Understanding cancer of the vulva

About this booklet

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

The booklet explains the signs and symptoms of vulval cancer, how it is diagnosed, and the treatments you might have. It also has information about the feelings you might experience, and how your relationships, work and finances might be affected.

We hope it helps you deal with some of the questions or feelings you may have.

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

How to use this booklet

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

On pages 112 to 120, there are details of other organisations that can help.

Quotes

In this booklet, we have included quotes from people who have had cancer of the vulva, which you may find helpful. Some are from our Online Community (**macmillan.org.uk/community**). The others are from people who have chosen to share their story with us. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 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**.

Contents

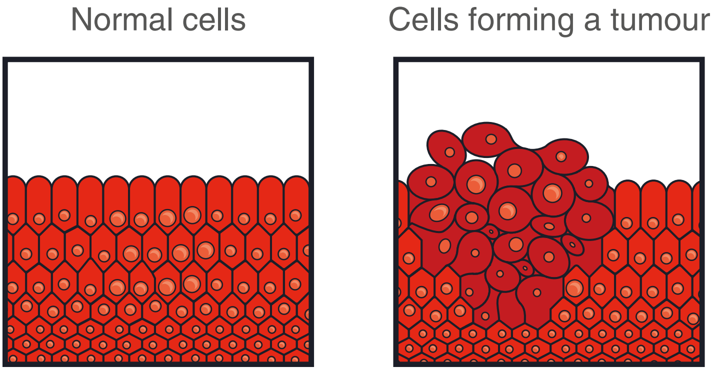
ABOUT CANCER OF THE VULVA

What is cancer?

Cells are tiny building blocks that make up the body’s organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old, damaged or no longer needed. When this happens, the cell gets a signal from the body to stop working and die.

Sometimes these signals can go wrong, and the cell becomes abnormal. The abnormal cell may keep dividing to make more and more abnormal cells. These can form a lump, called a tumour.

Cells forming a tumour



Normal cells

Cells forming a tumour

Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample of cells from it. This is called a biopsy (see page 25). The doctors examine the sample under a microscope to look for cancer cells.

A tumour that is not cancer (a benign tumour) may grow, but it cannot spread to anywhere else in the body. It usually only causes problems if it grows and presses on nearby organs.

A tumour that is cancer (a malignant tumour) can grow into nearby tissue.

Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system (see page 10). When these cancer cells reach another part of the body, they may grow and form another tumour. This is called a secondary cancer or a metastasis.

The vulva

The vulva is the name given to the visible female sex organs outside the body (see page 9). People who have a vulva include women, transgender (trans) men and people assigned female at birth.

The vulva is made up of:

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

Between the labia are two 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 is the outer tip of the clitoris. The clitoris is a sensitive structure that helps with sexual response and orgasm.

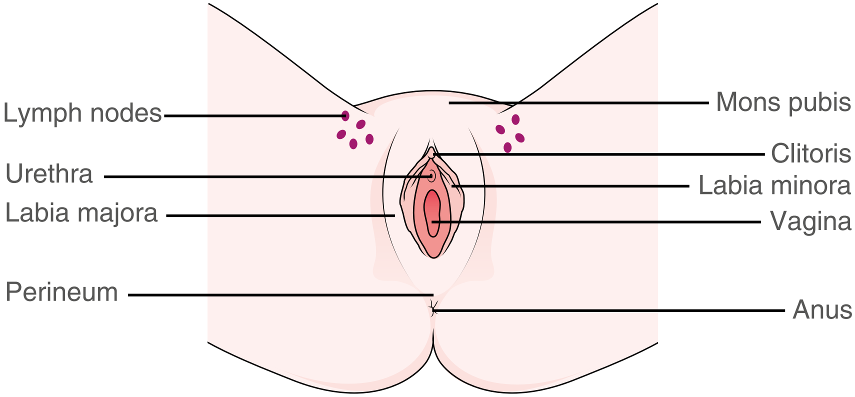
On either side of the vagina are two small glands called Bartholin's glands. These make a fluid that acts as a lubricant during sex.

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). The area of skin between the anus and vulva is called the perineum.

The area where the skin creases at the top of each leg is called the groin. There are lymph nodes under the skin of the groin. These are part of the body's lymphatic system (see page 10).

The vulva



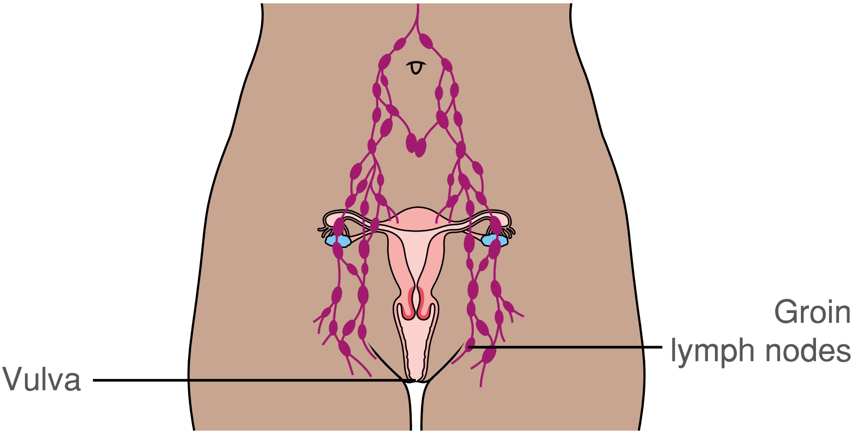
Vulval cancer and the lymphatic system

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

Lymph nodes (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 in this way, 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. About 1,300 women are diagnosed with it each year in the UK. It can affect anyone who has a vulva. This includes women, trans men and people assigned female at birth.

Vulval cancer can affect any part of the vulva (see pages 8 to 9). The most common area for it to develop is the skin of the labia. It can also sometimes affect the tip of the clitoris or the Bartholin's glands.

Squamous cell carcinoma

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

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

Rarer types

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

Melanoma

This is a type of skin cancer that develops from cells that produce the pigment that gives skin its colour. Rarely it can develop in the skin of the vulva. We have more information about this in our booklet **Understanding melanoma and treatment with surgery** (see page 108).

Basal cell carcinoma

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

Sarcoma

Sarcomas develop from cells in tissue such as:

- muscle
- fat
- blood vessels under the skin.

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

Adenocarcinoma

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

Bartholin gland cancer

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

Causes and risk factors

The exact cause of vulval cancer is unknown. However, some risk factors can increase the chances of developing it. Having one or more risk factors does not mean you will 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 people who are diagnosed with vulval cancer are aged 65 or over.

Vulval cancer in older people is usually linked to a skin condition called lichen sclerosus (LS) – see page 16.

Vulval cancer in younger people is often linked to human papilloma virus infection (HPV) and smoking – see page 17.

HPV

The main risk factor for vulval cancer is an infection called the human papilloma virus (HPV). There are over 100 types of this virus. Some can affect the vulva and cause abnormal cell changes that may develop into vulval cancer.

HPV is common and most people are infected with it at some point. It can be passed on through any type of sexual contact. It is often shared between sexual partners. Using a condom or other barrier contraception may reduce the risk of infection with HPV, but it does not offer complete protection.

