



Radiotherapy for vulval cancer

A guide for patients and their carers

We care, we discover, we teach



Contents

| | |
|--|-----------|
| Section 1: Introduction | 2 |
| ■ What treatments are available?..... | 3 |
| ■ When is radiotherapy offered and what are the benefits? | 3 |
| ■ The areas being treated..... | 6 |
| ■ Agreeing to treatment..... | 6 |
| ■ Stopping smoking | 8 |
| Section 2: Planning and treatment | 9 |
| ■ What is radiotherapy? | 9 |
| ■ How does radiotherapy work?..... | 9 |
| ■ When will radiotherapy begin? | 9 |
| ■ Planning the treatment..... | 10 |
| ■ What happens during treatment? | 12 |
| ■ Some questions about radiotherapy..... | 14 |
| ■ Prescriptions..... | 16 |
| ■ Questions you may want to ask your doctor | 16 |
| ■ Gynae Advice Nurse-Led Clinic | 17 |
| Section 3: Side effects | 18 |
| ■ Side effects of radiotherapy | 18 |
| ■ Skin | 18 |
| ■ Bowel | 21 |
| ■ Bladder | 23 |
| ■ Fatigue | 24 |
| ■ Shrinking/closing of the vagina..... | 24 |
| ■ Sexual intercourse after treatment | 28 |

| | |
|---|-----------|
| ■ Nausea | 28 |
| ■ Pubic hair loss | 29 |
| ■ Vaginal discharge | 29 |
| ■ Why do side effects happen? | 29 |
| ■ Late effects | 30 |
| Section 4: Research at The Christie | 34 |
| Section 5: After the treatment | 35 |
| ■ Follow-up after treatment for gynaecological cancer ... | 35 |
| ■ Travel and holidays | 39 |
| Section 6: Consent | 40 |
| Section 7: Personal record | 42 |
| Section 8: Further information | 44 |
| ■ Macmillan Cancer Support | 44 |
| ■ Christie information..... | 45 |
| ■ Student training | 46 |
| ■ The Christie Hotline..... | 46 |
| ■ Benefits and finance..... | 47 |
| ■ Useful contacts | 49 |

Introduction

This booklet is written for women who are having radiotherapy to the vulva and/or groin areas for vulval cancer. It describes all possible treatments and some may not apply to you.

The doctor or nurse clinician will discuss your treatment with you and explain anything you do not understand. Please share this booklet with your family and friends. They can have a role in supporting you. It is important that they feel well-informed and understand what is happening. If you would like more detailed information about your own treatment please ask the staff. There is also a DVD on radiotherapy which you can take home to watch. Please ask you doctor, nurse or radiographer.

What treatments are available?

Some women with vulval cancer may benefit from having chemotherapy. With cancer of the vulva, this may be weekly chemotherapy with a drug called cisplatin along with radiotherapy. The doctor or nurse will discuss with you what is recommended for your situation. We advise you to read the information on this treatment in the Christie booklet "Chemotherapy, a guide" and the leaflet on cisplatin.

When is radiotherapy offered and what are the benefits?

Each woman has her treatment planned individually, and your doctor at The Christie will discuss with you the type and length of treatment that is recommended for your condition. The chart overleaf lists reasons for your treatment and the benefits of treatment that you are being offered.

Chart to show treatment options when radiotherapy is offered for vulval cancer

My treatment is being offered for:



| When is radiotherapy offered? | Vulval cancer when surgery is not possible. | Vulval cancer after surgery where there is a risk of cancer cells being left behind. |
|--|--|---|
| What type of radiotherapy? | 20-25 treatments of radiotherapy followed by 10 treatments to the main site(s) of the tumour. | 20-25 treatments of radiotherapy. If the tumour involves the groins then treatment is recommended to the groins in addition. |
| Will I need chemotherapy? | Cisplatin chemotherapy with radiotherapy may be offered. Patients need to be generally fit and well and have a good kidney function. | Cisplatin chemotherapy with radiotherapy may be offered. Patients need to be fit and well and have good kidney function. |
| What is the aim of treatment? | Reduce the tumour, prevent it spreading, with the aim of getting rid of it altogether. | Treatment is offered as a follow-up (adjuvant) treatment with the aim of reducing the chance of your cancer coming back. |
| Are there any alternative treatments? | Normally there are not because surgery has already been ruled out. Ask the treating team and they will explain if this is an option. | No, not normally |
| What will happen if I decline treatment | Your tumour will continue to grow. It may spread to other areas of your body and cause you increasing symptoms. | You should be offered regular follow-up appointments with your gynaecologist who can refer you back for radiotherapy in the future if you require it. |



Vulval cancer after surgery where cancer was found in lymph glands or tissues in the groins.

20-25 treatments of radiotherapy from the outside to the groin areas only.

Cisplatin chemotherapy with radiotherapy may be offered. Patients need to be generally fit and well and have a good kidney function.

Treatment is being offered as there is a risk that some cancer cells may not have been removed. With further treatment the risk is reduced.

No, not normally.

You should be offered regular follow-up appointments with your gynaecologist who can refer you back for radiotherapy in the future if you require it.



Advanced vulval cancer when it is not possible to cure.

Lower doses of radiotherapy are given, often over a shorter period of time, such as 1 to 3 weeks (5 to 15 treatments).

Chemotherapy is sometimes considered at a later date.

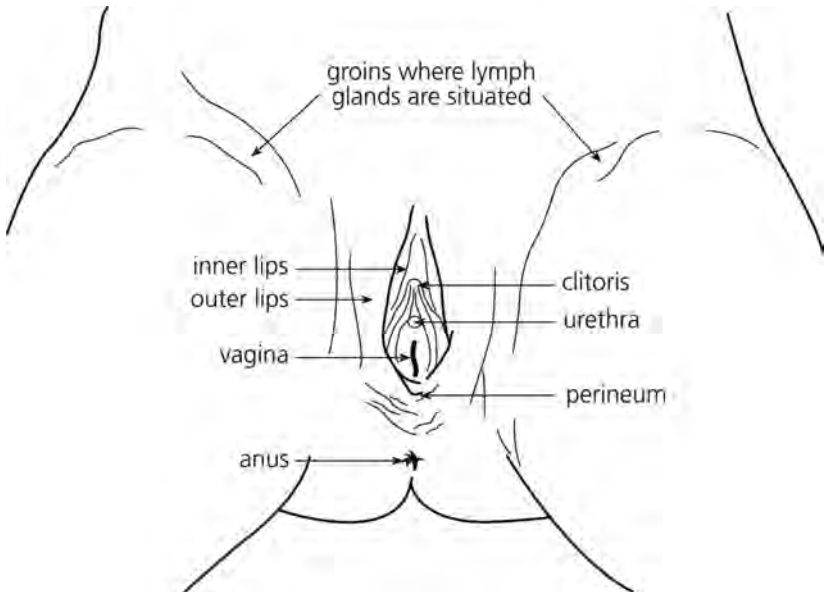
To improve quality of life by shrinking the tumour to reduce symptoms such as pain or bleeding.

