



Understanding Vulvar and Vaginal Cancers

A guide for women with cancer,
their families and friends

Cancer
information

Cancer Council Helpline

13 11 20

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Understanding Vulvar and Vaginal Cancers

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Check the publication date above to ensure this copy is up to date.

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Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

Cancer Council NSW

Cancer Council is the leading cancer charity in NSW. It plays a unique and important role in the fight against cancer through undertaking high-quality research, advocating on cancer issues, providing information and services to the public and people with cancer, and raising funds for cancer programs. This booklet is funded through the generosity of the people of NSW. To make a donation to help defeat cancer, visit Cancer Council's website at www.cancerCouncil.com.au or phone 1300 780 113.



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Introduction

This booklet has been prepared to help you understand more about two uncommon gynaecological diseases: cancer of the vulva and cancer of the vagina.

Many people feel understandably shocked and upset when told they have cancer. We hope this booklet will help you understand how vulvar and vaginal cancers are diagnosed and treated – because they are managed differently, detailed information is on pages 8–27 and pages 28–46 (tabbed sections). Information about side effects for both cancers are on pages 47–56. We also include details about support services.

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, we hope this information will answer some of your questions and help you think about other questions to ask your treatment team.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary. You may also like to pass this booklet to your family and friends for their information.

If you're reading this book for someone who doesn't understand English, let them know that Cancer Council **13 11 20** can arrange telephone support in different languages. They can also call the Translating and Interpreting Service (TIS National) direct on **13 14 50**.



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What is cancer?

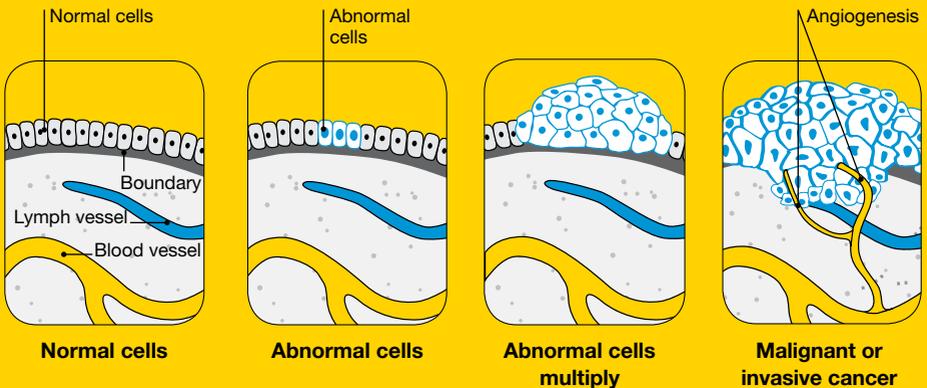
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

Sometimes cells don't grow, divide and die in the usual way. This may cause blood or lymph fluid in the body to become abnormal, or form a lump called a tumour. A tumour can be benign or malignant.

Benign tumour – Cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

Malignant tumour – This is made up of cancerous cells, which have the ability to spread by travelling through the bloodstream or lymphatic system (lymph fluid).

How cancer starts



The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell affected.

A malignant tumour that has not spread to other parts of the body is called localised cancer. A tumour may invade deeper into surrounding tissue and can grow its own blood vessels (angiogenesis).

If cancerous cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, vaginal cancer that has spread to the cervix is called metastatic vaginal cancer, even though the person may be experiencing symptoms caused by problems in the cervix.

How cancer spreads

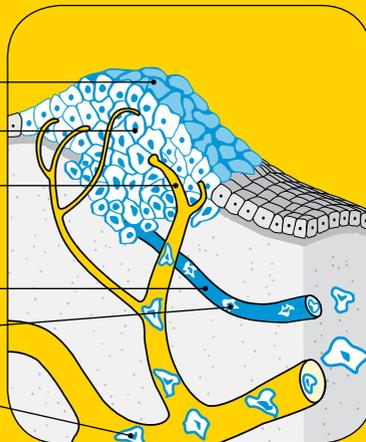
Primary cancer

Local invasion

Angiogenesis –
tumours grow their
own blood vessels

Lymph vessel

Metastasis –
cells invade other
parts of the body via
blood vessels and
lymph vessels





The vulva and vagina

The vulva and vagina are parts of the female reproductive system.

The vagina is a muscular tube that is sometimes called the birth canal. It is about 7.5–10 cm long and extends from the opening of the uterus, the cervix, to the external part of a woman's genitals, the vulva. The vagina is the passageway through which menstrual blood flows, sexual intercourse occurs and a baby is born.

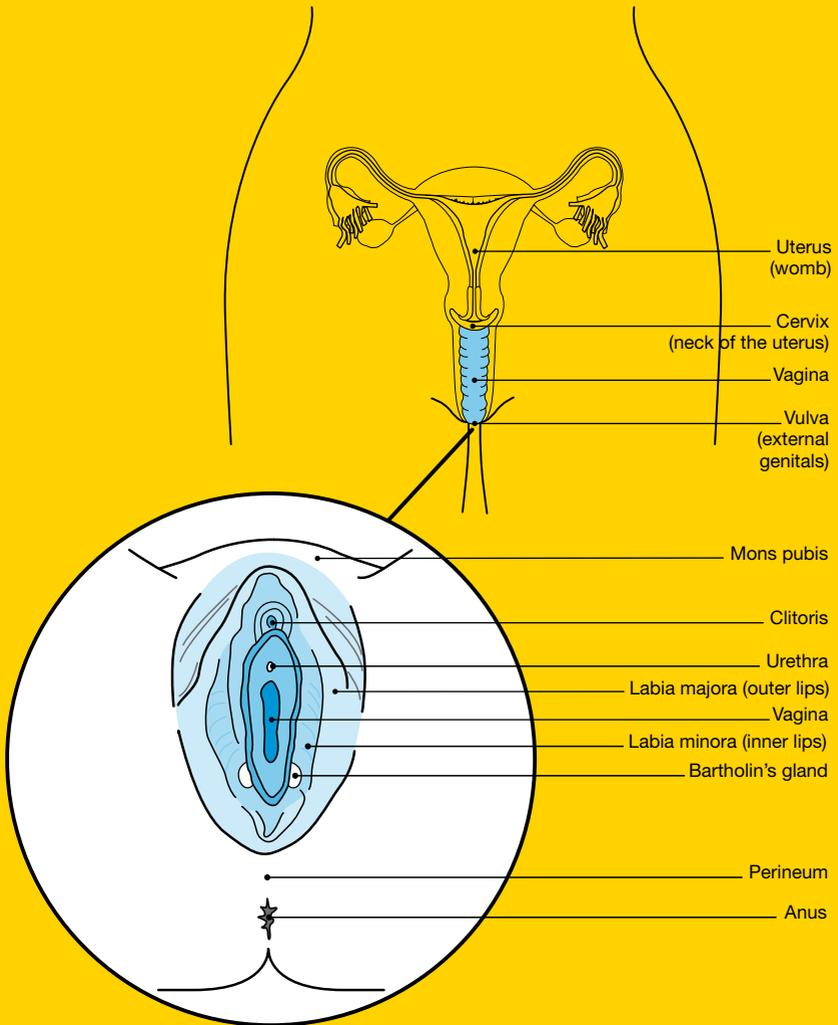
The vulva is a general term used to describe a woman's external organs. The main parts of the vulva are the:

- **mons pubis** – the soft, fatty mound of tissue covered with pubic hair, above the labia
- **labia** – two large, outer lips (the labia majora), which surround two inner lips (the labia minora) that may be smaller or thinner
- **clitoris** – a highly sensitive organ found where the labia minora join at the top. When stimulated, the clitoris fills with blood and enlarges in size. Stimulation of the clitoris can result in sexual excitement and orgasm or climax.

The opening of the vagina is below the clitoris. There are also small glands near the opening of the vagina, called Bartholin's glands, that produce mucus to lubricate the vagina.

The vulva is covered in skin, and the skin between the vulva and anus is called the perineum.

The vulva and vagina





Cancer of the vulva

This chapter has information about the symptoms, risks, diagnosis and treatment of cancer of the vulva. This type of cancer is also known as vulvar cancer or vulval cancer. For information about side effects, see the *Managing side effects* chapter on pages 47–56.

Q: What is vulvar cancer?

Cancer of the vulva can start in any part of the external female sex organs. It most commonly develops in the labia minora, the inner edges of the labia majora and the perineum. Less often, it may involve the clitoris or the Bartholin's glands.

Types of vulvar cancer

squamous cell carcinoma	<ul style="list-style-type: none">• affects the skin cells of the vulva
vulvar melanoma	<ul style="list-style-type: none">• a type of skin cancer that develops from the cells that give the skin its colour (melanocytes)
adenocarcinoma	<ul style="list-style-type: none">• begins in the glandular cells lining the skin of the vulva• one type is extramammary Paget's disease, which looks like eczema
verrucous carcinoma	<ul style="list-style-type: none">• slow-growing cancer that looks like a large wart
sarcoma	<ul style="list-style-type: none">• develops from muscle, fat and connective tissue• tends to grow faster than other types of vulvar cancer

Q: What are the symptoms?

There are often no obvious symptoms of vulvar cancer. However, you may have one or more of the following:

- a lump, sore, swelling or wart-like growth on the vulva
- itching, burning and soreness or pain in the vulva
- thickened, raised, red, white or dark brown skin patches
- a mole on the vulva that changes shape or colour
- blood, pus or other discharge coming from a lesion or sore spot, which may have an offensive or unusual odour or colour (not related to your menstrual period).

