

Understanding cancer of the vulva



About this booklet

This booklet is about cancer of the vulva (vulval cancer). It is for anyone who has been diagnosed with vulval cancer. There is also information for carers, family members and friends.

The booklet explains how vulval cancer may be treated. It also has information about looking after yourself and getting support. We hope it helps you deal with some of the questions or feelings you may have.

We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the [contents list](#) to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages [120 to 131](#), there are details of other organisations that can help.

There is also space to write down [questions and notes](#) for your doctor or nurse.

Quotes

In this booklet, we have included quotes from people who have had vulval cancer, which you may find helpful. These are from people who have chosen to share their story with us. To share your experience, visit macmillan.org.uk/shareyourstory

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on [0808 808 00 00](tel:0808 808 00 00), 7 days a week, 8am to 8pm, or visit macmillan.org.uk

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using Relay UK on [18001 0808 808 00 00](tel:18001 0808 808 00 00), or use the Relay UK app.

We have some information in different languages and formats, including audio, easy read, Braille, large print, interactive PDFs and translations. To order these, visit macmillan.org.uk/otherformats or call [0808 808 00 00](tel:0808 808 00 00).

Contents

About cancer of the vulva	5
Staging and grading of vulval cancer	17
Preparing for treatment	23
Treating vulval cancer	31
After treatment	83
Your feelings and relationships	101
Financial support and work	107
Further information	113



About cancer of the vulva

What is cancer?	6
The vulva	8
Types of vulval cancer	12
Finding out you have vulval cancer	14
Your data and the cancer registry	15

What is cancer?

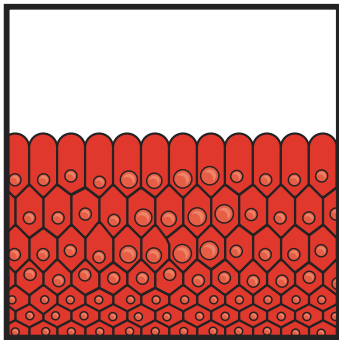
Our bodies are made up of tiny building blocks called cells. Inside every cell is a set of genes. Genes are the instructions the cell needs to work properly.

The instructions send signals to cells to grow and divide and make new cells. This is how our bodies grow and heal. Over time, cells become old or damaged. When this happens, signals tell the cell to stop working and die.

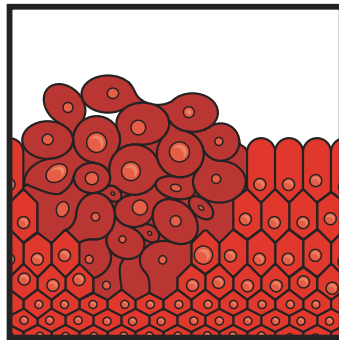
Sometimes genes in the cell can develop changes. If a gene is changed, it may not give the correct instructions anymore. A change in a gene is called a gene variant or mutation.

Gene variants in a cell may stop the cell working normally. Cancer may develop if cells like this multiply in an abnormal way and grow out of control. Over time, these cells can grow into a lump called a tumour.

Abnormal cells forming a tumour



Normal cells



Cells forming a tumour

Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample to look for cancer cells. This is called a biopsy.

Tumours that are not cancer are called benign. Benign tumours cannot spread anywhere else in the body. But they can cause problems if they grow and press on nearby organs.

Tumours that are cancer are called malignant. Malignant tumours can grow into nearby tissue and spread to other parts of the body.

Cancer can spread from one place (the primary site) to another through the blood or [lymphatic system](#). When cancer spreads and grows somewhere else, it is called a secondary cancer or metastasis.

Cancer can start in any type of cell. This includes tissue or skin cells and cells that form the lining of the organs. It can also start in stem cells in the bone marrow. Stem cells make blood cells. Cancer that starts in stem cells does not cause a tumour. Instead, the stem cells create abnormal blood cells that behave differently from healthy blood cells.

The vulva

Vulvas are the visible sex organs that surround the opening of the vagina outside the body. People who have a vulva include women, transgender (trans) men and people assigned female at birth.

The vulva is made up of:

- 2 thin, delicate folds of skin called the labia minora
- 2 large, hair-covered folds called the labia majora – these surround the labia minora.

Between the labia are 2 openings:

- the entrance of the vagina – this is the birth canal
- the opening of the urethra – this is the tube that drains urine from the bladder.

At the front of the vulva is the outer tip of the clitoris. The clitoris is a sensitive structure that helps with sexual response and orgasm.

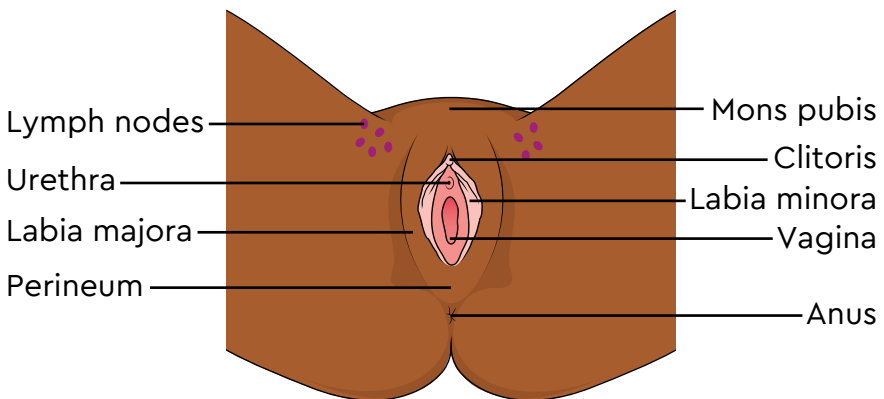
On either side of the vagina are 2 small glands called Bartholin's glands. These make a fluid that acts as a lubricant during sex.

Above the vulva is an area of fatty tissue called the mons pubis.

Further back, in between the buttocks, is the opening to the back passage (anus). The area of skin between the anus and vulva is called the perineum.

The area where the skin creases at the top of each leg is called the groin. There are lymph nodes under the skin of the groin. These are part of the body's [lymphatic system](#).

The vulva and lymph nodes



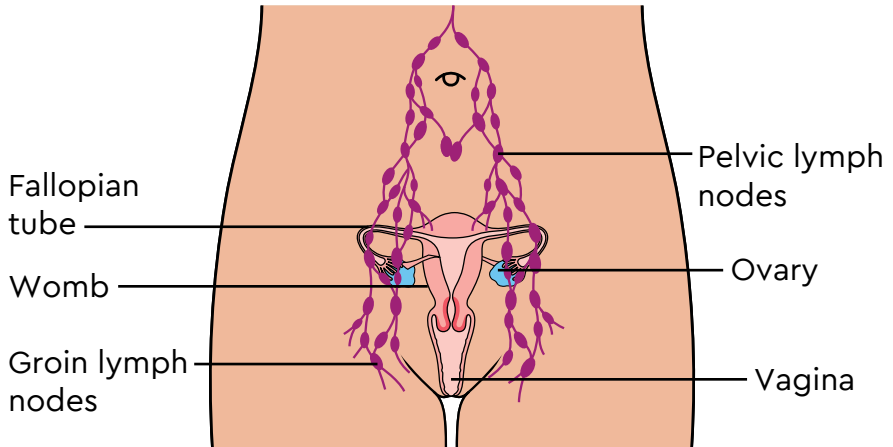
Vulval cancer and the lymphatic system

The lymphatic system helps to protect us from infection and disease. It also drains lymph fluid from the tissues of the body before returning it to the blood. The lymphatic system is made up of fine tubes called lymphatic vessels that connect to groups of lymph nodes throughout the body.

Lymph nodes are small and bean shaped. They are sometimes called lymph glands. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, lymph nodes often swell as they fight the infection.

Sometimes, cancer can spread through the lymphatic system. If vulval cancer spreads in this way, it is most likely to affect the lymph nodes in the groin.

The vulva and lymph nodes in the groin



Types of vulval cancer

Cancer of the vulva is rare. Around 1,400 women are diagnosed with it each year in the UK. It can affect anyone who has a vulva. This may include women, transgender (trans) men and people assigned female at birth.

Vulval cancer can affect any part of [the vulva](#). The most common area for it to develop is the skin of the labia. It can also sometimes affect the tip of the clitoris or the Bartholin's glands.

Squamous cell carcinoma

This is the most common type of vulval cancer. 9 in 10 vulval cancers (90%) are squamous cell carcinomas. It can take many years to develop. It usually starts with pre-cancerous changes to the outer layer of the skin cells of the vulva.

Verrucous carcinoma is a very rare, slow-growing type of squamous cell carcinoma that looks like a large wart.

Rarer types

There are other types of vulval cancer, but these are not as common.

Melanoma

This is a type of skin cancer that develops from cells that produce the pigment that gives skin its colour. Rarely it can develop in the skin of the vulva.

Basal cell carcinoma

This is a cancer that develops from cells called basal cells. These are found in the deepest layer of the skin of the vulva.

Adenocarcinoma

This is a cancer that develops from cells that line the glands in the vulval skin.

Bartholin's gland cancer

This is a cancer that develops in the Bartholin's glands at the opening of the vagina.

Sarcoma

Sarcomas develop from cells in tissue such as:

- muscle
- fat
- blood vessels under the skin.

They tend to grow more quickly than other types of vulval cancer.

Finding out you have vulval cancer

Being diagnosed can cause many different emotions. There is no right or wrong way to feel. You may have been worrying about having cancer for a while. Or your diagnosis might have been unexpected. Having tests and waiting for test results can be a difficult time.

This information is written for people who have already been diagnosed with vulval cancer. We have more information about possible causes, risk factors and symptoms of vulval cancer as well as tests used to diagnose vulval cancer. Visit macmillan.org.uk/vulval-cancer

Waiting for treatment to start can be a difficult time. You may be worried about telling people and about what treatment options you will have. You might choose to spend some time reading about the cancer, or you may prefer to wait until you meet with your cancer doctor. Do what feels right for you.

If you need support, you can contact our cancer support specialists on the Macmillan Support Line. They will be able to talk to you about what has happened and any worries you have.

Call the Macmillan Support Line free on
[0808 808 00 00](tel:08088080000), 7 days a week, 8am to 8pm.



Your data and the cancer registry

When you are diagnosed with cancer, some information about you, your diagnosis and your treatment is collected in a cancer registry.

The information is used to help understand cancer in the UK better. This is important for planning and improving health and care services. It can be used to ensure that people living with cancer get the best possible care and support.

Hospitals automatically send information to the cancer registry. There are strict rules about how the information is stored, accessed and used. Information about health is sensitive, so by law it has to be kept under the highest levels of security.

If you have any questions, talk to your doctor or nurse. If you do not want your information included in the registry, you can contact the [cancer registry](#) in your country to opt out.



Staging and grading of vulval cancer

Staging and grading

18

Staging and grading

The stage of a cancer explains its size and whether it has spread beyond the area it first started in. Knowing the stage of the cancer will help you and your doctor decide on the best [treatment](#) for you.

Number staging

The number staging system is often used for vulval cancer. It may help to look at the [diagram of the vulva](#) when you are reading this.

Stage 1 and 2 cancers are often called early stage cancers. Stage 3 and 4 cancers are called advanced stage cancers.