Chemotherapy can sometimes be considered in certain situations.

Your tumour will continue to grow. It may spread to other areas of your body and cause you increasing symptoms. We would suggest that you are referred for supportive palliative care.

The areas being treated

This diagram may be useful to help you understand where your cancer is and the area to be treated with radiotherapy. Your doctor may draw on them to help explain your treatment.



The Vulva

Agreeing to treatment

Consent to treatment

The doctors, clinic nurses and radiographers will normally give you some written information to support what they have said about your treatment. At the time your treatment is planned, you will have the opportunity to discuss anything you do not understand, or any worries or concerns you may have.

We will ask you to sign a consent form (see page 40) agreeing to accept the treatment that you are being offered. The key messages in the consent form for radiotherapy are included in this booklet for you to read and consider. It is important that you understand what the planned treatment involves and that you have been given the opportunity to discuss any concerns before you sign the consent form.

Your doctor will ask you to sign a consent form before treatment to say that you agree to the treatment and understand about the possible long term effects.

In younger women who are still having periods, radiotherapy to the pelvis causes the ovaries to stop working because they are very sensitive to radiation. This means, unfortunately, that you will no longer be able to have children and will have an early menopause. If infertility is an issue for you and your partner, please let the doctor who is planning your treatment know so that this can be discussed further with you and then, if appropriate, they can arrange for you to see a fertility specialist urgently.

You are entitled to request a second opinion from another doctor who specialises in treating this cancer. You can ask your own consultant or your GP to refer you. Your consent may be withdrawn at any time before or during this treatment. Should you decide to withdraw your consent then a member of your treating team will discuss the possible consequences with you.

Radiation can be harmful to the unborn child. It is important to let the radiographers know if you have missed a period or suspect that you might be pregnant before the treatment planning session.

Stopping smoking

Many of the effects of radiotherapy can be made worse by a lack of oxygen getting to the parts of the body treated by radiotherapy. Stopping smoking is the best way for you to increase the oxygen getting to your tissues and this may help to prevent or lessen side effects. Most people who smoke are much more likely to stop smoking if they have support. You can be referred or refer yourself to the smoking cessation service at The Christie, phone 0161 446 8236. This is explained in the leaflet 'Smoking cessation and alcohol advice services' or by discussing it with any of your treating team. Alternatively, your GP or local pharmacy should be able to direct you to your local stop smoking service.

Planning and treatment

What is radiotherapy?

Radiotherapy uses exact, carefully measured doses of radiation to treat diseases. It is often given in small doses called fractions over a specified period of days or weeks.

Most patients having radiotherapy are treated using a high energy beam of x-rays delivered to the precise area by a machine called a linear accelerator. The rays are used only to treat the tumour and a small surrounding area.

The radiographers treating you are highly trained professional men and women. They will be able to answer any questions or concerns you may have. The dose given will depend on the exact type of cancer you have, so you may find that you are having a different number of treatments from other women you meet at the hospital.

How does radiotherapy work?

Our bodies are made up of cells and all cells are able to divide. If radiation hits a cell that is dividing the cell will be damaged. Cancer cells are much less able than normal cells to repair the damage, so more of the cancer cells will be destroyed.

When will radiotherapy begin?

The radiographers will be able to tell you exactly when you will start your treatment during your initial radiotherapy planning appointment. As everybody's treatment varies, the amount of time needed to plan the treatment varies. You may have between 5 and 35 treatments.

The specialist doctor who is in charge of your treatment is a clinical oncologist. He or she will examine you and may arrange for tests such as x-rays, scans and blood tests. These are to check your general health, and to help decide the details of your treatment.

You will be cared for by a team of doctors including consultants, registrars and foundation year 2 doctors (FY 2), radiographers and nurses. The team also has a nurse clinician who specialises in caring for women with gynaecological cancers. In choosing your treatment, your clinical oncologist at The Christie has carefully considered the nature of your illness and your particular needs with regard to your treatment plan.

Planning the treatment

Treatment preparation may be done on a special x-ray machine called a RTP (Radiotherapy Planning) Scanner which is a type of CT scanner. The scanner provides the doctors with images from which your treatment is planned. When you are having an RTP scan you may be asked to have an injection of special contrast before your scan which helps to

get clearer pictures and improves the planning of your treatment. A marker may be placed on the skin or in the vagina to help the treatment planning process. If you have not had surgery as part of your treatment a second scan may be done in the third week of your treatment to plan the final two weeks, sometimes referred to as 'a boost'.



CT Scanner

The scan and images are to help plan your treatment. They are not for diagnostic purposes and so are generally not useful for giving any update on how your cancer is progressing.

When you are sent your appointment letter for your scan, we will enclose a leaflet which will explain in more detail what will happen. During this planning session the radiographers may draw some marks on your pelvis with a skin pen. These marks do wash off and so some permanent marks, like tiny black freckles, will need to be made. These will help the radiographers set you up in the correct position for treatment every day.

During the scan you will need to lie flat on your back and stay still for a short time. Unfortunately the bed has to be very firm for technical reasons and is similar to the bed that you will lie on when you have your radiotherapy treatment each day. If you find it uncomfortable to lie on your back, sit or lie on a hard surface, you may want to take some extra painkillers 30 to 60 minutes before your scan. It is always a good idea to bring any painkillers you might want with you to the scan appointment. If pain is a problem for you, please speak to one of the team or your specialist nurse **before** your scan.

At your scan appointment you will be seen by one of the doctors or the nurse clinician who will explain the treatment, the reason it is being offered and potential short and long-term side effects.

The scan pictures are loaded on to a specialised computer and your consultant will then plan your treatment with the support of the technical team.

This is a complex process that usually takes 1 to 2 weeks to complete and is done individually for each patient.

What happens during treatment?

On the day of your first treatment, you will come to the radiotherapy department. If you are an inpatient, a male or female radiotherapy care assistant may collect you from your ward and escort you to the department. On the treatment unit you will meet a radiotherapy support worker. They help patients plan their appointments for the treatment.

The radiographers will have the details of your treatment which the doctor has carefully planned. They will explain to you exactly what will happen. The Christie is a training centre, so you may meet male and female students in the radiotherapy department who may be involved in the delivery of your treatment. If you have any objections please let the radiographers know.

The radiographers will discuss the treatment with you and how to minimise side effects. They will also check whether you are still happy to go ahead with your treatment. This is the ideal opportunity to ask any questions you may have.