Usually, the body's immune system gets rid of the virus naturally. There are no symptoms and often the virus does not cause damage. Most people will never know they had it.

In some people, the immune system does not clear the infection and the virus stays in the body for longer. We do not know exactly why this is. If the virus affects the vulva for longer, it can start to cause damage that may eventually cause cancer.

Vulval cancer itself is not infectious. You cannot catch cancer or pass it on to other people.

The NHS offers a vaccine to people between the ages of 11 and 13 to prevent HPV.

A weak immune system

Your immune system helps protect your body from infection and illness. A weak immune system is less likely to get rid of infections like HPV. Your immune system can be weakened by:

- smoking
- some medical conditions, such as HIV
- medicines used to suppress your immune system after an organ transplant.

If you are worried that you have a weakened immune system, talk to your GP or specialist nurse, if you have one. They will be able to give you further advice.

Vulval skin conditions

Some skin conditions of the vulva can increase your risk of developing vulval cancer.

Lichen sclerosus (LS) and lichen planus (LP)

These are 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 called vulval LS or vulval LP.

Less than 5 in every 100 women (5%) who have vulval LS or LP develop vulval cancer. Over a long period of time, the inflammation caused by these skin conditions may increase the risk of cancer developing.

We have more information about these conditions on our website (see page 108).

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 people who have been through the menopause. In a small number of cases, cancer is found underneath the area where the Paget’s disease is.

Vulval intraepithelial neoplasia (VIN)

The term VIN describes changes that happen in the skin that covers the vulva. If the changes become more severe, there is a chance cancer might develop after many years. VIN is called a pre-cancerous condition.

VIN is divided into two main types:

- **HSIL – High-grade squamous intraepithelial lesion of the vulva**. This is more common. It is usually linked to a virus called HPV. This type was previously called **VIN usual type (uVIN)**.
- **dVIN – VIN differentiated type.** This is rarer. It often occurs together with other skin conditions that can affect the vulva, such as lichen sclerosus (LS) or lichen planus (LP). It is not usually linked to HPV.

Smoking

Smoking increases the risk of developing both VIN and vulval cancer. Smoking makes the immune system less effective and less able to get rid of HPV. This may be one of the reasons it increases the risk of vulval cancer.

CIN

High-grade abnormal cell changes in the cervix (called CIN 3) may increase the risk of developing vulval cancer. This may be related to shared risk factors, such as HPV infection and smoking.

> ‘I want to increase awareness. I’m spreading the word and speaking about a subject that can be taboo. If you have symptoms but are too embarrassed to get them checked, then it’s not going to be diagnosed.’

Clare, diagnosed with vulval cancer

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 peeing (passing urine)
- vulval tenderness or pain
- a sore or ulcerated area on the vulva
- a mole on the vulva that changes shape or colour
- a lump in the groin.

Many people find it embarrassing talking about symptoms like these. 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 early.

DIAGNOSING CANCER OF THE VULVA

How cancer of the vulva is diagnosed

If you have symptoms, you usually begin by seeing your GP. If they think that your symptoms could be caused by cancer, they will refer you to a specialist clinic or doctor. This is often a doctor who specialises in female reproductive system cancers (a gynaecological cancer specialist).

The main tests for vulval cancer are an examination of the vulva and a small sample (biopsy) of any abnormal looking areas. You can usually have these tests during an outpatient appointment. You may have them under a general anaesthetic if:

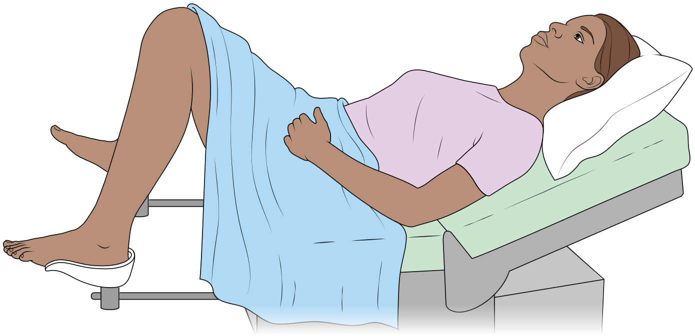
- there is a narrowing of the vagina due to lichen sclerosus (LS)
- the vulva is too sore for a full examination.

Vulval examination

The vulva is an intimate and private part of the body. If you are worried or embarrassed about having this test, tell your doctor or nurse so they can give you support.

For the test, you will undress from the waist down. You then lie down on your back on a bed or examination couch. Some clinics have ones with foot or leg supports you can rest your legs on. You will be asked to lie with your knees bent and apart.

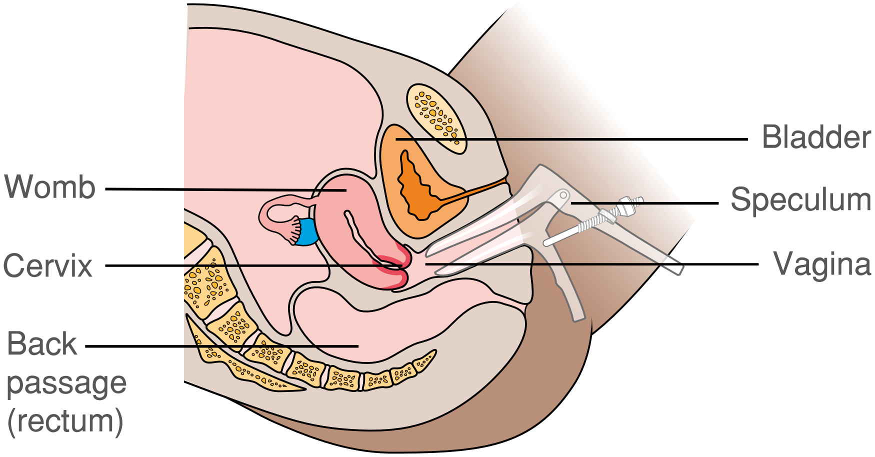
Having a vulval examination



The doctor may use a bright light and a magnifier to examine the vulva. This helps them see the skin more clearly. They may take small samples of tissue from any areas that look abnormal. This is called a biopsy (see page 25).

The doctor may also check the vagina and cervix. To do this they put an instrument called a speculum into the vagina. This holds the vagina open so they can see the cervix. It should not hurt, but sometimes it can feel uncomfortable.

How a speculum works



The doctor may also gently put a gloved finger into the back passage (rectum) to feel for any abnormal areas there.

Biopsy

A biopsy is a small sample of tissue. The doctor collects samples from the affected area of the vulva. They send these to a laboratory to be examined under a microscope.

Before taking a sample, the doctor numbs the skin of the vulva with a small injection of local anaesthetic. This may sting for a few seconds. When they take the sample of tissue it should not hurt, but sometimes it can feel uncomfortable.

If the vulval area is 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 take about 7 to 10 days for the results of your biopsy to be ready. Waiting for your results can be difficult. It may help to talk to a family member or close friend.

Further tests

If your vulval examination and biopsy show cancer, your doctor will arrange further tests to check if the cancer has spread. This is called staging (see pages 36 to 39). 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 which of the following tests you may need.