Stage 1

The cancer is only in the vulval area and has not spread to the lymph nodes.

Stage 1A

The cancer is up to 2cm in size and has grown up to 1mm deep into the skin.

Stage 1B

The cancer is more than 2cm in size, or it has grown more than 1mm deep into the skin.

Stage 2

The cancer is any size and has spread to nearby areas such as the:

- lower part of the urethra – this is the tube you pass urine through
- lower part of the vagina
- anus.

It has not spread to lymph nodes.

Stage 3

The cancer is any size and has spread to nearby areas. It may have spread to nearby lymph nodes.

Stage 3A

The cancer has spread to the:

- upper part of the urethra
- upper part of the vagina
- bladder
- rectum.

Or the cancer has spread to the nearby lymph nodes, but they are 5mm or smaller in size.

Stage 3B

The cancer has spread to the lymph nodes, and they are more than 5mm in size.

Stage 3C

The cancer has spread to the lymph nodes and has also spread outside the capsule that surrounds the lymph node.

Stage 4

Stage 4 is divided into 2 stages.

Stage 4A

The cancer is any size and has done any of the following:

- It has become fixed to the pelvic bone.
- It has spread to lymph nodes in the groin, and these lymph nodes have formed an ulcer or cannot be moved – they have become fixed.

Stage 4B

The cancer has spread to:

- the lymph nodes in the pelvis
- other parts of the body that are further away, such as the lungs.

TNM staging

Another staging system called TNM staging is sometimes used.

TNM stands for tumour, node and metastases.

T describes the size of the tumour. This is usually a number between 1 and 4. 1 is a small cancer and 4 is a larger or more advanced cancer.

N describes whether the cancer has spread to the lymph nodes. The number can be between 0 and 3. 0 means there are no cancer cells in the lymph nodes. 3 means more lymph nodes are affected by cancer.

M describes whether the cancer has spread to another part of the body. This is called metastatic or secondary cancer. The number is either 0 or 1. 0 means the cancer has not spread to other parts of the body. 1 means it has spread.

Grading

Grading is how the cancer cells look under a microscope compared to normal cells. The grade may help your doctor decide whether you need further treatment after surgery:

- Grade 1 or low grade or well differentiated means the cancer cells look similar to normal cells, and they usually grow slowly and are less likely to spread.
- Grade 2 or moderate grade or intermediate grade means the cancer cells look more abnormal, and they are slightly faster growing.
- Grade 3 or high grade or poorly differentiated means the cancer cells look very different from normal cells, and they may grow more quickly.

Grading is now less commonly used for vulval cancer. This is because doctors can tell more about how cancer cells may behave if an infection called human papillomavirus (HPV) is present in the vulval cancer cells. HPV is the main risk factor for vulval cancer.

We have more information about HPV and the causes and risk factors of vulval cancer on our website. Visit:

- [macmillan.org.uk/HPV](https://www.macmillan.org.uk/HPV)
- [macmillan.org.uk/vulval-cancer-causes](https://www.macmillan.org.uk/vulval-cancer-causes)



Preparing for treatment

Treatment overview

24

Treatment overview

Treatment for vulval cancer may include surgery, radiotherapy and chemotherapy. Your cancer team will explain the different treatments.

Your treatment plan is based on:

- the [type](#) of vulval cancer
- the [stage and grade](#) of the cancer
- your general health
- your personal preferences.

If [surgery](#) is possible, this is usually the main treatment. The aim is to completely remove the cancer.

Chemotherapy and radiotherapy may be given together as the main treatment instead of surgery. This is called [chemoradiation](#). Or you may have [radiotherapy](#) on its own.

Radiotherapy and chemotherapy may be given after surgery to reduce the risk of the cancer coming back. Sometimes they may be used to shrink the cancer before surgery.

Cancer that comes back may be treated again with surgery, radiotherapy or chemotherapy.

If the cancer has spread to other parts of the body, this is called advanced or metastatic cancer. Chemotherapy or radiotherapy may be used on their own to treat advanced or metastatic cancer. The aim is to manage any symptoms caused by the cancer and improve quality of life. This is called palliative treatment.

How your treatment is planned

After your test results, you and your doctor start to talk about your treatment. Your doctor usually meets with other specialists to get their opinions too.



Multidisciplinary team (MDT) meeting

A team of specialists meet to talk about the best treatment for you. This is called a multidisciplinary team (MDT).

The MDT uses national treatment guidelines or the latest evidence for the type of cancer you have. If you have any treatment preferences, your doctor will tell them about this.

The MDT will usually include the following professionals:

- A gynaecological oncologist is a surgeon who treats cancers of the female reproductive system.
- An oncologist is a doctor who treats people who have cancer.
- A clinical nurse specialist (CNS) is a nurse who gives information about cancer, and support during treatment.
- A plastic surgeon is a doctor who does operations (surgery) to repair or reconstruct tissue and skin.
- A radiologist is a doctor who looks at scans and x-rays to diagnose problems.
- A pathologist is a doctor who looks at cells or body tissue under a microscope to diagnose cancer.

It may also include other healthcare professionals, such as:

- a dietitian
- a physiotherapist
- an occupational therapist
- a radiographer
- a psychologist
- a counsellor.

Talking about your treatment plan

After the MDT meeting, you will usually meet with your cancer doctor and specialist nurse. They will talk to you about your treatment plan. It can help to write down your questions before you meet with them.

You may want to ask a family member or friend to come with you. They can help remember what is said and talk with you about it afterwards. You need to know as much as possible before you can make any treatment decisions.

Your cancer doctor should explain:

- the aim of the treatment – whether it is to cure the cancer or control it
- the benefits of the treatment
- the disadvantages of the treatment – for example, the risks and side effects
- any other treatments that may be available
- what may happen if you do not have the treatment.

Cancer treatments can be complex. It can also be hard to concentrate on what you are being told if you are feeling anxious. If the doctor says something you do not understand, ask them to explain it again.

Most people worry about the side effects of treatment. Your doctor or nurse will explain how side effects can be controlled and what you can do to manage them. They can also tell you whether your treatment is likely to cause any late effects and how these can be managed.

You may need more than one meeting with your cancer doctor or specialist nurse to talk about your treatment plan.

Making treatment decisions

You and your doctor can decide together on the best treatment plan for you. Your doctor is an expert in the best treatments. But you know your preferences and what is important to you. You can decide how involved you want to be in your treatment plan.

Sometimes doctors need to review a treatment plan. This may be when more information about the cancer becomes available – for example, when the doctor knows the results of surgery to remove the cancer. It may mean making more decisions with your doctor.

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on [talking about your treatment plan](#).

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment.

Always talk to your doctor about any concerns you have, so they can give you the best advice.

We have more information about consent on our website. Visit [macmillan.org.uk/treatment-consent](https://www.macmillan.org.uk/treatment-consent)

Second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your cancer doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your cancer doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you meet with for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website. Visit macmillan.org.uk/second-opinion



Group Room

Fire
exit

Treatment Room 2



Treating vulval cancer

Surgery	32
Radiotherapy	54
Chemotherapy	72
Immunotherapy	79
Clinical trials – research	80

Surgery

The aim of surgery is to remove all the cancer. The surgeon will remove the area of skin where the cancer is and some healthy tissue all around it.

How much tissue they need to remove depends on different things. This includes the [size of the cancer](#) and where in the vulva it is. They may also [remove some lymph nodes](#) during the operation.

Your surgeon will talk with you about your operation and what it will involve. They will explain whether you are likely to need further operations to [reconstruct the vulva](#). A specialist nurse will also give you information and support before and after your operation. It is important to ask any questions and talk about any worries you have about the surgery.

Your surgeon or specialist nurse will also explain what to expect after surgery and about possible side effects. It is important to understand the possible changes and the support your team can give you to help you cope.

Types of surgery

There are different operations to treat cancer of the vulva, depending on the size and position of the cancer. If the cancer is very small, it may be possible to remove only a small area of the vulva. If the cancer is larger, you may need a bigger operation to remove more of the vulva. Many people may also need some lymph nodes removed during surgery.

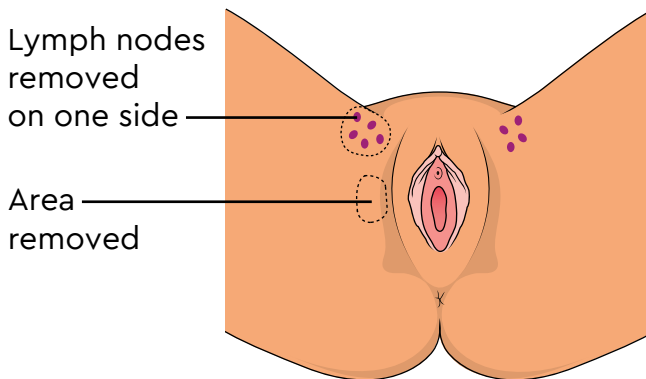
Wide local excision

This operation is sometimes called a radical local excision. The surgeon takes away the cancer and a border of healthy tissue all around the cancer. This is called the margin. The margin is usually at least 1cm wide. This helps to lower the risk of the cancer coming back.

If there are other vulval skin changes in the surrounding area, the surgeon usually removes this during surgery as well – for example, this may include vulval intraepithelial neoplasia (VIN). We have more information on our website. Visit macmillan.org.uk/VIN

You may have lymph nodes removed from one or both sides of the groin as well. This depends on where the cancer is, its size and how deeply it has grown.

Vulval surgery



Partial vulvectomy

If the tumour is larger, more of the vulval skin will be removed. This is to make sure there is a border of healthy tissue all around the cancer. This border of healthy tissue is called the margin. This helps to lower the risk of the cancer coming back.

This operation is sometimes called a radical partial vulvectomy.

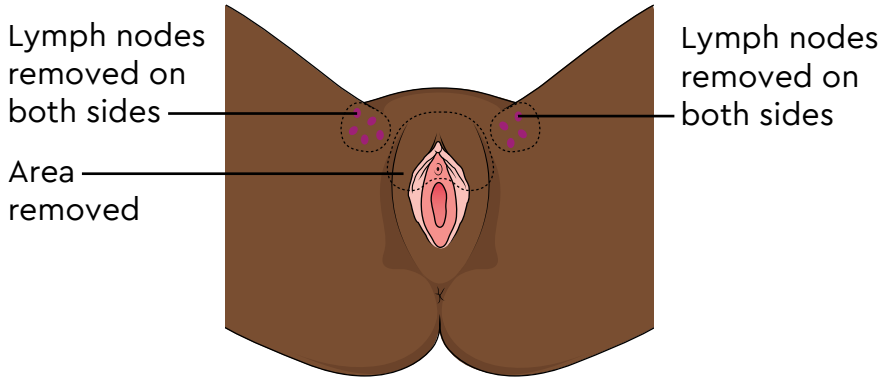
You may also have lymph nodes removed from one or both sides of the groin. This may depend on where the cancer is, its size and how deeply it has grown.

Surgery to remove the front area of the vulva is called an [anterior vulvectomy](#). This operation sometimes involves removing part of the clitoris or the end of the urethra – this is the tube that drains urine (pee) from the bladder. Removing part of the urethra does not usually affect how you pee. But some people find that it affects the spray of the pee.

