MACMILLAN
CANCER SUPPORT

# UNDERSTANDING CANCER OF THE VULVA





## About this booklet

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

The booklet explains what vulval cancer is, how it is usually diagnosed and treated, and how you might want to manage any side effects. We hope it gives you an idea of what to expect and offers some helpful tips.

We hope it helps you deal with some of the questions or feelings you may have. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

#### For more information

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

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

If you are deaf or hard of hearing, call us using NGT (Text Relay) on 18001 0808 808 00 00, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print, and translations. To order these visit macmillan.org.uk/ otherformats or call 0808 808 00 00.

#### How to use this booklet

The booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

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

We have included quotes from our online community and Gail, who has had cancer of the vulva, which you may find helpful. She is also on the cover of this booklet.

#### Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you is collected in a national database. This is called the cancer registry. It is used to plan and improve health and care services. Your hospital will give information about you, your cancer diagnosis and treatment to the registry automatically, unless you ask them not to. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions about the registry. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out. You can find more information at macmillan.org.uk/ cancerregistry

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# ABOUT CANCER OF THE VULVA

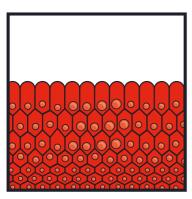
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### What is cancer?

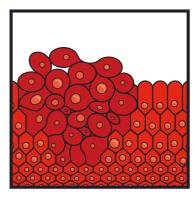
Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop 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. 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 name given to all the visible sex organs of a woman (see picture on page 9). It is made up of:

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

Between the labia are 2 openings:

- the entrance of the vagina (birth canal)
- the opening of the tube that drains urine from the bladder (the urethra).

At the front of the vulva, above the vagina and urethra, is the clitoris. This small structure is very sensitive and helps a woman reach sexual climax (orgasm).

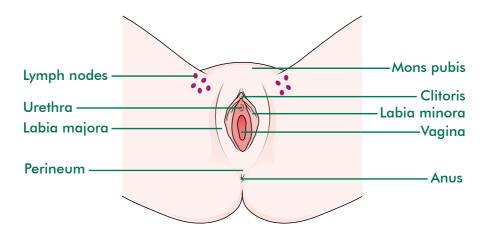
On either side of the vagina are 2 small glands called Bartholin's glands. These make a fluid that acts as a lubricant during sex.

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

Further back, under the legs, is the opening to the back passage (anus). It is separated from the vulva by an area of skin 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



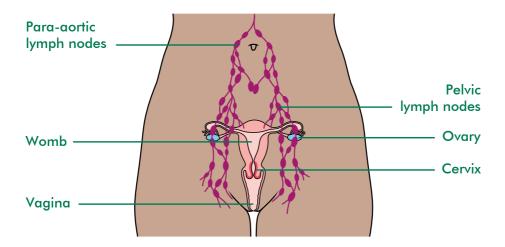
# The lymphatic system

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

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

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

#### The lymphatic system



# Types of vulval cancer

Cancer of the vulva is rare. Just over 1,300 women are diagnosed with it each year in the UK. It is most common in women aged 65 and over. But younger women can also be affected. About 15 in every 100 vulval cancers (15%) develop in women aged under 50.

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

#### 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. 9 in 10 vulval cancers (90%) are squamous cell carcinomas.

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

#### 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 5 in 100 vulval cancers (5%) are melanomas. There is more information about melanomas on our website and in our booklet **Understanding melanoma** – see page 122.

#### Basal cell carcinoma

This type of vulval cancer is rare. It develops from cells called basal cells that are found in the deepest layer of the skin of the vulva. Around 2 in 100 vulval cancers (2%) are basal cell carcinomas.

#### Sarcoma

This type of vulval cancer is rare. Sarcomas develop from cells in tissue such as muscle, fat or blood vessels under the skin. They tend to grow more quickly than other types of vulval cancer. Around 1 to 2 in 100 vulval cancers (1 to 2%) are sarcomas. To find out more about sarcomas, you can call the Macmillan Support Line on 0808 808 00 00 or visit macmillan.org.uk

#### Adenocarcinoma

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

#### Bartholin gland cancer

This type of vulval cancer is extremely rare. It develops in the Bartholin glands at the opening of the vagina.



# Causes and risk factors of vulval cancer

The exact cause of vulval cancer is unknown. However, things called risk factors can increase a woman's chances of developing it. Having one or more risk factors does not mean you will definitely get cancer. And if you do not have any risk factors, it does not mean you will not get vulval cancer.

#### Age

The risk of developing vulval cancer increases with age. Most of the women who are diagnosed with vulval cancer are aged 65 or over. Vulval cancer in older women is usually linked to a skin condition called **lichen sclerosus** (see page 15).

Vulval cancer is becoming more common in younger women, where it is often linked to human papillomavirus infection (HPV) and smoking (see pages 15 to 16).

#### **Vulval skin conditions**

Some long-term (chronic) skin conditions of the vulva can increase a woman's risk of developing vulval cancer. These include:

- vulval lichen sclerosus
- vulval lichen planus
- Paget's disease.

#### Lichen sclerosus (LS) and lichen planus (LP)

Lichen sclerosus and lichen planus are fairly common, non-cancerous skin conditions. They can affect different parts of the body, but commonly affect the vulva. When they affect the skin of the vulva, they are known as **vulval LS** or **LP**. There is more information on these on our website - see page 122.

Less than 5 in every 100 (less than 5%) of women who have vulval LS or LP develop vulval cancer. It is thought that, over a long period of time, the inflammation caused by these skin conditions increases the risk of cancer developing.

#### Paget's disease of the vulva

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

#### **HPV**

Human papilloma virus (HPV) is a very common infection. It is usually passed between people during sex. There are more than 100 types of HPV, and each has a number. Some types (particularly 16, 18, and 33) are linked to vulval cancer and pre-cancerous changes called VIN (see page 16).

Most women with an HPV infection do not 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. There is more information on HPV on our website - see page 122.

A vaccination against HPV is offered to girls aged 12 to 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.

#### Vulval intraepithelial neoplasia (VIN)

The term VIN describes changes that can happen in the skin that covers the vulva. If the changes become more severe, there is a chance that cancer might develop after many years. So VIN is called a pre-cancerous condition. There is more information on VIN on our website - see page 122.

There are 2 types of VIN:

#### VIN usual type

This type is linked to HPV and mainly affects younger women aged 35 to 55.

#### **VIN** differentiated type

This type is linked to lichen sclerosus and mainly affects women over the age of 55.

#### **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 HPV. This may be one reason why it increases the risk of vulval cancer. The NHS has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live.

#### Cervical intraepithelial neoplasia (CIN) or cervical cancer

Women with pre-cancerous changes in the cells of the cervix (CIN), or those who have had cervical cancer, have an increased risk of developing cancer of the vulva. This may be related to shared risk factors, such as HPV infection and smoking. There is more information about CIN on our website and in our booklet Understanding cervical screening tests and CIN see page 122.

#### Lowered immunity

The immune system is part of the body's defence against infections. Having a lowered immunity because of illness or treatment can increase the risk of vulval cancer. This could be if:

- you have HIV
- you are taking medicines to suppress your immune system after an organ transplant.

If you are worried that you are at risk of developing vulval cancer because you have lowered immunity, talk to your GP or specialist nurse, if you have one. They will be able to give you further advice.

# **Symptoms**

The most common symptoms of vulval cancer are:

- itching, burning, or soreness of the vulva that does not 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, that is not related to 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
- a lump in the groin.

All of these symptoms can happen with conditions other than cancer, but it is always important to get them checked by your GP.

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, vulval cancer is easier to treat and cure if it is diagnosed at an early stage.





# DIAGNOSING CANCER OF THE VULVA

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# How cancer of the vulva is diagnosed

If you have symptoms, you will usually begin by seeing your GP, who will examine you. If they think that your symptoms could be caused by cancer, they will refer you to a doctor who specialises in women's cancers (gynaecological cancer specialist).

