

Radiotherapy for a Soft Tissue Sarcoma



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Radiotherapy for a Soft Tissue Sarcoma

This leaflet is for patients receiving radiotherapy for a soft tissue sarcoma. It describes:

- What is radiotherapy?
- Your radiotherapy planning and treatment.
- The effects that you may experience during and after treatment, and how best to cope with them.
- Who to contact if you have any questions or concerns.

Your doctor, radiographer or specialist nurse will explain specific aspects of your treatment.

What is Radiotherapy?

Radiotherapy is the use of carefully measured doses of radiation to treat cancer. It is used to treat where the cancer is or was, plus a small surrounding area. It damages the cells and stops them dividing and growing. It is normally given in small daily doses, over a period of days or weeks.

Radiotherapy is used to treat sarcomas in several ways. You may have radiotherapy:

- Before surgery to minimise the risk of cancer cells being left behind.
- After surgery to reduce the risk of your cancer returning.
- To help control or reduce symptoms of advanced sarcoma.

Your doctor, specialist nurse or specialist radiographer will explain your treatment to you in detail. If you have any questions, please ask and they will be happy to answer them.

Preparation for radiotherapy

Sometimes we have to make a special positioning aid for you. This is usually if you are having a limb (arm or leg) or an area of your head or neck treated. It is made for you in the Mould Room. It is used to:

- Immobilise the area that is being treated.
- Ensure that you are in the same position each day for treatment.
- Minimise the number of positioning marks needed on your skin.

Mould Room Visit

The positioning aid is sometimes called a shell, mask or mould. It is made using a sheet of plastic which is softened using warm water. It is then shaped around the area we want to treat. It is kept in position until it cools. This takes about 5 minutes. When it has cooled, it hardens and keeps its shape.

Depending on the area to be treated, we may also use some other positioning aids, such as putty or small bean bags. These can help to keep you supported during treatment and increase accuracy.

The mould room staff are called clinical technologists. They will talk you through everything. This can be a busy appointment and there may be other staff members present. They will introduce themselves to you. Your appointment will last about an hour.

Sometimes, you **may** need to have a second visit to the mould room. This is to check that your immobilisation device is a good fit and is comfortable. This appointment takes around 30 minutes.

Your immobilisation device will be used for each radiotherapy appointment.

Picture 1: Immobilisation device for treatment of a limb



Picture 2: Immobilisation device for treatment of the head or neck area



If you are having an area of your pelvis, abdomen or chest treated, you do not usually need a personalised immobilisation device. You therefore do not need to go to the mould room.

Sometimes it may be necessary to treat part of the groin area. We may ask you to move your genitalia (testicles and penis) away from the treatment area. We will ask you to place your genitalia into a special sling made from bandage with a loop on the end. You will be able to do this whilst covered so there is no need for you to be exposed. We would advise that you wear a loose fitting pair of underpants.

Radiotherapy planning: CT scan

To plan your treatment you will have a CT planning scan of the area that needs to be treated. This is very similar to any other CT scan you may have had, however it is used specifically to plan your treatment. There are no results from it.

Picture 3: CT scanner



Your radiographers will ask you to lie on the CT couch. You may need to remove some items of clothing. They will cover you as much as possible. They will place some pen marks and small markers on your skin or on your immobilisation device. They may also place wire over your scar to help it show up on the scan.

Your radiographers will leave the room before starting the scan. They are watching you at all times. The scan takes approximately five minutes.

When the scan is finished, your radiographers may replace the small marks on your skin with permanent tattoos that look like

tiny freckles. If you have an immobilisation device, the marks will be put on this. However, it may still be necessary to give you tattoos as well. These marks and tattoos will be used to ensure you are in the correct position each day for treatment.

Treatment

You will have your radiotherapy treatment at the Beatson West of Scotland Cancer Centre, in the radiotherapy department. Treatment is daily, Monday to Friday. Although most people receive their treatment as an outpatient, it may be more appropriate or practical for you to receive your treatment as an inpatient. Your doctor or specialist nurse will discuss this with you.

