

Three large, overlapping teal arcs on the left side of the page, resembling a stylized radiotherapy beam or a signal.

External Beam Radiotherapy (EBRT) for Adults for the treatment of a Soft Tissue Sarcoma

A horizontal teal bar with a white border, containing the word 'Radiotherapy' in white text.

Radiotherapy

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If you have any questions before starting your treatment, please contact the Information and Support Radiographer at Clatterbridge Cancer Centre - Wirral, Monday to Friday (9am - 5pm) on **0151 556 5314**.

The Clatterbridge Cancer Centre Hotline 0800 169 5555

If you are unwell during or up to 8 weeks following your cancer treatment please call The Clatterbridge Cancer Centre Hotline.

Your call will be answered by a dedicated nurse advisor. This line is available 24 hours a day, 7 days a week.



This information is for adult patients who are going to receive radiotherapy for a soft tissue sarcoma.

Sarcomas are rare cancers that develop in the 'soft tissues' of the body, e.g. the muscle, blood vessels and the fatty and fibrous tissues.

This leaflet describes what to expect when you attend The Clatterbridge Cancer Centre.



A photograph of a treatment unit

When radiotherapy is given

Radiotherapy is usually given to reduce the risk of cancer returning after surgery or to reduce the size of the tumour, if you haven't had surgery. When recommending radiotherapy, your radiotherapy doctor (Clinical Oncologist) will discuss the benefits/risks with you.

Radiotherapy is treatment that uses high energy X-rays. The X-rays are aimed specifically at the site of the cancer and it is well established in treating soft tissue sarcomas.

Radiotherapy is designed to treat as little of normal (healthy) body tissue as possible. Treatment is usually given over a period of weeks, which allows normal cells to recover from the effects of radiation. The duration of treatment can be up to 7 weeks, treating daily Monday-Friday. Treatment takes approximately 15 minutes per day. The exact schedule will be decided by your oncology doctor and is usually confirmed on your first visit to the radiotherapy department. We will give you a list of appointment to take away.

You might find it helpful to read our booklet 'Radiotherapy', which explains how radiotherapy works and gives further information about the hospital and our services.

When attending the department, it is usual for the staff to ask:

- If you have a pace maker
- For women of child bearing age, if there is any possibility of pregnancy



Radiotherapy and fertility

If the area to be treated is close to, or includes, the organs of reproduction, i.e. the pelvis and/or the upper thigh area, your fertility (ability to have children) may be affected. If this is likely to be the case, your oncology doctor will discuss this in detail.

Retaining your fertility after completion of radiotherapy may or may not be important to you. If required, we will refer you to a local specialist centre for further advice and information. It is important to be referred before starting your radiotherapy.

Support

During your treatment, you will meet radiographers, physiotherapist and your oncology doctor. We also have our Cancer Rehabilitation and Support Team (CReST) which includes a number of support services. Other hospitals, as well as CCC staff may contact the CReST team to ask their service to support you.

Macmillan Clinical Nurse Specialist (CNS) for Sarcoma

Our CNS works as part of the Specialist Sarcoma Multi-disciplinary Team for the North West Coast. The role provides specialist advice, symptom control, information and ongoing holistic needs support for patients and their partners/carers undergoing treatment and follow up for Sarcoma. Our CNS aims be present at your weekly radiotherapy review and, after completion of your treatment, again at your follow up clinic appointments.

On completion of your radiotherapy, you will receive an end of treatment summary for your information and a copy will be posted to your GP.

What to expect on your first pre-treatment planning appointment

Your first appointment will be at the pre-treatment (planning) department at Clatterbridge Cancer Centre - Wirral. You should expect to be at the Centre (but may not be) for a few hours.

Before treatment begins, we need to work out the best way of treating you; this is called treatment planning. The procedure varies according to the area to be treated. One of the considerations is to assess what position is comfortable for you when lying on the treatment machine bed, which will also satisfy our needs about the technical aspect of treatment delivery.

People having treatment to a limb or the head and neck will first visit our department called the Mould Room - see later.

Physiotherapy assessment

People having radiotherapy to a limb will be offered an assessment by our physiotherapy service. We will try to arrange this on the same day as your planning appointment. We will telephone you before you attend the Centre to discuss your physiotherapy appointment.

At this appointment, we will assess you and give advice regarding exercise and activity whilst undergoing radiotherapy. We will then, in agreement with you, arrange any follow-up appointments that may be needed. For the initial assessment, you should expect to be with the physiotherapist for approximately 45 minutes. If you



have not had an appointment with our physiotherapist by the time you start your radiotherapy, please contact our physiotherapy team directly on **0151 556 5146**.