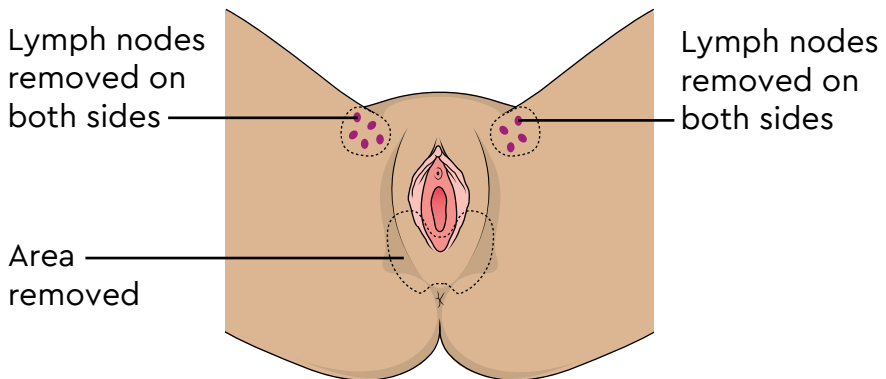
Surgery to remove the back area of the vulva is called a [posterior vulvectomy](#).

When only one side of the vulva is removed, it is called a [hemi-vulvectomy](#).

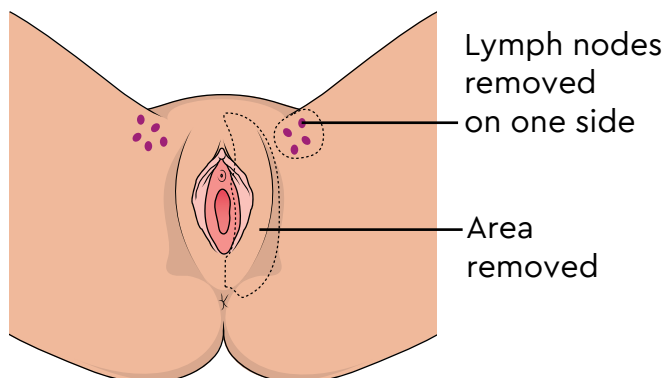
Anterior vulvectomy



Posterior vulvectomy



Hemi-vulvectomy



Vulvectomy

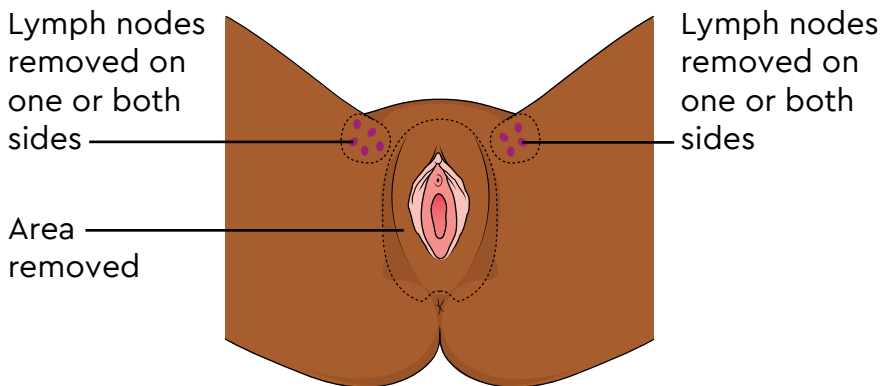
This operation removes the whole vulva, including the inner and outer labia, and the clitoris. It is also called a radical or total vulvectomy.

This type of surgery may be needed if the cancer is:

- very large
- in the middle part of the vulva
- affecting lots of areas of the vulva, and with other vulval skin changes covering a large area.

The lymph nodes are also removed from one or both sides of the groin. Your surgeon and specialist nurse can explain more about this operation.

Radical vulvectomy



Removing and checking the lymph nodes in the groin

Your surgeon or specialist nurse may talk to you about removing lymph nodes in the groin. They will explain what to expect and about any possible side effects.

During the operation, the surgeon may also remove:

- some nearby lymph nodes to check them for cancer cells – this is called a sentinel lymph node biopsy (SLNB)
- lymph nodes affected by cancer from one or both sides of the groin
- lymph nodes that are likely to contain cancer cells from one or both sides of the groin.

We have more information about sentinel lymph node biopsies on our website. Visit macmillan.org.uk/SLNB-vulval-cancer

Reconstructing the vulva

Depending on the area that is removed, you may need surgery to reconstruct the shape and form of the vulva. This is usually at the same time as the operation to remove the cancer. But it can also be done later.

If only a small amount of skin is removed from the vulva, you may not need reconstruction. The surgeon may be able to stitch the remaining skin neatly together. Or they may leave it to heal naturally. This will also depend on the site of the cancer.

If a larger area of skin is removed, you may need to have a reconstruction with a skin graft or skin flap.

Skin grafts

The surgeon takes a piece of skin from another part of the body and places it over the area where the cancer was removed from.

The place where the surgeon takes the skin from is called the donor site. This is usually the thigh or buttock. The place where the surgeon moves the skin to is called the grafted area. The amount of skin they take depends on the area they need to cover. Your surgeon will tell you more about this.

Skin flaps

A skin flap is a slightly thicker layer of skin than a graft. The surgeon takes it from an area close to the vulva. They cut the flap away but leave it partially connected so it still has a blood supply. The surgeon moves the flap over the wound and stitches it in place. If you have a skin flap, you may need to stay in hospital for a few days.

Skin flap surgery is very specialised. You may have to travel to a different hospital to have it. If you need a skin flap, your surgeon will tell you more about it.

Pelvic exenteration

Pelvic exenteration is a major operation where any affected organs are removed. It may be offered if the cancer has spread to organs close to the vulva. This includes the:

- womb
- bladder
- lower bowel.

It may still be possible to have an operation to remove the cancer.

Recovery after this type of operation can be difficult both physically and emotionally. So it is not done very often. But sometimes this operation may be the only way to completely remove the cancer.

This type of surgery is rare for vulval cancer. This is because it is more common to have chemotherapy and radiotherapy together. This is called [chemoradiation](#).

We have more information on our website about pelvic exenteration for women and people assigned female at birth. Visit macmillan.org.uk/pelvic-exenteration-for-women

Your doctor can also give you more information.

Stoma

For some people, surgery will involve having a stoma. But this is not common. A stoma is when the surgeon makes an opening through the tummy (abdomen) wall. It lets the bowel connect to the surface of the tummy.

Stool (poo) no longer passes out of the rectum and anus in the usual way. Instead, it passes out of the stoma, into a disposable bag that is worn over the stoma.

A stoma may be temporary or permanent depending on the reason you are having it. Your cancer doctor or specialist nurse will explain this to you.

You may need a stoma:

- if the cancer has affected the anus or rectum, and your surgery involves removing these areas
- to manage symptoms until you have had other treatments, such as chemotherapy or radiotherapy.

It can take time to adjust to having a stoma. If you need a stoma as part of your surgery, you will meet a stoma nurse. They will give you lots of information and support, before and after your surgery.

We have more information about stomas on our website. Visit [macmillan.org.uk/what-is-a-stoma](https://www.macmillan.org.uk/what-is-a-stoma)





Before your operation

If you smoke, try to stop or smoke less before your operation. This will help reduce your risk of chest problems. It will also help your wound heal after the operation.

Your GP can help you if you want to stop smoking. [Stop smoking organisations](#) can also help. We have more information about stopping smoking online. Visit macmillan.org.uk/stop-smoking

You usually go to a pre-assessment clinic a few days or weeks before the operation. You will have tests to check that you are fit for surgery. These may include blood tests and an electrocardiogram (ECG) to check your heart.

A member of the surgical team and a specialist nurse will explain the operation to you. Make sure you tell them if you have any questions or concerns about the operation.

You will also have an appointment with the doctor who will give you the anaesthetic. They are called an anaesthetist. They will talk to you about the anaesthetic and how to control your pain after the operation.

You usually go to hospital on the day of your operation. Sometimes, you may go the day before. Your doctor or nurse will tell you when you need to arrive.

You will be given elastic stockings to wear during and after the operation. These are called TED stockings. They prevent blood clots forming in your legs.

After your operation

How quickly you recover depends on the type of operation you have.

The nurses will advise you to start moving around as soon as possible. While you are in bed, it is important to move your legs regularly and do deep breathing exercises. This helps prevent chest infections and blood clots. A physiotherapist will show you how to do these exercises.

You may also have regular injections of a blood thinning drug to help reduce the risk of blood clots. You usually continue the injections after you go home. Your nurse will teach you or a relative how to give the injections, or arrange for a district nurse to visit you at home.

If you have had [lymph nodes removed from your groin](#), try to put your feet up when you are sitting down. This helps to reduce leg swelling.

In the ward

You will be given fluids into a vein in your hand or arm. This is called a drip or intravenous infusion. It will be taken out when you are eating and drinking again.

You usually have a tube put in that drains urine from your bladder. This is called a catheter. It may be taken out a few hours after your surgery, or it may need to stay in for longer.

If your [lymph nodes have been removed](#), you will have a drainage tube going into your groin. This is to remove fluid that may collect there.

The drain is connected to a small suction bottle. Your nurse removes it from your groin when most of the excess fluid has drained off. This usually takes a few days. You can go home with the drain if needed. A practice nurse or a community nurse may check it when you are at home. Or you might have it checked and removed at the hospital.

Pain

It is normal to have some pain or discomfort for a few days after surgery. Painkillers can help with this. It is important to tell your doctor or nurse as soon as possible if the pain is not controlled. They may need to change your painkillers.

Immediately after your operation, you may have strong painkillers in one of the following ways:

- The nurse may give you painkillers as an injection into a muscle.
- You may have an epidural. This is a small, thin tube in your back that goes into the space around your spinal cord. It will give you continuous pain relief.
- You may have a patient-controlled analgesia pump (PCA pump). This is attached to a fine tube (cannula) in a vein in your arm. You control the pump by pressing a button when you need more painkiller. It is fine to press the handset whenever you have pain. The pump will not let you give yourself too much painkiller.

When you no longer need strong painkillers, you will get painkillers as tablets. You may get a supply to take home with you. Tell your nurse or doctor if you are still in pain, so they can change the dose or the type of painkiller.

Your wound

The nurses will help you care for your wounds in hospital. They will also give you advice about caring for your wounds at home.

Some people do not need a dressing on the vulval wound. The area is cleaned by gently rinsing with water and carefully drying. This usually happens at least once a day until you go home.

If you do have a dressing, your nurse will change it regularly and remove it after a few days.

If you have groin wounds, the dressings need to be changed regularly. Sometimes, wounds near the groin take longer to heal than wounds in other areas.

If you had a [skin graft](#), you may have dressings on the area the skin was taken from. This is called the donor site.

Usually, these dressings stay on until new skin has grown. How long it takes to heal depends on how much skin was removed. Your surgeon or specialist nurse can give you more information.

Sometimes vacuum-assisted therapy (VAC® therapy) can help wounds heal. VAC® therapy uses a pump or suction machine attached to a dressing on the wound. It gently draws fluid out of the wound and helps with healing by encouraging blood flow to the affected area. VAC® therapy may be in hospital or managed at home by a community nurse.

