



Understanding Vulvar and Vaginal Cancers

A guide for people with cancer,
their families and friends

A blue circle containing the text "Cancer information". A thin orange line extends from the bottom of the circle, curving down and then left, ending in a small telephone handset icon.

Cancer
information

For information & support, call

13 11 20

Understanding Vulvar and Vaginal Cancers

A guide for people with cancer, their families and friends

First published November 2011. This edition October 2020.
© Cancer Council Australia 2020. ISBN 978 1 925651 97 3

Understanding Vulvar and Vaginal Cancers is reviewed approximately every two years.
Check the publication date above to ensure this copy is up to date.

Editors: Rosemary McDonald and Ruth Sheard. Designer: Eleonora Pelosi. Printer: SOS Print + Media Group.

Acknowledgements

This edition has been developed by Cancer Council NSW on behalf of all other state and territory Cancer Councils as part of a National Cancer Information Subcommittee initiative.

We thank the reviewers of this booklet: A/Prof Alison Brand, Director, Gynaecological Oncology, Westmead Hospital, NSW; Ellen Barlow, Clinical Nurse Consultant, Royal Hospital for Women, NSW; Jane Conroy-Wright, Consumer; Rebecca James, 13 11 20 Consultant, Cancer Council SA; Suparna Karpe, Clinical Psychologist, Gynaecological Oncology, Westmead Hospital, NSW; Dr Pearly Khaw, Consultant Radiation Oncologist, Peter MacCallum Cancer Centre, VIC; Sally McCoull, Consumer; A/Prof Orla McNally, Gynaecological Oncologist and Director, Oncology/Dysplasia, The Royal Women's Hospital, and Director, Gynaecology Tumour Stream, Victorian Comprehensive Cancer Centre, VIC; Haley McNamara, Social Worker and Project Manager, Care at End of Life Project, Queensland Health, QLD; Tamara Wraith, Senior Clinician – Physiotherapy, The Royal Women's Hospital, VIC. We also thank the health professionals, consumers and editorial teams who have worked on previous editions of this title.

This booklet is funded through the generosity of the people of Australia.

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

Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit cancer.org.au or call your local Cancer Council.



Cancer Council Australia

Level 14, 477 Pitt Street, Sydney NSW 2000

Telephone 02 8063 4100 **Facsimile** 02 8063 4101

Email info@cancer.org.au **Website** cancer.org.au

ABN 91 130 793 725

About this booklet

This booklet has been prepared to help you understand more about vulvar and vaginal cancers. Many people feel shocked and upset when told they have cancer. We hope this booklet helps you, your family and friends understand how vulvar and vaginal cancers are diagnosed and treated. We also include information about support services.

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, this information may answer some of your questions and help you think about what to ask your treatment team (see page 68 for a question checklist).

This booklet contains separate information for vulvar cancer and vaginal cancer – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary (see page 69). You may also like to pass this booklet to family and friends for their information.

How this booklet was developed

This information was developed with help from a range of health professionals and people affected by vulvar and vaginal cancers. It is based on international clinical practice guidelines.¹⁻²

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. You can also visit your local Cancer Council website (see back cover).



**Cancer
Council
13 11 20**

Contents

What is cancer?	4
-----------------------	---

The vulva and the vagina	6
--------------------------------	---

Making treatment decisions.....	8
---------------------------------	---

Which health professionals will I see?.....	10
---	----

Vulvar cancer 12

What is vulvar cancer?	12
------------------------------	----

What are the types of vulvar cancer?.....	12
---	----

What are the symptoms?	13
------------------------------	----

How common is it?	14
-------------------------	----

What are the risk factors?	14
----------------------------------	----

Diagnosis.....	16
----------------	----

Staging vulvar cancer.....	20
----------------------------	----

Prognosis	21
-----------------	----

Treatment.....	22
----------------	----

Surgery	22
---------------	----

Radiation therapy	29
-------------------------	----

Chemotherapy.....	33
-------------------	----

Palliative treatment.....	34
---------------------------	----

Vaginal cancer 36

What is vaginal cancer?	36
-------------------------------	----

What are the symptoms?	37
------------------------------	----

How common is it?	38
-------------------------	----

What are the risk factors?.....	38
---------------------------------	----

Diagnosis.....	40
----------------	----

Staging vaginal cancer	41
------------------------------	----

Prognosis	42
-----------------	----

Treatment.....	43
Radiation therapy	43
Surgery	46
Chemotherapy.....	47
Palliative treatment.....	48
Managing side effects.....	50
Fatigue.....	50
Changes to the vulva.....	51
Changes to the vagina	52
Bladder and bowel changes.....	54
Lymphoedema.....	56
Menopause.....	57
Impact on sexuality	58
Looking after yourself	60
Life after treatment	62
Follow-up appointments	63
What if the cancer returns?	63
Seeking support	64
Support from Cancer Council	65
Useful websites	66
Caring for someone with cancer	67
Question checklist.....	68
Glossary	69
How you can help.....	72



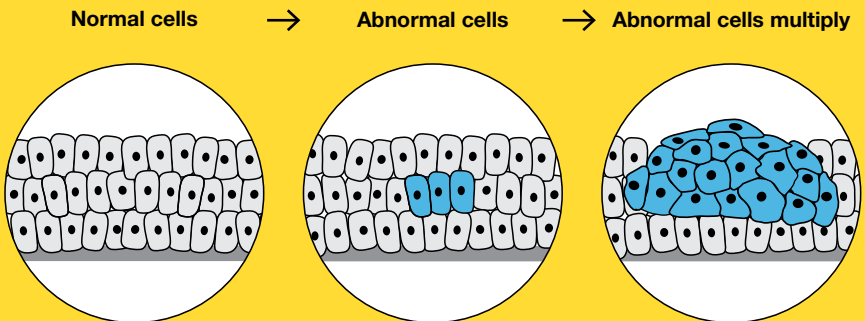
What is cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks – they make up tissues and organs. 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, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. In solid cancers, such as vulvar or vaginal cancer, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into

How cancer starts

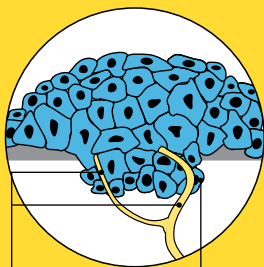


cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops is called the primary cancer. It is considered localised cancer if it has not spread to other parts of the body. If the primary cancer 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 bones is called metastatic vaginal cancer, even though the main symptoms may be coming from the bones.

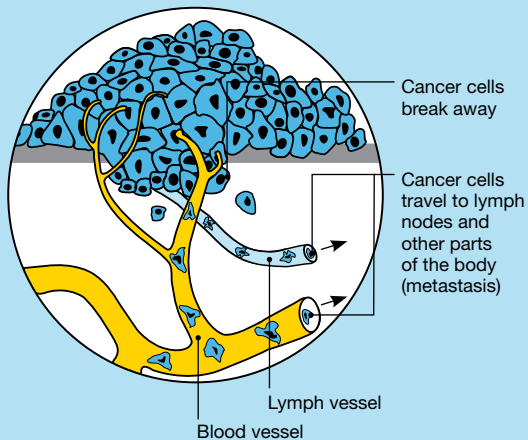
How cancer spreads

→ Malignant cancer



Grows own
blood vessels
(angiogenesis)

Invades
surrounding
tissue



Cancer cells
break away

Cancer cells
travel to lymph
nodes and
other parts of
the body
(metastasis)

Lymph vessel

Blood vessel



The vulva and the vagina

The vulva and the vagina are parts of the female reproductive system, which also includes the ovaries, fallopian tubes, uterus and cervix.

The vulva

The vulva is a general term for a female's external sexual organs (genitals). The main parts of the vulva are the:

- **mons pubis** – the soft, fatty mound of tissue covered with pubic hair, above the labia
- **labia majora** – two large, outer fleshy lips, which surround and protect the inner lips known as labia minora
- **labia minora** – two inner lips (may be smaller or thinner than the labia majora)
- **clitoris** – the main organ for sexual pleasure in females. It is located where the labia minora join at the top of the vulva. During arousal, the clitoris fills with blood and becomes erect, and touching it can lead to sexual climax (orgasm)
- **Bartholin glands** – two small glands near the opening of the vagina. They produce mucus to moisten (lubricate) the vagina.

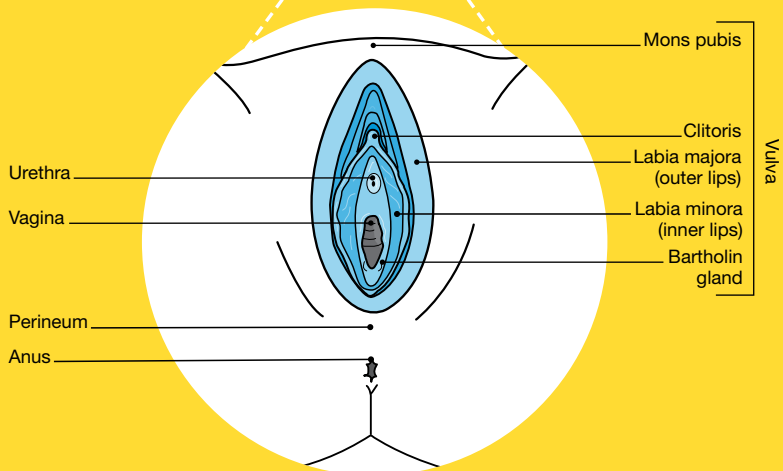
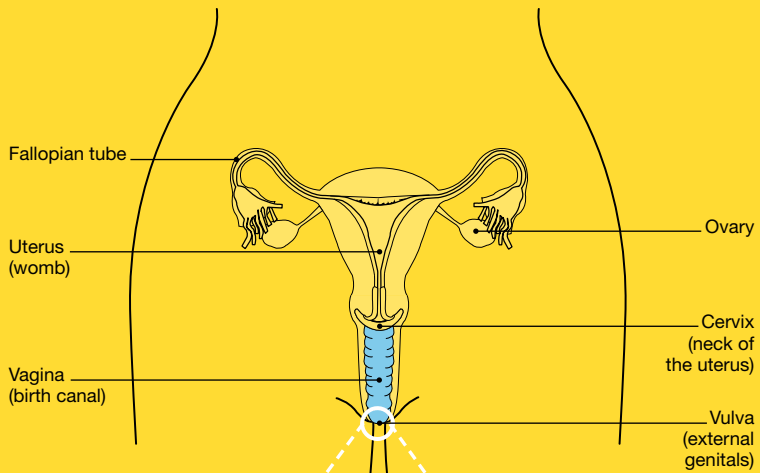
The vagina

Sometimes called the birth canal, the vagina is a muscular tube about 7–10 cm long that extends from the cervix to the vulva. The vaginal opening is where menstrual blood flows out of the body during a period, sexual intercourse occurs, and a baby leaves the body.

