



# Understanding Vulvar and Vaginal Cancers

A guide for women with cancer,  
their families and friends

Cancer  
information

For information & support, call

**13 11 20**



## Understanding Vulvar and Vaginal Cancers

A guide for women with cancer, their families and friends

First published November 2011. This edition October 2016.

© Cancer Council Australia 2016. ISBN 978 1 925136 24 1

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

Editor: Jenni Bruce. 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 Publications Working Group initiative.

We thank the reviewers of this booklet: Professor Selvan Pather, Senior Staff Specialist, Chris O'Brien Lifehouse, NSW; Dr Tiffany Daly, Radiation Oncologist, Mater Cancer Care Centre, South Brisbane, QLD; Anne Mellon, Gynaecological Clinical Nurse Consultant, Gynaecological Oncology, Hunter New England Centre for Gynaecological Cancer, and Chair, Gynaecological Oncology Specialist Practice Network, Cancer Nurses Society of Australia, NSW; Deb Roffe, 13 11 20 Consultant, Cancer Council SA, SA; Juliane Samara, Gynaecological and Brain/Central Nervous System Tumour Cancer Specialist Nurse, Canberra Region Cancer Centre, ACT; Robyn Teuma, Consumer; Dr Charlotte Tottman, Clinical Psychologist, Allied Consultant Psychologists and Flinders University, SA; Dr Paige Tucker, Research Registrar and Gynaecological Oncology Clinical and Surgical Assistant, St John of God Subiaco Hospital, WA.

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](http://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](mailto:info@cancer.org.au) **Website** [cancer.org.au](http://cancer.org.au)

ABN 91 130 793 725

# Introduction

This booklet has been prepared to help you understand more about two diseases of the female reproductive system: vulvar cancer and vaginal cancer.

Many people feel shocked and upset when told they have cancer. We hope this booklet will help you understand how vulvar and vaginal cancers are diagnosed and treated. They are managed differently, so you will find information about vulvar cancer on pages 8–32 and about vaginal cancer on pages 33–46. Tips for managing side effects for both cancers appear on pages 49–59.

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, we hope this information will answer some questions and help you think about other questions to ask your treatment team. You may also like to pass this booklet to your 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 clinical practice guidelines.<sup>1</sup>

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. Turn to the last page of this book for more details.



**Cancer  
Council  
13 11 20**

# Contents

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

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

## **Vulvar cancer** .....

What is vulvar cancer? .....	8
What are the symptoms? .....	9
How common is it? .....	9
What are the risk factors? .....	10
Which health professionals will I see?.....	12
Diagnosis.....	14
Staging vulvar cancer.....	19
Prognosis .....	20
Treatment.....	21
Key points .....	32

## **Vaginal cancer** .....

What is vaginal cancer? .....	33
What are the symptoms? .....	34
How common is it? .....	35
What are the risk factors? .....	35
Which health professionals will I see?.....	36
Diagnosis.....	37
Staging vaginal cancer.....	38
Prognosis .....	39
Treatment.....	40
Key points .....	46

<b>Making treatment decisions.....</b>	<b>47</b>
Talking with doctors .....	47
A second opinion .....	48
Taking part in a clinical trial .....	48
<b>Managing side effects.....</b>	<b>49</b>
Fatigue.....	49
Changes to the vagina .....	50
Changes to the vulva.....	52
Bladder and bowel problems .....	54
Lymphoedema.....	56
Menopause.....	57
Impact on sexuality .....	58
<b>Looking after yourself .....</b>	<b>60</b>
Relationships with others .....	61
Effect on your emotions .....	61
Life after treatment .....	62
<b>Seeking support .....</b>	<b>64</b>
Practical and financial help .....	64
Talk to someone who's been there .....	64
<b>Caring for someone with cancer .....</b>	<b>66</b>
<b>Useful websites .....</b>	<b>67</b>
<b>Question checklist.....</b>	<b>68</b>
<b>Glossary .....</b>	<b>69</b>



# What is cancer?

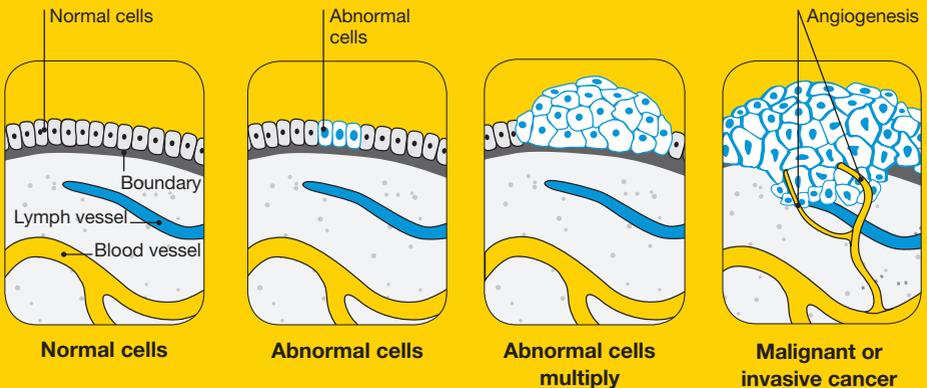
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

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

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

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

## How cancer starts



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

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

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

## How cancer spreads

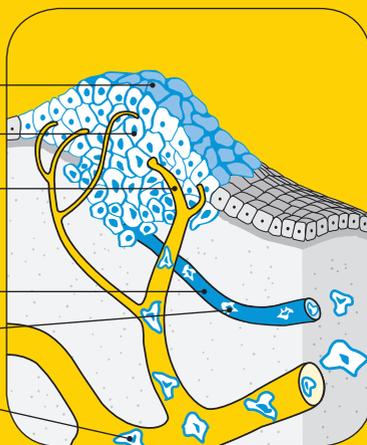
Primary cancer

Local invasion

Angiogenesis –  
tumours grow their  
own blood vessels

Lymph vessel

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





# The vulva and the vagina

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

## The vulva

The vulva is a general term for a woman'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 lips, which surround 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 women. It is located where the labia minora join at the top. During arousal, the clitoris fills with blood and becomes erect, and its stimulation can lead to sexual climax (orgasm)
- **Bartholin glands** – two small glands near the opening of the vagina. They produce mucus to lubricate the vagina.