Some types of stitches are left in place and dissolve away over time. If you do not have this type, your stitches or staples will be removed. Usually this is about 7 to 10 days after your operation. If you have had [reconstruction surgery](#), your surgeon may leave them in for longer.

Wound infections can happen after surgery. It is important to tell your cancer doctor or specialist nurse if you get any of these signs of infection, even after you go home:

- the wound feels hot or swollen
- the wound changes in colour and looks darker or red
- discharge (fluid or pus) is coming from the wound
- you feel unwell
- you have a fever or high temperature.

Constipation

It is normal not to have bowel movements for a few days after your operation. This may be caused by:

- the operation
- your painkillers
- changes to your diet and activity levels.

Your cancer doctor may give you laxatives to prevent constipation. Tell them if bowel movements are painful or difficult. They can give you extra laxatives to help.

How the vulva looks

If you have never looked at your vulva before, the idea of doing so may seem strange. It is okay not to look at all. It is also natural to want to know how things have changed after surgery.

To start with, you will have some bruising and swelling around the vulva. This should slowly get better as you recover from surgery. Some types of surgery will change how the vulva looks long term. Your nurse can explain what to expect and give you support and advice.

You may want to be by yourself when you look for the first time. Or you might want a nurse, partner, relative or close friend with you. Whoever you choose, make sure it is someone that you trust and can talk to about your [feelings](#).

Do not force yourself to look before you feel ready. Remember that you may feel shocked, even if you are well prepared. People cope with changes in appearance differently. Some people may not be upset. Others may find these changes harder to cope with.

We have more information in our booklets:

- [Body image and cancer](#) – this is also available as an [audiobook](#)
- [Feel more like you](#).

You can listen to our audiobooks or order booklets for free.
Visit orders.macmillan.org.uk or call [0808 808 00 00](tel:08088080000).



Getting support

It is common to feel upset and tearful after the operation. This is often a reaction to:

- the diagnosis of cancer
- having the operation
- adjusting to any changes after surgery.

These feelings may go after some time, or you may continue to feel this way. Tell your cancer doctor, specialist nurse or GP if you are not feeling better or if you begin to feel very low. You may need extra help and support.

Some hospitals have local support groups for people who have gynaecological cancers, such as vulval cancer. If you think you would find a support group helpful, ask your specialist nurse if there is one in your hospital or local area.

You may want to talk about your feelings with an [organisation that specialises in vulval cancer](#).

You could also join an online support group, such as our Online Community. You can chat with other people who have vulval cancer. Or you can just read the posts or blogs. For more information or to join, visit macmillan.org.uk/community

Going home from hospital

When you go home, you will not be able to do a lot straight away. You will need to rest for a few weeks. But it is important to keep moving. How long it takes you to recover depends on the type of operation you had.

If you had major surgery, it is very important not to lift any heavy objects for at least 6 to 8 weeks. This will let the skin heal completely.

You may find some movements uncomfortable if you had [lymph nodes removed from the groin](#). This may include walking or getting into a bath. This is normal and will get easier as your wounds heal.

You can usually start driving about 6 weeks after the operation. Always check with your cancer doctor or specialist nurse and car insurance provider before driving. They may want you to wait longer before you drive again.

If your operation involved removing only a small amount of skin, your recovery will be much quicker. Your doctor will tell you what to expect and how to look after yourself.

Here are some helpful tips for coping after surgery to the vulval area:

- Keep your wound clean. You could rinse the area with a handheld shower. Or you may find it easier to use something called a sitz bath. This is a small basin that fits over the toilet. This lets you soak just your buttocks and genital area.
- Keep your wound dry. Try using a hairdryer on a cool setting to dry the vulval skin. Or gently pat your skin dry with a clean towel.
- Avoid using any lotions, perfumed products and talcum powders in the area where you had your operation.

- If passing urine (peeing) makes your wound sting, try pouring a small jug of lukewarm water over the wound while you are passing urine.
- Wear loose-fitting clothing made from cotton rather than synthetic material.
- Some people will need to wear underwear to hold pads or dressings in place. But if you can avoid wearing underwear, this may feel more comfortable.
- If you are constipated, ask your doctor for laxatives.
- Take short walks, but avoid doing a lot of walking until the skin has healed.

Before you leave hospital, your team may arrange for a district nurse to visit you at home. They can also organise other support services if you need them. If you need help with a wound or a wound drain, the community nurses can visit you at home.



Sex

Your surgeon will usually advise not to have sex for at least 6 weeks after your operation. This gives your wound time to heal properly. After that, most people will be able to gradually get back to their usual sex life. But you may need more time before you feel ready, especially if you are having other treatments as well.

Some people may develop tightening and scar tissue at the entrance to the vagina. This can make sex painful and difficult. It is important to talk to your cancer doctor or specialist nurse if this happens. They can give you advice and support. They may suggest using lubrication to help. They may also give you vaginal dilators to reduce tightening.

If the clitoris was removed at the time of surgery, sex can feel different. It may be more difficult to orgasm. Your cancer doctor or specialist nurse will talk to you about this before the operation.

We have more information about how treatment may [affect your sex life](#). We also have more information in our [booklet](#) and [audiobook](#) **Cancer and your sex life**.

You can listen to our audiobooks or order booklets for free.
Visit orders.macmillan.org.uk or call [0808 808 00 00](tel:08088080000).



Bladder and bowel problems after surgery

Surgery for vulval cancer does not usually cause long term bladder or bowel problems.

If part of the vulva is removed, the stream of urine may spray or flow to one side. This may feel a little odd the first few times you pass urine. This also may happen if you have the lower part of the urethra removed – this is the tube that you pass urine through.

Sometimes, if you have the lowest end of the bowel (anus and rectum) removed, this may affect how you have a bowel movement. Your doctor or nurse will talk to you about any possible side effects before the operation.

Nerve damage

Sometimes surgery affects the nerves and causes numbness, tingling, or pins and needles in the area around the vulva. It can also cause a change in sensation in the groin or down the legs. This usually improves in the months after surgery. Sometimes it is permanent.

Follow-up

At your follow-up appointment, your surgeon will check how you are recovering from the operation. They will also give you information about any further treatment you may need.

If you have any problems or worries before this follow-up appointment, contact your cancer team for advice. [More help and support](#) is available.

Radiotherapy

Radiotherapy uses high-energy rays, such as x-rays, to treat cancer cells. The type of radiotherapy usually used to treat vulval cancer is called [external beam radiotherapy](#). This is when the treatment is given from a machine outside the body.

Sometimes treatment is given by putting a radioactive source inside the body. This is called [internal radiotherapy or brachytherapy](#).

You may have radiotherapy:

- before surgery – to try to shrink the cancer and make a smaller operation possible
- after surgery – to reduce the risk of the cancer coming back if the cancer was not completely removed or was close to the border (margin) of the tissue removed and you cannot have further surgery
- as your main treatment if you cannot have surgery – it may be given along with chemotherapy (chemoradiation)
- if cancer was in the lymph nodes
- if vulval cancer has come back.

You may also have radiotherapy if the vulval cancer has spread to other parts of the body. This is called advanced or metastatic cancer. If the cancer is advanced, the aim of radiotherapy is often to improve quality of life by shrinking the tumour and reducing symptoms. This is known as palliative radiotherapy.

Your cancer team will explain your treatment and how it is given.

Chemoradiation

Chemoradation is when radiotherapy is given with chemotherapy.

The chemotherapy drugs make the cancer cells more sensitive to radiotherapy. This can help make the radiotherapy work better. The chemotherapy drug most commonly used is cisplatin. You usually have chemotherapy once a week throughout your radiotherapy.

If you have chemoradiation, your side effects may be worse than if you were having just one treatment type. Your cancer doctor, specialist nurse or radiographer will tell you how to manage and treat any side effects.

We have more information about chemotherapy drugs on our website. Visit [macmillan.org.uk/treatment-and-drugs](https://www.macmillan.org.uk/treatment-and-drugs)



Fertility

Radiotherapy to the pelvis can affect your fertility – this is the ability to get pregnant. If this is important to you, talk to your cancer doctor, specialist nurse or radiographer before treatment begins. They can refer you to a fertility specialist to talk through fertility options.

We have more information about this:

- in our booklet [Cancer and fertility](#)
- on our website at [macmillan.org.uk/fertility](https://www.macmillan.org.uk/fertility)

Planning your radiotherapy

Your cancer team will plan your radiotherapy. The planning makes sure that treatment:

- targets the cancer accurately
- causes as little damage as possible to nearby tissue.

First planning visit

Your first planning visit takes 30 to 60 minutes. The staff in the radiotherapy department will tell you what to expect. It is important you feel involved in your treatment, so ask them any questions you have.

They will tell you whether you need to prepare in any way. This usually includes having a full bladder for the scan. Sometimes you may be asked to take medicine to help empty your bowel. If you need to do this, you will also have to do it for each radiotherapy session.

You usually have a CT scan of the area. This helps your doctor and radiotherapy team plan your radiotherapy.

During the scan, you need to lie in the same position that you will be in for all your radiotherapy treatment. If you are uncomfortable, tell the radiographers so they can help.

You may have some small, permanent markings made on your skin. The marks are about the size of a pinpoint. They help the radiographer make sure you are in the right position for each session of radiotherapy.

These marks will only be made with your permission. If you are worried about them, talk to your radiographer.

We have more information about having a CT scan on our website. Visit [macmillan.org.uk/ct-scan](https://www.macmillan.org.uk/ct-scan)

Having external beam radiotherapy

External beam radiotherapy is given using a machine that looks like a large x-ray machine or CT scanner. There are different types of radiotherapy machine. The most commonly used machine is called a linear accelerator (LINAC).

You have treatment in the radiotherapy department at the hospital. You usually have it as an outpatient once a day from Monday to Friday, with a rest on the weekend. Each session of treatment takes a few minutes. It is sometimes called a fraction. Your appointment usually takes between 10 and 15 minutes to allow you time to get into the right position for your treatment.

The number of treatments you have depends on the type and size of the cancer. The course of treatment for vulval cancer usually lasts a few weeks.

Before your first treatment, the radiographers explain what to expect. At the beginning of each session, they make sure you are in the correct position and ask you to keep as still as possible. They leave the room for a few minutes while you have your treatment. The radiographers can see and hear you from outside the room. There is usually an intercom, so you can talk to them if you need to during your treatment.

The treatment itself is not painful. The radiotherapy machine does not touch you, but it may make a buzzing noise.

Once your treatment session has finished, the radiographers help you off the treatment couch. The treatment does not make you radioactive. It is safe for you to be around other people. This includes children and people who are pregnant.

Having internal radiotherapy (brachytherapy)

Internal radiotherapy is called brachytherapy. It uses a radioactive material that is put inside the body to treat the cancer. This gives a high dose of radiotherapy to the tumour. The treatment is planned carefully to minimise the dose to nearby areas. It may be given at the end of external radiotherapy, or sometimes as a treatment on its own.

Brachytherapy for vulval cancer is usually given using thin plastic tubes called implants. These are usually put in under general anaesthetic. They are sometimes put in after spinal anaesthetic – this is an injection of painkillers into the spine. The doctor gently inserts the implants into the skin of the vulva. Sometimes brachytherapy is given using needles instead of tubes.