Urethra, anus and perineum

Below the clitoris is the urethra, for passing urine. Further down is the entrance to the vagina, and behind that is the anus. The area of skin between the vagina and the anus is called the perineum.

The female reproductive system





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, or you might be anxious to get started. Check with your specialist how soon treatment should begin – often it won't affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as you can before making a decision.

Know your options – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see pages 10–11) and if the treatment centre is the most appropriate one for you. You may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

Record the details – When your doctor first tells you that you have cancer, you may not remember everything you are told. Taking notes can help, or you might like to ask if you can record the discussion. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

Ask questions – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 68 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

Consider a second opinion – You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or reassure you that you have explored all options.

Specialists are used to people doing this. Your general practitioner (GP) or specialist 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 second specialist.

It's your decision – Adults have the right to accept or refuse any treatment that they are offered. For example, some people with advanced cancer choose treatment that has significant side effects even if it gives only a small benefit for a short period of time. Others decide to focus their treatment on quality of life. You may want to discuss your decision with the treatment team, GP, family and friends.

► See our *Cancer Care and Your Rights* booklet.

Should I join 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.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time.

For more information, visit australiancancertrials.gov.au.

► See our *Understanding Clinical Trials and Research* booklet.

Which health professionals will I see?

Your GP will arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a specialist, such as a gynaecologist or gynaecological oncologist. The specialist will arrange further tests.

If vulvar or vaginal cancer is diagnosed, the specialist will consider treatment options. Often these will be discussed with other health

Health professionals you may see

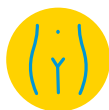
GP	assists with treatment decisions; works in partnership with your specialists in providing ongoing care
gynaecologist*	specialises in diseases of the female reproductive system; may diagnose vulvar or vaginal cancer and then refer you to a gynaecological oncologist
gynaecological oncologist*	diagnoses and performs surgery for cancers of the female reproductive system (gynaecological cancers), such as vulvar and vaginal cancers
radiation oncologist*	treats cancer by prescribing and overseeing a course of radiation therapy
medical oncologist*	treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy
reconstructive/ plastic surgeon*	performs surgery that restores, repairs or reconstructs the appearance and function of the genitals after the cancer is removed

professionals at what is known as a multidisciplinary team (MDT) meeting. During and after treatment, you will see a range of health professionals who specialise in different aspects of your care.

To ensure the best outcome, it is recommended that you are treated in a specialist centre for gynaecological cancer. Call Cancer Council 13 11 20 for more information and to ask about patient travel assistance that may be available.

nurse	administers drugs and provides care, information and support throughout treatment
cancer care coordinator	coordinates your care, liaises with other members of the MDT and supports you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)
psychiatrist*, psychologist, counsellor	helps you manage your emotional response to diagnosis and treatment; may also help with emotional issues affecting sexuality
social worker	links you to support services and helps you with emotional, practical and financial issues
dietitian	recommends an eating plan to follow while you are in treatment and recovery
women's health physiotherapist	treats physical problems associated with treatment for gynaecological cancers, such as bladder and bowel issues, sexual issues and pelvic pain

* *Specialist doctor*



Vulvar cancer

This chapter discusses symptoms, risk factors, diagnosis and treatment of vulvar cancer (also known as vulval cancer or cancer of the vulva). For information about managing treatment side effects, see pages 50–59.

Q: What is vulvar cancer?

A: Vulvar cancer can start in any part of the external female sex organs (genitals) – see diagram, page 7. It most commonly develops in the labia majora, labia minora and the perineum. Less often, it involves the clitoris, mons pubis or Bartholin glands.

Q: What are the types of vulvar cancer?

A: The types of vulvar cancer are named after the cells they start in.

Squamous cell carcinoma (SCC) – the most common type, accounting for about 90% of all vulvar cancers in Australia. It starts in the thin, flat (squamous) cells covering the vulva. The two main subtypes of vulvar SCC are keratinising and warty or basaloid. Verrucous carcinoma is a rare subtype that looks like a large wart and grows slowly.

Vulvar (mucosal) melanoma – about 2–4% of vulvar cancers. It starts in the cells that give the skin its colour (melanocytes), which are also found in the lining of the vulva. Vulvar melanomas are not related to having too much ultraviolet radiation from the sun.

Sarcoma – a rare type that starts in cells in muscle, fat and other tissue under the skin. It tends to grow faster than other types.

Adenocarcinoma – a rare type that develops from the mucus-producing (glandular) cells in the Bartholin glands or other vulvar glands.

Basal cell carcinoma (BCC) – although the most common form of skin cancer, BCC is a very rare type of vulvar cancer. It starts in the tall (basal) cells in the skin's lower layer.

Q: What are the symptoms?

A: There are often few obvious symptoms of early vulvar cancer. The cancer is commonly diagnosed after a history of vulvar symptoms over several months or years. These may include:

- itching, burning and soreness or pain in the vulva
- a lump, sore, swelling or wart-like growth on the vulva
- thickened, raised skin patches (may be red, white or dark brown)
- a mole on the vulva that changes shape or colour
- blood, pus or other discharge coming from an area of skin or a sore spot in the vulva, which may have a strong or unusual smell or colour (not related to your menstrual period)
- an ulcer that won't heal
- hard or swollen lymph nodes in the groin area.

Some symptoms are obvious, while others need to be touched or seen. Most people don't look at their vulva, so they don't know what is normal for them. The vulva can be difficult to see without a mirror, and some people feel uncomfortable examining their genitals. If you feel any pain in your genital area or notice any of these symptoms, visit your GP for a check-up.

Q: How common is it?

A: Vulvar cancer is not common – each year in Australia, about 390 women are diagnosed with vulvar cancer.³ Although it most commonly affects women who have gone through menopause, diagnoses of vulvar cancer in women under 60 have increased in recent years. This is likely to be due to rising rates of infection with human papillomavirus (HPV, see below).⁴ Anyone with a vulva can get vulvar cancer – women, transgender men and intersex people. For information specific to your situation, speak to your doctor.

Q: What are the risk factors?

A: The exact cause of vulvar cancer is unknown, but there are several things that increase the risk of developing it.

Vulvar intraepithelial neoplasia (VIN) – This is a precancerous condition that causes changes in the skin of the vulva. The vulva may itch, burn or feel sore. Often there are no symptoms at all. VIN may disappear on its own, but some people need treatment. The condition sometimes becomes cancerous – about one in three women diagnosed with vulvar cancer also has VIN.

Human papillomavirus (HPV) – HPV is a sexually transmitted infection that can cause people to develop VIN. It can be many years between infection with HPV and the first signs of VIN or vulvar cancer. HPV is a common virus and most people with this virus don't develop vulvar or any other type of cancer. Although HPV is sexually transmitted, vulvar cancer itself is not contagious and it can't be passed on to other people through sexual contact.



HPV has been linked to several cancers, including vulvar, vaginal, cervical, anal, and mouth and throat cancers. Studies have shown that HPV vaccination can reduce the risk of developing abnormal cell changes that may lead to cancer, even at an older age. Talk to your doctor about whether the HPV vaccination may be of benefit to you.

Abnormal cervical screening test – If any abnormal cell changes are found on a cervical screening test (see page 18), you have a slightly higher risk of developing vulvar cancer.

Other skin conditions – Vulvar lichen planus, vulvar lichen sclerosus and extramammary Paget’s disease are skin conditions that can cause itching and soreness. If not treated, they can cause permanent scarring, narrow the vaginal opening and, in a small number of people, develop into vulvar cancer after many years.

Other cancers – If you have had cervical cancer or vaginal cancer, you have an increased risk of developing vulvar cancer.

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

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

Diagnosis

The main tests used to diagnose vulvar cancer are a physical examination, a procedure called a colposcopy and, most importantly, the removal of a tissue sample (biopsy). Because vulvar cancer is sometimes associated with cervical and vaginal cancers, the doctor may also check for abnormal cells in the cervix and vagina.

Physical examination

Your doctor will ask to do a physical examination of your groin and pelvic area, including the genitals. You will remove your clothing from the waist down, then lie on a table with your knees up and legs apart. If you feel embarrassed or scared about this examination, let your doctor know. A nurse may be present, but you can also ask for a family member or friend to be in the room with you for support.

Although the vulva is the outer part of your genitals, the doctor may also do an internal examination at the same time to check your vagina and cervix. This involves the doctor gently inserting an instrument with smooth, curved sides (speculum) into your vagina. A lubricant is used to make the speculum easier to insert. The sides of the speculum spread the vaginal walls apart so the doctor can see the vagina and cervix. If you have a skin condition (such as lichen planus or lichen sclerosus) that has narrowed the vagina, this examination may be done under a general anaesthetic.

“ I felt uncomfortable for a few days after having the colposcopy and biopsy, but a hot water bottle and mild painkillers helped. ” *Gina*

Colposcopy

The doctor uses a magnifying instrument called a colposcope to look at the vulva, vagina and cervix in detail. The colposcope is placed near your vulva but does not enter your body. A colposcopy that examines the vulva is sometimes called a vulvoscopy, and one that examines the vagina may be called a vaginoscopy.