Blood tests

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

Chest x-ray

This uses x-rays to take a picture of your chest. It may be done to:

- check your general health
- look at your lungs and heart.

Having a chest x-ray is not painful. It only takes a few minutes. It uses a small amount of radiation, which is very unlikely to harm you.

CT scan

A CT scan makes a three-dimensional (3D) picture of the inside of the body using x-rays taken by the CT scanner. It uses a small amount of radiation. This is very unlikely to harm you. It will not harm anyone you come into contact with.

You will get an appointment letter telling you if you need to do anything before the scan. You may be asked not to eat or drink for a few hours before the scan. If this is a problem for you, call the number on your appointment letter.

You have the scan at the hospital. The person who works the scanner is called a radiographer. They help you prepare for the scan. You may have a drink or injection of a dye. This is called a contrast. It helps show certain areas of the body more clearly. The contrast may make you feel hot all over for a few minutes. It is important to let your doctor know if you are allergic to iodine or have asthma. This is because you could have a more serious reaction.

The scan takes 5 to 10 minutes, but you may be in the department for longer. You will lie very still on a narrow bed. The bed moves slowly back and forward through the donut-shaped scanner.


Having a CT scan

MRI scan

An MRI scan uses magnetism to build up a detailed picture of areas of your body.

The scanner is a powerful magnet. You will be asked to complete and sign a checklist to make sure it is safe for you. The checklist asks about any metal implants you may have, such as a pacemaker or surgical clips. You should also tell your doctor if you have ever worked with metal or in the metal industry. Tiny fragments of metal can sometimes lodge in the body.

You have the scan in the x-ray department at the hospital. A person called a radiographer works the scanner. They may give you an injection of a dye, called a contrast. It helps show certain areas of the body more clearly.

During the test, you need to lie very still on a bed inside a long cylinder (tube). If you are worried about feeling claustrophobic, you may be able to have a sedative to help you relax. Talk to your GP or doctor about this before the scan.

The scan takes 15 to 90 minutes. It is painless but you may find it uncomfortable to lie still for that long. After the scan is finished you can usually go home.

PET or PET-CT scan

A PET scan uses low-dose radiation to check the activity of cells in different parts of the body. It is sometimes given together with a CT scan. This is called a PET-CT scan. It can give more detailed information about cancer or abnormal areas seen on x-rays, CT scans or MRI scans. PET scans are not suitable for everyone. Your doctor or specialist nurse can tell you whether they might be helpful for you.

PET scans are not available at all hospitals, so you may have to travel to a specialist centre to have one. If you are pregnant or breastfeeding, you should phone the scanning department before the test for advice.

About an hour before the scan, the radiographer will inject a radioactive substance into a vein, usually in the arm. This is called a tracer. While you wait to have the scan, you will be encouraged to drink. Drinking water helps move the tracer around your body. Very rarely, some people are allergic to the tracer. This can make them feel breathless, sweaty or weak. Tell the radiographer straight away if you feel unwell.

The person who works the scanner is called a radiographer. The scan takes about 30 to 60 minutes. You will lie on a narrow bed. The bed moves slowly back and forward through the donut-shaped scanner. You can usually go home after the scan. The amount of radioactive substance used is very small. But you will be advised not to have close contact with pregnant women, babies and young children for up to 24 hours 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.

The doctor or nurse gently passes a thin tube with a camera and light on the end (a cystoscope) through the urethra into the bladder. If there are any abnormal areas, they can use the cystoscope to take a small sample of cells (biopsy) – see page 25. 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 get 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 the back passage. The doctor can see any abnormal areas by using a tiny light and camera on the end of the proctoscope. If needed, 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.

Exam under anaesthetic (EUA)

This is an examination of the vulva, vagina, cervix and anus, done under a general anaesthetic. It lets your doctor examine you fully 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 this test and what to expect afterwards.

Lymph node tests

A common place for vulval cancer to spread to is the lymph nodes in the groin (see page 10). Your doctor will check these nodes for swelling. Having swollen lymph nodes does not always mean that the cancer has spread. For example, an infection can also cause lymph nodes to swell.

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

An ultrasound uses sound waves to make up a picture of an 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 shows abnormal lymph nodes, the doctor may do a fine needle aspiration. This is a quick and simple test. The doctor injects some local anaesthetic into the skin of the groin to numb the area. Using the ultrasound scan as a guide, the doctor puts a fine needle through the numbed area and into the lymph node to collect a small sample of cells.

The sample is checked under a microscope to see if there are cancer cells. If they show cancer cells, the groin lymph nodes will be removed during an operation or treated with radiotherapy.

Sentinel lymph node biopsy (SLNB)

The sentinel nodes are the first lymph nodes (see page 10) that fluid drains to from the vulva. If the cancer has spread to nearby nodes, these sentinel nodes are most likely to be affected.

Your doctor may suggest checking the sentinel nodes for cancer cells with a test called a sentinel lymph node biopsy (SLNB). This test can find small amounts of cancer that cannot be felt as swelling or seen on a scan.

Before the SLNB, you usually have a scan to show which are the sentinel lymph nodes. Your scan may be the day before or the same day as the SLNB.

For the scan, you undress from the waist down. You then lie down on your back. The doctor uses local anaesthetic cream or a spray to numb the area of the vulva affected by cancer. They gently inject a small amount of radioactive liquid. The liquid drains into the nearest lymph nodes. You have scans over the next 90 minutes to show how and where the liquid goes. The doctor may also make marks with a marker pen on your skin. These marks and the scan pictures are useful when you have the SLNB.

The SLNB is a small operation done under a general or regional (spinal) anaesthetic. It is usually at the same time as an operation to remove the cancer.

During the operation, the doctor injects a dye into the area of the vulva affected by cancer. The dye stains the lymph nodes so the surgeon can find them. The surgeon also uses a probe that detects the radioactive liquid from the scan. They carefully find the sentinel lymph nodes and remove them.

After surgery, the nodes are sent to a laboratory and examined under a microscope to see if they hold cancer cells. If they show cancer cells, the remaining groin lymph nodes will need to be removed with another operation or treated with radiotherapy. If the sentinel nodes do not contain cancer cells, it is unlikely that other lymph nodes are affected. You do not need to have further surgery or radiotherapy.

Staging and grading

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

Number staging

The number staging system is often used for vulval cancer. It may help to look at the diagram of the vulva when you are reading this explanation (see page 9). Stage 1 and 2 cancers are often called early-stage cancers. Stage 3 and 4 cancers are called advanced-stage cancers.

Stage 1

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

Stage 1A

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

Stage 1B

The cancer is more than 2cm in size. Or 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 locally 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 3A

The cancer has spread to one lymph node. Or the cancer has spread to two lymph nodes that are 5mm or more in size.

Stage 3B

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

Stage 3C

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

Stage 4

Stage 4 is divided into two stages.

Stage 4A

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

- 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 (have become fixed).

Stage 4B

The cancer has spread to:

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

TNM staging

Another system called TNM staging is sometimes used. TNM stands for tumour, node and metastases.

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

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

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

Grading

Grading is how the cancer cells look under the microscope compared with normal cells. The grade helps your doctor 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.

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. 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.