The radiographers will take you into the treatment room and ask you to remove or loosen your clothing around your pelvis so that they can see the marks made during treatment planning. They will help you onto the treatment bed. The radiographers will then adjust the bed and your position so that you are in the correct position for the treatment. They will try to make you as comfortable as possible as you will be asked to keep still for the duration of the treatment.

The radiotherapy machines are quite large and you may find them a little frightening to begin with, but there is no need to worry – the treatment is painless. Each session may take about 15 minutes but the actual treatment only lasts a few minutes. The radiographers operate the machines from outside the room. When all the adjustments have been made and you are in exactly the right position, the radiographers

will make sure you are all right and then leave the room to switch the machine on. There is nothing to feel and nothing to see. The machines make a buzzing noise when they are giving treatment.

If you feel particularly anxious or are having difficulties with having radiotherapy, please speak to the radiographers. There may be things that they can suggest that might help. This may include referring you for support to the CALMS team who provide complementary therapies.



The treatment machine

During your treatment the radiographers will need to take images of the area you are having treated. This will be done at the same time as your treatment and you probably will not notice that the images have been taken. Some machines have the ability to complete a scan of the treatment area. All of these images are purely to check that you are in the correct position and not to check how the tumour is responding to treatment. Please do not feel abandoned. A closed circuit television on the control desk gives the radiographers a clear view of you and they will be watching you all the time. If you feel you need to cough or sneeze the radiographers will tell you beforehand how to let them know this. They will switch off the machine and come in immediately.

Once your treatment has finished the radiographers will help you off the bed and arrange your next visit. You are then able to return home or to your ward.

It is very important that you do not miss treatment days as this may make your treatment less effective. If you feel you are unable to attend for any reason please telephone the

staff on your treatment machine and discuss the problem with a radiographer. If, whilst you are at home, the side effects become severe such as uncontrollable diarrhoea, heavy bleeding, difficulty in passing urine, fever, severe tiredness or pain, it is important to **contact The Christie Hotline 0161 446 3658. It is open 24 hours a day, 7 days a week for advice.**

Some questions about radiotherapy

Is radiotherapy safe?

Radiation used in medical treatment is given in controlled, carefully measured doses. The aim is to include all tissues that could possibly contain cancer cells whilst minimising the dose to the normal tissue.

Will I be radioactive?

No. Patients treated by x-rays do not become radioactive. The radiation does not stay in your body after treatment, so you cannot do anyone else any harm. It is safe for you to mix with other people including children and pregnant women and to have visitors if you are on the wards.

I already have problems with my health. Will radiotherapy treatment make them worse?

Not usually. The treatment may make you feel more tired than normal. Please tell your treatment team about any existing medical conditions and continue with any medication that you may be taking unless your doctor or nurse tell you otherwise. Ask your Christie doctor if you are worried about any other health problems.

Can I come for treatment at any time of the day?

If you are having treatment as an outpatient, the radiographers will give you an appointment time for the first treatment when you attend for your planning session. After that you can

arrange with your treating team the time that suits you and the machine. Please try and be as flexible as possible and give priority to your treatment sessions over general appointments. The time you prefer may not be available at the start of your treatment because of the large number of patients on the treatment unit. If you need a specific time with valid reasons, please give the radiographers at least 48 hours notice.

The time we give you may vary half an hour either way each day due to emergencies and so on. Each day, we will give you an appointment time for the following day.

Once a week, you will meet your consultant or one of their team. If you are having radiotherapy alone then you do not need an appointment for this. We will take you to the clinic before or after your radiotherapy. If you are having chemotherapy, you will usually have a pre-booked appointment in the chemotherapy clinic.

If you are coming by ambulance transport we will give you a morning or afternoon appointment to fit in with your consultant's clinic. If you are an inpatient, the treating team will send a care assistant for you when they have a free slot.

Will I be treated as an outpatient or an inpatient?

You will usually have your treatment as an outpatient. Some people continue to work during part of their treatment. However, after daily travel and treatment, you may feel tired and need to rest.

Your doctor or nurse clinician will have discussed with you about travelling daily for your treatment as an outpatient. However, if you do become unwell during your treatment we will usually admit you as an inpatient to support you through your radiotherapy. You will not have to stay in bed, so bring suitable day wear, so that you can get dressed if you feel well enough.

What happens if I need transport for radiotherapy treatment?

Many patients are able to bring themselves or can ask a friend or relative to help them out. If you think you may need ambulance transport, please discuss this with a radiotherapy support worker or radiographer on your first visit to the radiotherapy department. Ambulance transport can be arranged subject to eligibility criteria based on medical need. There also needs to be a medical need for you to bring an escort on hospital transport.

There can be delays for some time either side of your appointment because of the high demand for transport. Please take this into account when you are deciding whether to use ambulance transport or not.

Hospital transport is provided by North West Ambulance Service and Arriva; however, you can contact the transport liaison office at The Christie or directly on 0161 446 8114 or 8143 for advice about transport.

Prescriptions

Prescriptions from The Christie pharmacy are free for NHS patients. You will need an exemption certificate to get free prescriptions from a community pharmacy. Exemption certificates are available from the pharmacy and benefits advisers at The Christie and from your GP.

Questions you may want to ask your doctor

- What type and extent (stage) of disease do I have?
- Why are you recommending radiotherapy for me?
- What might be the benefits and side effects?
- Is there any alternative treatment, and, if not, why is this?
- Is there any treatment that will mean I can still have children?
- What will the radiotherapy involve and how many times will I have to visit the hospital?
- Will there be any lasting effects from treatment?

Gynae Advice Nurse-Led Clinic

During the time you will be coming to the hospital for your radiotherapy we will give you an outpatient appointment for the gynae advice clinic to see one of the specialist nurses. They will address any particular concerns or questions that you may have about the treatment, vaginal dilators, sex, fertility issues and the menopause. Some patients find it helpful to bring their partner to this appointment. It is also an opportunity to assess whether you may benefit from some additional support.

Side effects

Side effects of radiotherapy

Acute side effects are temporary and they do not happen to all women. They generally develop during the second half of the course of treatment usually after 7 to 14 days, and last for 4 to 6 weeks after the treatment ends. The time taken to recover does vary from patient to patient. If you have any questions about side effects, please ask any member of the team treating you.

Skin

The skin in the area where you are having radiotherapy may be affected by your treatment. Your skin may:

- feel warm to the touch
- be more sensitive or feel sore
- become pinker than normal
(this is not so obvious on darker skin)
- become dry and flaky
- feel itchy or prickly
- peel and weep
- have a burning sensation.

When will these skin changes occur?

This varies, but the changes mentioned above usually occur later on in the treatment, and sometimes when treatment has finished and for a few weeks afterwards.

Will I experience all the changes described?

Not always. Each person's skin reacts to radiotherapy in a different way. There are also other factors such as skin sensitivity and which area of the body is being treated. Some people having radiotherapy will not be aware of any skin changes, whilst other people may have some or all of the side effects described.