You will lie on your back on an examination table or semi-upright on a colposcopy chair, with your knees up and apart. The doctor will use a speculum to spread the walls of the vagina apart, and then apply a vinegar-like liquid or iodine to your vulva and vagina. This makes it easier to see abnormal cells through the colposcope. The liquid may sting or burn, and you may have a brown discharge afterwards. During a colposcopy, the doctor will usually take a biopsy (see below) from the vulva and/or the vagina.

You will be advised not to have sex or put anything in your vagina (e.g. tampons, medicine) for 24 hours before a colposcopy. Talk to your doctor about whether you should take over-the-counter pain medicines about an hour before the procedure to ease discomfort.

Biopsy

During a colposcopy, your doctor will usually take a small tissue sample (biopsy) from the vulvar area and possibly also the vaginal area. A biopsy is the best way to diagnose vulvar cancer.

The doctor will usually put a local anaesthetic into the affected area of your vulva to numb it before the biopsy. There should not be any pain when the sample is taken, but you may feel a little discomfort.

If large areas of the vulva look suspicious, you may have several biopsies taken under general anaesthetic. This is known as vulvar mapping and it helps the doctor plan the best treatment for you.

After the biopsy, your vulva may bleed a little. Sometimes stitches are needed to close up the wound. Your doctor will explain how much bleeding to expect afterwards and how to care for the wound. You may have some soreness, which can be relieved by taking painkillers. You will be advised not to have sex or put anything in your vagina (e.g. tampons, medicine) for 24 hours after the biopsy.

The tissue sample will be sent to a laboratory, and a specialist doctor called a pathologist will look at 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.

Cervical screening test

If you haven't had one recently, your doctor may do a cervical screening test. This test has replaced the Pap test.

The cervical screening test looks for cancer-causing types of HPV in a sample of cells taken from the cervix or vagina. While the speculum is in place for the physical examination, the doctor will use a small brush or swab to remove some cells from the surface of the cervix. This can feel slightly uncomfortable, but it usually takes only a minute or two.

The sample is sent to a laboratory to check for HPV. If HPV is found, the pathologist will do an additional test on the sample to check for cell changes.

Further tests


Once the cancer is confirmed, you may have some of the following tests to determine the size of the cancer and find out whether it has spread.

Blood tests – These check your general health, and how well your kidneys and liver are working.

Chest x-ray – This painless scan produces an image of your lungs.

CT scan – A CT (computerised tomography) scan uses x-ray beams to create detailed pictures of the inside of your body. Before the scan, you may be given a drink or injection of a dye called contrast that makes the pictures clearer. The CT scanner is large and round like a doughnut. You will lie on a flat table that moves in and out of the scanner. The scan is painless and takes 5–10 minutes.

MRI scan – An MRI (magnetic resonance imaging) scan uses a magnet and radio waves to create detailed pictures of the inside of your body. Sometimes dye is injected before the scan to make the pictures clearer. You will lie on a treatment table that slides into a metal cylinder that is open at both ends. The machine can be quite noisy, but you will usually be given earplugs or headphones. If you think you may become distressed or are claustrophobic, talk to the medical team beforehand – they may offer you medicine to help you relax.



Before having scans, tell the doctor if you have any allergies or have had a reaction to contrast during previous scans. You should also let them know if you have diabetes or kidney disease or are pregnant.

Ultrasound – Uses soundwaves to create a picture of an area of your body. It may be used to check the lymph nodes in your groin.

PET-CT scan – A PET (positron emission tomography) scan combined with a CT provides more detailed information about the cancer. Only some people need this test, and it is currently not funded by Medicare for vulvar cancer.

Proctoscopy – The doctor uses a slender tube with a camera and light (proctoscope) to look inside the rectum and anus. This can be done under local or general anaesthetic.

Cystoscopy – The doctor uses a slender, flexible tube with a camera and light (cystoscope) to look inside the urethra and bladder. This can be done under local or general anaesthetic.

Staging vulvar cancer

Based on the test results, 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 from the vulva to other parts of the body.

Your doctor may also tell you the grade of the cancer cells. This gives you an idea of how fast the cancer may grow. Low-grade (grade 1) 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 health care team recommend the most appropriate treatment for you.

Stages of vulvar cancer

In Australia, vulvar cancer is usually staged using the staging system from the International Federation of Gynecology and Obstetrics (FIGO).

stage 1	Cancer is found only in the vulva or perineum.
stage 2	Cancer is found in the vulva and/or perineum and has also spread to the lower urethra, the lower vagina or the anus.
stage 3	Cancer is found in the vulva and/or perineum and in lymph nodes of the groin (it can be stage 3 whether or not it has spread to the urethra, vagina or anus).
stage 4	Cancer has spread to the upper urethra, upper vagina or more distant 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 anyone to predict the exact course of the disease. Instead, your doctor can give you an idea about the general prognosis for people with the same type and stage of vulvar cancer. In most cases, the earlier vulvar cancer is diagnosed, the better the chances of successful treatment.

To work out your prognosis, your doctor will consider your test results; the type of vulvar cancer you have; the stage and grade of the cancer; whether the cancer has spread to the lymph nodes; and other factors such as your age, fitness and overall health. In most cases, the doctor will not have enough information to assess prognosis until after the surgery to remove the cancer (see next page).

Treatment

Vulvar cancer usually takes many years to develop, but it is easier to treat at an early stage. Treatment may involve surgery, radiation therapy and chemotherapy. You may have one of these treatments or a combination.

The treatment recommended by your doctor will depend on the results of your tests, the type of cancer, where the cancer is, whether it has spread, your age and your general health. You'll have regular check-ups to see whether the cancer has responded to treatment.

Surgery

Surgery is the main treatment for vulvar cancer. Your gynaecological oncologist will talk to you about the most suitable type of surgery, as well as the risks and any possible complications.

The type of operation recommended depends on how far the cancer has spread. The box on the opposite page provides more information about the main types of surgery.

All tissue removed during surgery is checked for cancer cells by a pathologist. The results will help confirm the type of vulvar cancer you have and how far it has spread throughout the body.



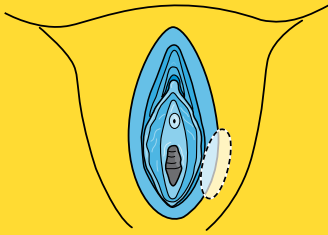
Cancer Council produces information booklets on surgery, radiation therapy and chemotherapy. Call **13 11 20** for free copies or find them on your local Cancer Council website.

Types of vulvar surgery

You may have one of the following types of surgery. A small border (1 cm) of healthy tissue (called a margin) is usually removed around the cancer.



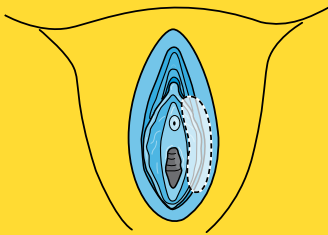
Local excision



Local excision – Recommended for precancerous changes only. The precancerous area is cut out with little need for margins.

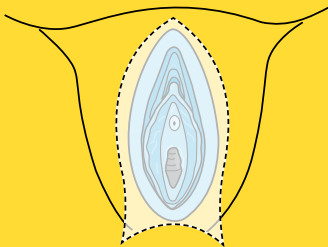
Wide local excision – Recommended for small cancers. The surgeon cuts out the cancer and a margin. May also have a lymph node dissection (see page 24).

Partial radical vulvectomy



Recommended for cancers that are confined to either side of the vulva, or the front or back only. This may mean that a large part of the vulva is removed. Usually, nearby lymph nodes are also removed (lymph node dissection, see page 24).

Complete radical vulvectomy



Recommended for cancers that cover a large area of the vulva. The surgeon removes the entire vulva, which may include the clitoris, and removes deep tissue around the vulva. Usually, nearby lymph nodes are also removed (lymph node dissection, see page 24).

Treatment of lymph nodes

Cancer cells can spread from the vulva to the lymph nodes in the groin. You may have one of the following procedures:

Lymph node dissection – The gynaecological oncologist will remove a number of lymph nodes from one or both sides of the groin. This is called an inguinal lymph node dissection or lymphadenectomy.

Sentinel lymph node biopsy – Instead of a full lymph node dissection, the surgeon may perform a sentinel lymph node biopsy. This test helps to identify which lymph node the cancer is most likely to spread to first (known as the sentinel lymph node).

The sentinel node can be identified with a blue dye and/or a radioactive tracer. You will usually have a local anaesthetic injected into the tumour, then a small amount of radioactive dye injected near the site of the cancer. This procedure is called a lymphoscintigraphy and it normally happens in a radiology department either the day before or the morning of your surgery. During the surgery, blue dye may also be injected to help identify the sentinel node. The dye will flow to the sentinel lymph node and the surgeon will remove it for testing.

If a pathologist finds cancer cells in the sentinel lymph node, the remaining nodes in the area may need to be removed in another operation or treated with radiation therapy. If the sentinel node does not contain cancer cells, a full lymph node dissection is not required. A sentinel lymph node biopsy can help the doctor avoid removing more lymph nodes than necessary and minimise side effects such as lymphoedema (see box on opposite page).



Sometimes, the removal of lymph nodes in the groin can stop or slow the natural flow of lymphatic fluid. When this happens, it can cause one or both legs to swell. This is known as lymphoedema – see page 56 for more information and some tips on managing this side effect.

Reconstructive surgery

The surgeon will aim to remove all of the vulvar cancer while preserving as much normal tissue as possible. However, a margin of healthy tissue around the cancer must also be removed to reduce the risk of the cancer coming back (recurring) in the same area.

Most people will be able to have the remaining skin drawn together with stitches, but if a large area of skin is removed, you may need a skin graft or skin flap. In this case, flaps of skin in the vulvar area are moved to cover the wound.

