Understanding Vulva and Vagina Cancers
A guide for women with cancer, their families and friends

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Information sheets about cancer of the vulva and cancer of the vagina first published January 2005 and revised August 2007.
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Note to reader
Always consult your doctor before beginning any health treatment. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your doctor’s or other health professional’s advice. However, you may wish to discuss issues raised in this booklet with them. All care is taken to ensure that the information in this booklet is accurate at the time of publication.

Cancer Council NSW
Cancer Council is the leading cancer charity in NSW. It plays a unique and important role in the fight against cancer through undertaking high-quality research, advocating on cancer issues, providing information and services to the public and people with cancer, and raising funds for cancer programs.

This booklet is funded through the generosity of the people of NSW. To make a donation to help defeat cancer, visit Cancer Council’s website at www.cancercouncil.com.au or phone 1300 780 113.
This booklet has been prepared to help you understand more about two rare gynaecological diseases: cancer of the vulva and cancer of the vagina.

Many people feel understandably shocked and upset when told they have cancer. We hope this booklet will help you understand how vulvar and vaginal cancers are diagnosed and treated. We also include information about support services.

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

You may like to pass this booklet to your family and friends for their information. If you’re reading this booklet for someone who doesn’t understand English, let them know that Cancer Council Helpline 13 11 20 can arrange telephone support in different languages.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary.

Cancer of the vulva and cancer of the vagina are diagnosed and treated differently. Information about cancer of the vulva is on pages 8–26; vaginal cancer is discussed on pages 27–44. Detailed information about side effects for both are on pages 45–53.
What is cancer?

Cancer is a disease of the cells, which are the body’s basic building blocks. Our bodies constantly make new cells to help us grow, to replace worn-out cells and to heal damaged cells after an injury.

Normally cells grow and multiply in an orderly way, but sometimes something goes wrong with this process and cells grow in an uncontrolled way. This uncontrolled growth may result in a lump called a tumour or may develop into abnormal blood cells.

A tumour can be benign (not cancer) or malignant (cancer). A benign tumour does not spread to other parts of the body. A malignant tumour is made up of cancer cells, which grow out of control and are able to spread. The cancer that first develops in a tissue or organ is called the primary cancer. When it first
develops, a malignant tumour may not have invaded nearby tissue. This is known as a cancer in-situ (carcinoma in-situ) or localised cancer. As the tumour grows it may spread, becoming invasive cancer.

Cancer cells can spread to other parts of the body by travelling through the bloodstream or lymphatic system. They may continue to grow into another tumour at this new site. This 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 still called vaginal cancer, even though the person may be experiencing symptoms caused by problems in the cervix.

**How cancer spreads**

- **Primary cancer**
- **Local invasion**
- **Angiogenesis** – tumours grow their own blood vessels
- **Lymph vessel**
- **Metastasis** – cells invade other parts of the body via blood vessels and lymph vessels
The vulva and vagina are parts of the female reproductive system.

The vagina is a muscular tube that is sometimes called the birth canal. It extends from the opening of the uterus to the external part of a woman’s sex organs (vulva). The vagina is the passageway through which menstrual blood flows, sexual intercourse occurs, and a baby is born.

The vulva is a general term describing a woman’s external sex organs. The main parts of the vulva are the:

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

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

The skin between the vulva and anus is called the perineum.
The vulva and vagina

- Uterus
- Cervix
- Vagina
- Vulva (external genitals)
- Mons pubis
- Clitoris
- Urethra
- Outer lips (labia majora)
- Vagina
- Inner lips (labia minora)
- Bartholin’s gland
- Perineum
- Anus
Cancer of the vulva

This chapter has information about the symptoms, causes, diagnosis and treatment of cancer of the vulva. This type of cancer is also known as vulvar cancer or vulval cancer.

Detailed information about side effects can be found in the *Managing side effects* chapter on pages 45–53.

**What is vulvar cancer?**

Cancer of the vulva can start in any part of the external female sex organs. The most common areas for cancer to develop are the labia minora, the inner edges of the labia majora and the perineum. Less often, vulvar cancer may involve the clitoris. It can also begin in or spread to the Bartholin’s glands.

There are several types of vulvar cancer:

- **Squamous cell carcinoma** – The most common type, making up about 90% of all cases. It affects the skin cells of the vulva.
- **Vulvar melanoma** – A type of skin cancer that develops from the cells that give the skin its colour. About 2–4% of vulvar cancers are melanoma.
- **Adenocarcinoma** – Cancer that begins in the glandular cells lining the skin of the vulva.
- **Verrucous carcinoma** – Slow-growing cancer that looks like a large wart.
- **Sarcomas** – Cancers that develop from tissue cells, including muscle, fat under the skin and connective tissue. Sarcomas tend to grow faster than other types of vulvar cancer.
What are the symptoms?
There are often no obvious symptoms of vulvar cancer. However, you may have one or more of the following symptoms:
- bloody, pussy or smelly vaginal discharge not related to your menstrual period
- itching, burning and soreness or pain in the vulva
- a lump, sore, swelling or wart-like growth on the vulva
- thickened, raised, red, white or dark brown skin patches
- a mole on the vulva that changes shape or colour.

Many women don’t look at their vulva, so they do not know what is normal for them. Some women don’t look because it is difficult to see. Others feel uncomfortable or think that their vulva is ugly. However, if you feel any pain in your genital area or notice any of the above symptoms, you should schedule a checkup with your GP.

How common is it?
Each year, about 280 Australian women are diagnosed with vulvar cancer. It usually affects post-menopausal women between the ages of 55–75, but it can sometimes occur in younger or older women.

"Why do we have to be ashamed about having vulvar cancer? No one is embarrassed when they have breast cancer. When you connect with another woman who has had vulvar cancer, you soon find out that there is no need for shame or embarrassment." Patient
What are the causes?
The exact cause of vulvar cancer is unknown, but there are some factors known to increase the risk of developing it:

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

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

**Other skin conditions** – Non-cancerous (benign) skin conditions such as vulvar lichen sclerosus, vulvar lichen planus and extramammary Paget’s disease can cause itching and soreness, and after many years, may develop into cancer.

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

Vulvar cancer is not contagious and it can’t be passed to other people through sexual contact. It is also not caused by an inherited faulty gene so it can’t be passed on to children.
Diagnosis
If you have symptoms of vulvar cancer, your doctor will do a physical examination. Local anaesthetic may be used to numb the vulva and surrounding area. Your doctor may also do a blood test to check your general health.

You may have some of the following tests:

Vulvoscopy
During a vulvoscopy, the doctor uses a microscope called a colposcope to examine your vulva. (See page 31 for an illustration of a colposcope.)

You will lie on your back on an examination table with your legs spread. The doctor will apply some fluid to your vulva, which will make it easier to see abnormal cells. The doctor will use the colposcope – and sometimes a handheld magnifying glass – to look at your vulva.

Your doctor will usually take a small tissue sample (biopsy) during the vulvoscopy. A local anaesthetic will be used to numb the area before the biopsy is taken.

Biopsy
A biopsy is the best way to diagnose cancer of the vulva. The doctor will put a local anaesthetic into the suspicious area of your vulva to numb it and remove some skin. Your vulva may bleed a little, but it is usually not a large wound. Tell your doctor if you feel any pain, as you may be able to have more anaesthetic.
The tissue is sent to a laboratory where a specialist called a pathologist examines the cells under a microscope. The pathologist will be able to confirm whether or not the cells are cancerous.