When the implants are in position, they are connected to the radiotherapy machine. The machine delivers the radiotherapy through the implants. How long the treatment takes depends on the type of radiotherapy.

The most common type is high dose radiotherapy (HDR). Each treatment usually takes around 30 minutes. The implants stay in place for 2 or 3 days until you have completed your treatments.

Sometimes brachytherapy may be given as pulsed dose radiotherapy (PDR). This may take up to one day.

Your cancer team will explain your [treatment plan](#) and what to expect. You cannot feel the radiotherapy when you are having it, but the tubes can be uncomfortable. The nurses will give you painkillers to help with this. They will remove the tubes when treatment is finished.

When the radiotherapy is being given, your team is careful to protect people around you from radiation. This may mean you need to be alone in a room during the treatment. Tell your team if you are worried about this so they can help. Safety measures may vary slightly in different hospitals. Your team will explain what to expect.

After your radiotherapy, there is no risk to people around you. You are not radioactive.

Side effects of radiotherapy

Your team plans your treatment carefully to reduce your risk of side effects. But most people have a few side effects during or after radiotherapy.

Side effects do not usually happen straight away. They may develop during treatment or in the days or weeks after treatment ends. After you finish radiotherapy, side effects can get worse before they get better. There may also be a small risk of side effects that are long term or that only start months or years after radiotherapy – these are called [late effects](#).

Smoking makes the side effects of radiotherapy worse. If you smoke, stopping smoking will help. If you want help or advice on how to stop smoking, talk to your doctor, GP or a specialist nurse. [Stop smoking organisations](#) may also be able to help.

We have more information about stopping smoking on our website. Visit [macmillan.org.uk/stop-smoking](https://www.macmillan.org.uk/stop-smoking)



Skin irritation

You may find that the skin around your vulva and groin gets dry and irritated. Let the radiotherapy team know as soon as possible if your skin in the treated area:

- is sore
- is itchy
- changes colour – the area may become darker if you have brown or black skin, or it may become red if you have white skin.

Your radiotherapy team will tell you how to care for your skin during treatment. Check with your radiographer before using any products such as soaps, cleansers or creams.

They will check your skin regularly and give you advice about managing any skin reactions. They may give you dressings, a gel or other products to help. They can also give you painkillers if you need them.

Use lukewarm water to wash the area and gently pat the area dry with a soft towel. Do not use talcum powder or perfume on the area. These can cause irritation.

It can also help to wear loose-fitting clothes made from natural fibres, such as cotton.

Radiotherapy may also make your pubic hair fall out. It usually grows back after treatment, but it may be thinner.



Tiredness

Radiotherapy often makes people feel tired. Tiredness (fatigue) may get worse as treatment goes on. If you are having radiotherapy alongside other treatments, such as surgery or chemotherapy, you may feel more tired. But there are things you can do to help, such as:

- get plenty of rest
- do some gentle exercise, such as going for short walks
- eat a healthy diet and drink plenty of fluids
- ask others for help with everyday tasks, if you have friends or family members who can support you.

After treatment finishes, you may continue to feel tired for weeks or months. If it does not get better, tell your cancer doctor or specialist nurse.

We have more information about coping with fatigue in our booklet [Coping with fatigue \(tiredness\)](#).

This booklet is also available as an audiobook. Visit macmillan.org.uk/fatigueaudio

Bladder side effects

Radiotherapy can irritate the bladder. You may feel like you need to pass urine more often. You may also have a burning feeling when you pass urine (pee). Drinking at least 2 litres (8 glasses) of water or other fluids each day can help.

Your team can advise you about coping with any bladder problems. There are drugs that can improve bladder side effects and help you feel more comfortable. If the problems do not improve within a few weeks, the team may arrange tests.

“As a result of the radiotherapy, I had really bad bowel and bladder trouble, including diarrhoea. ”

Lynda, diagnosed with vulval cancer

Bowel side effects

Radiotherapy to the pelvis may irritate the bowel. You may have tummy (abdominal) cramps. You may need to pass stools (poo) more often. Or you may have loose stool (diarrhoea).

If you have cramps, tell your radiotherapy team. They can give you medicine to help.

Drink plenty of fluids if you have diarrhoea. Your doctor may also give you medicine to help. Your radiotherapy team will tell you whether you need to make any changes to your diet. It can be different for each person.

Changes in your blood

External radiotherapy can reduce the number of blood cells made by the bone marrow. This is more likely to happen if you are having [chemoradiation](#).

If your white blood cells are low, you are more likely to get an infection and need antibiotics. If your red blood cell count is low, you may feel tired and need a blood transfusion. Your hospital team will arrange for you to have regular blood tests if needed.

Vaginal discharge

You may have a light vaginal discharge after treatment has ended. Tell your cancer doctor, specialist nurse or radiographer if the discharge:

- continues or becomes heavy
- changes colour
- begins to smell.

Possible late effects

Radiotherapy to the pelvic area can sometimes cause effects months or years after treatment. These are called late effects. They may be permanent. If they happen, there are lots of ways to manage and treat them.

It is always important to tell your GP or cancer doctor about any new symptoms that develop a long time after treatment. They need to check them, as they may not be caused by radiotherapy.

Early menopause

Radiotherapy to the pelvis affects the ovaries. If you have not already been through the menopause, this treatment may cause an early menopause. This means your periods will stop and you will no longer be able to get pregnant.

Symptoms of the menopause include:

- hot flushes and sweats
- loss of interest in sex
- mood swings and poor concentration
- vaginal dryness.

You may be able to take hormone replacement therapy (HRT) to help with some of the symptoms. There are other ways to manage symptoms if you cannot have HRT or do not want it. Your doctor can tell you about treatments and other options that may help.

We have more information about menopause on our website.

Visit [macmillan.org.uk/menopausal-symptoms](https://www.macmillan.org.uk/menopausal-symptoms)

Vaginal changes

Radiotherapy can make the vagina narrower and less stretchy. The vaginal walls may be dry and thin, and can stick together. This can make vaginal sex and internal examinations uncomfortable.

Your cancer team may give you vaginal dilators and lubricants to help prevent narrowing. We have more information about [dilators](#).

Vaginal dryness

This can feel uncomfortable, particularly during vaginal sex. Vaginal dryness can also make you more likely to get infections, such as thrush. Let your doctor know if you have symptoms such as itching or soreness.

The following products can help with vaginal dryness and make sex more comfortable:

- Lubricants are a gel or liquid you apply before or during sex to make the vagina wetter.
- Vaginal moisturisers are creams you apply regularly to draw moisture into the vaginal walls.
- Vaginal oestrogen is a cream, small pellet (pessary) or ring that releases the hormone oestrogen into the vagina, if you have had the menopause.

Your GP or cancer team can prescribe these products. You can also buy lubricants and moisturisers from a pharmacy, supermarket or online.

Some products, such as oil-based lubricants, will damage latex condoms or caps (diaphragms) and make them less effective. Always check the instructions.

Some products may have ingredients that cause irritation or make you more likely to get thrush. Try to use products that do not contain any preservatives, scents or parabens. If you are not sure, ask your cancer team, GP or pharmacist for advice.

Vaginal bleeding

After pelvic radiotherapy, the vagina may bleed easily after vaginal sex. This may be because:

- the walls of the vagina have become fragile
- the vaginal tissue is sticking together
- scar tissue has caused the vagina to narrow.

If you have any bleeding, always tell your cancer doctor, specialist nurse or radiographer. They will check why you are bleeding and give you advice. If the bleeding is minor, you may find it does not trouble you much once you know the cause.

Changes to the vulva

The skin of the vulva may become permanently discoloured. It may redden or darken. Radiotherapy can also damage the small blood vessels in the skin. This can cause red or purple spidery marks inside the vagina and around the vulval area.

You may have some swelling in the vulva for months or sometimes years after radiotherapy. You can reduce this with a gentle, upwards massage. A specialist nurse or physiotherapist can teach you how to do this.

“Radiotherapy can leave your vulva and groin skin damaged or scarred. It can be hard to talk about vulval cancer and how you are struggling with changes to your body.”

Clare, diagnosed with vulval cancer

Bowel or bladder changes

Radiotherapy can cause bowel or bladder side effects. These can be short term problems, or they can sometimes be permanent. If your bowel is affected, you may:

- have more bowel movements
- need to go to the toilet more urgently than usual
- have diarrhoea
- have constipation and wind.

If the bladder is affected, you may need to pass urine (pee) more often or more urgently.

The blood vessels in the bowel and bladder can become more fragile. This can cause blood in urine (pee) or stool (poo).

There are often ways to manage bladder and bowel problems. Talk to your cancer team, GP or physiotherapist. They may give you medicines or advice that can help. If you have bleeding, they can check what the cause is.

They can also refer you to a specialist for treatment or more support if you need it. For example, this may be support with strengthening your pelvic floor muscles.

Lymphoedema

Pelvic radiotherapy may increase the risk of fluid build-up (swelling) in one or both legs. It may also affect the pelvic area. This is called lymphoedema.

It is not common, but the risk is higher if you have surgery to remove the lymph nodes as well as radiotherapy. We have more information about how to reduce the risk of [lymphoedema](#).

We also have more information about lymphoedema:

- in our [booklet](#) and [audiobook](#) **Understanding lymphoedema**
- on our website at macmillan.org.uk/lymphoedema

Late changes to the pelvic bones

Radiotherapy can cause thinning of the bones in the pelvis. This often does not have any symptoms. But it can be seen on scans. Sometimes it may cause fractures in the pelvis called insufficiency fractures. These can cause pain in the lower back or pelvis.

Tell your cancer doctor, specialist nurse or GP if you have any pain. They can arrange a test to check for this. They can also give you painkillers and refer you to a physiotherapist.

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. Cytotoxic means toxic to cells. These drugs affect the way cancer cells grow and divide. But they also affect normal cells.

You may have chemotherapy:

- after surgery to reduce the risk of cancer coming back – this is called adjuvant treatment, and you usually have radiotherapy at the same time (chemoradiation)
- with radiotherapy as your main treatment if surgery is not possible – this is called chemoradiation
- to shrink the cancer before surgery or radiotherapy – this is called neo-adjuvant chemotherapy
- if the cancer comes back
- to treat the symptoms of advanced cancer that cannot be cured – this is called palliative treatment.

Having chemotherapy

You can usually have chemotherapy as an outpatient. Sometimes you may need to stay in hospital for a few days.

Most drugs are given into a vein (intravenously). But some drugs can be given by mouth as tablets or capsules. Intravenous chemotherapy is a session of treatment that you have over several hours or days. You then have a rest period of a few weeks. This allows your body to recover from any side effects.

The chemotherapy and rest period make up a cycle of treatment. Your cancer specialist will tell you how many cycles of treatment you will have.

Side effects

Medicines can usually control side effects of chemotherapy. Most side effects usually go away when treatment ends. But some may be permanent. Not all drugs cause the same side effects, and some people may have very few side effects.

Your cancer doctor, specialist nurse or pharmacist will tell you more about what to expect. Always tell them about any side effects you have. They can give you advice on how to manage them.

The main chemotherapy drugs used to treat vulval cancer are:

- cisplatin
- fluorouracil (5FU)
- capecitabine
- carboplatin
- paclitaxel.

