

A practical guide to
understanding cancer

UNDERSTANDING CANCER OF THE VULVA

**WE ARE
MACMILLAN.**
CANCER SUPPORT

Contents

About this booklet	2
About cancer of the vulva	5
Diagnosing cancer of the vulva	19
Treating cancer of the vulva	31
After your treatment	73
Your feelings and relationships	85
Work and financial support	95
Further information	101

About this booklet

This booklet is about cancer of the vulva (vulval cancer). We hope it answers your questions and helps you deal with any emotions you have. We've also listed other sources of support and information.

In this booklet, we've included some comments from people who've had vulval cancer. Some are members of our online community (macmillan.org.uk/community) and others have chosen to share their story with us. To share yours, visit macmillan.org.uk/cancervoices

We can't advise you about the best treatment for you. This information can only come from your doctor, who knows your full medical history.

If you'd like to discuss this information, call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8pm. If you're hard of hearing, you can use textphone **0808 808 0121** or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit macmillan.org.uk

Turn to pages 107–112 for some useful addresses and websites.

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.





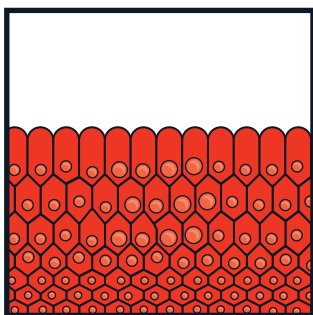
ABOUT CANCER OF THE VULVA

What is cancer?	6
The vulva	8
The lymphatic system	10
Types of vulval cancer	11
Causes and risk factors	14
Symptoms	17

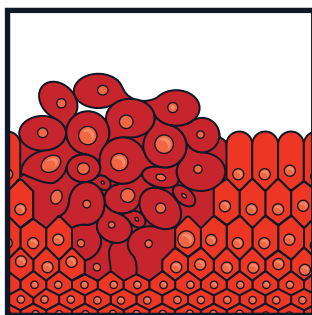
What is cancer?

Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop growing. When a cell is no longer needed or can't be repaired, it gets a signal to stop working and die.

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing making more and more abnormal cells. These eventually form a lump (**tumour**). Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a **biopsy**. The doctors examine the sample under a microscope to look for cancer cells.



Normal cells



Cells forming a tumour

A lump that is not cancerous (**benign**) may grow but cannot spread to anywhere else in the body. It usually only causes problems if it puts pressure on nearby organs.

A lump that is cancer (**malignant**) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or lymphatic system (see page 10). When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a **secondary cancer** or a **metastasis**.

The vulva

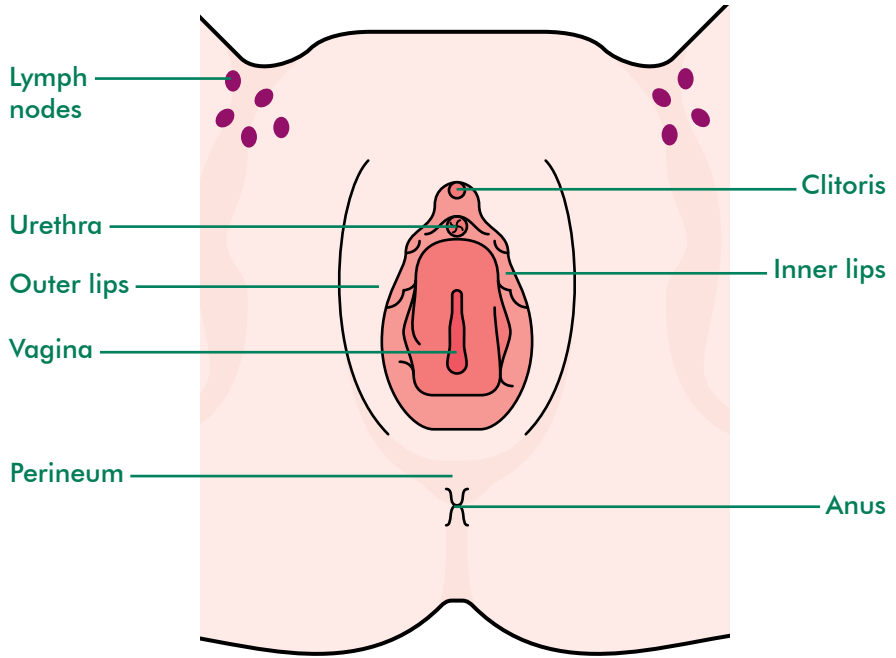
The vulva is the area of skin between a woman's legs. It's made up of all the visible sex organs.

The vulva includes:

- two outer lips (the labia majora), which surround two inner lips (the labia minora)
- the clitoris, which is a small structure at the front of the vulva – it's a sexual organ that helps women reach climax (orgasm)
- the opening of the urethra – this is just behind the clitoris and is where urine comes out
- the vaginal opening (birth canal).

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

The area where the skin creases at the top of each leg is called the groin. The groin contains lymph nodes, which are part of the lymphatic system (see page 10).



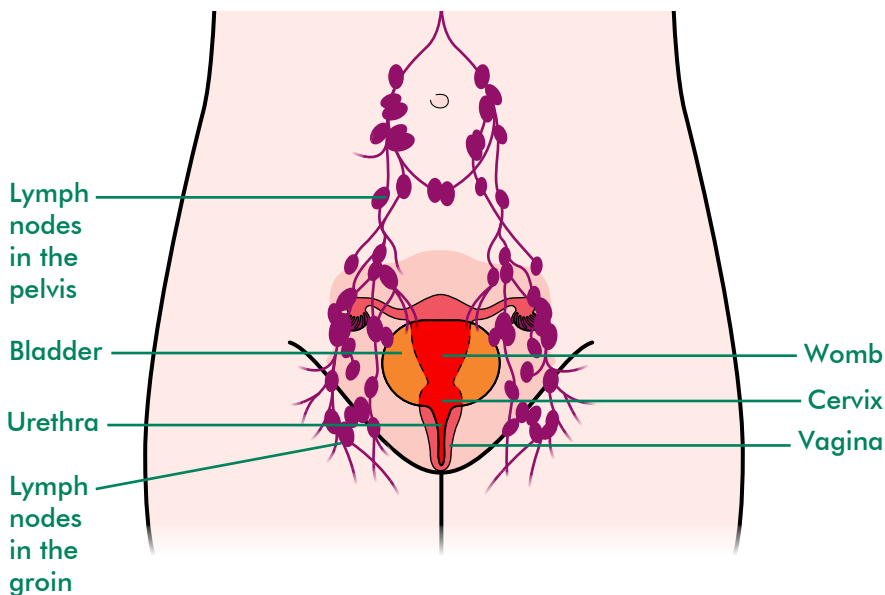
The vulva

The lymphatic system

Your lymphatic system helps to protect you from infection and disease. It's part of the body's immune system. It is made up of fine tubes called lymphatic vessels. These connect to groups of bean-shaped lymph nodes (sometimes called lymph glands) all over the body.

A liquid called lymph travels around the body in the lymphatic vessels. As it does, the lymph nodes filter out any bacteria (germs) and disease from the fluid. Once the lymph is filtered, it goes back into the blood. If you have an infection, such as a sore throat, the lymph nodes close by often swell while they fight it.

Sometimes, cancer can spread through the lymphatic system. If vulval cancer spreads to the lymphatic system, it's most likely to go to the lymph nodes in the groin.



The lymph nodes in the groin and pelvis, and surrounding structures

Types of vulval cancer

Cancer of the vulva is rare. Just over 1,170 women are diagnosed with it each year in the UK. It's most likely to occur in women over the age of 60, but the number of younger women who are affected is increasing.

Vulval cancer can occur on any part of the external female sex organs (see pages 8–9). The inner edges of the labia majora and the labia minora are the most common areas for it to develop. Vulval cancer can also sometimes affect the perineum.

Squamous cell carcinoma

This is the most common type of vulval cancer. 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. Squamous cell carcinomas account for 9 out of 10 vulval cancers (90%).

Vulval melanoma

This is the second most common type of vulval cancer. Melanomas develop from cells that produce the pigment that gives skin its colour. Around 4 out of 100 vulval cancers (4%) are melanomas.

Verrucous carcinoma

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



Adenocarcinoma

This is very rare. Adenocarcinoma of the vulva develops from cells that line the glands in the vulval skin.

Basal cell carcinoma

This type of vulval cancer is also very rare. It develops from cells called basal cells that are found in the deepest layer of the skin of the vulva.

Sarcoma

Sarcomas of the vulva are extremely rare. Sarcomas develop from cells in tissue such as muscle or fat under the skin. They tend to grow more quickly than other types of vulval cancer.

Causes and risk factors

The exact causes of vulval cancer are unknown. There are some risk factors that can increase a woman's chances of developing it.

Age

The risk of developing vulval cancer increases with age. About 8 out of 10 women who are diagnosed with vulval cancer (80%) are over the age of 60. Vulval cancer in older women is usually linked to a skin condition called lichen sclerosis (see below).

Vulval cancer is becoming more common in younger women, where it's often linked to human papillomavirus infection (HPV – see opposite page).

Vulval skin conditions

Women who have non-cancerous skin conditions of the vulva, such as **vulval lichen sclerosis** or **vulval lichen planus**, have a higher risk of developing vulval cancer. About 3–5 out of every 100 women who have lichen sclerosis (3–5%) develop vulval cancer. It's thought that over a long period of time the inflammation caused by these skin conditions increases the risk of cancer developing.



We can send you more information about lichen sclerosis and lichen planus.

Human papillomavirus (HPV)

HPV is a very common infection. It is usually passed between people during sex. There are many different types of HPV, and each has a number. Some types (particularly 16, 18 and 31) are linked to vulval cancer and pre-cancerous changes called **VIN** (see page 16).

Most women with HPV infection don't have any problems, as their immune system quickly gets rid of the virus. But in a few women, the virus stays and may cause abnormal changes in the skin of the vulva, and sometimes vulval cancer.

A vaccination against HPV is offered to girls aged 12–13 in the UK. This protects against HPV types 16 and 18.

It may take several years to see whether this vaccination reduces the number of vulval cancers. This is because vulval cancers can take a long time to develop.



We can send you more information about HPV and HPV vaccines.

