor or their team of any side effects or problems that you are having. If you need any repeat medication that you have been given from your consultant you should mention it during your clinic appointment.

**Are there any side effects?**

When you were consented for your radiotherapy your doctor will have explained the potential side effects.

The most common side effects often occur during the course of radiotherapy treatment and may continue for a few weeks after treatment has finished. Side effects which occur six months or longer after your treatment has finished are called late side effects.

If you have any questions about side effects please ask any member of the treatment team.

**What are the possible early (acute) side effects?**

These side effects are usually mild and normally start to occur approximately 2 weeks in to the treatment and be at their worst at completion of radiotherapy. They should gradually settle down in the
weeks after your radiotherapy has finished and by the time you attend your post radiotherapy follow up appointment.

Please see acute side effects table to summarise the acute side effects commonly experienced by patients undergoing radiotherapy. Please read on for more detail.

<table>
<thead>
<tr>
<th>Acute side effects</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>Skin</td>
<td>The skin around the area being treated can become pink and irritated, sometimes sore.</td>
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<tr>
<td>Diarrhoea</td>
<td>Irritation of the back passage can lead to loose and more frequent bowel movements. Speak to a member of staff as dietary changes and/or medication can help.</td>
</tr>
<tr>
<td>Bladder problems</td>
<td>Radiotherapy irritates the lining of the bladder which can upset your usual bladder habits and cause discomfort when going to the toilet.</td>
</tr>
<tr>
<td>Blood in stool</td>
<td>It is not uncommon to notice blood in your stools. Just let a member of staff know.</td>
</tr>
<tr>
<td>Haemorrhoids</td>
<td>If you have or have had haemorrhoids, the radiotherapy can make them worse or make them come back.</td>
</tr>
<tr>
<td>Hair loss</td>
<td>Pubic hair in the area may stop growing. It should come back but may be thinner.</td>
</tr>
<tr>
<td>Tiredness</td>
<td>Treatment can make you tired and can last for a few weeks after you finish.</td>
</tr>
</tbody>
</table>

**Skin:** Radiation can irritate the skin in the area being treated. After about 2 weeks treatment you may notice the skin becomes pink and irritated between your bottom cheeks. Do not put any creams or medications on this area unless told to do so by a member of the treatment staff as some creams/medications contain ingredients which can make the skin worse.

The radiographers and your doctor will be looking and checking for this and will advise appropriate care. Do let them know if you are starting to feel sore.

**Bowels:** Radiotherapy can disrupt your normal bowel habits. This is because we are treating your pelvis with radiation so your back passage can become irritated. You may notice that your stools become loose during the treatment and you may experience diarrhoea and/or pass mucus. This is a normal reaction to the treatment. If this happens we will encourage you to drink plenty of fluids throughout the day to replace the fluids you lose when you suffer from diarrhoea. Do tell the radiographers as they are able to recommend medication to help and they can offer advice on how to alter your diet to help reduce these
problems. Sometimes radiotherapy can cause the opposite effect and some patients experience constipation.

It is not uncommon to find a small amount of blood in your stool. This is quite normal but do let a member of staff know if this occurs.

**Bladder problems:** Radiotherapy can irritate the lining of the bladder leading to:

- A need to pass water more often than normal (urinary frequency)
- A feeling that you cannot hold your water, making the need to empty your bladder feel desperate (urgency)
- A burning sensation when emptying the bladder, similar to cystitis (radiation cystitis).
- Blood and debris in the urine (haematuria)

You can help reduce these side effects by following these recommendations:

- Avoid caffeine (this is in tea, coffee and cola unless it is specifically the decaffeinated variety)
- Avoid alcohol as this too can irritate the bladder
- Drink 2 litres of fluid a day to keep your urine diluted (clear urine rather than dark yellow) Don’t be tempted to drink less to avoid going to the toilet, as this will make you become dehydrated and your urine will be more concentrated (it will look very dark yellow in colour) which will irritate the bladder lining further

**Tiredness:** Radiotherapy can make you feel tired. This can be partly because of the travelling involved in attending the hospital every day as well as the treatment. This may continue for a few weeks after you have finished your treatment.

**Haemorrhoids:** If you have haemorrhoids the treatment can irritate them further, or cause them to come back if you have had them before.

**Hair loss:** You may lose your pubic hair if it is in the area being treated. This should grow back after treatment but may grow back thinner.