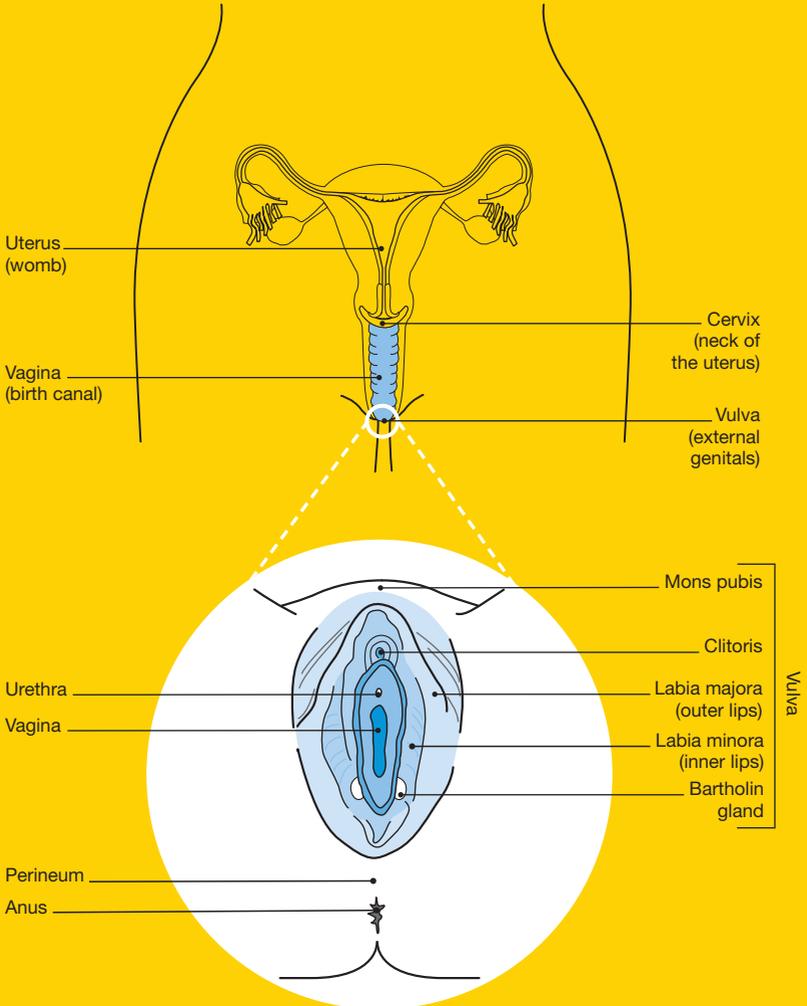
## The vagina

Sometimes called the birth canal, the vagina is a muscular channel about 7–10 cm long that extends down from the neck of the uterus (called the cervix) to the vulva. The vagina is the passageway through which menstrual blood flows, sexual intercourse occurs and a baby is born.

## Urethra, anus and perineum

Beneath the clitoris is the urethra, for passing urine. Further back is the entrance to the vagina, and below that is the anus. The area of skin between the vagina and the anus is called the perineum.

# Female sexual anatomy





# Vulvar cancer

This chapter discusses symptoms, risk factors, diagnosis and treatment for vulvar cancer (also known as vulval cancer or cancer of the vulva). For information about side effects, see pages 49–59.

## Q: What is vulvar cancer?

**A:** Vulvar cancer can start in any part of the external female sex organs (genitals). It most commonly develops in the labia minora, the inner edges of the labia majora, and the perineum. Less often, it involves the clitoris or Bartholin glands.

### Types of vulvar cancer

<b>squamous cell carcinoma (SCC)</b>	<ul style="list-style-type: none"><li>• starts in thin, flat (squamous) cells that line the vulva</li><li>• makes up about 90% of vulvar cancers</li><li>• includes verrucous carcinoma, a rare type of vulvar cancer that looks like a large wart and grows slowly</li></ul>
<b>vulvar melanoma</b>	<ul style="list-style-type: none"><li>• a type of skin cancer that develops from the cells that give the skin its colour (melanocytes)</li><li>• makes up about 2–4% of vulvar cancers</li></ul>
<b>adenocarcinoma</b>	<ul style="list-style-type: none"><li>• develops from the mucus-producing (glandular) cells in the Bartholin glands or other vulvar glands</li><li>• includes extramammary Paget's disease, which looks like eczema</li><li>• a rare type of vulvar cancer</li></ul>
<b>sarcoma</b>	<ul style="list-style-type: none"><li>• starts in muscle, fat and other tissue under the skin</li><li>• tends to grow faster than other vulvar cancers</li><li>• a rare type of vulvar cancer</li></ul>
<b>basal cell carcinoma (BCC)</b>	<ul style="list-style-type: none"><li>• starts in tall cells in the lower layer of the skin</li><li>• the most common form of skin cancer, but a very rare type of vulvar cancer</li></ul>

## Q: What are the symptoms?

- A:** Women with early vulvar cancer may have few obvious symptoms, but most women are diagnosed after a long history of vulvar symptoms. These may include one or more of the following:
- 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 a lesion or sore spot, which may have an offensive or unusual odour or colour (not related to your menstrual period)
  - hard or swollen lymph nodes (see page 22) in the groin area.

Many women don't examine their vulva, so they don't know what is normal for them. The vulva can be difficult to see without a mirror, and some women feel uncomfortable examining their genitals. However, if you feel any pain in your genital area or notice any of the symptoms listed above, visit your general practitioner (GP).

## Q: How common is it?

- A:** Each year, about 300 Australian women are diagnosed with vulvar cancer. It most commonly affects women who have gone through menopause, and the average age at diagnosis is 67.<sup>2</sup> However, vulvar cancer can occur in younger women.

“ 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*

## Q: What are the risk factors?

A: The exact cause of vulvar cancer is unknown, but some factors 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. VIN may disappear on its own, but most women with VIN need some treatment. The condition sometimes becomes cancerous – about one in three women with vulvar cancer also has VIN.

**Human papillomavirus (HPV)** – Also known as the wart virus, HPV is a sexually transmitted infection that can cause women to develop VIN. It can be many years between the initial infection with HPV and the first signs of VIN or vulvar cancer. HPV is a very common virus and most women with HPV don't develop vulvar or any other type of cancer.

**Abnormal Pap test** – If a woman has had any abnormal cell changes detected on a Pap test (see page 17), she has a slightly higher risk of developing vulvar cancer.

**Other skin conditions** – Some skin conditions such as vulvar lichen planus and vulvar lichen sclerosis can cause

itching and soreness. If not treated, these conditions can cause permanent scarring. In a small number of women, they may develop into cancer after many years.

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

Although HPV is sexually transmitted, vulvar cancer itself is not contagious and it can't be passed on to other people through sexual contact. It is also not caused by an inherited faulty gene, so it can't be passed on to children.



HPV has been linked to a number of cancers, including vulvar, vaginal, cervical, anal and oral cancers. Studies have shown that HPV vaccination can reduce the risk of having abnormal cell changes that may lead to cancer, even in older women. Talk to your doctor about whether the HPV vaccination may be of benefit to you.

## Q: Which health professionals will I see?

**A:** Your GP will probably arrange the first tests to assess your symptoms. You will then be referred to a gynaecologist or gynaecological oncologist.

### MDT health professionals

<b>GP</b>	explains information provided by specialists; assists you with treatment decisions; helps you obtain practical and emotional support; and works in partnership with your specialists in providing your ongoing care
<b>gynaecologist*</b>	specialises in treating diseases of the female reproductive system; may diagnose vulvar or vaginal cancer and then refer you to a gynaecological oncologist
<b>gynaecological oncologist*</b>	specialises in diagnosing and treating cancers of the female reproductive system (gynaecological cancers), such as vulvar and vaginal cancers
<b>radiation oncologist*</b>	prescribes and coordinates the course of radiotherapy
<b>medical oncologist*</b>	prescribes and coordinates the course of chemotherapy
<b>reconstructive/plastic surgeon*</b>	specialises in complex surgical techniques to restore the appearance of the genitals after the cancer is removed
<b>nurses</b>	administer treatment and provide care, information and support throughout treatment

You will be cared for by a range of health professionals who specialise in different aspects of your treatment. This is called a multidisciplinary team or MDT. The table below lists some of the health professionals you may see.

<b>cancer care coordinator, clinical nurse consultant (CNC) or cancer nurse specialist</b>	coordinates your care; liaises with other members of the MDT; and supports you and your family throughout treatment
<b>nurse practitioner</b>	nurse who has had additional training and may be able to prescribe some medicines and refer you to other health professionals
<b>consultant psychiatrist*, clinical psychologist, counsellor</b>	helps you manage your emotional response to diagnosis and treatment; may also help with emotional issues affecting sexuality
<b>social worker</b>	links you to support services and helps you with emotional or practical issues
<b>dietitian</b>	recommends the best eating plan to follow while you are in treatment and recovery
<b>physiotherapist</b>	helps manage physical problems, such as weak pelvic floor muscles and pain
<b>occupational therapist</b>	assists in adapting your living and working environment to help you resume activities

*\*Specialist doctor*

## Diagnosis

If you have any of the symptoms listed on page 9, your first step will be to visit your GP, who will conduct initial tests. If you need further tests, the GP will refer you to a specialist such as a gynaecologist or gynaecological oncologist (see page 12).