TREATING CANCER OF THE VULVA

Treatment overview

Treatment for vulval cancer may include surgery, radiotherapy and chemotherapy. Your treatment plan is based on:

- the type of vulval cancer (see pages 11 to 12)
- the stage and grade of the cancer (see pages 36 to 39)
- your general health
- your personal preferences.

If surgery is possible, this is usually the main treatment (see pages 50 to 67). The aim is to completely remove the cancer.

Radiotherapy and chemotherapy may be used to shrink the cancer before surgery (see pages 68 to 87). Or they may be used after surgery to reduce the risk of the cancer coming back. Sometimes these treatments are used as the main treatment if you cannot have surgery. Radiotherapy and chemotherapy can be given separately or together. When given together this is called chemoradiation (see page 69).

Cancer that comes back may be treated again with surgery, radiotherapy or chemotherapy. If the cancer has spread to other parts of the body (advanced or metastatic cancer), chemotherapy or radiotherapy may be used on their own. The aim is to manage any symptoms caused by the cancer and improve quality of life. This is called palliative treatment.

How your treatment is planned

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

Multidisciplinary team (MDT) meeting

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

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

The MDT will usually include the following professionals:

- Gynaecological oncologist – a surgeon who treats cancers of the female reproductive system.
- Oncologist – a doctor who treats people who have cancer.
- Clinical nurse specialist (CNS) – a nurse who gives information about cancer, and support during treatment.
- Plastic surgeon – a doctor who does operations (surgery) to repair or reconstruct tissue and skin.
- Radiologist – a doctor who looks at scans and x-rays to diagnose problems.
- Pathologist – a doctor who looks at cells or body tissue under a microscope to diagnose cancer.

It may also include other healthcare professionals, such as:

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

Talking about your treatment plan

After the MDT meeting, you will usually see your specialist doctor and nurse. They will talk to you about your treatment plan. It can help to write down your questions before you see them. You may want to ask a family member or friend to come with you. They can help remember what is said and talk with you about it afterwards. You need to know as much as possible before you can make any treatment decisions.

Your specialist doctor should explain:

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

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

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

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

Making treatment decisions

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

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

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan (see pages 46 to 47).

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

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

Second opinion

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

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

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

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

Surgery for vulval cancer

The aim of surgery is to remove all the cancer. 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 may also:

- remove some nearby lymph nodes to check them for cancer cells (sentinel lymph node biopsy) – see pages 34 to 35
- remove lymph nodes affected by cancer from one or both sides of the groin
- remove lymph nodes that are likely to contain cancer from one or both sides of the groin.

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

Your team will also explain what to expect after surgery (see pages 58 to 67). Some operations may change how the vulva looks and feels. They can sometimes affect your sex life or your ability to pass urine (pee) or stools (poo). If you have a lot of lymph nodes removed, this can affect fluid drainage from the legs and vulva. It can cause swelling called lymphoedema in one or both legs (see pages 95 to 97). It is important to understand the possible changes and the support your team can give you to help you cope.

Types of surgery

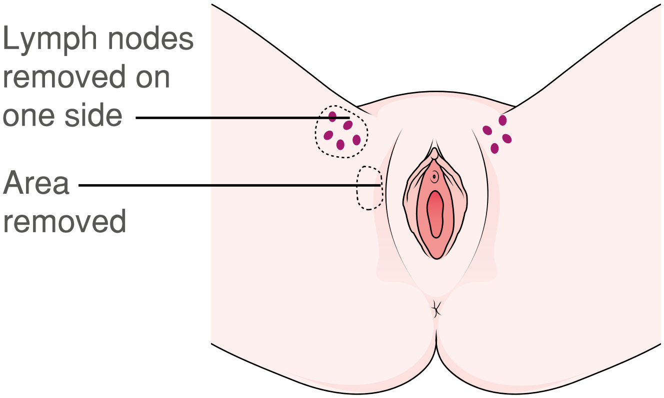
There are different operations to treat cancer of the vulva, depending on the size and position of the cancer. If the cancer is very small, it may be possible to remove only a small area of the vulva. If the cancer is larger, you may need a bigger operation.

Wide local excision

This operation is sometimes called a radical local excision. The surgeon takes away the cancer and a border (margin) of healthy tissue all around the cancer. 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



Partial vulvectomy

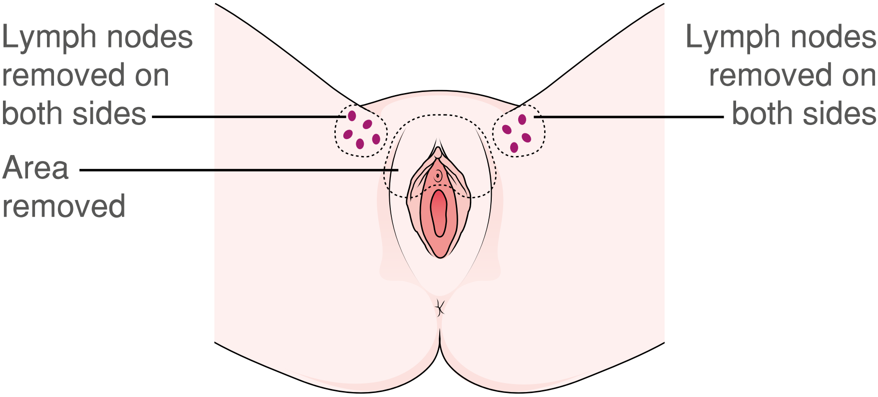
If the tumour is larger, more of the vulval skin will be removed. This is to make sure there is a border (margin) of healthy tissue all around the cancer. This operation is sometimes called a radical partial vulvectomy.

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

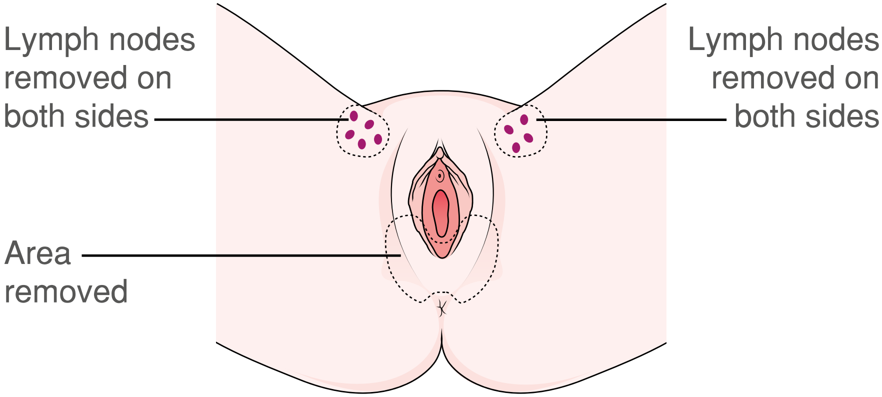
Surgery to remove the front area of the vulva is called an anterior vulvectomy. This operation sometimes involves removing part of the clitoris or the end of the tube that drains urine from the bladder (the urethra).

The following diagrams show different types of radical partial vulvectomy.