Please let the radiographers know if you are experiencing any side effects as they may be able to help.
What are the possible late side effects?

**Tiredness/lethargy:** Even if you haven’t had any tiredness during your radiotherapy, 4 – 6 weeks after treatment there may be a period of time when you feel particularly sleepy or that you feel you do not have the energy to do anything. This can last for 6 weeks or longer. This duration of tiredness can cause people to worry as it doesn’t seem to settle down but this is quite a normal reaction to the treatment. It will settle down.

**Bowels:** You may notice blood in your stools as the blood vessels in your back passage may become more fragile and blood may leak into your back passage, appearing in your stools.

Sometimes people experience a permanent change in their bowel habits. Your motions may become more frequent or looser. Do let your doctor know as soon as this starts as medications can be prescribed to help regulate your habits.

Rarely, small blockages can occur. These are caused by the tissue surrounding the bowel sticking together and sometimes surgery is required to correct this. This is very rare.

**Bladder:** Scarring from the radiotherapy may result in the need to go to the toilet more regularly and the feeling being more urgent. You may also experience a small amount of urine leakage (incontinence), especially when laughing, coughing or sneezing.

**Radiation induced tumours:** Radiotherapy can cause cancer and there is a very small risk of a secondary cancer developing in the area that has been treated. However because the risk of this happening is very small, the benefit of your radiotherapy treatment far outweighs this risk. Your consultant will discuss this with you.

**Sexual function:**

**Females**

- **Infertility and menopause:** Radiotherapy to the pelvis can lead to permanent infertility and is also likely to bring on an early menopause for ladies who are still having regular periods. It is important that you still continue to use contraception and do not start treatment if pregnant or become pregnant whilst on treatment. Do discuss this with your consultant before starting treatment.
• **Vaginal stenosis:** There is a chance the radiotherapy will cause the vagina to become narrowed, making sexual intercourse and future examinations uncomfortable. There are different options available to help deal with this issue, from sexual intercourse to vaginal dilators. This can be discussed with your consultant or health nurse.

**Males**

• **Infertility:** Radiotherapy to the pelvis can lead to permanent infertility. If this is a concern for you please discuss the option of sperm banking with your consultant before you start treatment. If you are sexually active you may notice a reduction in semen production and sperm count.

• **Erectile issues:** The treatment can result in difficulty in obtaining an erection due to damage to the nerves in this area. Please discuss this with your consultant as there are medications that can help and specialist staff you can discuss this with.

• **Contraception:** If you are sexually active it is recommended that you use contraception for 6 months after radiotherapy as sperm production will not stop straight away, however the sperm that is produced may be damaged. This could cause abnormalities if a child was to be conceived during this time.

**Skin care during your radiotherapy**

During your radiotherapy and for a while afterwards, you may develop a skin reaction in the area being treated. You may notice:

• Your skin gradually becoming pinker or darker, depending on your skin colour

• The skin may feel dry or tight, and sore

• A rash may also appear and feel itchy

• Sometimes the skin may blister or peel. If this happens you will be given further help as you may need dressings

A skin reaction may appear at any time but usually begins about 10 days after starting treatment.
What can affect my skin reaction?

- Having treatment to areas (groin, buttocks) where there are skin folds can make your skin reaction worse as the skin is warm, moist and may rub together causing friction
- Having chemotherapy alongside radiotherapy can make your skin reaction worse
- Smoking can make your skin reaction worse – if you need help to stop please ask for advice
- A skin reaction is more likely if you are overweight due to more skin folds

Your treatment team will talk to you about your usual daily skin care routine. They will let you know if any changes are advised. Please talk to them about any worries you have.

How can I help myself?

It may not be possible to stop a skin reaction but by following this advice you may feel more comfortable. This only applies to the skin in the area being treated.

- Wash the skin gently with soap and water; gently pat dry
- Wear loose fitting, natural fibre clothing next to the skin. For example, a cotton t-shirt
- Avoid rubbing the area
- Avoid extremes of temperature such as heating and cooling pads in the area being treated
- Avoid sticky tape on the area (such as Elastoplast™ or Micropore™)

It may also help to reduce irritation to the treated area if you use a moisturiser sparingly – gently smooth it on and apply in the direction of hair growth. Please stop using if it irritates your skin and talk to your treatment team.

If you are choosing a new moisturiser one that is sodium lauryl sulphate free would be best.