The graft or flap will be done as part of the first operation, sometimes with the assistance of a reconstructive (plastic) surgeon. Rarely, the surgeon may take a thin piece of skin from another part of your body (usually your abdomen or thigh) and stitch it onto the operation site.

“ 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*

What to expect after surgery

After surgery, you will be monitored closely. You will need to take care while you recover. Your doctor will tell you when you can start regular activities again.



Recovery time

Your recovery time will depend on your age, the type of surgery you had and your general health. If only a small amount of skin is removed, the wound will heal quickly and you can go home in a day or two. If your lymph nodes are removed or the surgery is more extensive, recovery will take longer. You may spend up to a week in hospital.

Having pain relief

After an operation it is common to feel some pain, but this can be controlled. You will be given pain medicine as a tablet, through a drip into a vein (intravenously), through a drip into a space around the spinal cord (epidural), or through a button you press to give yourself a measured dose of pain relief (patient-controlled analgesia or PCA). After you go home, you can continue taking pain-relieving tablets as needed.



Bowel issues

Strong pain medicines and long periods in bed can make bowel motions difficult to pass (constipation). Avoid straining when having a bowel movement. Talk to your treatment team about taking laxatives if needed.



Stitches

Your doctor will tell you how soon you can sit up and walk after surgery and how to avoid the stitches coming apart. Stitches usually dissolve and disappear as the wound heals. Some surgeons use surgical glue instead of stitches. The glue falls off when the wound has healed.

Wound care

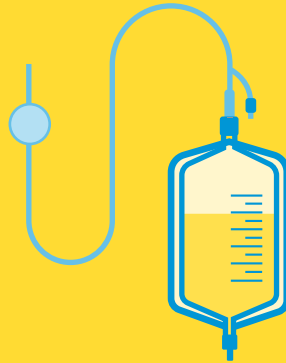


Infection is a risk after vulvar surgery, so keep the area clean and dry. While you are in hospital, the nurses will wash and dry the vulva for you a few times a day. They may also apply a cream to help prevent infection.

The nurses will show you how to look after the wound at home. You will need to wash it 2–3 times a day using a handheld shower or shallow basin (sitz bath). Use a soft, squeezable plastic water bottle to rinse the vulva with water after urinating or having a bowel movement. Dry the vulva well. If the area is numb, be careful patting it dry. Report any redness, pain, swelling, wound discharge or unusual smell to your doctor or nurse.

Tubes and drains

You may have a tube called a catheter to drain urine from your bladder. This helps keep your wound clean and dry. It will be removed before you leave hospital. There may also be a surgical drain to draw fluid away from the wound. You may go home with the drain in place if there is still fluid coming out. Community nurses can help you manage the care of the drain at home until it is removed.



What to wear

While you are in bed, you may need to wear compression stockings and have blood-thinning injections to prevent blood clots forming in your legs. Wear loose-fitting clothing and avoid underwear so your wound can air.



Do not put anything into your vagina after surgery until your doctor says the area is healed (usually 6–8 weeks). This includes using tampons and having sex.

Taking care of yourself at home after surgery

Rest – You will need to take things easy and get plenty of rest in the first week. Avoid sitting for long periods of time if it is uncomfortable, or try sitting on a pillow or doughnut cushion.

Exercise – Check with your gynaecological oncologist or nurse about when you can start doing your regular activities. You may not be able to lift anything heavy, but gentle exercise such as walking can help speed up recovery. Because of the risk of infection, avoid swimming until your doctor says you can.

Emotions – If you have lost part of your genital area, you may feel a sense of loss and grief. It may help to talk about how you are feeling with someone you trust. See page 61 for more information.

Sex – Sexual intercourse needs to be avoided for about 6–8 weeks after surgery. Ask your doctor when you can have sexual intercourse again, and explore other ways you and your partner can be intimate. You may feel concerned about the impact on your sex life after surgery. See page 58 for more information.

Using the toilet – If the opening to your urethra is affected, you may find that going to the toilet is different. The urine stream might spray in different directions or go to one side. See page 54 for tips on how to manage this.

Driving – You will need to avoid driving after the surgery until your wounds have healed and you are no longer in pain. Discuss this issue with your doctor.

Radiation therapy

Also known as radiotherapy, radiation therapy uses a controlled dose of radiation, such as x-rays, to kill or damage cancer cells. Whether you have radiation therapy 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 radiation therapy:

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

External beam radiation therapy (EBRT) – This is the most common type of radiation therapy for vulvar cancer. You will lie on a treatment table while a machine, called a linear accelerator, directs radiation towards the affected areas of the pelvis. EBRT is given daily, Monday to Friday, over 5–6 weeks. The exact number of sessions you have will depend on the type and size of the cancer. Each session takes about 20 minutes.

Radiation therapy to the vulva and groin doesn't hurt, but it can cause side effects (see next two pages). EBRT will not make you radioactive. It is safe for you to be with other people, including children, after your treatment.

Internal radiation therapy – Also called brachytherapy, this delivers radiation therapy directly to the tumour from inside your body. It is rarely used for vulvar cancer. See pages 44–45 for more information.

Short-term side effects of radiation therapy

The side effects you experience will vary depending on the dose of radiation and the areas treated. Many will be short-term side effects. These often get worse during treatment and just after the course of treatment has ended.

skin reactions (see also page 51)

The vulva may become sore and swollen, and feel like a bad sunburn. It may start by being pink or red and feeling itchy, and then peel, blister or weep. Your treatment team will recommend creams and pain relief to use until the skin heals. Wash the vulvar area with lukewarm, slightly salted water, and avoid perfumed products and talcum powder.

fatigue (see also page 50)

Your body uses a lot of energy to recover and travelling to treatment can also be tiring. The fatigue may last for weeks after treatment ends.

bladder and bowel problems (see also pages 54–55)

Radiation therapy can irritate the bladder and bowel. You may pass urine more often or with a burning sensation. Bowel motions may be more frequent, urgent or loose (diarrhoea), and you may pass more wind. Less commonly, you may have some blood in your faeces (poo). Always tell your doctor about any bleeding.

vaginal discharge

Radiation therapy may cause or increase vaginal discharge. Let your treatment team know if it smells bad or has blood in it. Do not wash inside the vagina with douches as this may cause infection.

Long-term or late effects of radiation therapy

Side effects can take several weeks to get better, though some may continue longer. Some side effects from radiation therapy may not show up until many months or years after treatment. These are called late effects.

<p>hair loss</p>	<p>You may lose your pubic hair. Sometimes, this can be permanent. Radiation therapy will not affect the hair on your head or other body areas.</p>
<p>bladder, bowel and rectal changes (see also pages 54–55)</p>	<p>Bladder changes (e.g. frequent or painful urination) and bowel changes (e.g. diarrhoea or wind) can appear months or years after radiation therapy ends. In some cases, a bowel blockage can occur. In rare cases, you may experience some bleeding from the rectum. Let your doctor know if you have pain in the abdomen, have any bleeding or cannot open your bowels.</p>
<p>lymphoedema (see also page 56)</p>	<p>Like surgery, radiation therapy can increase the risk of lymphoedema. If the lymph nodes and vessels have been removed during surgery or scarred during radiation therapy, lymph fluid can't drain properly. Lymph fluid can become trapped, causing the legs, vulva or mons pubis to swell.</p>
<p>narrowing of the vagina (see also pages 52–53)</p>	<p>The vagina can become drier, shorter and narrower (vaginal stenosis), which may make having sex and follow-up pelvic examinations uncomfortable or difficult. Your treatment team will suggest ways to prevent this.</p>
<p>menopause (see also page 57)</p>	<p>If you are premenopausal, radiation therapy to the pelvis can stop the ovaries producing hormones, which causes early menopause. Talk to your radiation oncologist about menopause or any fertility issues before starting treatment.</p>



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 radiation therapy, 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 intercourse. 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 too bad that people don't know more about this cancer. You hear about common types, like breast cancer. But even many GPs don'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.

Chemotherapy

Chemotherapy uses drugs to kill or slow the growth of cancer cells. The aim is to destroy cancer cells while causing the least possible damage to healthy cells. Chemotherapy for vulvar cancer may be given:

- during a course of radiation therapy, to make the radiation therapy treatment more effective (known as chemoradiation)
- to control cancer that has spread to other parts of the body
- as palliative treatment, to relieve the symptoms of the cancer.

The drugs are given by injection into a vein (intravenously). You will usually have several treatment sessions, with rest periods in between. Together, the session and rest period are called a cycle. Treatment is usually given during day visits to a hospital or clinic as an outpatient. Rarely, you may need to stay in hospital for a night or two.

Side effects of chemotherapy

There are many different types of chemotherapy drugs. The side effects will vary depending on the drugs you are given, the dosage and how you respond. Chemotherapy for vulvar cancer may also increase any skin soreness caused by radiation therapy. Your medical oncologist or nurse will discuss the likely side effects with you, including how they can be prevented or controlled with medicine.

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

Common side effects experienced after chemotherapy for vulvar cancer include feeling sick (nausea), tiredness (fatigue), and a reduced resistance to infections. Most side effects are temporary.

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.

➤ See our *Understanding Chemotherapy* booklet.

Palliative treatment

Palliative treatment helps to improve people's quality of life by managing the symptoms of cancer without trying to cure the disease. It is best thought of as supportive care. Many people think that palliative treatment is only for people at the end of their life, but it may help at any stage of advanced vulvar cancer. It is about living for as long as possible in the most comfortable way you can.

As well as slowing the spread of cancer, palliative treatment can relieve symptoms such as pain or bleeding. Treatment may include radiation therapy, chemotherapy or other drug therapies.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aims to meet your physical, emotional, practical, cultural, social and spiritual needs.

➤ See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets.



Key points about vulvar cancer

What it is

Vulvar cancer is cancer that starts in any part of the external female sexual organs (genitals). The most common type is squamous cell carcinoma.

