

# Understanding Cervical Cancer

*A guide for people with cancer, their families and friends*



For information & support, call **13 11 20**

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A guide for people with cancer, their families and friends

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*Understanding Cervical Cancer* is reviewed approximately every 2 years.

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

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### Note to reader

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

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

### Cancer Council

Cancer Council is Australia's peak non-government cancer control organisation. Through the 8 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 acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past, present and emerging.*



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# About this booklet

This booklet has been prepared to help you understand more about cervical cancer.

It is common to feel shocked and upset when told you have cervical cancer. We hope this booklet will help you, your family and friends understand how cervical cancer is diagnosed and treated. We also include information about support services.

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, this information may answer some of your questions and help you think about what to ask your treatment team (see page 63 for a question checklist).

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 (see page 64). You may also like to pass this booklet to family and friends for their information.

**How this booklet was developed** – This information was developed with help from a range of health professionals and people affected by cervical cancer. It is based on Australian and international clinical practice guidelines for cervical cancer.<sup>1-2</sup>



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

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## Key to icons

Icons are used throughout this booklet to indicate:



More information



Alert



Tips

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# What is cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks - they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

Normally, cells multiply and die in an orderly way, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. These abnormal cells may turn into cancer.

In solid cancers, such as cervical cancer, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

## How cancer starts

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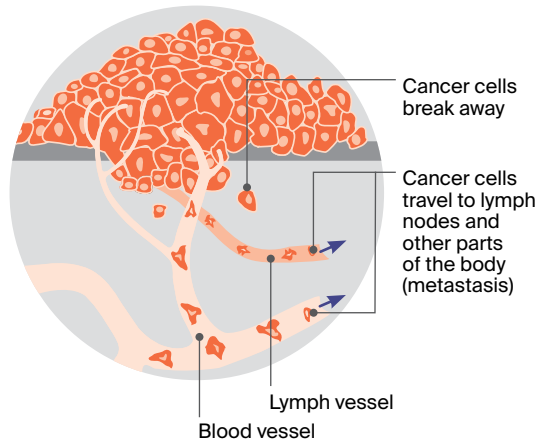
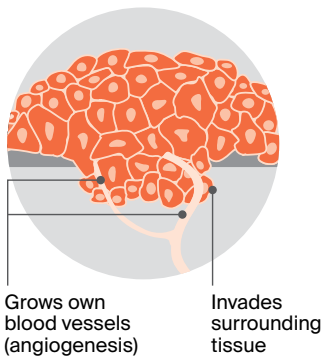


Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops is called the primary cancer. It is considered localised cancer if it has not spread to other parts of the body. If the primary cancer cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, cervical cancer that has spread to the lungs is called metastatic cervical cancer, even though the main symptoms may be coming from the lungs.

## How cancer spreads

### .....▶ Malignant cancer



# The cervix

The cervix is part of the female reproductive system, which also includes the ovaries, fallopian tubes, uterus (womb), vagina (birth canal) and vulva (external genitals).

## What the cervix does

The cervix connects the uterus to the vagina. The cervix:

- produces fluid to help keep the vagina healthy
- opens to let menstrual blood pass from the uterus into the vagina
- produces mucus that helps sperm travel up through the uterus and fallopian tubes to fertilise an egg that has been released from an ovary
- holds a developing baby in the uterus during pregnancy by remaining closed, then widens to allow a baby to be born through the vagina.

## Where cervical cancer starts

The cervix has an outer surface that opens into the vagina (ectocervix) and an inner surface that lines the cervical canal (endocervix). These surfaces are covered by 2 types of cells:

**Squamous cells** – flat, thin cells that cover the outer surface of the cervix (ectocervix). Cancer of the squamous cells is called squamous cell carcinoma (see page 8).