Vulval intraepithelial neoplasia (VIN)

This is a pre-cancerous condition that can occur in the skin of the vulva. In some women, VIN develops into vulval cancer. There are two types of VIN:

VIN usual type

This type is linked to HPV infection and mainly affects younger women under 50.

VIN differentiated

This type of VIN is linked to lichen sclerosus and more commonly affects women over 50.



We can send you more information about VIN.

Paget's disease of the vulva

This condition causes abnormal changes in the cells that cover the skin of the vulva. It's rare and usually only affects women who've been through the menopause. In a small number of women with Paget's disease of the vulva, cancer is found underneath the area.

Smoking

Smoking increases the risk of developing both VIN and vulval cancer. The longer a woman smokes for and the more cigarettes she smokes, the greater the risk. Smoking makes the immune system less effective and less able to get rid of the HPV virus. This may be one reason why it increases the risk of vulval cancer. If you are a smoker and want to stop, our booklet *Giving up smoking* has tips and advice.

Symptoms

The most common symptoms of vulval cancer are:

- itching, burning or soreness of the vulva that doesn't go away
- a lump, swelling or wart-like growth on the vulva
- thickened, raised, red, white or dark patches on the skin of the vulva
- bleeding, or a blood-stained vaginal discharge, not related to menstruation (periods)
- burning pain when passing urine
- tenderness or pain in the area of the vulva
- a sore or ulcerated area on the vulva
- a mole on the vulva that changes shape or colour.

All of these symptoms can happen with conditions other than cancer, but it's always important to get your doctor to check them.

Vulval cancer can take many years to develop. It usually starts with pre-cancerous cells that change slowly over several years into cancerous cells. As with other cancers, it's easier to treat and cure if it's diagnosed at an early stage.



DIAGNOSING CANCER OF THE VULVA

How cancer of the vulva is diagnosed	20
Staging and grading	26

How cancer of the vulva is diagnosed

You will usually see your GP first. They will examine you and arrange any tests you need.

If there is a possibility that you have vulval cancer, you should be referred to a specialist in women's cancers (gynaecological cancer specialist). Your doctor may also arrange for you to have a blood test and chest x-ray to check your general health.

Vulval examination

The gynaecological cancer specialist will ask you about your general health. They will also examine your vulval area. This can usually be done during an outpatient appointment.

The vulva is an intimate and private part of the body. Some women find it embarrassing or upsetting to have a vulval examination. If you feel this way, let your doctor or nurse know so they can give you support.

Before the examination, a nurse will help you position yourself on a couch. There may be special leg supports. The doctor may use a bright light and a magnifier to examine your vulva. This helps them see the skin more clearly. They may take small samples of tissue (biopsies) from any areas that look unusual (see opposite page). You may have a local anaesthetic for this.

The doctor will also do an internal examination to check your vagina and cervix for any abnormalities. They will use a plastic or metal instrument called a speculum. This holds the vaginal walls open. A liquid will be dabbed on to your cervix to help

show up any abnormal areas more clearly. You may also have a small sample of cells taken from the cervix. The doctor may also examine your back passage (anus).

If you have narrowing of the vagina due to lichen sclerosus (see page 14), or if your vulva is too sore for a full examination, the specialist can arrange to examine you while you're under a general anaesthetic (see page 25).

Biopsy

A biopsy is the best way to diagnose cancer of the vulva. A doctor takes a small sample of tissue from the affected area of the vulva. This is sent to a laboratory to be examined under a microscope.

You can have a biopsy as an outpatient. Before the biopsy, you will have a local anaesthetic injected into the skin of your vulva to numb it. This may sting for a few seconds. There shouldn't be any pain when the sample of tissue is taken from your vulva, but you may feel a little discomfort. Your doctor may put one or two stitches in the area where the biopsy was taken from.

Occasionally, if your vulval area is very painful, you may have your biopsy taken under a general anaesthetic.

After the biopsy, you may have some bleeding. This should gradually stop. If it gets worse or continues, tell your doctor. You may also feel sore. Painkillers or a warm bath can help.

It will probably take about 7–10 days for the results of your tests to be ready. Waiting for your results can be a difficult time. It may help to talk to a relative or close friend.



You may want to call one of our cancer support specialists on 0808 808 00 00.

Further tests

If your vulval examination and biopsy show that you have cancer of the vulva, your doctor will arrange some of the tests listed over the following pages. These are to see whether the cancer has spread. They also help your doctor plan your treatment:

Blood tests

You'll have blood taken to check your general health and how well your kidneys and liver are working.

Chest x-ray

This uses x-rays to take a picture of your chest, to check your lungs and heart.

CT (computerised tomography) scan

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10–30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan. The photograph opposite shows someone having a CT scan.

You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. It's important to let your doctor know if you are allergic to iodine or have asthma, because you could have a more serious reaction to the injection.

You'll probably be able to go home as soon as the scan is over.



MRI (magnetic resonance imaging) scan

This test uses magnetism to build up a detailed picture of areas of your body. The scanner is a powerful magnet, so you may be asked to complete and sign a checklist to make sure it's safe for you. The checklist asks about any metal implants you may have, for example a pacemaker, surgical clips or bone pins. You should also tell your doctor if you've ever worked with metal or in the metal industry, as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body, it's likely that you won't be able to have an MRI scan. In this situation, another type of scan can be used. Before the scan, you'll be asked to remove any metal belongings, including jewellery.

Below is a photograph of someone having an MRI scan.



Some people are given an injection of dye into a vein in the arm, which doesn't usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly.

During the test you'll lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It's painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It's also noisy, but you'll be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.

PET/CT scan

This is a combination of a CT scan, which takes a series of x-rays to build up a three-dimensional picture (see page 22), and a positron emission tomography (PET) scan. A PET scan uses low-dose radiation to measure the activity of cells in different parts of the body.

PET/CT scans give more detailed information about the part of the body being scanned. You may have to travel to a specialist centre to have one.

You can't eat for six hours before the scan, although you may be able to drink.

A mildly radioactive substance is injected into a vein, usually in your arm. The radiation dose used is very small. The scan is done after at least an hour's wait. It usually takes 30–90 minutes. You should be able to go home after the scan.

Examination under anaesthetic (EUA)

This is an examination of the vulva, done under a general anaesthetic. Your doctor will be able to examine you thoroughly, and check the extent of the cancer without causing you discomfort.

Staging and grading

Staging

The stage of a cancer is a term used to describe its size and whether it has spread beyond the area where it first started. Knowing the stage of the cancer will help you and your doctor decide on the most appropriate treatment.

This is a commonly used staging system for vulval cancer. It may help to look back at the diagram on page 9 when you're reading this chapter.

Stage 1

The cancer is only in the vulva and/or perineum (the area between the vagina and the anus).

Stage 1 is further divided into:

Stage 1A

The cancer is 2cm or less in size, and has grown 1mm or less deep into the skin.

Stage 1B

The cancer is more than 2cm in size **OR** the cancer is any size and has grown more than 1mm deep into the skin.

Stage 2

The cancer is any size and has spread to other areas such as the lower part of the urethra, the vagina or the anus.

Stage 3

The cancer has spread to the lymph nodes in the right or left side of the groin (see page 10).

Stage 3 is further divided into:

Stage 3A

The cancer has spread to one lymph node that is 5mm or more in size **OR** the cancer has spread to one or two lymph nodes that are less than 5mm in size.

Stage 3B

The cancer has spread to two or more lymph nodes that are 5mm or more in size **OR** the cancer has spread to three or more lymph nodes that are less than 5mm in size.

Stage 3C

The cancer has spread to any number of lymph nodes, and it has also spread outside the capsule that surrounds the lymph node.

Stage 4

Stage 4 is divided into:

Stage 4A

The cancer is any size and has spread to other areas such as the urethra and/or vagina, the bladder or the rectum, or it has become fixed to the pelvic bone **OR** the cancer has spread to lymph nodes in the groin, and these lymph nodes have formed an ulcer or are not moveable.

Stage 4B

The cancer has spread to the lymph nodes in the pelvis, or to other parts of the body that are further away, such as the liver or lungs.

Gynaecologists often call stage 1 and 2 cancers **early-stage cancers**, and stage 3 and 4 cancers **advanced-stage cancers**. However, some gynaecologists only call stage 1 cancers early-stage cancers.

Grading

The grade of a cancer gives an idea of how quickly it might grow. The grade is based on what the cancer cells look like under a microscope when compared with normal cells. Knowing the grade helps your doctor decide whether you need further treatment after surgery.

Grade 1 or low-grade

The cancer cells look similar to normal cells (they are well differentiated) and usually grow slowly. The cancer cells are less likely to spread.

Grade 2 or moderate- or intermediate-grade

The cancer cells look more abnormal (they are moderately differentiated) and grow slightly faster than grade 1 cells.

Grade 3 or high-grade

The cancer cells look very different from normal cells (they are poorly differentiated) and may grow quicker than grade 1 or 2 cells.





TREATING CANCER OF THE VULVA

Planning treatment	32
Surgery	37
Radiotherapy	57
Chemotherapy	65
Research – clinical trials	70

Planning treatment

Surgery is the main treatment for vulval cancer (see pages 37–55). For many women, surgery can cure the cancer. Surgery may be used alone or with radiotherapy (see pages 57–63) or chemotherapy (see pages 65–68).

The aim of surgery is to completely remove the cancer. It's important that all the cancer is removed. At the same time, your surgeon will try to keep the appearance and function of the vulva and nearby tissues as normal as possible.

You may have radiotherapy to shrink the cancer before surgery. You may also have radiotherapy after surgery. This is to make sure any remaining cancer cells are destroyed. Radiotherapy and chemotherapy can also be used together (chemoradiation). If the cancer has spread to other parts of the body, chemotherapy may be used on its own.

How treatment is planned

In most hospitals, a team of specialists will talk to you about the treatment they feel is best for your situation.

This multidisciplinary team (MDT) will include:

- a **gynaecological oncologist** (a surgeon who specialises in gynaecological cancers)
- a **medical oncologist** (a doctor who specialises in treating cancer with chemotherapy)

- a **clinical oncologist** (a doctor who specialises in treating cancer with radiotherapy and chemotherapy)
- a **radiologist** (a doctor who specialises in reading scans)
- a **gynaecology-oncology specialist nurse** (clinical nurse specialist), who will be your main contact and will make sure you get help and support throughout your treatment
- a **plastic surgeon** (a doctor who specialises in reconstructive surgery).

