JASCAP
FIGHTING CANCER – LIVING WITH IT

Cancer of the vulva

From the JASCAP booklet series

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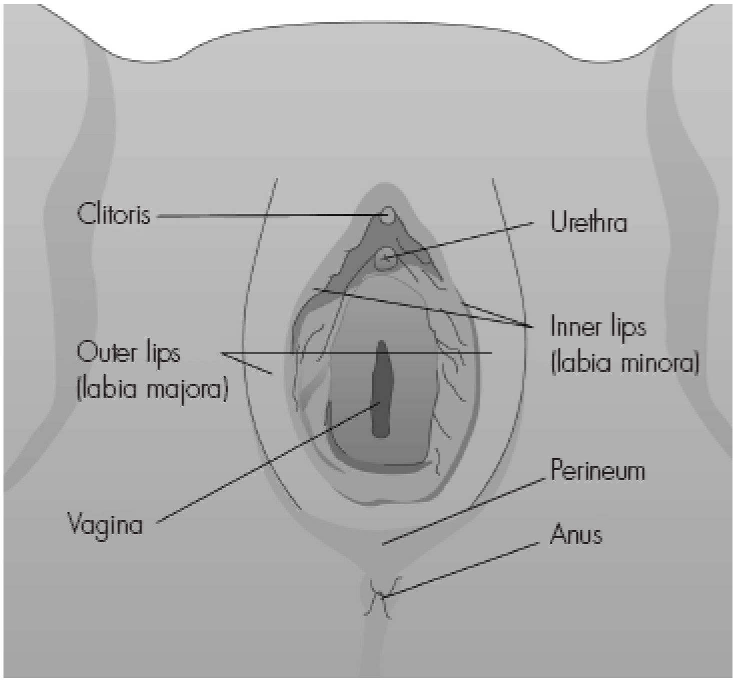
The vulva

The vulva is the area of skin between a woman's legs and is made up of all the visible sex organs. It consists of two outer lips (the labia majora) which are covered in pubic hair and surround two inner lips (the labia minora) which are thin and delicate.



At the front of the vulva is the tiny structure (the clitoris) that helps women reach a sexual climax (orgasm). Just behind the clitoris is the opening through which women pass urine (the urethra), and just behind this is the birth canal (vagina).The opening to the back passage (anus) is close to, but separate from, the vulva. The area of skin between the vulva and the anus is called the perineum. All these structures are visible from outside the body.

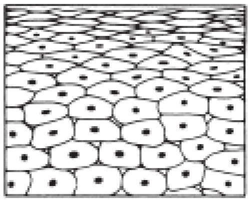
In the groin, where the skin creases at the top of each leg, are glands called lymph nodes, which are part of the lymphatic system. This system is an important part of the body's natural defence against disease, and the lymph nodes can become swollen if they are affected by an infection or cancer.

Cancer of the vulva is rare: each year just over 1000 women in the UK are diagnosed with it. It usually affects women between the ages of 55 and 75, but can occur in younger or older women. It is becoming more common in younger women. Cancer of the vulva can occur on any part of the external female sex organs. The inner edges of the labia majora and the labia minora are the most common areas for it to develop. Less often, cancer may also involve the clitoris or the Bartholin glands (small glands, one on each side of the vagina). It can also sometimes affect the perineum.

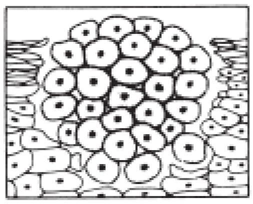
What is cancer?

The organs and tissues of the body are made up of tiny building blocks called cells. Cancer is a disease of these cells.

Cells in different parts of the body may look and work differently but most reproduce themselves in the same way. Cells are constantly becoming old and dying, and new cells are produced to replace them. Normally, cells divide in an orderly and controlled manner. If for some reason the process gets out of control, the cells carry on dividing, developing into a lump which is called a **tumour**.



Normal cells



Cells forming a tumour

Tumours can be either **benign** or **malignant**. Cancer is the name given to a malignant tumour. Doctors can tell if a tumour is benign or malignant by examining a small sample of cells under a microscope. This is called a **biopsy**.

In a benign tumour the cells do not spread to other parts of the body and so are not cancerous. However, if they continue to grow at the original site, they may cause a problem by pressing on the surrounding organs.

A malignant tumour consists of cancer cells that have the ability to spread beyond the original area. If the tumour is left untreated, it may spread into and destroy surrounding tissue. Sometimes cells break away from the original (primary) cancer. They may spread to other organs in the body through the bloodstream or lymphatic system.

The lymphatic system is part of the immune system - the body's natural defence against infection and disease. It is a complex system made up of organs, such as bone marrow, the thymus, the spleen, and lymph nodes. The lymph nodes (or glands) throughout the body are connected by a network of tiny lymphatic ducts.

When the cancer cells reach a new area they may go on dividing and form a new tumour. This is known as a **secondary cancer** or **metastasis**.

It is important to realise that cancer is not a single disease with a single type of treatment. There are more than 200 different kinds of cancer, each with its own name and treatment.

Types of cancer

Carcinomas

The majority of cancers, about 85% (85 in a 100), are carcinomas. They start in the epithelium, which is the covering (or lining) of organs and of the body (the skin). The common forms of breast, lung, prostate and bowel cancer are all carcinomas.

Carcinomas are named after the type of epithelial cell that they started in and the part of the body that is affected. There are four different types of epithelial cells:

squamous cells - that line different parts of the body, such as the mouth, gullet (oesophagus), and the airways
adeno cells - form the lining of all the glands in the body and can be found in organs such as the stomach, ovaries, kidneys and prostate
transitional cells - are only found in the lining of the bladder and parts of the urinary system
basal cells - that are found in one of the layers of the skin.

A cancer that starts in squamous cells is called a squamous cell carcinoma. A cancer that starts in glandular cells is called an adenocarcinoma. Cancers that start in transitional cells are transitional cell carcinomas, and those that start in basal cells are basal cell carcinomas.

Leukaemias and lymphomas

These occur in the tissues where white blood cells (which fight infection in the body) are formed, i.e. the bone marrow and lymphatic system. Leukaemia and lymphoma are quite rare and make up about 6.5% (6.5 in 100) of all cancers.

Sarcomas

Sarcomas are very rare. They are a group of cancers that form in the connective or supportive tissues of the body such as muscle, bone and fatty tissue. They account for less than 1% (1 in 100) of cancers.

Sarcomas are split into two main types:

bone sarcomas - that are found in the bones
soft tissue sarcomas - that develop in the other supportive tissues of the body.

