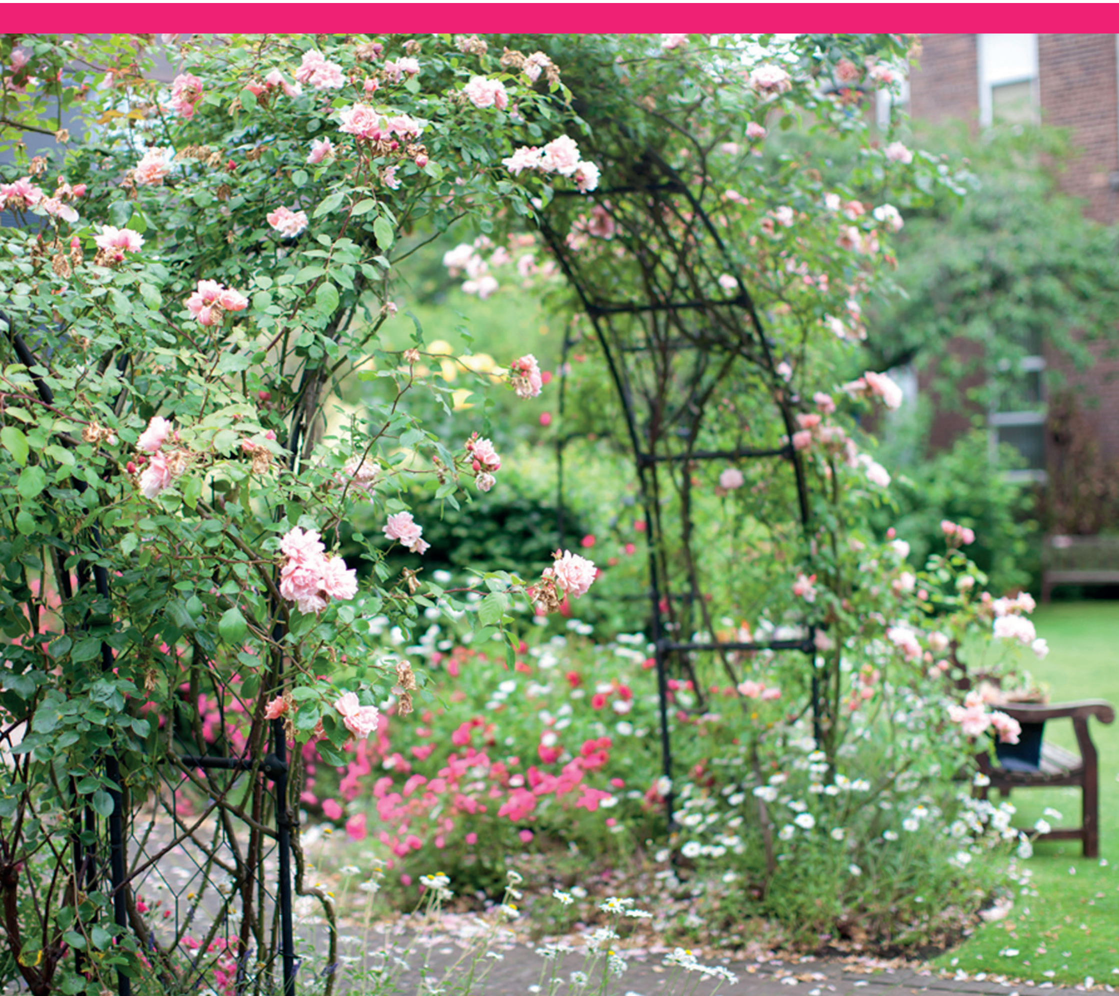
The Christie
NHS Foundation Trust

Radiotherapy for gynaecological cancers
A guide for patients and their carers



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The Christie website

For more information about The Christie and our services, please visit **www.christie.nhs.uk** or visit the cancer information centres at Withington, Oldham, Salford or Macclesfield.

Introduction

This booklet is written for people who are having radiotherapy to the pelvis for gynaecological cancers such as cancer of the womb, cervix or vagina. It describes all possible treatments, and some may not apply to you. The doctor or advanced practitioner 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 helping you. It's 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.

Please note:

Mobile phones can be used while in the department. However, you may be asked to turn your mobile on silent or vibrate while treatment takes place to avoid distracting the treating team.

What treatments are available?

