A patient guide to radiotherapy treatment for anal cancer

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

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. During the procedure you will 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 have will depend on your condition. Your doctor will discuss this with you in more detail.

Queen Elizabeth Hospital, Birmingham is a teaching hospital and have student radiographers in the department everyday who are supervised by trained staff. Your radiotherapy will be delivered by radiographers, both male and female.

Unfortunately some healthy cells within the treated area can also be affected, resulting in some side effects. These side effects will be discussed further on in this leaflet.

Radiotherapy treatment does not make you radioactive so it is safe to be around children and others 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 may damage an unborn foetus. 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.
Why do I need radiotherapy?
Radiotherapy can be used as the main treatment for cancer or it can be used after surgery in order to treat smaller cancer cells that may have been missed.

What are the benefits of radiotherapy?
For most patients, the benefit of radiotherapy will be to control or potentially cure your cancer symptoms. Your doctor will discuss this with you in more detail at your first appointment.
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 these options with you.

Chemotherapy with radiotherapy (chemo–radiation)
Chemotherapy (a cancer treatment using medicine) is regularly used with radiotherapy for anal cancer and your doctor will inform you if they think chemotherapy is required. Chemotherapy for anal cancer is often given in the first and fifth week of your radiotherapy treatment. During those weeks you will need to stay in hospital overnight. On the morning of the first day of your treatment, you will be admitted into hospital to begin your chemotherapy. Your chemotherapy will be given through a drip and a porter will collect you to take you to the radiotherapy department for your treatment. You will have regular blood tests during your radiotherapy, the radiographers will organise these tests and you will be given the appropriate forms.
What will happen if I do not have treatment?
Without treatment, your cancer will continue to grow, which may mean your symptoms worsen. The cancer may then spread away from the original area and become incurable.

What if I have a pacemaker?
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 throughout 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 (a CT scan). You will be sent an appointment to attend the CT scanner in Radiotherapy, The Cancer Centre, Queen Elizabeth Hospital, Birmingham.

The appointment will take approximately 50 minutes.

The CT scan will be of your pelvis, this will enable your radiotherapy treatment to be planned. A CT 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 usually 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. If you have ever had a reaction to
contrast 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, except your underwear. Females 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 during the procedure.

During the CT scan some marks will be drawn on your skin to plan your radiotherapy treatment. These marks can be washed off when you get home.

After your scan the radiographers will ask your permission to make 3 – 4 tiny permanent dots (tattoos 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 do not want these tattoos, please discuss available alternatives with your radiographers at the time of your CT scan.

Once your scan is complete 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 as your treatment will need to be planned and this can be a complex process.

You will be asked if you have a preference for morning or afternoon treatment 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 the department treats a large number of patients each day.

If you require hospital transport for your radiotherapy treatment please discuss this with the radiographers.
Filling your bladder

Each time you attend for radiotherapy 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 may experience and ensure treatment is accurate.

Each time you undergo 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 arrive for my first radiotherapy appointment?

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 scan. On the first day of your treatment you should go directly to your allocated treatment room. If you cannot remember where this is, please ask at the reception desk in the Cancer Centre, or a member of staff. Place your appointment card in the box outside your treatment 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 arrive for treatment please empty your bladder and then drink 4 cups or 500 millilitres of fluid, 30 minutes before your appointment.

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

When you enter 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 lower clothes 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 couch will be moved closer to the radiotherapy machine. The radiographers will dim the room lights so that they can see the machine lights. They will then line up your tattoos and ensure you are in the correct position for treatment, some further pen marks will be put on your skin. The marks do not indicate where you are having treatment but are used to check your position during treatment and monitor if you have moved.

The machine will move around you but does not touch you at any point during your treatment. 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.

In some cases your radiographers may move the machine around you to perform a short scan of your pelvis. This allows them to view more images to ensure you are in the correct position. These images cannot be used to measure your response to radiotherapy. If this scan is part of your procedure it will be explained to you at your first appointment.

When the machine switches on you may hear some buzzing or bleeping noises, this is normal. When the treatment has finished you should remain in the same position until the radiographer enters the room and allows you to move. This is for your safety. Your first session of treatment normally takes 20 minutes.
What happens at my next radiotherapy appointments?

After your first treatment appointments are usually quicker as initial checks and measurement will have been performed in your first radiotherapy session. When you arrive please put your appointment card in the box outside your treatment room. Appointments usually take between 15–20 minutes.

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 radiographer.

What if there is a delay?

If you are kept waiting and are unable to hold a full bladder 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.
Will I see a doctor during my radiotherapy course?

During the course of your treatment you will be monitored by your radiographers and you will be seen by your doctor or one of their team. Please be aware that your radiotherapy appointment time will be scheduled to coincide with your 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.

You should tell your doctor or their team if you are experiencing any side effects or problems. If you need any repeat medication that you have been given from your consultant you should mention this during your clinic appointment.

Are there any side effects to my radiotherapy?

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 your radiotherapy treatment and may continue for a few weeks after treatment has finished. Side effects which occur six months or longer after treatment has finished are called late side effects.

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

What early (acute) side effects may I experience?