Your GP may also arrange for you to have a blood test and chest x-ray to check your general health.

#### At the hospital

The specialist will ask you about your general health and any previous medical problems you have had. They will also examine your vulval area. They can usually do this during an outpatient appointment.

#### **Vulval** examination

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 your test, the doctor or nurse will help you position yourself on a specially designed chair or examination table. There may be special leg supports.

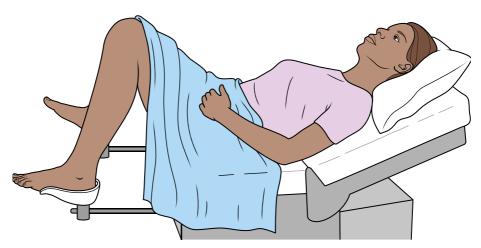
The doctor may use a bright light and a magnifier to examine your vulva. This helps them see the skin more clearly. They may take small samples of tissue biopsies from any areas that look unusual (see pages 24 to 25). You may have a local anaesthetic for this.

The doctor will also 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 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).

The specialist can arrange to examine you while you are under a general anaesthetic (see page 29) if:

- you have narrowing of the vagina due to lichen sclerosus (see pages 14 to 15)
- your vulva is too sore for a full examination.

#### Having a vulval examination



#### **Biopsy**

A doctor takes a small sample of tissue from the affected area of the vulva. They send this to a laboratory to be examined under a microscope.

There are 2 types of biopsy:

- excisional biopsy
- punch biopsy.

An **excisional biopsy** is often used for small areas. The doctor will remove the whole affected area. They may put 1 or 2 stitches in the area where they took the biopsy from.

A **punch biopsy** is often used to take a sample from a larger area. It is done using a small instrument that takes a small core of the affected area. You do not normally need any stitches after a punch biopsy.

#### Having the biopsy

You usually 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 should not be any pain when the sample of tissue is taken from your vulva, but you may feel a little discomfort.

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 for a few days. This should gradually stop. If it gets worse or continues, tell your doctor. You should use sanitary pads rather than tampons until the bleeding has settled. Keep the area clean by rinsing with water after every bowel movement.

You may also feel sore. Painkillers or a warm bath can help.

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

#### **Further tests**

If your vulval examination and biopsy show that you have cancer of the vulva, your doctor will arrange some more tests. These are to see whether the cancer has spread. This is called **staging** (see pages 33 to 35).

The results will help you and your doctor decide on the best treatment for you. Some tests may be repeated during and after treatment to check your progress. Your doctor or specialist nurse will explain this to you.

You may have some of the following tests:

#### **Blood tests**

You may have blood samples taken to check your general health and how well your liver and kidneys are working. We have more detailed information about having a blood test.

#### **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 to 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 4 hours before the 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 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, such as a pacemaker, surgical clips, bone pins, etc. 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. 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, 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 6 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 to 90 minutes. You should be able to go home after the scan.

#### Cystoscopy

A cystoscopy is an examination of the lining of the bladder. It may be done to check if the cancer has spread to the tube that you pass urine through (urethra) or to the bladder.

You may have this test under a local anaesthetic using a gel to numb the opening of the urethra. Sometimes a cystoscopy is done as part of an examination under a general anaesthetic (see page 29).

The doctor or nurse gently passes a thin tube with a camera and light on the end (a cystoscope) through your urethra into the bladder. If there are any abnormal areas, they can use the cystoscope to take biopsies. The test should only take a few minutes

You may have symptoms, such as a burning pain when passing urine, for a few days after the test. Speak to your doctor if your symptoms aet worse or do not go away after a couple of days.

#### **Proctoscopy**

This is an examination of the lower end of the large bowel (anus and rectum).

You will be asked to lie curled on your left side while the doctor gently passes a tube (proctoscope) into your back passage. The doctor can see any abnormal areas by using a tiny light and camera on the end of the proctoscope. If necessary, they can take a small sample of cells (biopsy). A proctoscopy can be uncomfortable. Tell the doctor or nurse if you find it painful.

You should be able to go home as soon as the proctoscopy is over.

#### Examination under anaesthetic (EUA)

This is an examination of the vulva, vagina and cervix, done under a general anaesthetic. It allows your doctor to examine you thoroughly and check the extent of the cancer without causing you discomfort. They may also remove small samples of tissue (biopsy).

During the EUA, your doctor may look into your bladder (cystoscopy) and the lower end of your large bowel (proctoscopy) to see if the cancer has spread.

You may have some light bleeding for a couple of days after an EUA. Your doctor or nurse can tell you more about the examination and what to expect afterwards.

#### Lymph node assessment

A common place for vulval cancer to spread is to the lymph nodes in the groin. Your doctor will examine these nodes to see if they look or feel swollen.

Having swollen lymph nodes does not necessarily mean that the cancer has spread. An infection, for example, can also cause lymph nodes to swell.

If any of your lymph nodes are swollen, your specialist may suggest that you have an ultrasound and a fine needle aspiration to check them.

You may be offered a sentinel lymph node biopsy (SLNB) (see pages 31 to 32). This is a small operation that can tell your doctors more about your situation and help them plan the best treatment for you. It is usually done at the same time as the operation to remove the cancer.

#### Ultrasound scan of the groin

Ultrasound uses sound waves to make up a picture of a particular area of the body. It is painless and only takes a few minutes.

Once you are in a comfortable position, some gel is spread onto your groin. A small device like a microphone, which produces sound waves, is passed over the area. A computer converts the sound waves into a picture. If the ultrasound of the lymph nodes is abnormal, the doctor will do a fine needle aspiration of the node or nodes.

#### Fine needle aspiration (FNA)

This is a quick and simple test. First, the doctor injects some local anaesthetic into the skin of your groin to numb the area. Using the ultrasound scan as a guide, the doctor puts a fine needle into the lymph node and withdraws a sample of cells into the syringe.

The cells are examined under a microscope to see if they contain any cancer cells. If they do, all your remaining lymph nodes will need to be removed or treated with radiotherapy.

#### Sentinel lymph node biopsy (SLNB)

If the cancer is under 4cm in size and only in one place, your doctor may suggest a test called a sentinel lymph node biopsy.

The sentinel nodes are the first nodes that lymph fluid drains to from your vulva. This means that if the cancer has spread to nearby nodes, the sentinel nodes are the ones that are most likely to be affected.

An SLNB can tell your doctors more about your situation and help them plan the best treatment for you. It is not a treatment.

If the sentinel nodes do not contain cancer cells, it is unlikely that other lymph nodes are affected. This means you will not need to have surgery to remove them.

If they do contain cancer cells, all your remaining lymph nodes will need to be removed (see page 53) or treated with radiotherapy (see pages 66 to 77).

#### Having a sentinel lymph node biopsy

An SNLB is a small operation done under a general anaesthetic.

A few hours before the operation, the surgeon injects a tiny amount of radioactive liquid close to the cancer. The liquid makes the sentinel lymph nodes radioactive.

During the operation, the doctor injects a blue dye into the same area. The dye stains the sentinel lymph nodes blue so the surgeon can see them.

The surgeon uses a probe that detects radioactivity to help them find the sentinel lymph nodes. The sentinel nodes are then removed. They are sent to a laboratory and examined under a microscope to see if they contain cancer cells.

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

#### Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you is collected in a national database. This is called the cancer registry. It helps the NHS and other organisations plan and improve health and care services. Your hospital will give information about you, your cancer diagnosis and treatment to the registry automatically, unless you ask them not to. As with all medical records, there are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research. You can find more information at macmillan.org.uk/cancerregistry

Talk to your doctor or nurse if you have any questions about the registry. If you do not want your information included in the registry, you can contact the cancer registry in your country.

# Staging and grading

The stage of a cancer describes 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.

The number staging system is commonly used for vulval cancer. It may help to look at the diagram of the vulva when you are reading this explanation (see pages 8 to 9).