A course of external beam radiotherapy treatment (XRT).

or

Internal treatment called brachytherapy where radioactive sources are placed in the womb and/or vagina. We will nurse you in bed until this treatment is finished. Sometimes it is necessary to repeat this type of treatment.

or

A combination of both types of treatment.

Some people with gynaecological cancers may also benefit from having chemotherapy. With cancer of the cervix, vulva or vagina this may be weekly chemotherapy (with a drug called cisplatin) along with the external beam radiotherapy. For cancer of the womb this may be chemotherapy every 3 weeks (with drugs carboplatin and paclitaxel) before having radiotherapy. The doctor or advanced practitioner will discuss with you what is recommended. We advise you to read the information on these treatments in the booklet '**SACT, a guide**' and the leaflets on **cisplatin**, **carboplatin** and **paclitaxel,** which are available from the nurses or doctors treating you.

When is radiotherapy offered and what are the benefits?

Each person has their 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 doctor will use the chart overleaf to explain the reasons for your treatment and the benefits of treatment you are being offered.

Chart to show your type of cancer and treatment choices

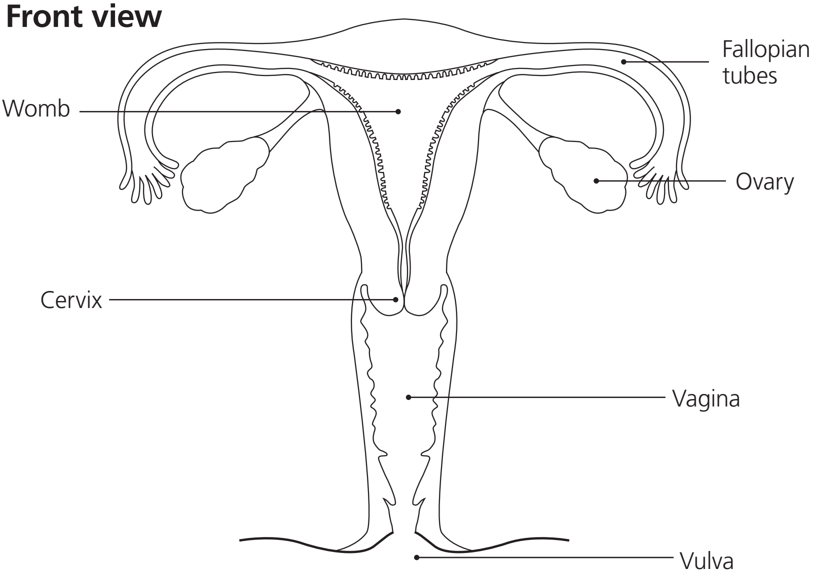
My treatment is being offered for:	☐	☐
When is radiotherapy offered?	**Cervix or vaginal cancer when surgery is not possible.**	**Womb/uterus cancer after a hysterectomy** where there is a risk of cancer cells being left behind.
What type of radiotherapy?	25 treatments of radiotherapy from the outside followed by brachytherapy (internal) treatment or a further 10 external treatments (boost).	23 treatments of radiotherapy from the outside and/or brachytherapy (internal) treatment.
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.	For certain types of cancer a course of carboplatin/ paclitaxel chemotherapy may be recommended before or after you start radiotherapy.
What is the aim of treatment?	To reduce the tumour, prevent it spreading, or 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.

☐	☐
Cervix cancer after a hysterectomy where cancer was found in lymph glands or tissues beside the cervix.	**Womb/uterus cancer where surgery is considered too high a risk** because of medical conditions e.g. heart disease or obesity.
25 treatments of radiotherapy from the outside. Sometimes followed by brachytherapy (internal) treatment.	Treatment is tailored to each patient and can involve 5 to 23 treatments of radiotherapy from the outside or both brachytherapy (internal) and external.
Cisplatin chemotherapy with radiotherapy may be offered. Patients need to be generally fit and well and have a good kidney function.	Not normally.
Treatment is being offered as there is a risk that some cancer cells may not have been removed. With this treatment the risk is reduced.	To control the tumour and in some instances to get rid of it altogether.
No, not normally.	Surgery has normally already been ruled out. Hormone and chemotherapy treatments can be useful in controlling some cancers but they do not get rid of the cancer.
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.	Your tumour will continue to grow. It may spread to other areas of your body and cause you increasing symptoms.