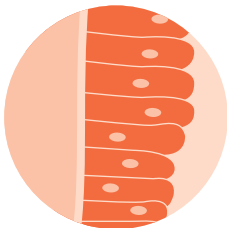
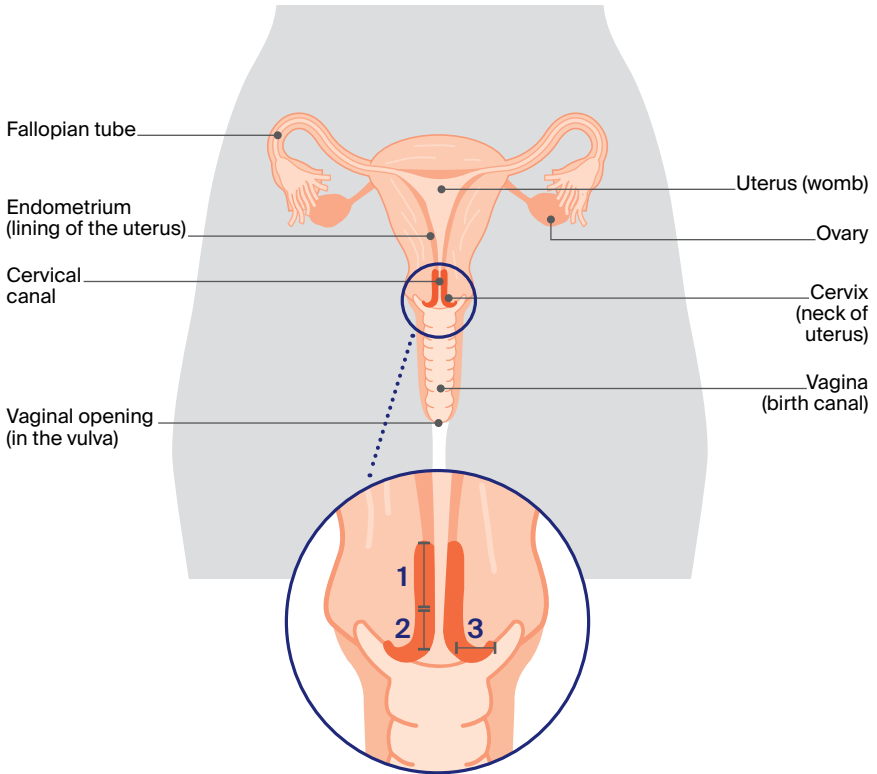
**Glandular cells** – column-shaped cells that cover the inner surface of the cervix (cervical canal or endocervix). Cancer of the glandular cells is called adenocarcinoma (see page 8).

The area where the squamous cells and glandular cells meet is known as the transformation zone. This is where most cervical cancers start.

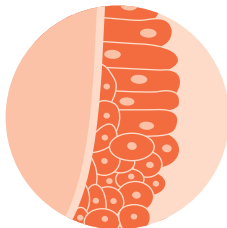


# The female reproductive system

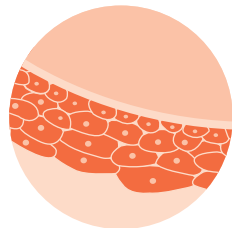
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**1. Endocervix**  
Glandular cells



**2. Transformation zone**



**3. Ectocervix**  
Squamous cells

# Key questions

## Q: What is cervical cancer?

**A:** Cervical cancer begins when abnormal cells in the lining of the cervix grow uncontrollably. Cancer most commonly starts in the area of the cervix called the transformation zone (see pages 6–7). It may then spread to tissues around the cervix, such as the vagina, or to other parts of the body, such as the lymph nodes, lungs or liver.

## Q: What types are there?

**A:** There are 2 main types of cervical cancer:

- **squamous cell carcinoma (SCC)** – the most common type (about 6 out of 10 cases), starts in the squamous cells of the cervix
- **adenocarcinoma** – a less common type (about 3 out of 10 cases), starts in the glandular cells of the cervix. Adenocarcinoma is more difficult to diagnose because it occurs higher up in the cervix and the abnormal glandular cells are harder to find.

A small number of cervical cancers (less than 1 in 20 cases) feature both squamous cells and glandular cells. These cancers are known as adenosquamous carcinomas or mixed carcinomas. Other rarer types of cancer that can start in the cervix include small cell carcinoma, clear cell adenocarcinoma and cervical sarcoma.