Many women don't examine their vulva, so they don't know what is normal for them. Some women don't look because it is difficult to see without a mirror. Others feel uncomfortable examining their vulva. However, if you feel any pain in your genital area or notice any of the symptoms listed above, you should make an appointment with your general practitioner (GP).

Q: How common is it?

Each year, about 300 Australian women are diagnosed with cancer of the vulva. It most commonly affects post-menopausal women. The incidence is highest for women older than 80. However, vulvar cancer can sometimes occur in younger women.

Squamous cell carcinoma is the most common type of vulvar cancer, making up about 9 out of 10 cases. The other types of vulvar cancer are less common.

Q: What are the risks?

The exact cause of vulvar cancer is unknown, but there are some factors known to increase the risk of developing it:

Vulvar intraepithelial neoplasia (VIN) – This is a pre-cancerous condition of the vulva. The skin of the vulva changes and may itch, burn or feel sore. VIN may disappear without treatment, but it can sometimes become cancerous. About one in three women who develop vulvar cancer has VIN.

Human papillomavirus (HPV) – Also known as the wart virus, HPV is a sexually transmitted infection that can cause women to develop VIN. Although having HPV increases the risk of vulvar cancer, HPV is a very common virus and most women with HPV don't develop vulvar cancer.

Other skin conditions – Some skin conditions such as vulvar lichen sclerosus and vulvar lichen planus can cause itching and soreness and, after many years, may develop into cancer.

Smoking – Cigarette smoking increases the risk of developing VIN and cancer of the vulva. This may be because smoking can make the immune system work less effectively.



Vulvar cancer is not contagious and it can't be passed to other people through sexual contact. It is also not caused by an inherited faulty gene so it can't be passed on to children.

Weakened immune system – Women who have had an organ transplant or who have human immunodeficiency virus (HIV) may be at higher risk of developing vulvar cancer because their immune system is not working normally.

Diagnosis

If you have any of the symptoms listed on page 9, your first step will be to visit your GP.

See your GP

Your doctor will ask to do a physical examination of your groin and pelvic area. If the area is painful or sensitive, you may be given a local anaesthetic to numb it during the examination.

If you feel embarrassed or scared about having a physical examination, let your doctor know. If you wish, you can also ask for someone else, such as a nurse or a family member, to be present. The doctor may arrange for a vulvoscopy or biopsy, and may also do an internal examination.

Vulvoscopy

During a vulvoscopy, the doctor uses a microscope called a colposcope to view your vulva. It does not enter the body.

You will be asked to lie on your back on an examination table with your knees bent and legs separated. The doctor will apply a vinegar-like liquid to your vulva, which makes it easier to see abnormal cells through the colposcope.

Biopsy

During the vulvoscopy, your doctor will usually take a small tissue sample (biopsy) from the vulva area. A biopsy is the best way to diagnose cancer of the vulva.

The doctor may put a local anaesthetic into the affected area of your vulva to numb it while the biopsy is taken. The biopsy can be done using a small scalpel instrument, which has a circular blade to remove 3–4 mm of tissue.

There shouldn't be any pain when the sample of tissue is taken from your vulva, but you may feel a little discomfort. Afterwards, your vulva may bleed a little, and sometimes stitches are needed to close up the wound. Ask your doctor how much bleeding to expect after the biopsy, and how to care for the wound and keep it from becoming infected. You may have some soreness, which can be relieved by pain-killers and taking a warm bath.

The tissue is sent to a laboratory where a specialist called a pathologist examines the cells under a microscope. The pathologist will be able to confirm whether or not the cells are cancerous, and which type of vulvar cancer it is.

💬 Why do we have to be ashamed about having vulvar cancer? When you connect with another woman who has had vulvar cancer, you soon find out that there is no need for shame or embarrassment. 💬 *Jane*

Internal examination

Although the vulva is the outer part of your genitals, the doctor may also ask to do an internal examination to look at your vagina, cervix, bladder and rectum.

Some women with skin conditions such as lichen planus or lichen sclerosus have narrowing of the vagina, so the internal examination will be done under a general anaesthetic.

Pap smear – If you haven't had one recently, your doctor may do a Pap smear (test) to check the cells inside the vagina and cervix. During this test, you will lie on a table with your knees up and apart. The doctor will gently insert an instrument with smooth, curved sides (speculum) into your vagina. A lubricant is used to guide the speculum. The sides of the speculum spread the vaginal walls apart so the doctor can see your vagina and cervix. An instrument such as a brush or swab is used to remove some cells from the surface of the cervix.

Colposcopy – The doctor may use a colposcope to look inside your vagina. This is like a microscope that helps the doctor to find any abnormality that may be too small to see with the naked eye. The colposcope doesn't go inside your vagina; the doctor looks through it from the outside. During this examination, the doctor may take a biopsy.

You may also have other tests to view the inside of your bladder and urethra (cystoscopy) or your rectum and anus (proctoscopy). These will be done under a general anaesthetic.

Further tests

Sometimes further tests are needed to determine your general health, the size and position of the cancer, and whether the cancer has spread. These may include:

Blood test – This checks the number of cells in your blood, and how well your kidneys and liver are working.

Chest x-ray – A painless scan of your lungs.

Examination under anaesthetic – The doctor can give you a general anaesthetic so the vulva can be thoroughly examined without any pain.

CT scan – A computerised tomography scan. This scan takes three-dimensional x-rays of the inside of your body.

MRI scan – A magnetic resonance imaging scan. You will lie on the treatment table inside a cylinder that uses a magnetic field to create pictures of your body. Some women feel claustrophobic during this scan. Tell your medical team if you feel anxious, as they may be able to help you relax.



Before a CT or MRI scan, you may be given an injection or asked to drink a liquid called a contrast to make the images on the computer appear clearer. Some people are allergic to the iodine in the contrast liquid, so tell the doctor if you have any allergies.

Staging vulvar cancer

Based on the test results, your doctor will tell you the stage of the cancer. This is a way to describe its size and whether it has spread. Your doctor may also tell you the grade of the cells. This tells you how quickly the cancer may develop. Knowing the stage and grade of the cancer helps your doctor recommend the most appropriate treatment. Low-grade (grade 1) cancer cells are slow growing and are less likely to spread. High-grade (grade 3) cells look more abnormal and are more likely to grow and spread quickly.

Stage	Description
Stage 0 carcinoma in-situ	Early cancer. Abnormal cells are found only on the surface of the vulval skin.
Stage 1	Cancer is found only in the vulva and/or perineum. The affected area is 2 cm or less in size.
Stage 2	Cancer is found only in the vulva and/or perineum. The affected area is more than 2 cm in size.
Stage 3	Cancer is found in the vulva and/or perineum, and has also spread to the urethra, vagina, anus or lymph nodes.
Stage 4	Cancer has spread beyond the urethra, vagina and anus into the lining of the bladder or bowel. The cancer may also have spread to the lymph nodes in the pelvis or to other parts of the body.

Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your doctor, but it is not possible for any doctor to predict the exact course of your disease. Instead, your doctor can give you an idea about common issues that affect people with cancer of the vulva.

In most cases, the earlier vulvar cancer is diagnosed, the better the chances of successful treatment. Many women manage the condition for years with regular check-ups with their specialists.

Test results, the type of vulvar cancer you have, the rate and depth of tumour growth, how well you respond to treatment, and other factors such as age, general fitness and medical history are all important in assessing your prognosis.

Which health professionals will I see?

Your GP (general practitioner) will probably arrange the first tests to assess your symptoms. You will then be referred to a gynaecological oncologist.

You will be cared for by a range of health professionals who specialise in different aspects of your treatment. This is called a multidisciplinary team or MDT.

See opposite for a list of health professionals you may see.

Health professional	Role
gynaecological oncologist	a surgeon who specialises in treating gynaecological cancers, such as cancer of the vulva
radiation oncologist	prescribes and coordinates the course of radiotherapy
medical oncologist	prescribes and coordinates the course of chemotherapy
cancer care coordinator	provides support throughout treatment and liaises with other health professionals
nurses	administer treatment and provide support and assistance through all stages of your treatment, including recovery
dietitian	recommends the best eating plan to follow when you are in treatment and recovery
sex counsellor	helps you deal with physical or emotional issues affecting your sexuality
social worker	advises you on support services
physiotherapist, occupational therapist	assist you with getting back to normal activities
counsellor, psychologist	provide emotional support and help manage anxiety and depression

Treatment

Cancer of the vulva usually takes many years to develop but, like other types of cancer, it is easier to treat and cure at an early stage. Treatment may involve surgery, radiotherapy and chemotherapy. You may have one of these treatments or a combination.

Surgery

Surgery is the main treatment for cancer of the vulva. The type of operation you have depends on the stage of the cancer. One of the following types of surgery may be done:

Laser surgery – This operation uses a narrow beam of intense light (laser) as a knife to remove a small tumour. This is not done to treat invasive cancer.

Wide local excision – In this operation, the surgeon removes the cancerous part of your vulva and about a 1 cm border of healthy tissue around the cancer (called the margin).

Radical local excision – The surgeon cuts out the cancer and a larger area of normal tissue all around the cancer. The nearby lymph nodes in the groin may also be removed (known as lymph node dissection).

Removing part of the vulva (partial vulvectomy) – The affected part of the vulva is removed. The surgeon may also take out some healthy tissue around the cancerous tissue (a wide local excision). This may mean that a significant portion of the vulva is removed.