The machine that delivers your radiotherapy is called a linear accelerator. Your radiographers will explain the procedure to you and answer any questions you may have.

Picture 4: Linear accelerator



For each treatment, you will lie on the couch just as you did in the CT scanner. Your radiographers will move the machine and the couch into the correct position. They will then leave the room for a few minutes to switch the machine on. Your radiographers will be watching you all the time on a television screen. The whole procedure only takes about 15 minutes. There is nothing to feel during treatment or immediately afterwards.

You will see your doctor or specialist nurse once a week while you are having treatment. This is to check how you are coping with the radiotherapy and answer any questions you may have. If you have any questions or concerns you can also ask your radiographers.

Early side effects of treatment (acute effects)

These are the side effects most people commonly experience during the course of radiotherapy and for a few weeks after it finishes. These effects vary from person to person and can last a different length of time for each person. The side effects can get gradually worse during treatment and for about 10-14 days afterwards. The majority of side effects wear off within 6 weeks of radiotherapy stopping. Please ask if you are unsure or have questions.

- **Tiredness:** You may begin to feel quite tired during treatment or just after treatment finishes. A sensible balance between rest and activity may be most beneficial. Research has shown that gentle exercise is also beneficial for people who have had a cancer diagnosis both in the short and longer term. There are programmes available that can help with this. Please let us know if you are interested in finding out more.
- **Hair loss (temporary or permanent):** You will only lose hair in the area being treated. This usually starts 2-3 weeks into treatment.

- **Skin reaction (in the area we treat):** Your skin may become pink, itchy, dry or sore. Some patients experience broken skin that can weep. Skin reactions can often be worse in areas where there is a skin fold, such as the groin or armpit. Your doctor, specialist nurse or radiographers can give you specific advice.

Following the skin care advice below can help stop your skin from feeling uncomfortable:

- You can wash the skin that is being treated with lukewarm water and your normal soap. Don't use a flannel etc.
- Pat the skin dry rather than rubbing it.
- If you want to use moisturising cream on the treated area, please check with your doctor, specialist nurse or radiographer. Do not use if your skin is broken.
- If you wish to remove hair in the treated area, you can use an electric razor. Please do not use any hair removal products. You may wish to shave the area before starting your radiotherapy.
- Avoid sun exposure, swimming, saunas and Jacuzzis.
- Follow these instructions during your radiotherapy and until any skin reaction settles.

Below are some common side effects that you may experience depending on the area you are having treated. Your doctor and specialist nurse will give you more specific information.

☐ **Effects if you are having treatment to a limb**

- » **Swelling:** If you are having a limb treated this may swell during or after treatment. This can be due to inflammation caused by the treatment. This is a normal reaction to the radiotherapy. It can help to keep the limb raised when you are sitting down. The swelling usually settles after you finish your treatment, however in a few patients this may persist.

- » **Joint Stiffness:** You may experience stiffness in your limb.
- ☐ **Effects if you are having treatment to your pelvis/abdomen (tummy)**
 - » **Bowel:** You may notice a change in your bowel movements. You may need to move your bowels more frequently and the stools you pass may be softer. This may be accompanied by colicky or wind pains. You should drink plenty of fluids and try to eat a normal, well balanced diet.
 - » **Bladder:** The inside of the bladder may become a little irritated, like cystitis. You may need to pass urine more often than usual, and may have a burning sensation when passing urine. Drinking plenty of water will help.
 - » **Feeling sick:** You may feel sick. Your doctor may prescribe some medicine to help with this.
- ☐ **Effects if you are having treatment to your chest/chest wall area**
 - » **Gullet:** You may feel a discomfort in your gullet, like a lump is in the way of swallowing food. This is due to the gullet being irritated by the treatment. There is a liquid medicine which your doctor or specialist nurse can prescribe for you if this becomes a problem. This will settle down within a few weeks of completing your treatment.
 - » **Cough:** You may develop a dry cough. This should settle a few weeks after treatment finishes.
- ☐ **Effects if you are having treatment to your head or neck area**
 - » **Mouth, Throat and Gullet:** The cells lining the inside of your mouth, throat and gullet are very sensitive to radiation. You may therefore experience soreness, ulceration, redness, cracks and bleeding in these areas. We will give you mouthwashes, and pain killers to treat

these effects. Remember, only use the medication given to you by the Beatson staff for these issues.