### Tests to diagnose vulvar cancer

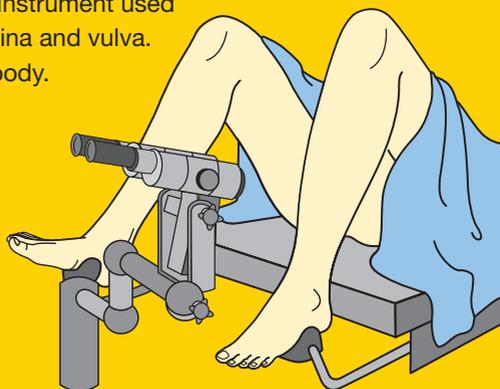
The main tests used to diagnose vulvar cancer are a physical examination, a procedure called a colposcopy (see opposite), and the removal of a tissue sample (biopsy). Because vulvar cancer is sometimes associated with cervical cancer, the doctor may check for abnormal cells in the vagina and cervix as part of these initial tests.

**Physical examination** – Your doctor will examine your groin and pelvic area, including the genitals. You will remove your clothing from the waist down and lie on a table with your knees bent and legs apart. If you feel worried about this examination, let your doctor know. A nurse may be present during the examination, but you can also ask for a family member to be in the room.

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. This examination may be done under a general anaesthetic if you have a skin condition such as lichen planus or lichen sclerosus that has narrowed the vagina.

## Viewing the vulva and vagina

The colposcope is an instrument used to view the cervix, vagina and vulva. It is not put into your body.



**Colposcopy** – To examine the vulva and vagina in detail, the doctor uses a magnifying instrument called a colposcope. The colposcope does not go into the vagina; the doctor looks through it from the outside. 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 with your knees up and apart. The doctor will apply a vinegar-like liquid or iodine to your vulva and vagina, which makes it easier to see abnormal cells through the colposcope. This may sting or burn, and you may have a brown discharge afterwards. During a colposcopy, the doctor will usually take a biopsy (see next page) from the vulva and/or the vagina.

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

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 relief about an hour before the procedure to ease discomfort.

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

The doctor may 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.

Afterwards, your vulva may bleed a little, and sometimes stitches are needed to close up the wound. Ask your doctor how much bleeding to expect after the biopsy, and how to care for the wound to keep it from becoming infected. You may have some soreness, which can be relieved by taking painkillers, and will be advised not to have sex or put anything in your vagina for 24 hours after the colposcopy.

The tissue sample will be sent to a laboratory, and a specialist called a pathologist will examine 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.

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.

**Pap test** – If you haven't had one recently, your doctor may do a Pap test (also called a Pap smear) to check the cells inside the vagina and cervix. This will be done during the internal examination while the speculum is in place. A small brush or swab is used to remove some cells from the surface of the cervix. This tissue sample is sent to a laboratory to check for abnormalities.

## Further tests

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

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

**Chest x-ray** – A painless scan that produces a detailed image of your lungs.

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

**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.



The dye used in a CT or MRI scan usually contains iodine. If you have had a reaction to the dye in a previous scan, tell your medical team beforehand. You should also let them know if you are diabetic, have kidney disease, are pregnant or have a pacemaker.

**CT scan** – A computerised tomography scan. This scan uses x-rays and a computer to create detailed, cross-sectional 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. If you have the injection, you may feel hot all over for a few minutes.

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** – A magnetic resonance imaging scan. This type of scan uses a powerful magnet and radio waves to create detailed, cross-sectional pictures of the inside of your body. Sometimes, dye will be 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. Some people feel anxious lying in the narrow cylinder. Tell your medical team beforehand if you feel concerned, as they may offer you some medicine to help you relax.

## Staging vulvar cancer

Based on the test results, your doctor will be able to tell you the stage of the cancer. This is a way to describe its size and whether and how far it has spread. In Australia, vulvar cancer is usually staged using the staging system from the International Federation of Gynecology and Obstetrics (FIGO).

### Vulvar cancer staging

<b>Stage I</b>	Cancer is found only in the vulva or perineum.
<b>Stage II</b>	Cancer is found in the vulva and/or perineum and has also spread to the lower urethra, the lower vagina or the anus.
<b>Stage III</b>	Cancer is found in the vulva and/or perineum and in lymph nodes of the groin (it can be stage III whether or not it has spread to the urethra, vagina or anus).
<b>Stage IV</b>	Cancer has spread to the upper urethra, upper vagina or more 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 develop. Low-grade (grade 1) cancer cells are slow growing and are less likely to spread. High-grade (grade 3) cells look more abnormal, and are more likely to grow and spread quickly.

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

## Prognosis

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

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

In most cases, the earlier that vulvar cancer is diagnosed, the better the chances of successful treatment. To work out your prognosis, the doctor will consider:

- your test results
- the type of vulvar cancer you have
- the stage and grade of the cancer
- how well you respond to treatment
- other factors such as age, general fitness and medical history.

In some cases, the doctor will not have enough information to assess prognosis until after the surgery to remove the cancer (see opposite page).



Cancer Council produces information booklets on surgery, radiotherapy and chemotherapy. Call **13 11 20** for free copies or download digital versions from your local Cancer Council website.

“ 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*

## Treatment

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

### Surgery

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

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

**Radical local excision** – The surgeon cuts out the cancer and a larger area of normal tissue all around the cancer. The nearby lymph nodes in the groin may also be removed (see next page).

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

**Radical vulvectomy** – The surgeon removes the entire vulva, sometimes including the clitoris. Usually, nearby lymph nodes are also removed (lymph node dissection).

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



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 tips to manage this side effect.

**Sentinel lymph node biopsy** – Before a lymph node dissection, the surgeon may perform a sentinel lymph node biopsy. You will have an anaesthetic and an injection of radioactive dye near the site of the cancer. This test helps to identify the lymph node most likely to be the first to have cancer spread to it. The dye will flow to this node, and the surgeon will remove it and determine whether it's necessary to remove more lymph nodes.

A sentinel lymph node biopsy can help the doctor avoid removing more lymph nodes than necessary and thus minimise side effects such as lymphoedema (see box above). Your doctor will talk to you about this type of biopsy and the associated risks.

**Pelvic exenteration** – This operation is no longer commonly done for vulvar cancer, but may sometimes be considered for advanced cancer that has spread beyond the vulva. A pelvic exenteration removes all the affected organs, such as the lower bowel, bladder, uterus and vagina. Because the bladder and bowel are removed, the surgeon will make two openings (stomas) in the abdomen so that urine and faeces can be collected in stoma bags. Your surgeon will only recommend this surgery if you are fit enough to make a good recovery.

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

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

“ 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

Your recovery time after the operation will depend on the type of surgery you have. If a small amount of skin is removed, the wound will probably heal quickly. If your lymph nodes are removed or the surgery is more extensive, recovery will take longer.