Tests

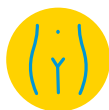
- The main tests are a physical examination, a colposcopy and the removal of a tissue sample (biopsy).
- You may also have a cervical screening test to check for abnormal cells in the vagina and cervix.
- Other tests are not always needed but may include a blood test and imaging scans.

Main treatment

Surgery is the main treatment. The type of operation you have depends on how far the cancer has spread. Small vulvar cancers may be removed with a local or wide local excision. A partial or complete vulvectomy may be used to remove more advanced vulvar cancer. Lymph nodes may also be removed.

Other treatments

- Radiation therapy (radiotherapy) uses radiation to kill or damage cancer cells. External beam radiation therapy is the most common type used for vulvar cancer.
- Chemotherapy uses drugs to kill or damage cancer cells.
- For advanced vulvar cancer, palliative treatment can help manage symptoms and improve quality of life.



Vaginal cancer

This chapter discusses symptoms, risk factors, diagnosis and treatment of primary vaginal cancer (also known as cancer of the vagina). For information about managing treatment side effects, see pages 50–59.

Q: What is vaginal cancer?

A: Primary vaginal cancer is any cancer that starts in the vagina. There are several types named after the cells they start in (see table below). Some cancers of the vagina have spread from a cancer elsewhere in the body. These are called secondary vaginal cancers (see box on opposite page).

Types of primary vaginal cancer

squamous cell carcinoma (SCC)	<ul style="list-style-type: none">• starts in the thin, flat (squamous) cells lining the vagina• makes up about 85% of vaginal cancers
adenocarcinoma	<ul style="list-style-type: none">• develops from the mucus-producing (glandular) cells of the vagina• includes clear cell carcinoma• makes up 5–10% of vaginal cancers
vaginal (mucosal) melanoma	<ul style="list-style-type: none">• starts in the cells that give the skin its colour (melanocytes), which are also found in the lining of the vagina• a rare form of vaginal cancer
sarcoma	<ul style="list-style-type: none">• develops from muscle, fat and other tissue deep in the wall of the vagina• a rare form of vaginal cancer

Secondary vaginal cancer

Secondary cancer in the vagina is more common than primary vaginal cancer. This means the cancer has spread from another part of the body, such as the cervix, uterus, vulva, bladder, bowel or other nearby organs. Secondary vaginal cancer is managed differently from primary vaginal cancer. For more information, see the Cancer Council booklet about the original cancer and speak to your treatment team.

► See our *Living with Advanced Cancer* booklet.

Q: What are the symptoms?

A: There are often no obvious symptoms of vaginal cancer. The cancer is sometimes found by a routine cervical screening test (see page 18).

If symptoms do occur, they may include one or more of the following:

- bloody vaginal discharge not related to your menstrual period, which may have a strong or unusual smell
- pain during sexual intercourse
- bleeding after sexual intercourse
- pain in the pelvic area or rectum
- a lump in the vagina
- bladder problems, such as blood in the urine or passing urine frequently or during the night.

Not everyone with these symptoms has vaginal cancer. Other conditions can also cause these changes, but if you have any symptoms, make an appointment to visit your GP.

Q: How common is it?

A: Vaginal cancer is one of the rarest types of cancer affecting the female reproductive system (gynaecological cancer). Each year in Australia, about 100 women are diagnosed with vaginal cancer, and it is more common in women over 60.³ However, vaginal cancer, particularly adenocarcinoma, can sometimes occur in younger women.

Anyone with a vagina can get vaginal cancer – women, transgender men and intersex people. For information specific to your situation, speak to your doctor.

Q: What are the risk factors?

A: The exact cause of vaginal cancer is unknown, but there are several factors that increase the risk of developing it.

Vaginal intraepithelial neoplasia (VAIN) – This is a precancerous condition that often has no symptoms. It means that the cells in the lining of the vagina are abnormal and may develop into cancer after many years. However, most people with VAIN do not develop vaginal cancer.

Human papillomavirus (HPV) – HPV is a sexually transmitted infection that can cause some people to develop VAIN. It can be many years between infection with HPV and the first signs of VAIN or vaginal cancer. HPV is a common virus and most people with HPV don't develop vaginal or any other type of cancer (see also box on page 15).

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

History of gynaecological cancer – If you have previously been diagnosed with cervical cancer or early cervical cell changes that were considered to be precancerous, you may be more likely to be diagnosed with vaginal cancer. For more information, see our *Understanding Cervical Cancer* booklet.

Diethylstilboestrol (DES) – This synthetic hormone drug has been identified as a cause of a type of vaginal adenocarcinoma called clear cell carcinoma.

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. About one in 1000 DES daughters develops clear cell carcinoma of the vagina or cervix.



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

Diagnosis

The main tests used to diagnose vaginal cancer are a physical examination, a cervical screening test, a procedure called a colposcopy, and the removal of a tissue sample (biopsy).

Physical examination

Your doctor will ask to do a physical examination of your vagina, groin and pelvic area. You will remove your clothing from the waist down, then lie on a table with your knees bent and legs apart. The doctor may arrange for you to have the examination under a general anaesthetic if the area is very painful. If you feel embarrassed or scared about this examination, let your doctor know. A nurse may be present, but you can also ask for a family member or friend to be in the room.

Cervical screening test

During the physical examination, you may have a cervical screening test to check the cells inside the vagina and cervix. See page 18 for a description of this test. The results may show early cell changes in the lining of the vagina. This condition is called vaginal intraepithelial neoplasia or VAIN (see page 38).

Colposcopy and biopsy

During the physical examination, the doctor may use a magnifying instrument called a colposcope to look at your vagina, cervix and vulva. This procedure is known as a colposcopy, or sometimes a vaginoscopy. The doctor may take a tissue sample (biopsy) during the colposcopy. See pages 17–18 for a description of these tests. The tissue sample will be sent to a laboratory, and a pathologist will look at the cells under a microscope to see if they are cancerous.

Further tests

If the tests already described show that you have vaginal cancer, further tests may be needed to find out whether the cancer cells have spread. You will probably not need to have all of these tests but they may include a blood test, a chest x-ray, a CT or PET-CT scan, an MRI scan, a cystoscopy or a proctoscopy. See pages 19–20 for a description of these tests.

Staging vaginal cancer

Based on the test results, 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 from the vagina to other parts of the body.

Stages of vaginal cancer

In Australia, vaginal cancer is usually staged using the staging system from the International Federation of Gynecology and Obstetrics (FIGO).

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

Your doctor may also tell you the grade of the cancer cells. This gives you an idea of how quickly the cancer may grow. 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 health care team recommend the most appropriate treatment for you.

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 anyone to predict the exact course of the disease. Instead, your doctor can give you an idea about the general prognosis for people with the same type and stage of vaginal cancer.

Some people with vaginal cancer may want to know the statistics for people in similar situations, while others may not find the numbers helpful. Do what feels right for you.

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

You will have regular check-ups to see whether the cancer has responded to treatment.

Treatment

The treatment recommended by your doctor will depend on the results of your tests, the type of cancer, where the cancer is, whether it has spread and your general health. Treatment may involve radiation therapy, surgery, chemotherapy or a combination of these treatments. Most people with vaginal cancer will have radiation therapy because vaginal cancer that is close to the urethra, bladder and rectum is often difficult to remove completely with surgery. Surgery may be used for small cancers found in the upper part of the vagina.

Radiation therapy

Also known as radiotherapy, radiation therapy uses a controlled dose of radiation, such as x-rays, to kill or damage cancer cells. Radiation therapy is a common treatment for vaginal cancer. Some people with vaginal cancer are treated with a combination of radiation therapy and chemotherapy (see pages 47–48). This is called chemoradiation or chemoradiotherapy. Radiation therapy can also be used to control symptoms of advanced cancer (palliative treatment).

There are two main ways of delivering radiation therapy: externally and internally. Most people with vaginal cancer have both types of radiation therapy. Your radiation oncologist will recommend the course of treatment most suitable for you.



Cancer Council produces information booklets on radiation therapy, surgery and chemotherapy. Call **13 11 20** for free copies or find them on your local Cancer Council website.

External beam radiation therapy (EBRT) – This precisely delivers radiation to the cancer from outside the body. You will lie on a treatment table under a machine called a linear accelerator, which directs radiation towards the affected areas of the pelvis.

EBRT is usually given daily, Monday to Friday, over 4–6 weeks. The exact number of treatment sessions you have will depend on the type and size of the cancer, and whether it has spread to the lymph nodes. Each session takes about 20 minutes and is painless.

Internal radiation therapy – Also called brachytherapy, internal radiation therapy delivers radiation directly to the tumour from inside your body. It can be given in fewer treatment sessions because radiation doesn't have to travel through the body.

The main type of internal radiation therapy used for vaginal cancer is high-dose-rate (HDR) brachytherapy. You may have this after finishing a course of EBRT.

Brachytherapy can be delivered in a number of ways. The simplest way is through a vaginal cylinder, which is a hollow applicator with a rounded tip placed inside the vagina. The tube inside the cylinder is connected to a machine that delivers the radioactive seed.

Your vagina may feel stretched and uncomfortable, but the treatment is reasonably painless. You can take painkillers or you may be given a local anaesthetic to make you feel more comfortable when the cylinder is inserted. Treatment takes about 10–20 minutes. You may need to have 3–4 sessions to deliver the right amount of radiation to treat the cancer.

A more complex form of brachytherapy may be used if the cancer is still quite thick and bulky after EBRT. You will be admitted to hospital to have this type of brachytherapy. Hollow needles are inserted in and around the cancer under anaesthetic. A radioactive seed travels inside the needle and delivers radiation directly to the cancer.

The needles stay in place for 2–3 days until treatment is completed. During that time, you will be connected to the brachytherapy machine for at least three treatments and you must lie flat on a special bed until the needles are removed. You will be given pain-relieving medicine while you are in hospital. You are not radioactive between treatments, so family and friends can visit you in hospital. There are only a few centres in Australia where this treatment is available.