- » **Saliva:** You may find that your saliva becomes thicker, stickier and there is less of it. This can be worse in the mornings and can take some time to loosen and clear. This thick saliva or mucus can make you feel sick or vomit. If you are feeling sick, please let your radiographers or specialist nurse know.

You may be more at risk of infections in your mouth due to a lack of saliva. This can be seen as white patches on the inner surface of your cheeks or on your tongue (oral thrush). If you notice this, please let your radiographers or specialist nurse know.

There is a separate leaflet called 'Looking after your Mouth', which discusses in detail how to look after your mouth and teeth during and after treatment. If you are not given this leaflet, please ask for it and let us know if you have any concerns about your mouth.

- » **Swallowing:** It may become uncomfortable and painful to swallow. When this happens we will give you medicine to take before meals to help you swallow. We will also give you appropriate painkillers.

It may be easier to eat a softer diet such as scrambled eggs, soups, and puddings etc. Try using more gravies and sauces. Avoid food that is too hot, too cold, spicy or acidic. You can increase the nourishment in your food by adding more full fat milk and cream to porridge, soups etc. and adding cheese and butter to mashed potatoes. We recommend that you try to drink as much as possible during your treatment. At least 8-10 glasses of fluid a day is ideal.

Contact your GP to have any medicines you already take changed to a liquid or soluble form. It is very important to continue with all your medicines. It is important you let us know if you are having difficulties.

- » **Skin:** Your skin may become red like a bad sunburn reaction. The best way to protect this is to use the creams and moisturisers supplied by the Beatson only. Use a loose fitting scarf or a hat to protect the skin from sun exposure. Do not use perfumed products on this area. If you shave, use an electric razor during your treatment and until any skin reaction has settled.
- » **Weight:** We will weigh you at the start of treatment and every week thereafter at your weekly review. If you lose weight or need advice, our dieticians will help you. They may prescribe food supplements. They may also recommend that a feeding tube may be helpful. This will be explained to you in detail if it needs to be done. You will need to be admitted to the ward for a short time- usually 3-4 days. This is so we can explain how to look after your feeding tube at home. This is a common requirement with this treatment so do not be alarmed.
- » **Taste:** Your sense of taste may change or be lost completely for some time. A lot of people find that food tastes more salty than usual. This usually improves but can take several months. Very few people lose their sense of taste forever.
- » **Your Voice:** Your voice may become hoarse or weaker for a time. Avoiding smoking and smoky places will help this. Your throat may become sore and uncomfortable when talking and your voice will become tired. Speak quietly and gently, giving your voice rests throughout the day. Our Speech Therapist will be able to give you further advice if you need it.

If you have a tracheostomy (breathing tube in your throat) or have had a laryngectomy (voice box removed), we will offer any extra advice you may need to cope with this during your treatment. It is sometimes necessary to add extra moisture to the air you breathe, to balance any drying effect of the radiotherapy. There

are many ways to do this, including different stoma protectors and a nebuliser.

- » **Swelling:** After neck surgery, if any of your glands have been taken away, your neck and chin area will swell slightly. This will get worse while you are having treatment but will improve slowly when treatment is completed. You will have been given exercises by the physiotherapist after your surgery. You should continue doing these exercises moving your face and neck muscles gently, through their full range of movement, to prevent stiffness and reduce any swelling. This should not be painful, so please let us know if you are having difficulties and we will arrange for you to see a physiotherapist.