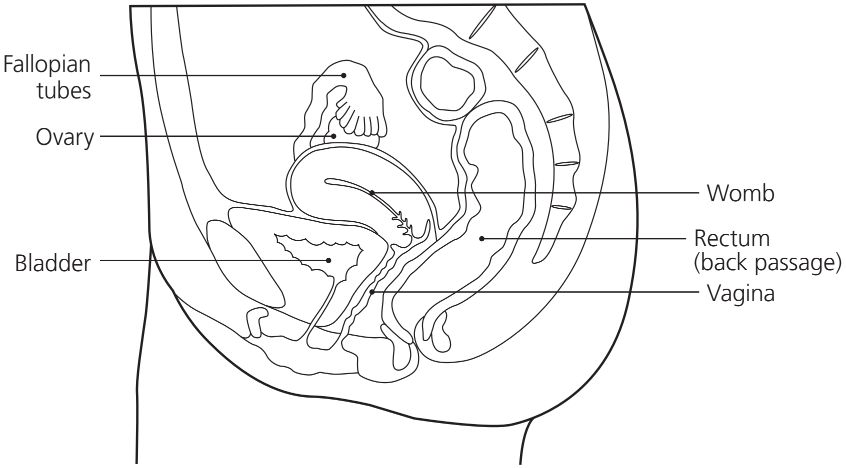
The areas being treated

These diagrams 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.

Front view



Side view



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 being 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 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.

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 an unborn child. It is important to let the radiographers know if you have missed a period, or suspect that you might be pregnant before you are exposed to any radiation.

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. This may help to 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 956 1215** or **07392 278408**. 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.

External beam

What is radiotherapy?

Radiotherapy uses exact, carefully measured doses of radiation to treat diseases. It is often given in small doses 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 professionals and 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 patients 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 it 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 specialist doctor who is in charge of your treatment is a clinical oncologist. They 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 on the details of your treatment.

You will be cared for by a team of doctors, nurses and radiographers. The team also has an advanced practitioner who specialises in caring for women with gynaecological cancers.

Your clinical oncologist at The Christie has carefully considered the nature of your illness, and your particular needs with regard to your treatment plan. During your initial radiotherapy planning appointment, the radiographers will be able to tell you exactly when you will start your treatment. As everybody's treatment varies, the amount of time needed to plan the treatment varies. You may have between 5 and 30 treatments.


CT Scanner

Planning the treatment

Treatment preparation may be done on a RTP (radiotherapy planning) scanner which is a type of CT scan. The scanner provides the doctors with images from which your treatment is planned. You may be asked have an injection of a special contrast before your scan which helps to get clearer pictures and improves the planning of your treatment. You may also be asked to drink water before the scan so that your bladder is comfortably full for the scan and for each of your radiotherapy treatments.

During this planning session the radiographers will 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 is very firm for technical reasons and is similar to the bed you will lie on when you have your radiotherapy treatment each day. If you find it uncomfortable to lie on your back or sit/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 need with you. Please discuss any particular concerns you have with your doctor or specialist nurse.

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

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

This is a complex process that usually takes 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 porter 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.

A patient being positioned by a radiographer before treatment begins

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 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 you are having difficulties with having radiotherapy, please speak to the radiographers. There may be things that they can suggest that might help such as referring you for support to the CALMS team who provide complementary therapies.

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. If you are having treatment for cervical or vaginal cancer, you may have an MRI scan during the fifth week of radiotherapy. The main reason for this is to assess whether brachytherapy is possible and whether this would be the best treatment for you.

A closed circuit television on the control desk gives the radiographers a clear view of you and they will be able to see you the whole 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 they 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, while 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** which 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 while 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, apart from when you are actually having brachytherapy (internal) treatment.

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. You often don't need a booked appointment but will be told where to wait in 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 suite will send a porter for you when they have a free slot and you will be seen regularly on the ward by your medical team.

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 advanced practitioner 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 an external provider and you need to be ready 2 hours prior to your appointment time. You can contact the transport liaison office at The Christie directly on **0161 446 8114** or **8143** for advice.

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 your GP or your specialist nurse can help you.

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?

Supporting Women After Cancer Needs (SWAN) Clinic

During the time you will be coming to the hospital for radiotherapy, we will give you an outpatient appointment for the SWAN 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 and menopause. If you would find it helpful to visit the brachytherapy treatment room before coming in to hospital, then this can usually be arranged at this appointment. Some patients find it helpful to bring their husband or partner to this appointment. It is also an opportunity to assess whether you may benefit from some additional support.