After brachytherapy you may feel uncomfortable in the vaginal region. Painkillers can help if needed.

Side effects of radiation therapy

The side effects you experience vary depending on the radiation dose and the areas treated. Many will be short-term side effects. These often get worse during treatment and just after the course of treatment has ended, before starting to get better. Some side effects may be late effects, not appearing until many months or years after treatment.

Radiation therapy that is targeted to the vaginal area has similar side effects to radiation therapy targeted to the vulvar area. Before your treatment starts, talk to your radiation oncologist about possible side effects. For a description of common side effects, see pages 30–31. For ways to manage treatment side effects, see pages 50–59.

Surgery

Some vaginal cancers may need to be removed with an operation. The gynaecological oncologist will try to remove all of the cancer along with some of the 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 (see page 24).

There are several different operations for vaginal cancer. The type of surgery recommended depends on the size and position of the cancer. Your gynaecological oncologist will talk to you about the risks and complications of your surgery, as well as possible side effects.

Removing part of the vagina (partial vaginectomy) – Only the affected part of the vagina is removed.

Removing the whole vagina (total vaginectomy) – The entire vagina is removed.

Removing the whole vagina and surrounding tissue (radical vaginectomy) – The entire vagina and surrounding tissue is removed. In some cases, a reconstructive (plastic) surgeon can make a new vagina using skin and muscle from other parts of your body. This is called vaginal reconstruction or formation of a neovagina. It is done so you can have sexual intercourse if that is important to you and your partner.

Hysterectomy – Some people also need to have their uterus and cervix removed (total hysterectomy). Your gynaecological oncologist will let you know whether it is also necessary to remove your ovaries and fallopian tubes (salpingo-oophorectomy). If you are premenopausal, it

is unlikely that the ovaries will need to be removed as vaginal cancer is not affected by hormones. Removing your ovaries would bring on menopause. See page 57 for ways to manage menopause.

Recovery after surgery

How long you stay in hospital and what side effects you experience will depend on the type of surgery you have. Most people are in hospital for a few days to a week. Recovery from vaginal surgery is similar to after vulvar surgery (see pages 26–28). In addition, you can expect some light vaginal bleeding, which should stop within two weeks.

Chemotherapy

Chemotherapy uses drugs to kill or slow the growth of cancer cells. It is usually given if the vaginal cancer is advanced or returns after treatment, and may be combined with surgery or radiation therapy.

The drugs are usually given by injection into a vein (intravenously) and sometimes as tablets. You will usually have several treatment sessions, with rest periods in between. Together, the session and rest period are called a cycle. Treatment is usually given to you during day visits to a hospital or clinic as an outpatient. Rarely, you may need to stay in hospital for a few nights.

Side effects of chemotherapy

Most people have some side effects from chemotherapy. There are many different types of chemotherapy drugs, and the side effects will 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 prevented or controlled with medicine.

Common side effects experienced after chemotherapy for vaginal cancer include feeling sick (nausea), tiredness (fatigue), hair loss and a reduced resistance to infections. Chemotherapy may also increase any skin soreness caused by radiation therapy. 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.

Palliative treatment

Palliative treatment helps to improve people's quality of life by managing the symptoms of cancer without trying to cure the disease. It is best thought of as supportive care.

Many people think that palliative treatment is only for people at the end of their life, but it may help at any stage of advanced vaginal cancer. It is about living for as long as possible in the most comfortable way you can.

As well as slowing the spread of cancer, palliative treatment can relieve symptoms such as pain or bleeding. Treatment may include radiation therapy, chemotherapy or other drug therapies.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aims to meet your physical, emotional, cultural, social and spiritual needs.

- ▶ See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets.



Key points about vaginal cancer

What it is

- Primary vaginal cancer is any cancer that starts in the vagina. The main type is squamous cell carcinoma.
- Secondary vaginal cancer is cancer that has spread to the vagina from another part of the body.

Tests

- The main tests are a physical examination, a cervical screening test, a colposcopy and the removal of a tissue sample (biopsy).
- Other tests are not always needed but may include a blood test, a chest x-ray, a CT or PET-CT scan, an MRI scan, a cystoscopy or a proctoscopy.

Main treatment

Radiation therapy is the main treatment for vaginal cancer. It uses radiation to kill or damage the cancer cells. Most people have external beam radiation therapy (EBRT) as well as internal radiation therapy (brachytherapy). Side effects may be short term or long term.

Other treatments

- Surgery may be used to try to cut out the affected part of the vagina. Other organs and lymph nodes may also be removed.
- Chemotherapy uses drugs to kill or damage cancer cells. It is usually given if the cancer is advanced or if it returns after treatment.
- For advanced vaginal cancer, palliative treatment can help manage symptoms and improve quality of life.



Managing side effects

It will take some time to recover from the physical and emotional changes caused by treatment for vulvar or vaginal cancer. Treatment side effects can vary – some people experience many side effects, while others have few. Side effects may last from a few weeks to a few months or, in some cases, years or permanently. This chapter includes ways to reduce or manage the discomfort that side effects may cause.

Fatigue

It is common to feel very tired and lack energy during and after cancer treatment. Your tiredness may continue for a while after treatment has finished. Some people find it takes them a few years to feel well again.



Tips for managing fatigue

- Plan your day. Set small manageable goals and rest before you get too tired.
- Keep your schedule as regular as possible, e.g. avoid sleeping in, go to bed at your usual time and take a short nap if you get tired throughout the day.
- Ask for and accept offers of help from family and friends, e.g. with shopping, errands and childcare.
- Eat a healthy, well-balanced diet to keep energy levels up.
- Regular light to moderate exercise has been shown to reduce fatigue. Even a walk around the block can help. Talk to your doctor about the amount and type of exercise suitable for you. A physiotherapist or exercise physiologist can develop a program that is right for you.
- Don't expect to be able to instantly do everything you used to do right away. Gradually increase the amount of activity you do each day.

Changes to the vulva

Whether you have been diagnosed with vulvar or vaginal cancer, the treatments may affect the vulva.

People who have had surgery to their vulva have different feelings about looking at changes to their genital area. 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.

Radiation therapy may make your skin dry, itchy and tender in the treatment area. Your skin may temporarily look red, tanned or sunburnt, and then peel or blister. These skin reactions can be painful and may worsen in the two weeks after treatment finishes, but will gradually get better after that.

Tips for managing changes to the vulva

- After surgery to the vulva, some people 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.
- After radiation therapy, use lukewarm water to wash your genital area and gently pat it dry with a towel. Avoid using any perfumed products or talcum powder on the area.
- Talk to your treatment team about creams to soothe and protect the skin, and also about pain relief if necessary.



Changes to the vagina

Treatments for vulvar or vaginal cancer can also affect the vagina. Radiation therapy targeted to the vulva or vagina can make the area tender during treatment and for a few weeks afterwards. Over time, this irritation can cause scarring, which may make the vagina drier, narrower, shorter and less flexible (vaginal stenosis).

Surgery for vulvar cancer may cause scar tissue to form around the outside of the vulva, narrowing the entrance to the vagina. This can make



Tips for managing changes to the vagina

- It is important to keep the vagina open and supple, even if you don't plan to be sexually active. As well as making sexual intercourse more comfortable, it makes it easier for your doctor to do regular cervical screening tests as well as vaginal examinations to check whether the cancer has come back.
- If cancer treatment has narrowed or shortened the vagina, you may be advised to use vaginal dilators to help keep the vagina open and prevent it from closing over.
- Vaginal dilators are tube-shaped devices made from plastic or silicone. They come in different sizes. Begin with the smallest and move to larger ones as each size becomes more comfortable.
- Make sure any soreness or inflammation has settled before you start using the first dilator. This is usually 2–6 weeks after treatment ends.
- Find a quiet, private place. Using a water-based lubricant, slowly insert a dilator into the vagina and leave it there for 5–10 minutes. You will need to do this 3–5 times a week, usually for many months.
- Using dilators can be challenging. Your nurse, doctor

penetration during sex painful. Surgery for vaginal cancer may also make the vagina shorter or narrower. Whether sexual intercourse is still possible after vaginal surgery depends on the extent of the operation.

Changes to your body can affect the way you feel about yourself (your self-esteem) and make you feel self-conscious. You may feel less confident about who you are and what you can do. Try to see yourself as a whole person (body, mind and personality) instead of focusing on the parts that have changed.

or pelvic floor physiotherapist will give you more detailed instructions about when and how to start using them. They will also provide the dilators or let you know where to buy them.

- Ask your doctor if applying a hormone cream or a vaginal moisturiser will help with vaginal discomfort and dryness. Hormone creams are available on prescription, while vaginal moisturisers are available over the counter from pharmacies.
- Some people like to use vibrators (available from sex shops and online) to gradually widen the vagina. Talk to your treatment team if you would prefer to use vibrators.
- Although dryness, shortening and narrowing of the vagina can make sexual intercourse uncomfortable or difficult, having sex regularly – if you are able to and want to – may help keep the vagina open.
- Extra lubrication may make sexual intercourse more comfortable. Choose a water-based or silicone-based gel without perfumes or colouring. For more tips on managing sexual changes, see page 58.
- If you don't have a sexual partner or don't feel emotionally or physically ready to have sexual intercourse, talk to your doctor about using dilators to keep your vagina open.



If your GP refers you to an allied health professional as part of a Chronic Disease Management Plan, you may be eligible for a Medicare rebate for up to five visits each year. Ask your GP for more details.

Bladder and bowel changes

Radiation therapy and surgery to the vulva or vagina can cause bladder and bowel problems. Most are temporary, but sometimes the changes are permanent. Talk to your treatment team for more information.

