NHS

The Clatterbridge
Cancer Centre
NHS Foundation Trust

Radiotherapy to the Vulva

Radiotherapy

A guide for patients and carers

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This information is for patients who are going to receive radiotherapy for cancer of the vulva.

You might also find it helpful to read our booklet called "Radiotherapy" which describes what to expect when you come to the hospital.

The Clatterbridge Cancer Centre Hotline 0800 169 5555
If you are unwell during or up to 6 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.

A photograph of a treatment unit

When radiotherapy is used

Radiotherapy is often used in combination with surgery, but in some cases it is the preferred treatment. External beam radiotherapy (radiation given outside of the body) is given as a 5-7 weeks course of treatment. The treated area may include the lower pelvis and/or vulva and/or groins, so some of the information given within this leaflet may not apply to you. Your oncology doctor will also explain why radiotherapy is recommended for you and what to expect during and after treatment.

Your treatment may include chemotherapy. If this applies to you, it will be discussed in detail, including the need to have blood tests. Chemotherapy in addition to radiotherapy is likely to cause increased side effects, so your recovery may be slower. If this applies to you, we will ask you to attend a chemotherapy pre-assessment clinic and more information will be given then.

Preparation for the planning CT scan and treatment

When you arrive for your planning appointment, we will ask you to drink some water. The fluid in the bladder helps to move the bowel out of the pelvis, thus helping to reduce bowel-related side effects. The radiographers will talk to you about this in detail when you attend. You will be asked to drink water before every treatment appointment too. Don't worry if the fullness of your bladder feels different from day to day, but avoid being treated with a very full or empty bladder. The radiographers will talk to you about this in detail when you attend. Eat and drink as usual before you come for the appointment.

Clinical Nurse Specialist (CNS) in Gynaecological Cancer

This service is available to patients with a diagnosis of gynaecological cancer and their carers to ensure they receive the written and verbal information on the management of their cancer and any symptoms, advice on treatment options and psychological support. Appointments into this service may be automatically booked as part of your care. If you do not receive an appointment to see our Clinical Nurse Specialist, please discuss this with your treatment radiographers.

General information about side effects of treatment

Every patient is different and you may not have the same side effects as somebody else. Most side effects are temporary. They usually start around the second week of treatment and will continue for 2 -3 weeks after your radiotherapy has finished. They then start to settle, taking a few weeks to do so. Sometimes, it takes a few months for the effects to settle completely.

During your treatment, a Therapeutic Radiographer or nurse will be able to answer any questions and deal with most of your problems. However, your doctor will also see you regularly throughout your treatment. It is important to tell us how you are feeling so that we can give you medicines and advice on how to cope.

Side effects during and immediately after finishing treatment

Your skin

The skin in the treated areas is sensitive and likely to become sore during your course of radiotherapy. **Please speak to the Therapeutic Radiographers if your skin becomes uncomfortable or you experience any skin changes.**

Your bladder

Radiotherapy can irritate your bladder so you may feel the need to pass urine more often (frequency), get an urgent call to do so (urgency) and you may feel a burning sensation. Tell your doctor, radiographer or nurse if this sensation lasts for a few days. We may test your urine to rule out a urinary infection.

You can help yourself by drinking more fluid, at least 2 litres (4 pints) of fluid each day until the symptoms settle. Water is best; avoid fizzy drinks. If you can, take no more than 1-2 drinks containing caffeine per day. These include tea, coffee and cola-type drinks. Take alcoholic drinks in moderation if you wish, but stop if you notice any irritation. Cut down on the amount you drink in the evening if you need to use the toilet during the night.

Your bowels

The treatment can irritate your bowels, causing cramp-like discomfort. You may have to open your bowels more often, sometimes only passing small amounts. You may also get the urge to open your bowels, but pass only wind and mucus. A few people find their bowels become stubborn. We may ask you to change your diet if these effects are troublesome. Tell us if you have any known bowel-related conditions and if your bowel habits are changing.

Feeling sickly (nausea)

This can happen and we will give you medication; it is important to treat so that it does not affect your eating and drinking.

Tiredness and fatigue (low energy levels)

It is quite common to feel tired during treatment. Let us know if this affects you; we may do a blood test.

It may persist for several weeks afterwards. It is important to rest when you feel the need to do so. Ask for, or accept, offers of help. If you live alone, do only the things that are necessary until you feel stronger. Gradually, you will recover.