The MDT may also include other healthcare professionals, such as a dietitian, physiotherapist, occupational therapist, psychologist or counsellor.

The type of treatment you have is based on:

- the type of vulval cancer you have
- its stage and grade
- your general health
- your personal preferences.

Giving your consent

Before you have any treatment, your doctor will explain its aims. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent, and before you are asked to sign the form you should be given full information about:

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you don't understand what you've been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it's not unusual to need repeated explanations. It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

People sometimes feel that hospital staff are too busy to answer their questions, but it's important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

You can always ask for more time if you feel that you can't make a decision when your treatment is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you don't have it. It's essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You don't have to give a reason for not wanting treatment, but it can help to let the staff know your concerns so they can give you the best advice.

The benefits and disadvantages of treatment

Many people are frightened at the idea of having cancer treatments, particularly because of the side effects that can occur. However, these can usually be controlled with medicines. Treatment can be given for different reasons, and the potential benefits will vary depending on your individual situation.

If the cancer is advanced and has spread to other parts of the body, treatment may only be able to control it, improving symptoms and quality of life. However, for some people in this situation, the treatment will have no effect on the cancer and they will get the side effects without any of the benefit.

If you've been offered treatment that aims to cure the cancer, deciding whether to accept it may not be difficult. However, if a cure is not possible and the purpose of treatment is to control the cancer for a period of time, it may be more difficult to decide whether to go ahead.

Making decisions about treatment in these circumstances is always difficult, and you may need to discuss in detail with your doctor whether you wish to have treatment. If you choose not to have it, you can still be given supportive (palliative) care, with medicines to control any symptoms.

Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide on the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion. Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.



Surgery

Your surgeon will talk with you about the most appropriate type of surgery. A gynaecological nurse specialist will also give you information and support before and after your operation.

The aim of surgery is to remove all the cancer affecting the vulva. The surgeon will take away the area of skin where the cancer is, and a border (margin) of healthy tissue all around it (see pages 40–43). In the same operation, they will also usually remove the lymph nodes from one or both sides of the groin (see below). Women who have larger tumours may need more surgery to reconstruct the vulva (see pages 44).

Surgery to the lymph nodes

Most women have lymph nodes removed from one or both sides of their groin. This is to:

- try to remove any cancerous lymph nodes – if vulval cancer spreads, it usually goes to the lymph nodes in the groin.
- give information about the stage of the cancer, which helps when making decisions about other treatments.

Having many lymph nodes removed can affect fluid drainage from the legs and vulva. Because of this, some women develop increased swelling in one or both legs. This may happen months or years after their operation and is called **lymphoedema** (see pages 75–76)

Early-stage vulval cancer (see pages 26–28) and rarer types of vulval cancer do not usually spread to the lymph nodes. Your doctor will tell you more about whether you'll need to have lymph nodes removed.

Other ways of checking lymph nodes

Research is currently looking into other ways of checking the lymph nodes without removing lots of them. This aims to reduce the risk of lymphoedema. By using these other tests, only women who definitely have cancer in their lymph nodes need to have them removed.

Sentinel lymph node biopsy (SLNB)

This involves removing and checking one or more selected lymph nodes, called sentinel nodes, for cancer. The sentinel node is the first node that fluid drains to from the vulva, so it's the first lymph node the cancer could spread to. If the sentinel nodes are free from cancer, it's likely that no further lymph nodes have cancer cells in them, and that no more lymph nodes need to be removed.

To find the sentinel node(s), the surgeon injects a tiny amount of radioactive liquid close to the cancer, a few hours before the operation. During the operation, they inject a blue dye into the same area. The nodes that stain blue and take up the radioactive liquid are the sentinel nodes. These nodes are removed and tested for cancer cells.

If the sentinel nodes don't contain any cancer cells, then you won't need to have any more lymph nodes removed. However, if there are cancer cells in one or more sentinel nodes, all the remaining lymph nodes will need to be removed or treated with radiotherapy.

If you are eligible for an SLNB, you may have it done as part of a clinical trial. Your doctor or nurse will be able to tell you whether a SLNB is suitable for you.

Ultrasound scan of the groin and needle biopsy

This involves having an ultrasound scan, which is painless and only takes a few minutes. Some gel is spread onto your groin and a small device that produces soundwaves is passed over the area. The soundwaves produce a picture of your lymph nodes, which can be seen on a computer screen. The doctor will look for changes in the size or appearance of the lymph nodes.

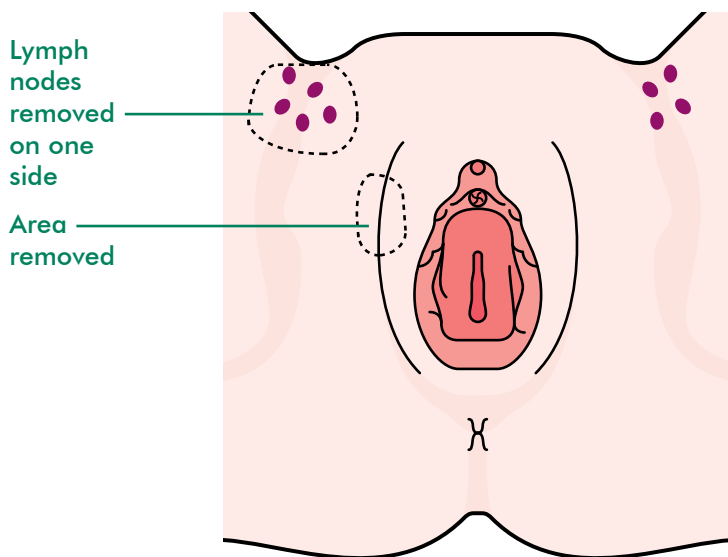
A small sample of cells (biopsy) may be taken from a lymph node during the scan. First, the doctor injects some local anaesthetic into the skin of your groin to numb the area. This may sting for a few seconds. Using the ultrasound images as a guide, the doctor then puts a small needle into a lymph node and draws a sample of cells into a syringe. The sample is then sent to a laboratory, where it will be checked for cancer cells.

Surgery to remove cancer of the vulva

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 more major operation.

Radical wide local excision (also called a radical local excision or wide local excision)

This operation takes away the cancer and a border (margin) of healthy tissue all around the cancer. The margin is usually at least 1.5cm. Lymph nodes are also usually removed from the groin on the same side as the cancer.

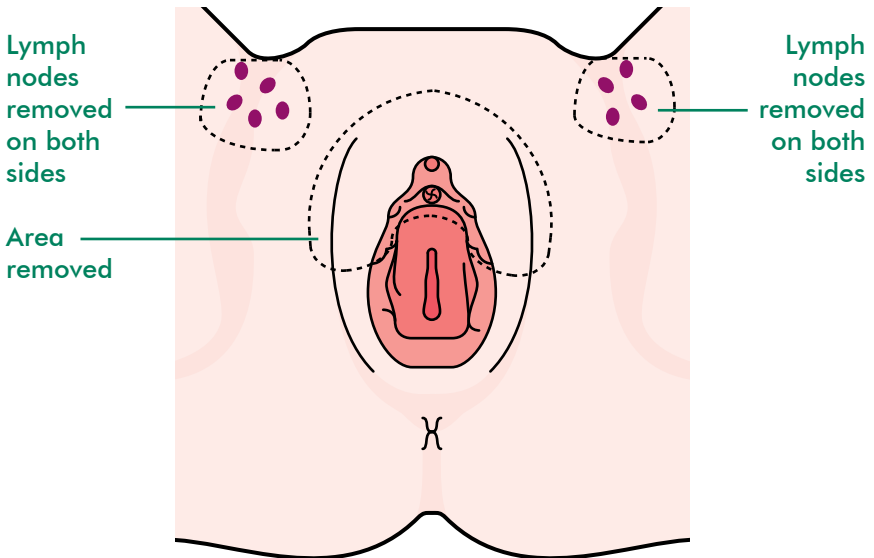


Radical partial vulvectomy (also called a partial vulvectomy)

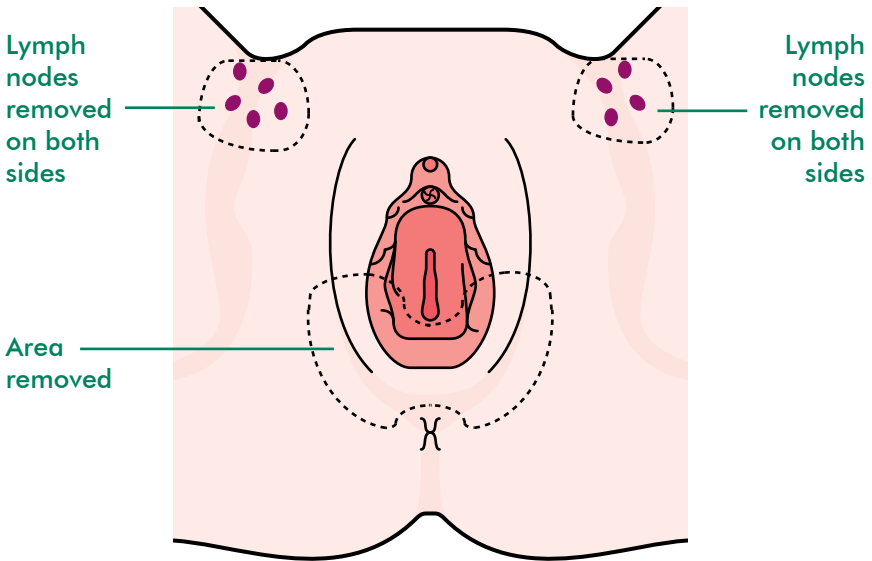
The following three diagrams show different types of radical partial vulvectomy.

This operation removes part of the vulva. You may have lymph nodes removed from one or both sides of the groin as well, depending on where the cancer is.