Others forms of cancer

Brain tumours and other very rare forms of cancer make up the remainder of cancers.

Your feelings about having vulval cancer

Most people feel overwhelmed when they are told that they have cancer. Many different emotions arise, which can cause confusion and frequent mood swings. You might not have all the feelings discussed below or experience them in the same order.

These emotions are part of the process that many people go through in trying to come to terms with their illness. Partners, family members and friends often have similar feelings, and may need as much support and guidance in coping with their feelings as you do.

Reactions differ from one person to another − there is no right or wrong way to feel. Some of the common emotional effects are mentioned below. However, reactions vary and people have different emotions at different times.

Our section on the emotional effects of cancer discusses the feelings and emotions that you may experience and has advice on how to cope with them.

Shock and disbelief
Fear and uncertainty
Denial
Anger
Blame and guilt
Resentment
Withdrawal and isolation

Shock and disbelief

'I can't believe it' / 'It can't be true'

This is often the immediate reaction when cancer is diagnosed. You may feel numb and unable to believe what is happening or to express any emotion. You may find that you can take in only a small amount of information and so you have to keep asking the same questions again and again, or you need to be told the same bits of information repeatedly. This need for repetition is a common reaction to shock.

Some people may find that their feelings of disbelief make it difficult for them to talk about their illness with their family and friends. Other people may feel an overwhelming urge to discuss it with those around them.

You might find our section on talking about your cancer helpful.

Fear and uncertainty

'Am I going to die?'/ 'Will I be in pain?'

Cancer is a frightening word surrounded by fears and myths. One of the greatest fears expressed by almost all newly diagnosed cancer patients is 'Am I going to die?'

In fact, many cancers are curable if caught at an early enough stage. When a cancer is not completely curable, modern treatments often mean that it can be controlled for years and many patients can live an almost normal life.

'Will I be in pain?' and 'Will any pain be unbearable?' are other common fears. In fact, some people with cancer have no pain at all. If you do have pain, there are many modern drugs and other techniques which are very successful at relieving it or keeping it under control. Our information on controlling cancer pain, describes these methods.

Many people are anxious about their treatment: whether or not it will work and how to cope with possible side effects. It is best to discuss your individual treatment and possible outcomes in detail with your doctor.

Some people are afraid of the hospital itself. It can be a frightening place, especially if you have never been in one before, but talk about your fears to your doctor or nurse. They should be able to reassure you.

You may find that doctors cannot answer your questions fully, or that their answers sound vague. For example, it is often impossible for them to say for certain that they have completely removed the tumour. Doctors know approximately how many people will benefit from a certain treatment, but cannot predict the future for a particular person. Many people find this uncertainty hard to live with.

Uncertainty about the future can cause a lot of tension, but fears may be worse than the reality. Gaining some knowledge about your illness can be reassuring. Discussing what you have found out with your family and friends can help to relieve some of the worry.

Denial

'There's nothing really wrong with me' / ‘I haven't got cancer'

Many people cope with their illness by not wanting to know anything about it, or not wanting to talk about it. If that's the way you feel, then just say quite firmly to the people around you that you would prefer not to talk about your illness, at least for the time being.

Sometimes, however, it is the other way round. You may find that it is your family and friends who are denying your illness. They may appear to ignore the fact that you have cancer, perhaps by playing down your anxieties and symptoms or deliberately changing the subject. If this upsets or hurts you because you want them to support you by sharing what you feel, try telling them. Start perhaps by reassuring them that you do know what is happening and that it will help you if you can talk to them.

Anger

'Why me of all people?' / 'And why right now?'

Anger can hide other feelings, such as fear or sadness. You may direct your anger at the people who are closest to you and at the doctors and nurses who are caring for you.

It is understandable that you may be deeply upset by many aspects of your illness and there is no need to feel guilty about your angry thoughts or irritable moods. However, relatives and friends may not always realise that your anger is really directed at your illness and not against them. If you can, it may be helpful to tell them this at a time when you are not feeling quite so angry. If you would find that difficult, perhaps you could show them this section of the website.

Blame and guilt

'If I hadn't...this would never have happened'

Sometimes people blame themselves or other people for their illness, trying to find reasons to explain why it should have happened to them. This may be because we often feel better if we know why something has happened. However, since in most cases it is impossible to know exactly what has caused a person’s cancer there is no reason for you to feel that you are to blame.

Resentment

'It's all right for you − you haven't got to put up with this'

Understandably, you may be feeling resentful and miserable because you have cancer while other people are well. Similar feelings of resentment may crop up from time to time during the course of your illness and treatment for a variety of reasons. Relatives too can sometimes resent the changes that your illness makes to their lives.

It is usually helpful to bring these feelings out into the open so that they can be discussed. Keeping your resentment to yourself can make everyone feel angry and guilty.

Withdrawal and isolation

'Please leave me alone'

There may be times during your illness when you want to be left alone to sort out your thoughts and emotions. This can be hard for your family and friends who want to share this difficult time with you. It will make it easier for them to cope, however, if you reassure them that although you may not feel like discussing your illness at the moment, you will talk to them about it when you are ready.

Sometimes depression can stop you wanting to talk. If you or your family think you may be depressed, discuss this with your GP. They can prescribe antidepressant drugs for you, or refer you to a doctor or counsellor who specialises in the emotional problems of people with cancer.

Causes of vulval cancer

Cancer of the vulva is rare: each year just over 1000 women in the UK are diagnosed with it. Research is going on all the time into the cause of vulval cancer. The following have been identified as things that might increase the risk that people will develop cancer of the vulva:

Human papilloma virus (HPV) This is an infection that can be associated with vulval cancer. HPV is passed between people during sex and there are many different types. Some types, such as types 6 and 11 can cause genital warts, but are not usually associated with the development of cancer. Others are considered more likely to cause cancer and these include HPV types 16, 18 and 31. These types can lead to pre-cancerous changes called VIN.

Vulval intraepithelial neoplasia (VIN) is a pre-cancerous condition that can occur in the skin of the vulva, and is linked to HPV infection. There are three levels of abnormality − VIN1, VIN2 and VIN3. VIN3 is the most abnormal, and in some women can develop into cancer of the vulva if it is not treated. Almost one-third of vulval cancers develop in women who have VIN.

Vulval skin conditions Women who have certain non-cancerous skin conditions of the vulva over a long period of time, have a higher risk of developing cancer of the vulva. The conditions are called vulval lichen sclerosus and vulval lichen planus. They can cause long-term inflammation of the skin in the vulval area. Almost two-thirds of vulval cancers occur in women who have lichen sclerosus. But it is important to remember that only 1−2% (1–2 in 100) of women who have lichen sclerosus will go on to develop vulval cancer. We can send you information about lichen sclerosus and lichen planus.