How you can help

Caring for your skin

- Wash the treated area gently with warm water (avoid extremes in temperature). Showers are preferable to baths. Continue to use shower products as normal. If preferred, aqueous cream can be used as a soap substitute but this is unlikely to reduce the chance of skin reactions occurring.
- If you regularly moisturise your skin, you can continue to do so whilst having radiotherapy treatment. Use your normal moisturiser. You do not need to change this unless you find that it starts to irritate your skin. We recommend that you avoid using products that contain 'sodium lauryl sulfate' as this can irritate the skin. If you have any questions or concerns, please ask a member of your team for further advice. If your skin becomes blistered or broken during treatment, please stop using the moisturising cream.
- If you find that your skin is irritated following the use of a product, it is advisable to stop using that product for the time being.
- Dry the skin using a soft towel or a hairdryer on a cool setting.
- Do not apply toiletries such as perfume or talcum powder on the skin that is being treated.

- If your skin becomes itchy, we can give you some cream that might help.
- Do not wax or use depilatory creams, or shave in the treatment area as this can irritate the skin. It is important not to stick certain types of dressings or tapes on to treated skin. Ask the advice of your doctor, nurse or radiographer if you wear a dressing on the treated area.
- Please tell the staff if you are having any discharge or odour from the treated area, as there may be a risk of infection. If urine is splashing on your sore skin try sitting in different positions on the toilet. It may help to use a clean jug filled with warm water to cleanse the area as you pass urine and then pat dry afterwards.
- When using the toilet only use a soft toilet paper. If it feels sore when you use toilet paper, then try a clean, dry flannel or soft towel. Pat dry and use a fresh clean one each day.
- Walking around a lot can make the skin more sore as it rubs against itself, so you may find you have to rest when the reaction is at its worst.

Clothing

- Avoid wearing tight restrictive clothing against treated skin, or clothing that will constantly rub the area. Wear skirts rather than trousers. As much as possible, remove any underwear.
- Natural fibres such as cotton are preferable to man-made fibres such as nylon. Cotton allows perspiration to evaporate more effectively, causes less friction and is therefore generally more comfortable.
- Avoid wearing tights and support undergarments.
- Avoid wearing sanitary towels, panty liners and incontinence

pads. If it is essential for you to wear any of these please ask for advice about the most suitable products.

How we can help

- If you are having treatment either as an inpatient or outpatient your treatment area will be assessed on a regular basis.
- Patients may need additional painkillers or adjustments made to their medication. Your treating team will assess this every time they see you but if pain is a problem in between these reviews, please let the radiographers know. They will be able to ask a member of the team to come and see you, if necessary.
- Occasionally patients benefit from coming into hospital to be supported and nursed through the worst of their skin reaction.
- If you are coming for treatment as an outpatient and start to feel that you are not coping please let the radiographer, nurse or doctor looking after you know and then they will be able to discuss the options with you.

How long do these skin changes last?

When radiotherapy finishes the skin may stay as it is for a few weeks before it starts to get better. Once healing begins, most people find that this progresses more quickly than expected and in most women, the skin heals in 4 to 6 weeks. We advise you to continue to follow the skin care guidelines. When the skin has healed, you can begin to use your normal toiletries. If you have any worries before, during or following your treatment about skin changes please talk to your doctor, nurse or radiographer.

You can contact The Christie Hotline for advice and support on 0161 446 3658.

Bowel

Your bowels may become disturbed due to your treatment. For most women, this is in the form of diarrhoea but occasionally it can be constipation. Diarrhoea can start after about two weeks of treatment and last for several weeks after treatment ends. With the diarrhoea, patients often get increased “wind”, severe urgency, intermittent abdominal gripes/cramps, abdominal bloating and may pass mucus.

What you can do to help...

It is important that you continue to eat nourishing food during and after treatment. Ask the nursing or radiotherapy staff for a copy of **Eating – Help Yourself** which has information about coping with problems such as loss of appetite. If diarrhoea becomes a persistent problem, you will need to follow a lower fibre diet to ease your symptoms. Fibre is the part of grains (flours and cereals), pulses, vegetables and fruit which is not digested and passes down the gut.

Follow the lower fibre diet for as long as your side effects last, then gradually resume your normal diet by adding one new food each day that contains fibre, then if the diarrhoea returns you should be able to work out which food has caused it and eliminate this from the diet for a further few weeks.

If you have diabetes and you have developed diarrhoea, still follow the lower fibre diet advice but make sure you eat meals and snacks containing low fibre starchy foods such as white bread, white rice and cereals. Once your symptoms have resolved, go back to your normal diabetic diet.

- Replace wholewheat or oat-based cereals with Rice Krispies, Cornflakes or Special K.
- Replace wholewheat biscuits with biscuits made from white flour such as Rich Tea, Marie biscuits or custard creams.

- Avoid nuts and pulses (baked beans, kidney beans, peas and lentils).
- Take only small amounts of fruit and vegetables and avoid eating the skin.

Some people also find it helpful to cut down on fat by avoiding fried foods, pastries, cream cakes and fatty meat.

If you have diarrhoea you must drink enough to replace the fluid that is being lost. Aim for a minimum of 10 to 12 drinks a day.

If you are following this diet for more than a week, a complete multivitamin and mineral supplement is recommended daily such as Centrum, Boots A-Z, Sanatogen A-Z Complete or Nature's Best A-Z multi.

If you have followed a lower fibre diet and are still having problems with diarrhoea, we can prescribe Fybogel (also called Senokot High Fibre or Normacol). These act by absorbing fluid and help to form more solid, less frequent motions. These are often taken by people who have Irritable Bowel Syndrome and can help with both diarrhoea and constipation. Take these until your bowel symptoms settle. Fybogel is a powder which needs to be mixed with water or a fizzy drink and then drunk immediately. If your bowel problems persist, then you may need additional medication such as loperamide (Imodium®) or codeine phosphate which can be prescribed for you.

The bowel symptoms vary greatly between patients. Most people start to see some improvement 2 to 3 weeks after treatment has finished. Some patients are virtually back to normal within 6 weeks, for others they remain unsettled for several months and for some they never return to what was normal for them.

Bladder

Radiotherapy can irritate the bladder and give symptoms similar to cystitis such as increased frequency and burning or difficulty when passing urine. We recommend that you take plenty of fluids, at least a litre a day preferably 2 to 3 litres. It is best to avoid drinking lots of tea and coffee and avoid all alcohol. Some people find a glass of cranberry juice a day helpful.

Bladder and bowel problems gradually get better, and many people are back to normal at their follow-up clinic visit six weeks after treatment.