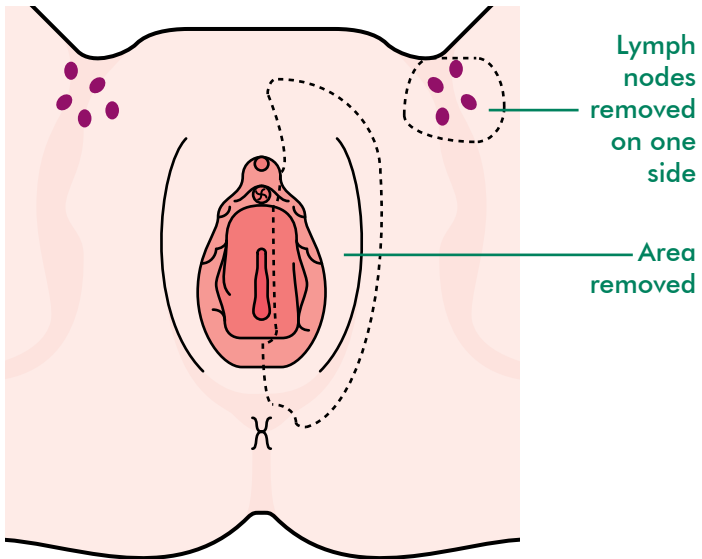
Radical partial vulvectomy upper



Radical partial vulvectomy lower

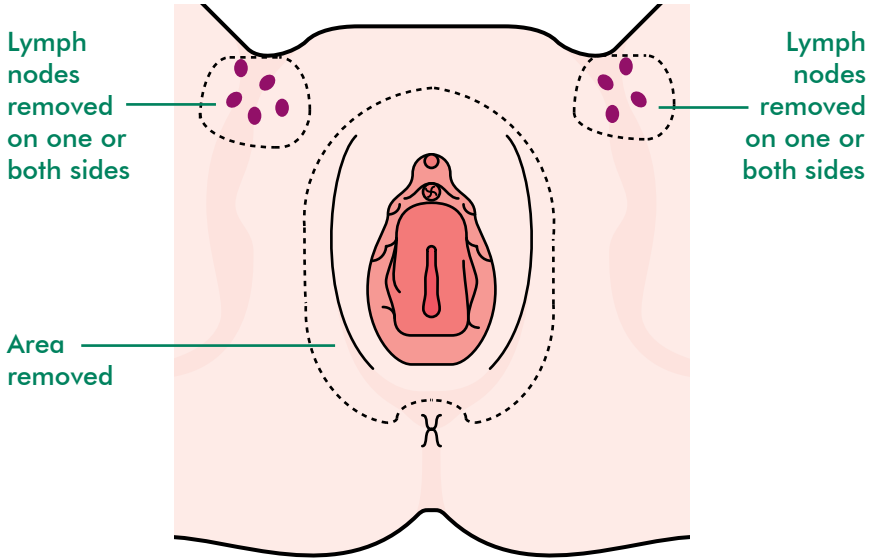


Radical partial vulvectomy side



Radical vulvectomy

This operation removes the entire vulva, including the inner and outer labia and the clitoris. The lymph nodes are also removed from one or both sides of your groin.



Reconstructing the vulva

If you need surgery to reconstruct the vulva, it's usually done at the same time as the operation to remove the cancer.

If only a small amount of skin is removed from your vulva, the surgeon may be able to stitch the remaining skin neatly together. However, if a larger area of skin is taken away, you may need to have skin flaps or a skin graft.

For a skin flap, the surgeon partly removes some skin near the vulva and transfers it on to the area to cover the wound.

A skin graft involves the surgeon taking a piece of skin from another part of the body (usually the thigh or abdomen) and placing it over the area where the cancer was removed.

If you need a skin flap or skin graft, a plastic surgeon will also be involved in the surgery.

Surgery for vulval cancer that has spread (pelvic exenteration)

If the cancer has spread to organs close to the vulva, such as the womb, bladder or lower bowel, it may still be possible to remove the cancer. This involves a major operation called a pelvic exenteration, where any affected organs are removed. Recovery following this type of operation can be difficult both physically and emotionally, so it's not done very often. But this operation can be worthwhile for some women, as it may be able to completely remove the cancer, even when it's advanced.



We have more detailed information about pelvic exenteration that we can send you.

Before your operation

If you smoke, try to give up or cut down before your operation. This will help reduce your risk of getting chest problems such as an infection. It will also help your wound heal after the operation. Your GP can help you if you want to give up smoking.

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

A member of the surgical team will discuss the operation with you. You'll also meet the doctor who will give you the anaesthetic (the anaesthetist). You'll be given special elastic stockings called TED stockings to wear during and after the operation. This is to prevent blood clots forming in your legs.

It's a good idea to talk to your nurse or doctor about any questions or concerns that you have about the operation.



You may find it helpful to read our booklet
Giving up smoking.

After your operation

How quickly you recover will depend on the type of operation you have. You'll be encouraged to start moving around as soon as possible. While you're in bed, it's important to move your legs regularly and do deep breathing exercises. This is to help 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.

If you've had lymph nodes removed from your groin, you'll be encouraged to put your feet up when you're sitting down. This helps fluid to drain in your legs.

In the ward

After your operation, you'll be given fluids into a vein in your hand or arm. This is called a drip or intravenous infusion. Once you're eating and drinking normally again, it's taken out. You'll usually have a tube (catheter) that drains urine from your bladder. It's put in during the operation. 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'll have a tube (drain) going into your groin. This is to remove any fluid that may collect there. The drain is connected to a small suction bottle. Your nurse will remove it from your groin when most of the excess fluid has been drained off – this usually takes a few days.



Your wound

You may not have any dressings on your vulval wound. The area is likely to be kept clean by being gently rinsed with fluid. This is usually done three times a day until you go home. If you do have a dressing, your nurse will remove it after a few days and change it regularly, to keep the area clean and help the skin to heal.

If you have any wounds in your groin area, they will be covered with dressings, which will need to be changed regularly. Sometimes, wounds near the groin can heal more slowly than wounds in other areas. You may have vacuum-assisted (VAC®) therapy. VAC therapy uses a pump or suction machine, which is attached to a dressing on your wound. It draws fluid out of the wound and also helps with healing by encouraging blood flow to the affected area. This can be done in hospital or managed at home by a district nurse.

If you don't have stitches that dissolve, you will probably have your stitches or staples removed about 7–10 days after your operation.

If you've had a skin graft, you may need dressings on the area the skin was taken from. Usually these dressings stay in place until new skin has formed. Your nurse will explain more about this to you.

Wound infection

This can be a complication of the surgery. Signs of infection include warmth, redness and swelling around the wound, or discharge coming from it. You may also feel unwell with a fever. Tell your nurse or doctor if you get any of these symptoms, even after you go home.

Pain

There are effective ways to prevent and control pain after surgery. Depending on the extent of your surgery, you may need a strong painkiller for the first day or two after your operation. There are different types of strong painkiller:

- You may have painkillers by injection into a muscle. The nurses will do this.
- You may have a patient-controlled analgesia (PCA) pump. This means you can give yourself an extra dose of pain relief if you feel sore. The machine is set to make sure you can't have too much.
- Some women have painkillers through an epidural infusion for the first few days. The anaesthetist puts a fine tube into your back during surgery. They connect the tube to a pump to give you a continuous dose of painkillers.

When you no longer need strong painkillers, you will have milder painkillers as tablets. Tell your nurses and doctors if you're in pain, so they can give you the dose of painkillers that's right for you.

Constipation

You may not have bowel movements for a few days after your operation. This is normal and may be due to the combined effects of the operation, painkillers and changes to your diet and activity levels. You may be prescribed laxatives to prevent constipation. If opening your bowels is painful or difficult, let your doctors know so they can prescribe extra laxatives to help.

Changes to your vulva

After surgery, you may have some bruising and swelling around your vulva. This should gradually disappear with time. You may have some numbness or altered sensation around the area after surgery. This is because of the effects of surgery on the nerves close by. It often improves over a period of months.

Some types of vulval surgery can change the appearance of your genital area. How you approach looking at the vulval area after your operation will be very personal to you. If you've never looked at your vulva before, the idea of doing so may seem strange. You may not want to look at the area at all, or you may want a nurse with you when you look for the first time. A nurse can explain what's happened to the area and offer support and advice. You may prefer to look alone or with a partner, relative or friend. Whoever you choose, make sure it's someone that you trust and can talk to about your feelings.

Don't force yourself to do things before you feel ready. If you decide to look at the area where you had surgery, remember that you may feel shocked, even if you were well prepared. This is understandable. You may want to talk about your feelings with one of the organisations listed on pages 107–110.

Getting support

It's common to feel upset and tearful after the operation. This can be a natural reaction to the diagnosis of cancer, the effects of the operation and being away from home and family. You may find these feelings go after a few days, or you may continue to feel this way after you go home. Tell your doctor or specialist nurse if you aren't feeling better or if you begin to feel very low, as you may need extra help and support. You can read more about coping with your feelings on pages 86–89. There are also contact details for support organisations on pages 107–110.

Some hospitals have local support groups for women who have gynaecological cancers. If you think you'd find a support group helpful, tell your clinical nurse specialist. They can tell you if there's one in your hospital or local area.

You could also join an online support group. Visit our social networking site at **macmillan.org.uk/community** There, you can chat with other people who have vulval cancer, or just read through the posts or blogs other people have written.

'Look after yourself and take it easy. I am feeling better now but get very tired, so I do a little and rest a little. We went on holiday when my treatment finished, so give yourself something to look forward to if you can. It helped me.'

Patricia

Going home

When you go home, you won't be able to do a lot straight away. You'll need to rest for a few weeks. How long it takes you to recover will depend on the extent of your surgery.

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

It's best to wait about eight weeks before going back to work, but you may need longer if you heal more slowly.

You can usually start driving after six weeks, but you should check with your specialist and car insurance provider first, as 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 advise you on what to expect and the precautions you should take. Here are some other helpful tips:

- Avoid wearing tight clothing and using any lotions, perfumes and talcum powders in the area where you had your operation.
- Avoid doing a lot of walking until the skin has healed.
- Frequent baths with warm water can soothe the wound and help healing, but avoid using scented bath oils and bubble bath. Some women find it easier to use a 'sitz bath' (a type of bath that fits over the toilet and allows you to soak just your buttocks and genital area). If you can't get a sitz bath locally, you can buy one online.

- If passing urine makes your wound sting, try pouring a small jug of warm or tepid water over the wound while you're still sitting on the toilet.
- A hairdryer on a cool setting can be a comfortable way of drying the vulval skin. You can also try gently patting your skin dry with a clean towel.
- Wear loose-fitting skirts.
- If you can avoid wearing underwear, this may help to keep you more comfortable. However, it won't be possible to avoid wearing underwear if you have to keep pads in place.
- If you become constipated, ask your doctor to prescribe you some laxatives.