Paget's disease This is a rare type of cancer of the vulva which can sometimes be linked with a cancer elsewhere in the pelvic area or the digestive system.

Smoking Cigarette smoking may increase the risk of developing both VIN and vulval cancer. This may be because it can make the immune system work less effectively.

Like other cancers, cancer of the vulva is not infectious and can’t be passed on to other people. It is not caused by an inherited faulty gene and so other members of your family are not likely to be at risk of developing it.

Symptoms of vulval cancer

The most common symptoms of cancer of the vulva are:

itching, burning and soreness of the vulva

- a lump, swelling or wart-like growth
- thickened, raised, red, white or dark patches on the skin of the vulva
- bleeding or a blood-stained vaginal discharge
- burning pain when passing urine
- pain in the area of the vulva
- a sore or ulcerated area on the vulva
- a mole on the vulva that changes shape or colour.

Any of these symptoms can be due to conditions other than cancer, but always get your doctor to check them.

Cancer of the vulva can take many years to develop as it usually grows slowly. As with other cancers, it is easier to treat and cure if it is diagnosed at an early stage.

Types of vulval cancer

Squamous cell carcinoma

Nine out of ten (90%) of cancers of the vulva develop from squamous cells in the outer layer of the vulva. Squamous cell cancers usually grow very slowly over a few years.

Vulval melanoma

Melanomas develop from the pigment-producing cells that give the skin its colour. Vulval melanoma is the second most common type of vulval cancer, but is much less common than the squamous cell type. Only about 4 out of every 100 (4%) vulval cancers are melanoma.

Adenocarcinoma

These are very rare. Adenocarcinoma of the vulva develops from cells that line glands in the vulval skin. Paget's disease of the vulva is a condition where adenocarcinoma cells spread out from these glands and across the skin of the vulva.

Verrucous carcinoma

Verrucous carcinoma is a rare, very slow-growing type which looks like a large wart.

Sarcomas

Sarcomas of the vulva are extremely rare. Sarcomas develop from cells in tissue such as muscle or fat under the skin. They tend to grow more quickly than other types of cancer. Several different types of sarcoma can affect the vulva, including:

- leiomyosarcomas and rhabdomyosarcomas (which develop from muscle cells)
- angiosarcomas (from blood vessels)
- neurofibrosarcomas (from nerve cells)
- epithelioid sarcomas (from cells in the skin).

Diagnosis of vulval cancer

Usually you begin by seeing your GP, who will examine you. If there is any possibility of you having vulval cancer you should be referred to a gynaecological cancer specialist (specialist in women's cancers). Your doctor may also arrange for you to have a blood test and chest x-ray to check your general health.

At the hospital the gynaecologist will take your medical history and will examine your vulval area. They may also carry out some tests. The nurse will help you to position yourself on a couch that has special leg supports. Understandably, some women find this kind of examination embarrassing or upsetting. If you feel like this let your doctor or nurse know so that they can support you emotionally.

To examine your vulva the doctor may use a colposcope. This helps to identify any abnormal areas. The colposcope is like a small microscope with a bright light that can magnify areas so that the cells can be seen more clearly. The colposcope stays outside the body. A biopsy will be taken.

You will also have an internal examination to check your vagina and cervix for any abnormality. The doctor will use a speculum (a plastic or metal instrument) to hold the vaginal walls open. A liquid is then dabbed on to the cervix to make any abnormal areas show up more clearly. A colposcope is used to examine the cervix. Sometimes a small sample of cells from the cervix will be taken. Some women with lichen planus or lichen sclerosus can have narrowing of the vagina. In this situation it may be necessary to have the sample of cells taken under a general anaesthetic.

The doctor may also examine your back passage (anus) to check for any abnormal lumps. The skin around your back passage may be examined.

Biopsy

This procedure can usually be done in the outpatients clinic. Anaesthetic cream is applied to the vulva to numb the area, and then an injection of local anaesthetic is given. The doctor takes the biopsy (a small amount of cells) from the abnormal area using a biopsy instrument. The biopsy is examined under a microscope by a pathologist. This is the best way of diagnosing cancer of the vulva. Because the local anaesthetic numbs the area there should be no pain, but you may feel a little discomfort during the biopsy. Afterwards, you may have slight bleeding (let your doctor know if it is more than this), and slight soreness. The soreness can be relieved with mild painkillers and a warm bath. The doctor will usually see you about 7–10 days after the biopsy to give you the results. Waiting for the results can be a stressful time and support organisations can help you to cope.

Further tests for vulval cancer

After a diagnosis is made, further tests are often needed to find out about the size and position of the cancer, and whether it has spread. This process is called staging, and may take some time. The results will help you and your doctor to decide on the best treatment for you. These tests may be done again (during treatment, or when treatment ends) to check the effectiveness of the treatment. Although tests are useful, no one test can diagnose a vulval cancer. Occasionally other medical conditions can give similar results, making it difficult to decide what is and is not cancer. Doctors piece together information from different tests and examinations, along with your symptoms and medical history. They then put all this information in context.

The following tests are most often used with cancer of the vulva.

Blood test
Chest x-ray
CT (CAT) scan
Magnetic resonance imaging (MRI scan)
Examination under anaesthetic (EUA)

Blood test

A sample of your blood is taken to check your general health, the number of cells in your blood (blood count) and to see how well your kidneys and liver are working.

Chest x-ray

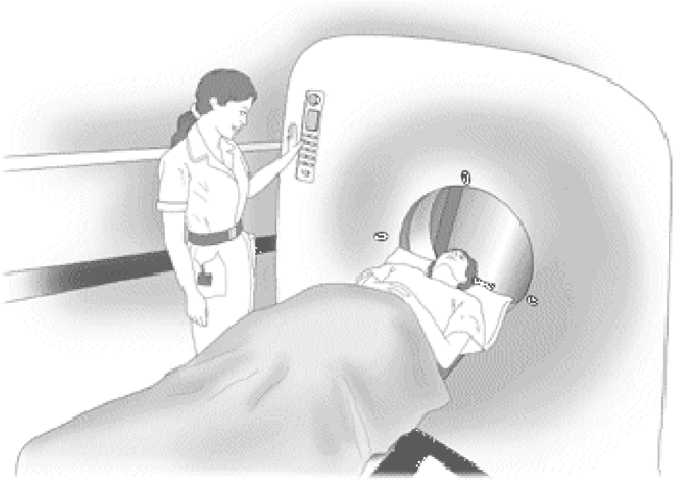
This is taken to check that your lungs and heart are healthy.