### Pain

- You will be given medicine to reduce any pain.
- For the first day or two, pain medicine may be given by injection into a muscle; by a drip into a vein (intravenous or IV drip); by a drip into a space around the spinal cord (epidural), which numbs the body from the waist down; or by injection into specific nerves during or after the surgery (nerve block).
- When you are ready, you will switch to pain-relieving pills or tablets. After you go home, you can continue taking these for as long as needed.
- Strong pain medicines and long periods in bed can make bowel motions difficult to pass (constipation). Talk to your treatment team about this, as medication can help.

### Tubes and stitches

- 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 be a surgical drain placed in the wound to draw fluid away from the incision. The drain needs to stay in until it is not draining too much fluid, so you may go home with the drain still in place. If this is the case, community nurses can help you manage the care of the drain at home until it is removed.

- Your doctor will tell you how soon you can sit following surgery and how to walk to avoid the stitches coming apart. Stitches usually dissolve and disappear as the wound heals. Otherwise, they will be removed within a couple of weeks.
- Some surgeons use surgical glue instead of stitches. The glue falls off when the wound is healed.

### Wound care

- Infection rates after vulvar surgery are very high, so it is vital to 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 an ointment to help prevent infection.
- The nurses will show you how to look after the wound at home. You will need to wash it two to three times a day using a handheld shower or a shallow basin (sitz bath).
- Dry the vulva well. If the area is numb, be careful patting it dry. Some women use a hair dryer (on a low heat setting and at a safe distance).
- To ventilate the wound, wear loose fitting clothing and try not to wear underwear.
- Report any redness, pain, swelling, wound discharge or unusual odour to your surgeon or nurse.

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



## Recovering from surgery at home

When you return home from hospital after surgery for vulvar cancer, there will be a period of recovery and adjustment.



### Rest

Get plenty of rest in the first week after you return home. Take it easy and only do what is comfortable. However, avoid sitting for long periods of time as this can put pressure on the wound.



### Exercise

Check with your surgeon or nurse about when you can start doing your regular activities. You may not be able to lift anything heavy or drive for 6–8 weeks, but gentle exercise such as walking can speed up recovery.



### Emotions

If you have lost part of your genital area, you may feel a sense of loss and grief. You can call Cancer Council **13 11 20** for support.

### 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. For tips, see pages 54–55.



### Sexuality

You may feel concerned about the impact on your sex life. See page 58 for information.

## Radiotherapy

Radiotherapy uses radiation, such as x-rays, to kill or damage cancer cells. It is also known as radiation therapy. Whether you have radiotherapy will depend on the stage of the cancer, its size, whether it has spread to the lymph nodes and, if so, how many nodes are affected. You can have radiotherapy:

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

**External radiotherapy** – Also called external beam radiotherapy (EBRT), this is the most common radiotherapy for vulvar cancer. You will lie on a treatment table while a machine, called a linear accelerator, directs radiation towards the areas of the vulva that are affected or at risk. Treatment is usually given daily, Monday to Friday, over 5–6 weeks. The number of sessions will depend on the type and size of the cancer. Each session takes about 20 minutes.

Radiotherapy to the vulva and groin is painless, but it can cause side effects (see next two pages). External radiotherapy will not make you radioactive. It is safe for you to be with other people, including children, after your treatment.

**Internal radiotherapy** – Also called brachytherapy, this delivers radiotherapy to the tumour from inside your body. It is not used often for vulvar cancer. See page 41 for more information.

## Side effects of radiotherapy

The side effects you experience will vary depending on the radiotherapy dose and areas treated. Many will be short-term side effects that occur during treatment or within a few weeks of finishing.

### Short-term side effects

#### Fatigue (see also page 49)

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

#### Bowel and bladder problems (see also pages 54–55)

Radiotherapy can irritate the bowel and bladder. Bowel motions may be more frequent or urgent or may become loose (diarrhoea), or you may pass more wind than normal. Less commonly, women may have some blood in the stools (faeces), but always tell your doctor about any bleeding. You may also pass urine more often or have a burning sensation when you pass urine.

#### Nausea and vomiting

Because the radiotherapy is directed near your abdomen, you may feel sick (nauseous), with or without vomiting, for several hours after each treatment. Your doctor may prescribe anti-nausea medicine to help prevent this.

#### Vaginal discharge

Radiotherapy may cause or increase a vaginal discharge. Let your treatment team know if it is foul smelling or bloody. Do not wash inside the vagina with douches as this may cause infection.

#### Skin redness, soreness and swelling

The vulva may become sore and swollen. It may start by being pink or red and feeling itchy, and progress to peeling, blistering or weeping. Your treatment team will recommend creams and pain relief to use until the skin heals. Wash the area with lukewarm water or weak salt baths, and avoid perfumed products and talcum powder.

Side effects often get worse 1–2 weeks after the end of treatment, before starting to get better. Some side effects may continue for longer or they may be late effects, not appearing until some time after treatment.

## Long-term or late effects

### Hair loss

You may lose your pubic hair. For some women, this can be permanent. It will not affect the hair on your head or other parts of your body.

### Bowel and bladder changes (see also pages 54–55)

Bowel changes, such as diarrhoea or wind, and bladder changes, such as frequent or painful urination, can also be late effects, appearing some weeks after radiotherapy finishes. In rare cases, blockage of the bowel can occur, so it is important to let your doctor know if you have pain in the abdomen and cannot open your bowels.

### Lymphoedema (see also page 56)

Radiation can scar the lymph nodes and vessels and stop them draining lymph fluid properly from the legs, making the legs swollen. This can occur months or years after radiotherapy, and it is easier to treat if recognised early.

### Narrowing of the vagina (see also pages 50–51)

The vagina can become dryer, shorter and narrower (vaginal stenosis), which may make sex and follow-up pelvic examinations uncomfortable or difficult. Your treatment team will suggest strategies to prevent this, such as the use of vaginal dilators.

### Menopause (see also page 57)

In premenopausal women, radiotherapy to the pelvis can stop the ovaries producing hormones, and this causes early menopause. Your periods will stop, you will no longer be able to become pregnant and you may have menopausal symptoms. Talk to your radiation oncologist about any menopause or fertility issues before treatment.

## Chemotherapy

Chemotherapy uses drugs known as cytotoxics to kill or slow the growth of cancer cells. For women with vulvar cancer, treatment may be given:

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

Chemotherapy may be given as tablets, in a cream applied to the vulva or, more commonly, by injection into a vein (intravenously).

Most women have several treatment sessions (a cycle), followed by a break. Treatment can often be given to you during day visits to a hospital or clinic as an outpatient, but sometimes you may need to stay in hospital for a few nights.

## 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 your individual response. Your medical oncologist or nurse will discuss the likely side effects with you, including how they can be prevented or controlled with medication.

Common side effects experienced after chemotherapy for vulvar cancer include:

- feeling sick (nausea)
- tiredness (fatigue)
- a reduced resistance to infections.

Chemotherapy for vulvar cancer may also increase any skin soreness caused by radiotherapy. Some women find that they are able to continue with their usual activities during treatment, while others find they need to take things more slowly.

To find out more about chemotherapy and its side effects, call Cancer Council 13 11 20 and ask for a free copy of the *Understanding Chemotherapy* booklet, or download a digital version from your local Cancer Council website.

## Palliative treatment

In some cases of advanced vulvar cancer, the medical team may talk to you about palliative treatment. Palliative treatment helps to improve quality of life by alleviating symptoms of cancer. It can be used at any stage of advanced cancer.

As well as slowing the spread of cancer, palliative treatment can relieve pain and help manage other symptoms. Treatment may include radiotherapy, chemotherapy or other drug therapies.

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

Call Cancer Council 13 11 20 to request free booklets on palliative care or advanced cancer, or download digital versions from your local Cancer Council website.