If your skin breaks/blisters you should stop using moisturiser. Your treatment team will advise you further.
• You may swim if your skin is not broken. Shower after swimming to wash off the chlorine and apply your moisturiser. Please stop swimming if it irritates your skin

• Avoid sun exposure and protect the area from direct sunlight. You can wear a brimmed hat and/or cover up with clothing. Be careful in the sun for at least a year after you have finished your treatment course. Use a sunscreen with a minimum UVB sun protection factor (SPF) of 30 and UVA protection as your skin will be more sensitive

• Your treatment team will let you know if this advice changes during treatment

It may also help to maintain good fluid intake and eat a nutritionally well–balanced diet.

After your treatment has finished, your skin will continue to be more sensitive. Your reaction may worsen for the next 7–10 days before starting to improve. Most patients find their skin has healed around 4 weeks after treatment finishes. If the skin has broken, healing may take longer than this.

Who do I contact if I have any questions or concerns whilst on treatment?

All our staff are here to make sure your treatment goes as smoothly as possible and to support you through this difficult period. If you have any questions about your treatment or side effects, please do not hesitate to ask your doctor or any of the radiographers for advice.

During your treatment and for up to 6 weeks after if you need urgent advice please contact the oncology hotline on 07789 651 543.

In the event that your call is not answered, please leave a message stating your name, hospital number and contact telephone number.

What do I need to do once I have finished my treatment?

Once you have completed your treatment your side effects may continue for a few weeks and even worsen so please then continue with the advice that was given to you during your radiotherapy until the side effects stop. If you are unsure of what to do please ask a
radiographer or your doctor before you finish your treatment. You will be seen by your doctor when you have completed your treatment and this will be 6–12 weeks after the end of your treatment. This appointment will be at the hospital where you originally saw your radiotherapy doctor. If you do not receive an appointment in the post within this time then please contact the secretary of your doctor who will be able to check this for you.

Your follow up appointments will continue for months/years. During these appointments it is important that you mention any side effects or problems that have occurred since completing your treatment. This enables your medical team to manage any late side effects in the best way possible.

How can I get to the Queen Elizabeth Hospital, Birmingham?

**Train:** University station is the closest train station to the hospital and is only a 5–10 minute walk away. There is also a shuttle bus running from the train station to the Cancer Centre, Old QE hospital for those patients who have difficulty walking.

**Driving:** Car parking in car park D is free for patients attending daily radiotherapy treatment appointments. Car park D is located directly opposite the doors to the Cancer Centre, Heritage Building. The postcode for your satellite navigation device is B15 2TH.

If you do drive, please bring in the ticket you have taken to access the car park and the radiographers will exchange this for a prepaid one so you can exit the car park without charge.

**Hospital transport** is available for patients who are not well enough to travel by their own means. If you use hospital transport it can mean spending many hours away from home and travelling long distances (you will be collected/returned on a schedule) therefore we recommend you use other forms of transport if you can. Please ask staff for details.

Alternatively you may arrange to stay in the Bromley Wing at the Queen Elizabeth Hospital. It is comfortable accommodation with meals from Monday– Friday for people who are able to look after themselves. Outside treatment times you are free to entertain yourself, have visitors or go out. Accommodation here is free and can be arranged by contacting the Bromley Wing on 0121 627 2406.
You may also find these organisations helpful:

**Macmillan**: www.macmillan.org.uk or 0808 8080000

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**Radiotherapy Contact Numbers**

**Patrick Room – Cancer Centre, Queen Elizabeth Hospital**

Information and support for people with cancer and their families:
Telephone 0121 371 3537/9

**Oncology hotline**

For urgent medical problems out–of–hours when attending for treatment and up to 6 week after radiotherapy or chemotherapy has finished: Telephone 07789 651543

**Radiotherapy Treatment Rooms** – direct telephone numbers

Room 1 0121 371 5077
Room 2 0121 371 5076
Room 4 0121 371 5090 (Tomotherapy)
Room 5 0121 371 5085
Room 6 0121 371 5098 (Tomotherapy)
Room 7 0121 371 5084
Room 10 0121 371 5079
Room 11 0121 371 5080

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The Trust provides free monthly health talks on a variety of medical conditions and treatments. For more information visit www.uhb.nhs.uk/health-talks.htm

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**Radiotherapy**

**Queen Elizabeth Hospital Birmingham**

Mindelsohn Way, Edgbaston, Birmingham B15 2GW

Telephone: 0121 627 2000