LGBTQ+

If you identify as LGBTQ+, you may have different or additional needs or concerns. Your treating team are here to support you. It helps them to know your sexual orientation or gender so they can provide you with the right information and appropriate support to help you get through the best treatment for you.

Side effects

Side effects of external and internal treatment

Acute side effects are temporary and they do not happen to all patients. 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.

Bowel

Pelvic radiotherapy can cause damage to the gut which affects its normal function. This may mean difficulty digesting and absorbing, or becoming more sensitive to some foods. It is important that you continue to eat nourishing food during and after treatment. Ask the nursing or radiotherapy staff for a copy of The Christie booklet ‘Eating – help yourself’. It can also be obtained from the cancer information centre or The Christie website. If you are struggling with the side-effects of treatment, it is important that you let your team know.

It is important that you remain hydrated. This will help to keep your stools soft and encourage movement if you are constipated, and will replace fluids lost if experiencing diarrrhoea. Examples can be found in the ‘Eating – help yourself’ booklet.

There is little scientific evidence about the best diet to follow to manage your symptoms. Food exclusions often lead to an unnecessary restrictive diet and cause anxiety over the foods we eat, unexpected weight loss and nutritional deficiencies. Dietary advice may be given to you by your team, this should be tailored to you based on your treatment, symptoms and test results. For example, it can be quite common to have too much bowel gas or ‘wind’, this can interfere with the radiotherapy treatment plan so some patients will be given special instructions and a dietary sheet ‘Dietary advice: reducing bowel gas before and during radiotherapy’. This is usually only meant to be followed for a short time during treatment and you should try to return to your normal diet as soon as you are able.

If you are not managing to eat a balanced diet, a daily over the counter complete multivitamin and mineral supplement is advised. This can be purchased from the supermarket or pharmacy.

Many patients develop diarrhoea during treatment, and are prescribed medication such as Fybogel which acts as a bowel regulator, it 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 patients 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

In a small number of cases, 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.

Following brachytherapy, if you get symptoms of cystitis such as burning, stinging, going more frequently or smelly urine, then you should see your GP. You may need antibiotics as there is a small risk of getting an infection when you have had a catheter. Bladder and bowel problems gradually get better, and most people are back to normal at their follow-up clinic visit 6 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 Christie patient information booklet 'Be active, stay active' which is available from the cancer information centre. Tiredness often affects people after treatment ends, so you may need help with housework and shopping. Some patients 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 treatment 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.

Vaginal changes

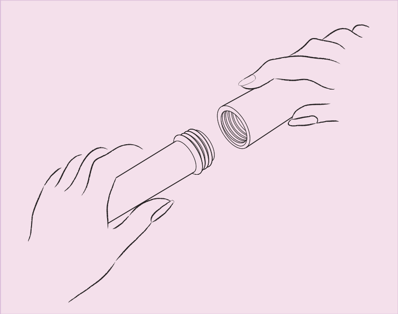
If your radiotherapy includes the vagina then you may be at risk of vaginal stenosis (shrinking, narrowing, shortening) caused by scar tissue forming in the vagina following treatment. This is more common if you are having brachytherapy (internal radiotherapy) as well as pelvic radiotherapy. If you are at risk of this, it will be discussed at the start of your treatment. You will be given extra guidance and support about dilating the vagina, which helps to keep the vagina open and normal. This is a very personal area of care, and some patients will choose not to do this. However, this can lead to the vagina becoming shorter and narrower, making it more difficult in the future to have vaginal examinations or resume sexual intercourse.

Your vagina can be kept open by vaginal dilation. Dilation means ‘stretching and opening’ and can be done by:

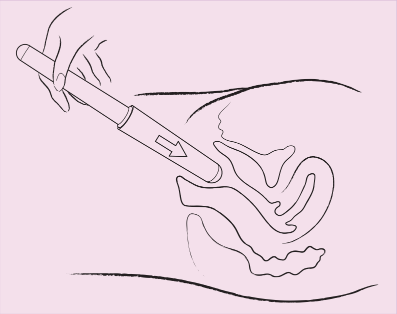
1. Use of a dilator
2. Sexual intercourse
3. A combination of intercourse and dilator use

At your SWAN appointment we will give you a vaginal dilator and some lubricating gel and we will explain to you how to use it. Lubricants such as ‘Sylk’ and ‘YES WB’ can be prescribed 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 feel free to discuss any aspect of this with a member of your medical team or at your SWAN appointment. Your feelings will always be respected.