#### Staging

#### Stage 1

The cancer is only in the vulva, the area between the vagina and the anus (perineum), or in both these areas. It has not spread to lymph nodes.

Stage 1 is divided into 2 stages:

#### Stage 1A

The cancer is up to 2cm 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 nearby areas such as:

- the lower part of the tube you pass urine through (urethra)
- the lower part of the vagina
- the anus

It has not spread to lymph nodes.

#### Stage 3

The cancer has spread to nearby lymph nodes.

Stage 3 is divided into 3 stages:

#### Stage 3A

The cancer has spread to one lymph node that is 5mm or more in size **OR** the cancer has spread to 1 or 2 lymph nodes that are under 5mm in size.

#### Stage 3B

The cancer has spread to 2 or more lymph nodes that are 5mm or more in size **OR** the cancer has spread to 3 or more lymph nodes that are under 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 2 stages:

### Stage 4A

The cancer is any size and has either:

- spread into the upper part of the urethra, the vagina, the bladder, or the rectum
- become fixed to the pelvic bone
- spread to lymph nodes in the groin, and these lymph nodes have formed an ulcer or cannot be moved (they have become fixed).

### Stage 4B

The cancer has spread to:

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

Gynaecologists often call stage 1 and 2 cancers early-stage cancers, and stage 3 and 4 cancers advanced-stage cancers.

# Grading

Grading is about how the cancer cells look under the microscope compared with normal cells. The grade helps your doctor to decide if you need further treatment after surgery.

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



# TREATING CANCER OF THE YULVA

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# Treatment overview

Treatments for vulval cancer include surgery, radiotherapy, and chemotherapy.

The type of treatment you have is based on:

- the type of vulval cancer (see pages 11 to 12)
- the stage and grade of the cancer (see pages 33 to 35)
- your general health
- your personal preferences.

Surgery is the main treatment (see pages 46 to 65). For many women, surgery can cure the cancer. Surgery may also be used to remove some lymph nodes (see page 53).

The aim of surgery is to completely remove the cancer. Your surgeon will try to keep the appearance and function of the vulva and nearby tissues as normal as possible.

Radiotherapy may be used to shrink the cancer before surgery (see pages 66 to 77). You may also have radiotherapy after surgery. This is to make sure any remaining cancer cells are destroyed. You may also have radiotherapy if:

- you cannot have surgery because the cancer is too close to other structures, such as the tube you pass urine from (urethra) or the muscle that controls your bowel
- you have other medical conditions and cannot have a general anaesthetic.

Chemotherapy is sometimes used before surgery to shrink the cancer (see pages 80 to 86). If the cancer has spread to other parts of the body, or if it comes back after treatment, chemotherapy may be used on its own.

Radiotherapy and chemotherapy can also be used together. This is called **chemoradiation** (see page 78).



# How treatment is planned

You should be treated by a specialist gynaecological cancer team. These teams are based in larger cancer centres, so you may have to travel for your treatment. They will meet to discuss and decide the best treatment for you. They will consider your own wishes too.

This multidisciplinary team (MDT) will include:

- a gynaecological oncologist a surgeon who specialises in gynaecological cancers
- **oncologists** doctors who specialise in cancer treatments such as radiotherapy, chemotherapy, and targeted therapy drugs
- a **gynae-oncology nurse specialist** a nurse 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
- a radiologist a doctor who analyses x-rays and scans
- a pathologist a doctor who examines cancer cells under a microscope and advises on the type and extent of the cancer.

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

After the team has met, your specialist will discuss your treatment options with you. You can ask questions about anything you do not understand or are worried about. You should also be given a telephone number for your specialist nurse or key worker who you can contact if you have any questions when you get home.

You can also talk to our cancer support specialists on 0808 808 00 00



# **Giving consent**

Before you have any treatment, your doctor will explain its aims. They will 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.

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. Treatment can be given for different reasons and the potential benefits will vary depending upon 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 will still be given supportive (palliative) care, with medicines to control any symptoms.

You can change your mind about your treatment. For example, if you are thinking of stopping treatment, or would like to start treatment that you have previously chosen not to have. It's a good idea to talk things through with your doctor or specialist nurse before making your decision. You may also want to talk to your family or close friends.

# **Second opinion**

Your multidisciplinary team (MDT) uses national treatment guidelines to decide 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. You may also find it helpful to have a list of questions ready so that you can make sure your concerns are covered during the discussion.



# Surgery for vulval cancer

Your surgeon will talk with you about the most suitable type of surgery. A gynaecological nurse specialist will also give you information and support before and after your operation. It is important to ask them any questions you have and talk about any worries you have about the surgery.

The aim of surgery is to remove all the cancer affecting the vulva. The surgeon will remove the area of skin where the cancer is, and a border (margin) of healthy tissue all around it. In the same operation, the surgeon will also take samples (biopsies) from the lymph nodes (see page 53) from one or both sides of the groin.

Women who have larger tumours may need more surgery to reconstruct the vulva (see page 51).

Some operations may change how your vulva looks and feels, which can affect your sex life. This can be difficult to deal with. Your team will explain any possible changes and give you support to help you cope.

'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

# Surgery to remove cancer of the vulva

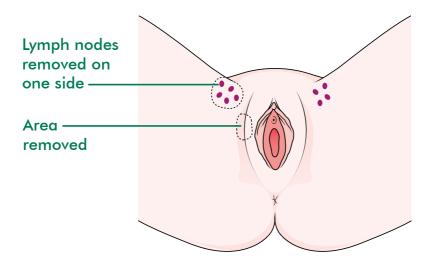
There are different operations to treat cancer of the vulva, depending on the size and position of the cancer. If the cancer is very small, it may be possible to remove only a small area of the vulva. If the cancer is larger, you may need a more major operation.

### Wide local excision

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

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

### Wide local excision



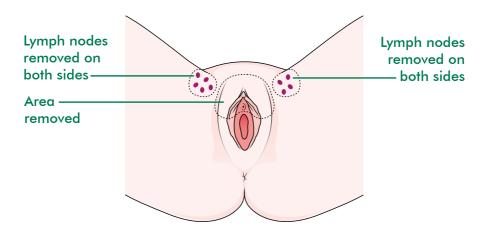
# Removing part of the vulva – partial vulvectomy

If the tumour is larger, more of the vulval skin will be removed. This is to make sure there is a border (margin) of healthy tissue all around the cancer. This operation is sometimes called a radical partial vulvectomy.

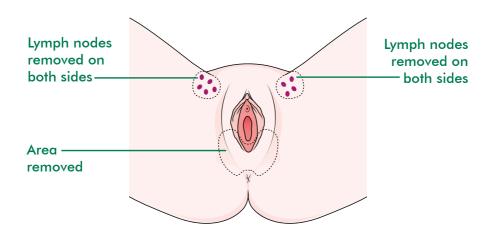
You may have lymph nodes removed from one or both sides of the groin as well, depending on where the cancer is.

The following 3 diagrams show different types of radical partial vulvectomy.

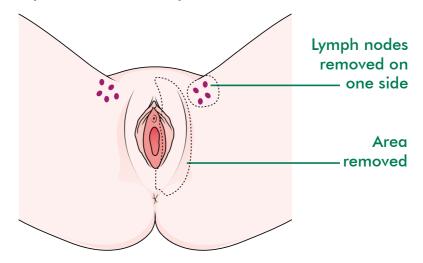
# Radical partial vulvectomy – upper



# Radical partial vulvectomy – lower



# Radical partial vulvectomy – side

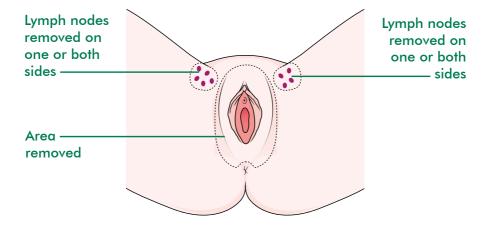


# Removing the whole vulva – vulvectomy

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

The lymph nodes are also removed from one or both sides of your groin.

