Treatment for Cancer of the Vulva

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**Introduction**

This leaflet is designed to explain your treatment for cancer of the vulva. It describes the treatment and any side-effects you may experience during and after treatment. As each person is different, the effects of treatment can vary from one person to another.

It is important that you understand everything about your treatment and its side-effects before you start. We will explain each aspect of your treatment. We will not carry out any procedures without asking for your consent except in an emergency situation when all necessary steps will be taken to ensure your safety. We hope this leaflet will answer most questions or concerns you may have. Please use it as a general guide, and your oncologist will discuss your individual treatment with you in more detail.

**Treatment**

You have been diagnosed with a cancer of the vulva.

The treatments we offer for cancer of the vulva are **radiotherapy** and **chemotherapy**. You may have radiotherapy on its own or with chemotherapy. Your doctor will discuss your treatment with you and explain the choice of treatment for you in more detail.

Please remember that your treatment is tailored to your individual needs and so might not be the same as the treatment the person next to you in the waiting room is having.

**Radiotherapy**

Radiotherapy is the treatment of cancer with radiation using x-rays. The radiation works by destroying cancer cells. It also affects normal cells in the treated area but unlike the cancer cells these will recover.

**External Beam Radiotherapy (EBRT)** is treatment using high energy x-rays that are given from outside the body. A machine called a **linear accelerator** directs the x-rays at the exact area of the body being treated (in this case the pelvis). This treatment is given as an outpatient unless your doctor feels that you need to come into hospital.

**External beam radiotherapy**

**Preparing for treatment**

Before you start your radiotherapy treatment we need to plan it carefully. **We will send you a list of appointments for the planning and daily treatments.**

- Your radiotherapy treatment will be planned at the **CT scanner** and/or **simulator**. These are special types of x-ray machines that we use to take pictures or scans of your pelvis.
• You will need to have a comfortably full bladder at the time of scanning and when you come for each of your radiotherapy treatments. This usually involves drinking about ½ litre of fluid 30 minutes before your scan or treatment. **If you need to empty your bladder before the scan, please tell one of the radiographers. They will ask you to drink some water and wait for 15 to 20 minutes**
• The radiographers will ask you or help you to lie on the couch for the scan or x-ray. You will need to slip your clothes and pants down below the waist for this but your radiographers will cover you as much as possible
• When you are lying as comfortably as possible, your radiographers will take scans or x-rays of your pelvis. This will take about **20 minutes** and you won’t feel anything
• We will then ask your permission to put three tiny permanent marks (tattoos) on your tummy, one on the front and one on each side. These permanent marks are about the size of a small freckle. The treatment radiographers will use these marks to make
We will use your scans/x-rays to produce an individual treatment plan for you and you will start your radiotherapy treatment about a week later.

**Treatment**
The treatment is given by directing high energy x-rays at the area of the cancer. The x-rays are produced by a large machine called a **linear accelerator**, which you will lie beneath.

Radiotherapy is not painful but you must lie still for a few minutes while your treatment is being delivered. The radiographers will position you each day on the treatment couch using
the permanent marks you received at the CT simulator. Once you are in the correct position the radiographers will leave the room for a few minutes while the treatment is being delivered. They are watching you all the time outside at the control panel. The linear accelerator machine will make a buzzing noise while the treatment is being given.

Treatments are given Monday to Friday with a break at the weekends. The total number of treatments will depend on the type and size of the cancer, and your doctor will discuss this with you individually. Before you start treatment we will give you a list of all your treatment appointments. Every Monday you will be seen briefly in clinic by your oncologist or one of the team members to check how you are getting on and discuss any side-effects you may have. The treatment does not make you radioactive and it is perfectly safe afterwards for you to be with other people, including children.

**Side effects during and after treatment**

Below are some of the side-effects you may experience during your radiotherapy. It is important to remember that these can vary from one person to another and they may not happen to everyone. The side-effects may last for a few weeks after your treatment is finished.

If you have any questions about side-effects please speak to your radiographers.

**Bowels**

The treatment can sometimes irritate your bowels. This usually causes diarrhoea but some women may become constipated. You may also feel the need to open your bowels more often but find that nothing happens. If you are having diarrhoea you might also have painful wind or cramps and your tummy may feel bloated. You might pass some clear mucus.