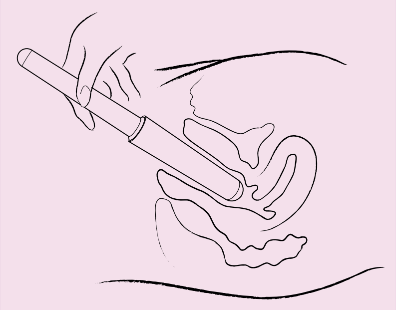
Vaginal dilation



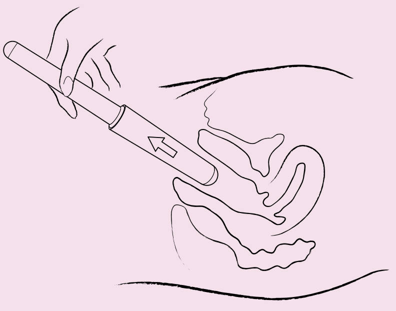
1. Connect size 1 (smallest) cone to the size 2 cone. Apply lubricating gel.



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 4 weeks after finishing your treatment, and continue to use it once a day, every day, for 6 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 the ward staff or specialist nurse for a replacement. You should not feel any pain or discomfort if you are gentle and stay relaxed while 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 1 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 it 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 5 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 then contact your specialist nurse. Most patients should be able to progress to the second size dilator within a few days. If, after 1 to 2 weeks, this is easy and comfortable to use, then progress to the third and fourth size dilator. Remember, it is important to use a 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 6 week check-up, even if you are not going to have intercourse or you are having it infrequently, we still recommend you continue to use the dilator daily for another 4 weeks and then 2 to 3 times a week for the next 2 to 3 years. You can talk to a member of the nursing/medical team at any point.

Sexual relations

It is important in close relationships to continue to have intimacy but we suggest that you avoid intercourse during radiotherapy. The top of your vagina can become inflamed and you may find intercourse uncomfortable. Also, if you have a cervical cancer, then intercourse can lead to increased bleeding. We, therefore, recommend that you do not have intercourse while you are having radiotherapy and for a short time afterwards to allow the area to heal.

However, a course of radiotherapy is the equivalent of a major operation, and it may be some months before you feel interested in the physical aspect of your relationship and your vagina is fully healed and comfortable. Many patients find that their vagina is a little dry, and at first it may help to use a vaginal moisturiser for day-to-day dryness and lubricant during intercourse or while using a dilator. Your doctor or nurse can recommend a good quality lubricant, such as ‘Sylk’ or ‘YES WB’.

If these problems last for months after treatment, please discuss this with your doctor at the follow-up visits as we would like to help you get back to your normal lifestyle. Sex is not harmful to you and will not make the cancer return.

Nausea

Some people may feel sick during their 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.

Skin/pubic hair

Most radiotherapy treatments to the pelvis do not cause sore skin. We will advise you at the start of treatment if your treatment is likely to do so, and what you can do to help yourself. Some patients do find that their pubic hair falls out during or shortly after treatment, this usually grows back but is often thinner.

Vaginal discharge or bleeding

You may find that you have a vaginal discharge. If you have had internal treatment you may have light bleeding. These are not unusual and may continue for a time after you get home. It is not likely, but if the discharge or bleeding alters in any way (for example, becomes heavier or smells unpleasant or if there is bright red heavy bleeding), phone **The Christie Hotline on 0161 446 3658** (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 diagrams on page 6 show, the bladder and bowel are very close to the cervix and womb (uterus), so they can be affected by the radiotherapy too. When planning a patient'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 people are more sensitive to radiation than others, and are more likely to experience side effects. At present, it is not possible to identify these people before treatment starts. Also, in some patients 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, bone and bladder problems.

Cancers can damage the tissues that they are growing in. Cancer of the cervix can grow towards the bowel, and/or bladder 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 visit the Macmillan Cancer Support website **www.macmilan.org.uk** and search for 'late side effects of pelvic radiotherapy'.

There is also further information available at the Pelvic Radiation Disease Association website **www.prda.org.uk**

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.

Bladder, bowel and vagina

At least half of patients treated may develop bladder, bowel or vaginal problems, but for most 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.