Removing the whole vulva (radical vulvectomy) – The surgeon removes the entire vulva, including the clitoris. Usually, surrounding lymph nodes are also removed.

Removing vulval cancer that has spread (pelvic exenteration) – This operation removes all the affected organs, such as the lower bowel, bladder, uterus or vagina. This operation is no longer commonly done. Your surgeon will only consider this if you are fit enough to make a good recovery. However, it may be done for advanced cancer that has spread beyond the vulva.

The surgeon will aim to remove all of the cancer while preserving as much normal tissue as possible. However, it is essential to remove a margin of healthy tissue around the cancer to reduce the risk of the cancer coming back (recurring) in this area.

It is usually possible to stitch the remaining skin together, but if a large area of skin is removed, you may need a skin graft or skin flap. To do this, the surgeon may take a thin piece of skin from another part of your body (usually your thigh or abdomen) and stitch it onto the operation site. It may be possible to move flaps of skin in the vulvar area to cover the wound. The graft or flap will be done as part of the same operation.

Lymph node dissection – The lymph nodes (also called lymph glands) are part of the lymphatic system. Vulvar cancer often spreads first to the lymph nodes in the groin, so these nodes are often removed from one or both sides of the groin. This is called an inguinal lymph node dissection.

The surgeon may perform a sentinel lymph node biopsy. You will have an anaesthetic and an injection of radioactive dye near the site of the cancer. This is done to identify the lymph node most likely to be the first to have cancer spread to it. The dye will flow to this node, and the surgeon will remove it and determine whether it's necessary to remove more lymph nodes. Your doctor will talk to you about this type of biopsy and the associated risks.

Sometimes removing lymph nodes in the groin can stop or slow the natural flow of lymphatic fluid. When this happens, it can cause the legs to swell. This is known as lymphoedema – see page 53.

What to expect after surgery

Pain-killers	Catheter	Wound care
<p>You will have medication to reduce any pain. Some women have an injection into a space around their spinal cord, called an epidural. This numbs the body from the waist down.</p>	<p>A tube called a catheter will drain urine and will help keep your wound clean and dry. This will be removed within a few days.</p>	<p>Stitches usually dissolve and disappear as the wound heals, otherwise they will be removed within a couple of weeks. The wound will need to be kept clean and dry and the nurses will show you the best way to do this. Some women have a dressing that is changed regularly. The surgical site will be washed regularly (peri toilets). If your vulva is numb, be careful patting it dry because you won't realise how much pressure you are using. Some women prefer to use a hair dryer on a low heat setting to dry the area.</p>

Recovery after surgery

Your recovery time after the operation will depend on the type of surgery you have. If a small amount of skin is removed, the wound will probably heal quickly. If your lymph nodes are removed or the surgery is more extensive, recovery will take longer. Women with stitches should try to keep their knees together when getting out of bed so the stitches do not tear.

The emotional impact of having cancer and surgery is significant, and you may wonder how it could affect your sexuality (see *Sexuality, intimacy and cancer* on pages 61–62).

Using the toilet	Exercise and movement	Surgical drains
<p>If the opening to your urethra was removed or affected, you may find that going to the toilet is different. The urine stream might spray in different directions or go to one side. For suggestions on managing this problem, see page 52.</p>	<p>Start gently moving around as soon as your doctor says it's okay. If you have skin grafts or flaps, or if you have had a groin lymph node dissection, you may need bed rest for a few days. The nurse or physiotherapist can help you do regular leg and breathing exercises, and you can ask for pain relief before you start moving around. When you return home, you will need to take it easy. You may not be able to lift anything heavy or drive for 6–8 weeks.</p>	<p>After some operations, women have a surgical drain placed in the wound to draw fluid away from the incision. The drain needs to remain in place until it is not draining too much fluid, so you may go home with it still in place. Community nurses will help you manage the care of the drain at home until it is removed.</p>

Radiotherapy

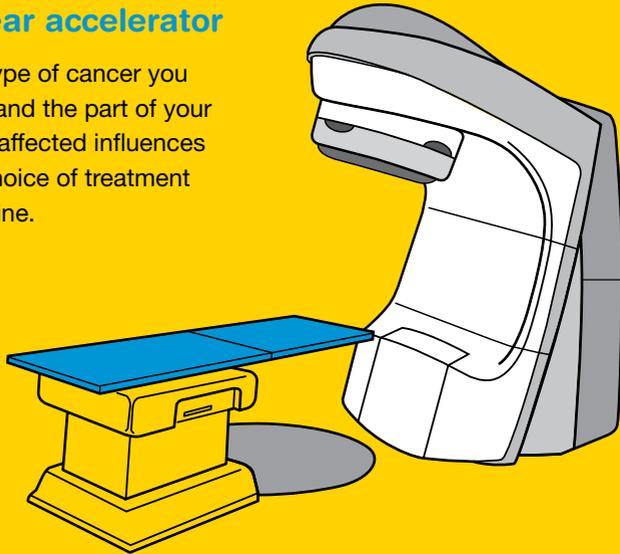
Radiotherapy uses high-energy x-rays to destroy or kill cancer cells. Whether you have radiotherapy or not will depend on the stage of the cancer, its size, whether it has spread to the lymph nodes and, if so, how many nodes are affected.

You can have radiotherapy:

- before surgery to shrink the cancer and make it easier to remove (neo-adjuvant treatment)
- after surgery to get rid of any remaining cancer cells and reduce the risk of the cancer coming back (adjuvant treatment)
- instead of surgery
- to control symptoms of advanced cancer.

Linear accelerator

The type of cancer you have and the part of your body affected influences the choice of treatment machine.



External radiotherapy – External radiotherapy (or external beam) is the most common type of radiotherapy for cancer of the vulva. You will lie on a treatment table while a machine, called a linear accelerator, directs radiotherapy at the affected area of the vulva. Treatment is usually given daily over a few weeks – the number of radiotherapy sessions you have will depend on the type and size of the cancer. Each treatment takes about 10–15 minutes.

Radiotherapy to the vulva and groin is painless, but it can cause side effects. The side effects you experience depend on the radiotherapy dose and the length of your treatment, see page 24. External radiotherapy will not make you radioactive. It is safe for you to be with other people, including children, after your treatment.

Internal radiotherapy – Internal radiotherapy (brachytherapy) delivers radiotherapy directly to the tumour from the inside of your body. This is a less common treatment for vulvar cancer.

You will be given a general anaesthetic, and a special temporary applicator will be inserted into your vulva. Radioactive sources, such as pellets, are inserted into the applicator to deliver treatment. You can have this treatment as an inpatient in hospital (low-dose-rate treatment), or receive shorter outpatient treatment sessions (high-dose-rate treatment).

For more detailed information, see pages 38–40. Ask your doctor or nurse for details regarding safety precautions for visitors. You can also call Cancer Council 13 11 20 for a free copy of *Understanding Radiotherapy* or download it from your local website.

Side effects of radiotherapy

You may have some of the following side effects:

Skin redness, soreness and swelling – After radiotherapy the vulva may become sore and swollen. Wash the area with lukewarm water and avoid using perfumed products, lotions or talcum powder.

Hair loss – You may lose your pubic hair. For some women, this can be permanent.

Lymphoedema – Radiation to the groin can increase the risk of swelling in the legs, see page 53.

Narrowing of the vagina – Radiotherapy can cause your vagina to shorten and narrow, which may make sex uncomfortable or difficult. For information, see pages 47–48.

Cystitis – This is inflammation to the bladder lining. Cystitis can make you feel like you want to pass urine frequently and/or give you a burning sensation when you pass urine.

Diarrhoea – Radiotherapy can irritate the bowel and cause you to have loose stools. If this is a problem, let your doctor know.



See pages 51–52 for information about coping with side effects affecting the bladder and bowel.

Chemotherapy

Chemotherapy uses cytotoxic drugs to kill or slow the growth of cancer cells. Treatment is often given:

- during the course of radiotherapy, to make the treatment more effective
- to control cancer that has spread to other parts of the body
- as palliative treatment, to relieve the symptoms of the cancer.

Chemotherapy may be given as tablets, in a cream applied to the vulva or, more commonly, by injection into a vein (intravenously). Most women have several treatment sessions, followed by a break. Treatment can often be given to you during visits to a hospital or clinic as an outpatient, but sometimes you may need to spend a few days in hospital.

Side effects of chemotherapy

There are many different types of chemotherapy drugs and the side effects vary depending on the drugs you are given. Your medical oncologist or nurse will discuss the likely side effects with you, including how they can be controlled with medication.

Common problems include feeling sick (nausea), tiredness and a reduced resistance to infections. Chemotherapy for vulvar cancer may also increase any skin soreness caused by radiotherapy. Some people find that they are able to continue with their usual activities during treatment, while others find they need to take things more slowly. For more information, call Cancer Council 13 11 20 for a free copy of *Understanding Chemotherapy* or download it from your local website.

Palliative treatment

Palliative treatment helps to improve quality of life by reducing symptoms of cancer when it is no longer possible to cure the disease. It is particularly important for people with advanced cancer, but it's not just for end of life care and it can be used at different stages of cancer.

Pain relief is often the focus of palliative treatment. This may be managed with radiotherapy, chemotherapy or other medication. However, palliative treatment can also involve the management of other physical and emotional issues.



You can call Cancer Council **13 11 20** for free booklets about palliative care and advanced cancer.