What to expect when you attend the Mould Room

When you attend the Mould Room we will make a device (cast) which is individually made to ensure it fits well and is comfortable. Its purpose is to help you to stay still and to place the majority/all of the treatment marks onto it, rather than your skin. The cast is then used for each treatment.

A number of staff may be involved at this stage and, when they are making your cast, they will be talking in technical terms about your treatment. Please try not to be alarmed about anything that is said; we will explain everything to you and you can ask questions at any time. Once the technical details are agreed, it usually only takes a few minutes to make the cast.

We use various materials and more than one type may be used. The most commonly used are a vacuum formed cushion and thermoplastic (a plastic material that becomes mouldable above a specific temperature and firm again upon cooling).

Making a vacuum formed cushion

A vacuum formed cushion is a sealed bag containing small spheres of light material. The bag is gently formed around (but not enclosing) the area of interest and the air is then pumped out of the bag causing it to become firm.

Making a thermoplastic cast

The cast starts as a flat sheet of plastic attached to a frame. It is first placed in a warm water bath where the plastic becomes soft and flexible. Then it is placed over and onto your body; it feels like a warm, wet flannel. Using our fingers and gentle pressure we mould the plastic sheet to your shape, which can feel a little strange, but is painless. The plastic cools and sets in approximately 5 minutes and is ready to use straight away.

After the Mould Room, the planning scan usually follows shortly afterwards. Staff will discuss this with you in detail on the day.



An example of the use of a vacuum-formed cushion and thermoplastic cast used when giving radiotherapy to the ankle/foot area.



Planning CT scan

Next, you will go to Planning department to have a CT scan using the cast made in the mould room. The scan takes a few minutes. The CT scan, together with any previous scans/reports from surgery etc., is used to design your individual treatment map. It is usual to start your radiotherapy 1-2 weeks after the scan.

Those having radiotherapy to an area in the chest, abdomen or pelvis usually do not require an individual cast, so will not have to go to the Mould Room. Instead, we support your limbs with our standard leg and arms rests (shaped pillows) to help you stay still during the CT scan. At the end of the scan, we will ask your permission to tattoo a few small, but permanent, marks. These marks are reference, rather than treatment marks.

A few people will have an injection of a dye called contrast agent into a vein during the scan. If you need this, we will discuss this with you on the day.

Radiotherapy treatment

Radiographers operate the radiotherapy machines to give you the precise radiotherapy treatment, as prescribed by your oncology doctor in the planning process. On your first visit, they will explain to you what is going to happen, take you into the treatment room and set up your treatment using any cast made in the Mould Room and/or the reference marks.

Radiotherapy treatment is completely painless. The appointment time is usually 15 minutes, but the treatment only takes a few

minutes. You will be alone in the room during the treatment, but the radiographers will be watching you carefully on a closed circuit television system.

General information about the side effects of radiotherapy treatment

The usual pattern for the development of temporary (acute) side effects is to gradually start 5-10 days after the first treatment. They usually persist and may worsen; the effects usually being most troublesome about 10 days after the last radiotherapy treatment. After this, the healing process begins. The side effects usually settle over the following 8 weeks. You will be reviewed during treatment and given medicines and advice to help you cope.

During your treatment, a radiographer or nurse will be able to answer any questions and help you deal with most of your problems. Your oncology doctor will also see you regularly throughout your treatment. It is important to let us know about your side effects, how you are coping and if you need any extra support.

Early side effects

Your skin

The majority of people experience a moderate to severe skin reaction which is likely to require the use of a dressing and/or painkillers. If you are working or have a busy lifestyle, you need



to consider how these symptoms may affect you and plan ways to help you manage day-to-day. If you have any concerns, please discuss them with your treatment radiographers.

Any soreness should start to heal between two to four weeks after your treatment has finished. If your skin becomes uncomfortable, ask the radiographer or nurse for advice.

Skin care - ways in which you can help yourself

Washing

- You can wash the area gently using lukewarm water and a mild unperfumed soap, such as baby soap
- A shower is preferable than a bath. Do not use a powerful water jet directly onto the skin. If you only have a bath, have a quick wash in the bath to avoid soaking the skin. If your skin becomes sore and weeps, you may have to temporarily stop bathing those areas
- Use your hands to wash the area, rather than a flannel or sponge. Dry the area gently using a soft towel and use a patting action

Skin care products

- Once you have started your radiotherapy, only use products on the skin in the treated area that we recommend to soothe the skin
- While you are receiving radiotherapy, you should stop using your usual toiletries on the skin of the treated area, e.g. bubble bath etc. After you have finished your radiotherapy, you can start using toiletries again once the skin reaction is no longer causing you discomfort

- If the treated area includes hair that you normally remove, it is best to remove the hair before you start your treatment. After you have finished your radiotherapy, you can start hair removal again once any skin soreness is no longer causing you discomfort

Clothing

If required, wear a loose garment, made of a natural fibre (cotton or silk) next to the skin in the treated area. You should also try to protect the skin from the extremes of the weather, as exposure to cold wind or bright sunlight will increase the risk of developing a skin reaction.