Fatigue

You may feel tired during treatment so rest is important, although a small amount of exercise each day has been found to be beneficial in reducing fatigue. This is explained further in the DVD/booklet **'Be Active, Stay Active: a guide to exercising during and after cancer treatment'** which is available from the information centre. Tiredness often affects people after treatment ends, so you may need help with housework and shopping. Some women also have aching and stiffness in their joints and muscles. As your strength returns, as it will do, you can gradually take up your normal daily activities.

Radiotherapy can be a demanding treatment. If you are feeling low or are not coping, let the nurses, doctors or radiographers treating you know so they can discuss with you what might help.

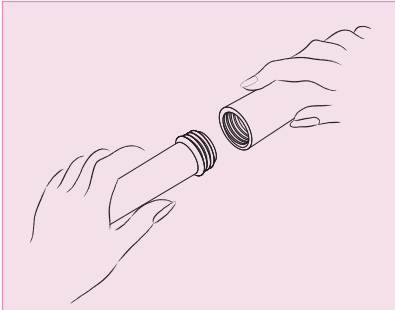
Shrinking/closing of the vagina

Radiotherapy to the vulva produces a side effect which needs your personal care and attention. This side effect is called vaginal atrophy (shrinking) and is a result of scar tissue forming in the vagina following this treatment. You will need to follow instructions carefully. If you do not, your vagina could shorten and become narrower and can close. So it is important that you keep your vagina open to prevent any problems when you come for your check up, or when you start sexual intercourse again, as well as for your general well-being and comfort. Your vagina can be kept open by vaginal dilation. Dilation means 'stretching and opening' and can be done by:

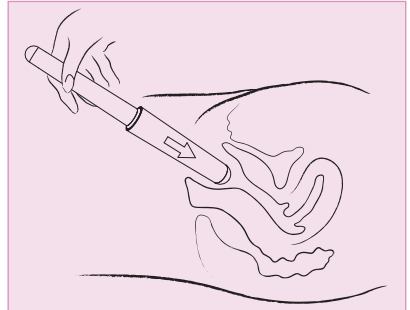
1. Use of a dilator
2. Sexual intercourse
3. A combination of intercourse and dilator use.

Vaginal dilators are normally discussed, explained and given to you at the Gynae Advice appointment, along with some lubricating gel. **Generally we recommend lubricants such as 'Sylk' and 'Yes' that can be prescribed by your GP or purchased from a pharmacy.** Obviously this is a personal area of care and some people have reservations or strong feelings about using a dilator. Please discuss this with a member of the team that is looking after you. Your feelings will always be respected.

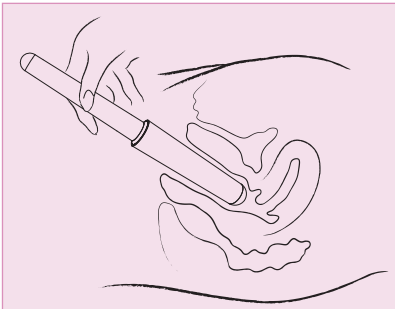
Vaginal dilation



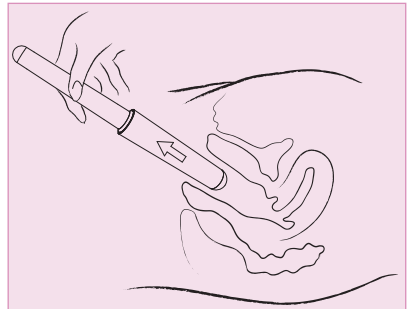
1. Connect size one (smallest) cone to the size 2 cone. Apply lubricating gel.



2. Get into a comfortable position, apply lubricating gel to the entrance of the vagina, and slowly insert dilator into the vagina as far as it will go.



3. Gently move the dilator from side to side, up and down and then circular movements for approximately 5 minutes to gently open and stretch the vagina.



4. Remove the dilator, wash with soap and water and dry.

How to use your dilator

Start using your dilator about four weeks after finishing your treatment when your skin has healed and it feels comfortable and continue to use it once a day, every day, for six weeks. We would then advise you to continue the use of the dilator 2 to 3 times a week.

Examine the dilator before each use to be sure that it is smooth. If there are cracks or rough edges, do not use it. Phone your specialist nurse or nurse clinician for a replacement. You should not feel any pain or discomfort if you are gentle and stay relaxed whilst using the dilator.

Starting with the smallest size dilator, attach the size 1 (smallest) to the size 2 cone and apply some gel to the dilator and to the entrance of the vagina. Lie on your back in bed with your knees bent and slightly apart. Some people prefer to insert the dilator standing with one leg raised on a chair, or squatting. (You may find it is easier in the bath, or after a bath, when you are relaxed). Insert the dilator into your vagina gently and as deeply as you can without discomfort but you should be able to feel it gently bounce off the top of the vagina when it reaches the end. Then gently move the dilator from side to side, up and down and then circular movements (see diagrams). Also gently stretch the vagina upwards by gently pushing upwards and letting the dilator bounce off the top of the vagina. This helps to keep the elasticity of this area which is particularly important if you are going to have intercourse in the future. Continue this for five minutes. Now take it out and clean it with hot soapy water, rinsing it well. If you are able to do this easily, then next time try using the next size dilator and progress up the sizes.

Do not be alarmed if slight bleeding or spotting occurs following dilator use. This is a normal reaction. Do not use force inserting the dilator. If you are unable to insert it easily, postpone it for a few days or contact your specialist nurse or nurse clinician (0161 446 8101). Most women should be able to progress to the second size dilator within a few days. If, after a week or two, this is easy and comfortable to use, then progress to the third and fourth size dilator. Remember it is important that you should use the dilator of the right size that reaches the top of your vagina (you should be able to gauge this yourself) and that you use the dilator regularly.

After your six week check-up even if you are not going to have intercourse or you are having it infrequently, we still recommend you to continue to use the dilator daily for another four weeks then 2 to 3 times a week for the next 2 to 3 years. You can then talk to a member of the nursing/ medical team before you stop using it.

Sexual intercourse after treatment

It is important in close relationships to continue to have intimacy, but we suggest that initially following treatment you avoid intercourse until the skin has healed, the area feels comfortable and you are comfortably able to use an appropriate size dilator. You may find your vagina drier than usual and you may need a lubricant. There are many lubricants that you can buy from the supermarket or chemist which can often be found by the condom display. Alternatively, there are some lubricants such as 'Sylk' and 'Yes' that can be prescribed or purchased from a pharmacy. If you want more information about lubricants ask a member of the team when you are seen in clinic or phone the nurse clinician or your nurse specialist. You may have some slight bleeding or spotting following intercourse and may feel some degree of discomfort. Do not be frightened by this. As the tissues begin to stretch, the bleeding and discomfort should subside.

Please tell us when you come back to clinic if you have any difficulty. You are not a danger to your sexual partner. You cannot transmit cancer, and no radiation remains in your body once the treatment session is completed.