CT (CAT) scan

A CT scan takes a series of x-rays, which builds up a three-dimensional picture of the inside of the body. The scan is painless but takes from 10 to 30 minutes. CT scans use a small amount of radiation, which will be very unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan.

You may be given a drink or injection of a dye which allows particular areas to be seen more clearly. For a few minutes, this may make you feel hot all over. If you are allergic to iodine or have asthma you could have a more serious reaction to the injection, so it is important to let your doctor know beforehand.

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



Magnetic resonance imaging (MRI scan)

This test is similar to a CT scan but uses magnetism instead of x-rays to build up a detailed picture of areas of your body.

During the test you will be asked to lie very still on a couch inside a long tube for about 30 minutes. It is painless but can be slightly uncomfortable, and some people feel a bit claustrophobic during the scan. It is also noisy, but you will be given earplugs or headphones. Some people are given an injection of dye into a vein in the arm, but this usually does not cause any discomfort. It will probably take several days to get the results of your tests, and this waiting period is likely to be a worrying time for you.

Examination under anaesthetic (EUA)

This is an examination of the vulva carried out under a general anaesthetic. It allows the doctor to examine you thoroughly without causing any discomfort and to check the extent of the cancer.

Staging and grading of vulval cancer

The stage of a cancer is a term used to describe its size and whether it has spread beyond its original area of the body. Grading refers to the appearance of cancer cells when they are looked at under the microscope. The grade gives an idea of how quickly the cancer may develop. Knowing the extent of the cancer and the grade helps the doctors to decide on the most appropriate treatment.

Staging
Grading

Staging

A commonly used staging system is described below:

Stage 0 or carcinoma in situ This is very early cancer (some doctors describe it as pre-cancer). The cancer is found in the vulva only and is only in the surface of the skin.

Stage 1 Cancer is found only in the vulva and/or the space between the opening of the rectum and the vagina (perineum).The affected area is 2 cm (about 1 inch), or less, wide.

Stage 2 Cancer is found in the vulva and/or the perineum. The affected area is larger than 2 cm (1 inch).

Stage 3 Cancer is found in the vulva and/or perineum and has spread to nearby tissues such as the lower part of the urethra (the tube through which urine passes), the vagina, the anus (the opening of the rectum) and/or nearby lymph nodes.

Stage 4 The cancer has spread beyond the urethra, vagina and anus into the lining of the bladder or the bowel; or, it may have spread to the lymph nodes in the pelvis or to other parts of the body.

Grading

There are three grades; grade 1 (low-grade), grade 2 (moderate-grade) and grade 3 (high-grade).

Low-grade means that the cancer cells look very much like the normal cells of the vulva. They usually grow slowly and are less likely to spread.
Moderate-grade means the cells look more abnormal than low-grade cells but not as abnormal as high-grade cells.
High-grade means the cells look very abnormal. They are likely to grow more quickly and are more likely to spread.

Treatment for vulval cancer

Types of treatment
Treatment planning
Giving your consent
Benefits and disadvantages of treatment
Second opinion

Types of treatment

Surgery is the main treatment for cancer of the vulva. It may be used either alone or in combination with radiotherapy and chemotherapy. All these treatments are explained in more detail in the following pages.

During surgery only the minimum amount of tissue that is necessary to get rid of the tumour will be removed. However, the type of surgery will depend on the size and position of the cancer. It is sometimes possible to have a small operation to remove the cancer, together with some surrounding normal tissue. Sometimes this may be all the treatment that is needed. Unfortunately, some women may need a larger operation that involves removing the labia and sometimes the clitoris.

Radiotherapy may sometimes be given to shrink the cancer before surgery. It can also be given after surgery to make sure any remaining cells are destroyed, or it can be used instead of surgery. Often radiotherapy and chemotherapy can be used together (chemoradiation) to make them more effective. Occasionally, if the cancer has spread to other parts of the body, chemotherapy may be used on its own.

The main treatment for cancer of the vulva is surgery. Radiotherapy and chemotherapy may also be used.

Treatment planning

Your doctor will plan your treatment by taking into consideration a number of factors, including the type of cancer, its position and size, whether it has spread (stage) and your general health. Cancer specialists follow national guidelines for treating vulval cancer. The treatment you have will be based on the guidelines, but tailored to your particular situation.

Sometimes you may be asked to take part in a clinical trial of a new treatment.

If you have any questions about your treatment, don’t be afraid to ask your doctor or nurse. It often helps to make a list of questions for your doctor and to take a close friend or relative with you. They can remind you of questions you wanted to ask, and afterwards help you remember what the doctor said.

Giving your consent

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

- the type and extent of the treatment you are advised to have
- the advantages and disadvantages of the treatment
- any possible other treatments that may be available
- any significant risks or side effects of the treatment.

If you do not understand what you have been told, let the staff know straightaway so that they can explain again. Some cancer treatments are complex, so it is not unusual for people to need repeated explanations. Again, it can be helpful to have a friend or relative with you.

People often feel that the hospital staff are too busy to answer their questions, but it is important for you to be aware of how the treatment is likely to affect you. The staff should be willing to make time for you to ask questions.

You can always ask for more time to decide about the treatment, if you feel that you can't make a decision when it is first explained to you. You are also free to choose not to have the treatment, and the staff can explain what may happen if you do not have it.

It is important to tell a doctor, or the nurse in charge, so that they can record your decision in your medical notes. You do not have to give a reason for not wanting to have treatment, but it can be helpful to let the staff know your concerns so that they can give you the best advice.

Benefits and disadvantages of treatment

Many people are frightened at the idea of having cancer treatments, because of the side effects that can occur. However, although many of the treatments can cause side effects, these can usually be well controlled.

Treatment can be given for different reasons and the potential benefits will vary depending upon the individual situation.

Early-stage vulval cancer

In women with early-stage vulval cancer, surgery is often done with the aim of curing the cancer. Occasionally, additional treatments are also given to reduce the risks of it coming back.

Advanced vulval cancer

If the cancer is at a more advanced stage the treatment may only be able to control it, leading to an improvement in symptoms and a better quality of life. However, for some people the treatment will have no effect upon the cancer and they will get the side effects without any of the benefit.

Treatment decisions

If you have been offered treatment that aims to cure your cancer, deciding whether or not to accept it may not be difficult. However, if a cure is not possible and the treatment is being given to control the cancer for a period of time, it may be more difficult to decide whether to go ahead with treatment. Making decisions about treatment in these circumstances is always difficult, and you may need to discuss this in detail with your doctor. If you choose not to have treatment, you can still have supportive (palliative) care, with medicines to control any symptoms.