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

If you haven’t had one recently, your doctor may do a Pap test. During this test, the doctor puts an instrument with smooth, curved sides (speculum) into your vagina. The sides gently spread the vaginal walls apart so the doctor can see your vagina and cervix. A tool such as a brush or spatula is used to scrape some cells from the surface of the cervix.

The doctor may use a colposcope to look inside your vagina (see diagram on page 31). During this examination, the doctor may take a biopsy.

You may also have a cystoscopy to examine your bladder and urethra, and a proctoscopy to look inside your rectum and anus. These will be done under a general anaesthetic.

Some women with skin conditions such as lichen planus or lichen sclerosus have narrowing of the vagina, so the internal examination will be done under a general anaesthetic.
Further tests
Sometimes further tests are needed to determine the size and position of the cancer, and whether it has spread:

- **Blood test** – A blood sample is taken to check the number of cells in your blood, and to see how well your kidneys and liver are working.

- **Chest x-ray** – A painless x-ray scan of your lungs, heart or abdomen.

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

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

- **MRI scan** – A magnetic resonance imaging scan. You will lie on the treatment table inside a cylinder that uses a magnetic field to create pictures of your body. Some women feel claustrophobic during this scan – your medical team may be able to give you medication to reduce this feeling.

Before a CT or MRI scan, you may be given an injection or asked to drink a liquid called a contrast. This helps to make the images on the computer clearer.
**Staging vulvar cancer**

Based on test results, your doctor will tell you the stage of the cancer. This is a way to describe its size and whether it has spread beyond its original site.

<table>
<thead>
<tr>
<th>Carcinoma in-situ (Stage 0)</th>
<th>Early cancer. Abnormal cells are found only on the surface of the vulval skin.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1</td>
<td>Cancer is found only in the vulva and/or perineum. The affected area is 2 cm or less in size.</td>
</tr>
<tr>
<td>Stage 2</td>
<td>Cancer is found only in the vulva and/or perineum. The affected area is more than 2 cm in size.</td>
</tr>
<tr>
<td>Stage 3</td>
<td>Cancer is found in the vulva and/or perineum, and has also spread to nearby tissues such as the urethra, vagina, anus or lymph nodes.</td>
</tr>
<tr>
<td>Stage 4</td>
<td>Cancer has spread beyond the urethra, vagina and anus into the lining of the bladder or bowel. The cancer may also have spread to the lymph nodes in the pelvis or to other parts of the body.</td>
</tr>
</tbody>
</table>

Your doctor may also tell you the grade of the cells. This tells you how quickly the cancer may develop. Low-grade cancer cells are slow growing and less likely to spread. High-grade cells look more abnormal and are more likely to grow and spread quickly.

Knowing the stage and grade of the cancer helps your doctor decide on the most appropriate treatment.
**Prognosis**

Prognosis means the expected outcome of a disease. You will need 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.

The earlier vulvar cancer is diagnosed, the better the chances of successful treatment and cure.

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

**Which health professionals will I see?**

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

You will be cared for by a range of health professionals who specialise in different aspects of your treatment. This is called a multidisciplinary team. See the following page for a list of health professionals you may see.

> Sometimes my extended family members would criticise and add further to the load. It was helpful for me to focus on the advice of the health care team.  

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*Carer*
### Health professional | Role
--- | ---
gynaecological oncologist | a surgeon who specialises in treating gynaecological cancers, such as cancer of the vulva
radiation oncologist | prescribes and coordinates the course of radiotherapy
medical oncologist | prescribes and coordinates the course of chemotherapy
nurses | care for you after surgery and during treatment, and provide support and assistance through all stages of your treatment
dietitian | recommends the best eating plan to follow while you are in treatment and recovery
social worker, physiotherapist, counsellor, sex therapist, psychologist | advise you on support services and help you get back to normal activities

**Treatment**

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

Surgery is the main treatment for cancer of the vulva. The type of operation you have depends on the stage of the cancer.

- **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 groin lymph nodes may also be removed (known as lymph node dissection).

- **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, including the clitoris. Usually, surrounding lymph nodes are also removed.

- **Pelvic exenteration** – This operation is done if the cancer has spread beyond the vulva. The surgeon takes out the affected organs, such as the lower bowel, bladder, uterus or vagina.

The surgeon will aim to remove all of the cancer while preserving as much normal tissue as possible. However, it is important that a margin of healthy tissue around the cancer is removed to reduce
the risk of the cancer coming back (recurring) in this area. Usually only a small amount of healthy skin is removed and it is possible to stitch the remaining skin together.

If it is necessary to remove a large area of skin, 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 on to the operation site. It may be possible to move flaps of skin in the vulvar area to cover the wound. The graft or flap will be done as part of the same operation.

**Lymph nodes**

The lymph nodes (also called lymph glands) in the groin are usually the first place to which vulvar cancer spreads. Lymph nodes are part of the lymphatic system and are found mainly in the groin, neck and armpits.

Lymph node surgery is usually not needed if the cancer is less than 1 mm deep. Women with deeper cancers will probably have nodes from one or both sides of the groin removed.

If the cancer is small, the surgeon may perform a sentinel lymph node biopsy. You will have an anaesthetic and an injection of radioactive dye. This dye will identify the lymph node most likely to be the first to have cancer spread to it. The surgeon can remove this node and analyse it to decide whether further treatment is necessary. Your doctor will talk to you about the risks of having this type of biopsy.

Removing lymph nodes can cause your legs to swell (lymphoedema). See page 50 for information.
Recovery after surgery
Your recovery time after the operation will depend on the type of surgery you have. If a small amount of skin is removed, the wound will probably heal quickly. If your lymph nodes are removed or your surgery is more extensive, recovery will take longer.

- **Pain-killers** – You will have medication to reduce any pain. Some women have an injection into a space around their spinal cord, called an epidural. This numbs the body from the waist down.

- **Catheter** – A tube called a catheter will drain urine and keep your wound clean and dry. This will be removed within a few days.

- **Wound care** – If you have stitches, they will usually dissolve as the wound heals. If not, they will be removed within a couple weeks of surgery. It is important to try to keep your wound clean. Some women have a dressing that is changed regularly. You will have frequent washes to the surgical site. Try to keep your vulva as dry as possible. If your vulva is numb, be careful patting it dry because you won’t realise how much pressure you are using. Some women prefer to use a hair dryer on a low heat setting to dry the area.

- **Exercise and movement** – You should start gently moving around as soon as possible after your operation. If you have skin grafts or flaps you may need bed rest for a few days. Women with stitches should try to keep their knees together when getting out of bed so the stitches do not tear. The nurse or physiotherapist can help you do regular leg and breathing exercises.
When you return home, you will need to take it easy. You may not be able to lift anything heavy or drive for 6–8 weeks.

- **Using the toilet** – You may find that going to the toilet is different. The urine stream may spray in different directions or drip down one leg. For suggestions on managing this problem, see page 48.

The emotional impact of having cancer and surgery is significant. You may wonder how it could affect your sexuality. See pages 57–64.