Exercise

If you like to swim, please avoid doing so during your course of radiotherapy and afterwards until any skin reaction has settled.

Take care when exercising to avoid trauma to the skin within the treated area.

Use of Dressings

The use of tape onto treated skin to secure a dressing should be avoided, as removal of the tape causes additional injury to the skin.

Sun Awareness

During treatment, the skin reaction can be heightened by exposure to sunshine. If the skin of the treated area is normally not covered by clothing, for example, the face, neckline and arms, you may need to wear different clothing, such as long sleeved t-shirts or a



hat, if you are outside during sunny weather. While outside, help protect your skin by using areas of shade whenever possible. Avoid the use of sun cream.

Once you have completed your radiotherapy, in the longer term, the skin in the treated area will be more sensitive to the sun. You need to be more careful in protecting your skin from excessive exposure to sunlight. Use a high factor sun cream. Sun protection clothing is also available.

Skin folds

Often, a skin reaction may be worse in areas where skin surfaces naturally rub together, such as the groin and between the buttocks. Skin folds within the treated area should be gently washed, dried, and gently moisturised with creams issued by staff in the radiotherapy department. If the skin becomes sore, apply other creams as directed.

Tiredness

It is quite common to feel more tired than usual during your treatment and for several weeks after treatment has finished. It is important to rest when you feel the need to do so and ask your family and friends to help when they can. Gradually, you will get back to doing your normal activities. If you live alone, only do the things that are necessary.

Hair Loss

You will only lose hair in the area being treated. Hair loss will occur approximately 2-3 weeks into treatment and may be temporary or permanent.

If you are being treated for a sarcoma of the limb, you may experience:

- Temporary swelling and tenderness in your limb as treatment progresses. This is normal and is due to inflammation of the tissues caused by radiotherapy. This will settle after treatment has finished, but in a few patients it may persist
- Stiffness in your limb. This is usually due to the effects of the radiotherapy causing slight swelling on the underlying muscle tissue

Feeling Sick (nausea)

Depending on the area of the body being treated, you may feel sick. Should this occur, let us know.

Effects if area treated includes the pelvis or abdomen

You may experience an increase in the number of bowel movements, loose motions and your tummy may feel bloated and tender. It is still important to continue to eat a normal, well-balanced diet.

You may experience irritation to the bladder, which can lead to other symptoms, such as the need to pass urine more often, and you may feel a burning sensation when you pass urine. You may also notice a slowing of the stream of urine and feel an urgent need to pass urine.

If you have any of these symptoms, please let us know so we can prescribe medication and give advice as necessary.



Effects when the chest/chest wall area is treated

Any organ included in the treatment area will become inflamed causing discomfort. Consequently, you may develop a dry cough and or discomfort when you swallow.

Delayed healing

There is a small risk of delayed wound healing, if radiotherapy is given prior to surgery.

Long term (late) side effects

There are some possible longer term side effects which your oncology doctor will discuss with you. These can occur months, or even years, after treatment. These late effects depend on what part of the body was treated by radiotherapy. Some late effects can be treated with medication. Rarely, a surgical operation may be needed.

Skin colour changes

Rarely, the skin in the treated area can become discoloured (usually slightly darker than your normal skin colour) or mottled. There may be patches of small blood vessels near the surface of the skin.

Swelling of the limb (lymphoedema)

If you have a sarcoma arising in the pelvis or limb, there is a possibility that the limb(s) below the level of the surgery may be inclined to swell in the future. This is due to the build-up of lymphatic fluid (a clear fluid that helps fight infection and disease),

which flows through the lymphatic vessels. The lymphatic vessels are part of the lymphatic system, which helps to fight infection and maintains a balance of fluids in the body.

Radiotherapy significantly increases the risk of swelling and causes scar tissue to form, which interrupts the normal flow of lymphatic fluid. The chance of this happening depends on several factors; not only the size and position of the tumour and the extent of the surgery, but on how much of your limb is treated with radiotherapy.

If it is considered a significant risk for you, your oncology doctor will discuss this with you in detail.

If you have had the pelvis or lower limb treated, prolonged standing and being overweight can increase the risk of developing lymphoedema. Regular gentle intermittent exercise is helpful, e.g. swimming or walking. Your doctor may also suggest that you are seen by a Lymphoedema team for advice and treatment. If you do develop swelling after treatment is completed, it is advisable to contact your GP, who can refer you to a specialist Lymphoedema practitioner.