Second opinion

A number of cancer specialists work together as a team to decide the most suitable treatment for each patient. Even so, you may want to have another medical opinion. Most doctors will be willing to refer you to another specialist for a second opinion, if you feel it will be helpful. The second opinion may cause a delay in the start of your treatment, so you and your doctor need to be confident that it will provide useful information. If you decide to have a second opinion, it may be a good idea to take a friend or relative with you, and to have a list of questions ready, so that you can make sure your concerns are covered during the consultation.

Treating vulval cancer with surgery

Your doctor will discuss with you the most appropriate type of surgery, depending on the stage of your cancer. Before your operation, make sure you have talked it over fully with your doctor. You will also be able to speak to a gynaecological nurse specialist who can give you information and support, particularly in the period before and after your operation.

Types of surgery
Lymph nodes
Sentinel node biopsy
Before your operation

Types of surgery

All operations for cancer of the vulva will remove the area of the skin where the cancer is. This can range from removing the cancer and a small surrounding area of healthy tissue, to a radical vulvectomy in which the labia and sometimes the clitoris are removed.

The cancer will be removed using one of the following operations:

Wide local excision takes out the cancer and a border (margin) of healthy cells, usually at least 1cm, all around the cancer. Sometimes doctors use laser treatment to remove the abnormal cells instead of a blade (scalpel). A laser is a high-energy beam of light.

Radical local excision takes out the cancer and a larger area of normal tissue all around the cancer. The lymph nodes may be removed (known as lymph node dissection).

Partial vulvectomy removes part of the vulva.

Radical vulvectomy takes out the entire vulva including the inner and outer labia and the clitoris. Usually the surrounding lymph nodes are also removed.

Pelvic exenteration is done if the cancer has spread beyond the vulva to the organs nearby. These include: the lower bowel, the bladder and the cervix, the uterus and vagina. The surgeon removes any affected organs. Any surgery aims to completely remove the cancer while also preserving as much normal tissue as possible.

Usually only a small amount of unaffected skin is removed with the cancer, so it is often possible to stitch the remaining skin neatly together. However, if it is necessary to remove quite a lot of skin, you may need to have a skin graft, or skin flaps. To do this, the surgeon may take a thin piece of skin from another part of the body (usually the thigh or abdomen) and stitch it on to the operation site. It may be possible to move (rotate) flaps of skin in the vulval area to cover the wound.

A radical vulvectomy is a major operation on a physical, emotional and sexual level. Many hospitals that offer this kind of surgery also have specialist nurses who can support you and help you to talk through how you are feeling. Some of the issues that vulval surgery raises are discussed in the section 'How surgery may affect your sex life'.

Lymph nodes

The lymph nodes in the groin are usually the first place to which vulval cancer can spread. Lymph nodes are part of the lymphatic system, and are found mainly in the groin, neck and armpits. In order to plan treatment it helps doctors to know whether any cancer cells have spread from the vulva to the lymph nodes in the groins.

If the cancer is deeper than one millimeter, you may be advised to have the lymph nodes surgically removed from one or both groins. This is to check for cancer cells. The lymph nodes are usually removed through a separate cut (incision) in each groin. If the vulval cancer is at the very earliest stage you will not usually need to have any surgery to your lymph nodes.

Sentinel node biopsy

A new method of checking whether the cancer has spread into the lymph nodes is currently being tried in research trials. It involves injecting a tiny amount of radioactive liquid around the area of the cancer before the operation and then scanning the nodes to see which one has first taken up the radioactive liquid. A blue dye is also injected into the area of the cancer during the operation, which stains the lymph nodes blue. The surgeon removes only the first one or two lymph nodes that the fluid goes into (known as the sentinel nodes). The nodes are then be tested to see whether they contain cancer cells. It is hoped that this method of checking the lymph glands will cause less lymphoedema (see after surgery) than the other methods, but will be as effective at detecting the cancer.

Before your operation

You are usually admitted to hospital a day or so before your operation. When you arrive on the ward you will be shown around and the nurses will take your medical and personal details.

Make sure that you talk to your nurse or doctor about any questions or concerns that you have.

It often helps to write any questions down so that you don't forget them, or have a close friend or relative with you when you talk to the doctor or nurse.

You will be seen on the ward by a member of the surgical team. They will take your full medical history before examining you and arranging for any further tests that may be necessary. Once the results of the tests are known, your doctor will discuss these and the operation with you. The type of operation you need will have been explained to you before your admission to hospital.

Preparation

You will be asked to wear special elastic stockings during and after the operation (until you are discharged home) to prevent blood clots forming in your legs. The doctor who will give you your anaesthetic (the anaesthetist) will come to see you to explain the anaesthetic details to you.

Treating vulval cancer with radiotherapy

Radiotherapy treats cancer by using high-energy rays which destroy the cancer cells, while doing as little harm as possible to normal cells.

When radiotherapy is used
External radiotherapy
Internal radiotherapy

When radiotherapy is used

Radiotherapy may be given to the vulva and the lymph nodes after surgery. This is to make sure that any remaining cancer cells are destroyed, and so reduce the risk of the cancer coming back. Whether you have radiotherapy or not will depend on the stage of your cancer, its size, and also whether it has spread to the lymph nodes (and if so, how many are affected).

Sometimes radiotherapy is given before surgery to shrink the cancer and make it easier to remove.

If the cancer is known to have spread to the lymph nodes, radiotherapy may be used instead of surgery to treat this area. Radiotherapy and chemotherapy may be given at the same time. This is known as **chemoradiation**.

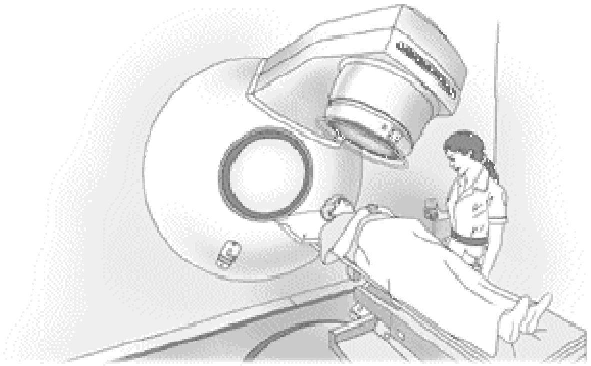
In advanced vulval cancer (where the cancer has come back or spread) radiotherapy may be used to shrink a tumour and reduce symptoms to improve quality of life. This is known as **palliative radiotherapy**.