Cystitis – Radiation therapy can irritate the lining of the bladder. You may feel like you want to pass urine often or have a burning sensation when you pass urine. This is called cystitis. Try to drink plenty of water to make your urine less concentrated. Over-the-counter urinary alkalinisers (e.g. Ural) can help by making the urine less acidic. Your doctor may also prescribe medicine to treat cystitis.

Difficulty urinating – After surgery to the genital area, your urine may spray in different directions or off to one side. This can be messy and frustrating. It may help to sit down towards the back of the toilet seat or adjust your position to direct the flow of urine. Camping stores, some pharmacies and online retailers also sell reusable silicone funnels (often known as female urination devices) that you can use to direct the urine. Over time, the urine stream may flow in a more manageable way.

Urinary incontinence – Incontinence is when urine leaks from your bladder without your control. Bladder control may change after surgery or radiation therapy to the vulva or vagina. Some people find they need to pass urine more often or feel that they need to go in a hurry. Others

may leak 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. They may suggest exercises to strengthen your pelvic floor muscles. For more information, contact the Continence Foundation of Australia on 1800 33 00 66 or at continence.org.au.

Changed bowel movements – After surgery or radiation therapy, some people notice bowel problems. You may experience diarrhoea, constipation or stomach cramps. In rare cases, the bowel may become blocked (bowel obstruction). Your doctor may be able to prescribe medicines to help prevent or relieve these side effects. They can also refer you to a dietitian who can suggest changes to your diet. Try using a footstool when opening your bowels. This mimics a squat position, which is the natural position for going to the toilet as it lengthens and loosens the pelvic floor muscles. Avoid straining to empty your bowels as this weakens the pelvic floor muscles.

Blood in urine or bowel movements – The blood vessels in the bowel and bladder can become more fragile after radiation therapy. This can cause blood to appear in your urine or bowel movements, even months or years after treatment. Always seek advice from your specialist or GP if you notice new or unusual bleeding. Keep in mind that it may not be related to your treatment.

🗨️ 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*

Lymphoedema

Lymphoedema is a swelling of part of the body (see page 31). After treatment for vulvar or vaginal cancer, lymphoedema usually affects a leg or the genitals. Sometimes, the swelling can take months or years to develop. The risk of damage to the lymph nodes or vessels increases for people who have both radiation therapy and surgery, but some people who are at risk never develop lymphoedema. Although it may be permanent, lymphoedema can usually be managed. Talk to a lymphoedema professional about tailoring a treatment plan for you.

► See our *Understanding Lymphoedema* fact sheet.



Tips for managing lymphoedema

- Look for signs of lymphoedema and see a lymphoedema practitioner as soon as they appear. Early treatment avoids symptoms becoming worse.
- Visit lymphoedema.org.au to find a lymphoedema practitioner or ask your doctor for a referral. Ask your GP if you are eligible for a Medicare rebate for sessions with a lymphoedema practitioner.
- Maintain a healthy body weight.
- Keep your skin clean and moisturised. Clip and care for your toenails.
- Avoid cuts, scratches, burns, insect bites, sunburn and injections in your legs.
- Wear a professionally fitted compression garment, if advised by your lymphoedema practitioner. For details about compression garment schemes visit lymphoedema.org.au.
- Do leg exercises to move fluid out of the affected area and into other lymph channels.
- If your legs or genitals are red, swollen or hot, let your doctor or nurse know as soon as possible.

Menopause

If you have not yet been through menopause, some treatments for vaginal cancer and, rarely, vulvar cancer, can cause early menopause. Your periods will stop and you may have symptoms such as hot flushes, insomnia, dry or itchy skin, mood swings, or loss of interest in sex (low libido). Loss of the hormone oestrogen at menopause may also cause bones to weaken and break more easily (osteoporosis). After menopause, you will not be able to become pregnant. If this is a concern for you, talk to your doctor before treatment begins.

► See our *Understanding Fertility* booklet.



Tips for managing menopause symptoms

- Talk to your doctor about the benefits and risks of menopause hormone therapy (MHT, previously called hormone replacement therapy or HRT). MHT may increase the risk of some diseases. If you were already on MHT when cancer was diagnosed, there should be no need to stop taking it as neither vaginal or vulvar cancer are caused or affected by hormones.
- Ask your doctor about having a bone density test or taking medicine to prevent your bones from becoming weak.
- Regular weight-bearing exercise will help keep your bones strong. Osteoporosis Australia has more information – call **1800 242 141** or visit **osteoporosis.org.au**.
- Meditation and relaxation techniques can help reduce stress and lessen symptoms. Call **13 11 20** for free relaxation and meditation recordings.
- Cognitive behaviour therapy has been shown to help people manage menopause symptoms such as anxiety, stress and insomnia. Ask your GP for more information.

Impact on sexuality

Vulvar or vaginal cancer can affect your sexuality in physical and emotional ways. Sometimes radiation therapy or surgery to the pelvic area can affect nerves and tissue in this area, causing scarring, narrowing of the vagina, swelling and soreness (see pages 51–53). The experience of having cancer can also reduce your desire for sex (libido).

Take time to explore and touch your body to find out what feels good. Many people are able to have sexual intercourse after treatment and some can still experience an orgasm even if their clitoris has been removed. Others may have to try different sexual positions or activities. Remember that for most people, sex is more than just intercourse. It involves feelings of intimacy, as well as being able to give and receive pleasure. A sex therapist or psychologist can help you adjust to changes and help you find new ways to express intimacy and enjoy sex.

➤ See our *Sexuality, Intimacy and Cancer* booklet.



Tips for managing sexual changes

- Give yourself time to get used to any physical changes.
- Talk about your feelings with your sexual partner, if you have one. Let them know if you don't feel like having sex, or if you find intercourse uncomfortable.
- Talk to your doctor about ways to manage side effects that change your sex life (see also pages 52–53).
- Explore other ways to climax, such as caressing the breasts, inner thighs, feet or buttocks.
- See *Intimacy and sexuality for women with gynaecological cancer – starting a conversation* at canceraustralia.gov.au.



Key points about managing side effects

Common side effects

Some people experience few side effects from treatment, while others have many. Common side effects include fatigue, changes to the vulva and vagina, bladder and bowel changes, lymphoedema, menopause and sexual changes.

Managing side effects

Talk to your treatment team about any symptoms or side effects you have. They may be able to suggest ways to reduce or manage discomfort caused by side effects.

Changes to the vulva and vagina

Treatment can change the way the vulva and vagina look and feel. You may be advised to use creams to soothe and protect the skin or vaginal dilators to help keep the vaginal walls open and supple. It's natural to feel anxious and upset about any changes to your body.

Menopause

Treatment may cause menopause. This means your periods stop, you may have symptoms such as hot flushes and mood swings, and you will not be able to become pregnant. If you are concerned about your fertility, talk to your medical team as soon as possible.

Sexuality

Cancer and its treatment may affect sexuality in physical and emotional ways. A sex therapist or psychologist may be able to help you find new strategies for expressing intimacy and enjoying sex.



Looking after yourself

Cancer can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has free booklets and programs to help you during and after treatment. Call 13 11 20 to find out more, or visit your local Cancer Council website (see back cover).

Eating well – Healthy food can help you cope with treatment and side effects. A dietitian can explain how to manage any special dietary needs or eating problems, and choose the best foods for your situation.

➤ See our *Nutrition and Cancer* booklet.

Staying active – Physical activity can reduce tiredness, improve circulation and lift mood. The right exercise for you depends on what you are used to, how you feel and your doctor's advice.

➤ See our *Exercise for People Living with Cancer* booklet.

Complementary therapies – Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as massage, relaxation and acupuncture can 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.

➤ See our *Understanding Complementary Therapies* booklet.



Alternative therapies are therapies used instead of conventional medical treatments. These are unlikely to be scientifically tested and may prevent successful treatment of the cancer. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

Effect on your emotions

Most people 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 radiation therapy, 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. 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 help and support.

Work and money – Cancer can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check with a social worker or Cancer Council whether any financial assistance is available to you.

➤ See our *Cancer and Your Finances* and *Cancer, Work & You* booklets.

Relationships – Having cancer can affect your relationships with family, friends and colleagues in different ways. Cancer is stressful, tiring and upsetting, and this may strain relationships. It may also result in positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening, and do the same for those around you. It may help to discuss your feelings with each other.

➤ See our *Emotions and Cancer* booklet.



Life after treatment

For most people, the cancer experience doesn't end on the last day of treatment. Life after cancer treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry that every ache and pain means the cancer is coming back.

Some people say that they feel pressure to return to “normal life”. It is important to allow yourself time to adjust to the physical and emotional changes, and establish a new daily routine at your own pace. Your family and friends may also need time to adjust.

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.

➤ See our *Living Well After Cancer* booklet.

Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression.

This is quite common among people who have had cancer.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people

can get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call Beyond Blue on **1300 22 4636** or visit **beyondblue.org.au**. For 24-hour crisis support, call Lifeline **13 11 14** or visit **lifeline.org.au**.

Follow-up appointments

After treatment ends, you will have regular appointments to monitor your health, manage any long-term side effects and check that the cancer hasn't come back or spread. During these check-ups, you will usually have a physical examination and you may have blood tests, x-rays or scans. You will also be able to discuss how you're feeling and mention any concerns you may have.

When a follow-up appointment or test is approaching, many people find that they think more about the cancer and may feel anxious. Talk to your treatment team or call Cancer Council 13 11 20 if you are finding it hard to manage this anxiety.

For the first few years, you will probably have a check-up every three months. People who have had surgery 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 symptoms or health problems.

What if the cancer returns?

For some people, vulvar or vaginal cancer does come back after treatment, which is known as a recurrence. This is why it's important to have regular check-ups.

If the cancer recurs, your doctor may consider further treatment such as surgery, chemotherapy or radiation therapy. The type of treatment you have will depend on where the cancer has recurred, what treatment you have already had, the stage and grade of the cancer (see pages 20–21 and 41–42), and your preferences.



Seeking support

A cancer diagnosis can affect every aspect of your life. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Cancer also often creates practical and financial issues.