Hair loss

The loss of pubic hair is a possibility, but it should start to return soon after you have finished treatment.

Appetite and eating well

You may find your appetite is reduced during treatment. Eating as well as you can, can help you to cope with and recover from treatment. Our Dieticians have written a leaflet ‘Eating Well Coping with Side Effects’ which is available to you. If you need further advice from a Dietician, this can be arranged.

Fertility and sexual activity

Radiotherapy to the pelvis affects the ovaries and uterus. This means you will be unable to have children (being infertile). If you are still having periods, they may stop within a few months of finishing treatment.

If you are sexually active, further advice can be given upon request.

Possible long-term or permanent side effects

The majority usually develop within the 1st or 2nd year, but can start many years later.

Changes to skin

The following changes can occur:

- The colour may change becoming permanently lighter and/or darker
- Its appearance and texture can change; atrophy (thinning) and telangiectasia (tiny red streaks in the skin caused by changes in the tiny blood vessels) can occur

These effects can result in the skin being drier, irritable and more sensitive to damage.

About Lymphoedema

If you had surgery and/or radiotherapy to the lymph glands in the pelvis, there is a life-long risk of developing lymphoedema in the lower body.

Lymphoedema is the abnormal collection of lymph fluid in the tissues. This may develop following treatment, because the vessels and glands of the lymphatic system work less efficiently, creating a swelling of the tissues, swelling of the legs being most common.

It is a long-lasting condition, which can be controlled but is unlikely to completely go away.

During radiotherapy treatment, and for the first couple of months afterwards, some people experience tightness/heaviness or aching and/or swelling of the legs. This may be a reaction to your radiotherapy treatment and often will settle without active treatment.

The early signs of true lymphoedema are tightness, heaviness or aching of the legs, as mentioned before, but may include swelling to your ankles or feet. You may notice that your shoes become tight. Your groins or genital area (between the top of your legs) may become swollen.

Simple steps to lower the chance of developing Lymphoedema

The skin is a barrier to infection and any small injury to it can allow bacteria into the tissues. Infection can lead to the development of lymphoedema, so it is important to take extra care of the skin by:

- Promptly treating any fungal infections (athletes foot) in your groin or feet
- Avoiding damage to the skin, e.g. from cuts/grazes, wet shaving, insect bites/stings
- Protecting your legs by wearing long trousers, if gardening
- Using sun block to the legs in the summer months to protect the skin and avoid sunburn
- Moisturising your skin of the lower body daily with a simple moisturiser to keep it in good condition

If a skin injury occurs, always clean it and apply antiseptic cream. If you notice signs of an infection (area around an injury becoming raised, red/pink, tender or hot), see your GP as soon as possible.

Further advice

Avoid standing for long periods of time and elevate your legs when at rest. You may find that regular gentle exercise, e.g. swimming or walking is helpful as it helps the muscles of your lower body to move body fluids around.

If you are concerned that you may have developed lymphoedema, contact the Gynaecological Cancer Clinical Nurse Specialist during your radiotherapy treatment. During your follow-up, if you have concerns, you will be referred to a Specialist Practitioner in Lymphoedema.

Changes to the bladder

There is a small risk of long term changes to the bladder. Your bladder function may be different after treatment and possibly not return to normal. You may need to empty your bladder more frequently, especially at night and/or be unable to hold as much urine for as long, due to the loss of elasticity (ability to stretch) of the bladder wall.

Changes to your diet, bladder training and the use of medicines can often help, but occasionally, these problems can be more troublesome. Referral to specialist staff can be helpful and will be discussed at your follow-up appointments.

Changes to bowel

It may take six months or more for the bowel to settle into a regular pattern. There is a moderate risk of long term changes to bowel habits. This includes having an urgent call for a bowel movement (urgency), or more frequent bowel movements, which could be loose and contain blood. In some, looseness of the bowel is related to the type of foods eaten. The ability of the bowel to digest foods can also be affected. Report any changes to your bowels at the follow-up appointments or see your GP, as further investigation and intervention are often beneficial.

Rarely, there can be serious damage to the bowel that may require surgery and the possibility of a colostomy. Approximately less than 1 in 20 people go on to need a colostomy after radiotherapy.