We have a separate section on radiotherapy, which gives detailed information about the treatment and its side effects.

Each woman's treatment will be designed individually. A course of treatment may be with external radiotherapy only, or may consist of two or more ‘phases’ of treatment. The first phase may be external x-ray treatment and the second may involve more external treatment given to a smaller area, or may be internal radiotherapy with radioactive wires. Internal radiotherapy is known as brachytherapy. Sometimes a mould may be used to hold radioactive metal next to the vulva to give a dose of radiotherapy. These treatments are 'tailor-made', and the details of the treatment will be discussed with you beforehand.

External radiotherapy

External radiotherapy is normally given as a series of short daily treatments in the hospital radiotherapy department. High-energy x-rays are directed from a machine at the area of the cancer. The treatments are usually given from Monday to Friday, with a rest at the weekend. The number of treatments will depend on the type and size of the cancer but the whole course of treatment for vulval cancer will usually last a few weeks. Each treatment takes around 10–15 minutes. Your doctor will discuss the treatment and possible side effects with you.



Before each session of radiotherapy the radiographer will position you carefully on the couch and make sure that you are comfortable. During your treatment you will be left alone in the room, but you will be able to talk to the radiographer who will be watching you carefully from the next room.

Radiotherapy is not painful, but you have to lie still for a few minutes while your treatment is being given. External radiotherapy will not make you radioactive and it is perfectly safe for you to be with other people, including children, after your treatment.

Side effects

Radiotherapy to the vulva and groin causes general side effects such as diarrhoea and tiredness, and it can also cause other specific side effects. These side effects can be mild or troublesome, depending on the strength of the radiotherapy dose and the length of your treatment. Your radiotherapy doctor (clinical oncologist) will tell you what to expect.

Skin reaction As the skin in the area of the vulva and groin is very sensitive, radiotherapy will cause soreness. Only use lukewarm water to wash the treatment area, and pat the area dry gently with a towel. Talc or perfume may cause irritation, so avoid using these. Your specialist can prescribe cream to help soothe the soreness. Your radiographer or nurse can advise you on how to look after your skin during this time.

Inflammation of the bladder lining (cystitis) Radiotherapy to the groin may cause inflammation of the lining of the bladder, which can make you feel that you want to pass urine frequently. You may also feel a burning sensation when you pass urine. Your doctor can prescribe medicines that can make passing urine less uncomfortable. It helps to drink plenty of water and other fluids to make your urine more dilute.

Diarrhoea Radiotherapy may also irritate the bowel and cause some diarrhoea. If this is a problem let your doctor know, as medicines can be prescribed to reduce it. It is important to drink plenty of water to replace the fluid lost through diarrhoea.

Tiredness As radiotherapy makes you tired, try to get as much rest as you can, especially if you have to travel a long way for treatment each day.

The side effects listed above may continue for several weeks and then gradually disappear once your course of treatment is over. It is important to tell your doctor if they continue.

Hair loss Radiotherapy can make your hair fall out in the area being treated, and this may be permanent.

Narrowing of the vagina The vagina can be affected by radiotherapy to the pelvic area. While having radiotherapy, and for a few weeks after treatment, the vagina will become tender. In the long term this irritation can leave scarring which makes the vagina narrower and less flexible. This may make having sex uncomfortable or difficult. Because of this you will be advised to use a vaginal dilator with a lubricating jelly, to keep the vaginal walls open and supple. The dilators are usually made of plastic and can be given to you by your nurse or doctor, who will advise you how to use them.

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

We have a section on pelvic radiotherapy in women, which has information on side effects, and ideas on how to cope with them.

Internal radiotherapy

Internal radiotherapy (also called interstitial radiotherapy, implant therapy, or brachytherapy) involves putting a radioactive material directly into the cancer. This type of therapy is given by inserting radioactive needles or wires into the cancer while you are under a general anaesthetic. Over a few days, the needles or wires give a high dose of radiotherapy directly to the tumour from the inside.

As the implant is radioactive you will need to stay in your room in hospital, and visitors will be limited. While the radioactive wires or needles are in place, low levels of radiation are given out from them. You will need to stay in a single room in hospital for a few days, until the doctor has removed the radioactive needles or wires from your body.

Although it will be safe for your family and close friends to visit you for short periods, children and pregnant women will not be allowed to visit, to avoid any chance of them being exposed to even tiny amounts of radiation.

The doctors and nurses caring for you will also only be able to stay in your room for short periods at a time. This is because they may be looking after several people having internal radiotherapy treatment, and they must keep their exposure to the low level of radioactivity to a minimum.

The safety measures and visiting restrictions might make you feel very isolated, frightened and depressed, at a time when you might want people around you. If you have these feelings it is important that you let the staff looking after you know. It might also be helpful to take in plenty of reading material and things to keep you occupied while you are in isolation. The isolation only lasts as long as the radioactive wires are in place (usually for a few days). Once the wires are removed the radioactivity disappears and it is perfectly safe to be with other people.

Side effects

While the needles are in place, the tissues around them will become swollen. This usually settles by the time they are removed. The treated area will become sore about 5–10 days after the needles or wires have been removed and this may last for several weeks. Your doctor can prescribe painkillers to help to relieve the discomfort.

Long-term effects of radiotherapy to the vulva

As the skin of the vulva is very sensitive to radiation it can become discoloured (reddened or darker) and swollen for months or sometimes years after radiotherapy. The swelling can be reduced by gentle, upwards massage, which you can be taught to do by a specialist nurse or physiotherapist, but unfortunately the discoloration of the skin is permanent.

Treating vulval cancer with chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. Chemotherapy drugs are sometimes given as tablets or, more usually, by injection into a vein (intravenously). Chemotherapy can often be given to you as an outpatient, but sometimes it will mean spending a few days in hospital.

Chemotherapy may be used at the same time as radiotherapy, to improve the effectiveness of treatment. There are different ways in which this is done, depending on the drugs used and the chemotherapy plan that is being followed.

Sometimes it means that chemotherapy is given continuously over a four-day period during the first and last week of the radiotherapy treatment. More commonly it is given once a week during the radiotherapy course.

Our section on chemotherapy discusses the treatment and its side effects in more detail. This section also includes information about individual drugs you may have as part of your treatment, and their particular side effects.

Side effects

Chemotherapy can cause unpleasant side effects, but for women with vulval cancer that has come back or spread it can also make them feel better by relieving the symptoms of the cancer. Most people have some side effects from chemotherapy, but these can usually be well controlled with medicines.