## Key points

- Vulvar cancer is also known as vulval cancer or cancer of the vulva. There are several types of vulvar cancer.
- Symptoms may include burning, itching, pain, a lump, coloured skin patches, or a mole that changes in colour.
- A condition known as vulvar intraepithelial neoplasia (VIN) can increase the risk of developing vulvar cancer.
- Tests for vulvar cancer include a physical examination of the groin and pelvic area, a biopsy and scans.
- The cancer's stage describes its size and whether and how far it has spread. The grade tells how quickly it is growing.
- The prognosis is the expected outcome of the disease. In general, the earlier vulvar cancer is diagnosed, the better the outcome.
- You may see a range of health professionals, including a gynaecologist or gynaecological oncologist.
- Surgery is the main treatment for vulvar cancer. The type of operation you have depends on the stage of the cancer. The lymph nodes in the groin may also be removed.
- Radiotherapy uses radiation to kill cancer cells. The most common type of radiotherapy for vulvar cancer is external radiotherapy. Side effects may be short-term or long-term or may appear later.
- Chemotherapy uses cytotoxic drugs to kill or damage cancer cells. Side effects can include nausea and fatigue.
- For advanced vulvar cancer, palliative treatment can help with symptoms and improve quality of life. It is an important part of palliative care.



# Vaginal cancer

This chapter discusses symptoms, causes, diagnosis and treatment of primary vaginal cancer (also known as cancer of the vagina). Detailed information about side effects can be found in the *Managing side effects* chapter (see pages 49–59).

## Q: What is vaginal cancer?

**A:** Primary vaginal cancer is any cancer that starts in the vagina. There are several types (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 next page).

### Types of primary vaginal cancer

<b>squamous cell carcinoma (SCC)</b>	<ul style="list-style-type: none"><li>• starts in thin, flat (squamous) cells that line the vagina</li><li>• most likely to occur in the upper vagina</li><li>• usually grows slowly over many years</li><li>• makes up about 85% of vaginal cancers</li></ul>
<b>adenocarcinoma</b>	<ul style="list-style-type: none"><li>• develops from the mucus-producing (glandular) cells of the vagina</li><li>• more likely to spread to the lungs and lymph nodes</li><li>• makes up 5–10% of vaginal cancers</li><li>• includes clear cell carcinoma</li></ul>
<b>vaginal melanoma</b>	<ul style="list-style-type: none"><li>• a type of skin cancer that develops from the cells that give the skin its colour (melanocytes)</li><li>• a rare form of vaginal cancer</li></ul>
<b>sarcoma</b>	<ul style="list-style-type: none"><li>• develops from muscle, fat and other tissue deep in the wall of the vagina</li><li>• a rare form of vaginal cancer</li></ul>

## 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 to primary vaginal cancer. For more information, speak to your treatment team. For a free copy of *Living with Advanced Cancer*, call Cancer Council **13 11 20** or visit your local Cancer Council website.

## Q: What are the symptoms?

**A:** There are often no obvious symptoms of vaginal cancer. The cancer is sometimes found by a routine Pap test (see page 17).

You may have one or more of the following symptoms:

- bloody vaginal discharge not related to your menstrual period, which may have an offensive or unusual odour
- pain during sexual intercourse
- bleeding after sexual intercourse
- pain in the pelvic area 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 with 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 70 women are diagnosed with vaginal cancer, and the average age at diagnosis is 70.<sup>2</sup> However, vaginal cancer, particularly adenocarcinoma, can sometimes occur in younger women.

## Q: What are the risk factors?

**A:** The exact cause of vaginal cancer is unknown, but factors known to increase the risk include:

**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 women with VAIN do not develop vaginal cancer.

**Human papillomavirus (HPV)** – Also known as the wart virus, HPV is a sexually transmitted infection that can cause women to develop VAIN. It can be many years between the initial infection with HPV and the first signs of VAIN or vaginal cancer. HPV is a very common virus and most women with HPV don't develop vaginal or any other type of cancer.

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

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

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

**Diethylstilboestrol (DES)** – This synthetic hormone drug has been identified as a cause of a 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. If you are concerned about this risk, see your GP.

## **Q: Which health professionals will I see?**

**A:** Your GP will probably arrange the first tests to assess your symptoms. You will then be referred to a gynaecologist or gynaecological oncologist. You will be cared for by a range of health professionals in a multidisciplinary team or MDT. See pages 12–13 for a list of the health professionals you may see.



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 and can't be passed on to your children. For more information on the risk factors, call Cancer Council **13 11 20**.

## Diagnosis

If you have any of the symptoms listed on page 34, your first step will be to visit your GP, who will conduct initial tests. If you need further tests, you will see a specialist such as a gynaecologist or gynaecological oncologist (see page 12).

### Tests to diagnose vaginal cancer

The main tests used to diagnose vaginal cancer are a physical examination, a Pap 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 and lie on a table with your knees bent and legs apart.

If you feel embarrassed or scared about this examination, let your doctor know. A nurse may be present during the examination, but you can also ask for a family member to be in the room.

The doctor may arrange for you to have the examination under a general anaesthetic if the area is very painful.

**Pap test** – During the physical examination, you may have a Pap test (Pap smear) to check the cells inside the vagina and cervix. See page 17 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 35).

**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 15–16 for a description of these tests.

The biopsy is then sent to a laboratory, and a specialist doctor called a pathologist will examine the cells under a microscope. The pathologist will be able to check for cell abnormalities.

### **Further tests**

If the tests described above show that you have vaginal cancer, further tests may be needed to find out whether the cancer cells have spread. These may include a blood test, chest x-ray, cystoscopy, proctoscopy, and CT and MRI scans. See pages 17–18 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 and how far it has spread beyond its original site.

### Vaginal cancer staging

<b>Stage I</b>	Cancer is found only in the vagina.
<b>Stage II</b>	Cancer has begun to spread through the vaginal wall, but it has not spread into the wall of the pelvis.
<b>Stage III</b>	Cancer has spread to the pelvis. It may also be in the lymph nodes close to the vagina.
<b>Stage IV</b>	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 develop. A low-grade (grade 1) cancer means that the cells are slow-growing and less likely to spread. High-grade (grade 3) cells look more abnormal, and are more likely to grow and spread quickly.

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

## Prognosis

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

for women 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.

## Treatment

How vaginal cancer is treated depends on several factors, including your general health and the stage, grade and type of cancer.

Treatment may involve radiotherapy, surgery and/or chemotherapy.

### Radiotherapy

Also known as radiation therapy, this treatment uses radiation, such as x-rays, to kill or damage cancer cells. Radiotherapy is a common treatment for vaginal cancer. Some women with vaginal cancer are treated with a combination of radiotherapy and chemotherapy (see pages 44–45). This is called chemoradiotherapy or chemoradiation. Radiotherapy can also be used to control symptoms of advanced cancer (palliative treatment).



Cancer Council produces information booklets on radiotherapy, surgery and chemotherapy. Call **13 11 20** for free copies or download digital versions from your local Cancer Council website.

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

**External radiotherapy** – Also known as external beam radiotherapy (EBRT), external radiotherapy directs the treatment at the cancer from outside the body. You will lie on a treatment table under a machine called a linear accelerator, which delivers the radiation.

External radiotherapy is usually given as a series of 20-minute daily treatments, Monday to Friday, over 4–6 weeks. The exact number of sessions you have will depend on the type and size of the cancer, and whether it has spread to the lymph nodes.

Radiotherapy to the vagina and groin is painless, but it can cause side effects (see next page).