Early menopause

Radiotherapy to the pelvis will bring on the menopause in those who are still having periods. The symptoms of the menopause (periods stopping, hot flushes, dry skin, vaginal dryness and difficulty in concentrating) often start during, or soon after, your radiotherapy. Your oncology doctor may advise the use of hormone replacement therapy (HRT) if your symptoms are troublesome.

Sexual health

The tissues of the vagina will be affected, causing it to become narrow, shorter and stretch less than before treatment. To lessen these effects, we ask all patients to regularly use a vaginal dilator (smooth plastic tube). Even if you are sexually active, their use is recommended so that internal examinations cause as little discomfort as possible. You will be offered more information, advice and a set of dilators during your course of radiotherapy.

Vaginal dryness can occur, but the use of a water-based lubrication during intercourse can be helpful.

These changes can lead to discomfort during intercourse. The diagnosis and treatment can affect you in many ways, including sexual intimacy. If this affects you and/or your relationships, please talk to your GP or Gynaecological CNS who can refer you to a specialist service, e.g. counselling (as a couple or alone).

The Cancer Information and Support Centre has a number of useful information booklets, e.g. "Sexuality and Cancer, How treatment affects your sex life". See useful contact details.

Noticing blood

Radiotherapy can affect the tissues causing **slight** shows of blood in the urine, bowel motions or after sex. If you notice passing more than this, see your GP as it needs to be investigated further.

Changes to bone

Stiffness of the hips can occur following treatment. This may be investigated by a scan, if necessary.

Recovery and follow-up

Side effects can continue for a few weeks after finishing radiotherapy. Meanwhile, continue to use any medicines we have given you. Your skin may take several weeks to settle and support from a District Nurse is recommended. We will discuss this with you. Contact them or your GP if you are in difficulty, especially with pain. You can also contact staff at the radiotherapy centre for advice.

It is important to attend follow-up appointments with your oncology doctor. The first appointment is usually about 6 weeks after finishing treatment.

It may take many months before you feel that you have recovered fully. If you are feeling low or experience mood swings, talk to your GP, oncology doctor or key worker.

Some find it useful to have the support of others who have experience of cancer by attending a local support group. Contact the Cancer Information & Support Centre for more details.

Macmillan provides booklets about coping and living with cancer and treatment side effects. These can be ordered by telephoning 0808 808 00 00.

Maggie's is a charity providing free cancer support and information to anybody who been affected by cancer. Our Cancer Nurse Specialists, Psychologists and benefits advisors are here to support you during treatment or after your treatment has finished.

The Maggie's Centres allow you to share experiences with others in a similar situation around our kitchen table. We provide courses on survivorship, bereavement, stress management, mindfulness, tai chi, yoga, relaxation or cancer support groups. You do not need an appointment or a referral to access any support from Maggie's, you can just drop in. Our telephone number is 0151 334 4301.

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

The Clatterbridge Cancer Centre leaflets titles:

- Radiotherapy booklet
- Use of vaginal dilators when receiving radiotherapy to the pelvis
- Lymphoedema Advice

Many people with Lymphoedema find support groups helpful. Details for local and national groups and more are available from The Lymphoedema Support Network.

Telephone: 020 7351 0990 (Administration) or
www.lymphoedema.org or

Useful contact details

Clatterbridge Cancer Centre - Liverpool

65 Pembroke Place, Liverpool, L7 8YA
Tel: 0151 556 5000
www.clatterbridgecc.nhs.uk

Clatterbridge Cancer Centre - Wirral
Clatterbridge Road, Bebington, Wirral, CH63 4JY
Tel: 0151 556 5000
www.clatterbridgecc.nhs.uk

Clatterbridge Cancer Centre - Aintree
Lower Lane, Fazakerley, Liverpool, L9 7AL
Tel: 0151 556 5959
www.clatterbridgecc.nhs.uk

Gynaecological Cancer Nurse Specialist 0151 556 5134

Macmillan Cancer Support

89 Albert Embankment, London, SE1 7UQ
www.macmillan.org.uk
Telephone 0808 808 0000

Cancer Information and Support Centre:

Clatterbridge Cancer Centre – Liverpool
Tel: 0151 318 8805

Maggie’s Centre - Wirral
Tel: 0151 334 4301

Society of Radiographers
www.sor.org

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.

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