If your bowel symptoms persist for more than a year after treatment or they settle and then return (even years later) then please let your oncology team know about it. They may suggest a referral to a gastroenterologist who specialises in the effects of pelvic radiotherapy (pelvic radiation disease).

In a minority of patients (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 patients 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 patients 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. Your treating team will discuss with you if this is something you are particularly at risk from.

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

- Look after your skin on the legs and/or pelvic area. Keep it clean and well-moisturised and protect from any break in the skin that can be caused from cuts, grazes, insect bites or 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 of the legs or genital area then contact your GP immediately as you may need to be treated promptly with antibiotics.

The Macmillan booklet ‘Understanding Lymphoedema’ is available on their website **www.macmillan.org.uk** and contains a lot more information and useful advice. Alternatively, ask your specialist nurse for advice or written information. If you notice any signs of developing lymphoedema such as swelling, please contact your treating team or your local specialist nurse who will then give you further advice and offer to refer you on to the 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 Royal Osteoporosis Society by visiting **www.theros.org.uk** or calling their helpline on **0808 800 0035** or email **nurses@theros.org.uk**.

Infertility and early menopause

The treatment causes infertility which is permanent and will result in an early menopause.

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 a concern 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.

Some patients 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. If you would like more information about this, please ask the team treating you. The following websites also have further information:

Rock My Menopause www.rockmymenopause.com

Menopause Matters www.menopausematters.co.uk
For accurate, up to date information about menopause and treatment options.

Daisy Network for younger women www.daisynetwork.org

Research at The Christie

The Christie, along with the Manchester Cancer Research Centre, is a major centre for cancer research of all kinds. Your doctor may discuss a particular trial with you in clinic, or staff may ask you if you are willing to help with some of the clinical trials and audits that are going on. We would encourage you to ask about suitable trials at any time. We will give you detailed written information regarding the trial and its purposes. You will have time to consider your answer, discuss with family and friends and ask questions before you decide whether to take part or not. You are under no obligation to take part in any trials.

If you take part in a clinical trial, you will meet the research nurse or research radiographer who help to run the trials. You are free to withdraw from a trial at any time and for any reason. This will not affect your relationship with medical staff.

If you are in a clinical trial your follow up may be more frequent and your research nurse will discuss this with you.

After the treatment

Follow-up after treatment for gynaecological cancer

What happens after my treatment at The Christie?

When your radiotherapy treatment has finished, an 'end of treatment' letter will be sent to you and your GP. You will have regular follow-up appointments. Patients who have had a combined treatment of surgery followed by radiotherapy or chemotherapy with radiotherapy will normally have 1 outpatient appointment at The Christie and then be referred back to the gynaecologist at the hospital where you were first seen. Your appointments with the oncologist will usually be at The Christie.

Women who have been treated with radiotherapy or chemo-radiotherapy but have not had an operation will normally have all their appointments at The Christie.

When will my first appointment be?

Your first appointment will be about 6 weeks after your treatment finishes. 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. This is usually by phone unless you request a face to face appointment.

Follow-up plan

Follow-up appointments are usually arranged:

- every 3 months in the first year
- every 4 months in the second year
- every 6 months in the third, fourth and fifth year

Will I have a scan?

Most patients will be followed up with regular consultations. Whether you are scanned routinely following radiotherapy treatment or not depends on where your original cancer was and whether you have previously had surgery.

If your treatment has been for cervical or vaginal cancer and you have not previously had surgery, then patients are commonly scanned at 3 months after they have completed their radiotherapy using an MRI and PET/CT scan. 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 3 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 3 months.

If you have already had an operation to remove the cancer (for example a hysterectomy) then scans are not carried out routinely during the follow-up period as the original cancer has been removed.

Currently most patients having follow-up appointments at The Christie will then have a further MRI at 1 year, then a CT scan at 2 and 3 years. If you are uncertain please speak you your nurse or doctor.

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 have follow-up appointments.

When will I know that the cancer is gone?

Women with gynaecological cancer who are going to develop a recurrence of their cancer are most likely to do this within 2 to 3 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 2 years after treatment. For women with the common types of cancer of the cervix, uterus or vagina, it is unusual for them to have further problems from their cancer if they are free of any problems at 5 years.

Do I need further smear tests?

We do not recommend that you have further smear tests from the cervix or vagina if you have had radiotherapy to the pelvis. These are not helpful because radiotherapy makes it very difficult to understand the smear tests.