Key points

- Cancer of the vulva is also known as vulvar or vulval cancer. There are several types, and it can start in any part of the vulva.
- Symptoms may include a lump, burning, itching, pain, coloured skin patches or a mole that changes in colour.
- Some factors, such as vulvar intraepithelial neoplasia (VIN), can increase the risk of developing vulvar cancer.
- Your doctor will confirm the diagnosis with a physical examination of the groin and pelvic area, biopsy and scans.
- The stage of the cancer describes its size and if it has spread. The grade tells how quickly the cells are growing.
- The earlier vulvar cancer is diagnosed, the better the chances of successful treatment.
- You may see a range of health professionals, including a gynaecological oncologist.
- Surgery is the main treatment for vulvar cancer. The type of operation you have depends on the stage of the cancer. The lymph nodes in the groin may also be removed.
- Radiotherapy uses x-rays to destroy cancer cells. You may have external radiotherapy or internal radiotherapy (brachytherapy). Side effects vary depending on the type of radiotherapy you have.
- Chemotherapy uses anti-cancer drugs to kill cancer cells. Side effects can include nausea and fatigue.
- Palliative treatment may be given to manage cancer symptoms and improve quality of life.



Cancer of the vagina

This chapter has information about the symptoms, causes, diagnosis and treatment of primary cancer of the vagina.

Detailed information about side effects can be found in the *Managing side effects* chapter on pages 47–56.

Q: What is vaginal cancer?

There are two types of vaginal cancer: cancer that starts in the vagina (primary cancer) and cancer that has spread to the vagina (secondary cancer). There are several types of primary vaginal cancer. However, two main types make up about 85% of all cases:

- **Squamous cell carcinoma (SCC)** – This is the most common type of cancer, affecting cells covering the surface of the vagina. It usually grows slowly over many years.
- **Adenocarcinoma** – A type of cancer that begins in the glandular cells lining the vagina. This type is more likely to spread to the lungs and lymph nodes.

Other cancers, such as melanoma or sarcoma, can also affect the vagina, but this is rare.

Secondary cancer in the vagina is more common than primary vaginal cancer. This means the cancer has spread from another part of the body. The cancer may spread from the cervix (the neck of the uterus), uterus (the womb), vulva, or nearby organs such as the bladder or bowel.

Q: What are the symptoms?

There are often no obvious symptoms of vaginal cancer. The cancer is sometimes found through a routine Pap smear (see page 32).

You may have one or more of the following symptoms:

- bloody vaginal discharge not related to your menstrual period, which may have an offensive or unusual odour
- pain during sexual intercourse
- bleeding after sexual intercourse
- pain in the pelvic area
- a lump in the vagina.

Some women also have bladder and bowel problems. You may have blood in your urine or feel the urge to pass urine frequently or during the night. Pain in the rectum can sometimes occur.

If you have any symptoms, make an appointment with your GP.

Q: How common is it?

Cancer of the vagina is one of the rarest types of gynaecological cancer. Each year in Australia, approximately 70 women are diagnosed with vaginal cancer.

Squamous cell carcinoma usually affects women aged 50–70.

Adenocarcinoma is more likely to affect young women under 25, but it can also occur in other age groups.

Q: What are the risks?

The exact cause of vaginal cancer is unknown, but factors that increase the risk include:

Vaginal intraepithelial neoplasia (VAIN) – This is a pre-cancerous condition of the vagina that is sometimes caused by human papillomavirus (HPV). VAIN often doesn't cause symptoms, and many women are diagnosed while having tests for other reasons. It means that the cells in the inner lining of the vagina are abnormal and they may develop into cancer after many years. However, not all women with VAIN develop cancer.

Vaginal adenosis – This condition causes abnormal cells to form in the tissue of the vagina. This is usually the result of DES exposure (see opposite).

Human papillomavirus (HPV) – Sometimes known as the wart virus, HPV is a common sexually transmitted infection. There are many different types of HPV and only some increase the risk of developing vaginal cancer. Most women with HPV do not develop cancer of the vagina.

Smoking tobacco – Cigarette smoking doubles the risk of developing vaginal cancer. This may be because smoking can make the immune system work less effectively.

Radiotherapy to the pelvis – If you have had radiotherapy to the pelvis for another reason, you are at a slightly higher risk of vaginal cancer. This complication is very rare.

History of gynaecological cancer – Cancer of the vagina is more likely to be diagnosed in women who have had cervical cancer or early cervical cell changes that were considered to be precancerous.

Diethylstilboestrol (DES) – This synthetic hormone drug has been identified as a cause of a particular type of vaginal cancer. Between 1938 and 1971 – and occasionally beyond – DES was prescribed to pregnant women to prevent miscarriages. It is no longer prescribed to pregnant women in Australia.

The female children of women who took DES (called DES daughters) have an increased risk of developing a range of health problems, including vaginal adenocarcinoma.

About one in 1000 DES daughters develop adenocarcinoma, particularly a type called clear cell carcinoma. This incidence of DES-related adenocarcinoma is highest for women who were exposed during the first three months of their mother's pregnancy. The risk appears to be highest for those in their teenage years and early twenties. However, older women have also been diagnosed. If you are concerned about this risk, see your GP. They may recommend you have an annual gynaecological check-up.

Vaginal cancer is not infectious and it can't be passed to other people through sexual contact. It is not caused by an inherited faulty gene and can't be passed on to children. For more information on the risk factors, call Cancer Council **13 11 20**.



Diagnosis

If you have any of the symptoms listed on page 29, your doctor will ask to do a physical examination of your groin and pelvic area. If the area is painful or sensitive, you may be given a local anaesthetic to numb it during the examination.

If you feel embarrassed or scared about having a physical examination, let your doctor know. If you wish, you can also ask for someone else, such as a nurse or your partner, to be present.

The doctor may also arrange some of the following tests.

Pap smear

You may have a Pap smear (Pap test) to check the cells inside the vagina and cervix.

During this test, you will lie on a table with your knees up and apart. The doctor will gently insert an instrument with smooth, curved sides (speculum) into your vagina. A lubricant is used to guide the speculum. The sides of the speculum spread the vaginal walls apart so the doctor can see your vagina and cervix. The doctor uses a small instrument, such as a brush or swab, to remove some cells from the surface of the cervix. The tissue sample is sent to a lab, where it is checked for abnormalities.

The results of the Pap smear may show that you have early cell changes in the lining of the vagina. This condition is called vaginal intraepithelial neoplasia or VAIN, see page 30.

Colposcopy and biopsy

The doctor will do an internal examination to look at your vagina, cervix and vulva. This is called a colposcopy. You will be advised not to have sex or put anything into your vagina (e.g. tampons, medicine) for 24 hours before a colposcopy.

During this procedure, you will lie on your back on an examination table with your buttocks near the end of the table, your legs separated and your feet on footrests. The doctor will insert an instrument called a speculum into the vagina, and will look through a microscope called a colposcope to examine the vaginal canal. The colposcope is not put into your body, but the doctor looks through it from the outside. The doctor will place a vinegar-like liquid into your vagina, which makes it easier to see abnormal cells through the colposcope.

Your doctor may take a tissue sample (biopsy) during the colposcopy. The tissue is sent to a laboratory where a specialist called a pathologist examines the cells under a microscope. The pathologist will be able to check for cell abnormalities.

You may feel uncomfortable during the colposcopy. Some women are advised to take pain relief, such as ibuprofen, about an hour before the procedure to ease cramping and discomfort. Talk to your doctor about this before the test.

“ I felt uncomfortable for a few days after the colposcopy but a hot water bottle and mild pain-killers helped. ” Gina

Further tests

If the tests described on pages 32–33 show that you have vaginal cancer, further tests may be necessary to find out whether cancer cells have spread:

Blood test – This checks the number of cells in your blood, and how well your kidneys and liver are working.

Cystoscopy – The doctor uses a slender tube with a lens and a light (cystoscope) to look into the urethra and bladder. This is done under general anaesthetic.

Chest x-ray – A painless scan of your lungs.

CT scan – A computerised tomography scan. This scan takes three-dimensional x-rays of the inside of your body.

MRI scan – A magnetic resonance imaging scan. You will lie on the treatment table inside a cylinder that uses a magnetic field to create pictures of your body. Some women feel claustrophobic during this scan. Tell your medical team if you feel anxious, as they may be able to help you relax.



Before a CT or MRI scan, you may be given an injection or asked to drink a liquid called a contrast to make the images on the computer appear clearer. Some people are allergic to the iodine in the contrast liquid, so tell the doctor if you have any allergies.

Staging vaginal cancer

Based on the results of the diagnostic tests, your doctor will tell you the stage of the cancer.

Staging is a way to describe the size of the cancer and whether it has spread beyond its original site. Your doctor may also tell you the grade of the cancer cells. This gives you an idea of how quickly the cancer may develop.

A low-grade (grade 1) cancer means that the cells are slow growing and less likely to spread. High-grade (grade 3) cells look more abnormal and are more likely to grow and spread quickly.

Knowing the stage and grade of the cancer helps your medical team decide on the most appropriate treatment.

Staging	
Stage 1	The cancer is found only in the vagina.
Stage 2	Cancer has begun to spread through the vaginal wall, but it has not spread into the walls of the pelvis.
Stage 3	Cancer has spread to the pelvis. It may also be in the lymph nodes close to the vagina.
Stage 4	Cancer has spread beyond the vagina and surrounding area into the lining of the bladder or bowel. The cancer may also have spread to other parts of the body.

Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your doctor, but it is not possible for any doctor to predict the exact course of your disease. Instead, your doctor can give you an idea about common issues that affect women with cancer of the vagina.