Late side effects of treatment (chronic effects)

The late side effects of radiotherapy can occur months or years after radiotherapy has finished. The side effects depend on the area treated. These late side effects are the hardest to predict and, unfortunately, when they do occur they are permanent.

Your radiotherapy doctor will have explained the potential late side effects of radiotherapy to you as part of the consent process.

The effects may include:

- **Lymphoedema (swelling):** Lymphoedema is swelling due to the lymph nodes and vessels being affected by the radiotherapy. The lymph fluid is then unable to pass through the vessels, and this build up can cause swelling. If you are overweight or your work requires prolonged standing you are more likely to develop swelling. Speak to your doctor if you are concerned. You may be referred to a lymphoedema specialist.
- **Arthritis:** If you have radiotherapy to one of your joints, it may become stiff. It is important to do regular exercise to keep the joint mobile. There are exercise programmes

available that can help with this. Please let us know if you are interested in finding out more.

- **Fracture:** Radiotherapy carries a small risk of making the bone in the treated area more likely to fracture.
- **Fibrosis:** Radiotherapy is associated with long – term scarring (fibrosis) of the area treated. This is due to thickening of the muscles and tissues within the treated area. Good skin care, usage of water – based moisturisers, avoidance of sun exposure and stretching/exercising can help in minimising these side effects.
- **Skin:** The area treated will always be more sensitive to the effects of the sun. When treatment has finished, we advise you use sunscreen with both UVA/UVB protection and minimum SPF 50.
- **Fertility:** If you are having your pelvis or abdomen treated, your testes or ovaries may receive some of the radiation dose. This can cause infertility. Your doctor will discuss this with you.
- **Second cancer:** When having radiotherapy there is a small risk of developing a new cancer in the area that was treated. This could happen many years after you finish your treatment and the likelihood of it is very small. Please discuss it with the medical team if you have concerns.

What happens after I finish my radiotherapy treatment?

Your doctor may send you for a chest X-ray soon after your treatment has finished. If this applies to you, your doctor or specialist nurse will discuss it with you.

You will be given an outpatient appointment for 6 to 8 weeks after the end of your treatment.

Your doctor will explain what your follow up plan will be. If you have any questions, please ask.

Frequently asked questions

Can I change the time of my appointments?

You will receive the contact number for our Booking Office with your appointment letter. If you need to change your times, please contact them at the earliest opportunity.

I have another appointment/event to attend at the same time as my Radiotherapy, can I miss my Radiotherapy?

It is important that you attend for every Radiotherapy treatment. It may be possible for us to change your appointment time so that you can attend both- please speak to your Radiographers as soon as possible.

Can someone come in to the CT Simulator/Treatment Room with me?

No. As there is radiation being used, only staff are allowed in with you.

Are there male and female staff involved in my care?

Yes.

Who operates the CT simulators and the Treatment machines?

Therapy Radiographers operate both machines. They are specially trained staff and are registered with the Health and Care Professions Council (HCPC).

Are there students in the Radiotherapy Department?

Yes, we have student radiographers and student nurses within the department. They will always be supervised. If you do not wish to have a student involved in your care, please speak with your radiographer/nurse.

Can I have treatment nearer to my home?

The Beatson West of Scotland Cancer Centre is a specialist centre with Radiotherapy facilities. It is one of only 5 centres in Scotland. It will be your closest hospital able to deliver this treatment.

What happens if I develop side effects during treatment?

You will be reviewed during your treatment and we will monitor your side effects. We will give you advice and prescribe any medications you may require due to these side effects. We can also liaise with your District Nurse for ongoing support after Radiotherapy if required.

Can I exercise during my treatment?

A sensible balance between rest and activity is best. Research has shown that gentle exercise can be beneficial in both the short and long term.

Do I get any scans during treatment to see if my treatment is working?

No. You will have images taken during your treatment but these are only used to check your position. You will have a follow up arranged for after your treatment has finished and all side effects have settled. It will be assessed then.

Does the Radiotherapy hurt?

No. You won't feel anything during treatment.

Where can I get help?