Before you leave hospital, the staff can arrange for a district nurse to visit you at home. They can also organise other support services if you need them.

'I had a vulvectomy last year. I found leaving my knickers off was most comfortable. I also wore loose boxer shorts – I found men's comfy, as they didn't touch the wounds. Be kind to yourself and give yourself time to recover.'

Sue

Sex

Coping with a cancer diagnosis and the effects of surgery to an intimate part of your body can understandably affect your sex life. It's safe to start having sex again once your wound has completely healed, which usually takes about 6–8 weeks. However, many women need longer than this to feel physically or emotionally ready for sex. A few women may develop some tightening and scar tissue at the entrance to the vagina, which can make sex more difficult. If this happens, it's important to discuss it with your doctor or nurse. They can give you advice and support.

You can read more about sex and sexuality after treatment on pages 77–78.



Follow-up

You'll have an appointment with your surgeon in the outpatient clinic 4–6 weeks after surgery. They will check how well your skin is healing and discuss any problems with you.

If you have any problems or worries before this follow-up appointment, contact your hospital doctor or the nurses on your ward for advice.

There's more information about follow-up after treatment on page 74.

'I have had a few surgeries. After my last operation I could not drive or sit properly for around four weeks, and after then I had to be careful how I sat down. I found that sitting on a rubber ring helped.'

Helen



Radiotherapy

Radiotherapy uses high-energy rays to destroy cancer cells. You may have radiotherapy before surgery to try to shrink the cancer, making a smaller operation possible. You may also have radiotherapy after surgery if the cancer isn't completely removed or if there is cancer in the lymph nodes.

Radiotherapy is also used to treat vulval cancer that has come back or spread. If the cancer is advanced, the main aim of radiotherapy may be to improve quality of life by shrinking the tumour and reducing symptoms. This is known as **palliative radiotherapy**. Sometimes, chemotherapy is given with radiotherapy. This is called **chemoradiation** (see page 65).



Our booklet *Understanding radiotherapy* gives more information about the treatment and its side effects. Our video at macmillan.org.uk/radiotherapy shows a radiotherapy machine and explains how treatment is given.

Radiotherapy can be **internal** or **external**. Radiotherapy for vulval cancer is usually external (see page 58). However, occasionally internal radiotherapy (see pages 58–59) is given on its own or in combination with external radiotherapy.

Planning your radiotherapy

Radiotherapy has to be carefully planned to make sure it's as effective as possible. It's planned by a cancer specialist (clinical oncologist) and it may take a few visits.

On your first visit to the radiotherapy department, you'll be asked to have a CT scan (see page 22) or to lie under a machine called a simulator, which takes x-rays of the area to be treated.

Depending on your type of treatment, you may need some small marks made on your skin to help the radiographer (who gives you your treatment) position you accurately and to show where the rays will be directed. These marks must stay visible throughout your treatment, and permanent marks (like tiny tattoos) are usually used. These are extremely small, and will only be done with your permission. It may be a little uncomfortable while they are done.

External radiotherapy

High-energy x-rays are directed from a machine to the area of the cancer. You normally have external radiotherapy as a series of short, daily treatments in the hospital radiotherapy department. You'll go to hospital for your treatment Monday–Friday and then have a rest at the weekend. The number of treatments you have will depend on the type and size of the cancer. The whole course of treatment for vulval cancer will usually last a few weeks.

Internal radiotherapy (brachytherapy)

For internal radiotherapy, your doctor will insert a radioactive source directly into the cancer. This gives a high dose of radiotherapy to the tumour. As the radiation doesn't travel far, your surrounding organs won't be affected.

The source is left there for some time, which can range from 30 minutes to a couple of days. It depends on the amount of radiation needed. You can talk to your doctor about whether brachytherapy is suitable for you.

Side effects of radiotherapy

You may develop side effects during your treatment. These usually improve gradually over a few weeks or months after treatment finishes. Radiotherapy affects people in different ways, so it's difficult to predict exactly how you'll react to your treatment. Let your team know about any side effects you have during or after treatment, as there are often things that can be done to help.

Skin irritation

You may find the skin around your vulva and groin becomes dry and irritated. Your specialist can prescribe cream to help soothe the soreness. Use lukewarm water to wash the area, and gently pat the area dry with a soft towel. You shouldn't use talcum powder or perfume, as these can cause irritation. Your radiographer or nurse will advise you on how to look after your skin during treatment.

Bladder changes

Radiotherapy can irritate the bladder, which can make you feel like you want to pass urine more often. You may also have a burning feeling when you pass urine. Your doctor can prescribe medicines to make passing urine more comfortable. Try drinking at least two litres (three pints) of water or other fluids each day to help with the symptoms.



Bowel changes

Radiotherapy may also irritate the bowel and cause diarrhoea. If this is a problem, tell your doctor. Medicines can be prescribed to help. It's important to drink plenty of water to replace the fluid lost through diarrhoea.

Tiredness (fatigue)

Many people feel tired when having radiotherapy. Tiredness can continue for weeks or months after your treatment has finished. It can often be made worse by having to travel to hospital each day, or by other treatments such as surgery or chemotherapy. Pace yourself and save you energy for the things you have to do, and that you enjoy. Get plenty of rest but balance this with some physical activity, such as short walks, which will give you more energy.

Hair loss

Radiotherapy for cancer of the vulva can make your pubic hair fall out. It may grow back after treatment, but for some women the hair loss may be permanent.



We can send you more information about coping with bowel changes and fatigue.

Early menopause

Radiotherapy to the pelvis affects the ovaries and may cause you to have an early menopause.

Symptoms of the menopause can include:

- hot flushes and sweats
- lower sex drive
- mood swings and poor concentration
- vaginal dryness
- hot flushes and sweats.

You may be able to take hormone replacement therapy (HRT) to help with some of the symptoms. There are different ways to manage symptoms if you can't have HRT or don't want it. Your doctor will be able to talk to you about HRT and other options for managing symptoms of an early menopause.

If you still have periods and you have an early menopause, you won't be able to become pregnant. It's important to talk to your cancer specialist about your fertility before treatment starts.

Becoming infertile can be hard to cope with, whether or not you already have children. Some women find it helpful to talk to a trained counsellor. You can ask your doctor or nurse to arrange this for you.

Narrowing of the vagina

While you're having radiotherapy, and for a few weeks afterwards, your vagina will be tender. The radiotherapy may cause some scarring, which makes the vagina narrower and less flexible. This may make having sex uncomfortable or difficult. You may be advised to use vaginal dilators with a lubricating jelly, to keep the vaginal walls open and supple. The dilators are usually made of plastic. Your nurse or doctor can give them to you and explain how to use them. You won't need to use vaginal dilators if you only have radiotherapy to your groin, rather than to your vulval area.

Applying a hormone cream to your vagina may also help. These are available on prescription from your doctor. Regular sex may also help to prevent the vagina from shrinking, but you may not feel ready for sex for some time.

You can read more about sexuality after treatment on pages 77–78.



We have a booklet called *Pelvic radiotherapy in women – managing side effects during treatment*, which has more information and advice.

Swelling

The vulva is very sensitive to radiation. You may get some swelling in the vulva for months or sometimes years after radiotherapy. The swelling can be reduced by gentle, upwards massage, which a specialist nurse or physiotherapist can teach you to do.

Changes to the skin

The skin of the vulva may become permanently discoloured (reddened or darker).



Chemotherapy

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

You can usually have the treatment as an outpatient (see the photo opposite), but sometimes you may need to spend a few days in hospital.

Chemotherapy is often used to help control vulval cancer that has spread to other parts of the body. It may also be given at the same time as radiotherapy (known as chemoradiation). Giving chemotherapy in combination with radiotherapy helps make the treatment more effective. There are different ways of giving chemoradiation. Your doctors will discuss your treatment plan with you.



Our booklet *Understanding chemotherapy* has more information on the treatment and side effects.

Side effects

Chemotherapy can cause side effects. Many of these can be well controlled with medicines and will usually go away when treatment finishes. Your doctor or nurse will tell you more about what to expect. Always tell them about your side effects, as there are usually ways they can help. When chemotherapy is given with radiotherapy (chemoradiation), the side effects of the radiotherapy may be increased.

Over the next few pages we describe the main side effects, as well as some ways to reduce or control them.

Risk of infection

Chemotherapy can reduce the number of white blood cells, which help fight infection. If the number of your white blood cells is low, you'll be more prone to infections. A low white blood cell count is called **neutropenia**.

Always contact the hospital immediately on the 24-hour contact number you've been given and speak to a nurse or doctor if:

- you develop a high temperature, which may be over 37.5°C (99.5°F) or over 38°C (100.4°F) depending on the hospital's policy – follow the advice that you have been given by your chemotherapy team
- you suddenly feel unwell, even with a normal temperature
- you feel shivery and shaky
- you have any symptoms of an infection such as a cold, sore throat, cough, passing urine frequently (urine infection), or diarrhoea.

If necessary, you'll be given antibiotics to treat any infection. You'll have a blood test before each cycle of chemotherapy to make sure your white blood cells have recovered. Occasionally your treatment may need to be delayed if the number of your white blood cells is still low.

Bruising and bleeding

Chemotherapy can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. If you develop any unexplained bruising or bleeding, such as nosebleeds, bleeding gums, blood spots or rashes on the skin, contact your doctor or the hospital straight away.

Anaemia (reduced number of red blood cells)

If chemotherapy reduces the number of red blood cells in your blood, you may become very tired and feel you have no energy. You may also become breathless and feel dizzy and light-headed. These symptoms happen because the red blood cells contain haemoglobin, which carries oxygen around the body.

If your haemoglobin is low, you may be offered a blood transfusion. You'll feel more energetic and any breathlessness will be eased.

Feeling sick

Some chemotherapy drugs can make you feel sick (nauseated) or possibly be sick (vomit). Your cancer specialist will prescribe anti-sickness (anti-emetic) drugs to prevent this. Let your doctor or nurse know if your anti-sickness drugs are not helping, as there are several different types you can take.

Loss of appetite

Some people lose their appetite while they're having chemotherapy. This can be mild and may only last a few days. If you don't feel like eating during treatment, you could try replacing some meals with nutritious drinks or a soft diet. If it doesn't improve, you can ask to see a dietician.