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

Brachytherapy can be given as low-dose rate (LDR), which requires a hospital stay over a number of days, or high-dose rate (HDR), which delivers an intense dose and usually means you can go home the same day. For vaginal cancer, HDR has been shown to be as effective as LDR, so LDR is rarely used.

At each HDR treatment session, you will be given pain medicine to make you more comfortable, and then a thin radioactive applicator, shaped like a tampon, will be put into your vagina. You will have to lie still while this is in place. Some women are given a general anaesthetic and have other small probes inserted near the cancer.

A machine delivers the radiation through the applicator for about 10–15 minutes. The applicator is taken out after the dose of radiation is delivered. If several sessions are needed, the applicator will be reinserted each time, but the doctor can use techniques that make it easier to get the applicator in the right place.

During a brachytherapy session, the tissue around the applicator will become temporarily inflamed and swollen. This will settle by the time the applicator is removed, but the treated area will feel sore afterwards. The pain should ease over a couple of weeks. Your doctor can prescribe painkillers to help relieve the discomfort.

## **Side effects of radiotherapy**

The side effects you experience vary depending on the radiotherapy dose and the areas treated. Many will be short-term side effects that occur during treatment or within a few weeks of finishing. They often get worse 1–2 weeks after the end of treatment, before starting to get better. Some side effects may be late effects, not appearing until some time after treatment.

Radiotherapy that is targeted to the vaginal area has similar side effects to radiotherapy targeted to the vulvar area. For a description of common side effects, see pages 28–29.



External radiotherapy and HDR brachytherapy will not make you radioactive. It is safe for you to be with both adults and children after your treatment sessions are over and when you are at home.

## Surgery

The cancer may need to be removed with an operation. The surgeon 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.

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

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

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

**Hysterectomy** – Some women also need to have a radical hysterectomy. This means the uterus and cervix are removed. Your gynaecological oncologist will let you know whether it is

also necessary to remove your ovaries and fallopian tubes (salpingo oophorectomy). If you have this type of surgery, it will cause menopause. See page 57 for ways to manage menopause.

## **Recovery after surgery**

The length of your hospital stay and the side effects that you experience will depend on the type of surgery you have. Most women are in hospital for a few days to a week. See pages 24–26 for what to expect as you recover from surgery.

## **Chemotherapy**

Chemotherapy uses drugs known as cytotoxics 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 radiotherapy.

The drugs are sometimes given as tablets or, more commonly, by injection into a vein (intravenously). You will usually have a number of treatment sessions (a cycle), followed by a break. Treatment can often be given to you during day visits to a hospital or clinic as an outpatient, but sometimes 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 used. Your medical oncologist or nurse will discuss the likely side effects with you, including how they can be prevented or controlled with medication.

Common side effects experienced after chemotherapy for vaginal cancer include:

- feeling sick (nausea)
- tiredness (fatigue)
- hair loss
- a reduced resistance to infections.

Chemotherapy may also increase any skin soreness caused by radiotherapy. Some people find that they are able to lead a fairly normal life during their treatment, while others become very tired and need to take things more slowly.

## Palliative treatment

In some cases of advanced vaginal cancer, the medical team may talk to you about palliative treatment. Palliative treatment helps to improve quality of life by alleviating symptoms of cancer. It can be used at any stage of advanced cancer.

As well as slowing the spread of cancer, palliative treatment can relieve pain and help manage other symptoms. Treatment may include radiotherapy, chemotherapy or other drug therapies.

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

Call Cancer Council 13 11 20 to request free booklets on palliative care and advanced cancer, or download digital versions from your local Cancer Council website.



## Key points

- The two most common types of primary vaginal cancer are squamous cell carcinoma and adenocarcinoma.
- Symptoms may include bloody vaginal discharge, pain during sex, bleeding after sex, and a lump in the vagina.
- A condition known as vaginal intraepithelial neoplasia (VAIN) can increase your risk. Female children of women who took a drug called diethylstilboestrol (DES) during pregnancy are also at an increased risk.
- Diagnostic tests may include a Pap test, an examination of the vagina (colposcopy) and a tissue sample (biopsy).
- The cancer's stage describes its size and whether it has spread. The grade tells how quickly the cells are growing.
- The earlier vaginal cancer is diagnosed, the better the chances that treatment will be successful.
- You may see a range of health professionals, including a gynaecologist or gynaecological oncologist.
- Radiotherapy uses radiation to kill cancer cells. Most women with vaginal cancer have both external and internal radiotherapy. Side effects may be short-term or long-term or may appear later.
- During surgery, the affected part of the vagina is cut out. Other organs may also be removed.
- Chemotherapy uses drugs to kill cancer cells. It is usually given if the cancer is advanced or if it returns after treatment.
- For advanced vaginal cancer, palliative treatment may be given to manage symptoms and improve quality of life.



# Making treatment decisions

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

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

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

## Talking with doctors

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

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

## A second opinion

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

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

## Taking part in a clinical trial

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

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

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



# Managing side effects

It will take some time to recover from your treatment for vulvar or vaginal cancer. As well as physical changes, you will also have to cope with the emotional impact of treatment (see pages 61–62).

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

## Fatigue

It is common to feel tired or fatigued during and after cancer treatment. This can be a side effect of treatment, but can also be caused by travelling to treatment and dealing with emotions. Your tiredness may continue for a while after treatment has finished. Some women find it takes them a few years to feel well again.

### Tips for managing fatigue

- Work out your priorities, so you save your energy for the most important things.
- Allow yourself enough rest so you can recover, but balance this with regular exercise, which can help reduce treatment-related fatigue.
- Ask family and friends for practical support, such as help with shopping, errands and childcare.
- For a free copy of *Living Well After Cancer*, call Cancer Council **13 11 20** or visit your local Cancer Council website.



## Changes to the vagina

Whether you have vulvar or vaginal cancer, the treatments may affect the vagina.

Radiotherapy targeted to the vulva or vagina can make the area tender during treatment and for a few weeks afterwards. In the long term, this irritation can cause scarring, which may make the vagina dryer, narrower, shorter and less flexible (vaginal stenosis).



### Tips for keeping the vagina open and supple

- Keeping the vagina open and supple can make vaginal sex more comfortable, but it is important whether or not you plan to be sexually active. It will allow your doctor to do a vaginal examination at follow-up visits to check for a recurrence of cancer, as well as regular Pap tests.
- If cancer treatment has narrowed or shortened the vagina, you may be advised to use a vaginal dilator to help keep the vagina open and prevent it from closing over.
- Vaginal dilators are shaped like tampons and made from plastic or rubber. They come in different sizes, so you start with the smallest size and progress to larger ones as each size becomes more comfortable. Using a lubricant, you insert a dilator into the vagina and leave it there for up to five minutes. You will need to do this at least three times a week, usually for many months.
- Your nurse or doctor will give you a set of dilators or let you know where to buy them, and can give you more detailed instructions about when and how to start using them.

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 intercourse painful.

Surgery for vaginal cancer may make the vagina shorter or narrower (vaginal stenosis). Whether intercourse is still possible after vaginal surgery depends on the extent of the operation. See page 58 for information about managing the impact on sexuality.

- Ask your doctor if applying a hormone cream or a vaginal moisturiser to your vagina will help. 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 instead of vaginal dilators.
- Although dryness, shortening and narrowing of the vagina can make sexual intercourse uncomfortable or difficult, having intercourse regularly – if you are able to and want to – may help keep the vagina open. Using a water-based or silicone-based lubricant, such as Sylk, Pjur or Astroglide, and trying different sexual positions can help.
- Some women do not have a sexual partner or do not feel emotionally or physically ready to have penetrative sex after cancer treatment. If you do not want to have sex, this is okay, but talk to your doctor about using dilators to keep your vagina open.