## Q: How common is cervical cancer?

**A:** Anyone with a cervix can get cervical cancer – women, transgender men and people with an intersex variation. Each year in Australia, about 960 women are diagnosed with cervical cancer.<sup>3</sup>

Cervical cancer is most commonly diagnosed over the age of 30 years. More than half of all cervical cancer cases occur in those aged 30–49 years, but it can occur at any age.

Diagnoses of cervical cancer in Australia reduced significantly after a national screening program was introduced in the 1990s. The introduction of a national human papillomavirus (HPV) vaccination program in 2007 (see page 12) and improvements to the screening program in 2017 are expected to further reduce rates of cervical cancer.

## **Q: What are the symptoms?**

**A:** Precancerous cervical cell changes (see next page) usually have no symptoms. The only way to know if there are abnormal cells in the cervix that may develop into cancer is to have a cervical screening test (see pages 13–14). Cervical cancer symptoms may include:

- vaginal bleeding between periods, after menopause, or during or after sexual intercourse
- pelvic pain
- pain during sexual intercourse
- a change to your usual vaginal discharge (e.g. there may be more discharge or it may have a strong or unusual smell or colour).

Any of these symptoms can happen for other reasons, but it is best to rule out cervical cancer. See your general practitioner (GP) if you are worried or the symptoms are ongoing. This is important for anyone with a cervix – whether heterosexual, lesbian, bisexual, transgender or someone with an intersex variation – even if you are up to date with cervical screening tests.

## What are precancerous cervical cell changes?

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Sometimes the squamous cells and glandular cells in the cervix start to change, and appear abnormal when viewed under a microscope. These early cervical cell changes may be precancerous. This means there is an area of abnormal tissue (a lesion) that is not cancer, but may lead to cancer.

Some people with precancerous changes of the cervix will develop cervical cancer, so it is important to investigate any cervical cell changes.

### How precancerous cell changes start

Precancerous cervical cell changes are caused by some types of the human papillomavirus (HPV). The latest evidence suggests that all squamous cell cancers and about 9 out of 10 adenocarcinomas are caused by HPV.

HPV and cervical cell changes don't usually cause symptoms but can be found during a routine cervical screening test (see pages 13–14).

There are 2 main types of cervical cells that can have precancerous changes – squamous cells and glandular cells.

### Abnormal squamous cells

Previously called cervical intraepithelial neoplasia (CIN), these are now called squamous intraepithelial lesions (SIL). They can be classified as either low grade (LSIL) or high grade (HSIL), depending on how abnormal the cells are and how deep they are in the surface of the cervix.

LSIL usually disappear without treatment, while HSIL can be precancerous. High-grade abnormalities have the potential to develop into early cervical cancer if they are not found and treated.

### Abnormal glandular cells

High-grade precancer in glandular cells is called adenocarcinoma in situ (AIS or ACIS). AIS is not cancer, but needs treatment to reduce the chance that it develops into adenocarcinoma.

### Treating cervical cell changes

Finding and treating precancerous cervical cell changes will prevent them developing into cervical cancer. See pages 18–20 for information about how precancerous cervical cell changes are treated.

## Q: What causes cervical cancer?

**A:** Almost all cases of cervical cancer are caused by an infection with the human papillomavirus (HPV). Other factors known to increase the risk of cervical cancer are discussed on pages 12–13.

**Infection with HPV** – HPV is the name for a group of viruses. Infection with HPV is common. It affects the surface of different areas of the body, such as the cervix, vagina and skin. Some types of HPV cause cancer, while others can cause common warts on the hands and feet.

There are more than 100 different types of HPV, including over 40 types that can infect the genitals. Genital HPV is usually spread during close contact with genital skin during sexual activity. This includes penetrative sex as well as oral sex and other forms of sexual activity (e.g. using sex toys). Using condoms or dental dams offers some protection against HPV.

About 4 out of 5 people will become infected with at least one type of genital HPV at some point in their lifetime. Most people will not know they have HPV because it doesn't cause symptoms. In most people, the virus is cleared quickly by the immune system and no treatment is needed. If the infection doesn't go away, there's an increased risk of developing changes in the cervix. These changes usually develop slowly over many years.