Some women with cancer of the vagina may want to know the prognosis for women in similar situations, while others may not find the numbers helpful, or may even not want to know them. Do what feels right for you.

In most cases, the earlier vaginal cancer is diagnosed, the better the chances of successful treatment and cure.

Test results, the type of vaginal cancer you have, the rate and depth of tumour growth, how well you respond to treatment, and other factors such as age, fitness and medical history are all important in assessing your prognosis.

Which health professionals will I see?

Your GP (general practitioner) will probably arrange the first tests to assess your symptoms. You will then be referred to a gynaecological oncologist.

You will be cared for by a range of health professionals who specialise in different aspects of your treatment. This is called a multidisciplinary team or MDT.

Health professional	Role
gynaecological oncologist	a surgeon who specialises in treating gynaecological cancers, such as cancer of the vagina
radiation oncologist	prescribes and coordinates the course of radiotherapy
medical oncologist	prescribes and coordinates the course of chemotherapy
cancer care coordinator	provides support throughout treatment and liaises with other health professionals
nurses	administer treatment and provide support and assistance through all stages of your treatment, including recovery
dietitian	recommends the best eating plan to follow when you are in treatment and recovery
sex counsellor	helps you deal with physical or emotional issues affecting your sexuality
social worker	advises you on support services
physiotherapist, occupational therapist	assist you with getting back to normal activities
counsellor, psychologist	provide emotional support and help manage anxiety and depression

Treatment

Treatment depends on a number of factors including your general health and the stage, grade and type of cancer you have.

Treatment may involve radiotherapy, surgery and chemotherapy. You may have one of these treatments or a combination.

Radiotherapy

Radiotherapy is the treatment of cancer using high-energy x-rays to kill or destroy cancer cells. It is a common treatment for women with cancer of the vagina. Some women are treated with a combination of radiotherapy and chemotherapy (see page 44). It can also be used to control symptoms of advanced cancer.

Radiotherapy can be delivered in two ways: externally or internally. Most women with vaginal cancer have both types of radiotherapy. Your radiation oncologist will recommend the type of treatment most suitable for you.

External radiotherapy – External radiotherapy, also called external beam radiotherapy or EBRT, means that radiotherapy beams are directed at the cancer from outside the body. You will lie on a treatment table and under the machine that delivers radiation.



External radiotherapy will not make you radioactive. It is safe for you to be with other people, including children, after your treatment sessions are over and when you are at home.

External radiotherapy is usually given as a series of 10–15 minute daily treatments, Monday to Friday, over 4–6 weeks. The exact number of sessions you have will depend on the type and size of the cancer.

Radiotherapy to the vagina is a painless treatment, but it can cause side effects. The side effects you experience depend on your radiotherapy dose and the length of your treatment.

Internal radiotherapy – Internal radiotherapy, also called brachytherapy, is a way of delivering radiotherapy directly to the tumour from the inside of your body. You may have this after finishing a course of external radiotherapy.

A thin, temporary radioactive applicator, shaped like a tampon, will be put into your vagina. Some women are given a general anaesthetic and have other small probes inserted near the cancer. You will have to lie still while this is in place. You will receive treatment through the applicator or probes – either as low-dose or high-dose treatment (see page 40).

For both types of brachytherapy, the tissue around the applicator will become swollen. This usually settles by the time it is removed, but the treated area will feel sore afterwards. The pain should ease over a couple of weeks. Your doctor can prescribe pain-killers to help relieve the discomfort.

To find out about side effects see page 41. For further information about radiotherapy and its side effects, call Cancer Council 13 11 20.

Types of internal radiotherapy

Low-dose rate (LDR)

- Treatment is delivered in hospital over 1–5 days.
- The applicator is inserted into the vagina, and held in place by gauze or stitches. You will be given pain medication so you are more comfortable.
- A machine delivers the radiation through the applicator.
- You will need to stay in bed during treatment to keep the applicator from moving. A tube (catheter) in your bladder will drain urine.
- Family and friends can visit you for short periods, but children and pregnant women won't be allowed to see you to avoid the chance of them being exposed to radiation.
- Being alone can be difficult. Ask if you can bring things to do (e.g. books, mobile phone). Discuss your feelings with your medical team.

High-dose rate (HDR)

- You can have treatment as an inpatient or outpatient.
- An intense dose can be delivered in a few hours.
- The applicator is inserted into your vagina. You will be given pain medication to help make you more comfortable.
- A machine delivers the radiation through the applicator for 10–15 minutes. The applicator is taken out after the dose of radiation is delivered.
- If several treatment sessions are needed, the applicator will be re-inserted each time, but the doctor may use some techniques to make it easier to get the applicator in the right place.
- Once the treatment is completed, it will be safe for you to be around other people, including children.

Side effects of radiotherapy

The most common effects occur during or soon after radiotherapy, but will vary depending on the dose and length of your treatment:

Narrowing of the vagina – Radiotherapy can shorten and narrow the vagina, which may make sex and follow-up pelvic examinations uncomfortable or difficult. See pages 61–62.

Bleeding and discharge – You may have slight bleeding or discharge from the vagina once the radiotherapy has ended. If this continues or becomes heavy, let your doctor or nurse know.

Hair loss – You may lose your pubic hair. For some women, this can be permanent.

Bowel and bladder problems – Radiotherapy can temporarily cause inflammation to the lining of the bladder (cystitis) and loose stools (diarrhoea). A longer-term side effect may be blood in your urine or stools. See page 51.

Lymphoedema – Radiation to the groin can increase the risk of swelling in the legs. See page 53.

Menopause – If you have cancer of the vagina and have radiotherapy to the pelvis, your ovaries may stop producing hormones and you may go through menopause. During menopause, your periods will stop and you may have symptoms such as hot flushes, dry or itchy skin, mood swings, or loss of libido (interest in sex). See page 54.

Surgery

The cancer may need to be removed with an operation.

The surgeon will try to remove all of the cancer along with some surrounding healthy tissue, called a margin. This helps reduce the risk of the cancer coming back. Some lymph nodes in your pelvis may also be removed.

Types of vaginal surgery

There are a number of different operations for cancer of the vagina. The type of surgery you have depends on the size and position of the cancer.

- **Removing part of the vagina (partial vaginectomy)** – The affected part of the vagina is removed.
- **Removing the whole vagina (radical vaginectomy)** – The entire vagina is removed. In some cases, a plastic (reconstructive) surgeon can make a new vagina using skin and muscle from other parts of your body. This is called vaginoplasty or vaginal reconstruction, and it may be done to improve the appearance of your genitals.

Some women also need to have a radical hysterectomy. This means the uterus and cervix are removed. Your gynaecological oncologist will let you know whether it is also necessary to remove your ovaries and fallopian tubes (salpingo oophorectomy). If you have this type of surgery, it will cause menopause. See page 54 for ways to manage menopause.

What to expect after surgery

Pain-killers	You will be given medication to reduce any pain. Tell your doctor or nurses if you are uncomfortable so they can adjust the dose.
Catheter	A tube called a catheter will drain urine and will help keep your wound clean and dry. This will be removed within a few days.
Exercise and movement	You will be encouraged to start moving around as soon as possible after your operation. While you are in hospital, you may wear leg compression garments and be given injections of medication to prevent blood clots forming (thrombosis). The nurse or a physiotherapist can help you do regular gentle leg exercises to prevent thrombosis, as well as deep breathing exercises to prevent a chest infection.
Sexuality	<p>Depending on the amount of tissue removed, the remaining or reconstructed vagina may be stretched so that you may still be able to have sexual intercourse. However, scar tissue in your vagina can cause pain and you may not be able to have an orgasm through penetration.</p> <p>Surgery to the vagina does not affect the clitoris, so it is still possible to have an orgasm through direct stimulation, oral sex and masturbation. For tips about dealing with changes to your sex life, see pages 61–62.</p>

Recovery after surgery

The length of your hospital stay and the side effects that you experience will depend on the type of surgery you have. Most women are in hospital for a few days to a week.

When you return home, you will need to take it easy. You may not be able to lift anything heavy or drive for 6–8 weeks.

Chemotherapy

Chemotherapy uses cytotoxic drugs to kill or slow the growth of cancer cells. This treatment is usually given if the cancer is advanced or if it returns after treatment. Chemotherapy is usually given with surgery or radiotherapy.

Drugs are sometimes given as tablets or, more commonly, by injection into a vein (intravenously). You will usually have a treatment session, followed by a break. Treatment can often be given to you during visits to a hospital or clinic as an outpatient, but sometimes you may spend a few days in hospital.

Side effects of chemotherapy

Most people have some side effects from chemotherapy. There are many different types of chemotherapy drugs and the side effects vary depending on the drugs used. However, these can usually be controlled with medication.

Common problems include feeling sick (nausea), tiredness, hair loss and a reduced resistance to infections. Chemotherapy may also increase any skin soreness caused by radiotherapy.

Some people find that they are able to lead a fairly normal life during their treatment, while others become very tired and need to take things more slowly. Do as much as you feel you can, and try not to overdo it. For more information, call 13 11 20 for a free booklet about chemotherapy and its side effects.

Palliative treatment

Palliative treatment helps to improve quality of life by reducing symptoms of cancer when it is no longer possible to cure the disease. It is particularly important for people with advanced cancer, but it's not just for end of life care and it can be used at different stages of cancer.

Often treatment is concerned with pain relief. You may be given radiotherapy, chemotherapy or other medication. However, palliative treatment can also involve the management of other physical and emotional issues.

You can call Cancer Council 13 11 20 for free booklets about palliative care and advanced cancer.