Information and Support

All our staff are here to make sure your treatment goes as smoothly as possible and will try to help with any questions or problems you may have. Further specialist help is available from:

Radiotherapy Team:

- Dr Saurabh Vohra, Consultant Clinical Oncologist
- Dr Ioanna Nixon, Consultant clinical Oncologist
- **Sarcoma Nurse Specialist** (Beatson) ☎ 0141 301 7262
- **Specialist Radiographer** (Beatson) ☎ 0141 301 9903
- **Information and Support Radiographer** (Beatson) ☎ 0141 301 7427
- **Macmillan Information Radiographer and Counsellor** (Beatson) ☎ 0141 301 7423

The Beatson Cancer Centre has a **Radiotherapy Advice Line** available for patients who have completed treatment. This is an answer phone service, which is available Monday - Friday. Please leave your name, contact telephone number and a brief description of your concern. We will return your call as soon as possible. It can help us if you also leave your hospital number or date of birth. ☎ **0141 301 7432**

The Cancer Centre also has a **Cancer Treatment Helpline** for urgent calls. This is for patients on or within 6 weeks of treatment who have **urgent or severe** symptoms such as:

- Shivering or flu-like symptoms.
- Temperature greater than 37.5°C.
- Gum/nose bleeds or unusual bruising.
- Worsening or sudden breathlessness.
- Leg weakness/difficulty walking.
- Severe nausea/vomiting/diarrhoea/constipation.
- Sudden increased or uncontrolled pain.

- Other concerning symptoms associated with your cancer treatment.

The line is available 24 hours for emergencies, although it would be helpful if you called early in the day if this is at all possible.

For Urgent Calls:

Beatson 8am-8pm 📞 0141 301 7990

National 8pm-8am 📞 0800 917 7711

Counselling and Clinical Psychology

Within the Cancer Centre there is a counselling and clinical psychology service that may be able to help with worries and difficulties you might be having before, during or after treatment. If you think this may be helpful, please ask staff to put you in touch.

Other organisations providing support and information

- **Scottish Sarcoma Website:** 🌐 www.ssn.scot.nhs.uk
- **Sarcoma UK:** 📞 0808 801 0401
Offers support for anyone affected by sarcoma cancer.
🌐 www.sarcoma.org.uk
- **CLIC Sargent cancer care for children:** 📞 0300 330 0803
Provides emotional support, practical and financial help and holidays for children and young people (under 21 yrs).
🌐 www.clicsargent.org.uk
- **Disabled Living Foundation:** 📞 0300 999 0004
🌐 www.dlf.org.uk
- **Limbless Association:** 📞 0800 644 0185
Information and advice for people of all ages with amputations.
🌐 www.limbless-association.org

- **Macmillan Cancer Support:** ☎ 0808 808 0000
Providing practical, medical, emotional and financial advice for those affected by cancer.
🌐 www.macmillan.org.uk
- **Cancer Support Scotland – The Calman Centre, Gartnavel Complex. Freephone** ☎ 0800 652 4531
Provides emotional and practical support on a one-to-one basis and through community based groups. Complementary therapies and counselling available.
🌐 www.cancersupportscotland.org
- **Maggie’s Gartnavel:** ☎ 0141 357 2269
- **Maggie’s Lanarkshire, Monklands Hospital:**
☎ 01236 771199
- **Maggie’s Forth Valley:** ☎ 01324 868 069
Maggie’s Centre provides a comprehensive cancer support programme for people and their families affected by cancer.
🌐 www.maggies.org
- **Macmillan Benefits Team** (within the Beatson)
☎ 0141 301 7374
Offers free and confidential benefits advice for people affected by cancer and their carers
- **Beatson West of Scotland Cancer Centre**
To find out more about our Centre please visit
🌐 www.beatson.scot.nhs.uk
- **NHS 24:** 111

You may find some useful information on the websites listed above. However, it is important to note that The Beatson West of Scotland Cancer Centre cannot accept responsibility for the quality and content of any information provided by other organisations.

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