# Radical vulvectomy



# Reconstructing the vulva

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

If only a small amount of skin is removed from the vulva, the surgeon may be able to stitch the remaining skin neatly together. This will also depend on the site of the cancer.

If a larger area of skin is removed, you may need to have a skin graft or skin flap. Skin grafts and flaps are done by a plastic surgeon.

# Skin grafts

The plastic surgeon will take a piece of skin from another part of the body (usually the thigh or buttock) and place it over the area where the cancer was removed. The place where the skin is taken from is known as the **donor site**. The place where it is moved to is called the **grafted area**. The amount of skin that is taken depends on the area to be covered. Your doctor or specialist nurse will tell you more about this.

# Skin flaps

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

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

# Surgery for vulval cancer that has spread

If the cancer has spread to organs close to the vulva, such as the womb, bladder or lower bowel, you will usually be offered a combination of radiotherapy and chemotherapy. It may still be possible to have an operation to remove the cancer. This involves a major operation called a **pelvic exenteration**, where any affected organs are removed. For more information on pelvic exenteration, call the Macmillan Support Line on 0808 808 00 00 or visit macmillan.org.uk

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



# 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
- find out information about the stage of the cancer, which helps when making decisions about other treatments.

Early-stage vulval cancer stage 1A and some rarer types of vulval cancer do not usually spread to the lymph nodes (see pages 33 to 35). Your doctor will tell you more about whether they will need to remove lymph nodes.

If you have had a sentinel lymph node biopsy (SLNB) and no cancer cells were found, you will not need to have any lymph nodes removed (see pages 31 to 32). Your doctor can tell you if you can have a SLNB.

Removing many lymph nodes 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 the operation and is called lymphoedema (see pages 92 to 94).

# **Before your operation**

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

You will usually go to a pre-assessment clinic a few days or weeks before the operation. You will have tests to check you are fit for surgery, such as blood tests and an echocardiogram (ECG) to check your heart.

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

You will also see the doctor who will give you your anaesthetic (the anaesthetist). They will talk to you about the anaesthetic and explain how your pain will be controlled after the operation.

You will 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.

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

# After your operation

### Recovery

How quickly you recover will depend on the type of operation you have. You will be encouraged to start moving around as soon as possible. While you are in bed, it is important to move your legs regularly and do deep breathing exercises. This 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. You may need to continue the injections after you go home. Your nurse will teach you or a relative how to give the injections, or arrange for a district nurse to visit you at home.

If you have had lymph nodes removed from your groin, you will be encouraged to put your feet up when you are sitting down. This helps to reduce leg swelling.

### **Drips and drains**

You will be given fluids into a vein in your hand or arm. This is called a drip or intravenous (IV) infusion. This will be taken out as soon as you are eating and drinking normally.

You will usually have a tube (catheter) to drain urine from your bladder. It is usually taken out a few days after your surgery, but sometimes it may need to stay in for longer.

If your lymph nodes have been removed, you will have a drainage tube going into your groin. This is to remove 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. If needed, you can go home with the drain. A practice nurse or a district nurse may check it when you are at home. Or you might have it checked and removed at the hospital.

### **Pain**

It is normal to have some pain or discomfort for a few days after surgery. But this can be controlled with painkillers. It is important to let your doctor or nurse know as soon as possible if the pain is not controlled, so that they can change your painkillers.

Immediately after your operation you may have strong painkillers. You may be given painkillers through one of the following straight after your operation:

- By injection into a muscle The nurses will do this for you.
- An **epidural** This is a small, thin tube in your back that goes into the space around your spinal cord. An epidural will give you continuous pain relief.
- A patient-controlled analgesia pump (PCA pump) The pump is attached to a fine tube (cannula), in a vein in your arm. You control the pump using a handset that you press when you need more of the painkiller. It is fine to press the handset whenever you have pain. The pump is designed so that you cannot give yourself too much painkiller.

When you no longer need strong painkillers, you will be given milder painkillers as tablets. You may be given a supply to take home. Tell your nurse or doctor if you are still in pain, so they can adjust the dose or give you a different painkiller.

### 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 water and carefully dried. This is usually done 3 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 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 do not have stitches that dissolve, your stitches or staples will probably be removed about 7 to 10 days after your operation.

If you have had a skin graft, you may need dressings on the area the skin was taken from (the donor site). Usually these dressings stay in place until new skin has formed. How long the site takes to heal will depend on how much skin was removed. Your doctor or nurse will explain more about this to you.

### Wound infection

Wound infections can be a complication of the surgery. Signs of a wound infection include:

- heat
- redness
- swelling
- discharge (fluid or pus coming from the wound)
- feeling unwell
- a fever or high temperature.

Tell your nurse or doctor if you get any of these symptoms, even after you go home.

# 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 bowel is painful or difficult, let your doctors know so they can prescribe extra laxatives to help.

# How your vulva looks

After surgery, you will have some bruising and swelling around your vulva. This should gradually disappear with time.

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 have 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 someone with you when you look for the first time. A nurse can explain what has happened to the area and give you support and advice. You may prefer to look alone or with a nurse, partner, relative, or close friend. Whoever you choose, make sure it is someone that you trust and can talk to about your feelings.

Do not 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. People cope with changes in appearance differently. Some people may not be very upset by them. Others find these changes harder to cope with. You may want to talk about your feelings with an organisation that specialises in vulval cancer (see pages 127 to 129).

# **Getting support**

It is common to feel upset and tearful after the operation (see pages 106 to 113). 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 are not feeling better or if you begin to feel very low, as you may need extra help and support (see pages 127 to 129).

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

You could also join an online support group, such as our Online Community at macmillan.org.uk/community. You can chat with other people who have vulval cancer, or just read through the posts or blogs other people have written.

'You need all the support you can get, so let your loved ones know. It is nothing to be ashamed of, although it is embarrassing. It is important that you have people in your corner.'

Joolz



# Going home

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

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

If you have had lymph nodes removed from your groin you may find some movement uncomfortable, such as walking or getting into a bath. This is normal and it will get easier as the wounds heal.

You can usually start driving after about 6 weeks, but you should check with your doctor or nurse and car insurance provider first. 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. See the next page (page 63) for tips to help your recovery.

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 (see page 113). If you need help with a wound or a wound drain, the district nurses can visit you at home to help with this.

Here are some other helpful tips to help your recovery:

- Avoid wearing tight clothing or clothing made from synthetic materials – cotton is better. You may find loose-fitting skirts comfortable.
- Avoid 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. Short walks are better
- Keeping your wound clean and dry is important. You could rinse the area with a hand-held shower. 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 cannot 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 are 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.
- If you can avoid wearing underwear, this may help to keep you more comfortable. However, it will not be possible if you have to keep pads in place.
- If you become constipated, ask your doctor to prescribe you some laxatives.

Hospital staff can arrange a district nurse, who can visit you at home and organise other support services for you (see page 113).

### Follow-up

At your follow-up appointment, your surgeon will check how you are healing and ask how you have been recovering after the operation.

They will also discuss the results of the operation with you and advise you if you need any further treatment.

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

### Sex

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

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 is important to discuss it with your doctor or nurse. They can give you advice and support.

If the clitoris was removed at the time of surgery, sex can feel different and it can be more difficult to become aroused (see pages 95 to 97). Your doctor or nurse will discuss this with you before the operation.

There is more information on our website and in our booklet Cancer and your sex life - information for women see page 122.

# Bladder and bowel problems after surgery

Most women who have surgery for vulval cancer will not have any problems with their bladder or bowel.

Sometimes when part of the vulva has been removed, the stream of urine may flow to one side or spray. This may feel a little odd the first few times you pass urine.

Rarely, if the cancer has spread to the tube that you pass urine through (urethra) or the lower end of the large bowel (anus and rectum) these areas will be included in the operation. This may affect how you pass urine or have a bowel movement. Your doctor or nurse will discuss this with you before the operation.