Fibrosis (thickening of the tissues)

Some patients may experience long-term fibrosis or thickening of the muscle, joints and tissues that have been treated. The skin in the area being treated may feel 'leathery' due to loss of elasticity and suppleness. Regular stretching exercises, good skin care, the use of water-based moisturisers and sun avoidance can minimise these effects.



Female patients receiving radiotherapy to the pelvis-fibrosis can affect the organs of reproduction. Should this be the case, your oncology doctor will discuss this with you in detail.

Breast development

When given to the young, radiotherapy is known to affect breast development. If you are receiving radiotherapy to the front of the chest and it is likely that this may affect you, we will discuss this with you in detail.

Fracture

There is a small risk that any bone in the treated area will be at an increased risk of fracture.

Risk of developing a second malignancy

Treatment with radiotherapy carries a small increased risk of developing a new cancer, usually within the treatment area and occurring many years later. This risk is balanced against your current health needs and will be discussed with you.

Recovery

Towards the end of the course of radiotherapy, we will assess the condition of your skin and, if required, request a District Nurse to visit you during the first few weeks after completion of treatment.

Continue to follow any advice given by our physiotherapist.

For some people the diagnosis of cancer, together with the experience of treatment, can affect how you feel and sometimes how you behave.

Some symptoms may affect your life in ways you don't expect, such as sexual intimacy. Often, these feelings become more apparent once you have completed all your treatments. You should discuss any concerns with your GP or your oncology doctor at your follow-up appointments. Referrals to specialist staff, e.g. a psychologist or occupational therapist can be beneficial.

It can sometimes take many months before you feel you have recovered from the treatment side effects. If you are feeling low or experience mood swings, it may be useful to speak to your GP or oncology doctor. Some patients find it useful to have the support of others who have experience of cancer by attending local support groups. You can get further information from the Macmillan Information & Support Centre and the Maggie's Centre.

Alternatively, if you are familiar with using the internet, the major cancer charity websites have online forums and support.

Follow-up appointments

It is important to attend these appointments. The first follow-up appointment with the oncologist will be about 4-6 weeks after completion of treatment at the specialist sarcoma clinic in Liverpool. Following this, you will be seen on a regular basis and will again have a clinical examination, X-rays and scans. If you have any concerns in-between appointments, it is possible to rearrange the appointments to an earlier date. See your GP or contact your Sarcoma Specialist Nurse.



Who to contact when you need advice

The Clatterbridge Cancer Centre Physiotherapy Team

0151 556 5146

Clinical Nurse Specialist for Sarcoma

0151 556 5554 or 07824 598 339

Sarcoma UK

Sarcoma UK is an organisation specialising in sarcomas. For further information telephone **0207250 8271** or their website

www.sarcoma.org.uk

Macmillan Cancer Support

Macmillan booklets about coping and living with cancer and treatment side effects are available free of charge. These can be ordered by telephoning **0808 808 0000** or by visiting a Macmillan Information Centre (sited in the main entrances of Clatterbridge Cancer Centre - Wirral and Clatterbridge Cancer Centre - Aintree).

Macmillan Cancer Support

0808 808 0000 Monday to Friday, 9am to 8pm or

www.macmillan.org.uk

Macmillan Cancer Information and Support at

Clatterbridge Cancer Centre - Wirral 0151 556 5570

Clatterbridge Cancer Centre - Aintree 0151 556 5959

How we produce our information

All of our leaflets are produced by staff at The Clatterbridge Cancer Centre and this information is not sponsored or influenced in any way. Every effort is made to ensure that the information included in this leaflet is accurate and complete and we hope that it will add to any professional advice you have had. All our leaflets are evidence based where appropriate and they are regularly reviewed and updated. If you are concerned about your health in any way, you should consult your healthcare team.

We rely on a number of sources to gather evidence for our information. All of our information is in line with accepted national or international guidelines where possible. Where no guidelines exist, we rely on other reliable sources such as systematic reviews, published clinical trials data or a consensus review of experts. We also use medical textbooks, journals and government publications.

References for this leaflet can be obtained by telephoning 0151 556 5570.

If you need this leaflet in large print, Braille, audio or different language, please call 0151 556 5570.

If you have a comment, concern, compliment or complaint, please call 0151 556 5203.

The Clatterbridge Cancer Centre NHS Foundation Trust
Clatterbridge Road, Bebington,
Wirral, CH63 4JY.

Tel: 0151 556 5000

Web: www.clatterbridgecc.nhs.uk

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