Sore mouth

Your mouth may become sore or dry, or you may notice small ulcers during treatment. Some people find that sucking on ice is soothing. Drinking plenty of fluids and cleaning your teeth regularly and gently with a soft toothbrush can help. Tell your nurse or doctor if you have any of these problems. They can prescribe mouthwashes and medicine to prevent or clear mouth infections.

Hair loss

Some chemotherapy drugs cause hair loss. Some people have complete hair loss including eyelashes and eyebrows, while others only experience partial hair loss or thinning. It depends on which chemotherapy drugs you are having. Your doctor or nurse can tell you more about what to expect.

If you do experience hair loss, your hair should start to grow back within about 3–6 months after treatment. It may grow back straighter, curlier, finer, or a slightly different colour than it was before. Your nurse can give you advice about coping with hair loss and how to look after your scalp.

Tiredness (fatigue)

You're likely to become tired and have to take things slowly. Try to pace yourself and save your energy for things that you want to do or that need doing. Balance rest with some physical activity – even going for short walks will help increase your energy levels.



We have more information about the side effects above and how to cope with them. Call us to order more booklets. There are also videos about many side effects at macmillan.org.uk/cancerinformationvideos



Research – clinical trials

Cancer research trials are carried out to try to find new and better treatments for cancer. Trials that are carried out on patients are known as clinical trials. These may be carried out to:

- test new treatments, such as new chemotherapy drugs or targeted therapies
- look at new combinations of existing treatments, or change the way they are given to make them more effective or reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- find out which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different type of surgery, chemotherapy, hormone therapy, radiotherapy, or other treatment is better than what is already available.

Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and develop new treatments. You will be carefully monitored during and after the study.

Usually, several hospitals around the country take part in these trials. It's important to bear in mind that some treatments that look promising at first are often later found not to be as good as existing treatments or to have side effects that outweigh the benefits.

If you decide not to take part in a trial, your decision will be respected and you don't have to give a reason. However, it can help to let the staff know your concerns so that they can give you the best advice. There will be no change in the way that you're treated by the hospital staff, and you'll be offered the standard treatment for your situation.



Our booklet *Understanding cancer research trials (clinical trials)* describes clinical trials in more detail.

Blood and tumour samples

Blood and tumour samples may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you take part in a trial you may also give other samples, which may be frozen and stored for future use when new research techniques become available. Your name will be removed from the samples so you can't be identified.

The research may be carried out at the hospital where you are treated, or at another one. This type of research takes a long time, and results may not be available for many years. The samples will be used to increase knowledge about the causes of cancer and its treatment, which will hopefully improve the outlook for future patients.



AFTER YOUR TREATMENT

Follow-up	74
Effects after treatment	75
Sexuality	77
Well-being and recovery	79

Follow-up

After your treatment has finished, you'll usually have regular check-ups. Your appointments will be every few months at first, but eventually they may be once a year.

Appointments are a good opportunity to talk to your doctor or nurse about any concerns you have. But if you notice any new symptoms or have any problems between appointments, you can contact your doctor or nurse for advice.

Many women find that for a while, they get quite anxious before appointments. You may worry about the cancer coming back. This is natural. It can help to get support from family, friends or one of the organisations listed on pages 107–110.

You can also speak to our cancer support specialists on **0808 808 00 00**.

Effects after treatment

Lymphoedema

If the lymph nodes in your groin have been removed by surgery, or if you've had radiotherapy to the area, fluid sometimes builds up in one or both legs. This is called lymphoedema.

The lymph nodes are part of our immune system and help us fight infection. If they're damaged, lymph fluid (which flows along fine tubes between the lymph nodes) can build up. See page 10 for more information.

Lymphoedema can develop months or even years after treatment, causing one or occasionally both legs to become swollen. There are things you can do to reduce your risk of lymphoedema – in particular, protecting the skin on your legs and feet. Infections can trigger lymphoedema, so it's important to avoid damage to the skin. If you get swelling in your foot or leg, always get it checked by your doctor or nurse.

What you can do

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

- Keep your skin clean and moisturise it every day with unperfumed cream or oil to keep it in good condition.
- Wash small grazes and cuts straight away, put on antiseptic cream and cover if necessary.
- See your GP straight away if you get signs of infection around a cut, for example if it becomes red, hot or swollen.
- Try to avoid having very hot baths and showers.

- Wear shoes that are the right fit and size for your feet.
- Cover up or use a high-factor sunscreen (SPF 30 or above) on sunny days.
- Keep to a healthy weight and keep physically active.
- Avoid standing in the same position for too long.

Managing lymphoedema

If you develop lymphoedema, you should be referred to a clinic for specialist advice. There are lots of things that can be done to reduce the swelling and stop it getting worse.

At the lymphoedema clinic, you'll be given advice on caring for your skin. You'll also be shown positioning exercises and how to do self-massage. A specialist will measure you for a compression garment to wear on the affected leg to reduce the swelling. They may also recommend other treatments for you.



Our booklet *Understanding lymphoedema* has more detailed information. We also have several helpful videos at macmillan.org.uk/lymphoedema

Sexuality

Having treatment to a part of the body that's normally only associated with the most intimate and private parts of your life can bring up all kinds of feelings. These range from shame to fear and anger.

It may take some months before you really begin to enjoy sex again after treatment. Don't be surprised if you feel very unsure about it. Remember that you need to look after yourself and allow yourself time to heal. If you have a partner, talk to them and be as honest as you can about what you want and don't want. It's fine to say no to any kind of sexual contact that doesn't feel right.

Some women find that at first, intercourse isn't physically possible because of the way their vulva has healed after treatment. For example, there may be some tightening or scar tissue from either surgery or radiotherapy. There are a number of things that can help with this, so it's important to talk to your specialist nurse or medical team if you're having problems.

The treatment may have changed the way your genital area looks or feels. Many women worry that if their clitoris has been removed, they won't be able to have orgasms. This isn't always the case, although you may need to be patient while exploring different ways to reach a climax. Your doctor or nurse can discuss this with you.

You may want to speak to a sex therapist or counsellor who is experienced in this area. A sex therapist can help you adjust to physical changes and explore different ways of getting sexual satisfaction. Your clinical nurse specialist or doctor should be able to refer you to a sex therapist.

If you have a partner, you may feel worried about being rejected because of the changes to your body. Try to be open and talk to them about this. It's good to look at ways of overcoming any problems as a couple.

Sometimes, difficulties arise in the relationship. If this happens to you, you may find counselling helpful, either with your partner or on your own. Counselling may make it possible for you and your partner to work through your feelings and reach a new level of closeness and understanding. Your doctor or nurse specialist will be able to refer you for counselling. Our cancer support specialists, or the College of Sexual and Relationship Therapists (see page 107), can also advise you on how to find counselling in your area.

If you don't have a partner at the moment, you may feel worried about starting a new relationship in the future. Talk to your nurse specialist about how you're feeling. They may be able to put you in touch with someone who has had the same type of treatment. Some of the support organisations on pages 107–109 may also be able to do this.

There are lots of people on Macmillan's Online Community sharing their experiences of cancer. There is a group specifically for vulval cancer. Visit **macmillan.org.uk/community**



We have a booklet called *Sexuality and cancer – information for women*, which you may find helpful. There are also videos on our website about coping with sexual changes. Visit **macmillan.org.uk/sex**

Well-being and recovery

After treatment, you'll probably be keen to get back to a sense of ordinary life. But you may still be coping with the side effects of treatment and with some difficult emotions (see pages 86–89). Recovery takes time, so try not to be hard on yourself.

Some women choose to make some positive lifestyle changes. Even if you had a healthy lifestyle before cancer, you may be more focused on making the most of your health. We've included information over the next few pages that may help you focus on what you can do.



Our booklet *Life after cancer treatment* discusses how to cope after treatment.

Eat healthily

Eating healthily will give you more energy and help you to recover. Try to eat plenty of fresh fruit and vegetables (five portions a day). If you eat meat, cut down on processed and red meats, and eat more chicken and fish.

Be physically active

Being physically active helps to build up your energy levels, keep your weight healthy, and it reduces stress and the risk of other health conditions. It also reduces the risk of bone thinning in women who have had an early menopause.

Your GP or cancer specialist may be able to refer you to an exercise group specifically for people with cancer. These are run by trained professionals.



Stop smoking and stick to sensible drinking

If you're a smoker, giving up smoking is one of the healthiest decisions you can make. Continuing to smoke increases the risk of developing smoking-related cancers and heart disease.

Alcohol has also been linked with an increased risk of some types of cancer. It can also contribute to weight gain. It's recommended that women drink no more than two units of alcohol a day, or 14 units a week.



We can send you more information about eating well after cancer, keeping physically active and giving up smoking. Visit be.macmillan.org.uk or call us on 0808 808 00 00.

Getting help and support

Different people can help you during and after your treatment.

Practical help

If you need help at home during or after treatment, a **nurse** or **hospital social worker** may be able to arrange this.

A **social worker** or **benefits adviser** can tell you about benefits you may be able to claim and help if you are struggling with costs (see pages 96–97).

If you need help with a wound or a wound drain, the **district nurses** can visit you at home to help with this.

Complementary therapies

Some women find that using a complementary therapy helps them relax or cope with treatment side effects. Some hospitals or support groups offer therapies such as relaxation or aromatherapy. Our booklet *Cancer and complementary therapies* has more information.

Support groups

Self-help or support groups offer the chance to talk to other women who may be in a similar situation to you, and facing the same challenges. Joining a group can be helpful if you live alone, or don't feel able to talk about your feelings with people you know. Not everyone finds talking in a group easy, so it might not be right for you. Try visiting one to see what the group is like before you join.

You can call us on **0808 808 00 00** or visit **macmillan.org.uk/supportgroups** for information about cancer support groups across the UK.

Online support

Many people get support through the internet. There are online support groups, social networking sites, forums, chat rooms and blogs for people affected by cancer. You can use these to share your experiences of vulval cancer, and get and give advice.

Our online community (macmillan.org.uk/community) is a social networking site where you can talk to people in our chat rooms, blog your journey, make friends and join support groups.

'Everyone is so supportive on Macmillan's Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

Mal



YOUR FEELINGS AND RELATIONSHIPS

Your feelings	86
If you are a relative or friend	90
Talking to children	91
Who can help?	92

Your feelings

It's common to feel overwhelmed by different feelings when you're told that you have cancer. We talk about some of these here. Partners, family and friends may also have some of the same feelings.