### Nerve damage

After surgery, some women have numbness, tingling or pins and needles in the area around the vulva. You may also have a change in sensation in your groin or down your legs. This is because of the effects of surgery on the nerves close by. These effects usually improve over a period of months, although for some women they can be permanent.

> 'Someone suggested squirting water from a drinking bottle over sore parts while urinating, to dilute and prevent stinging. Yup, it works! A little strange, but effective.'

**N**gaire

# Radiotherapy

Radiotherapy uses high-energy rays to destroy cancer cells. Sometimes, chemotherapy is given with radiotherapy. This is called **chemoradiation** (see page 78).

You may have radiotherapy:

- before surgery, to try to shrink the cancer and make a smaller operation possible
- after surgery, to reduce the risk of the cancer coming back it may be used if the cancer was not completely removed, or if there was cancer in the lymph nodes
- if you cannot have surgery
- if vulval cancer 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**.

# **Fertility**

Radiotherapy to the pelvis can affect your fertility. If you would like to have children in the future, your cancer doctor can refer you to a fertility specialist before treatment begins. They can talk through possible fertility options with you. There is more information about cancer and fertility on our website and in our booklet Cancer treatment and fertility: information for women - see page 122.

# How radiotherapy is given

Radiotherapy can be internal or external. Radiotherapy for vulval cancer is usually external. Occasionally internal radiotherapy is given, in combination with external radiotherapy.

# **External radiotherapy**

External radiotherapy uses a machine called a linear accelerator. It is like a large x-ray machine. A radiographer gives you the treatment in the radiotherapy department at the hospital. You have it as an outpatient once a day from Monday to Friday, with a rest at the weekend. Each session of treatment takes a few minutes. 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.

External radiotherapy is painless. It will not make you radioactive, and it is safe for you to be around other people. This includes children and pregnant women.

# 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 does not travel far, your surrounding organs will not be affected.

The radioactive source is left in the cancer 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.

# Planning your treatment

Your radiotherapy will be planned by your clinical oncologist with the support of a technical team. The planning is done to make sure that:

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

### First planning visit

Your first planning visit will take 30 to 60 minutes. The staff in the radiotherapy department will explain what to expect. It is important you feel involved in your treatment, so ask as many questions as you need to. The staff will tell you beforehand if you need to prepare in any way.

You will usually have a CT scan of the area to be treated (see page 26). This helps your doctor and radiotherapy team plan the precise area for your radiotherapy. Before your scan, they may ask you to remove some of your clothes and to wear a gown.

During the scan, you need to lie still on a hard couch. If you feel uncomfortable when the radiographers position you on the couch, let them know, so they can make you more comfortable. This is important because, once you are comfortable, the details of your position will be recorded. You will need to lie in the same position on a similar couch for each treatment.

The information from the scan is fed into a planning computer. Your radiotherapy team will use this to work out the precise dose and area of your treatment.

The radiographer may need to make some small marks on your skin. This is to help them position you accurately and to show where the rays will be directed. These marks must stay visible throughout your treatment. They are usually permanent marks, like tiny tattoos. These will only be done with your permission. It may be a little uncomfortable when the small marks are made.

### **Treatment sessions**

At the beginning of each session of external radiotherapy your radiographer will explain to you what you will see and hear. Once you are comfortable, and in the correct position, you will be asked to keep as still as possible. The radiographers will leave the room for a few minutes while you have your treatment. You can talk to your radiographer, who will watch you from the next room via closed-circuit TV (CCTV). The radiotherapy machine does not touch you and the treatment is painless. You may hear a slight buzzing noise from it while your treatment is being given.

Once your treatment session has finished, the radiographers will come back and help you off the treatment couch. You will then be able to go home or, if you are staying in hospital, back to the ward.

# Side effects of radiotherapy

You may develop side effects over the course of your treatment. These usually improve over a few weeks or months after treatment finishes. Your doctor, nurse or radiographer will discuss this with you, so you know what to expect. Let them know about any side effects you have during or after treatment. There are often things that can help.

The side effects of radiotherapy are made worse by smoking. If you smoke, stopping smoking will help. If you want help or advice on how to give up, talk to your clinical oncologist, GP, or a specialist nurse. There are also organisations that offer advice and support to stop smoking.

There is more information about the side effects of radiotherapy and stopping smoking on our website and in our booklets **Pelvic** radiotherapy in women: managing side effects and Giving up smoking - see page 122.

### Skin irritation

You may find the skin around your vulva and groin becomes dry and irritated. Your radiographer or specialist nurse will advise you on how to look after your skin during treatment.

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 should not use talcum powder or perfume, as these can cause irritation.

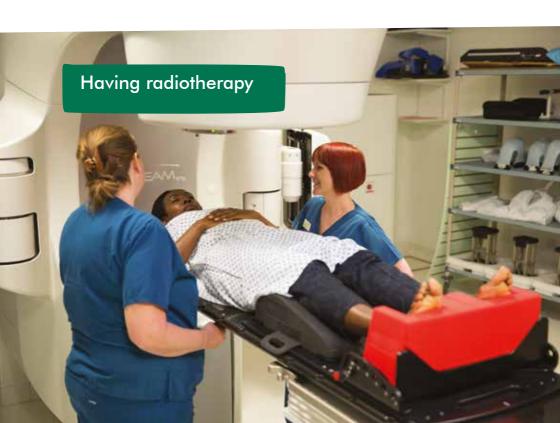
You may lose some of your pubic hair. It usually grows back after treatment, but may be thinner than it was before.

## **Tiredness**

This is a common side effect and may continue for some months after treatment is over. During treatment, you may need to rest more than usual. But it is good to do gentle exercise, such as walking, when you feel able. Once your treatment is over, gradually increase your activity. Try to balance rest periods with exercise such as walking. This will help build up your energy levels.

## **Bladder changes**

Radiotherapy can irritate the bladder. You may feel like you need to pass urine more often. You may also have a burning feeling when you pass urine. Your doctor can prescribe medicines to make passing urine more comfortable. Try drinking at least 2 litres (3.5 pints) of water or other fluids each day to help with the symptoms.



### **Bowel**

Radiotherapy to the pelvis may irritate your bowel and cause tummy (abdominal) cramps. If you have cramps tell your doctor, nurse, or radiographer. They can give you medication to help.

Your bowel may open more often or you may have diarrhoea. Drink plenty of fluids if you have diarrhoea. Your doctor may prescribe medication to help manage it.

It may also help to eat a low-fibre diet during treatment and for a couple of weeks after it. This means avoiding:

- wholemeal bread and pasta
- raw fruit
- cereals
- vegetables.

## Changes in your blood

External radiotherapy can reduce the number of blood cells made by your bone marrow. This is more likely to happen if you are having chemoradiation. If your white blood cells are low, you are more prone to infection and may need antibiotics. If your red blood cell count is low, you may feel tired and you may need a blood transfusion. Your hospital team will arrange for you to have regular blood tests if needed.

## Vaginal discharge

You may have a light vaginal discharge after treatment has finished. If it continues or becomes heavy, let your clinical oncologist or specialist nurse know.

## Possible late effects

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

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

There is more information about late effects on our website and in our booklet Managing the late effects of pelvic radiotherapy in women – see page 122.

## **Early menopause**

Radiotherapy to the pelvis affects the ovaries. This can stop the ovaries from working and cause you to have an early menopause. This means you will make less of the female hormone oestrogen and vou will no longer have monthly periods. This can happen about 2 to 3 months after the treatment starts.

Symptoms of the menopause can include:

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

Your healthcare team will discuss this with you before your treatment starts. They can also give you information about treatments to manage menopausal symptoms, such as hormone replacement therapy (HRT).

## Effects on the vagina

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

Your hospital team may recommend you use vaginal dilators to help. Dilators are tampon-shaped plastic tubes of different sizes, which you use with a lubricant.

Although dilators are commonly used, there is no strong evidence about how effective they are. Rarely, they may cause damage to the vagina, especially if they are not used correctly. Your specialist nurse or doctor will explain the best way to use them.