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**Ann’s story**

I went to my GP with an itch on my vulva in 2004. No specialists knew what it was – they diagnosed heat rash, candida and thrush, just to name a few.

In 2009 I saw a documentary about the research being done on dogs and their ability to smell cancer. Soon after, my dog sniffed and licked my trousers. I strongly believe my dog found the cancer.

I was sent to the gynaecological dermatologist and insisted on a biopsy. I was then referred to a surgeon. Ten days later, I had a partial vulvectomy. I was in hospital for six days then home for six days when the lymph wound opened up. My surgeon lent me a machine to suck out the fluid and heal the wound, but it took six months of using it to close up the wound. I had to go to the physiotherapist afterwards.

I’ve thrown my energies into spreading the word about vulval cancer. I tell women: if you have a persistent itch down there, get a biopsy!
Radiotherapy
Radiotherapy uses high-energy x-rays to destroy or kill cancer cells. Whether you have radiotherapy or not will depend on the stage of the cancer, its size, whether it has spread to the lymph nodes and, if so, how many nodes are affected. You can have radiotherapy:
- before surgery to shrink the cancer and make it easier to remove (neo-adjuvant treatment)
- after surgery to get rid of any remaining cancer cells and reduce the risk of the cancer coming back (adjuvant treatment)
- instead of surgery
- to control symptoms of advanced cancer.

External radiotherapy
External radiotherapy is the most common type of radiotherapy for cancer of the vulva. You will lie on a treatment table and a machine will direct radiotherapy at the cancer. Treatment is normally given as a series of 10–15 minute daily treatments. The number of radiotherapy sessions you have will depend on the type and size of the cancer, but the entire course of treatment will usually last a few weeks.

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

External radiotherapy will not make you radioactive. It is safe for you to be with other people, including children, after your treatment.
You may have some of the following side effects:

- **Skin redness, soreness and swelling** – The vulva is sensitive to radiation and the skin may become sore and swollen. Use lukewarm water to wash your vulva and avoid using perfumes, lotions or talcum powder. Your radiation therapist or nurse will advise you on skin care and swelling.

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

- **Lymphoedema** – Radiation to the groin can increase the risk of swelling in the legs – see page 50.

- **Narrowing of the vagina** – Radiotherapy can cause your vagina to shorten and narrow, which may make sex uncomfortable or difficult. For information, see page 45.

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

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

See page 48 for information about coping with side effects affecting the bladder and bowel.
Internal radiotherapy

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

You will be given a general anaesthetic, and thin radioactive needles or wires will be inserted into your body on or near the cancerous tissue.

Treatment will make you slightly radioactive, so you will be cared for in a single room in hospital for a few days until the wires or needles are removed. Although it will be safe for your family and friends to visit you for short periods, children and pregnant women won’t be allowed to visit to avoid the chance of them being exposed to radiation.

These safety measures and visiting restrictions might make you feel isolated, frightened and depressed at a time when you might want people around you. Talking to your medical team, seeing a counsellor or writing in a journal may help you.

While the needles are in place, the tissue around them will become swollen. This usually settles by the time the needles are taken out. The treated area will feel sore after the needles or wires have been removed. The pain should ease over a couple weeks. Your doctor can prescribe pain-killers to help relieve the discomfort.

For more information, call Cancer Council Helpline 13 11 20 for a free booklet about radiotherapy.
**Chemotherapy**

Chemotherapy uses anti-cancer drugs to kill or slow the growth of cancer cells. Treatment is often given:
- during the course of radiotherapy, to make 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.

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

**Side effects**

Most people have some side effects from chemotherapy. However, these can usually be controlled with medication.

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

There are many different types of chemotherapy drugs and the side effects vary. Some people find that they are able to lead a fairly normal life during their treatment, while others become very tired and need to take things more slowly. Do as much as you feel like and try not to overdo it.

For more information, call the Helpline for a free booklet about chemotherapy and its side effects.
**Palliative treatment**

Palliative treatment helps to improve people’s quality of life by reducing symptoms of cancer without trying to cure the disease. It is particularly important for people with advanced cancer. However, it is not just for end-of-life care and it can be used at different stages of cancer.

Often treatment is concerned with pain relief and stopping the spread of cancer, but it also involves the management of other physical and emotional symptoms. Treatment may include radiotherapy, chemotherapy or other medication.

For more information, call Cancer Council Helpline 13 11 20 for free information about palliative care and advanced cancer.
Key points

- Cancer of the vulva is also known as vulvar or vulval cancer. There are several types of vulvar cancer, and it can start in any part of the vulva.

- Symptoms include discharge, pain, burning, a lump, coloured patches or a mole that changes in colour.

- Some factors, such as vulvar intraepithelial neoplasia (VIN), can increase your risk.

- Your doctor will do tests to confirm the diagnosis. This may include examinations of your vulva and vagina, a tissue sample (biopsy), and scans.

- The stage of the cancer describes its size and if it has spread. The grade tells how quickly the cells are growing.

- The earlier vulvar cancer is diagnosed, the better the chances of successful treatment and cure. Your doctor will talk to you about the expected outcome of the disease (your prognosis).

- You may see a range of health professionals, including a gynaecological oncologist.

- Surgery is the main treatment for vulvar cancer. There are several types of operations. If the cancer has spread, lymph nodes may be removed.

- Radiotherapy uses x-rays to destroy cancer cells. You may have external radiotherapy or internal radiotherapy (brachytherapy). Side effects vary depending on the type of treatment you have.

- Chemotherapy uses anti-cancer drugs to kill cancer cells. Side effects can include nausea and fatigue.

- Palliative treatment can manage cancer symptoms without trying to cure the cancer.
Cancer of the vagina

This chapter has information about the symptoms, causes, diagnosis and treatment of vaginal cancer. Information about managing side effects can be found on pages 45–53.

What is vaginal cancer?
There are two main types of cancer that start in the vagina:
- **squamous cell carcinoma** – the most common type of cancer, affecting cells covering the surface of the vagina
- **adenocarcinoma** – a type of cancer that begins in the glandular cells lining the vagina.

It is more common to have secondary cancers in the vagina. This means the cancer has spread from another part of the body. The cancer may spread from the cervix, uterus (womb), vulva, or nearby organs such as the bladder or bowel.

What are the symptoms?
There are often no obvious symptoms of vaginal cancer. The cancer may be found through a routine Pap smear (see page 30).

You may have one or more of the following symptoms:
- bloody or smelly vaginal discharge not related to your menstrual period
- pain during sexual intercourse
- bleeding after sexual intercourse
- pain in the pelvic area
- a lump in the vagina.
Some women also have bladder and bowel problems. You may have blood in your urine or feel the urge to pass urine frequently or during the night. Pain in the rectum can sometimes occur.

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

**How common is it?**
Cancer of the vagina is one of the rarest types of gynaecological cancer. Each year in Australia, approximately 70 women are diagnosed.

Squamous cell carcinoma usually affects women aged 50–70. Adenocarcinoma commonly affects young women less than 25 years old, but it can also occur in other age groups.

**What are the causes?**
Some factors that increase the risk of vaginal cancer include:

**Vaginal intraepithelial neoplasia (VAIN)** – This is a pre-cancerous condition of the vagina that is sometimes caused by human papillomavirus (HPV). It means that the cells are abnormal and they may develop into cancer. Not all women with VAIN develop cancer.