Nausea

Very occasionally you may feel sick during your radiotherapy treatments, your taste changes or you go off your food. This is more likely to happen if you are having chemotherapy. Let the nurses or doctors looking after you know because they can suggest things that may help.

Pubic hair loss

Any pubic hair in the area being treated may fall out during or shortly after treatment. This usually grows back but is often thinner.

Vaginal discharge

You may find that you have a vaginal discharge. This is not unusual and may continue for a time after you get home. It is not likely, but if the discharge alters in any way (for example, becomes heavier or smells unpleasant), **phone The Christie Hotline 0161 446 3658 which is open 24 hours a day, 7 days a week for advice.**

Why do side effects happen?

The side effects happen because, as well as destroying cancer cells, radiotherapy can also damage healthy cells nearby. As the diagram on page 6 shows, the bladder opening (urethra) and bowel opening (anus) are very close to the vulva, so they can be affected by the radiotherapy too. When planning a woman's treatment, the doctors choose the dose that will give the best chance of destroying the cancer cells and reducing the symptoms – with the smallest possible effect on healthy tissue.

It seems that some women are more sensitive to radiation than others, and are more likely to experience side effects. At present, it is not possible to identify these women before treatment starts. Also, in some women the tumour itself can cause damage to the surrounding tissue and structures.

Late effects

There are some late side effects of radiotherapy that your doctor will discuss with you. These may occur months or years after your treatment and happen only in a very few cases. They can include long-lasting bowel, vaginal and bladder problems.

Cancers can damage the tissues in which they are growing. Cancer of the vulva can grow towards the anus, and/or bladder opening (urethra) and/or vagina and can weaken them before treatment. If the cancer is fully destroyed by the radiation, the tumour damage to the bladder, bowel and vagina may mean that it is impossible for this damage to be repaired, even after successful treatment. The extent to which this happens varies enormously, and depends on the size and extent of the tumour and its nature.

The following sections give a summary of the possible late effects of pelvic radiotherapy. If you would like more detailed information, please read the Macmillan Cancer Support booklet 'Pelvic radiotherapy in women – possible late effects' available from the cancer information centre or www.macmillan.org.uk

Bladder, bowel and vagina

At least half of women treated may develop bladder, bowel or vaginal problems, but for most women these effects will be mild and manageable. These can include some lasting alteration in bowel habit which can be controlled by altering diet, or needing to empty the bladder more frequently.

In a minority of women (3 to 10 in 100) long-term effects can be more serious and include such effects as narrowing of the bowel or bleeding from the bladder. If this happens, each woman is assessed and referred to a specialist who has experience of dealing with these problems. Some women

may need to have surgery to correct these problems (5 to 8 in 100). The risk of these serious effects for each patient is influenced by the combination of cancer treatment, size and stage of the cancer and pre-existing problems in the pelvic area. These figures are based on treatment outcomes from patients treated at The Christie.

Lymphoedema

This is swelling of the leg(s) and/or the pelvic region which occurs in a small number of women after gynaecological cancer. When it does occur it is usually in women who have had both surgery and radiotherapy, or where the tumour has spread to the lymph nodes. These treatments can disrupt the workings of the lymphatic system especially nearby lymph nodes.

It is difficult to predict who will go on to develop lymphoedema but there are certain precautions which you can take which will reduce your chance of developing it:

- Look after your skin in the leg and pelvic area. Keep it clean and well moisturised and protect from any breaks in the skin that can be caused from cuts, grazes, insect bites, sunburn.
- Try to exercise and keep active. Once you have recovered from treatment you can usually get back to your normal activities and exercise programme.
- Try and keep to a healthy weight. Being overweight can increase your risk of developing lymphoedema.
- If you see any signs of infection (redness, heat, swelling) in the skin of the legs or genital area then contact your GP immediately as you may need to be treated immediately with antibiotics.

The Macmillan booklet 'Understanding Lymphoedema' is available from the information centre and contains a lot more information and useful advice. Alternatively ask your specialist nurse/nurse clinician for advice or written information. If you notice any signs of developing lymphoedema then please contact your treating team or your local specialist nurse who will then give you further advice and offer to refer you on to your local Lymphoedema Service.

Bone changes

Pelvic radiotherapy can sometimes cause weakness in the pelvic bones. Also, the lack of the oestrogen hormone following the menopause can make bones weaker and more at risk of osteoporosis (bone thinning). This can lead to very fine, hair-like cracks in the bone which are called insufficiency fractures and can develop months or years after treatment. In some patients this can lead to discomfort and pain in the pelvic area which can make moving and walking difficult. Insufficiency fractures can often be diagnosed from an MRI scan which your hospital doctor can organise. The bone changes and pain when they do occur can often be helped by medication, dietary advice and exercise.

Many factors influence bone health but an early menopause (before 45 years) can increase the risk of developing osteoporosis. This means that there is a greater risk of fracturing a bone later in life. To assess bone density a dual energy x-ray absorptiometry (DEXA) scan is used. This can normally be arranged by your GP.

More information about bone health and osteoporosis can be obtained from the National Osteoporosis Society (www.nos.org.uk Helpline 0808 800 0035) and NHS Choices (www.nhs.uk).

Skin changes

Once the initial skin soreness settles you might notice a slight change to the colour and/or condition of your skin in the treated area. Sometimes treatment can result in permanent skin changes that may occur some time after your treatment has finished. Some women may find that they always need to use a moisturiser or emollient on this area of skin. You will need to protect the skin in the treatment area from the sun by either keeping it covered up or using a sunblock. Sunbeds are best avoided.

Infertility and early menopause

In women who have not yet gone through the menopause, this treatment causes infertility which is permanent and will result in an early menopause. As previously mentioned on page 7, if infertility is an issue for you or your partner, please discuss this with your treating team and they can arrange for you to see a fertility specialist.

Some women find that their periods stop while having radiotherapy. Others can have 2 or 3 periods following treatment before these stop altogether. At the same time, you may start to have menopausal symptoms such as hot flushes, night sweats, vaginal dryness, irritability and mood swings. Treatment and management of the menopause needs to be worked out individually for each woman because it depends on many factors including type of cancer, past medical history, age and so on. This needs to be discussed on an individual basis with each woman. If you would like more information about this, please ask the team treating you.

Menopause Matters www.menopausematters.co.uk

For accurate, up to date information about menopause and treatment options.

Research at The Christie

The Christie, along with the nearby Paterson Laboratory, is a major centre for cancer research of all kinds. You may be asked if you are willing to help with some of the clinical trials and audits that are going on. You are under no obligation to take part in any of these. You will meet some of the research nurses who help to run the trials. They will also give you support and advice throughout your treatment, whether you are taking part in a trial or not.