There are many sources of support and information to help you, your family and carers navigate all stages of the cancer experience, including:

- information about cancer and its treatment
- access to benefits and programs to ease the financial impact of cancer treatment
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- support groups and programs
- psychology and counselling services.

The availability of services may vary depending on where you live, and some services will be free but others might have a cost.

To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20.

“ 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

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

Cancer Council 13 11 20

Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).



Information resources

Cancer Council produces booklets and fact sheets on over 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call **13 11 20** or visit your local Cancer Council website (see back cover).

Practical help

Your local Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation services.



Legal and financial support

If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council **13 11 20** to ask if you are eligible.

Peer support services

You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call **13 11 20** or visit cancercouncil.com.au/OC.



Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

Australian	
Cancer Council Australia	cancer.org.au
Cancer Council Online Community	cancercouncil.com.au/OC
Cancer Council podcasts	cancercouncil.com.au/podcasts
Australasian Lymphology Association	lymphoedema.org.au
Australia New Zealand Gynaecological Oncology Group	anzgog.org.au
Australian Gynaecological Cancer Foundation	agcf.org.au
Australian Physiotherapy Association	australian.physio
Cancer Australia	canceraustralia.gov.au
Continence Foundation of Australia	continence.org.au
Dietitians Association of Australia	dietitiansaustralia.org.au
Exercise & Sports Science Australia	essa.org.au
Gynaecological Awareness Information Network	gain.org.au
Healthdirect Australia	healthdirect.gov.au
Pelvic Floor First	pelvicfloorfirst.org.au
Relationships Australia	relationships.org.au
International	
American Cancer Society	cancer.org
Cancer Research UK	cancerresearchuk.org
International Gynecologic Cancer Society	igcs.org
Macmillan Cancer Support (UK)	macmillan.org.uk



Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. What this means for you will vary depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20.

There is a wide range of support available to help you with the practical and emotional aspects of your caring role:

- You can find support services, such as Meals on Wheels, home help or visiting nurses, as well as information and resources, through the Carer Gateway. Call 1800 422 737 or visit carergateway.gov.au.
 - Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.
 - Carers Australia provides information and advocacy for carers. Visit carersaustralia.com.au.
 - Call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services.
- See our *Caring for Someone with Cancer* booklet.



If the person with vulvar or vaginal cancer is your sexual partner, how you both feel about sex may change, and communication will be more important than ever (see page 58). You may find our *Sexuality, Intimacy and Cancer* booklet and “Sex and Cancer” podcast episode helpful.



Question checklist

Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your own list.

Diagnosis

- What type of cancer do I have?
- Has the cancer spread? If so, where has it spread? How fast is it growing?
- Are the latest tests and treatments for this cancer available in this hospital?
- Will a multidisciplinary team be involved in my care?
- Are there clinical guidelines for this type of cancer?

Treatment

- What treatment do you recommend? What is the aim of the treatment?
- Are there other treatment choices for me? If not, why not?
- If I don't have the treatment, what should I expect?
- How long do I have to make a decision?
- I'm thinking of getting a second opinion. Can you recommend anyone?
- How long will treatment take? Will I have to stay in hospital?
- Are there any out-of-pocket expenses not covered by Medicare or my private health cover? Can the cost be reduced if I can't afford it?
- How will we know if the treatment is working?
- Are there any clinical trials or research studies I could join?
- How can I get a referral to palliative care if the cancer is advanced?

Side effects and after treatment

- What are the risks and possible side effects of each treatment?
- Will I have a lot of pain? What will be done about this?
- Can I work, drive and do my normal activities while having treatment?
- Will the treatment affect my sex life and fertility?
- Should I change my diet or physical activity during or after treatment?
- Are there any complementary therapies that might help me?
- Where can I get emotional support, such as counselling about body image or sexuality?
- How often will I need check-ups after treatment?
- If the cancer returns, how will I know? What treatments could I have?



Glossary

adenocarcinoma

A cancer that starts in the mucus-producing (glandular) cells that form part of the lining of internal organs.

Bartholin glands

Two small glands on either side of the vagina that produce mucus for lubrication.

biopsy

The removal of a sample of tissue from the body for examination under a microscope to help diagnose a disease.

brachytherapy

A type of internal radiation therapy in which radioactive material is placed into or near the tumour.

cervical screening test

A test that checks cells taken from the cervix for HPV. Replaced the Pap test.

chemotherapy

A cancer treatment that uses drugs to kill cancer cells or slow their growth.

clitoris

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

colposcopy

An examination of the vulva, vagina and cervix using a magnifying instrument called a colposcope. See also vaginoscopy and vulvoscopy.

CT scan

Computerised tomography scan. This scan uses x-rays to create cross-sectional pictures of the body.

cystitis

Inflammation of the bladder lining.

cystoscopy

A procedure that uses a cystoscope, a tube with a light and camera, to examine the vagina, cervix, urethra and bladder.

extramammary Paget's disease

A precancerous condition of the vulva. It may have an associated cancer at diagnosis or may develop into cancer.

groin

The area between the abdomen and thigh on either side of the body.

gynaecological cancers

Cancers of the female reproductive system. They include vulvar, vaginal, cervical, uterine and ovarian cancers.

gynaecological oncologist

A gynaecologist who specialises in treating cancer of the female reproductive organs.

gynaecologist

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

human papillomavirus (HPV)

A group of viruses that can cause infection in the skin surface of different body areas, including the genital area. HPV is a risk factor for some cancers.

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. The labia minora are the inner lips.

lymphatic system

A network of vessels, nodes and organs that removes excess fluid from tissues, absorbs fatty acids, transports fat and produces immune cells.

lymph fluid

A clear fluid that circulates around the body through the lymphatic system, carrying cells that fight infection.

lymph nodes

Small, bean-shaped structures that collect and destroy bacteria and viruses. Also called lymph glands.

lymphoedema

Swelling caused by a build-up of lymph fluid. Occurs when lymph vessels or nodes can't drain properly because they have been removed or damaged.

menopause

When a woman stops having periods (menstruating). This can happen naturally, because of cancer treatment or because the ovaries have been removed.

mons pubis

The area of fatty tissue above the labia. It is covered with pubic hair.

MRI scan

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

Pap test

Replaced by the cervical screening test.

pelvis

The lower part of the trunk of the body: roughly, the area that extends from hip to hip and waist to groin.

perineum

The area of skin between the vulva and the anus.

proctoscopy

An examination of the rectum and anus using an instrument called a proctoscope.

radiation therapy (radiotherapy)

The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread.

rectum

The last 15–20 cm of the large bowel, just above the anus.

sarcoma

A cancer that starts in the bone or in the soft tissue under the skin.

sentinel lymph node biopsy

A surgical procedure used to determine whether cancer has spread from the primary site to the lymphatic system.

sitz bath

A shallow bath in which only the hips and buttocks are immersed. Some are plastic bowls designed to fit on toilet seats.

speculum

An instrument used to hold open the vagina during an internal examination to see the vagina and cervix more clearly.

squamous cell carcinoma (SCC)

Cancer that starts in the squamous cells of the body, such as the skin, lungs, vagina and cervix.

urethra

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

vagina

A muscular canal about 7–10 cm long that extends from the entrance of the uterus to the vulva.

vaginal intraepithelial neoplasia (VAIN)

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

vaginal stenosis

Narrowing of the vagina. It may be caused by radiation therapy to the pelvic area or by vaginal surgery.

vaginectomy

An operation that removes some or 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.

vaginoscopy

An examination of the vagina with a colposcope, a magnifying instrument with a bright light.

vulva

The external sexual organs (genitals) of a woman. It includes 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.

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 magnifying instrument with a bright light.

wide local excision

A surgical procedure to remove a cancer and some healthy tissue around it.

Can't find a word here?

For more cancer-related words, visit:

- cancercouncil.com.au/words
- cancervic.org.au/glossary

References

1. National Comprehensive Cancer Network (US), *NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines): Vulvar Cancer*, Version 1.2020.
2. NF Hacker et al., "Cancer of the vagina", *International Journal of Gynecology and Obstetrics*, vol. 131, 2015, pp. S84–S87.
3. Australian Institute of Health and Welfare (AIHW), *Cancer data in Australia*, AIHW, Canberra, 2020. Available from: aihw.gov.au/reports/cancer/cancer-data-in-australia (viewed 21 September 2020).
4. YJ Kang et al., "Vulvar cancer in high-income countries: Increasing burden of disease", *International Journal of Cancer*, vol. 141, iss. 11, 2017, pp. 2174–86.



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 other Pink events, 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

13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

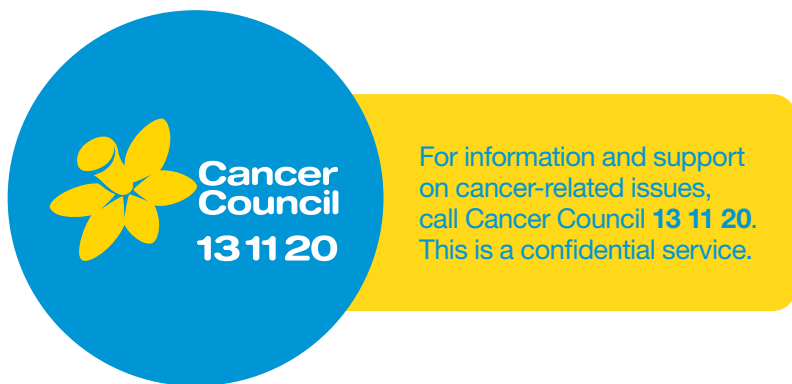
Cancer Council services and programs vary in each area.
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



Interpreter

If you need information in a language other than English, an interpreting service is available. Call 13 14 50.

If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. communications.gov.au/accesshub/nrs



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

*This booklet is funded through the generosity of the people of Australia.
To support Cancer Council, call your local Cancer Council or visit your local website.*