Fourteen types of genital HPV are known to cause cervical cancer. The cervical screening test is used to detect most of these types of HPV and the precancerous cell changes caused by the virus. See pages 13–14 for more information about screening. There is also a vaccine that protects people from some types of HPV (see next page).

## National HPV vaccination program

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Vaccination can prevent infection with HPV. The most common HPV vaccine used in Australia protects against 7 high-risk types of HPV known to cause about 9 out of 10 cervical cancers, as well as 2 types of HPV that cause most genital warts. The vaccine also offers some protection against less common cancers linked with HPV, including vaginal, vulvar and anal cancers.

Under the national HPV vaccination program, free vaccines are provided at school for all children aged 12–13.

If you weren't vaccinated at school, and are aged 45 years or under, ask your doctor if you may benefit from having the vaccine.

Even if you have been vaccinated against HPV, you will need regular screening tests (see opposite page) as the HPV vaccine does not protect against all types of HPV.

The HPV vaccine does not treat cervical cancer or precancerous cell changes. For more information, visit [hpvvaccine.org.au](http://hpvvaccine.org.au).

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## Q: What are the other risk factors?

**A:** Other factors that may increase the risk of developing cervical cancer include:

- **Smoking and passive smoking** – Chemicals in tobacco can damage the cells of the cervix, making it harder for the body to clear the HPV infection.
- **Using oral contraceptives (the pill) for a long time** – Research has shown that taking the pill for 5 years or more increases the risk of developing cervical cancer in people with HPV. The reason for this is unclear, and the risk is small. However, the pill can help protect against other types of cancer, such as cancer of the uterus and ovarian cancer. Talk to your doctor if you are concerned.
- **Having a weakened immune system** – The immune system helps rid the body of HPV. In some people, a weakened

immune system can increase the risk of developing cervical cancer, so more frequent cervical screening tests may be needed. This includes people with human immunodeficiency virus (HIV) and those who have had an organ transplant.

## Q: What is the cervical screening test?

**A:** Screening is organised testing to find precancer before it develops into cancer, as well as early cancers before symptoms appear. The cervical screening test - which has replaced the Pap test - finds cancer-causing types of HPV in cell samples taken from the cervix.

The National Cervical Screening Program recommends that women start cervical screening at age 25 and then have a test every 5 years. A final test is recommended between ages 70 and 74. All people with a cervix need regular screening. There are 2 ways to collect cells for a cervical screening test. In most cases, you can choose the way you prefer.

**Health provider collected** – During the test, a doctor or nurse gently inserts an instrument (called a speculum) into the vagina to widen the vaginal walls and get a clearer view of the cervix. They will then use a brush or spatula to remove some cells from the cervix. This can feel slightly uncomfortable, but usually takes only 1-2 minutes. The cell sample is then placed in a container of liquid and sent to a laboratory to check for HPV. If HPV is found, a specialist doctor called a pathologist will do an additional test on the sample to check for cell abnormalities. This is called liquid-based cytology (LBC).

**Self-collected** – This is done in a private space (e.g. a bathroom) in a health clinic. A health care provider will give you a self-collection

swab and explain how to collect your own cell sample. Or, if you prefer, the provider can assist you to collect the sample without using a speculum. Self-collection is only available to people who do not have any signs or symptoms of cancer. Self-collected samples are not suitable for liquid-based cytology, so if HPV is detected, you may be asked to return to have a health provider collect a second sample or be referred for a colposcopy (see page 16).

The test results are used to predict your level of risk for significant cervical changes. If the results show:

- **a higher risk** – you will be referred for a colposcopy (see page 16)
- **an intermediate risk** – you will be monitored with a follow-up screening test in 12 months
- **a low risk (no HPV detected)** – you will be due for your next cervical screening test in 5 years.

For more information, call Cancer Council 13 11 20 or visit [cervicalscreening.org.au](http://cervicalscreening.org.au).