After the treatment

Follow-up after treatment for gynaecological cancer

What happens after my treatment at The Christie?

At the end of your radiotherapy, an end of treatment letter will be sent to your GP. A copy will also be sent to you as a record of your treatment. If for any reason you would prefer not to receive this, please let your treating team know before you finish your treatment.

You will have regular follow-up appointments. You will normally alternate between seeing the oncologist who gave you the radiotherapy and seeing the gynaecologist who diagnosed your cancer. You will usually see the gynaecologist at the hospital where you were first seen. Your appointments with the oncologist may be at The Christie, or at your local hospital depending on where you live.

When will my first appointment be?

Your first appointment will be about 6 weeks after your treatment finishes with the team that gave your treatment. We will usually post this to you. The main aim of this is to check that the side effects of your treatment have settled. We will ask you some questions to check that your bowel and/or bladder symptoms are improving. We will also check whether any other symptoms you had relating to your cancer and treatment are getting better. The doctor will also examine you. This is to make sure that any tumour that could be felt/seen before treatment started is responding satisfactorily.

Follow-up plan

Follow-up appointments are usually arranged:

- every three months in the first year
- every four months in the second year
- every six months in the third, fourth and fifth year

Follow-up may be shared with the gynaecologist if you have had radiotherapy after an operation for your vulval cancer.

Will I have a scan?

Most women will be followed up with regular consultations and examinations. Whether you are scanned routinely following radiotherapy treatment or not depends on where your original cancer was and whether you have previously had surgery. The doctor or nurse clinician will discuss this with you at your first check-up appointment.

Following treatment for vulval cancer a lot of patients are best followed up regularly with a clinical examination which can pick up if the cancer has come back in the vulval or groin areas. If you have not previously had surgery, then some patients will have a MRI scan three months after they have completed their radiotherapy. The scans are not done earlier than this because it can be difficult to distinguish between changes due to the treatment and those due to the tumour. Even when the scan is done at three months after treatment it can still be difficult to interpret as there may not have been enough time for the body to have returned to normal following the treatment. If this is the case then patients often need another scan in a further three months.

If you have already had an operation to remove the cancer (a vulvectomy or wide local excision and removal of groin nodes) then scans are not carried out routinely during the follow-up period as the original cancer has been removed.

We do not routinely offer follow-up scans as recurrent disease can often be picked up with clinical examination. In vulval cancer, scans are generally used to identify if cancer has come back outside of the pelvic area but it has to be large enough to be seen on a scan (usually about 1cm in size or about half an inch). Unfortunately if the cancer returns outside of the pelvis, early detection of the cancer when it is small does not lead to a better outcome.

In other words, when all the initial treatment is complete, finding a recurrence earlier rather than later and then treating it sooner does not necessarily mean that a patient will live longer. In fact doing scans when patients feel well can lead to additional anxieties and generally are not useful.

So instead, we think it is better to scan patients only if they develop a problem, because at that point they have symptoms that may be helped by a course of treatment such as chemotherapy. Although the treatment might have side effects, these are often outweighed by the possibility that the treatment would decrease the symptoms from the cancer.

If you do have a scan and it is clear, then it means that there is no visible sign of any remaining tumour at the time when the scan was done. This is reassuring for you and the team treating you but it does not rule out further problems in the future, so you will need to continue to come to follow-up appointments.

When will I know that the cancer is gone?

Women with vulval cancer who are going to develop a recurrence of their cancer are most likely to do this within two years following treatment. The highest chance of recurrence is in the first year following treatment. This is why patients are seen frequently in the first two years after treatment. For women with the common types of vulval cancer it is unusual for them to have further problems from their cancer if they are free of any problems at five years.

What symptoms should I report or be worried by?

If you have the following symptoms you should contact The Christie or your gynaecologist or your GP to ask for an earlier appointment:

- new lump or soreness in the vulval area or groin
- persistent lower back pain or pelvic pain which is getting worse and especially if it is waking you at night.
- new swelling in one or both legs
- bleeding or discharge from the vagina or bowel, or from the bladder when passing urine
- a serious change in bladder or bowel habit.
- unexplained weight loss.

Treatment effects

A few women will develop symptoms that could be due to treatment effects. These can be similar to the symptoms caused by tumour recurring or an entirely different condition. Tests will help us to identify the cause of these symptoms to suggest appropriate treatment. These effects may occur some time after treatment finishes, even after several years.

If you have further tests or surgery at another hospital, it is important that you tell your doctors that you have had radiotherapy treatment before.

After you have had treatment for cancer it can be a worrying time. Please remember that you will have the same aches and pains that you have always had. If you develop a new health problem, this may not be related to your cancer and its treatment.

Travel and holidays

Most people do not feel like travelling for the first few weeks after their treatment. Every woman is different but it may take 4 to 6 weeks before your side effects settle and it may be some time after this before you feel like going on holiday. Once you feel like going on holiday there should be no problem travelling within the UK. However, if you are thinking about going abroad, make sure you have adequate health insurance which includes your cancer diagnosis. Even in Europe, you should have insurance as well as the European Health Insurance Card. This may mean that the cost of your insurance policy is higher than it has been previously. Some people have found it useful to get a quote for their insurance before booking a holiday, as this could affect your choice of destination. More information about this and other things to consider are in the booklets 'Getting Travel Insurance' and 'Travel and Cancer' Macmillan Cancer Support, available from the cancer information centre.

Consent for gynaecological radiotherapy

The doctor is here to help you. He or she will explain the proposed treatment and what the alternatives are. You can ask any questions and seek further information. You can refuse the treatment.

You may ask for a relative, or friend, or a nurse to be present.

Your treatment may involve:

- External beam radiotherapy to the vulva and/or groins

The doctor will ask you to sign a consent form, here are the key messages:

Early side-effects:

- This treatment can cause some degree of diarrhoea, tiredness, cystitis, loss of pubic hair and occasionally nausea. It will also cause redness and soreness of the skin in the treatment area and the skin may peel and weep. These side effects are usually temporary.

Long-term effects:

- In pre-menopausal women this treatment will stop the ovaries working causing an early menopause and infertility.
- This treatment carries a small risk of damage to the bladder, bowel, vagina and pelvic bones which can be long-term and sometimes require surgery.
- This treatment may cause some narrowing of the vagina which is usually preventable, but sometimes it impacts on sexual function.
- There may be change in colour of your skin in the treated area which may be permanent.

Before you sign the consent form...

The doctor will ask you:

- To agree that to the best of your knowledge you are not pregnant.
- To agree to what is proposed which will have been explained to you by the doctor named on the form.

You will need to check that all the information on the consent form is correct, and if you understand and are satisfied with the explanation. You will have time to consider the information before being asked to sign the consent form.

Personal record

This is for you to complete yourself. It can be useful to record your appointment times for radiotherapy and anything else that might arise.