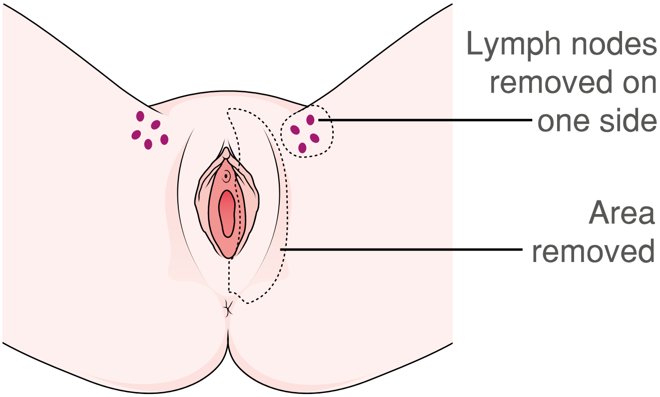
Anterior vulvectomy



Posterior vulvectomy



Hemi-vulvectomy

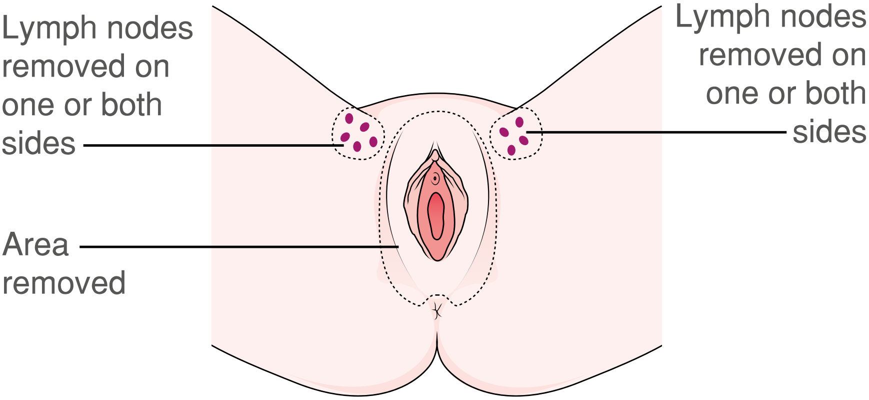


Vulvectomy

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

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

Total vulvectomy



Stoma

For some people, surgery will involve having a stoma. A stoma is an opening made during the operation through the tummy (abdomen) wall. It lets the bowel connect to the surface of the tummy. Stool no longer passes out of the rectum and anus in the usual way. Instead it passes out of the stoma, into a disposable bag that is worn over the stoma.

You may need a stoma:

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

It can take time to adjust to having a stoma. If you need to have one as part of your surgery, a stoma nurse will give you more information.

Reconstructing the vulva

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

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

If a larger area of skin is removed, you may need to have a skin graft or skin flap (see page 56).

Skin grafts

The 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 called the donor site. The place where it is moved to is called the grafted area. The amount of skin 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.

Pelvic exenteration

You will usually be offered a combination of radiotherapy and chemotherapy if the cancer has spread to organs close to the vulva. This includes the:

- womb
- bladder
- lower bowel.

It may still be possible to have an operation to remove the cancer. This involves a major operation called a pelvic exenteration, where any affected organs are removed. We have more information about pelvic exenteration on our website (see page 108).

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

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. The NHS also has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live (see page 114).

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. These may include blood tests and an electrocardiogram (ECG) to check your heart.

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

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

You will usually go to hospital on the day of your operation. Sometimes, you may go in 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

How quickly you recover will depend on the type of operation you have.

You will be advised 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 should try to put your feet up when you are sitting down. This helps to reduce leg swelling.

In the ward

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

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

If your lymph nodes have been removed, you will have a drainage tube going into your groin. This is to remove fluid that may collect there. The drain is connected to a small suction bottle. Your nurse removes it from your groin when most of the excess fluid has drained off. This usually takes a few days. You can go home with the drain if needed. A practice nurse or a 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. Painkillers can help with this. It is important to let your doctor or nurse know as soon as possible if the pain is not controlled. They may need to change your painkillers.

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

- Injection into a muscle – the nurses will do this for you as needed.
- 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.
- Patient-controlled analgesia pump (PCA pump) – this pump is attached to a fine tube (cannula), in a vein in your arm. You control the pump using a button that you press when you need more of the painkiller. It is fine to press the handset whenever you have pain. The pump will not let you give yourself too much painkiller.

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

Your wound

The nurses will help you look after your wounds in hospital and give you advice about caring for your wounds at home.

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

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

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

If you had a skin graft (see page 56), you may have dressings on the area the skin was taken from (donor site). Usually these dressings stay on until new skin has grown. How long it takes to heal will depend on how much skin was removed. Your doctor or nurse can give you more information.

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

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

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

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

Constipation

It is normal not to have bowel movements for a few days after your operation. The operation, your painkillers and changes to your diet and activity levels can cause this. Your doctor may give you laxatives to prevent constipation. If bowel movements are painful or difficult, tell your doctor. They can give you extra laxatives to help.

How the vulva looks

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

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

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

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

Getting support

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

- the diagnosis of cancer
- having the operation
- being away from your usual support network.

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

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

You may want to talk about your feelings with an organisation that specialises in vulval cancer. You could also join an online support group such as our Online Community. You can chat with other people who have vulval cancer. Or you can just read the posts or blogs other people have written. Visit **macmillan.org.uk/community**

Going home from hospital

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

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

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

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

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

- Wear loose-fitting clothing and clothing made from cotton rather than synthetic material.
- Avoid using any lotions, perfumes and talcum powders in the area where you had your operation.
- Take short walks but avoid doing a lot of walking until the skin has healed.
- Keep your wound clean. You could rinse the area with a hand-held shower. Or you may find it easier to use something called a sitz bath. This is a small basin that fits over the toilet. This lets you soak just your buttocks and genital area. If you cannot get a sitz bath locally, you can buy one online.
- Keep your wound dry. Try using a hairdryer on a cool setting to dry the vulval skin. Or gently pat your skin dry with a clean towel.
- If passing urine makes your wound sting, try pouring a small jug of lukewarm water over the wound while you are sitting on the toilet.
- Some people will need to wear underwear to hold pads or dressings in place. But if you can avoid wearing underwear, this may feel more comfortable.
- If you are constipated, ask your doctor for laxatives.

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

Sex

Your surgeon will usually advise not to have sex for at least 6 weeks after your operation. This gives your wound time to heal properly. After that most people will be able to gradually get back to their usual sex life (see pages 98 to 99). You may need time before you feel ready, especially if you are having other treatments as well.

A few people may develop tightening and scar tissue at the entrance to the vagina. This can make sex painful and difficult. It is important to talk to your doctor or nurse if this happens. They can give you advice and support. They may give you vaginal dilators to reduce tightening (see page 98). If the clitoris was removed at the time of surgery, sex can feel different. It may be more difficult to orgasm. Your doctor or nurse will discuss this with you before the operation.

Bladder and bowel problems after surgery

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

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

Rarely, surgery involves removing part of the tube that you pass urine through (urethra) or the lowest end of the bowel (anus and rectum). 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

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

Follow-up

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

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

Radiotherapy

Radiotherapy uses high-energy rays, such as x-rays, to treat cancer cells. For vulval cancer this treatment is usually given from a machine outside the body (external radiotherapy). Sometimes it is also given by putting a radioactive source inside the body (internal radiotherapy or brachytherapy).