**Vaginal adenosis** – This condition causes abnormal cells to form in the tissue of the vagina. This is usually the result of DES exposure (see opposite page).
Human papillomavirus (HPV) – Sometimes known as the wart virus, HPV is a sexually transmitted infection that increases the risk of vaginal cancer.

Smoking – Cigarette smoking doubles the risk of developing vaginal cancer.

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.

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

Female children of women who took DES (called DES daughters) have an increased risk of developing adenocarcinoma.

The risk appears to be highest for those in their teenage years and early 20s. However, older women have also been diagnosed, so DES daughters should have regular medical examinations throughout their lifetime.

Approximately one in 1,000 DES daughters develop adenocarcinoma, particularly a type called clear cell carcinoma.
History of gynaecological cancer – Cancer of the vagina is more likely to be diagnosed in women who have had cervical cancer or early cervical cell changes considered to be precancerous. It is sometimes more common in women who have had cancer of the uterus.

Vaginal cancer is not infectious and it can’t be passed to other people through sexual contact. It is not caused by an inherited faulty gene and can’t be passed on to children.

For more information on the risk factors, call Cancer Council Helpline 13 11 20.

Diagnosis

Women who have symptoms of vaginal cancer will have an examination by their doctor. This will include a physical examination of the groin and pelvic area to check for swollen glands. The doctor may also arrange some of the following tests:

Pap smear

You may have a Pap smear (Pap test) to check the cells inside the vagina and cervix. The doctor puts an instrument with smooth, curved sides (speculum) into your vagina. The speculum gently spreads the vaginal walls, and the doctor uses a tool such as a brush or spatula to scrape cells from the cervix. The tissue sample is sent to a lab, where it is checked for abnormalities. The results of the Pap smear may show that you have early cell changes in the lining of the vagina. This condition is called VAIN – see page 28.
**Colposcopy and biopsy**

The doctor will do an internal examination to look at your vagina. This is called a colposcopy.

In this procedure, you will lie on your back on an examination table with your buttocks near the end of the table and your feet on foot rests (stirrups). Your doctor may put some fluid inside your vagina, insert an instrument (speculum) and look through a microscope called a colposcope to examine the vaginal canal.

Your doctor may also take a tissue sample (biopsy) during the colposcopy. The tissue is sent to a laboratory where a specialist called a pathologist examines the cells under a microscope. The pathologist will be able to confirm that the cells are cancerous and tell you what type of cancer it is.
You may feel uncomfortable during the colposcopy. Some women take a pain-reliever, such as ibuprofen, about an hour beforehand to ease cramping and discomfort.

**Further tests**
If the above tests show that you have vaginal cancer, further tests may be necessary to find out whether cancer cells have spread:

- **Blood test** – A blood sample is taken to check the number of cells in your blood, and see how well your kidneys and liver are working.

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

- **Chest x-ray** – A painless x-ray scan of your lungs, heart or abdomen.

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

- **MRI scan** – A magnetic resonance imaging scan. You will lie on the treatment table inside a cylinder and a magnetic field will create pictures of your body. Some women feel
claustrophobic during this scan. Tell your medical team if you feel claustrophobic – you may be able to have medication to reduce any anxiety.

Before a CT or MRI scan, you may be given an injection or asked to drink a liquid called a contrast. This makes the images on the computer appear clearer. Tell the doctor if you are allergic to iodine, fish or dyes.

**Staging vaginal cancer**

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

Staging the cancer is a way to describe the size of the cancer and whether it has spread beyond its original site.

<table>
<thead>
<tr>
<th>Stage 1</th>
<th>Cancer is found only in the vagina.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 2</td>
<td>Cancer has begun to spread through the wall of the vagina, but it has not spread into the walls of the pelvis.</td>
</tr>
<tr>
<td>Stage 3</td>
<td>Cancer has spread to the pelvis. It may also be in the lymph nodes close to the vagina.</td>
</tr>
<tr>
<td>Stage 4</td>
<td>Cancer has spread beyond the vagina and surrounding area into the lining of the bladder or bowel. The cancer may also have spread to other parts of the body.</td>
</tr>
</tbody>
</table>
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 cancer means that the cells are slow growing and less likely to spread. High-grade cells look more abnormal and are more likely to grow and spread quickly.

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

**Prognosis**

Prognosis means the expected outcome of a disease. You will need 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.

The earlier vaginal cancer is diagnosed, the better the chances of successful treatment and cure.

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

“I was embarrassed to tell people I had a gynaecological cancer. If you have breast, bowel or lung cancer, people seem to know what to expect. When my body healed and I had time to process it, I felt less self-conscious. 

*Patient*
Which health professionals will I see?

Your GP (general practitioner) will probably arrange the first tests to assess your symptoms. You will then be referred to a gynaecological oncologist. You will be cared for by a range of health professionals who specialise in different aspects on your treatment. This is called a multidisciplinary team.

<table>
<thead>
<tr>
<th>Health professional</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>gynaecological oncologist</td>
<td>a surgeon who specialises in treating gynaecological cancers, such as cancer of the vagina</td>
</tr>
<tr>
<td>radiation oncologist</td>
<td>prescribes and coordinates the course of radiotherapy</td>
</tr>
<tr>
<td>medical oncologist</td>
<td>prescribes and coordinates the course of chemotherapy</td>
</tr>
<tr>
<td>nurses</td>
<td>care for you after surgery and during treatment, and provide support and assistance through all stages of your treatment</td>
</tr>
<tr>
<td>dietitian</td>
<td>recommends the best eating plan to follow while you are in treatment and recovery</td>
</tr>
<tr>
<td>social worker, physiotherapist, counsellor, sex therapist, psychologist</td>
<td>advise you on support services and help you get back to normal activities</td>
</tr>
</tbody>
</table>
Treatment

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

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

Radiotherapy

Radiotherapy is the treatment of cancer using high-energy x-rays to kill or destroy cancer cells. It is a common treatment for women with cancer of the vagina. In some women, radiotherapy is combined with chemotherapy (see page 42). It can also be used to control symptoms of advanced cancer.

Radiotherapy can be given in two ways: externally or internally (brachytherapy). Most women with vaginal cancer have both types of radiotherapy.

External radiotherapy

External radiotherapy means that radiotherapy beams are directed at the cancer from outside the body. You will lie on a treatment table and under the machine that delivers radiation.

External radiotherapy will not make you radioactive. It is safe for you to be with other people, including children, after your treatment sessions are over and when you are at home.
External radiotherapy is normally given as a series of 10–15 minute daily treatments, Monday to Friday, over about 4–6 weeks. The exact number of sessions you have will depend on the type and size of the cancer.

Radiotherapy to the vagina is a painless treatment, but it can cause side effects. The side effects you experience depend on your radiotherapy dose and the length of your treatment. See page 39.

**Internal radiotherapy**
Internal radiotherapy (brachytherapy) is a way of delivering radiotherapy directly to the tumour from the inside of your body.

You will be given a general anaesthetic and a thin radioactive applicator, shaped like a tampon, will be put into your vagina. Some women also have small radioactive needles or wires inserted on or near the cancer. You will have to lie still while the needles or wires are in place.