Lowered production of blood cells While the drugs are acting on the cancer cells in your body, they also temporarily reduce the number of normal cells in your blood. When these cells are reduced, you are more likely to get an infection and you may tire easily. If you have any signs of infection during chemotherapy, you will be given antibiotics. Less commonly, if people become anaemic due to the chemotherapy they may need a blood transfusion.

Nausea and vomiting Some chemotherapy drugs may cause nausea and vomiting. There are now very effective anti-sickness drugs (anti-emetics) to prevent or reduce nausea and vomiting. Your doctor will prescribe these for you. We can send you a factsheet on dealing with nausea and vomiting.

Sore mouth and loss of appetite Some chemotherapy drugs can make your mouth sore and cause small mouth ulcers. Regular mouthwashes are important and your nurse will show you how to do these properly. If you don't feel like eating during treatment you could try replacing some meals with nutritious soft drinks or a soft diet.

Hair loss Unfortunately, some chemotherapy drugs can make your hair fall out. You can ask your doctor if the drugs you are taking are likely to cause hair loss. People who lose their hair often cover up by wearing wigs, bandanas, hats or scarves. Most patients are entiltled to a free wig from the NHS. Your doctor or nurse will be able to arrange for a wig specialist to visit you. If your hair does fall out it will grow back over a period of 3–6 months, once the chemotherapy has finished.

Chemotherapy for vulval cancer may also increase any soreness of the skin caused by radiotherapy.

Although they may be hard to bear at the time, most of these side effects will disappear once your treatment is over.

Chemotherapy drugs affect different people in different ways. Some people find that they are able to lead a fairly normal life during their treatment, but many become very tired and have to take things much more slowly. Just do as much as you feel like and try not to overdo it.

Follow up after treatment for vulval cancer

After your treatment has finished, your specialist will ask you to go back to the hospital for regular check-ups. These are a good opportunity to discuss any worries or problems you may be having. You can also see your GP or your specialist doctor if, between your follow-up visits, you have a symptom which you cannot explain, lasts more than a week or is not getting better.

For people whose treatment is over apart from regular check-ups, our section on life after cancer, gives useful advice on how to keep healthy and adjust to life after cancer.

After surgery for vulval cancer

Your care and how quickly you recover after the operation will depend on the type of surgery you have had. Your doctor will explain all this to you beforehand. If the cancer is very small and only a minimal amount of skin is removed, the wound is likely to heal quickly. If your lymph nodes are removed, and particularly if you need more major surgery (such as a radical vulvectomy), healing and recovery will take longer.

Drips and drains
Pain
Physiotherapy
Dressings
Bowel movements
Going home
Lymphoedema

Drips and drains

When you go back to the ward you will have a drip in your arm, which gives you fluids into a vein. Once you can eat and drink normally again, probably after a couple of days, the drip will be taken out. You may also be given antibiotics through the drip to prevent you getting any infections. You will be given injections of blood thinning medicine just under the skin to prevent blood clots.

You will usually have a tube to drain urine from your bladder (catheter) put in while you are under the anaesthetic. You may have the catheter in for up to ten days. You may also have a dressing over the operation site. If your lymph glands have been removed you will probably have two tubes, called drains, going into the groin. This is to drain any fluid that may collect there. The drains are connected to small suction bottles.

Pain

After your operation you may have some pain or discomfort for a few days. You will be given painkillers, which are generally very effective at controlling any pain. At first you may be given the painkillers by injection into a muscle, or directly into your drip. Sometimes a small pump can be used to give painkillers into your bloodstream for the first few days. Many of these pumps allow you to control how much painkiller you receive (they are programmed so that you can not give yourself too much). Once you are eating and drinking properly again, you can be given your painkillers as tablets or a liquid.

Always let your doctor or nurse know if you have any pain or discomfort, as your painkillers, or the dose, can be changed to suit your needs. You may have a tube put into the fluid around your spinal cord (an epidural) so that painkillers can be given directly to this area.

Physiotherapy

If you have had major surgery you may be nursed in bed for the first 48 hours after your operation. After this you will be helped to get out of bed and encouraged to start gently moving around as soon as possible. The nurse or a physiotherapist will also help you do regular gentle leg exercises to prevent blood clots forming and deep breathing exercises to prevent any chest infections.

Dressings

You may not have any dressings on the vulval wound, as the area is likely to be kept clean by gently rinsing it with fluid. This is usually done three times a day until you go home. If you do have a dressing, it will be removed after a few days and changed regularly to keep the area clean and to help the skin to heal. Your stitches, if they are not dissolvable, will be removed when the skin has healed properly, usually in about 7−10 days.

If you have any groin wounds they will be covered with dressings, which will need to be changed regularly. The tubes will be removed from your groin when most of the excess fluid has been drained away. This may take about ten days, or sometimes longer. When the skin has healed your stitches will be removed and you will be able to go home.

Once you are at home, you will not need to put dressings on the area, but it is important to keep it clean and dry. The nurses on the ward will show you the best way to do this before you go home. In some situations a district nurse will be able to visit you at home to help with rinsing and keeping the area clean.

If you have had a skin graft, you may need dressings on the area where the skin was taken (the donor site). Usually these dressings stay in place until new skin has formed. Your nurse will explain more about this to you.

Bowel movements

You may find that your bowels do not open for a few days after your operation. This is quite usual. Once you are back to eating and drinking again, which is generally within a few days, your bowels should start to work normally again. It is likely that you will be prescribed laxatives after your operation to prevent constipation. If opening your bowels is painful, or difficult, let your doctors know and they can prescribe extra laxatives to help.

Going home

When you go home you will need to take things easy for a few weeks. The time it takes you to recover will depend on the extent of the surgery you have had.

If you have had major surgery, it is very important not to lift any heavy objects for at least six to eight weeks. This will help the skin to heal completely. It is advisable to wait about eight weeks before going back to work, but you may need longer if you heal more slowly. You can usually start driving after six weeks. Your car insurance company may specify a longer time before you can drive again, so it is helpful to contact them to check.

If your operation involved removing only a small amount of skin, your recovery will be much quicker. Your doctor will advise you on what to expect and on the precautions you should take. Here are some other helpful tips to consider:

- Avoid tight clothing and any lotions, perfumes and powders in the area of your operation.
- Don’t overdo walking until the skin has healed comfortably.
- Frequent baths can soothe the wound and help healing (but avoid scented bath oils/bubble bath).
- If passing urine makes your wound sting, try pouring a small jug of warm or tepid water over the wound while you are still sitting on the toilet.
- A hair dryer on a cool setting can be a more comfortable way of drying the vulval skin than a towel.
- Wear a loose fitting skirt and underslip (but no underwear) wherever possible as this may be more comfortable. (If you have to keep pads in place it will not be possible to avoid wearing underwear).
- If you tend to be constipated ask your doctor to prescribe some gentle laxatives for you.