The side effects listed in the table below are mild and normally start to occur approximately 2 weeks in to your radiotherapy treatment. Side effects are usually at their most severe at completion of radiotherapy, however they should gradually improve in the weeks after your radiotherapy has finished and should have settled by the time you attend your post radiotherapy follow up appointment.
Below is a table to summarise the acute side effects commonly experienced by patients undergoing radiotherapy.

<table>
<thead>
<tr>
<th>Acute side effects</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sore skin</td>
<td>Your skin will become sore and may start to weep during treatment. The radiographers will be watching for this, so do let them know if you are feeling sore.</td>
</tr>
<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 cause them to return.</td>
</tr>
<tr>
<td>Hair loss</td>
<td>Pubic hair in the area may stop growing. It should grow back but may be thinner.</td>
</tr>
<tr>
<td>Tiredness</td>
<td>Radiotherapy can make you tired due to travelling to hospital everyday as well as the treatment itself. This feeling can last for a few weeks after your radiotherapy has finished.</td>
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</table>
Side effects to the skin

Radiation can irritate the skin in the treated area and this is a common side effect when treating the anus. Two weeks after your treatment you may notice your skin becoming red and sore in between your bottom cheeks, groin area and genitals (scrotum and penis for men, vulva and vagina for a woman). The skin may also start to weep and the may break down as the treatment progresses.

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

Side effects to the bowels

Radiotherapy can disrupt your normal bowel movements. 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 (fluid produced from cells). 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 if you suffer from diarrhoea. You should tell the radiographers if you are experiencing diarrhoea as they are able to recommend medication and offer advice on how to alter your diet to help reduce these problems. In some cases 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 normal but do let a member of your treatment team know.
Side effects to the bladder

Radiotherapy can irritate the lining of the bladder and may cause the following side effects:

- 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
- 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 dehydrated and your urine will be more concentrated (it will look very dark yellow in colour) which will irritate the bladder lining further

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.

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.
Please let the radiographers know if you are experiencing any of the above side effects as they may be able to help.

What late side effects may I experience?

**Tiredness and lethargy**

Even if you have not experienced any tiredness during your course of radiotherapy after it has finished 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 and will settle.

**Bowels**

You may notice blood in your stools as the blood vessels in your back passage may become more fragile causing blood to leak into your back passage and appear in your stools.

Sometimes people experience a permanent change in their bowel habits. Your motions may become more frequent or looser. You should let your doctor know if you are experiencing loose stools as medication can be prescribed to help regulate movements.

In rare cases small blockages can occur. These are caused by the tissue surrounding the bowel sticking together and sometimes surgery is required to correct this, however again this is rare.

**Bladder**

Scarring from your radiotherapy treatment 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.
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 if you become pregnant whilst on treatment. If you do wish to have children you should discuss this with your consultant before beginning radiotherapy. Vaginal stenosis: There is a chance that your radiotherapy treatment may 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:** Radiotherapy 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.

- **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.

**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, the risk of this happening is very small and the benefit of your radiotherapy treatment far outweighs this risk. Your consultant will discuss this further with you.

**Caring for your skin during your radiotherapy treatment**

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
- Your skin may feel dry or tight, and sore
- A rash may also appear and feel itchy
- 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 10 days after starting treatment.

**What can make my skin reaction worse?**

- Having radiotherapy to areas, such as the groin or 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 daily skin care routine. They will let you know if any changes are advised. Please talk to them about any worries you may have.

**How can I help ease my skin reaction?**

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 and dry.

• Wear loose fitting, natural fibre clothing next to the skin. For example, a cotton t-shirt

• Avoid rubbing the treated 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™)

Irritation can also be reduced if you use moisturiser sparingly. You should gently smooth the moisturiser on to your skin and apply in the direction of hair growth. You should stop using the cream if it irritates your skin, and inform your treatment team. If you are choosing a new moisturiser, a sodium lauryl sulphate free alternative is advised.

If your skin breaks/blisters you should stop using moisturiser. Your treatment team will advise you further.

You can swim if your skin isn’t 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 your radiotherapy treatment has finished. 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.

You should maintain a 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 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?

All our staff at the Queen Elizabeth Hospital, Birmingham are here to make sure your radiotherapy 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 your course has finished, if you need urgent advice due to side effects or are feeling unwell contact the oncology hotline; 07789 651543.

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 when I have finished my radiotherapy?

Once you have completed your treatment, the acute side effects may continue for a few weeks even though you are no longer receiving treatment. 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 radiotherapy.

You will be seen by your doctor when you have completed your treatment and this will be 6–12 weeks after the course has ended. 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 after your radiotherapy has ended. 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 help manage any late side effects.

Attending your appointments

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, for those patients who have difficulty walking.

Driving

Car parking in Car Park D is free for patients attending for daily radiotherapy treatment. Car Park D is located directly opposite the doors to the Cancer Centre. The post code for your satellite navigation system 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 may exit the car park without charge.

**Hospital transport**

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 transport if you can. Please ask a member of 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
Tel: 0808 8080000

**Radiotherapy contact numbers**

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

Information and support to 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

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 or call 0121 371 4323.

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