You may have radiotherapy:

- before surgery – to try to shrink the cancer and make a smaller operation possible
- after surgery – to reduce the risk of the cancer coming back (this may be used if the cancer was not completely removed, or if cancer was in the lymph nodes)
- if you cannot have surgery
- if vulval cancer has come back or spread.

If the cancer is advanced, the aim of radiotherapy is often to improve your quality of life by shrinking the tumour and reducing symptoms. This is known as palliative radiotherapy.

Chemoradiation

Radiotherapy may be given with chemotherapy. This is called chemoradiation. The chemotherapy drugs make the cancer cells more sensitive to radiotherapy. This can help make the radiotherapy work better. The chemotherapy drug most commonly used is cisplatin. You will usually have it once a week throughout your radiotherapy.

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

Fertility

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

Planning your radiotherapy

With the support of a technical team, your clinical oncologist will plan your radiotherapy. The planning makes sure that treatment:

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

First planning visit

Your first planning visit takes 30 to 60 minutes. The staff in the radiotherapy department will tell you what to expect. It is important you feel involved in your treatment, so you should ask as many questions as you want to. They will tell you if you need to prepare in any way. This may include having a full bladder and taking medicine to help empty your bowel.

You usually have a CT scan of the area (see pages 26 to 27). This helps your doctor and radiotherapy team plan your radiotherapy. Before your scan, they may ask you to remove some clothes and wear a gown.

During the scan, you need to lie still on a hard couch. Tell the radiographers if you feel uncomfortable and they can help. It is important you are comfortable because you need to lie in the same position for each treatment. The radiographer will take a note of your position.

The information from the scan goes to a computer. Your radiotherapy team use this to work out the precise dose and area of your treatment.

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

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

Having external radiotherapy

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

You have treatment in the radiotherapy department at the hospital. You usually have it as an outpatient once a day from Monday to Friday, with a rest at the weekend. Each session of treatment takes a few minutes. The number of treatments you have depends on the type and size of the cancer. The course of treatment for vulval cancer usually lasts a few weeks.

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

Treatment is painless. The radiotherapy machine does not touch you but you may hear a slight buzzing noise from it.

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

Having internal radiotherapy (brachytherapy)

Internal radiotherapy (brachytherapy) uses a radioactive material that is put inside the body to treat the cancer. This gives a high dose of radiotherapy to the tumour. As the radiation does not travel far, it will not affect your nearby organs.

Brachytherapy for vulval cancer is given through thin hollow tubes that are placed inside the cancer. You will have a general anaesthetic or spinal anaesthetic (injection of painkillers into the spine) while the tubes are put in place.

When the tubes are in position, the radiotherapy may take from 30 minutes up to a couple of days. It depends on the amount of radiation needed. Your team will explain your treatment plan and what to expect. You cannot feel the radiotherapy when you are having it, but the tubes can be uncomfortable. The nurses will give you painkillers to help with this. They will remove the tubes when treatment is finished.

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

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

Side effects of radiotherapy

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

Side effects do not usually happen straight away. They may develop during treatment or in the days or weeks after treatment finishes. After you finish radiotherapy, side effects can sometimes get worse before they get better. There may also be a small risk of side effects that are long term or that only start months or years after radiotherapy (see pages 77 to 81).

Smoking makes the side effects of radiotherapy worse. If you smoke, stopping smoking will help. If you want help or advice on how to give up, talk to your doctor, GP or a specialist nurse. The NHS also has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live (see page 114).

> **'Radiotherapy can leave your vulva and groin skin damaged or scarred. It can be hard to talk about looking different and the way your body now looks. It can be difficult to talk about vulval cancer, let alone get help.'**
>
> **Clare, diagnosed with vulval cancer**

Skin irritation

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

- is sore
- is itchy
- changes colour.

Your radiotherapy team will tell you how to look after your skin during treatment. They will check your skin regularly and give you advice about managing any skin reactions. They may give you dressings, a gel or other products to help. They can also give you painkillers if you need them.

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

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

Tiredness

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

- get plenty of rest
- do some gentle exercise, such as short walks
- eat a healthy diet and drink plenty of fluids
- ask others for help with everyday jobs.

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

We have more information about this in our booklet **Coping with fatigue (tiredness)** – see page 108.

Bladder side effects

Radiotherapy can irritate the bladder. You may feel like you need to pass urine more often. You may also have a burning feeling when you pass urine. Drinking at least 2 litres (3½ pints) of water or other fluids each day can help.

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

Bowel side effects

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

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

Drink plenty of fluids if you have diarrhoea. Your doctor may also give you medicine to help. Your radiotherapy team may suggest you follow a low-fibre diet. This means during treatment, and for a few weeks after it, you should avoid:

- wholemeal bread and pasta
- raw fruit
- high-fibre cereals
- root 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 likely to get an infection and 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, tell your cancer doctor or specialist nurse.

Possible late effects

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

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

Early menopause

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

Symptoms of the menopause can include:

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

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

Vaginal changes

Radiotherapy can make your vagina narrower and less stretchy. The vaginal walls may be dry and thin, and can stick together. This can make vaginal sex and internal examinations uncomfortable. Your cancer team may give you vaginal dilators to help prevent narrowing (see pages 98 to 99).

Vaginal dryness

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

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

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

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

Some products, such as oil-based lubricants, will damage latex condoms or caps (diaphragms) and make them less effective. Always check the instructions. Some products may have ingredients that cause irritation or make you more likely to get thrush. If you are not sure, ask your GP, cancer team or pharmacist for advice.

Vaginal bleeding

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

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

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

Changes to the vulva

The skin of the vulva may become permanently discoloured. It may redden or go darker. You may have some swelling in the vulva for months or sometimes years after radiotherapy. You can reduce this with gentle, upwards massage. A specialist nurse or physiotherapist can teach you how to do this.

Bowel or bladder changes

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

- more bowel movements
- to go to the toilet more urgently than usual
- diarrhoea.

If the bladder is affected, you may need to urinate (pee) 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.

There are often ways to manage bladder and bowel problems. Talk to your cancer team, GP or physiotherapist. They may give you medicines or advice that can help. If you have bleeding, they can check what the cause is. They can also arrange for you to see a specialist for treatment or more support if you need it.

We have more information about managing bladder and bowel problems after radiotherapy in our booklets:

- **Understanding pelvic radiotherapy**
- **Managing the bowel late effects of pelvic radiotherapy**
- **Managing the bladder late effects of pelvic radiotherapy.**

See page 108 for ways to order these.

Lymphoedema

Pelvic radiotherapy may increase the risk of swelling in one or both legs. This is called lymphoedema (see pages 95 to 97). 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 legs
- treating any cuts, bites or grazes promptly
- seeing your GP without delay if you have any signs of infection in your feet or legs
- doing regular, gentle exercise such as walking
- keeping to a healthy weight.

We have more information in our booklet **Understanding lymphoedema** (see page 108).