If your skin is healing slowly, you may need to stay longer in hospital for further dressings. Sometimes a district nurse can come to your home to do these dressings.

Before you leave hospital the staff can arrange district nurses and other help for you at home.

You will be seen by your surgeon in the outpatients clinic after four to six weeks to check how well the skin is healing and to discuss any problems. This is called a follow-up appointment. If you have any problems or worries before your follow-up appointment, contact your hospital doctor or the nurses on your ward for advice.

Lymphoedema

If the lymph nodes in your groin have been removed by surgery, or if you have had radiotherapy to this part of your body, there is a risk of swelling of your leg or legs. The lymph nodes normally help to remove lymph fluid from your legs. Taking them away can block the flow of lymph. If this happens fluid will collect in the tissues under your skin. This can make your legs swell and is called lymphoedema. The condition can develop a few months or several years after treatment.

Lymphoedema can be treated with special massage techniques, exercises, bandaging and support stockings. Many hospitals have a nurse or physiotherapist who specialises in this treatment. The earlier it is started, the more likely treatment for lymphoedema is to be successful, so let your doctor know if you notice even mild swelling of your leg or foot.

If you have lymphoedema, your leg and foot will be more vulnerable to infection.

Listed below are some simple tips to help you care for your skin and reduce the risk of infection:

- Treat even small grazes and cuts with antiseptic and keep them clean until they heal. See your GP at the first signs of any infection – if the cut is inflamed or feels warm and tender.
- Wear long trousers when gardening to avoid being scratched.
- Avoid getting sunburnt.
- Keep your skin clean and dry and apply moisturising cream daily to keep it supple.
- To avoid cuts, use an electric razor if you shave your legs.
- If you are going on a long journey, wear support stockings.
- Do not have any injections in your legs.
- Dry between your toes carefully. If you notice any signs of athlete’s foot (soreness and/or peeling between the toes) treat it straightaway.
- Use nail clippers instead of scissors to cut your nails (as there is less risk of accidentally cutting the skin with clippers).

How surgery for vulval cancer may affect your sex life

Most women feel shocked and upset by the idea of having surgery to the vulva. When these strong feelings are combined with the trauma of surgery, as well as all the emotions that go with having a cancer diagnosis, it is understandable that your sex life will be affected.

Surgery to a part of the body which is normally associated only with the most intimate and private areas of our lives – sexuality and womanhood – can evoke all kinds of feelings, from deep shame to fear and anger. It is not something any of us would choose, and yet you will have had to do this in order to do the best thing for your health. This is a hard choice to make. Vulvectomy can permanently alter the outward appearance of the body and is a change that many women may find hard to accept. It may have an effect on how you feel about your sexuality and womanhood, and may well affect your needs and wants in relation to your sex life.

Although the area of the operation can heal within about six weeks, the emotional effects will probably take much longer to deal with, and need gentleness and sensitivity from yourself and the people close to you.

Sex

Some women find that, at first, intercourse is not physically possible because of the way the wound has healed. For example, there may be some tightening or scar tissue from either surgery or radiotherapy. Things can be done to help with this, so it’s important to mention it to your medical team.

It may take some months before you really begin to enjoy sex again. Don’t be surprised if you feel very unsure about it. Talk to your partner and be as honest as you can about what you want and don’t want. Remember that you need to make yourself and your healing a priority. Allow yourself to say no to any kind of sexual contact that does not feel right.

How you approach looking at the vulval area after your operation will be very personal to you. Some women do not want to look at the area at all and this is very natural. Some women may want a nurse to be with them if or when they look for the first time. A nurse can explain what has happened to the area and can offer professional support and advice. Other women may want to look alone or with a friend, partner or relative. Whoever you choose, make sure it is someone that you trust and can talk to about your feelings. If you have never have looked at your vulva before the idea of doing so may seem strange.

Don’t force yourself to do things before you feel ready. If you do decide to look at the area where your surgery was it will probably seem odd, however well prepared you may have been. You may feel shocked, and this is understandable. If the labia have been removed, you may be able to see the opening to the vagina much more clearly. If the clitoris has been removed there will be an area of flat skin without the usual folds of the vulva.

Many women worry that if their clitoris has been removed they will not be able to have orgasms. This is not necessarily the case, although you may need to be patient while exploring different ways to reach a climax. Your doctor or nurse may be able to discuss this with you. You may also wish to speak to a sex therapist or counsellor experienced in this area.

For most women sex is more than just being able to feel aroused, or to have orgasms. It involves fundamental feelings about intimacy and about being able to give and receive love. If we are not comfortable with the way our bodies look, this may affect our feelings about sex.

Some women worry about being rejected by their partner, or any potential new partner, because of the changes to their body. Intimate sexual relationships always have the challenge of sharing your fears, worries and needs with your partner. The time after surgery or treatment to the vulva is no different. You may be surprised by the amount of tolerance and trust, tenderness and love that exists between you and your partner. However, sometimes difficulties may arise in your relationship. If this happens, you may find counselling helpful, either with your partner or on your own. If you can do this, you may find that it is possible to work through these feelings to a new closeness and understanding.

We have a section on sexuality and cancer, which you may find helpful.

Research - clinical trials for vulval cancer

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

Clinical trials may be carried out to:

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

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

Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and develop new treatments. You will also be carefully monitored during and after the study. Usually, several hospitals around the country take part in these trials. It is important to bear in mind that some treatments that look promising at first are often later found not to be as good as existing treatments, or to have side effects that outweigh the benefits.

Blood and tumour samples

Many blood samples and bone marrow or tumour biopsies may be taken to find out what is wrong with you. Most of these are needed to make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. Some samples may be frozen and stored for future use, when new research techniques become available.

The research may be carried out at the hospital where you are treated, or it may be at another hospital. This type of research takes a long time, so you are unlikely to hear the results. The samples will, however, be used to increase knowledge about the causes of cancer and its treatment. This research will, hopefully, improve the outlook for future patients.

JASCAP resources

Talking about your cancer
Practical advice and guidance for cancer patients to help them communicate with family, friends, carers and health professionals about emotional and practical issues arising from a diagnosis of cancer and cancer treatment.

Talking to children about cancer
Practical advice and guidance to help parents with cancer talk to their children about their cancer.

Talking to someone with cancer
Practical advice and guidance for friends, carers and family members to help them talk to their friend or relative with cancer, and provide emotional and practical support.