Treatment will make you slightly radioactive, so you will be cared for in a single room in hospital for a few days until the wires or needles are removed. Although it will be safe for your family and friends to visit you for short periods, children and pregnant women won’t be allowed to visit to avoid the chance of them being exposed to radiation.

The safety measures and visiting restrictions may make you feel isolated, frightened and depressed. Talking to your medical team, seeing a counsellor or writing in a journal may help you.
While the needles are in place, the tissue around them will become swollen. This usually settles by the time the needles are removed. The treated area will feel sore after the needles or wires have been taken out. The pain should ease over a couple weeks. Your doctor can prescribe pain-killers to help relieve the discomfort.

Brachytherapy can cause short- and long-term side effects. The side effects you experience depend on your radiotherapy dose and the length of your treatment.

Linda’s story

My journey with vaginal cancer began a year ago. I had only been married a few weeks when I found a nodule on the left side of my vagina near the Bartholin’s gland that was a squamous cell carcinoma.

My gynaecological oncologist said the tumour was close to my anus, so surgery would not be the best option. Instead, I had external and internal radiotherapy and chemotherapy.

I found that the radiation burned me badly and it was difficult to sit down. I was on bed rest for two weeks. However, after five weeks of external radiotherapy, my tumour was completely gone and there was no evidence of cancer in any other part of my body.

I went into the hospital for three days of internal radiation to make sure the cancer was gone. After that, my treatment was finished. I’m thankful I didn’t have surgery, as for me, it would have meant removal of my anus.
Side effects of radiotherapy

External and internal radiotherapy can cause side effects. This happens because treatment can damage healthy cells as well as cancer cells. The most common effects occur during or soon after treatment:

- **Narrowing of the vagina** – Radiotherapy can cause your vagina to shorten and narrow, which may make sex uncomfortable or difficult. See page 45.

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

- **Hair loss** – You may permanently lose your pubic hair.

- **Bowel and bladder problems** – Radiotherapy can temporarily cause inflammation to the lining of the bladder (cystitis) and loose stools (diarrhoea). A longer-term side effect may be blood in your urine or stools. See page 48 for information.

- **Lymphoedema** – Radiation to the groin can increase the risk of swelling in the legs. See page 50.

- **Menopause** – Radiotherapy affects the uterus and ovaries. If you have not been through menopause, your periods will stop and you may have side effects such as hot flushes. See page 51.

For more information about radiotherapy and its side effects, call Cancer Council Helpline 13 11 20.
Surgery
The cancer may need to be removed with an operation. The type of surgery you have depends on the size and position of the cancer.

• **Partial vaginectomy** – The affected part of the vagina is removed.

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

The doctor will try to remove all of the cancer along with some surrounding healthy tissue, called a margin. This helps ensure that the cancer doesn’t come back. The surgeon may also take out some lymph nodes in the pelvis.

Some women also need to have a radical hysterectomy. This means the uterus, cervix, ovaries and Fallopian tubes are removed. This will cause menopause – see page 51.

Recovery after surgery
The length of your hospital stay will depend on the type of surgery you have. Most women are in hospital for a few days to a week.

• **Pain-killers** – You will be given medication to reduce any pain. Tell your doctor or nurses if you are uncomfortable so they can adjust the dose.
• **Catheter** – A tube called a catheter will drain urine and keep your wound clean and dry. This will be removed within a few days.

• **Exercise and movement** – You will be encouraged to start gently moving around as soon as possible after your operation. While you are in hospital, the nurse or a physiotherapist will help you do regular gentle leg exercises to prevent blood clots forming, as well as deep breathing exercises to prevent chest infection.

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

• **Sexuality** – Depending on the amount of tissue removed, the remaining or reconstructed vagina may be stretched so that you may still be able to have sexual intercourse. However, scar tissue in your vagina can cause pain and you may not be able to have an orgasm through penetration.

Surgery to the vagina does not affect the clitoris, so it is still possible to have an orgasm through direct stimulation, oral sex and masturbation. For tips about dealing with changes to your sex life, see page 59.

The emotional impact of having cancer and surgery is significant. It can affect how you feel about yourself as a woman, and impact your sexuality. For information, see page 57.
Chemotherapy
Chemotherapy uses anti-cancer drugs to kill or slow the growth of cancer cells. Treatment is usually given if the cancer is advanced or if it returns after treatment.

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

Side effects
Most people have some side effects from chemotherapy. However, these can usually be controlled with medication. Common problems include feeling sick (nausea), tiredness and a reduced resistance to infections. Chemotherapy for vaginal cancer may also increase any skin soreness caused by radiotherapy.

There are many different types of chemotherapy drugs and the side effects vary. Some people find that they are able to lead a fairly normal life during their treatment, while others become very tired and need to take things more slowly. Do as much as you feel like and try not to overdo it.

For more information, call the Helpline for a free booklet about chemotherapy and its side effects.
Palliative treatment

Palliative treatment helps to improve people’s quality of life by reducing symptoms of cancer without trying to cure the disease. It is particularly important for people with advanced cancer. However, it is not just for end-of-life care and it can be used at different stages of cancer.

Often treatment is concerned with pain relief and stopping the spread of cancer, but it also involves the management of other physical and emotional symptoms. Treatment may include radiotherapy, chemotherapy or other medication.

For more information, call Cancer Council Helpline 13 11 20 for free information about palliative care and advanced cancer.
Key points

- There are two types of vaginal cancer: adenocarcinoma and squamous cell carcinoma. Cancer sometimes spreads to the vagina from another part of the body (secondary cancer).

- Symptoms include discharge, pain during sex, bleeding and a lump in the vagina.

- Conditions such as vaginal intraepithelial neoplasia can increase your risk. Female children of women who took a drug called diethylstilboestrol are also at an increased risk.

- Diagnostic tests may include a Pap smear, an examination of your vagina (colposcopy) and a tissue sample (biopsy).

- The stage of the cancer describes its size and if it has spread. The grade tells how quickly the cells are growing.

- The earlier vaginal cancer is diagnosed, the better the chances of successful treatment and cure. Your doctor will talk to you about the expected outcome of the disease (your prognosis).

- You may see a range of health professionals, including a gynaecological oncologist.

- Radiotherapy uses x-rays to destroy cancer cells. Most women have external and internal radiotherapy (brachytherapy). Side effects depend on the type of treatment you have.

- During surgery, the affected part of the vagina is cut out. Other organs may also be removed.

- Chemotherapy uses drugs to kill cancer cells. It is usually given if the cancer is advanced or if it returns after treatment.

- Palliative treatment can manage cancer symptoms without trying to cure the cancer.
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 have to cope with the emotional impact of treatment – see page 57.

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

**Shortening and narrowing of the vagina**

Radiotherapy to the pelvic area can affect the vagina, which will become tender during the course of radiotherapy and for a few weeks after it ends. In the long term this irritation can leave scarring, which makes the vagina narrower and less flexible.

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

Using the dilator may keep the vagina from closing over, and allow your doctor to do a vaginal examination at follow-up visits to check for a recurrence of cancer. If you are told to use a dilator, your nurse or doctor can give you more detailed instructions about how long to use it.
Ask your doctor if applying a hormone cream to your vagina will help. Creams are available on prescription.