Key points

- The two most common types of primary vaginal cancer are squamous cell carcinoma and adenocarcinoma.
- Symptoms include discharge, pain during sex, bleeding and a lump in the vagina.
- Conditions such as vaginal intraepithelial neoplasia (VAIN) can increase your risk. Female children of women who took a drug called diethylstilboestrol (DES) during pregnancy are also at an increased risk.
- Diagnostic tests may include a Pap smear, an examination of your vagina (colposcopy) and a tissue sample (biopsy).
- The stage of the cancer describes its size and if it has spread. The grade tells how quickly the cells are growing.
- Your doctor will talk to you about your prognosis. The earlier vaginal cancer is diagnosed, the better the chances of successful treatment.
- You may see a range of health professionals, including a gynaecological oncologist.
- Radiotherapy uses x-rays to destroy cancer cells. Most women have external and internal radiotherapy (brachytherapy). Side effects vary depending on the type of radiotherapy you have.
- During surgery, the affected part of the vagina is cut out. Other organs may also be removed.
- Chemotherapy uses drugs to kill cancer cells. It is usually given if the cancer is advanced or if it returns after treatment.
- Palliative treatment may be given to manage cancer symptoms and improve quality of life.



Managing side effects

It will take some time to recover from your treatment for vulvar or vaginal cancer. As well as physical changes, you will also have to cope with the emotional impact of treatment – see page 60.

Treatment side effects can vary. Some women will have a few side effects; others will have more. Side effects may last from a few weeks to a few months or, in some cases, years or permanently. There are ways to reduce or manage the discomfort that physical side effects cause.

Shortening and narrowing of the vagina

Treatments for vaginal cancer can affect the vagina.

- **Radiotherapy** – This can make the pelvic area tender during the course of radiotherapy and for a few weeks after it ends. In the long term this irritation can leave scarring, which makes the vagina narrower and less flexible.
- **Surgery** – This may cause scar tissue to form around the outside of the vulva, narrowing the entrance to the vagina. This can make intercourse painful.

You may be advised to use a vaginal dilator to help keep the vaginal walls open and supple. A dilator is shaped like a tampon and is made from plastic or rubber. Used with a lubricant, it is usually inserted into the vagina for up to five minutes daily or every second day.

Using the dilator may keep the vagina from closing over, and allow your doctor to do a vaginal examination at follow-up visits to check for a recurrence of cancer. Regular use of the dilator can also make vaginal sex more comfortable. Your nurse or doctor can give you more detailed instructions about how to use it.

Ask your doctor if applying a hormone cream to your vagina will help. Creams are available on prescription.

Although shortening and narrowing of the vagina can make sexual intercourse uncomfortable or difficult, having intercourse regularly – if you are able to – may help prevent the vagina from narrowing. Using a water or silicone-based lubricant, such as Sylk™, pjur® or Astroglide®, and trying different sexual positions can help.

Some women do not have a sexual partner or do not feel emotionally or physically ready to have penetrative sex after cancer treatment. If you do not want to have sex, you should talk to your doctor about ways to keep your vagina open.

Changes to your body

Women who have had surgery to their genital region have different feelings about looking at changes to their genital area.

Some women don't want to look at the area or prefer to do it alone or with a partner or close friend. Others want a nurse to be with them when they look for the first time. A nurse can explain the changes to the vulvar area and can offer professional support and

“ I asked my husband to take pictures of my vulva so we could see it and talk about what happened. This helped him understand what I’d been through. ” *Trudy*

advice. Whoever you choose, make sure it is someone you trust and you can talk to openly about your feelings.

If you decide to look at your vulva, it is natural to feel shocked by any changes. If the labia have been removed, you will be able to see the opening to the vagina more clearly. If scar tissue has formed around the outside of the vagina, the entrance to the vagina will be narrower. If the clitoris has been removed, there will now be an area of flat skin without the usual folds of the vulva.

Tiredness

It is common to feel tired or fatigued during and after treatment. This is not only a side effect of the treatments. Travelling to treatment and dealing with your emotions can also cause fatigue.

Your tiredness may continue for a while after treatment has finished. Some women find it takes them a few years to feel well again. You may need to plan your activities so you can rest regularly. It can also be a good idea to ask family and friends for help and support.

For free printed information on life after cancer, call Cancer Council 13 11 20 and ask for a copy of *Living Well After Cancer*.



Kayleen's story

I had a painful lump on my vulva for about two years, and I was diagnosed with cancer two weeks before my wedding.

The cancer was advanced and had spread to my lymph nodes, so I had a vulvectomy to remove tissue all the way down to the bone. I also had six weeks of radiotherapy, which made the skin down there feel burnt and blistered. It took months to recover from treatment. There have been a lot of side effects. For instance, certain pants are still uncomfortable. And although I can urinate, I've had a few bladder infections.

In terms of sex, it would be possible to have penetrative intercourse, but it's too painful. I've had four children, and I'd rather go through the pain of childbirth than have sex. I don't want to be touched down there.

My partner's been fantastic and incredibly supportive – I couldn't

ask for anyone better. I'm part of a Facebook community and I know women whose partners haven't coped with it, especially if the woman can't have sex. My partner and I have found other ways to be intimate.

I've struggled with shame and depression throughout treatment and recovery. Since surgery, I've looked at my vulva from above. I haven't wanted to examine it closely with a mirror. It's a sensitive issue for me.

It's too bad that people don't know more about this cancer. You hear about common types, like breast cancer. But even many GPs didn't know much about vulvar cancer – the GPs I saw thought I had genital warts.

I'm over the embarrassment. If people ask, I tell them what type of cancer I had. If no-one talks about it, people won't know. I didn't know vulvar cancer existed before I was diagnosed.

Bowel and bladder problems

Radiotherapy can cause bladder and bowel problems. Most side effects are temporary, but for some women, the changes are permanent. Talk to your doctor for more information.

Cystitis – Inflammation to the lining of the bladder can make you feel like you want to pass urine frequently or give you a burning sensation when you pass urine. This is called cystitis. Try to drink plenty of water to make your urine less concentrated. Your doctor may be able to prescribe medication to help make you more comfortable.

Bleeding – The blood vessels in the bowel and bladder can become more fragile after radiotherapy treatment and this can cause blood to appear in the urine or stools. It may occur many months or years after treatment.

If you notice any bleeding, let your doctor know so that tests can be done and the appropriate treatment can be given.

Changed bowel movements – Some women have constipation or diarrhoea after treatment. You may also feel some pain in your abdomen. Your doctor may be able to prescribe medication to ease your side effects. Drinking more water may also help. Ask the hospital dietitian or nurse for advice.

Incontinence – Accidental or involuntary loss of urine is called incontinence. After treatment, some women find that they lose a few drops of urine when they cough, sneeze, strain or lift.

For ways to manage incontinence, talk to the hospital continence nurse or physiotherapist, or call the Continence Foundation of Australia on 1800 33 00 66 or visit www.continence.org.au.

Difficulty urinating – After surgery to the genital area, your urine stream may spray in different directions or off to one side. This can be messy and frustrating. If you usually squat or crouch over the toilet seat, it may help to sit down towards the back of the toilet seat. You can also buy a reusable silicone funnel to direct the urine. Over time, the urine stream should flow in a more manageable way.

“ My vulva is uneven, which makes peeing difficult. I used paper toilet seat covers as an instant fix and I purchased a female urination device called a GoGirl™. It works like a funnel. ” *Nadine*

Skin redness and soreness

Radiotherapy may make your skin dry and itchy in the treatment area. Your skin may temporarily look red, tanned or sunburnt.

Use lukewarm water to wash your genital area and gently pat it dry with a towel. Avoid using any soaps, creams, talcum powder or perfumes on the treatment area without your doctor's approval.

Your radiotherapy nurse can give you more advice about looking after your sensitive skin.

Lymphoedema

Lymphoedema is a swelling of part of the body, usually a limb such as the leg. It can occur if your lymph nodes have been removed or damaged by radiotherapy. Lymph fluid may be unable to drain properly, which can cause swelling.

Sometimes the swelling can take months or years to develop, while some people who are at risk never develop lymphoedema.

tips

Reducing the risk of lymphoedema

- Make an appointment with a lymphoedema specialist. Visit the Australasian Lymphology Association website, www.lymphoedema.org.au, to find a practitioner and to learn more about lymphoedema.
- Reduce the risk of infection by keeping your skin moist and caring for your nails.
- Avoid cuts, burns, insect bites, sunburn and injections in your legs.
- Talk to your nurse or lymphoedema specialist about wearing special bandages, stockings or a compression garment to help move fluid.
- Do leg exercises to help move fluid out of the affected area and into other lymph channels.
- Gently massage the swollen leg towards your heart to move the fluid out to other lymph channels.
- If you see any swelling or feel any heat in your legs, let your doctor or nurse know as soon as possible. Your hospital may have a lymphoedema specialist who can help you.

Menopause

If you have cancer of the vagina and have radiotherapy to the pelvis, your ovaries may stop producing hormones and you may go through menopause. During menopause, your periods will stop and you may have symptoms such as hot flushes, dry or itchy skin, mood swings, or loss of libido (interest in sex).