Other chemotherapy drugs may sometimes be used. Your cancer doctor or specialist nurse will talk to you about the treatment and drugs you are having.

We have information about these drugs on our website.
Visit [macmillan.org.uk/treatment-and-drugs](https://www.macmillan.org.uk/treatment-and-drugs)



Risk of infection

This treatment can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is sometimes called neutropenia.

An infection can be very serious when the number of white blood cells is low. It is important to get any infection treated as soon as possible.

If you have any of the following symptoms, contact the hospital straight away on the 24-hour number:

- a temperature above 37.5°C
- a temperature below 36°C
- you feel unwell, even with a normal temperature
- you have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery and shaking
- a sore throat
- a cough
- breathlessness
- diarrhoea
- needing to pass urine (pee) a lot, or discomfort when you pass urine.

It is important to follow any specific advice your cancer treatment team gives you.

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time, until your cell count increases.

You may be given a drug called G-CSF. This encourages the body to make more white blood cells. You have it as a small injection under the skin.

Bruising and bleeding

This treatment can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot.

If the number of platelets is low, you may bruise or bleed easily. You may have:

- nosebleeds
- bleeding gums
- heavy periods
- blood in your urine (pee) or stools (poo)
- tiny red, brown or purple spots on your skin that may look like a rash – these spots can be harder to see if you have black or brown skin.

If you have any unexplained bruising or bleeding, contact the hospital straight away on the 24-hour number. You may need a drip to give you extra platelets. This is called a platelet transfusion.

Anaemia (low number of red blood cells)

This treatment can reduce the number of red blood cells in your blood. Red blood cells carry oxygen around the body. If the number of red blood cells is low, this is called anaemia. You may feel:

- very low in energy
- breathless
- dizzy and light-headed.

If you have these symptoms, contact the hospital straight away on the 24-hour number. You may need treatment for anaemia. If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

Feeling sick

Your doctor, nurse or pharmacist will prescribe anti-sickness drugs to help prevent or control sickness. Take the drugs exactly as they tell you to, even if you do not feel sick. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluid often and eat small amounts regularly. It is important to drink enough fluids. If you continue to feel sick, or if you are sick (vomit) 1 to 2 times in 24 hours, contact the hospital on the 24-hour number as soon as possible. They will give you advice. They may change your anti-sickness treatment. Let them know if you still feel sick.

We have more information about managing nausea and vomiting on our website. Visit macmillan.org.uk/nausea-vomiting

Loss of appetite

This treatment can affect your appetite. Don't worry if you do not eat much for 1 or 2 days.

But if your appetite does not come back after a few days, or if you are losing weight, tell your doctor, nurse or pharmacist. They can give you advice. They may give you food or drink supplements. Or they may suggest changes to your diet or eating habits to help.

We have more information about this in our booklets and audiobooks [Healthy eating and cancer](#), [The building-up diet](#) and [Eating problems and cancer](#).

Sore mouth and throat

This treatment may cause a sore mouth and throat. You may also get mouth ulcers. This can make you more likely to get a mouth or throat infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

Contact the hospital straight away on the 24-hour number, if:

- a sore mouth or throat affects how much you can drink or eat
- your mouth, tongue, throat or lips have any blisters, ulcers or white patches.

They can give you advice, and mouthwash or medicines to help with the pain or to treat any infection. Follow their advice and make sure you:

- drink plenty of fluids
- avoid alcohol and tobacco
- avoid food or drinks that irritate your mouth and throat.

We have more information online at macmillan.org.uk/mouth-problems

Hair loss

Some chemotherapy drugs cause complete hair loss – including eyelashes, eyebrows and other body hair. Other drugs usually only cause partial hair loss or hair thinning. Your cancer doctor, specialist nurse or pharmacist can tell you what to expect.

Scalp cooling is a way of lowering the temperature of your scalp to help reduce hair loss. Your nurse can tell you whether this is an option for you.

Your nurse can talk to you about ways to cope with hair loss. There are ways to cover up hair loss if you want to. It is important to cover your head to protect your scalp when you are out in the sun.

Hair loss is usually temporary, and your hair will grow back after treatment ends. But rarely, the hair loss is permanent. Hair may not grow back. Or it may be thinner than before. If you are worried about this, talk to your cancer doctor or specialist nurse.

We have more information about managing hair loss in our [booklet](#) and [audiobook](#) **Coping with hair loss**.

Feeling tired

Feeling tired is a common side effect of this treatment. It is often worse towards the end of treatment and for some weeks after it ends. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can help you feel less tired. If you feel sleepy, do not drive or use machinery.

We have more information:

- in our [booklet](#) and [audiobook](#) **Coping with fatigue (tiredness)**
- on our website at macmillan.org.uk/fatigue

Immunotherapy

Immunotherapy drugs help stimulate the immune system to recognise and destroy cancer cells. Sometimes, this type of treatment is used to treat vulval cancer.

Your cancer doctor will explain whether this treatment is suitable for you. You may have it as part of a [clinical trial](#).

We have more information on our website about different types of immunotherapy, including how each drug is given and possible side effects. Visit [macmillan.org.uk/immunotherapy](https://www.macmillan.org.uk/immunotherapy)



Clinical trials – research

Clinical trials are a type of medical research involving people. They are important because they show which treatments are most effective and safe. This helps healthcare teams plan the best treatment for the people they care for.

Trials may test how effective a new treatment is compared to the current treatment used. Or they may get information about the safety and side effects of treatments.

Some trials help answer questions about treatments we already use. They may test whether combining treatments is more effective. Or they may research different ways to give a treatment so it works better or causes fewer side effects.

Clinical trials also research other areas of cancer care. These include diagnosis and managing side effects or symptoms.

We have more information about cancer clinical trials on our website. Visit macmillan.org.uk/clinical-trials



Taking part in a trial

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask them if there are any trials suitable for you.

Joining a trial is always your decision. If you join and then change your mind, you can leave at any time. You do not have to give a reason. Your healthcare team will support you whatever you decide. You will always have the standard treatment for the type and stage of cancer you have.

Not all hospitals have the expertise or resources to take part in certain trials. This means for some trials you may have to travel to a different hospital.

A research nurse or doctor will give you information about the trial. You can ask them any questions you have. It is important to understand what is involved before you agree ([consent](#)) to take part.

They will explain the possible benefits and any possible risks of the trial. Clinical trials are designed with safety measures to keep any risks to you as low as possible.

Some trials involve collecting blood samples, or tissue samples from a biopsy. This often happens as a standard part of your treatment. But your research nurse or doctor will explain if they need to take extra samples for the trial.

Your samples can only be stored and used for research if you give your permission. Your name is removed from the samples before they are used. This means you cannot be identified.



After treatment

Follow-up appointments	84
Lymphoedema	85
Effects on your sex life	88
Wellbeing and recovery	92
More help and support	96

Follow-up appointments

After your treatment has finished, you will usually have regular check-ups with your cancer doctor or specialist nurse. Your appointments may be every few months at first. Later, they may only be once a year.

Your cancer doctor or specialist nurse will check your [vulva and groin](#) area. You can talk to them about any problems or worries at these check-ups. But if you notice any new symptoms or have any problems between appointments, contact them for advice.

If you had vulval lichen sclerosus (LS) or vulval lichen planus (LP) before vulval cancer, you should keep meeting with your specialist doctor for those conditions too. After cancer treatment, you may still need ongoing treatment for the skin. Your doctor will speak to you about this.

We have more information about vulval LS and vulval LP on our website:

- macmillan.org.uk/lichen-sclerosus-vulva
- macmillan.org.uk/lichen-planus-vulva

Many people get anxious before their appointments. You may worry about the cancer coming back. This is natural. It can help to get support from family, friends or your specialist nurse. Or you can speak to our cancer support specialists on the Macmillan Support Line. Some [other organisations](#) also offer support to people affected by cancer of the vulva.

Call the Macmillan Support Line free on
[0808 808 00 00](tel:08088080000), 7 days a week, 8am to 8pm.



Lymphoedema

The lymph nodes are part of the body's immune system and help fight infection. A fluid called lymph fluid normally flows through these nodes. This may build up if the nodes:

- stop working normally because of radiotherapy
- are removed during surgery.

Fluid may collect and cause swelling in one or both legs, or the pubic area.

Not everyone gets lymphoedema after treatment for cancer of the vulva. But it can start months or years later.

There are treatments that help manage swelling. There are also things you can do to reduce your risk of getting lymphoedema. Your doctor or nurse may plan for you to meet with a specialist for advice.

Reducing your risk of lymphoedema

There are things you can do to reduce your risk of lymphoedema.

Look after your skin

- Keep your legs and feet clean, dry and well moisturised.
- Dry carefully between your toes after washing.
- Avoid having very hot baths and showers.
- Protect your skin from cuts, grazes, insect bites and sunburn.
- Wear shoes that are the right fit and size for your feet.

Use nail clippers instead of scissors to cut your toenails

You are less likely to cut the skin with these. It is also best not to push back or cut your cuticles.

Tell your doctor or lymphoedema specialist if you need extra help with your toenails. They can refer you to a foot specialist (chiropodist).

Look out for the early signs of infection

Wash small grazes and cuts straight away. Put on antiseptic cream and cover if needed. Contact your GP straight away if you have signs of infection, such as:

- flu-like symptoms
- any skin changes or swelling on your legs or feet.

Stay physically active

Regular exercise and physical activity will help lymph fluid to drain. Avoid standing in the same position for too long.

Keep to a healthy weight

You have a higher risk of lymphoedema if you are overweight. Your GP or practice nurse can tell you what your ideal weight should be. You can also ask them or a dietitian for advice and support on healthy eating.

We have more information in our [booklet](#) and [audiobook](#) **Healthy eating and cancer**.

Managing lymphoedema

To start with, lymphoedema may only cause slight swelling.

Contact your cancer doctor, specialist nurse or GP for advice if you have:

- any leg or foot swelling
- a tight, heavy or stiff feeling in your legs
- any skin changes on your legs or feet.

If you have signs of lymphoedema, they should refer you to a clinic for specialist advice.

The specialists at the lymphoedema clinic will give you advice on caring for your skin. They will also show you exercises and ways to massage your legs and feet to help fluid drain.

They will give you a support stocking (compression garment) to wear to reduce the swelling. A specialist will measure you for this and give you advice about using it. They may also recommend other treatments for you.

We have more information about lymphoedema in our [booklet](#) and [audiobook](#) **Understanding lymphoedema**.

You can listen to our audiobooks or order booklets for free.
Visit orders.macmillan.org.uk or call [0808 808 00 00](tel:08088080000).



Effects on your sex life

Life after cancer treatment is often challenging. It can be especially difficult to cope with changes to something as personal as your sex life. Your treatment may have caused changes that affect how your body responds sexually or how sex feels. It may also affect how you feel about your body, sex and your relationships.

It is common to have questions about sex or need more help after treatment. These things are not always easy to talk about. There is support available. Do not be afraid or embarrassed to ask for advice. Your cancer doctor or specialist nurse can help or arrange for you to meet with a specialist. They can tell you what can help.