## Vaginal dryness

This can feel uncomfortable, particularly during sex. Creams, gels, lubricants, or pessaries (small pellets that are put inside the vagina) can help.

There are lots of products you can try. You can buy them from chemists or online, or your doctor can prescribe them.

Moisturisers work by drawing moisture into the vaginal tissue. You apply them regularly.

You can also use lubricants when you have sex to make it feel more comfortable and pleasurable. Lubricants can be water-based or oil-based. You can buy them from chemists, some supermarkets, or online.

Vaginal dryness can make you more likely to get infections, such as thrush. Let your doctor know if you have symptoms, such as itching or soreness.



## Vaginal bleeding

After pelvic radiotherapy, the blood vessels in the lining of the vagina can become fragile. This means they can bleed more easily, especially after sex. Bleeding may also be caused by the vaginal tissue sticking together, or scar tissue causing the vagina to narrow.

If you have any bleeding, always let your cancer doctor or nurse know. They will examine you and explain whether it is likely to be caused by the radiotherapy. If the bleeding is minor, you may find that it does not trouble you much once you know the cause.

## Changes to the vulva

The skin of the vulva may become permanently discoloured (reddened or darker). You may have some swelling in the vulva for months or sometimes years after radiotherapy. This can be reduced by gentle, upwards massage. A specialist nurse or physiotherapist can teach you to do this.

## **Bowel or bladder changes**

After radiotherapy, some women may develop changes to the bowel or bladder. It is common to have some mild changes. But it is much less common to have severe side effects that affect your quality of life. If this happens, symptoms may develop months or sometimes years after radiotherapy treatment.

If your bowel is affected, you may have to go the toilet more often or more urgently than usual, or you may have diarrhoea.

If the bladder is affected you may need to go to the toilet more often or more urgently.

The blood vessels in the bowel and bladder can become more fragile. This can cause blood in your urine or bowel movements. If you have bleeding always tell your cancer doctor or GP so that it can be checked.

## Lymphoedema

Pelvic radiotherapy may increase the risk of swelling in one, or both, legs. This is called lymphoedema (see pages 92 to 94). It is not common but the risk is higher if you have surgery to remove the lymph nodes as well as radiotherapy. You can reduce the risk of lymphoedema by:

- taking care of the skin on your feet and legs
- avoiding cuts and insect bites on your feet and leas
- treating any cuts, bites, or grazes promptly
- seeing your GP without delay if you have any signs infection in your feet or leas
- regular gentle exercise such as walking
- keeping to a healthy weight.

## Changes to the pelvic bones

Radiotherapy can cause thinning of the bone in the pelvis. This often does not have any symptoms but is seen on scans. In some women it may cause fractures in the pelvis called insufficiency fractures. These can cause pain in the lower back or pelvis. If this happens, it can be treated with painkillers and physiotherapy.

## Chemoradiation

Radiotherapy may be given with chemotherapy (see pages 80 to 86). Doctors call this chemoradiation. The chemotherapy drugs can make the cancer cells more sensitive to radiotherapy.

The chemotherapy drug most commonly used is cisplatin. It is usually given once a week throughout your radiotherapy.

The side effects of chemoradiation are similar to radiotherapy side effects. But they can be more severe. Your doctor, radiographer, or specialist nurse can give you more information about chemoradiation and the possible side effects of treatment.



# 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, but sometimes you may need to stay in hospital for a few days.

You may be offered chemotherapy to help shrink the cancer before an operation. This is called **neo-adjuvant chemotherapy**.

You may sometimes have chemotherapy at the same time as radiotherapy. This is known as **chemoradiation** (see page 78). 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.

Chemotherapy is often used to help control vulval cancer that has spread to other parts of the body (advanced or metastatic vulval cancer – see pages 33 to 35).

The main chemotherapy drugs used to treat vulval cancer are:

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

Other chemotherapy drugs may sometimes be used. Your doctor or specialist nurse will talk to you about the treatment and any potential side effects.

## Having chemotherapy

You usually have chemotherapy as an outpatient. Most drugs are given into a vein (intravenously), but some can be given by mouth as tablets or capsules.

Intravenous chemotherapy is given as a session of treatment over several hours or days. You then have a rest period of a few weeks. This allows your body to recover from any side effects. The treatment and rest period make up a cycle of treatment. Your cancer specialist will tell you how many cycles of treatment you will have.

There is more information about chemotherapy on our website and in our booklet **Understanding chemotherapy** – see page 122.

## Side effects

Chemotherapy drugs may cause side effects. But these can usually be well controlled with medicines and will usually go away once treatment has finished. Not all drugs cause the same side effects, and some people may have very few. You can talk to your doctor or nurse about what to expect from the treatment that you are having.

When you have chemotherapy with radiotherapy (chemoradiation), the side effects of the radiotherapy may increase.

The main side effects are described here, as well as some ways to reduce or control them. There is more information about managing the side effects of chemotherapy on our website and in our booklet **Side effects of cancer treatment** – see page 122.

## Risk of infection

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

If you have an infection, it is important to treat it as soon as possible. Contact the hospital straight away on the 24-hour contact number you have if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection, such as:
  - feeling shivery
  - a sore throat
  - a cough
  - diarrhoea
  - needing to pass urine often.

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

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

## **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 dietitian.

### Sore mouth

Your mouth may become sore or dry, or you may notice small ulcers during treatment. Drinking plenty of fluids, and cleaning your teeth regularly and gently with a soft toothbrush, can help to reduce the risk of this happening. Tell your nurse or doctor if you have any of these problems, as they can prescribe mouthwashes and medicine to prevent or clear mouth infections.

### Hair loss

Some chemotherapy drugs cause hair loss. This can range from hair thinning to losing all your hair including eyelashes and eyebrows. The extent of hair loss depends on what chemotherapy drugs you have. Your doctor or nurse can tell you what to expect.

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

Your nurse can talk to you about ways to cope with hair loss. There are lots of ways you can cover up, if you choose to, such as using hats, wigs, turbans, scarves, or bandanas. It is important to cover your head to protect your scalp when you are out in the sun.

Hair loss is almost always temporary and hair grows back after treatment ends.

## Tiredness (fatique)

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.

## 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
- 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 workfind 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 is 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 do not 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 are treated by the hospital staff, and you will be offered the standard treatment for your situation.

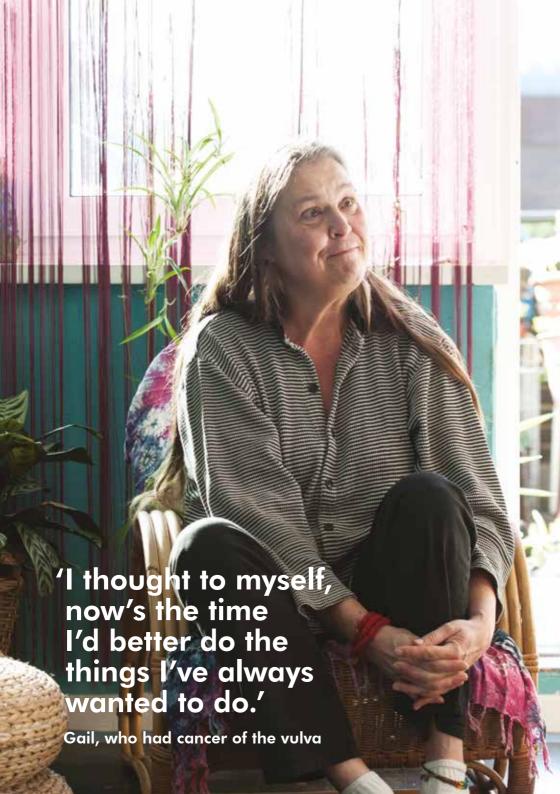
There is more information about clinical trials on our website and in our booklet Understanding cancer research trials (clinical trials) - see page 122.

## **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 not 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

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# Follow-up

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

You can talk to your doctor or nurse about any problems or worries at these check-ups. But if you notice any new symptoms or have any problems between appointments, contact your doctor or nurse for advice.