These symptoms do not usually develop until about the second or third week of treatment and may last for a few weeks after.

**Dietary advice**

There is no evidence at present that changing your diet during pelvic radiotherapy will help prevent or improve these symptoms.

We recommend that you continue eating your usual diet where possible. However if you are having problems it may be worth experimenting to see if any foods make your symptoms better or worse.

**Helpful hints to try if you have diarrhoea:**

- Fluids – drink plenty of fluids (8-10 cups / 2 litres per day) to replace the water lost with diarrhoea
- Avoid alcohol, strong caffeine drinks (e.g. coffee) and pure fruit juices. Fruit teas, diluting squash, weak tea/coffee or decaffeinated varieties of drinks are good alternatives
- Eat small, frequent meals
- Avoid nuts, pulses (e.g. beans, peas, lentils), seeds and skins of fruit and vegetables
- Cut down on raw and green leafy vegetables (e.g. cabbage, sprouts, broccoli)
- Cut down on highly spiced foods.
Bladder
Radiotherapy can irritate the bladder and cause symptoms like cystitis. You may find you need to pass urine more often and you may feel a burning sensation. We recommend that you drink plenty of fluids (at least one litre a day). Try to avoid drinking too much tea or coffee. Some women find that drinking cranberry juice helps. If you have to get up during the night to go to the toilet you might want to reduce the amount you drink in the evening.

Please tell the treatment radiographers if you have any of these symptoms, as we will ask you to bring in a urine sample so that we can test it to rule out an infection.

Tiredness
You may start to feel quite tired or fatigued towards the end of your treatment and this tiredness may last for several weeks after treatment is finished. If you do feel tired ask friends or family to help with housework or shopping and take rest when you need to. Although it is also important to get some light exercise like a short walk. Your energy will gradually return and you will be able to continue with your normal activities.

Skin care
Your radiotherapy treatment will cause your skin to become very sore and red. The skin may even break down. It can become especially sore in the area between your legs, around the groin and back passage. This can sometimes make going to the toilet uncomfortable. We will monitor your skin closely for any reaction to the treatment and provide you with creams or lotions to help with the discomfort. Often it becomes very painful we need to give pain killers to help.

Some people may need to come into hospital if their skin reaction is too painful.

Here is some skin care advice:

- It is important that you keep the area clean.
- Use only a mild soap e.g. simple soap or baby soap.
- Use tepid water and avoid rubbing the area when washing.
- Pat gently dry with a soft towel.
- Avoid bubble baths, shower gels, creams or lotions unless you have checked with a member of your treatment team.
- Wear loose clothing and cotton underwear. Try to avoid wearing nylon tights any length of time. Do not wear tights under trousers.
- Do not put anything on this area without checking with a member of your treatment team first.

If you need more advice please speak to your radiographers or a nurse.

Late effects of radiotherapy - fertility and menopause
One of the most unfortunate consequences of your treatment is that it will cause early menopause in those women who are still having their period. This unfortunately means that following your treatment, you will no longer be able to have children. This is something your doctor will discuss this in detail with you.

You may start to experience menopausal symptoms and your periods may stop during your treatment but normally this happens after treatment has finished. Your doctor will talk to you about the best way for you as an individual to manage these symptoms.

Other late effects of radiotherapy
There are some other late side-effects of radiotherapy that can occur in a very small number of patients. These effects can develop months or even years after your treatment has finished and it is important that you understand them before you consent to having the treatment. Your doctor will discuss them with you in detail and answer any questions you might have.
Bowel, bladder and vagina
There is a risk of some damage to the bowel or bladder. About a third of women may develop mild symptoms that may cause a change in their bowel and bladder habits. These effects can usually be managed with some medication or a change in your diet. In a small number of people the damage may be more severe and may mean an operation to correct it.

Scar tissue may form in the vagina causing it to become narrower and shorter. It may feel much tighter and drier. We will give you vaginal dilators, which you can start using at the end of your treatment to help prevent this. We will give more information about these nearer the time. You may also need to use a lubricant like KY jelly during sexual intercourse.