Late changes to the pelvic bones

Radiotherapy can cause thinning of the bones in the pelvis. This often does not have any symptoms but can be seen on scans. Sometimes it may cause fractures in the pelvis called insufficiency fractures. These can cause pain in the lower back or pelvis. If this happens, painkillers and physiotherapy can help.

Chemotherapy

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

You may have chemotherapy for the following reasons:

- To shrink the cancer before surgery or radiotherapy. This is called neo-adjuvant chemotherapy.
- After surgery to reduce the risk of cancer coming back. This is called adjuvant treatment. You may have radiotherapy at the same time (chemoradiation) – see page 69.
- With radiotherapy (chemoradiation) as your main treatment if surgery is not possible.
- To treat the symptoms of advanced cancer that cannot be cured. This is known as palliative treatment.

Having chemotherapy

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

Most drugs are given into a vein (intravenously), but some can be given by mouth as tablets or capsules. Intravenous chemotherapy is a session of treatment which you have over several hours or days. You then have a rest period of a few weeks. This allows your body to recover from any side effects. The treatment and rest period make up a cycle of treatment. Your cancer specialist will tell you how many cycles of treatment you will have.

Side effects

Medicines can usually control side effects of chemotherapy. Side effects will usually go away when treatment finishes. Not all drugs cause the same side effects, and some people may have very few. Your doctor or nurse will tell you more about what to expect. Always tell them about any side effects you have, as there are usually ways they can help.

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 drugs you are having.

The main side effects of chemotherapy and some ways to manage them are listed on pages 84 to 87. We also have more information in our booklet **Understanding chemotherapy** (see page 108).

Risk of infection

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

Symptoms of an infection include:

- feeling shivery
- a sore throat
- a cough
- diarrhoea
- needing to pass urine often.

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

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

G-CSF (granulocyte-colony stimulating factor) is a type of drug called a growth factor. It encourages the body to make more white blood cells.

Your doctor may give you G-CSF:

- if the number of white blood cells is very low
- to stop the number of white blood cells getting low.

You have it as a small injection under the skin.

Bruising and bleeding

This treatment can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. Tell your doctor if you have any bruising or bleeding that you cannot explain. This includes:

- nosebleeds
- bleeding gums
- tiny red or purple spots on the skin that may look like a rash.

Some people may need a drip to give them extra platelets. This is called a platelet transfusion.

Anaemia (low number of red blood cells)

This treatment can reduce the number of red blood cells in your blood. These cells carry oxygen around the body. If the number of red blood cells is low, you may be tired and breathless. Tell your doctor or nurse if you feel like this. If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

Feeling sick

You may feel sick during chemotherapy. Your doctor will give you anti-sickness drugs to help prevent or control sickness. Take the drugs exactly as your nurse or pharmacist tells you. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluids and eat small amounts often. If you continue to feel sick, or if you vomit more than once in 24 hours, contact the hospital as soon as possible. They will give you advice and may change the anti-sickness drug to one that works better for you.

Loss of appetite

This treatment can affect your appetite. Do not worry if you don't eat much for a day or two. But if your appetite does not come back after a few days, tell your nurse or dietitian. They will give you advice. They may give you food or drink supplements.

Sore mouth

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

If your mouth is sore:

- tell your nurse or doctor – they can give you a mouthwash or medicines to help
- try to drink plenty of fluids
- avoid alcohol, tobacco, and foods that irritate your mouth.

Hair loss

Some chemotherapy drugs cause complete hair loss including eyelashes, eyebrows and other body hair. Others usually only cause partial hair loss or thinning. Your cancer 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 ways to cover up hair loss if you want to. It is important to cover your head to protect your scalp when you are out in the sun.

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

Feeling tired

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

Immunotherapy

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

Your doctor will explain if this treatment is suitable for you. You may have it as part of a clinical trial. We have more information about different types of immunotherapy, including how each drug is given and possible side effects. Visit **macmillan.org.uk/immunotherapy**

Clinical trials

Clinical trials are medical research studies involving people. Doctors may use cancer clinical trials to:

- test new treatments to see if they work better than current treatments
- find which treatments have fewer side effects
- find new ways to combine treatments to see if they work better
- test new cancer drugs to find out more about them and their side effects
- improve the way treatments are given to try to reduce side effects.

Results from clinical trials can improve cancer treatments and help people live longer. Trials can also look at improving things like diagnosis and symptom management.

Taking part in a trial

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

Usually, cancer clinical trials happen in several hospitals around the country. You may have to travel to take part in a trial.

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

They will also explain the possible benefits and any possible risks of the trial. Clinical trials are designed to be as safe as possible. The researchers will monitor you closely during and after the trial.

If you decide not to take part in a trial, your cancer doctor and specialist nurse will respect your decision. You do not have to give a reason for not taking part. Your decision will not change your care. Your cancer doctor will give you the standard treatment for the type and stage of cancer you have.

Blood and tumour samples

During your diagnosis and treatment doctors often take blood samples. They may also take a small piece of tissue or a sample of cells. These tissue samples are called biopsies. The samples can be looked at under a microscope. Your cancer doctor may ask your permission to store and use these blood or tissue samples for cancer research. This will only happen after they have done all the tests you need.

Your samples can only be stored for research if you give your consent. Your cancer doctor can answer any questions you have.

Your name is removed from the samples before they are stored. This means you cannot be identified.

The samples may be used to:

- find out more about the causes of certain cancers
- develop new cancer drugs or treatments.

This type of research takes a long time. The results may not be available for many years.

AFTER YOUR TREATMENT

Follow-up appointments

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 (VLP) before vulval cancer (see pages 16 to 17), you should keep seeing your specialist doctor for those conditions too. After cancer treatment, you may still need ongoing treatment for the skin. Your doctor will speak to you about this.

Many people get anxious before their appointments. You may worry about the cancer coming back. This is natural. It can help to get support from family, friends or your specialist nurse. Or you can speak to our cancer support specialists on **0808 808 00 00**. Some other organisations also offer support to people affected by cancer of the vulva (see pages 112 to 119).

Lymphoedema

The lymph nodes (see page 10) are part of the body's immune system and help fight infection. A fluid called lymph fluid normally flows through these nodes. This may build up if the nodes:

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

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

Not everyone gets lymphoedema after treatment for cancer of the vulva. But it can start months or years later. There are treatments that help manage swelling. There are also things you can do to reduce your risk of getting lymphoedema. Your doctor or nurse may plan for you to see a specialist 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, dry and well moisturised.
- Dry carefully between your toes after washing.
- Avoid having very hot baths and showers.
- Protect your skin from cuts, grazes, insect bites and sunburn.
- Wear shoes that are the right fit and size for your feet.

Use nail clippers instead of scissors to cut your nails

You are less likely to cut the skin with these. It is also best not to push back or cut your cuticles. Tell your doctor or lymphoedema specialist if you need extra help with the nails on your feet. They can refer you to a foot specialist (chiropodist).

Look out for the early signs of infection

Wash small grazes and cuts straight away, put on anti-septic 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 your GP, practice nurse 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.

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

We have more information in our booklet **Understanding lymphoedema** (see page 108).