Although shortening and narrowing of the vagina can make sexual intercourse uncomfortable or difficult, having intercourse regularly – if you are able to – may help prevent the vagina from narrowing.

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

**Vulvar cancer and scar tissue**

Surgery to the vulva may cause scar tissue to form around the outside of the vulva, narrowing the entrance to the vagina. This can make intercourse painful. Using plenty of lubricant, such as Sylk®, and trying different sexual positions can help.

**Changes to your body**

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

Some women don’t want to look at the area. Others want a nurse to be with them when they look for the first time. A nurse can explain what has happened to the vulvar area and can offer professional support and advice.
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. Scar tissue can form around the outside of the vagina, narrowing the entrance to it. If the clitoris has been removed, there will now be an area of flat skin without the usual folds of the vulva.

Some women prefer to look alone or with a partner, friend or relative. Whoever you choose, make sure it is someone you trust and you can talk to openly about your feelings.

**Tiredness**

It is common to feel tired or fatigued during and after treatment. This is not only a side effect of the treatments. Travelling to treatment, doing housework and working can cause fatigue.

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

For more information on managing fatigue call Cancer Council Helpline 13 11 20 for information about life after cancer.
Bowel and bladder problems

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

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

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

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

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

**Incontinence** – Accidental or involuntary loss of urine is called incontinence. After treatment, some women find they need to pass urine more often or feel that they need to go to the toilet in a hurry. Others may lose a few drops when they cough, sneeze, strain or lift.

For ways to manage incontinence, contact the continence nurse or physiotherapist in your hospital. You can also call the Continence Foundation of Australia on 1800 330 066 or visit its website at www.continence.org.au.

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

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

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

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

Symptoms include redness, swelling, warmth of the skin, pain in the leg and fever. Symptoms can take months or years to develop. Some people who are at risk never develop lymphoedema.

**tips**

- Wear special bandages, stockings or a compression garment to help move fluid.
- Reduce your risk of infection by caring for your skin and nails, and keeping the skin moist.
- Avoid cuts, burns, insect bites, sunburn and injections in your legs.
- Exercise your legs to help move fluid out of the affected area and into other lymph channels.
- Gently massage the swollen leg towards your heart to move the fluid out to other lymph channels.
- Make an appointment with a lymphoedema specialist – for instance, a specialist massage therapist. A directory of lymphoedema practitioners is available at [www.nlpr.asn.au](http://www.nlpr.asn.au).
- If you see any swelling or feel any heat in your legs, let your doctor or nurse know as soon as possible. Your hospital may have a lymphoedema specialist who can treat you.
- For more information about lymphoedema and a list of support groups, go to [www.lymphoedema.org.au](http://www.lymphoedema.org.au).
Menopause

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

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

- You can use oestrogen, contained in creams or pessaries, to relieve vaginal dryness. Moisturisers without oestrogen can also be used.
- Extra lubrication may make intercourse more comfortable. Choose a water or silicone-based gel without perfumes or colouring to reduce irritation (e.g. Sylk® or Pjur®).
- Hormone replacement therapy (HRT) can help reduce symptoms. Studies have shown that using HRT with oestrogen and progestogen for longer than five years can increase the risk of some diseases, such as breast cancer.
- Talk to your gynaecological oncologist about the benefits and risks of HRT for you. If you were already on HRT when the cancer was diagnosed, you will need to weigh up the risks of continuing it.
- Eat a healthy diet with lots of fresh fruits and vegetables, and wholegrains. Ask your doctor for advice if you want to try any herbal remedies or diet modifications.
Infertility
If treatment causes you to go through menopause, this will mean you are no longer able to become pregnant (infertile). If this is a concern for you, talk to your doctor about your fertility and any options available to you before you start treatment. There may be some ways to preserve your fertility, or you may be able to store eggs for use by a surrogate.

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

tips
- Eat three serves of calcium-rich food daily (e.g. glass of milk, tub of yoghurt, slice of hard cheese).
- Do regular weight-bearing exercise.
- Avoid smoking.
- Talk to your health care provider about having a bone density test or taking medication to prevent your bones from becoming weak and brittle.
- Get vitamin D from limited sun exposure. Just a few minutes in the sun on most days of the week during summer, and 2–3 hours per week during winter will give most people enough vitamin D. Exposure should be before 10 am and after 3 pm to avoid sunburn.
- Contact Osteoporosis Australia on (02) 9518 8140 or www.osteoporosis.org.au for more information.
Key points

• There are ways to reduce or manage discomfort caused by side effects.

• Radiotherapy to the pelvic area can make the vagina narrower and less flexible. You may be advised to use a dilator or have sex to help keep the vaginal walls open and supple.

• If the appearance of your vulva has changed, you may not want to look at it. It is normal to feel anxious and upset about changes to your body. You may decide to look at your vulva with a nurse, partner, friend or relative.

• You might feel tired during and after treatment. Plan to rest regularly and get support from a community nurse, family and friends, if possible.

• Treatment can cause bladder and bowel problems such as bleeding, incontinence, or cystitis. For some women, urine may spray in different directions or down one leg.

• If your skin is red and sore due to radiotherapy, use lukewarm water to wash your genitals and avoid using creams, perfumes or talcum powder.

• Your legs may swell if your lymph nodes have been removed or damaged. This is called lymphoedema. Symptoms include redness, swelling, warmth of the skin, pain in the leg and fever. 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 want to have children in the future, talk to your medical team about preserving your fertility.
Sometimes it is difficult to decide on the right treatment. You may feel that everything is happening so fast you don’t have time to think things through, but there is usually time to consider what sort of treatment you want.

Waiting for test results and for treatment to begin can be difficult. While some people feel overwhelmed by information, others want as much information as they can find. Making sure you understand enough about your disease, the treatment and its side effects will help you make your own decisions.

- If you are offered a choice of treatments, you will need to weigh up their advantages and disadvantages. Consider how important any side effects are to you, particularly those that affect your lifestyle.

- If you have a partner, you may also want to talk about treatment options with them. You can also talk to friends and family.

- If only one type of treatment is recommended, ask your doctor to explain why other treatment choices have not been offered.

You have the right to accept or refuse any treatment.

Some people with more advanced cancer will choose treatment, even if it only offers a small chance of cure. Others want to make sure the benefits of treatment outweigh any side effects so they have the best possible quality of life. Some people may choose options that don’t try to cure the cancer but make them feel as well as possible.
Talking with doctors
When your doctor first tells you that you have cancer it is very stressful and you may not remember many details about what you are told. You may want to see the doctor a few times before deciding on treatment.

If your doctor uses medical terms you don’t understand, it’s okay to ask for a simpler explanation. You can also check a word’s meaning in the glossary (see page 71).

Before you see the doctor it may help to write down your questions – see the list of suggested questions on page 70. Taking notes or recording the discussion can also 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 have several questions for your doctor, you may want to book a longer appointment.

A second opinion
Getting a second opinion from another specialist may be a valuable part of your decision-making process. It can confirm or clarify your doctor’s recommendations and reassure you that you have explored all of your options.

Some people feel uncomfortable asking their doctor for a second opinion, but specialists are used to patients 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 may decide you would prefer to be treated by the doctor who provided the second opinion.