Bones
Radiotherapy can weaken the bones within the area treated. This can sometimes cause small fractures in these bones. These usually do not need any treatment and the fractures often will heal by themselves.

Lymphoedema
Lymphoedema is the build up of fluid in the arms or legs that causes swelling. Radiotherapy to the pelvis can cause lymphoedema of the legs. This can become a long-term problem for a few of our patients and they may need to attend a specialist lymphodoema clinic for help with it.

It is important to try and remember that the benefits of the treatment outweigh the effects and if you have any concerns about anything we will be happy to discuss them with you.

Chemotherapy
As part of your treatment, you may have chemotherapy once a week. Chemotherapy is the use of anti-cancer drugs to destroy cancer cells. It is often used at the same time as radiotherapy because it can help to make the treatment more effective. It is thought that chemotherapy and radiotherapy work together to make the tumour more sensitive to the effects of radiotherapy.

The chemotherapy that you will have is a drug called Cisplatin. This is given as a drip (infusion) through a fine tube inserted into a vein in the back of your hand or forearm. You will have this once a week and takes approximately three hours to give.

On the day that you have your chemotherapy you will go to the ward first thing in the morning. You will have your radiotherapy as normal on this day but it will be after your chemotherapy is finished.

Your radiographers and nurses will make sure you have all the information you need.

Possible side-effects
Each person’s reaction to chemotherapy is different. Some people have very few side-effects while others may experience more. Below are a few of the most common side-effects experienced whilst receiving Cisplatin chemotherapy.

Sickness (nausea) and vomiting: A few people who receive Cisplatin chemotherapy tell us they have felt nauseous (sick) usually the day after receiving chemotherapy. As part of the
chemotherapy you will receive some anti-sickness tablets. The chemotherapy nurses will give you these tablets before the chemotherapy. They will also give you some to take home. Using these tablets as directed should help prevent any nausea during chemotherapy.

**Lowered resistance to infection:** Cisplatin can reduce the production of white blood cells by the bone marrow making you more prone to develop infection. You must contact your doctor immediately if your temperature goes above 38 °C or if you suddenly feel unwell. The production of red cells by the bone marrow may also be affected which would mean that you would become anaemic. We may need to arrange a blood transfusion for you if you are anaemic. A weekly blood test ensures that we are able to check on the white and red blood cell count.

**Alteration in kidney function:** Cisplatin chemotherapy has been seen to have an effect on the function of the kidneys. Usually this does not cause any symptoms and the effect on the kidneys is mild. A weekly blood test will check the kidney function.

**Effects on sensory nerves:** The chemotherapy can affect the sensory nerves. This can make your hands or feet tingle or feel numb. It is important that you let us know if you have any of these symptoms because we may want to change your dose. The drug can also affect the nerve involved in hearing and may result in a reduction in hearing.

**Hair loss:** this treatment usually does not cause hair loss.

**Allergic reaction:** Very rarely, Cisplatin can cause an allergic reaction. Signs of a reaction include skin rash and itching, redness of the face and dizziness. *You must let your doctor or specialist nurse know if you experience any of these symptoms.*

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**Caring for yourself during treatment**

During your treatment you will see the doctor, nurse or radiographer at the clinic. This is a routine clinic where we can:

- Check on how you are coping with the treatment
- Give advice and/or treatment for any side-effects you may be having
- Answer any questions you might have.

The clinic is on a Monday afternoon. If you have a morning appointment for your treatment we will ask you to change it to the afternoon on the Mondays.

Your treatment radiographers will assess you every day and if you have any concerns please speak to one of them.

Try to carry on with your normal daily activities as much as possible. If you become tired you may find you need to rest a bit more and find a balance between rest and normal daily life. Accept help from friends and family with housework or other chores. They will want to support you and this will help them to feel useful.

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**Sexual intercourse during treatment**

Sexual intercourse is a very personal and private subject and many people find it difficult to talk about. You can talk to our staff about any kind of concern you have, or ask to speak to your doctor about it.
We recommend that you do not have intercourse while you are having your radiotherapy treatment. This is because your vagina may become irritated and sore and you might get some bleeding.