We have more information about cancer and sex:

- in our [booklet](#) and [audiobook](#) **Cancer and your sex life**
- on our website at macmillan.org.uk/sex-and-cancer

“There are many side effects to vulval cancer. But some can be more tricky to talk about than others. You can become scared of sex – in case it hurts or you do more damage. ”

Clare, diagnosed with vulval cancer

Physical changes

It may be months before you feel ready to have sex after treatment. It is normal to feel unsure about it. Remember to look after yourself and give your body time to heal.

Be as honest as you can with partners about what you want or do not want. It is fine to say no to any kind of sexual contact that does not feel right.

You may have vaginal dryness. Your nurse can explain which types of lubricants are suitable for you. Surgery or radiotherapy can both cause scarring or tightness. This may mean sex is uncomfortable or painful. Tell your cancer doctor or specialist nurse if this happens. Depending on how you are affected, there are several things that can help.

Your cancer team may give you vaginal dilators to help prevent narrowing. Dilators are tampon-shaped plastic tubes of different sizes. You can use these regularly inside the vagina with a lubricant, to gently push the walls of the vagina apart. Your cancer team will explain how to use them safely.

Treatment may have changed the way your genital area looks or feels. If your clitoris was removed, you may worry that you will not be able to have orgasms. This is not always the case. You may need to allow yourself to get used to the changes and explore what feels good now.

It can be helpful to speak to a sex therapist. This is a healthcare professional who is trained to support people with sexual problems. They can often help you work out if a problem is physical, emotional or both. They offer advice and exercises that may help. Your GP, cancer doctor or specialist nurse should be able to refer you to a [sex therapist](#).

You and your partner

Some people worry about how current or future partners will react to the changes.

Try to be open with any partner and talk about this together. Sometimes counselling is helpful, either with your partner or on your own. It may help you work through any issues. Your GP, cancer doctor or nurse can often arrange counselling for you.

The [College of Sexual and Relationship Therapists \(COSRT\)](#) has a list of nationwide counsellors and therapists who can offer advice and support. Or you can talk to one of our cancer support specialists on the Macmillan Support Line.

[Lovehoney](#) also supports people to increase their understanding of sex and cancer, and ways to maintain a healthy sexual relationship during and after cancer treatment.

Call the Macmillan Support Line free on
[0808 808 00 00](tel:0808 808 00 00), 7 days a week, 8am to 8pm.



Wellbeing and recovery

After treatment, you may just want to get back to everyday life. But you may still be:

- coping with the side effects of treatment
- adjusting to physical changes
- dealing with some difficult emotions.

Recovery takes time, so do not rush it and try to be kind to yourself.

Some people choose to make lifestyle changes to improve their health and wellbeing. Even if you had a healthy lifestyle before cancer, you may be more focused on making the most of your health.

“ The first few months after leaving hospital, once the skin healed and everything settled down, were quite good. I had some counselling, and then joined an exercise programme. It was great to get my body moving again. ”

Lynda, diagnosed with vulval cancer

Be physically active

Being physically active after cancer treatment can:

- boost your energy levels
- help you keep to a healthy weight
- reduce stress and fatigue.

It can also reduce your risk of:

- bone thinning, if you have had an early menopause
- health problems such as diabetes, heart disease and some cancers

We have more information in our booklets:

- [Bone health and cancer treatment](#)
- [Heart health and cancer treatment](#)
- [Diabetes and cancer treatment](#).

Your GP or cancer doctor may be able to refer you to an exercise group for people with cancer. Ask them for advice about what is available in your local area. We have more information in our booklet [Physical activity and cancer](#).

Eat healthily

A healthy, balanced diet gives you more energy and will help you recover. Talk to your GP, specialist nurse or a dietitian if you have any special dietary or medical needs.

We have more information about healthy eating in our booklets and audiobooks:

- [Healthy eating and cancer](#)
- [The building-up diet.](#)

Drink less alcohol

Alcohol has been linked to a higher risk of some types of cancer and to weight gain. Drinking guidelines recommend that you should:

- not regularly drink more than 14 units in a week
- spread the alcohol units you drink in a week over 3 or more days
- try to have several alcohol-free days every week.

A unit of alcohol is half a pint of ordinary-strength beer, lager or cider, one small glass (125ml) of wine, or a single measure (25ml) of spirits.

Drinkaware has more information about alcohol and drinking guidelines. Visit drinkaware.co.uk

Stop smoking

If you smoke, stopping is the healthiest decision you can make. Stopping smoking reduces your risk of:

- heart and lung disease
- bone thinning (osteoporosis)
- smoking-related cancers.

If you want to stop, your GP can give you advice. Or you can contact a [stop smoking organisation](#).

We have more information about stopping smoking on our website. Visit macmillan.org.uk/stop-smoking

Complementary therapies

Some people use complementary therapies to help them relax or cope with treatment side effects. Some hospitals or support groups offer therapies such as relaxation or aromatherapy. Ask your cancer doctor or specialist nurse what is available in your area.

We have more information about complementary therapies:

- in our [booklet](#) and [audiobook](#) **Cancer and complementary therapies**.
- on our website at macmillan.org.uk/complementary-therapies

More help and support

More help and support is available. This includes practical help, support groups and online support.

Practical help

Before you start treatment, tell your cancer doctor or specialist nurse about any practical help you might need at home as you recover. They can give you advice and may be able to arrange help or equipment for you. If you need more support, talk to them again or contact your GP.

Support groups

A support group gives you the chance to talk to other people in a similar situation to you. It can be a place to share experiences, ask questions and support each other.

You are not expected to talk about anything you do not want to. It can take a few visits to feel comfortable enough to talk about personal things. Not everyone finds talking in a group easy. But you can go along to check what it is like before you decide to get involved.

You can search for groups in your area, ask someone from your healthcare team or visit macmillan.org.uk/inyourarea

You can also ask our cancer support specialists for more information on [0808 808 00 00](tel:08088080000).



“The Macmillan Online Community has been helpful. Thanks to the forums, I’ve found and connected with other people who have experienced what I have. I also use the Macmillan website and often share links with people affected by vulval cancer around the world. ”

Clare, diagnosed with vulval cancer

Online support

You can join an online support group or chat room. There are groups about different types of cancer. There are also more general groups where people chat about practical and emotional issues after treatment.

You can share your own thoughts and feelings by posting messages for others to read and reply to. Or if you prefer, you can just read other people's comments or posts. These messages can sometimes be uplifting. They can also be sad and difficult to read. It may help to know that other people feel like you do. You may feel less alone and learn how other people cope after treatment.

Online groups are quick and easy to join. They are also easy to leave, without any need for personal contact or explanations. You can talk to people in forums, blog about your experiences, make friends and join support groups. Our Online Community offers this type of support. Visit macmillan.org.uk/community



Your feelings and relationships

Your feelings	102
Relationships	103

Your feelings

It is common to have many different feelings when you are told you have cancer. You may feel shocked, scared, depressed, guilty or angry. This can be difficult to cope with. Partners, family and friends may also have some of the same feelings.

We have more information about emotions:

- in our [booklet](#) and [audiobook](#) **How are you feeling? The emotional effects of cancer**
- on our website at macmillan.org.uk/emotions

Your healthcare team will usually give you support. But you may feel you need more help. Talk to your cancer doctor, GP or specialist nurse. They can refer you to a specialist doctor, psychologist or counsellor who can help.

You can also call the Macmillan Support Line on [0808 808 00 00](tel:0808 808 00 00) and talk to one of our cancer support specialists.

Talking to family, friends or other people affected by cancer may help. For more information or for help finding local support groups, visit macmillan.org.uk/supportgroups Or talk to other people on our Online Community at macmillan.org.uk/community

There is more information about [other ways we can help](#).

Relationships

Cancer and its treatment are stressful and may affect your relationships. Your experience of cancer may strengthen your relationships with people close to you. Or it may put a strain on relationships. Any problems usually improve over time, especially if you talk openly with each other.

We have more information about relationships in our booklets:

- [Talking about cancer](#)
- [Cancer and relationships: support for partners, families and friends](#) – this is also available as an [audiobook](#).

We also have more information online at macmillan.org.uk/relationships

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You can support the person with cancer by listening and talking with them. We have more information about supporting someone in our [booklet](#) and [audiobook](#) **Talking with someone who has cancer**.

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers in our [booklet](#) and [audiobook](#) **Looking after someone with cancer**. Or on our website, visit macmillan.org.uk/carers

You can listen to our audiobooks or order booklets for free.
Visit orders.macmillan.org.uk or call [0808 808 00 00](tel:08088080000).



Talking to children and teenagers

Deciding what to tell children or teenagers about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. It may be best to start by giving them small amounts of information, and then tell them more when they are ready.

Use simple, straightforward language to explain what is happening. You can encourage them to talk to someone they trust, who can support them. They may also find support online.

We have more information in our [booklet](#) and [audiobook](#)

Talking to children and teenagers when an adult has cancer.

You can listen to our audiobooks or order booklets for free.
Visit orders.macmillan.org.uk or call [0808 808 00 00](tel:08088080000).







Financial support and work

Help with money and benefits 108

Work 110

Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to on our website. Visit macmillan.org.uk/sick-pay

We also have information for carers at macmillan.org.uk/carers

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- gov.uk if you live in England or Wales
- socialsecurity.gov.scot if you live in Scotland
- nidirect.gov.uk if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Macmillan has expert money advisers who can talk to you about your money worries, provide information about benefits, and recommend other useful organisations that can help. You can speak to them by calling the Macmillan Support Line for free on [0808 808 00 00](tel:08088080000). Please note the opening times may vary by service.

You can also get information about benefits and other types of financial help from [Citizens Advice](#) if you live in England, Scotland or Wales, or [Advice NI](#) if you live in Northern Ireland.

Our [booklet](#) and [audiobook](#) **Help with the cost of cancer** have lots more information.

Grants

You may be able to get some financial help from other charities – for example, one-off grants. For further information, contact the Macmillan Support Line on [0808 808 00 00](tel:08088080000).

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. We have information about insurance on our website. Visit macmillan.org.uk/insurance-cancer

We have more information about travel insurance in our [booklet](#) and [audiobook](#) **Travel and cancer**.

Our Online Community forum on travel insurance may also be helpful. Visit macmillan.org.uk/community

You can listen to our audiobooks or order booklets for free. Visit orders.macmillan.org.uk or call [0808 808 00 00](tel:08088080000).





Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager or human resources (HR) department soon after you are diagnosed. This will help them to support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others carry on working, sometimes with reduced hours or other changes to their job.

Your cancer doctor, GP or specialist nurse can help you decide whether you should stop working, and when and if you should go back to work.

Our booklets have more information that may be helpful:

- [Work and cancer](#) – this is also available as an [audiobook](#)
- [Working while caring for someone with cancer](#) – this is also available as an [audiobook](#)
- [Self-employment and cancer](#).

You can also find out more about your employment rights in our booklet [Your rights at work when you are affected by cancer](#).

There is also lots more information online at macmillan.org.uk/work

You can listen to our audiobooks or order booklets for free.
Visit orders.macmillan.org.uk or call [0808 808 00 00](tel:08088080000).





Further information

About our information	114
Other ways we can help you	116
Other useful organisations	120
Your notes and questions	132

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Our information has the PIF Tick quality mark for trusted health information. This means our information has been through a professional and strong production process.

Order what you need

You may want to order more booklets like this one.

Visit orders.macmillan.org.uk or call us on [0808 808 00 00](tel:08088080000).