## Changes to the vulva

Treatments for vulvar or vaginal cancer can also affect the vulva.

Women who have had surgery affecting 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.

Radiotherapy 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 vulvar surgery, some women don't want to look at the area or prefer to do it alone or with a partner or close friend. Others want a nurse to be with them.
- After radiotherapy, 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.



## Kayleen's story

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

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

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

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

ask for anyone better. I'm part of a Facebook community and I know women whose partners haven't coped with it, especially if the woman can't have 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.

## Bladder and bowel problems

Radiotherapy and surgery to the vulva or vagina can cause bladder and bowel problems. Most side effects are temporary, but for some women, the changes are permanent. Talk to your treatment team for more information.

### Effects on the bladder

**Cystitis** – Radiotherapy can irritate the lining of the bladder. You may feel like you want to pass urine frequently or you might experience a burning sensation when you pass urine. This is called cystitis. Try to drink plenty of water to make your urine less concentrated. Cranberry juice or over-the-counter urinary alkalisers (e.g. Ural) can help by making the urine less acidic. Your doctor may also prescribe medicine to treat cystitis.

**Urinary incontinence** – Accidental or involuntary loss of urine is called incontinence. After surgery or radiotherapy to the vulva or vagina, some women find that they lose a few drops of urine when they cough, sneeze, strain or lift. For ways to manage incontinence, talk to the hospital continence nurse or physiotherapist, visit the Australian Government's bladder and bowel website at [bladderbowel.gov.au](http://bladderbowel.gov.au), or contact the Continence Foundation of Australia at [continence.org.au](http://continence.org.au) or on 1800 33 00 66.

**Difficulty urinating** – After surgery to the genital area, your urine stream may spray in different directions or off to one side. This can be messy and frustrating. If you usually squat or crouch over the toilet seat, it may help to sit down towards the back of the toilet seat. 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.

“ 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*

**Bleeding** – The blood vessels in the bladder can become more fragile after radiotherapy and this can cause blood to appear in the urine. It may occur many months or years after treatment. If you notice any bleeding, let your doctor know so that tests can be done and treatment can be given if required.

## Effects on the bowel

**Changed bowel movements** – Some women have constipation or diarrhoea after surgery or radiotherapy to the pelvic region. You may also feel some pain in your abdomen. To ease these side effects, your doctor can prescribe medicine and suggest changes to your diet. Drinking more water may also help. Ask the hospital dietitian or nurse for advice.

**Bleeding** – The blood vessels in the bowel can become more fragile after radiotherapy and this can cause blood to appear in the stools (faeces). It may occur many months or years after treatment. If you notice any bleeding, let your doctor know so that tests can be done and treatment can be given if required.

## Lymphoedema

Lymphoedema is a swelling of part of the body. In the case of vulvar or vaginal cancer, lymphoedema usually affects a leg.

If lymph nodes in your pelvis or groin have been removed by surgery or damaged by radiotherapy, lymph fluid in the leg may be unable to drain properly, and this can cause the leg to swell up.

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



### Tips for managing lymphoedema

- Make an appointment with a lymphoedema practitioner. Ask your doctor – there may be one at your hospital. Visit [lymphoedema.org.au](http://lymphoedema.org.au) to find a practitioner and to learn more about lymphoedema.
- Reduce the risk of infection by keeping your skin moisturised and caring for your nails.
- Avoid cuts, burns, insect bites, sunburn and injections in your legs.
- Talk to a lymphoedema practitioner or your nurse about wearing compression bandages, stockings or other garments to improve the circulation of lymphatic fluid.
- Do leg exercises to move fluid out of the affected area and into other lymph channels.
- Gently massage the swollen leg towards your heart to move the fluid out to other lymph channels.
- If you see any swelling or feel any heat in your legs, let your doctor or nurse know as soon as possible.

## Menopause

In women who have not yet been through menopause, some treatments for vulvar or vaginal cancer can cause early (induced) menopause. Your periods will stop and you may have symptoms such as hot flushes, dry or itchy skin, mood swings, or loss of interest in sex (libido). Loss of 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.



### Tips for managing menopause

- Ask your doctor about using oestrogen, contained in creams or soluble blocks called pessaries, to relieve vaginal dryness. Vaginal moisturisers without oestrogen can also be used.
- Hormone replacement therapy (HRT) may help to reduce symptoms. Talk to your gynaecological oncologist about the benefits and risks of HRT for you. If you were already on HRT when the cancer was diagnosed, weigh up the risks of continuing it.
- Ask your doctor about having a bone density test or taking medicine to prevent your bones from becoming weak.
- For more information about osteoporosis, visit Osteoporosis Australia at [osteoporosis.org.au](http://osteoporosis.org.au) or call **1800 242 141**.
- To find out more about the impact of treatment on fertility, call Cancer Council **13 11 20** and ask for a copy of *Fertility and Cancer*, or visit your local Cancer Council website.

## Impact on sexuality

Vulvar or vaginal cancer can affect your sexuality in both physical and emotional ways. Treatment can cause physical side effects such as tiredness, scarring, narrowing of the vagina, swelling and soreness (see pages 49–52). The experience of having cancer can also reduce your desire for sex (libido).

You may have to explore new ways to enjoy sex, but remember that for most people, sex is more than orgasms. It involves feelings of intimacy, as well as being able to give and receive love.



### Tips for managing sexual changes

- Give yourself time to get used to any physical changes. Let your partner know if you don't feel like having sex, or if you find penetration uncomfortable.
- Talk to your doctor about ways to manage side effects that change your sex life. This may include using vaginal dilators and vaginal creams (see pages 50–51).
- Extra lubrication may make intercourse more comfortable. Choose a water-based or silicone-based gel without perfumes or colouring.
- Explore different ways to climax, such as caressing the breasts, inner thighs, feet or buttocks.
- Talk about your feelings with your sexual partner or doctor, or ask your treatment team for a referral to a sexual therapist or psychologist.
- Call **13 11 20** for a free copy of *Sexuality, Intimacy and Cancer*, or visit your local Cancer Council website.



## Key points

- There are ways to reduce or manage discomfort caused by side effects.
- You might feel tired during and after treatment. Plan to rest regularly and get support from a community nurse, family and friends, if possible.
- Radiotherapy to the pelvic area can make the vagina narrower and less flexible. You may be advised to use a vaginal dilator or have sex to help keep the vaginal walls open and supple.
- It is a personal decision whether or not you would like to look at your vulva after surgery. It is natural to feel anxious and upset about any changes to your body.
- Treatment can cause bladder and bowel problems such as bleeding, incontinence or cystitis. For some women, urine may spray in different directions or off to one side.
- If your lymph nodes have been removed or damaged, you may get swelling in one or both legs. This is called lymphoedema. There are ways to prevent or reduce the swelling.
- Treatment may cause you to go through menopause. This means your periods stop and you may have symptoms such as hot flushes and mood swings. Menopause will cause infertility. If you are concerned about your fertility, talk to your medical team as soon as possible.
- Cancer and its treatment may affect sexuality in physical and emotional ways. A sexual 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. You may find coping with body image and sexuality issues particularly difficult, and this may affect your emotions and relationships. It's important to try to look after your wellbeing as much as possible.

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

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

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

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

## Relationships with others

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

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

## Effect on your emotions

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

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

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

## 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 are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Your local Cancer Council may also run a counselling program.

The organisation [beyondblue](http://beyondblue.org.au) has information about coping with depression and anxiety.