You might have different reactions to the ones we describe here. There is no right or wrong way to feel. You'll cope with things in your own way. Talking to people close to you or other people affected by cancer can often help.

Shock and disbelief

You may find it hard to believe it when your doctor tells you that you have cancer. It's common to feel shocked and numb. You may not be able to take in much information and find that you keep asking the same questions again and again. At first, you might find it hard to talk to family and friends about the cancer. This usually gets easier as the shock wears off and it becomes more real to you. You may find you can't think or talk about anything but the cancer. This is because your mind is trying to process what you're going through.

Fear and anxiety

People can be very anxious or frightened about whether treatment will work and what will happen in the future. This uncertainty can be one of the hardest things to cope with. It can help to try to focus on what you can control. You may want to find out more about the cancer, its treatment and how to manage side effects. It can also help to talk about your feelings and to take time to do things that are important to you and that you enjoy.

Doctors often know roughly how many people can benefit from a type of treatment. But they can't be sure what will happen to an individual person. Although they may not be able to answer your questions fully, they can usually talk through any problems with you and give you some guidance.

Avoidance

Some people cope by not wanting to know very much about the cancer and by not talking about it. If you feel like this, let your family and friends know that you don't want to talk about it right now. You can also tell your doctor if there are things you don't want to know or talk about yet.

Occasionally, this avoidance can be extreme. Some people may not believe that they have cancer. This is sometimes called being in denial. It may stop them making decisions about treatment. If this happens, it's very important for them to get help from their doctor.

Sometimes, avoidance is the other way around. Family and friends may seem to avoid you and the fact that you have cancer. They may not want to talk about it or they might change the subject. This is usually because they are also finding the cancer difficult to cope with, and they may need support too. Try to let them know how this makes you feel and that talking openly with them about your illness will help you.

Anger

You may feel angry about your illness and sometimes resent other people for being well. These are normal reactions, especially when you feel frightened, stressed, out of control or unwell. You may get angry with the people close to you. Let them know that you are angry at your illness and not at them. Finding ways to help you relax and reduce stress can help with anger. This can include talking about or writing down how you feel, gentle exercise, breathing or relaxation therapy, yoga or meditation.

Guilt and blame

Some people feel guilty or blame themselves or others for the cancer. You may try to find reasons for why it has happened to you. Most of the time, it's impossible to know exactly what has caused a person's cancer. Over time, several different factors may act together to cause a cancer. Doctors don't fully understand all of these factors yet. Instead, try to focus on looking after yourself and getting the help and support you need.

Feeling alone

Some people feel alone because they don't have enough support. Family and friends may live far away, have other commitments or feel uncomfortable because of their own fears about cancer. Try to let your family and friends know how you feel and how they could support you more.

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find out about local support groups – visit **macmillan.org.uk/supportgroups** You can also talk to other people going through the same thing on our Online Community at **macmillan.org.uk/community**

It's normal to have times when you want to be left alone to sort out your feelings. But if you find you're avoiding people a lot of the time, then try to talk to your doctor or nurse.

If you need more help

These feelings can be very difficult to cope with and sometimes people need more help. This happens to lots of people and doesn't mean you're not coping.

If you feel anxious, panicky or sad a lot of the time, or think you may be depressed, talk to your doctor or nurse. They can refer you to a doctor or counsellor who can help. They may also prescribe medicine to help with anxiety or an antidepressant drug.



Our booklet *How are you feeling? The emotional effects of cancer* discusses the feelings you may have in more detail, and has suggestions for coping with them.

If you are a relative or friend

Some people find it hard to talk about cancer or share their feelings. You might think it's best to pretend everything is fine, and carry on as normal. You might not want to worry the person with cancer, or you might feel you're letting them down if you admit to being afraid. Unfortunately, denying strong emotions can make it even harder to talk, and may lead to the person with cancer feeling very isolated.

Partners, relatives and friends can help by listening carefully to what the person with cancer wants to say. It may be best not to rush into talking about the illness. Often it's enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking, to help friends and family support their loved ones affected by cancer. Visit **macmillan.org.uk/learnzone** to find out more.

Our booklet *Lost for words – how to talk to someone with cancer* has more suggestions if you have a friend or relative with cancer.

If you're looking after a family member or friend with cancer, you may find our booklet *Looking after someone with cancer* helpful. It's based on carers' experiences and has lots of practical tips and information.

We have more information about supporting someone with cancer at **macmillan.org.uk/carers**

Talking to children

Deciding what to tell your children or grandchildren about your cancer is difficult. An open, honest approach is usually best. Even very young children can sense when something is wrong, and their fears can sometimes be worse than the reality.

How much you tell your children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information and gradually tell them more to build up a picture of your illness.

Teenagers

Teenagers can have an especially hard time. At a stage when they want more freedom, they may be asked to take on new responsibilities and they may feel over-burdened. It's important that they can go on with their normal lives as much as possible and still get the support they need.

If they find it hard to talk to you, you could encourage them to talk to someone close who can support and listen to them, such as a grandparent, family friend, teacher or counsellor. They may also find it useful to look at the website **riprap.org.uk** which has been developed especially for teenagers who have a parent with cancer.



Our booklet *Talking to children and teenagers when an adult has cancer* includes discussion about sensitive topics. There's also a video on our website that may help, at macmillan.org.uk/talkingtochildren

Who can help?

Many people are available to help you and your family.

District nurses work closely with GPs and make regular visits to patients and their families at home if needed.


The **hospital social worker** can give you information about social services and benefits you may be able to claim, such as meals on wheels, a home helper or hospital fares. The social worker may also be able to arrange childcare for you during and after treatment.

In many areas of the country, there are also specialist nurses called **palliative care nurses**. They are experienced in assessing and treating symptoms of advanced cancer. Palliative care nurses are sometimes known as Macmillan nurses. However, many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you're at a clinic or in hospital.

Marie Curie nurses help care for people approaching the end of their lives in their own homes. Your GP or hospital specialist nurse can usually arrange a visit by a palliative care or Marie Curie nurse.

There's also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.



A close-up, over-the-shoulder shot of a person wearing a vibrant purple hoodie and black gloves. They are holding a thick black cable, possibly for charging or data transfer. In the background, a blue car is partially visible, parked on a paved surface. The scene is brightly lit, suggesting an outdoor setting.

'I had to return
to some work,
as I'm a single
mother and I've
got two boys at
college. They are
eating machines!'

Gail

WORK AND FINANCIAL SUPPORT

Financial help and benefits

96

Work

99

Financial help and benefits

If you are struggling to cope with the financial effects of cancer, help is available.

If you cannot work because you are ill, you may be able to get **Statutory Sick Pay**. Your employer will pay this for up to 28 weeks of sickness. If you qualify for it, they cannot pay you less.

Before your Statutory Sick Pay ends, or if you do not qualify for it, check whether you can get **Employment and Support Allowance (ESA)**. This benefit is for people who cannot work because they are ill or disabled.

There are two different types of ESA:

- contributory – you can get this if you have made enough national insurance contributions
- income-related – you can get this if your income and savings are below a certain level.

Since October 2013, a new benefit called **Universal Credit** has started replacing income-related ESA in England, Scotland and Wales. This benefit is for people who are looking for work or on a low income.

Personal Independence Payment (PIP) is a new benefit for people under 65 who find it difficult to walk or look after themselves (or both). You must have had these difficulties for at least three months, and they should be expected to last for the next nine months. Since April 2013, PIP has started to replace a similar older benefit called **Disability Living Allowance** in England, Scotland and Wales.

Attendance Allowance (AA) is for people aged 65 or over who find it difficult to look after themselves. You may qualify if you need help with things like getting out of bed, having a bath or dressing yourself. You don't need to have a carer, but you must have needed care for at least six months.

If you are terminally ill, you can apply for PIP, DLA or AA under the 'special rules'. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

Help for carers

Carers Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you don't qualify for it, you can apply for **Carer's Credit**. This helps you to build up qualifying years for a State Pension.

More information

The benefits system can be hard to understand, so it's a good idea to talk to an experienced welfare rights adviser. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**. We've just listed some benefits here, but there may be others you can get.

You can find out about state benefits and apply for them online at **gov.uk** (England, Scotland and Wales) and **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines or Citizens Advice (see page 111). In Northern Ireland, you can call the Benefit Enquiry Line Northern Ireland on **0800 220 674**.

Insurance

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on pages 111–112.



Our booklet *Help with the cost of cancer* has more information. Our booklets *Insurance* and *Getting travel insurance* may also be helpful. You might find our video at macmillan.org.uk/gettingfinancialhelp useful.

Work

You may need to take time off work during your treatment and for a while afterwards. It can be hard to judge the best time to go back to work, and this will depend mainly on the type of work you do and how much your income is affected. It's important to do what's right for you.

Getting back into your normal routine can be very helpful, and you may want to go back to work as soon as possible. It can be helpful to talk to your employer about the situation – it may be possible for you to work part-time or job share.

On the other hand, it can take a long time to recover fully from cancer treatment, and it may be many months before you feel ready to return to work. It's important not to take on too much, too soon. Your consultant, GP or specialist nurse can help you decide when and if you should go back to work.

Employment rights

The Equality Act 2010 protects anyone who has, or has had, cancer. Even if a person who had cancer in the past has been successfully treated and is now cured, they are still covered by the act. This means their employer must not discriminate against them for any reason, including their past cancer. The Disability Discrimination Act protects people in Northern Ireland.



Our booklets *Work and cancer*, *Working while caring for someone with cancer* and *Self-employment and cancer* have more information that may be helpful.

There's also more information at macmillan.org.uk/work



Gr 55000

ME BE

Your life and your choices, then about 35 years!

Standa's Cancer Support

Q-CONNECT

A guide for

A guide to benefits and financial help
for people affected by cancer
April 2016 - April 2017

HELP
WITH THE
COST
OF CANCER

FURTHER INFORMATION

About our information	102
Other ways we can help you	104
Other useful organisations	107

About our information

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

Order what you need

You may want to order more leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

All of our information is also available online at **macmillan.org.uk/cancerinformation**

There you'll also find videos featuring real-life 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
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**

If you'd like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email **reviewing@macmillan.org.uk** You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you. No one should face cancer alone.

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 free, confidential phone line is open Monday–Friday, 9am–8pm. Our cancer support specialists can:

- help with any medical questions you have about your cancer or treatment
- help you access benefits and give you financial advice
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

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's why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, 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](https://www.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](https://www.macmillan.org.uk/community)**

The Macmillan healthcare team

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.