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at macmillan.org.uk/information-and-support. You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- interactive PDFs
- large print
- translations.

Find out more at macmillan.org.uk/otherformats

If you would like us to produce information in a different format for you, email us at informationproductionteam@macmillan.org.uk or call us on [0808 808 00 00](tel:0808 808 00 00).

The language we use

We want everyone affected by cancer to feel our information is written for them.

We want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected.

To find out more about how we produce our information, visit macmillan.org.uk/ourinfo



Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our support line is made up of specialist teams who can help you with:

- emotional and practical support if you or someone you know has been diagnosed with cancer
- clinical information from our specialist nurses about things like diagnosis and treatments
- welfare rights advice, for information about benefits and general money worries.

To contact any of our teams, call the Macmillan Support Line for free on [0808 808 00 00](tel:08088080000). Or visit macmillan.org.uk/support-line to chat online and find the options and opening times.

Our trained cancer information advisers can listen and signpost you to further support.

Our cancer information nurse specialists can talk you through information about your diagnosis and treatment. They can help you understand what to expect from your diagnosis and provide information to help you manage symptoms and side effects.

If you are deaf or hard of hearing, call us using Relay UK on [18001 0808 808 00 00](tel:1800108088080000), or use the Relay UK app.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to macmillan.org.uk/talktous

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call [0808 808 00 00](tel:08088080000) and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Macmillan Information and Support Centres

Our Information and Support Centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

Find your nearest centre at macmillan.org.uk/informationcentres or call us on [0808 808 00 00](tel:08088080000).

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

Financial advice

Our expert money advisers on the Macmillan Support Line can help you deal with money worries and recommend other useful organisations that can help.

Help accessing benefits

You can speak to our money advisers for more information. Call us free on [0808 808 00 00](tel:08088080000). Visit macmillan.org.uk/financialsupport for more information about benefits.

Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide information to help you manage cancer at work. Visit macmillan.org.uk/work

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, family member or friend, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting macmillan.org.uk/selfhelpandsupport

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at macmillan.org.uk/community

You can also use our Ask an Expert service on the Online Community. You can ask a money adviser, cancer information nurse or an information and support adviser any questions you have.

Macmillan healthcare professionals

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

Vulval cancer support organisations

The Eve Appeal

Helpline **0808 802 0019**

www.eveappeal.org.uk

Offers information and support for anyone affected by gynaecological cancers. Also provides information about cervical screening and for transgender (trans), non-binary and intersex people.

The Lady Garden Foundation

www.ladygardenfoundation.com

Provides information and support to people with gynaecological cancers. Also raises awareness and funds research.

Lichen Sclerosus & Vulval Cancer UK Awareness

www.lsvcukawareness.co.uk

Provides information and support groups for people with lichen sclerosus and vulval cancer in the UK.

Women's Health Concern

www.womens-health-concern.org

Shares information and advice about women's gynaecological and sexual health, wellbeing and lifestyle concerns.

Early menopause and women's health support organisations

Daisy Network

www.daisynetwork.org

A support group for women who have early ovarian failure. The website gives information about premature menopause and related issues. It also has a mailing list for subscribers and details of other helpful groups.

Support with relationships and sexuality

College of Sexual and Relationship Therapists (COSRT)

www.cosrt.org.uk

A national specialist charity for sex and relationship therapy. Has a list of qualified practitioners and clinics providing sex and relationship therapy in the UK.

Lovehoney

www.lovehoney.co.uk/advice

Supports people living with cancer to feel empowered to discuss issues around sex, intimacy and cancer.

General cancer support organisations

Black Women Rising

www.blackwomenrisinguk.org

Aims to educate, inspire and bring opportunities for women from the BAME community. Shares stories and supports Black cancer patients and survivors through treatment and remission.

Cancer Black Care

Tel **0734 047 1970**

www.cancerblackcare.org.uk

Provides support for all those living with and affected by cancer, with an emphasis on Black people and people of colour.

Cancer Focus Northern Ireland

Helpline **0800 783 3339**

www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline **0808 800 4040**

www.cancerresearchuk.org

A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices

A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's

Tel **0300 123 1801**

www.maggies.org

Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 300 0118**

www.pennybrohn.org.uk

Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

Helpline **0808 808 1010**

www.tenovuscancercare.org.uk

Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

General health information

Drinkaware

www.drinkaware.co.uk

Provides independent alcohol advice, information and tools to help people make better choices about their drinking. Also has a web chat, for anyone concerned about their own drinking, or someone else's.

NHS.UK

www.nhs.uk

The UK's biggest health information website. Has service information for England.

NHS 111 Wales

111.wales.nhs.uk

NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88**

www.nhsinform.scot

NHS health information site for Scotland.

Northern Health and Social Care Trust

www.northerntrust.hscni.net

Provides information about health and social care services in Northern Ireland.

Patient UK

www.patient.info

Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health-related and illness-related websites.

Stop smoking services

NHS Smokefree Helpline (England)

Tel **0300 123 1044**

www.nhs.uk/better-health/quit-smoking

Offers information, advice and support to people who want to stop smoking or have already stopped and do not want to start again.

Quit Your Way Scotland

Tel **0800 84 84 84**

www.nhsinform.scot/quit-your-way-scotland

Scotland's national stop smoking support service. Offers advice and information about how to stop smoking. You can also chat online to an adviser.

Help Me Quit (Wales)

Tel **0808 085 2219**

Text 'HMQ' to **80818**

www.helpmequit.wales

Offers information, advice and support on stopping smoking in English and Welsh.

Stop Smoking NI (Northern Ireland)

www.stopsmokingni.info

Has information and advice about stopping smoking. Also links to other support organisations for people in Northern Ireland who want to give up smoking.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**

www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the therapist directory page.

UK Council for Psychotherapy (UKCP)

Tel **0207 014 9955**

www.psychotherapy.org.uk

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Anxiety UK

www.anxietyuk.org.uk

Provides help, information and support for people with anxiety, stress and anxiety-based depression.

Mind

Helpline **0300 123 3393**

www.mind.org.uk

Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **116 123**

Email jo@samaritans.org

www.samaritans.org

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**

www.adviceni.net

Provides advice on a variety of issues including financial, legal, housing and employment issues.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use its online webchat or find details for your local office by contacting:

England

Helpline **0800 144 8848**

www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**

www.cas.org.uk

Wales

Helpline **0800 702 2020**

www.citizensadvice.org.uk/wales

GOV.UK

www.gov.uk

Has information about social security benefits and public services in England, Scotland and Wales.

Support for older people

Age UK

Helpline **0800 678 1602**

www.ageuk.org.uk

Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

Support for LGBTQ+ people

LGBT Foundation

Tel **0345 330 3030**

www.lgbt.foundation

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

OUTpatients

www.outpatients.org.uk

A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. OUTpatients runs a peer support group with Maggie's Barts.

Support for carers

Carers Trust

Tel **0300 772 9600**

www.carers.org

Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline **0808 808 7777**

www.carersuk.org

Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

Cancer registries

The cancer registry is a national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services.

There is a cancer registry in each country in the UK. They are run by the following organisations.

England – National Disease Registration Service (NDRS)

digital.nhs.uk/ndrs/patients

Scotland – Public Health Scotland (PHS)

publichealthscotland.scot/population-health/conditions-and-diseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/overview

Wales – Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 010 4278**

phw.nhs.wales/wcisu

Northern Ireland – Northern Ireland Cancer Registry (NICR)

Tel **0289 097 6028**

qub.ac.uk/research-centres/nicr/AboutUs/Registry

[illegible]

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date, but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Professor Nick Reed.

With thanks to: Sarah Brain, Macmillan Gynaecology Clinical Nurse Specialist; Miss Stacey Bryan, Consultant Gynaecologist & Gynaecological Oncology Surgeon; Dr Rachel Cooper, Consultant Clinical Oncologist; and Vicki Hands, Advanced Clinical Practitioner in Radiotherapy Late Effects.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact informationproductionteam@macmillan.org.uk

Sources

Below is a sample of the sources used in our vulval cancer information. If you would like more information about the sources we use, please contact us at informationproductionteam@macmillan.org.uk

Morrison J, Baldwin P, Hanna L, Andreou A, Buckley L, Durrant L, et al. British Gynaecological Cancer Society (BGCS) vulval cancer guidelines: An update on recommendations for practice 2023. *European Journal of Obstetrics and Gynaecology and Reproductive Biology*. 2024;292: 210–238. Available from: www.doi.org/10.1016/j.ejogrb.2023.11.013 [accessed July 2026].

The Royal College of Radiographers. The Royal College of Radiologists expert panel recommendations for radiotherapy treatment for vulval cancer. 2024. Available from: www.rcr.ac.uk/media/l1zjohkm/rcr-vulval-cancer-treatment-recommendations.pdf [accessed July 2026].

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer.

They are produced by our cancer information specialists who, along with our nurses, money advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 ways you can help someone with cancer

1. **Share your cancer experience**

Support people living with cancer by telling your story, online, in the media or face to face.

2. **Campaign for change**

We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

3. **Help someone in your community**

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

4. **Raise money**

Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

5. **Give money**

Big or small, every penny helps. To make a one-off donation see over.

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order /
Charity Voucher made payable to
Macmillan Cancer Support
OR debit my:

Visa / MasterCard / CAF Charity
Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Do not let the taxman keep your money

Do you pay tax? If so, your gift
will be worth 25% more to us –
at no extra cost to you. All you
have to do is tick the box below,
and the tax office will give 25p
for every pound you give.

☐ I am a UK tax payer and
I would like Macmillan Cancer
Support to treat all donations
I make or have made to
Macmillan Cancer Support in the
last 4 years as Gift Aid donations,
until I notify you otherwise.

I understand that if I pay less Income Tax
and/or Capital Gains Tax than the amount of
Gift Aid claimed on all my donations in that
tax year it is my responsibility to pay any
difference. I understand Macmillan Cancer
Support will reclaim 25p of tax on every £1 that
I give.

Macmillan Cancer Support and our trading
companies would like to hold your details in
order to contact you about our fundraising,
campaigning and services for people affected
by cancer. If you would prefer us not to use
your details in this way please tick this box. ☐

In order to carry out our work we may need
to pass your details to agents or partners who
act on our behalf.

If you would rather donate online
go to macmillan.org.uk/donate



Registered with
**FUNDRAISING
REGULATOR**



Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations,
Freepost RUCY-XGCA-XTHU, Macmillan Cancer Support, PO Box 791, York House, York YO1 0NJ

This booklet is about cancer of the vulva (vulval cancer). It is for anyone who has been diagnosed with vulval cancer. There is also information for carers, family members and friends.

The booklet explains how vulval cancer may be treated. It also has information about feelings, practical issues and money.

At Macmillan, we know cancer can disrupt your whole life. We'll do whatever it takes to help everyone living with cancer in the UK get the support they need right now, and transform cancer care for the future.

For information, support or just someone to talk to, call [0808 808 00 00](tel:0808 808 00 00) or visit macmillan.org.uk

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using Relay UK on [18001 0808 808 00 00](tel:18001 0808 808 00 00), or use the Relay UK app.

Need information in different languages or formats? We produce information in audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit macmillan.org.uk/otherformats or call our support line.

Trusted
Information
Creator



Patient Information Forum