Having intercourse during treatment is not harmful. If you do continue to have intercourse during radiotherapy you must take care not to get pregnant. This is because the treatment can harm a foetus. As a precaution, use a condom with a lubricant.

If you are under the age of 55 the radiographers will ask you if there is a chance you could be pregnant. They will ask you:

- Before your CT scan
- Before your 1st treatment
- Once a week during your treatment.

It is important that you tell your radiographers if there is any chance that you could be pregnant.

**Immediate aftercare**

Any side-effects you have had will gradually settle within a few weeks of you finishing treatment (about three to six). Continue to follow any advice or instructions you have been given until the effects have passed.

We will give you information about vaginal dilators and resuming sexual activity and talk to you about any fears or concerns you have before you finish.

Some women may need to start Hormone Replacement Therapy (HRT). Your doctor will talk to you about this in detail.

You will be sent an appointment to see your doctor (clinical oncologist) about six weeks after the treatment ends. During this appointment you will have a chance to discuss your treatment and any side-effects you have experienced. The doctor will ask you questions and usually will need to examine you. You will be followed up for a total of five years:

First year:  every three months  
Second year: every four months  
Third – fifth years: every six months

Please note that after your treatment with radiotherapy you do not need to have any more smear tests - as the treatment makes it very difficult to interpret the smears.

You might find it quite difficult once all your treatment is finished. You no longer have the daily contact with the hospital staff who were available to answer your questions and give you support. If you do feel a bit lost do not worry this is quite normal. Below are some telephone numbers that you might find helpful.

**Team members**

**Doctors:** You will be under the care of a **consultant oncologist**, who is a senior medical doctor specialising in the treatment of cancer patients. There are also specialist registrars
attached to the team - senior trainees who are developing their expertise in cancer treatments.

**Radiographers:** Radiographers are health care professionals who are specially trained in the planning and delivery of radiotherapy treatment. They work closely with all members of the team and along with your doctor they plan your treatment. It is the radiographers who operate the machines that give your radiotherapy treatment. They will also explain all about your treatment and give you information about its effects and how best to cope.

**Nurses:** Nurses can give information and support to you and your family throughout your treatment. They will see you at any time during your treatment to give advice and help with any side-effects you may have. When you go for your chemotherapy the nurses will check you are well before giving you your chemotherapy treatment.

**Physicists:** Physicists and clinical technologists are responsible for the correct functioning of the radiotherapy treatment machines. They are also responsible for producing the best treatment plan for each patient according to the doctor’s request. They also calculate, check and prepare all the treatment plans for your treatment.

**Students:** We are part of a university hospital and are actively involved in teaching students. This is an important aspect to help train future doctors and other healthcare professionals. There may be occasions when students are present in clinics or on the ward, but if you feel that you would rather be seen without students present, let us know and we will respect you wish.

**Further support and information**

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<tr>
<th>Service</th>
<th>Contact Information</th>
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<tbody>
<tr>
<td>LA 4 Treatment room:</td>
<td>0131 537 2627</td>
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<tr>
<td>LA 5 Treatment room:</td>
<td>0131 537 2270</td>
</tr>
<tr>
<td>Clinical Nurse Specialist:</td>
<td>0131 537 2975</td>
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<tr>
<td>Consultant Radiographer:</td>
<td>0131 537 3725</td>
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<tr>
<td>Maggie’s Centre Edinburgh:</td>
<td>0131 537 3131 <a href="mailto:edinburgh@maggiescentres.org">edinburgh@maggiescentres.org</a></td>
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<td>Maggie’s Centre Fife:</td>
<td>01592 647997 <a href="mailto:fife@maggiescentres.org">fife@maggiescentres.org</a></td>
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<td>Cancerbackup:</td>
<td>0808 800 1234 <a href="http://www.cancerbackup.org.uk">www.cancerbackup.org.uk</a></td>
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<td>Macmillan Cancer Support:</td>
<td>0808 808 2020 <a href="http://www.macmillan.org.uk">www.macmillan.org.uk</a></td>
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<td>Benefits enquiry line:</td>
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<td>Disability Benefits enquiry line</td>
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Leaflet created by: Edinburgh Cancer Centre

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Please use this page to write down any questions you may have or take any notes on.