## Q: Which health professionals will I see?

**A:** Your GP will arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a specialist, who will arrange further tests.

If cervical cancer is diagnosed, the specialist will consider treatment options. Often these will be discussed with other health professionals at what is known as a multidisciplinary team (MDT) meeting. During and after treatment, you will see a range of health professionals who specialise in different aspects of your care (see opposite page).



## Health professionals you may see

<b>gynaecologist</b>	specialises in diseases of the female reproductive system; may diagnose cervical cancer and then refer you to a gynaecological oncologist
<b>gynaecological oncologist</b>	specialises in cancers of the female reproductive system; diagnoses and performs surgery for these cancers, including cervical cancer
<b>radiation oncologist</b>	treats cancer by prescribing and overseeing a course of radiation therapy
<b>medical oncologist</b>	treats cancer with drug therapies such as chemotherapy and targeted therapy
<b>radiologist</b>	analyses x-rays and scans; an interventional radiologist may also perform a biopsy under ultrasound or CT guidance, and deliver some treatments
<b>radiation therapist</b>	plans and delivers radiation therapy
<b>cancer care coordinator</b>	coordinates your care, liaises with MDT members, and supports you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)
<b>nurse or nurse practitioner</b>	administers drugs and provides care, information and support throughout treatment; a nurse practitioner works in an advanced nursing role and may prescribe some medicines and tests
<b>dietitian</b>	helps with nutrition concerns and recommends changes to diet during treatment and recovery
<b>social worker, psychologist</b>	link you to support services; help with emotional and practical problems associated with cancer and treatment
<b>women's health physiotherapist</b>	treats physical problems associated with treatment for gynaecological cancers and lymphoedema

# Diagnosis

If your cervical screening test results (see pages 13–14) suggest that you have a higher risk of developing cervical cancer, you will usually have more tests. You may also have tests to check for cervical cancer if you have symptoms.

Some tests allow your doctor to see the tissue in your cervix and surrounding areas more clearly. Other tests tell the doctor about your general health and whether the cancer has spread. You probably won't need to have all the tests described in this chapter.

## Colposcopy and biopsy

A colposcopy is a way of looking closely at the cervix and vagina to see if there are any abnormal or changed cells. It is done by a colposcopist, who is usually a gynaecologist, gynaecological oncologist or, in some clinics, a nurse practitioner.

A colposcopy takes only about 10–15 minutes. You will usually be advised not to have sex or put anything in your vagina (e.g. tampons) for 24 hours before the procedure.

A colposcopy is done with an instrument called a colposcope, which is a microscope with a light. The colposcope is placed near your genital area (vulva) but does not enter your body. You will lie on your back in an examination chair with your knees up and apart.

The colposcopist will use a speculum to spread the walls of your vagina apart, and will usually apply a vinegar-like liquid and iodine

to your cervix and vagina. This makes it easier to see any abnormal cells through the colposcope. You may feel a mild stinging or burning sensation, and you may have a brown discharge from the vagina after the procedure.

If the colposcopist sees any abnormal-looking areas during the colposcopy, they may take a tissue sample (biopsy) from the surface of the cervix. You may feel some pain for a short time while the tissue sample is taken.

You will be able to go home once the colposcopy and biopsy are done. The tissue sample is sent to a laboratory, and a pathologist will examine the cells under a microscope to see if they are abnormal (precancer or cancer). The results are usually available in about one week.

**Side effects of a colposcopy with biopsy** – After the procedure, it is common to have cramping that feels similar to pain you may have with your period (menstrual pain). This may last a short time and can be relieved with mild pain medicines such as paracetamol or non-steroidal anti-inflammatory drugs. You may also have some light bleeding or other vaginal discharge for up to a week.

To give the cervix time to heal and to reduce the risk of infection, your colposcopist may advise you not to have sexual intercourse or use tampons for a certain amount of time after the procedure.

*“My doctor said that because I had regular cervical screening tests, the cancer was picked up while it was small.”* KAREN

## Treating precancerous cell changes

If any of the tests show precancerous cell changes (see page 10), you may have one of the following procedures to remove the area of abnormal cells and prevent it developing into cervical cancer.