Go to [beyondblue.org.au](http://beyondblue.org.au) or call **1300 22 46 36** to order a fact sheet.

## Life after treatment

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

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

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

## Follow-up appointments

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

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

## What if the cancer returns?

For some people, vulvar or vaginal cancer does come back after treatment, which is known as a recurrence. If the cancer recurs, your doctor may consider further treatment such as surgery, chemotherapy or radiotherapy. 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 19 and 38–39), and your preferences.

“ You do get nervous and you tell yourself it's only a check-up – but it becomes this mountain. I have my scans on the Monday and see the doctor on the Wednesday, because I can't handle having to wait for the results any longer. ” *Georgina*



# Seeking support

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

## Practical and financial help

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

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

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

## Talk to someone who's been there

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

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

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

## Types of support

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

- **face-to-face support groups** – often held in community centres or hospitals
- **telephone support groups** – facilitated by trained counsellors
- **peer support programs** – match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums** – such as Cancer Council Online Community at [cancercouncil.com.au/onlinecommunity](http://cancercouncil.com.au/onlinecommunity).

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

“ My family members don't really understand what it's like to have cancer thrown at you, but in my support group, I don't feel like I have to explain. ” *Sam*



# Caring for someone with cancer

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

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

Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local services, as well as practical information and resources, through the Carer Gateway. Visit [carergateway.gov.au](http://carergateway.gov.au) or call 1800 422 737. Carers Australia is the national body representing carers in Australia. It works with the Carers Associations in each of the states and territories. Visit [carersaustralia.com.au](http://carersaustralia.com.au) or call 1800 242 636 for more information and resources.

Call Cancer Council 13 11 20 to find out more about carers' services and get a copy of *Caring for Someone with Cancer*.



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 it helpful to read Cancer Council's *Sexuality, Intimacy and Cancer* booklet.



# Useful websites

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

## Australian

---

Cancer Council Australia.....	<b>cancer.org.au</b>
Cancer Australia.....	<b>canceraustralia.gov.au</b>
Cancer Council Online Community.....	<b>cancercouncil.com.au/onlinecommunity</b>
Carer Gateway.....	<b>carergateway.gov.au</b>
Carers Australia.....	<b>carersaustralia.com.au</b>
Department of Health.....	<b>health.gov.au</b>
healthdirect Australia.....	<b>healthdirect.gov.au</b>
Australia New Zealand Gynaecological Oncology Group.....	<b>anzgog.org.au</b>
Gynaecological Cancer Society.....	<b>gcsau.org</b>
Gynaecological Awareness Information Network.....	<b>gain.org.au</b>
beyondblue.....	<b>beyondblue.org.au</b>
Bladder and Bowel.....	<b>bladderbowel.gov.au</b>
Continence Foundation of Australia.....	<b>continence.org.au</b>
Relationships Australia.....	<b>relationships.org.au</b>

## International

---

American Cancer Society.....	<b>cancer.org</b>
Cancer Research UK.....	<b>cancerresearchuk.org</b>
Eyes on the Prize (US).....	<b>eyesontheprize.org</b>
International Gynecologic Cancer Society.....	<b>igcs.org</b>
Macmillan Cancer Support (UK).....	<b>macmillan.org.uk</b>
National Cancer Institute (US).....	<b>cancer.gov</b>



## Question checklist

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

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



# Glossary

## **adenocarcinoma**

A cancer that starts in mucus-producing (glandular) cells.

## **Bartholin glands**

Small glands on either side of the vagina that secrete mucus.

## **biopsy**

The removal of a sample of tissue from the body for examination.

## **brachytherapy**

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

## **chemotherapy**

The use of cytotoxic drugs to kill cancer cells or slow their growth.

## **clitoris**

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

## **colposcopy**

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 three-dimensional pictures of the body.

## **cystitis**

Inflammation of the bladder lining.

## **cystoscopy**

A procedure that uses a tool called a cystoscope to see inside the urethra and bladder.

## **diethylstilboestrol (DES)**

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

## **extramammary Paget's disease**

A rare, slow-growing adenocarcinoma that appears as a rash on the vulva.

## **gynaecological cancers**

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

## **gynaecological oncologist**

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

## **gynaecologist**

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

## **human papillomavirus (HPV)**

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

## **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, which join at the top to cover the clitoris.

### **lymphatic system**

A network of tissues, capillaries, vessels, ducts and nodes that removes excess fluid from tissues, absorbs fatty acids and transports fat, and produces immune cells. Includes the bone marrow, spleen and lymph nodes.

### **lymph nodes**

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

### **lymphoedema**

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

### **menopause**

When a woman stops having periods (menstruating).

### **mons pubis**

In women, the area of fatty tissue above the labia. It is covered with pubic hair.

### **MRI scan**

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

### **Pap test**

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

### **pelvic exenteration**

The surgical removal of all organs from the pelvis, including the uterus,

ovaries, cervix, vagina, bladder and part of the bowel.

### **perineum**

The area of skin between the vulva and the anus.

### **proctoscopy**

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

### **radical hysterectomy**

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

### **radiotherapy**

The use of radiation, such as x-rays, to kill cancer or injure cells. Also called radiation therapy. Internal radiotherapy is called brachytherapy.

### **rectum**

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

### **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 if cancer has spread beyond a primary tumour into the lymphatic system.

### **sitz bath**

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

### **speculum**

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

### **squamous cell carcinoma**

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

### **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 that can develop into vaginal cancer if untreated.

### **vaginal stenosis**

Narrowing of the vagina. It may be caused by radiotherapy 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 areas. 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 a woman's outer sex organs (the vulva).

### **vulvoscopy**

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

### **wide local excision**

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

### **Can't find a word here?**

For more cancer-related words, visit:

- [cancerCouncil.com.au/words](http://cancerCouncil.com.au/words)
- [cancervic.org.au/glossary](http://cancervic.org.au/glossary)
- [cancersa.org.au/glossary](http://cancersa.org.au/glossary)

## **References**

1. Greater Metropolitan Clinical Taskforce, *Best Clinical Practice Gynaecological Cancer Guidelines 2009*, NSW Department of Health, North Sydney, NSW, 2009.
2. Cancer Australia, *Report to the nation – gynaecological cancers 2012*, Cancer Australia, Surry Hills, NSW, 2012.



# How you can help

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

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

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

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

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

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

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



# Cancer Council 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.

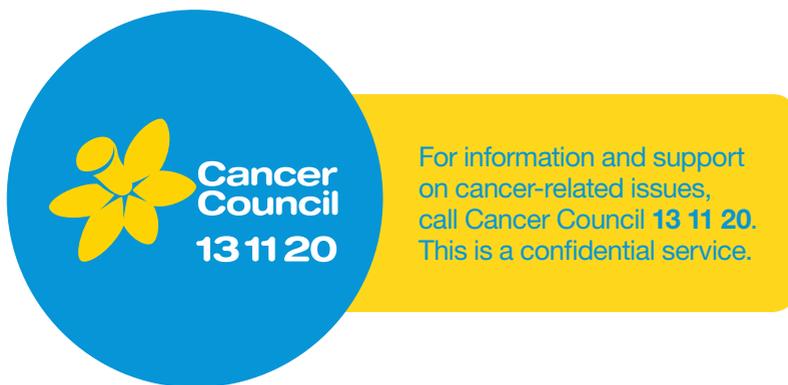
Cancer Council services and programs vary in each area.  
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



**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, contact us through the National Relay Service.**  
[www.relayservice.gov.au](http://www.relayservice.gov.au)



## 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.*