Treatment for vulvar cancer does not usually cause menopause. However, if you have your ovaries surgically removed, hormone production will stop and you will go through menopause.

tips

Managing menopause

- You can use oestrogen, contained in creams or pessaries, to relieve vaginal dryness. Moisturisers without oestrogen can also be used.
- Extra lubrication may make intercourse more comfortable. To reduce irritation, choose a water or silicone-based gel without perfumes or colouring (e.g. Sylk™, pjur®, Astroglide®).
- Hormone replacement therapy (HRT) may help to reduce symptoms. Talk to your gynaecological oncologist about the benefits and risks of HRT for you. If you were already on HRT when the cancer was diagnosed, you will need to weigh up the risks of continuing it.
- Eat a healthy diet with lots of fresh fruits and vegetables, and wholegrains. Try to do some regular light exercise, if you are able. Ask your doctor for advice if you want to try any herbal remedies or diet modifications.

Infertility

If treatment causes you to go through menopause, this will mean you are no longer able to become pregnant. If this is a concern for you, talk to your doctor about your fertility and any options available to you before you start treatment. There may be some ways to preserve your fertility. To find out more, call Cancer Council 13 11 20 for a free copy of *Fertility and Cancer*.

Osteoporosis

Loss of oestrogen at menopause may also cause bones to weaken and break more easily. This is called osteoporosis.

tips

Preventing osteoporosis

- Eat three serves of calcium-rich food daily (e.g. glass of milk, tub of yoghurt, slice of hard cheese).
- Do regular weight-bearing exercise.
- Get vitamin D from limited sun exposure; aim for a few minutes in the sun on most days of the week during summer, and 2–3 hours per week during winter. If you are concerned about your vitamin D, your GP can take a blood sample to check if your levels are deficient.
- Ask your doctor about having a bone density test or taking medication to prevent your bones from becoming weak.
- Avoid smoking.
- To find out more contact Osteoporosis Australia at www.osteoporosis.org.au or call 1800 242 141.



Key points

- There are ways to reduce or manage discomfort caused by side effects.
 - Radiotherapy to the pelvic area can make the vagina narrower and less flexible. You may be advised to use a vaginal dilator or have sex to help keep the vaginal walls open and supple.
 - It is a personal decision whether or not you would like to look at your vulva after surgery. It is natural to feel anxious and upset about any changes to your body.
 - You might feel tired during and after treatment. Plan to rest regularly and get support from a community nurse, family and friends, if possible.
 - Treatment can cause bladder and bowel problems such as bleeding, incontinence or cystitis. For some women, urine may spray in different directions or off to one side.
- The urine stream will usually become more normal over time, and there are some techniques or tools (such as reusable funnels) that can assist.
- If your skin is red and sore due to radiotherapy, use lukewarm water to wash your genitals and avoid using creams, perfumes or talcum powder.
 - If your lymph nodes have been removed or damaged, you may get swelling in one or both legs. This is called lymphoedema. There are ways to prevent or reduce the swelling.
 - Treatment may cause you to go through menopause. This means your periods stop and you may have symptoms such as hot flushes and mood swings. Menopause will cause infertility. If you are concerned about your fertility, talk to your medical team about this as soon as possible.



Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast. Check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that's based on your personal values. You may also want to discuss the options with your doctor, friends and family.

You have the right to accept or refuse any treatment offered. Some people with more advanced cancer choose treatment even if it only offers a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so that they have the best possible quality of life.

Talking with doctors

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If you are confused or want clarification, you can ask questions – see page 68 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

A second opinion

You may want to get a second opinion from another specialist to confirm or clarify your doctor's recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this.

Your doctor can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the doctor who provided the second opinion.

Taking part in a clinical trial

Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment.

Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

It may be helpful to talk to your specialist or clinical trials nurse, or get a second opinion. If you decide to take part, you can withdraw at any time. For more information, call 13 11 20 for a free copy of *Understanding Clinical Trials and Research* or visit www.australiancancertrials.gov.au.



Looking after yourself

Cancer can cause physical and emotional strain. It's important to try to look after your wellbeing as much as possible.

Nutrition – Eating healthy food can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation. Call Cancer Council 13 11 20 for a free copy of the *Nutrition and Cancer* booklet.

Staying active – Physical activity may help to reduce tiredness, improve circulation and elevate mood. The amount and type of exercise you do depends on what you are used to, how you feel, and your doctor's advice. Cancer Council's *Exercise for People Living with Cancer* booklet provides more information about the benefits of exercise, and outlines simple exercises that you may want to try.

Complementary therapies – These therapies are used with conventional medical treatments. You may have therapies such as massage, relaxation and acupuncture to increase your sense of control, decrease stress and anxiety, and improve your mood. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

Alternative therapies are used instead of conventional medical treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful. For more information, call 13 11 20 for a free copy of the *Understanding Complementary Therapies* booklet or visit your local Cancer Council website.

Relationships with others

Having cancer can affect your relationships with family, friends and colleagues. This may be because cancer is stressful, tiring and upsetting, or as a result of more positive changes to your values, priorities, or outlook on life.

Give yourself time to adjust to what's happening, and do the same for others. People may deal with the cancer in different ways – for example, by being overly positive, playing down fears, or keeping a distance. It may be helpful to discuss your feelings with each other.

Effect on your emotions

Most women feel shocked and upset about having cancer in one of the most intimate and private areas of their body. It is normal to experience a wide variety of emotions, including anger, fear and resentment. These feelings may become stronger over time as you learn to cope with the physical side effects of radiotherapy, surgery or chemotherapy.

Everyone has their own ways of coping with their emotions. Some people find it helpful to talk to friends or family, while others seek professional help from a specialist nurse or counsellor. Others prefer to keep their feelings to themselves.

There is no right or wrong way to cope. Help is available if you need it. It is important to give yourself, and your partner, family and friends time to deal with the emotions that cancer can cause. Call Cancer Council 13 11 20 for support.

Sexuality, intimacy and cancer

Having cancer can affect your sexuality in both physical and emotional ways.

Treatment for gynaecological cancer can cause physical side effects such as scarring, narrowing of the vagina, swelling and soreness, and tiredness (see pages 47–56). These side effects can affect your sexual response, and you may have to explore different ways to orgasm or climax.

Cancer may reduce your desire for sex (libido). It may take some months after treatment before you begin to desire and enjoy sexual activity. Don't be surprised if you feel very unsure about it. However, for most women, sex is more than arousal, intercourse and orgasms. It involves feelings of intimacy and acceptance, as well as being able to give and receive love.

It can be difficult to talk about your sexual needs, fears or worries with your sexual partner, especially if you meet a new partner during or after treatment. Allow yourself to say no to any kind of sexual contact that does not feel right.



You may want to ask your medical team for a referral to a sex counsellor or psychologist who can help you deal with these issues, including talking to a sexual partner. Cancer Council also produces a booklet called *Sexuality, Intimacy and Cancer* – call 13 11 20 or visit your local website for a copy.

tips

Managing sexual changes

- Give yourself time to get used to any physical changes.
- Talk to your doctor about ways to prevent or reduce side effects that affect your sex life.
- Let your partner know if you don't feel like having sex, or if you find penetration uncomfortable.
- Talk to your doctor about using a vaginal moisturiser or hormone creams that can help keep vaginal tissue supple and lubricated. Hormone creams are available on prescription.
- Use a vaginal dilator and water-based lubricant to keep the vagina open, as instructed by your medical team. This will also help make follow-up examinations easier, see pages 47–48.
- Try different sexual positions to see what feels most comfortable.
- Talk about your feelings with your sexual partner, doctor, sex therapist or counsellor. You can ask your medical team for a referral.
- Explore different ways to climax. There are many other parts of your body that, when caressed, can increase sexual excitement and lead to orgasm. The breasts, inner thighs, feet and buttocks are all sensitive areas of the body.

“ My husband's support was invaluable during treatment and recovery. I know things were difficult for him – it's not easy to see someone you love go through such a hard time. But we got through it together. ” *Nikki*

Life after treatment

For most women, the cancer experience doesn't end when treatment finishes. Life after cancer treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry whether every ache and pain means the cancer is coming back.

Some women say that they feel pressure to return to 'normal life', but they don't want life to return to how it was before cancer. Take some time to adjust to the physical and emotional changes, and re-establish a new daily routine at your own pace.

Cancer Council 13 11 20 can help you connect with other people who have had cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

Follow-up after treatment

After your treatment, you will need regular check-ups to confirm that the cancer hasn't come back. Your doctor may do blood tests, x-rays or other scans.

For the first few years, you will probably have a check-up every three months. Women who have had an operation may have additional follow-up appointments with their surgeon. Check-ups will become less frequent if you have no further problems. Between follow-up appointments, let your doctor know immediately of any health problems.

If the cancer comes back after initial treatment, it is known as a recurrence.



Seeking support

Cancer may cause you to experience a range of emotions, such as fear, sadness, anxiety, anger or frustration. It can also cause practical and financial problems.

Practical and financial help

There are many services that can help deal with practical or financial problems caused by the cancer. Benefits, pensions and programs can help pay for prescription medicines, transport costs and utility bills. Home care services, aids and appliances can also be arranged to help make life easier.

Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

If you need legal or financial advice, you should talk to a qualified professional about your situation. Cancer Council offers free legal and financial services in some states and territories for people who can't afford to pay – call 13 11 20 to ask if you are eligible.

Talk to someone who's been there

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone.

People often feel they can speak openly and share tips with others who have gone through a similar experience.

You may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some people say they can be even more open and honest in these support settings because they aren't trying to protect their loved ones.

Types of support

There are many ways to connect with others for mutual support and to share information. These include:

- **face-to-face support groups** – often held in community centres or hospitals
- **telephone support groups** – facilitated by trained counsellors
- **peer support programs** – match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums** – such as www.cancerconnections.com.au.