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

Financial advice

Our financial guidance team can give you advice on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00**

to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area.

Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work.

Visit **macmillan.org.uk/work**

Other useful organisations

There are lots of other organisations that can give you information or support.

Gynaecological cancer support organisations

Gynae C

Helen Jackson – Coordinator,
1 Bolingbroke Road,
Swindon SN2 2LB
Tel 01793 491116

Email info@gynaec.co.uk

www.gynaec.co.uk

Offers confidential support to women with gynaecological cancer, and their partners, families and friends.

RV Club

Tel 01977 640243

Confidential telephone support from someone who has been through vulval cancer and a radical vulvectomy.

Vulval Awareness Campaign Organisation

Tel 0161 747 5911

Email vacouk@yahoo.co.uk

www.vaco.co.uk

UK-wide organisation run by women who've had vulval cancer. Runs a support network, one-to-one telephone support and a website with useful information about vulval conditions.

Support with relationships and sexuality

The College of Sexual and Relationship Therapists

PO Box 13686,
London SW20 9ZH

Tel 020 8543 2707

Email info@cosrt.org.uk

www.cosrt.org.uk

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

Outsiders

34 North End Road,
London W14 0SH

Tel 07074 993 527

Email sexdis@outsiders.org.uk

www.outsiders.org.uk

A UK-wide community of people who feel socially isolated because of physical disabilities. Helps people gain confidence, make new friends and find partners. Runs the Sex and Disability Helpline, for disabled people with sexual problems. Also produces leaflets covering all aspects of sex.

Support with lymphoedema

Lymphoedema Support Network

St Luke's Crypt,
Sydney Street,
London SW3 6NH

Tel 020 7351 4480

Email adminlsn@lymphoedema.freemove.co.uk

www.lymphoedema.org

A national charity that provides information and support to people with lymphoedema.

General cancer information and support

Cancer Black Care

79 Acton Lane,
London NW10 8UT

Tel 020 8961 4151

Email

info@cancerblackcare.org.uk

www.cancerblackcare.org.uk

Offers information and support for people with cancer from ethnic communities, and their carers, families and friends.

Cancer Focus Northern Ireland

40–44 Eglantine Avenue,
Belfast BT9 6DX

Tel 0800 783 3339

(Mon–Fri, 9am–1pm)

Email hello@cancerfocusni.org

www.cancerfocusni.org

Offers a variety of services to people affected by cancer, including a free helpline, counselling and links to local support groups.

Cancer Support Scotland

Calman Cancer Support
Centre,

75 Shelley Road,
Glasgow G12 0ZE

Tel 0800 652 4531

Email [info@](mailto:info@cancersupportscotland.org)

cancersupportscotland.org

**[www.cancersupport
scotland.org](http://www.cancersupportscotland.org)**

Runs cancer support
groups throughout Scotland.
Also offers free complementary
therapies and counselling to
anyone affected by cancer.

The Rarer

Cancers Foundation

Unit 7B, Evelyn Court,
Grinstead Road,

London SE8 5AD

Tel 0800 334 5551

Email [patientsupport@](mailto:patientsupport@rarercancers.org)

rarercancers.org.uk

www.rarercancers.org

Aims to ensure that people with
rarer cancers have access to
the best services and outcomes.

Tenovus

Head Office,

Gleider House, Ty Glas Road,
Cardiff CF14 5BD

Tel 0808 808 1010

(Mon–Sun, 8am–8pm)

www.tenovus.org.uk

Aims to help everyone
get equal access to cancer
treatment and support.
Funds research and provides
support such as mobile
cancer support units, a free
helpline, an ‘Ask the nurse’
service on the website and
benefits advice.

General health information

Health and Social Care in Northern Ireland

www.hscni.net

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

NHS Choices

www.nhs.uk

The UK’s biggest
health information
website. Also has service
information for England.

NHS Direct Wales

www.nhsdirect.wales.nhs.uk

NHS health information
site for Wales.

NHS Inform

www.nhsinform.co.uk

NHS health information
site for Scotland.

Counselling and emotional support

Association for

Family Therapy (AFT)

7 Executive Suite,
St James Court,
Wilderspool Causeway,
Warrington WA4 6PS

Tel 01925 444414

www.aft.org.uk

Organisation offering therapy
to children, young people,
adults, couples and families
You can search for a therapist
on the website.

British Association

for Counselling and Psychotherapy (BACP)

BACP House,
15 St John's Business Park,
Lutterworth LE17 4HB

Tel 01455 883 300

Email bacp@bacp.co.uk

www.bacp.co.uk

Promotes awareness of
counselling and signposts
people to appropriate services.
You can search for a qualified
counsellor at **itsgoodtotalk.org.uk**

Financial or legal information

Benefit Enquiry Line

Northern Ireland

Tel 0800 220 674

(Mon–Wed and Fri, 9am–5pm,
Thu, 10am–5pm)

Textphone 0800 243 787

**[www.nidirect.gov.uk/
money-tax-and-benefits](http://www.nidirect.gov.uk/money-tax-and-benefits)**

Provides information
and advice about disability
benefits and carers' benefits.

Citizens Advice

Provides advice on financial, legal, housing and employment issues. Find details for your local office in the phone book or on one of the following websites:

England and Wales

www.citizensadvice.org.uk

Scotland

www.cas.org.uk

Northern Ireland

www.citizensadvice.co.uk

You can also find advice online in a range of languages at adviceguide.org.uk

Department for Work and Pensions (DWP) Disability Benefits Helpline

08457 123 456

Textphone 0845 722 4433

Personal Independence Payment Helpline

0845 850 3322

Textphone 0845 601 6677

Carer's Allowance Unit

0845 608 4321

Textphone 0845 604 5312

www.gov.uk/browse/benefits

Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

GOV.UK

www.gov.uk

Has comprehensive information about social security benefits and public services.

The Law Society of England and Wales

113 Chancery Lane,
London WC2A 1PL

Tel 0207 242 1222

Email

info.services@lawsociety.org.uk

www.lawsociety.org.uk

Provides details of solicitors in England and Wales. You can search a database of solicitors on the website.

The Law Society of Northern Ireland

96 Victoria Street,
Belfast BT1 3GN

Tel 028 9023 1614

Email info@lawsoc-ni.org

www.lawsoc-ni.org

Provides details of solicitors in Northern Ireland. You can search a directory of solicitors on the website.

The Law Society of Scotland

26 Drumsheugh Gardens,
Edinburgh EH3 7YR

Tel 0131 226 7411

Email lawscot@lawscot.org.uk

www.lawscot.org.uk

Provides details of solicitors in Scotland. You can search a database of solicitors on the website.

Turn2Us

Unit 9, Cefn Coed Parc,
Nantgarw,
Cardiff CF15 7QQ

Tel 0808 802 2000

(Mon–Fri, 9am–8pm)

Email info@turn2us.org.uk

www.turn2us.org.uk

Provides an online service to help the millions of people in financial need in the UK. Use its website to access information about the benefits and grants available to you from both statutory and voluntary organisations. You can apply for support directly from the website.

Support for carers

Carers UK

Tel (England, Scotland, Wales) 0808 808 7777

Tel (Northern Ireland)

028 9043 9843

(Wed–Thu, 10am–12pm
and 2–4pm)

Email

advice@carersuk.org

www.carersuk.org

Offers information and support to carers across the UK. Puts people in contact with support groups for carers in their area.

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.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by one of our Senior Medical Editors, Professor David Luesley, Consultant in Gynaecological Oncology; and by our Chief Medical Editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Dr Emma Crosbie, NIHR Clinician Scientist, Senior Lecturer and Honorary Consultant in Gynaecological Oncology; Vikki Jones, Macmillan Gynae-oncology Advanced Nurse Practitioner; Jane O'Mahoney, Macmillan Gynaecology Nurse Specialist; Dr Amanda Tristram, Senior Lecturer in Gynaecological Oncology; and the people affected by cancer who reviewed this edition.

Sources

Almadrones-Cassidy L. *Gynecologic cancers*. 1st edition. Oncology Nursing Society. 2010.

Ang C, et al. Exenterative surgery for recurrent gynaecological malignancies (review). *The Cochrane Library*. 2013. Issue 2. www.thecochranelibrary.com (accessed May 2014).

Ansink A, et al. Surgical interventions for early squamous cell carcinoma of the vulva (review). *The Cochrane Library*. 2008. Issue 4. www.thecochranelibrary.com (accessed May 2014).

Barakat R, et al. *Gynecologic oncology*. 6th edition. Wolters Kluwer/Lippincott Williams & Wilkins. 2013.

Elkas J, Berek J. *Vulvar cancer: clinical manifestations, diagnosis and pathology*. January 2014. UpToDate. www.uptodate.com (accessed June 2014).

Elkas J, Berek J. *Vulvar cancer: staging, treatment, and prognosis*. January 2014. UpToDate. www.uptodate.com (accessed May 2014).

Flynn P, et al. Interventions for psychosexual dysfunction in women treated for gynaecological malignancy (review). *The Cochrane Library*. 2009. Issue 3. www.thecochranelibrary.com (accessed May 2014) Royal College of Obstetricians and

Gynaecologists. Management of vulval cancer. RCOG Press, London. 2014.

Van der Velden K, Ansink A. Primary groin irradiation versus primary groin surgery for early vulvar cancer (review). *The Cochrane Library*. 2011. Issue 5. www.thecochranelibrary.com (accessed May 2014).

Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we're there 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.



Share your cancer experience

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

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.

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?

Raise money

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

Give money

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

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 / /

Don't 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 taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that 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'd rather donate online go to macmillan.org.uk/donate

Please cut out this form and return it in an envelope (no stamp required) to:
Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851,
89 Albert Embankment, London SE1 7UQ

More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way,
call Macmillan on 0808 808 00 00
(Mon–Fri, 9am–8pm) or visit macmillan.org.uk

Hard of hearing? Use textphone
0808 808 0121, or Text Relay.
Non-English speaker? Interpreters available.
Braille and large print versions on request.

© Macmillan Cancer Support, August 2014. 9th edition. MAC11643.
Next planned review 2017. Macmillan Cancer Support, registered
charity in England and Wales (261017), Scotland (SC039907) and the
Isle of Man (604). Printed using sustainable material. Please recycle.



**WE ARE
MACMILLAN.
CANCER SUPPORT**