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:

- pain lasting for 2 to 3 weeks, particularly if it keeps you awake
- 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

Treatment effects

A few patients 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 Global Health Insurance Card (GHIC). 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 Macmillan booklet ‘Travel and cancer’, available from the cancer information centre.

Further information

The Christie cancer information centres

The cancer information centres provide information and support on all aspects of cancer via a drop-in service face-to-face, over the telephone or via email. We can also signpost to other services or refer on to other professionals or voluntary organisations. We provide emotional support, a listening ear and practical information to anyone affected by cancer, including relatives, carers and friends, in a relaxed and confidential environment. We also provide a hair loss support service as well as access to the wig service.

Opening hours vary depending on location so please check with the centres in advance if you are making a special journey to see us:

- Withington: Telephone **0161 446 8439**
  email **the-christie.informationcentre@nhs.net**
- Salford: Telephone **0161 918 7804**
  email **salfordcancerinfo@srft.nhs.uk**
- Oldham: Telephone **0161 918 7745**
- Macclesfield: Telephone **01625 663128/663129**

Christie information

The Christie produces a range of patient information booklets available from the patient information centre. Booklets are free to patients coming to The Christie. If you would like a copy, please ask the staff or visit the cancer information centre where you are being treated.

Macmillan Cancer Support

This is a national charity which runs a cancer information service. The cancer support service freephone number is **0808 808 00 00** (8am to 8pm, 7 days a week). If you are hard of hearing you can make text relay calls by dialing **18001** followed by **0808 808 0000**. The Relay UK app is also available to download on Google Play or Apple App Store. If you are a non-English speaker, interpreters are available. Calls are answered by specially trained cancer nurses who 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 or by visiting their website: **www.macmillan.org.uk**

Information is available on cancer treatments and on living with cancer:

A range of their booklets are also available free to patients and their relatives or carers from The Christie cancer information centres.

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 by phoning **0808 800 4040**.

Maggie’s centre

Maggie’s provides free practical, emotional and social support to people with cancer, their families and friends. Staff are on hand to offer the support you need to find your way through cancer, including information about treatment, financial advice, psychological support, relaxation and exercise classes and nutritional advice. Or simply to sit quietly with a cup of tea.

No appointment needed. Support is free.

Drop-in, Monday to Friday between 9am and 5pm.

Maggie's Manchester, The Robert Parfett Building,15 Kinnaird Road, M20 4QL

Maggie's is the pavilion style building at the bottom of Kinnaird Road. Cross Wilmslow Road, turn left and then right onto Kinnaird Road.

Tel: **0161 641 4848**

Email: **manchester@maggiescentres.org**
www.maggies.org

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.

Benefits and financial information

You may have had to stop work and had a reduction in your income. To find out more about benefits you may be able to claim, contact The Christie cancer information centres, Maggie’s Centres or Citizens Advice.

The Christie Hotline

The service is available 24 hours a day, 7 days a week by calling **0161 446 3658**. 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.

Useful contacts

- Your consultant's secretary:

Dr Haslett	**0161 446 3330**
Dr Morrison	**0161 446 8278**
Dr Barraclough /Dr Burke	**0161 446 3406**

- Gynae clinical nurse specialist **0161 956 1106**
- Theatre administrator on **0161 446 3520** for any questions about appointments or transport issues when coming for brachytherapy
- BMRU (brachytherapy and molecular radiotherapy unit) on **0161 918 2030**

- If you are having problems with your appointment times during treatment, please contact the radiotherapy department on **0161 446 3485**

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

The Christie is committed to producing high quality, evidence based information for patients. Our patient information adheres to the principles and quality statements of the Information Standard.

If you would like to have details about the sources used please contact **the-christie.patient.information@nhs.net**

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.

Keyworker at local hospital:.. Tel no: ....

Keyworker 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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Contact The Christie Hotline for urgent support and specialist advice

The Christie Hotline: 0161 446 3658

Open 24 hours a day, 7 days a week

Visit the Cancer Information Centre

The Christie at Withington **0161 446 8100**
The Christie at Oldham **0161 918 7745**
The Christie at Salford **0161 918 7804**
The Christie at Macclesfield **0161 956 1704**

Open Monday to Friday, 10am – 4pm.

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

The Christie NHS Foundation Trust
Wilmslow Road
Manchester M20 4BX

0161 446 3000
www.christie.nhs.uk

The Christie Patient Information Service
October 2025 – Review October 2028

CHR/XRT/103/12.03.03 Version 6