**Taking part in a clinical trial**

Your doctor may suggest you consider taking part in a clinical trial. Doctors conduct clinical trials to test new or modified treatments to see if they are better than current treatments. Over the years, clinical trials have improved cancer treatment standards and led to better outcomes for patients.

If you are unsure about joining the trial, ask for a second opinion from an independent specialist.

If you decide to join a randomised controlled trial, you will be given either the best existing treatment or a promising new treatment. You will be chosen at random to receive one treatment or the other.

Being part of a trial gives you important rights. You have the right to withdraw at any time; doing so will not jeopardise your treatment for cancer.

For more information about clinical trials – such as questions to ask your doctor and how to find a trial that is suitable for you – call Cancer Council Helpline 13 11 20 for information.
Cancer can cause physical and emotional strain. Eating well, exercising and relaxing may help reduce stress and improve well-being. Addressing changes in your emotions and relationships early on is also very important.

**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 as you 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.

You may find the closeness of your relationship with your partner is affected – see page 61.

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

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“I did a lot of singing and writing to try to help get rid of the pain, to sift the sugar from the sand.”

*Patient*
Healthy eating
Eating nutritious food will help you to keep as well as possible and cope with cancer and treatment side effects.

Depending on your treatment, you may have special dietary needs. A dietitian can help you to plan the best foods for your situation. Cancer Council Helpline 13 11 20 can send you information about nutrition.

Being active
You will probably find it helpful to stay active and to exercise regularly if you can. Physical activity – even if gentle or for a short duration – helps to improve circulation, reduce tiredness and elevate mood.

The amount and type of exercise you do will depend on what you are used to, how well you feel and what your doctor advises. If you have had surgery, you should talk to your medical team before doing any vigorous or weight-bearing exercise. When you are able, you can make small changes to your daily activities such as walking to the shops or gardening.

Changing body image
Cancer treatment can change the way you feel about yourself (your self-esteem). Even though most people will not see your genital area, changes to its appearance may make you feel self-conscious or less confident.
Give yourself time to adapt to any changes. Try to see yourself as a whole person (body, mind and personality) instead of focusing only on the parts of you that have changed.

**Sexuality, intimacy and cancer**
Having cancer can affect your sexuality in both physical and emotional ways.

Treatment for gynaecological cancer can cause physical side effects such as scarring, narrowing of the vagina, swelling and soreness, and tiredness (see pages 45–49). These side effects can affect your sexual response, and you may have to explore different ways to orgasm or climax.

However, for most women, sex is more than arousal, intercourse and orgasms. It involves feelings of intimacy and acceptance, as well as being able to give and receive love.

It can be difficult to talk about your sexual needs, fears or worries with your sexual partner, especially if you meet a new partner during or after treatment. However, you may be surprised and encouraged by your partner’s tolerance, trust, tenderness and love when you open up about what you have experienced.

*tip*
Allow yourself to say no to any kind of sexual contact that does not feel right.
Cancer may reduce your desire for sex (libido). It may take some months after treatment before you begin to desire and enjoy sexual activity. Don’t be surprised if you feel very unsure about it.

Call Cancer Council Helpline 13 11 20 for more information about sexuality and intimacy.

tips

• Talk to your doctor about ways to prevent or reduce side effects that affect your sex life.

• Let your partner know if you don’t feel like having sex, or if you find penetration uncomfortable.

• Apply a vaginal moisturiser 2–3 times a week or use a hormone cream to keep vaginal tissue supple and lubricated. Hormone creams are available on prescription.

• Use a vaginal dilator to keep the vagina open, as instructed by your medical team.

• Use plenty of water-based lubricant and try different sexual positions.

• Talk about your feelings with your sexual partner, a sex therapist or a counsellor.

• Explore different ways to climax. There are many other parts of your body that, when caressed, can increase sexual excitement and lead to orgasm. The breasts, inner thighs, feet and buttocks are all sensitive areas of the body.
Relationships with others
The strong emotions you experience as a result of cancer may affect your relationships. Your experiences may cause you to make some changes in your life or develop a new outlook on your values, priorities and life in general.

Sharing those thoughts and feelings with your family, friends and work colleagues may strengthen your relationships.

If you feel uncomfortable talking about your feelings, take your time and approach others when you are ready. People usually appreciate insight into how you are feeling and guidance on providing support during and after treatment. Calling Cancer Council Helpline 13 11 20 may help you build your confidence to discuss your feelings with others.

While you are giving yourself time to adjust to cancer, do the same for your friends and family. Everyone will react in different ways – by putting on a happy face, playing down your anxiety, or even ignoring you. They are also adjusting in their own way to changes.

If someone’s behaviour upsets you, it may help to discuss how you both feel about the situation.

“My husband’s support was invaluable during treatment and recovery. I know things were difficult for him – it’s not easy to see someone you love go through such a hard time. But we got through it together.” *Patient*
Complementary therapies
Complementary therapies are treatments that may help you cope better with side effects such as pain. They may also increase your sense of control over what is happening to you, decrease your stress and anxiety, and improve your mood.

There are many types of complementary therapies, including acupuncture, massage, relaxation, meditation and herbal medicine. While some cancer treatment centres offer complementary therapies as part of their services, you may have to go to a private practitioner. Self-help CDs or DVDs can also guide you through some different techniques.

Let your doctor know about any complementary therapies you are using or thinking about trying. Some therapies may not be appropriate, depending on your conventional treatment. For example, herbs and nutritional supplements may interact with your medication, resulting in harmful side effects. Massage, acupuncture and exercise therapies may also need to be modified if you have lowered immunity, low platelets or fragile bones. Call the Helpline for more information and resources about complementary therapies.

Alternative therapies are commonly defined as those used instead of conventional treatments. These therapies may be harmful if people with cancer delay or stop using conventional treatments in favour of them. Examples include high-dose vitamin supplements, coffee enemas and magnet therapy.
Life after treatment

You may be surprised to find out that life after cancer treatment can present its own challenges. You will need to take some time to adjust to physical and emotional changes.

You may have mixed emotions. Beforehand, you may have been busy with appointments and focused on treatment, but afterwards you may feel anxious rather than secure. You might worry about every ache and pain and wonder if the cancer is coming back.

Some people say that after cancer they have changed priorities and see life with a new clarity. For example, you may decide to travel, spend more time with family, or do volunteer work. Although you might feel pressure to return to normal life, remember that you may not want your life to return to how it was before cancer.

You might find it helpful to:

- take time to adjust to physical and emotional changes
- re-establish a new daily routine at your own pace
- maintain a healthy diet and lifestyle
- schedule regular checkups with your doctor
- share your concerns with family and friends and tell them how to support you
- call Cancer Council Helpline 13 11 20 to connect with other people who have had cancer, or to request information about life after cancer.

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, talk to your doctor. You may be clinically depressed, and counselling or medication may help you.

**After treatment: follow-up**

After treatment, you will need regular checkups to confirm that the cancer has not come back. Your doctor may do blood tests, x-rays or other scans.

For the first few years, you will probably have a checkup every three months. Women who have had an operation may have additional follow-up appointments with their surgeon. Checkups will become less frequent if you have no further problems.

Between follow-up appointments, let your doctor know immediately if you have any health problems.