Effects on your sex life

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

It is common to have questions about sex or need more help after treatment. These things are not always easy to talk about. There is support available. Do not be afraid or embarrassed to ask for advice. Your cancer doctor or nurse can help or arrange for you to see a specialist. We have more information about cancer and sex in our booklet **Cancer and your sex life** and on our website (see page 108).

Physical changes

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

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.

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

Dilators are often used, but there is no strong evidence about how effective they are. Rarely, they may cause damage to the vagina, especially if not used correctly. Your cancer team will explain how to use them safely.

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

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

Try to be open with any partner and talk about this together. Sometimes counselling is helpful, either with your partner or on your own. Counselling may help you work through any issues and move on. Your GP, cancer doctor or nurse can often arrange counselling for you. Our cancer support specialists (see page 109), or the College of Sexual and Relationship Therapists (see page 115), can also give advice about finding a counsellor in your area.

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
- dealing with some difficult emotions.

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

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

> **‘I have found a YouTube yoga video on helping with panic and anxiety. I’m not good at lying on the floor, but just listening helped me get some sleep.’**
>
> **Jean**

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. We have information about healthy eating that you may find helpful in our booklet **Healthy eating and cancer** (see page 108).

Be physically active

Being physically active after cancer treatment can:

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

It can also reduce your risk of:

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

Your GP or cancer doctor may be able to refer you to an exercise group for people with cancer. Ask them for advice about what is available in your local area. We have more information about keeping active in our booklet **Physical activity and cancer** (see page 108).

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)
- smoking-related cancers.

If you want to stop, your GP can give you advice. 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 (see page 114).

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

- 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 and drinking guidelines 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. We have more information about complementary therapies in our booklet **Cancer and complementary therapies** (see page 108).

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 your GP.

Support groups

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

You are not expected to talk about anything you do not want to, 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, ask someone from your healthcare team or visit **macmillan.org.uk/inyourarea** You can also ask our cancer support specialists for more information (see page 109).

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 can sometimes be uplifting. They can also be sad and difficult to read. It may help to know that other people feel like you do. You may feel less alone and learn how other people cope after treatment.

Online groups are also easy to leave, without any need for personal contact or explanations. Our Online Community offers this type of support. 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. Visit **community.macmillan.org.uk/cancer_types/vulva-cancer-forum**

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

FURTHER INFORMATION

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 booklets or leaflets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

Online information

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

Other formats

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

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- 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 **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

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.

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 (Monday to Friday, 8am to 6pm).

We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you 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**

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

Other useful organisations

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

Vulval cancer support organisations

Women's Health Concern

www.womens-health-concern.org

Information and advice about women's gynaecological and sexual health, well-being and lifestyle concerns.

Vulva Awareness Campaign Organisation

www.vaco.co.uk

Support network, one-to-one telephone support and information for people affected by vulval cancer or other vulval conditions.

General cancer support organisations

Cancer Black Care

Tel **020 8961 4151**
www.cancerblackcare.org.uk

Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

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.

Cancer Research UK

Helpline **0808 800 4040** (Mon to Fri, 9am to 5pm)
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

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.

Macmillan Cancer Voices

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

Maggie's

Tel **0300 123 1801**
Email **enquiries@maggies.org**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Tenovus

Helpline **0808 808 1010**
Email **info@tenovuscancercare.org.uk**
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

General health information

Health and Social Care in Northern Ireland

online.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.111.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.

Patient UK

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

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300** (Mon to Fri, 10am to 4pm)
Email **bacp@bacp.co.uk**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their ‘How to find a therapist’ page.

College of Sexual and Relationship Therapists

www.cosrt.org.uk
Promotes high standards of professional practice among sexual and relationship therapists. Has a list of therapists throughout the UK.

UK Council for Psychotherapy (UKCP)

Tel **020 7014 9955** (Mon to Fri, 9am to 5pm)
Email **info@ukcp.org.uk**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

Helpline **0300 123 3393** (Mon to Fri, 9am to 6pm)
Email **info@mind.org.uk**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **116 123**
Email **jo@samaritans.org**
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271** (Mon, Tue, Wed and Fri, 9am to 5pm, and 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.

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 by contacting:

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

Civil Legal Advice

Helpline **0345 345 4345** (Mon to Fri, 9am to 8pm, and Sat, 9am to 12.30pm)
www.gov.uk/civil-legal-advice
Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English is not your first language.

GOV.UK

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

Law Centres Network

www.lawcentres.org.uk
Local Law Centres provide advice and legal assistance. They specialise in social welfare issues including disability and discrimination.

Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).

You should be able to find your local council's contact details in your phone book or visit:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

www.wlga.wales/welsh-local-authority-links

Macmillan Benefits Advice Service (Northern Ireland)

Tel **0300 1233 233**
Email **info@macmillanbenefitsservice.co.uk**

NiDirect

www.nidirect.gov.uk
Has information about benefits and public services in Northern Ireland.

Support with lymphoedema

Lymphoedema Support Network

Tel **020 7351 4480**
www.lymphoedema.org
Information and support for people affected by lymphoedema.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030** (Mon to Fri, 10am to 6pm)
Email **info@lgbt.foundation**
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Support for carers

Carers Trust

Tel **0300 772 9600**
Email **info@carers.org**
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline (England, Scotland, Wales) **0808 808 7777**
(Mon to Fri, 9am to 6pm)
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 local support groups for carers.

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 **0207 654 8000**
Email **enquiries@phe.gov.uk**
www.ndrs.nhs.uk
Tel (Ireland) **0214 318 014**
www.ncri.ie (Ireland)

Scottish Cancer Registry

www.ndrs.nhs.uk/cancer-registration-your-rights-and-privacy

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 010 4278**
phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu/

Northern Ireland Cancer Registry

Tel **0289 097 6028**
Email **nicr@qub.ac.uk**
www.qub.ac.uk/nicr

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, Professor Nick Reed, Consultant Clinical Oncologist.

With thanks to: Dr Rachel Cooper, Consultant Clinical Oncologist; Imelda Flanigan, Clinical Nurse Specialist; Dr Emma Hudson, Consultant Clinical Oncologist; Helen Manderville, Clinical Nurse Specialist; and Mr Jason Yap, Consultant Gynaecological Oncologist.

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

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

Sources

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

Morrison J, Baldwin P, Buckley L, et al. Gynaecological Cancer Society (BGCS) vulval cancer guidelines: recommendations for practice. 2020. Available from www.bgcs.org.uk/wp-content/uploads/2020/08/BGCS-vulval-guidelines-v22.pdf [accessed November 2020].

Rogers LJ, and Cuello MA. Cancer of the vulva. Int J Gynaecol Obstet, 2018; 143, S2, 4-13. Available from doi.org/10.1002/ijgo.12609 [accessed November 2020].

Can you do something to help?

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

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

5 ways you can help someone with cancer

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

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

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

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

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

Call us to find out more 0300 1000 200
macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

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

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Valid from ☐☐ ☐☐

Expiry date ☐☐ ☐☐

Issue no ☐☐☐

Security number ☐☐☐

Signature

Date / /

Do not let the taxman keep your money

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

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

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

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

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

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

FR Registered with FUNDRAISING REGULATOR

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

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

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

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using 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.

Trusted Information Creator
Patient Information Forum