Key worker at local hospital: Tel no:

Key worker at The Christie: Tel no:

Date of radiotherapy planning scan: Radiotherapy suite:

| Mon | Tues | Wed | Thur | Fri | Sat | Sun |
|-------------|-------------|-------------|-------------|-------------|-------------|-------------|
| Date: _____ | Date: _____ | Date: _____ | Date: _____ | Date: _____ | Date: _____ | Date: _____ |
| Date: _____ | Date: _____ | Date: _____ | Date: _____ | Date: _____ | Date: _____ | Date: _____ |
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Further information

Macmillan Cancer Support

This is a national charity which runs a cancer information service. The cancer support service freephone number is 0808 808 0000. (Monday to Friday, 9am to 8pm). If you are hard of hearing, use the textphone 0808 808 0121. If you are a non-English speaker, interpreters are available. Specially trained cancer nurses can give you information on all aspects of cancer and its treatment. Information and advice about finance and benefits are also available.

Macmillan Cancer Support publish booklets which are free to patients, their families and carers. You can get a copy by ringing the freephone number. The information is on their website: www.macmillan.org.uk

Information is available on cancer treatments – such as Understanding radiotherapy and Understanding chemotherapy. There are also booklets on living with cancer – some of these are listed below:

- Talking about your cancer
- Cancer and complementary therapies
- Travel and cancer
- Pelvic radiotherapy in women – possible late effects.

The cancer information centre at The Christie located on the glass link corridor has the full range of booklets available free to patients and their relatives/carers.

Cancer information in your language

If English is not your first language, you can speak to a nurse at Cancer Research UK through a qualified interpreter. The service is free and over 170 languages are available on 0808 800 4040.

Christie information

The Christie produces a range of patient information booklets and DVDs. Some of these are listed below:

■ **DVD: Radiotherapy: a guide**

DVDs can be borrowed to watch at home. Ask the staff on the ward, in outpatients or in Radiotherapy for copies. Available in English with sub-titles, Urdu, Bengali, Polish and Punjabi.

■ **Eating: Help Yourself**

This gives advice on eating problems when you don't feel well and you are having treatment. Other booklets give helpful advice on diet: **Advice about soft and liquidised foods, Nutritional drinks and Low fibre diet: a guide for patients and their carers**. Please ask staff for a copy.

■ **Be Active, Stay Active: a guide for exercising during and after treatment for cancer**

A booklet and DVD with a simple exercise programme you can follow. There is also more information about coping with fatigue and the benefits of exercise. Available with sub-titles, and in Urdu and Chinese.

Booklets are free to patients coming to The Christie. If you would like a copy, please ask the ward staff. If you are an outpatient please ask your nurse, doctor or radiographer.

Large print versions are available, please contact Patient Information on 0161 446 3576.

Student training

The Christie is a training hospital for postgraduate and undergraduate trainees so you may meet male and female students in all areas of the hospital. We train doctors, nurses, radiographers and other therapists in the treatment and care of cancer patients. Placements at The Christie are an important part of student training, so by allowing them to assist in your care, you will be making a valuable contribution to student education.

Students are always supervised by fully qualified staff. However, you have the right to decide if students can take part in your care. If you prefer them not to, please tell the doctor, nurse, radiographer or other therapist in charge as soon as possible. You have a right to do this and your treatment will not be affected in any way. We also try to respect the concerns of patients in relation to the gender of their doctor and other health professionals.

The Christie Hotline

The service is available 24 hours a day and 7 days a week. The Christie Hotline can provide help and support at every stage of treatment. All patients having radiotherapy can contact the Hotline for support and advice for radiotherapy reactions.

Contacting The Christie Hotline When you call the Hotline you will hear a 'welcome' message. Listen carefully and follow the instructions. The team aim to answer your call within 4 minutes. All calls are recorded for training and monitoring purposes. When you speak to the Hotline team, remember to report any new or worsening conditions.

The Christie Hotline
0161 446 3658

Benefits and finance

You may have had to stop work and had a reduction in your income. You may be able to get benefits or other financial help. You may be entitled to Personal Independence Payments but new claims cannot be made for Disability Living Allowance.

People over 65 may be able to claim Attendance Allowance.

Find out more:

- Disability Living Allowance, call the Disability Benefits Helpline on 08457 123 456
- Attendance Allowance, call 0845 605 6055
- Personal Independence Payment (PIP), call the PIP Claim line on 0800 917 2222
- Carer's benefits, call the Carer's Allowance Unit on 0845 608 4321
- Contact The Christie at Withington general and benefits advisers on 0161 446 8538 or 8539. The Christie at Oldham has a benefits advice session on Thursday afternoons phone 0161 918 7745
- Contact your local social services department for help with equipment and adaptations, or for an assessment of care needs
- Macmillan Cancer Support has an advice line on 0808 808 00 00

Useful websites: www.macmillan.org.uk or www.gov.uk

You may be able to claim travel costs for petrol and parking or public transport but not taxi fares if you receive: income-related Employment Support Allowance, Income Support, Universal Credit, Guaranteed Pension Credit or hold a valid tax credit exemption card. You may also be able to qualify for help if you are on a low income and have a valid HC2 or HC3 certificate. For advice please contact the general and benefits advisers on 0161 446 8538/8539 or ask your specialist nurse to refer you.

If you need specific advice regarding employment, you can self-refer to the employment advice worker on 0161 446 8498.

Useful contacts

■ Via your consultants' secretary

Dr Davidson – 0161 446 3330

Dr Livsey – 0161 446 8278

Dr Barraclough – 0161 446 3406

- Nurse clinician – 0161 446 8101
- Benefits Adviser – 0161 446 8539 or 8538
- Counsellor – 0161 446 8038
- Employment information and support – 0161 446 8498
- If you are having problems with your appointment times during treatment, please contact the radiotherapy department on 0161 446 3485

The Christie Website
www.christie.nhs.uk

Many of The Christie booklets and a list of UK help groups are available on The Christie website, the address is above. You can also access other patient information sites in the UK such as Macmillan CancerSupport and Cancerhelp UK via The Christie website.

We try to ensure that all our information given to patients is accurate, balanced and based on the most up-to-date scientific evidence. If you would like to have details about the sources used please contact **Patient.Information@christie.nhs.uk**



Visit the Cancer Information Centre:

The Christie at Withington Tel: 0161 446 8100

The Christie at Oldham Tel: 0161 918 7745

The Christie at Salford Tel: 0161 918 7804

Open Monday to Friday, 10am to 4pm.

Opening times can vary, please ring to check before making a special journey.



The Christie NHS Foundation Trust,
Wilmslow Road, Manchester,
M20 4BX, United Kingdom



T. 0161 446 3000

F. 0161 446 3977

Web: www.christie.nhs.uk

The Christie Patient Information Service
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