If you had vulval lichen sclerosus (VLS) or lichen planus (LP) before vulval cancer (see pages 14 to 15), you should continue to see your specialist for those conditions too. After cancer treatment, you may still need ongoing treatment for the skin. Your specialist will advise you about this.

Many people find that they get quite anxious before their appointments. You may worry about the cancer coming back. This is natural. It can help to get support from family, friends, or your specialist nurse. Or you can speak to our cancer support specialists on 0808 808 00 00. Some other organisations also offer support to people affected by cancer of the vulva (see pages 127 to 129).



# Lymphoedema

If you had lymph nodes removed during surgery, or if you had radiotherapy, you may develop lymphoedema. This means fluid collects and causes one or both legs to swell.

The lymph nodes are part of the body's immune system and help fight infection (see pages 8 to 10). A fluid called lymph fluid normally flows through these nodes. If the nodes stop working normally or are removed during cancer treatment, the lymph fluid may build up.

Not everyone gets lymphoedema after treatment for cancer of the vulva. But it can start months or years later. There are treatments that can help manage swelling. There are also things you can do to reduce your risk of developing it. Your doctor or nurse may arrange for you to see a specialist lymphoedema nurse for advice.

## Reducing your risk of lymphoedema

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

- Look after your skin. Keep your legs and feet clean and well moisturised. Avoid having very hot baths and showers. Protect your skin from cuts, grazes, insect bites, and sunburn. Wear shoes that are the right fit and size for your feet.
- Look out for the early signs of infection. Wash small grazes and cuts straight away, put on antiseptic cream, and cover if needed. Contact your GP straight away if you have signs of infection for example, if you have flu-like symptoms or if any skin on your legs or feet becomes red, hot, or swollen.
- Keep active. Regular exercise and physical activity will help lymph fluid to drain. Avoid standing in the same position for too long.
- Keep to a healthy weight. You have a higher risk of lymphoedema if you are overweight. Your GP or practice nurse can tell you what your ideal weight should be. You can also ask them, or a dietitian, for advice and support on healthy eating.

## Managing lymphoedema

To start with, lymphoedema may only cause slight swelling. Contact your cancer doctor, nurse or GP for advice if you have:

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

If you have signs of lymphoedema, 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.

The specialists at the lymphoedema clinic will give you advice on caring for your skin. They will also show you exercises and ways to massage your legs and feet to help fluid drain. They will give you a support stocking (compression garment) to wear to reduce the swelling. A specialist will measure you for this and give you advice about using it. They may also recommend other treatments for you.

There is more information about preventing and managing lymphoedema on our website and in our booklet **Understanding** lymphoedema – see page 122.

# **Effects on sexuality**

Life after cancer treatment is often challenging. It can be especially difficult to cope with changes to something as personal as your sexuality. Treatment for cancer of the vulva can cause physical changes that affect how your body responds sexually and how sex feels. It can also affect how you feel about your body, sex, and your relationships.

It is common to have questions about sexuality or need more help after treatment. But these things are not always easy to talk about. There is support available. Do not be afraid or embarrassed to ask for advice. Often your cancer doctor or nurse can help or can arrange for you to see a specialist.



## Physical changes

It may be some months before you feel ready to have sex after treatment. Do not be surprised if you feel very unsure about it. Remember to look after yourself and give your body time to heal. If you have a partner, talk to them and be as honest as you can about what you want or do not want. It is fine to say no to any kind of sexual contact that does not feel right.

Surgery or radiotherapy can both cause scarring or tightness. This may mean sex is uncomfortable or painful. Tell your cancer doctor or nurse if this happens. Depending on how you are affected, there are several things that can help.

Treatment may have changed the way your genital area looks or feels. If your clitoris was removed, you may worry that you will not be able to have orgasms. This is not always the case. You may need to be patient while you get used to the changes and explore different ways to reach a climax.

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

## You and your partner

You may also wonder how other people will feel about the changes to your body. Some people worry that a current or future partner will be shocked or unable to cope.

If you have a partner, try to be open with them and talk about this together. Sometimes counselling is helpful, either with your partner or on your own. Counselling may help you and your partner to work through any issues and move on. Your GP, cancer doctor, or nurse can often arrange counselling for you. Our cancer support specialists, or the College of Sexual and Relationship Therapists, can also give advice about finding a counsellor in your area (see page 127). You can speak to our cancer support specialists for free on the Macmillan Support Line on 0808 808 00 00.

You might want to talk to someone who has had the same type of treatment. Your cancer doctor or nurse may be able to arrange this for you. Some organisations may also offer this (see pages 127 to 129). Lots of people share their experiences of cancer on Macmillan's Online Community. There is a group for people affected by vulval cancer. Visit macmillan.org.uk/community

We have more information about sexuality and cancer and some videos about coping with sexual changes on our website and in our booklet Cancer and your sex life - information for women - see page 122.

# Well-being and recovery

After treatment, you may just want to get back to everyday life. But you may still be coping with the side effects of treatment, adjusting to physical changes or dealing with some difficult emotions (see pages 106 to 109). Recovery takes time, so do not rush it and try to be kind to yourself.

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

'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** 

## Eat healthily

A healthy, balanced diet gives you more energy and will help you to recover. Talk to your GP, specialist nurse or a dietitian if you have any special dietary or medical needs. There is more information about healthy eating on our website and in our booklet **Healthy eating and cancer** – see page 122.

## Be physically active

Being physically active after cancer treatment can:

- boost your energy levels
- keep your weight healthy
- reduce stress and fatique.

It can also reduce your risk of:

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

Your GP or cancer doctor may be able to refer you to an exercise group for people with cancer. Ask them for advice about what is available in your local area. There is more information about staying active on our website and in our Move more quide see page 122.

## Stop smoking and stick to sensible drinking

If you smoke, giving up is the healthiest decision you can make. Stopping smoking reduces your risk of heart and lung disease, bone thinning (osteoporosis), and smoking-related cancers. If you want to stop, your GP can give you advice. There is also more information about stopping smoking on our website and in our booklet Giving up smoking - see page 122.

Alcohol has also been linked to a higher risk of some types of cancer and to weight gain. If you drink alcohol:

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

A unit of alcohol is half a pint of ordinary-strength beer, lager or cider, one small glass (125ml) of wine, or a single measure (25ml) of spirits. There is more information about alcohol at drinkaware.co.uk

## **Complementary therapies**

Some people use complementary therapies to help them relax or cope with treatment side effects. Some hospitals or support groups offer therapies such as relaxation or aromatherapy. Ask your cancer doctor or nurse what is available in your area. There is also more information on our website and in our booklet Cancer and complementary therapies – see page 122.



## More help and support

## **Practical help**

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

## Support groups

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

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

You can search for groups in your area at macmillan.org.uk/ **supportgroups** or ask someone from your healthcare team. You can also ask our cancer support specialists for more information by calling the free Macmillan Support Line on 0808 808 00 00.

## Online support

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

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

Online groups are also easy to leave, without any need for personal contact or explanations.

Our Online Community offers this type of support on macmillan.org.uk/community. It is quick and easy to join. You can talk to people in our forums, blog about your experiences, make friends, and join support groups.





# YOUR FEELINGS AND RELATIONSHIPS

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# 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 anary 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.

There is more information about the feelings you may have in more detail and suggestions for coping with them on our website and in our booklet How are you feeling? The emotional effects of cancer – see page 122.

# 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 Talking to someone who has 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.



# 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. These may include meals on wheels, a home helper, or money to help with hospital transport 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.



# WORK AND FINANCIAL SUPPORT

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# 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 2 different types of ESA:

- contribution-based (contributory) you can get this if you have paid enough national insurance
- income-related (means tested) you can get this if you don't aualify for contribution based ESA or if your income is low.

ESA is gradually being replaced by a new benefit called Universal Credit. This benefit is for people below retirement age who are out of work or on a low income.