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**If the cancer comes back after initial treatment, it is known as recurrent cancer.**
When you are first diagnosed with cancer, and throughout the different stages of your treatment and recovery, it is normal to experience a range of emotions, such as fear, sadness, anxiety, anger and frustration. If sadness or anxiety is ongoing or severe, talk to your doctor.

It may help to talk about your feelings. Your partner, family members and friends can be a good source of support, or you might prefer to talk to:
- your treatment team
- a counsellor, social worker or psychologist
- your religious or spiritual adviser
- a support group – see page 67
- the Helpline.

If you need assistance, such as help around the house, it may be hard to tell people what would be useful. Some people prefer to ask a family member or friend to coordinate offers of help.

You may find that while some people you know are supportive, others may not even know what to say to you. If you have children, the prospect of telling them you have cancer can be frightening and unsettling. Cancer Council has a range of free resources to help people talk about cancer and deal with the emotions that cancer may bring up. Different resources are available for people with cancer, partners, carers, children, friends and colleagues.

Call Cancer Council Helpline 13 11 20 for resources and support. You can also download booklets from the Cancer Council website.
Practical and financial help

A serious disease often causes practical and financial difficulties. This can add to the stress and anxiety you may already be feeling about having cancer and going through treatment.

Many services are available to help so you don’t have to face these difficulties alone:

- Financial assistance, through benefits and pensions, can help pay for prescription medicines and travel to medical appointments.
- Home nursing care is available through community nursing services or local palliative care services.
- Meals on Wheels, home care services, aids and appliances can make life easier.

To find out more, talk to the hospital social worker, occupational therapist or physiotherapist, or call 13 11 20.

Cancer Council library*

Following a cancer diagnosis many people look for information about new types of treatment, the latest research findings and stories about how other people have coped.

Cancer Council has a range of books, CDs, DVDs and medical journals that may be helpful for you. Your local library may also have some relevant resources.

*This service is not available in Victoria and Queensland
Talk to someone who’s been there

Getting in touch with other people who have been through a similar experience can be beneficial. There are many ways to contact others for mutual support and to share information.

In these support settings, most people feel they can speak openly, share tips with others, and just be themselves.

You will probably find that you feel comfortable talking about your diagnosis and treatment, your relationships with friends and family, and your hopes and fears about the future.

Ask your nurse or social worker to tell you about support groups in your area. Call Cancer Council Helpline 13 11 20 to find out how you can connect with others.

Support services available in your community

Face-to-face support groups – often held in community centres or hospitals

Online discussion forums – where people can connect with each other any time – see www.cancerconnections.com.au

Telephone support groups – for certain situations or types of cancer, which trained counsellors facilitate

Cancer Council Connect – a confidential telephone service connecting you with a trained volunteer who has had a similar cancer experience.
You may be reading this booklet because you are caring for someone with cancer. Being a carer can be very stressful. 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 are open to carers as well as people with cancer. A support group can offer a valuable opportunity to share experiences and ways of coping.

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

Call Cancer Council Helpline 13 11 20 to find out more about different services or to request free information for carers.
The Internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of information.

### Australian
- Cancer Institute NSW ................................ [www.cancerinstitute.org.au](http://www.cancerinstitute.org.au)
- Gynaecological Cancer Society ...................... [www.gcsau.org](http://www.gcsau.org)
- Gynaecological Information Awareness Network ................................................... [www.gain.org.au](http://www.gain.org.au)

### International
- Macmillan Cancer Support ............................. [www.macmillan.org.uk](http://www.macmillan.org.uk)
- American Cancer Society ............................. [www.cancer.org](http://www.cancer.org)
- Eyes on the Prize ........................................ [http://eyesontheprize.org](http://eyesontheprize.org)
- Mayo Clinic ............................................. [www.mayoclinic.com](http://www.mayoclinic.com)
- Foundation for Women’s Cancer .................... [www.foundationforwomenscancer.org](http://www.foundationforwomenscancer.org)
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, it is okay to ask for clarification.

- What type of cancer do I have?
- How extensive is the cancer?
- What treatment do you recommend and why?
- Are there other treatment choices for me? If not, why not?
- What are the risks and possible side effects of each treatment?
- How will this impact my sex life?
- How long will treatment take? Will I have to stay in hospital?
- How much will treatment cost?
- 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 of new treatments?
- How frequently will I have checkups?
- Are there any complementary therapies that might help me?
You may come across new terms when reading this booklet or talking to health professionals. You can check the meaning of other health-related words on Cancer Council’s website at www.cancercouncil.com.au/words.

**adenocarcinoma**
A cancer that starts in the glandular tissue.

**Bartholin’s glands**
Small glands on each side of the vagina that secrete mucus for lubrication.

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

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

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

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

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

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

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

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

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

**extramammary Paget’s disease**
A rare, slow-growing skin condition that affects the epidermis of the vulva.

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

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

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

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

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

**menopause**
When a woman stops having periods (menstruating).

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

**MRI scan**
A magnetic resonance imaging scan. A scan that uses magnetism and radio waves to take detailed cross-sectional pictures of the body.
Pap smear
A test that can detect changes in cervical and vaginal cells. Cells are scraped off and sent for examination under a microscope. Also called a Pap test.

pelvic exenteration
The surgical removal of the affected organs in the pelvis.

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

proctoscopy
An examination of the end of the bowel and rectum using a tool called a proctoscope.

radical hysterectomy
An operation that removes the uterus, cervix, ovaries and Fallopian tubes.

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

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

sarcoma
A malignant tumour that starts in the connective tissue.

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

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

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

vagina
A muscular canal about 8–10 cm long that extends from the entrance of the uterus to the vulva.
vaginal adenosis
Abnormal cellular changes on the surface of the vagina.

vaginal intraepithelial neoplasia (VAIN)
A benign condition of the vagina that can develop into vaginal cancer if untreated.

vaginal reconstruction
See vaginoplasty.

vaginectomy
An operation that removes all of the vagina.

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

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

vulva
The external sexual organs of a woman. This 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.

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

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

vulvoscopy
An examination of the vulva using a microscope with a bright light called a colposcope.
How you can help

At Cancer Council we’re dedicated to defeating cancer. As well as funding more cancer research than any other charity in the state, we advocate for the highest quality of care for cancer patients and their families, and create cancer-smart communities by empowering people with knowledge about cancer, its prevention and early detection. We also offer direct financial assistance for those people in hardship as a result of having cancer. These achievements would not be possible without community support, great and small.

Join a Cancer Council event: Join one of our community fundraising events like 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 donation, whether large or small, will make a meaningful contribution to our fight to defeat cancer.

Buy sun protection products from our website or retail stores: Every purchase helps you prevent cancer and contributes financially to our work.

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 cancer issues and help us defeat cancer by living and promoting a cancer-smart lifestyle.

Join a research study: Cancer Council does research to investigate the causes, management, outcomes and impacts of different cancer types.

To find out more about how you or your family and friends can help, please call your local Cancer Council.
The Cancer Council Helpline is a telephone information service provided by Cancer Council NSW for people affected by cancer.

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

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

If you have difficulty communicating over the phone, contact the National Relay Service (www.relayservice.com.au). This service will help you communicate with a Cancer Council Helpline consultant.
For support and information on cancer and cancer-related issues, call Cancer Council Helpline. This is a confidential service.

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