Talk to your nurse, social worker or Cancer Council 13 11 20 about what is available in your area.



Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. Being a carer can be stressful and cause you much anxiety. Try to look after yourself – give yourself some time out and share your worries and concerns with somebody neutral such as a counsellor or your doctor.

Many cancer support groups and cancer education programs are open to carers, as well as people with cancer. Support groups and programs can offer valuable opportunities to share experiences and ways of coping.

Support services such as Home Help, Meals on Wheels or visiting nurses can help you in your caring role. There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Phone 1800 242 636 or visit www.carersaustralia.com.au for more information and resources.

You can also call Cancer Council 13 11 20 to find out more about carers' services and request a copy of the *Caring for Someone with Cancer* booklet. This booklet is also available online.



Useful websites

The internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of support and information.

Australian

beyondblue.....	www.beyondblue.org.au
Cancer Council Australia	www.cancer.org.au
Cancer Australia	canceraustralia.gov.au
Carers Australia	www.carersaustralia.com.au
Department of Health	www.health.gov.au
healthdirect Australia.....	www.healthdirect.gov.au

Gynaecological cancer websites

Australian Society of Gynaecologic Oncologists	www.asgo.net.au
Gynaecological Cancer Support	www.gynaecancersupport.org.au
Gynaecological Information Awareness Network.....	www.gain.org.au

International

American Cancer Society.....	www.cancer.org
Cancer Research UK.....	www.cancerresearch.org.uk
Eyes on the Prize.....	eyesonthepize.org
Foundation for Women's Cancer	www.foundationforwomenscancer.org
International Gynecologic Cancer Society	www.igcs.org
Macmillan Cancer Support.....	www.macmillan.org.uk
US National Cancer Institute	www.cancer.gov



Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don't understand, ask for clarification.

- What type of cancer do I have?
- How far has the cancer spread? How fast is it growing?
- What treatment do you recommend and why?
- Are there other treatment choices for me? If not, why not?
- What are the risks and possible side effects of each treatment?
- How long will treatment take? Will I have to stay in hospital?
- How much will treatment cost? How can the cost be reduced?
- Will I have a lot of pain with the treatment? What will be done about this?
- Are the latest tests and treatments for this type of cancer available in this hospital?
- Are there any clinical trials or research studies I could join?
- How frequently will I need check-ups after treatment?
- Who should I go to for my check-up appointments?
- Are there any complementary therapies that might help me?
- Should I change my diet during or after treatment?
- If the cancer comes back, how will I know?
- Where can I get emotional support, such as counselling about body image or sexuality?
- Can you refer me to a social worker or someone else who can help me access practical support?



Glossary

adenocarcinoma

A cancer that starts in the glandular tissue.

Bartholin's glands

Small glands on each side of the vagina that secrete mucus for lubrication.

brachytherapy

A type of radiotherapy treatment that implants radioactive material sealed in applicators into or near cancerous cells. Also called internal radiotherapy.

cancer

A disease of the body's cells that starts in the genes. Damaged genes cause cells to behave abnormally, and they may grow into a lump called a tumour.

chemotherapy

The use of cytotoxic drugs to treat cancer by killing cancer cells or slowing their growth.

clitoris

The main sexual pleasure organ for women. It is made up of erectile tissue with rich sensory nerve endings and becomes erect during arousal.

colposcopy

The examination of the cervix with a magnifying instrument called a colposcope, to check for abnormalities.

CT scan

A computerised tomography scan. This scan uses x-rays to create a three-dimensional picture of the body.

cystitis

Inflammation of the bladder lining.

cystoscopy

A procedure that uses a tool called a cystoscope to see inside the bladder and remove tissue samples or small tumours.

diethylstilboestrol (DES)

A synthetic hormone drug identified as a cause of vaginal cancer.

excision

A surgical procedure to remove diseased tissue. The surgeon may cut out the cancerous tissue and some tissue around it.

extramammary Paget's disease

A rare, slow-growing skin condition that affects the skin of the vulva.

gynaecological oncologist

A gynaecologist who has completed specialist training in treating women diagnosed with cancer of the reproductive organs.

gynaecologist

A doctor who specialises in treating diseases of the female reproductive system.

Human Papillomavirus (HPV)

A group of viruses that can cause infection in the skin surface of different areas of the body including the genital area. HPV may be a risk factor for some types of cancer. Also called the wart virus.

hysterectomy

The surgical removal of the uterus and the cervix.

inguinal lymph node dissection

Surgical removal of lymph nodes from the groin area.

labia

The lips of the vulva. The labia majora are the outer lips and the labia minora are the inner lips, which join at the top to cover the clitoris.

lymphoedema

Swelling caused by a build-up of lymph fluid. This happens when lymph vessels or nodes don't drain properly.

menopause

When a woman stops having periods (menstruating).

mons pubis

In women, the area of fatty tissue covered with pubic hair.

MRI scan

A magnetic resonance imaging scan. A scan that uses magnetism and radio waves to take detailed cross-sectional pictures of the body.

Pap smear

A test that can detect changes in cells of the vagina and cervix. Cells are scraped off and examined under a microscope. Also called a Pap test.

pelvic exenteration

The surgical removal of the affected organs in the pelvis.

perineum

The area of skin between the vulva (or, for males, the scrotum) and the anus.

proctoscopy

An examination of the end of the

bowel and rectum using a tool called a proctoscope.

radical hysterectomy

An operation that removes the uterus, cervix, ovaries and fallopian tubes.

radiotherapy

The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply. Internal radiotherapy is called brachytherapy.

rectum

The last 15–20 cm of the large bowel, which stores stools until a bowel movement occurs.

sarcoma

A malignant tumour that starts in the connective tissue.

sentinel lymph node biopsy

A surgical procedure used to determine if cancer has spread beyond a primary tumour into the lymphatic system.

speculum

An instrument used to hold the vagina open during an internal examination. It makes it easier to see the cervix clearly.

squamous cell carcinoma

A cancer that starts in the squamous cells of the body, such as in the skin or the vagina.

stage

Indicates the extent of a cancer and whether the disease has spread from an original site to other parts of the body.

urethra

The tube that carries urine from the bladder to the outside of the body.

vagina

A muscular canal about 8–10 cm long that extends from the entrance of the uterus to the vulva.

vaginal adenosis

Abnormal cellular changes on the surface of the vagina.

vaginal intraepithelial neoplasia (VAIN)

A benign condition of the vagina that can develop into vaginal cancer if untreated.

vaginal reconstruction

See vaginoplasty.

vaginectomy

An operation that removes all of the vagina.

vaginoplasty

An operation to create a new vagina using skin and muscle from other parts of the body. Also called a vaginal reconstruction.

verrucous carcinoma

A rare, slow-growing type of vulvar cancer that looks like a large wart.

vulva

The external sexual organs of a woman. These include the mons pubis, labia and clitoris.

vulvar intraepithelial neoplasia (VIN)

A condition that occurs in the skin of the vulva and can develop into vulvar cancer if untreated.

vulvar lichen planus

A non-cancerous condition affecting the skin in the vulvar area.

vulvar lichen sclerosus

A non-cancerous condition affecting the skin in the vulvar area.

vulvar melanoma

A type of vulvar cancer that develops from melanocytes, the pigment-producing cells that give skin its colour.

vulvectomy

Removal of some or all of the outer sex organs (the vulva). In a partial vulvectomy, part of the vulva is removed; in a radical vulvectomy, the entire vulva is removed.

vulvoscopy

An examination of the vulva using a colposcope, a microscope with a bright light.

wide local excision

An operation removing the cancer and a margin of healthy skin around it.

Can't find what you're looking for?

For more cancer-related words, visit www.cancercouncil.com.au/words or www.cancervic.org.au/glossary.



How you can help

At Cancer Council we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

Join a Cancer Council event: Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls Night In and Pink Ribbon Day, or hold your own fundraiser or become a volunteer.

Make a donation: Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

Buy Cancer Council sun protection products: Every purchase helps you prevent cancer and contribute financially to our goals.

Help us speak out for a cancer-smart community: We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

Join a research study: Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.



Cancer Council Helpline 13 11 20

Cancer Council Helpline is a telephone information service provided by Cancer Council NSW for people affected by cancer.

For the cost of a local call (except from mobiles), you can talk about any concerns confidentially with oncology health professionals. Helpline consultants can send you information and put you in touch with services in your area. If you need information in a language other than English, an interpreting service is available.

You can call the Helpline, Monday to Friday, 9am to 5pm.

If you have difficulty communicating over the phone, contact the National Relay Service (www.relayservice.com.au) to help you communicate with a Cancer Council Helpline consultant.

For more information, go to www.cancercouncil.com.au.

Regional offices

Metro Sydney

Woolloomooloo
02 9334 1600

Crows Nest
02 9334 1600

Greater Western

Sydney
Parramatta
02 9354 2000

Casula
02 9354 2000

Penrith
02 9354 2000

Hunter Central

Coast
Charlestown
02 4923 0700

Erina
02 4336 4500

Singleton
02 6571 2899

Northern

Byron Bay
02 6639 1300

Tamworth
02 6763 0900

Coffs Harbour
02 6659 8400

Lismore
02 6629 4396

Southern

North Wollongong
02 4223 0200

Bega
02 6492 1805

Western
Wagga Wagga
02 6937 2600

Orange
02 6392 0800



Cancer Council
Helpline

13 11 20

For support and information on cancer and cancer-related issues, call Cancer Council Helpline. This is a confidential service.

For further information and details please visit our website: www.cancercouncil.com.au