Personal Independence Payment (PIP) is a new benefit for people aged between 16 and 64. It is for people who have problems moving around and looking after themselves. You must have had these difficulties for at least 3 months and expect them to last for at least 9 months. PIP replaces an older benefit called **Disability Living Allowance (DLA)** for adults.

**Attendance Allowance (AA)** is for people aged 65 or over who have problems looking after themselves. You may qualify if you have problems with personal care, for example getting out of bed, having a bath or dressing yourself. You don't need to have a carer, but you must have had these problems for at least 6 months. If you are terminally ill, and may be expected to live for less than 6 months, you can apply for PIP, DLA, or AA under the special rules. It does not have to be certain and it does not matter if you live longer than 6 months. 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

Carer's 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 have 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, Wales and Scotland) 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 (see page 131) or Citizens Advice (see page 130).

Our booklet Help with the cost of cancer has more detailed information. You might also find our video useful at macmillan.org.uk/gettingfinancialhelp

#### 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 130 to 131.

There is more information on our website and in our booklet Insurance – see page 122.

### 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 lots more information at macmillan.org.uk/work



# FURTHER INFORMATION

About our information Other ways we can help you	122 124

# **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.

#### Online information

All of our information is also available at macmillan.org. uk/information-and-support There you will 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
- eBooks
- large print
- translations.

Find out more at macmillan. org.uk/otherformats If you would like us to produce information in a different format for you, email us at 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 is why we always involve them in our work. If you have 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 would like to hear more about becoming a reviewer, email reviewing@macmillan. org.uk You can get involved from home whenever you like, and we do not 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 are here to support you.

#### Talk to us

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

#### **Macmillan Support Line**

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- 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 would 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 is 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

#### **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

#### 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.

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

Mal

#### Help with money worries

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

#### Financial guidance

Our financial team can give you guidance 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/ financial support to find out more about how we can help you with your finances.

#### Help with work and cancer

Whether you are 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

#### My Organiser app

Our free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

# Other useful organisations

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

#### **Gynaecological cancer** support organisations

#### **RV Club Tel** 01977 640243 Confidential telephone support from someone who has been through vulval cancer and

#### **Vulva Awareness Campaign Organisation** Email vacouk@yahoo.com www.vaco.co.uk

a radical vulvectomy.

UK-wide organisation run by women who have 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

College of Sexual and

**Relationship Therapists** 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** Helpline 07770 884 985 (11am to 5pm weekdays) **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.

#### Counselling and emotional support

**Association for Family** Therapy and Systemic **Practice (AFT) 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) **Tel** 01455 883 300 Email bacp@bacp.co.uk Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a aualified counsellor at itsgoodtotalk.org.uk

#### General cancer support organisations

**Cancer Black Care** Tel 020 8961 4151 **Email** info@cancerblackcare. org.uk

www.cancerblackcare.org.uk Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

Cancer Focus Northern Ireland **Helpline** 0800 783 3339 (Mon to Fri, 9am to 1pm) Email nurseline@ cancerfocusni.org www.cancerfocusni.org Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling, and links to local support groups.

**Cancer Support Scotland Tel** 0800 652 4531 (Mon to Fri, 9am to 5pm) **Email** info@ cancersupportscotland.org www.cancersupportscotland. org

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

#### **Cancer registries**

#### The cancer registry

A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

National Cancer Registration and **Analysis Service Tel** 020 7654 8000 Email enquiries@phe.gov.uk www.ncras.nhs.uk Tel (Ireland) 021 4318 014 www.ncri.ie (Ireland)

**Scottish Cancer Registry Tel** 013 1275 7777 Email nss.csd@nhs.net www.isdscotland.org/ **Health-Topics/Cancer/ Scottish-Cancer-Registry** 

Welsh Cancer Intelligence and Surveillance **Unit (WCISU)** Tel 029 2037 3500 **Email** general.enquiries@wales.nhs.uk www.wcisu.wales.nhs.uk

Northern Ireland **Cancer Registry Tel** 028 9097 6028 Email nicr@qub.ac.uk www.qub.ac.uk/nicr

#### Financial or legal advice and information

**Benefit Enquiry Line** Northern Ireland Helpline 0800 22 2450 (Mon, Tue, Wed and Fri, 9am to 5pm, Thu, 10am to 5pm) **Textphone** 028 9031 1092 www.nidirect.gov.uk/ money-tax-and-benefits Provides information and advice about disability benefits and carers' benefits in Northern Ireland, You can also call the Make the Call helpline on 0800 232 1271 to check you are getting all the benefits you are eligible for.

#### Citizens Advice

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

**England** Helpline 03444 111 444 www.citizensadvice.org.uk

Wales Helpline 03444 77 2020 www.citizensadvice.org.uk/ wales

Scotland Helpline 0808 800 9060 www.citizensadvice.org.uk/ scotland

Northern Ireland Helpline 0800 028 1881 www.citizensadvice.co.uk **Department for Work** and Pensions (DWP) **Personal Independence** Payment (PIP) Helpline 0345 850 3322 **Textphone** 0345 601 6677 (Mon to Fri, 8am to 6pm) www.gov.uk/browse/ benefits Carer's Allowance Unit Tel 0800 731 0297 **Textphone** 0800 731 0317 (Mon to Fri, 8am to 6pm) www.gov.uk/carersallowance

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

The Law Society of Northern Ireland **Tel** 028 9023 1614 Email enquiry@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 **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

**Tel** 0808 802 2000

(Mon to Fri, 9am to 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.

#### 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.UK** www.nhs.uk

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

#### **NHS Direct Wales** www.nhsdirect.wales.nhs.uk NHS health information site for Wales.

NHS Inform Helpline 0800 22 44 88 (Daily, 8am to 10pm) www.nhsinform.scot NHS health information site for Scotland.

#### Support for carers

Carers UK Helpline (England, Scotland, Wales) 0808 808 7777 (Mon to Wed, 10am to 4pm) **Helpline (Northern Ireland)** 028 9043 9843 Email advice@carersuk.org www.carersuk.org Offers information and support to carers across the UK. Has an online forum and can put people in contact with support groups for carers in their area.

#### Support with lymphoedema

Lymphoedema **Support Network Tel** 020 7351 4480 Email admin@lsn.org.uk www.lymphoedema.org A national charity that provides information and support to people with lymphoedema.

#### **Disclaimer**

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

#### **Thanks**

This booklet has been written, revised, and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor, Prof David Luesley, Professor of Gynaecological Oncology. With thanks to: Dr Alexandra Lawrence, Consultant Gynaecological Oncologist; Dr Alexandra Taylor, Consultant Clinical Oncologist; Dr Eva Myriokefalitaki, Consultant Gynaecological Oncology Surgeon; Jane Evans, Macmillan Gynaecological Oncology Clinical Nurse Specialist; Dr Rosie Harrand, Consultant Clinical Oncologist; Sara Elias, Gynaeoncology Clinical Nurse Specialist; and the people affected by cancer who reviewed this edition.

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

#### Sources

We have listed a sample of the sources used in the publication below. If you would like further information about the sources we use, please contact cancerinformationteam@macmillan.org.uk

British Gynaecological Cancer Society and Royal College of Obstetricians & Gynaecologists. Guidelines for the diagnosis and management of vulval carcinoma. May 2014.

European Society of Gynaecological Oncology (ESGO). Vulvar Cancer Guidelines. 2017.

Han JJ and Kohn EC. The New FIGO Staging for Carcinoma of the Vulva, Cervix, Endometrium, and Sarcomas. 2009.

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Karam A et al. Squamous cell carcinoma of the vulva Staging and surgical treatment, UpToDate online. 2017.

# 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

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

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

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

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

#### If you'd rather donate online go to macmillan.org.uk/donate

Security number

Issue no

Signature

Date

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

REGULATOR

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

The booklet explains the signs and symptoms of vulval cancer, and how it is diagnosed and treated. It also has information about emotional, practical and financial issues.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) or visit macmillan.org.uk

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

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



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