### Large loop excision of the transformation zone

Large loop excision of the transformation zone (LLETZ) is the most common way to treat precancerous changes of the cervix. The abnormal tissue is removed using a thin wire loop that is heated electrically. The aim is to remove all the abnormal cells from the surface of the cervix. It may also be called loop electrosurgical excision procedure (LEEP).

The procedure is done under local anaesthetic in your doctor's clinic or under local or general anaesthetic in hospital. A LLETZ takes about 5–10 minutes. The tissue sample is sent to a laboratory for examination under a microscope. Results are usually available in 1–2 weeks.

**Side effects of a LLETZ** – After the procedure, you may have some vaginal bleeding and cramping. These side effects will usually ease in a few days, but you may notice some spotting for several weeks.

See your doctor if the bleeding lasts longer than 3–4 weeks, becomes heavy or has an unpleasant smell, or you develop fever or intense pelvic pain. To give your cervix time to heal and to prevent infection, you should not have sexual intercourse or use tampons for 4–6 weeks after the procedure. Showers are fine, but avoid baths, spas and swimming pools for about 4 weeks as these can increase the risk of infection.

After a LLETZ you can still become pregnant, but you may have a slightly higher risk of having the baby prematurely. Talk to your doctor before the procedure if you are concerned.

## Cone biopsy

This procedure is used when the abnormal cells are found in the cervical canal (see page 7), if a larger area needs to be removed or when early-stage cancer is suspected. In some cases, a cone biopsy is also used to treat very early-stage cancers, particularly if you would like to have children in the future.

A cone biopsy is usually done as day surgery in hospital under general anaesthetic. A surgical knife (scalpel) is used to remove a cone-shaped piece of tissue from the cervix (see page 30). A pathologist examines the tissue to make sure all the abnormal cells have been removed. Results are usually available in 1-2 weeks.

**Side effects of a cone biopsy** – After a cone biopsy, you may have some light bleeding or cramping for a few days. Avoid doing any heavy lifting for a few weeks, as the bleeding could become heavier or start again. If the bleeding lasts longer than 3-4 weeks, becomes heavy or has an unpleasant smell, or you develop fever or intense pelvic pain, see your doctor. You may notice a dark brown discharge for a few weeks, but this will pass. To give your cervix time to heal and to prevent infection, you should not have sexual intercourse or use tampons for 4-6 weeks.

A cone biopsy may weaken the cervix. You can still become pregnant after a cone biopsy, but you may be at a higher risk of having a miscarriage or having the baby prematurely. If you would like to become pregnant in the future, talk to your doctor before the procedure.

*“I had period-like pain for a few days after the cone biopsy but a hot water bottle and mild pain medicines helped a lot.”* JULIE

## **Laser surgery**

This procedure uses a laser beam instead of a knife to destroy or remove the abnormal cells.

A laser beam is a strong, hot beam of light. The laser beam is pointed at the cervix through the vagina. Laser surgery is done under either local or general anaesthetic. It takes about 5–10 minutes, and you can go home after the treatment when you have recovered from the anaesthetic.

Laser surgery works just as well as a LLETZ to remove precancerous cells and can be a better option if the precancerous cells extend from the cervix into the vagina or if the lesion on the cervix is very large.

**Side effects of laser surgery** – These are similar to those of LLETZ. You are usually able to return to your usual activities 2–3 days after having laser surgery, but you should not have sexual intercourse or use tampons for 4–6 weeks. You will also need to avoid baths, swimming pools and spas.

## **Further tests**

If any of the tests or procedures described on pages 16–20 show that you have cervical cancer, you may need further tests to find out whether the cancer has spread to other parts of your body. This is called staging (see page 24). You may have one or more of the tests described on the following pages.

## **Blood test**

You may have a blood test to check your general health, and how well your kidneys and liver are working.



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

## Imaging scans

Various imaging scans can create pictures of the inside of your body and provide different types of information. You may have one or more of the following imaging scans to find out if the cancer has spread to lymph nodes in the pelvis or abdomen, or to other organs in the body.

**CT scan** – A CT (computerised tomography) scan uses x-rays to take pictures of the inside of your body and then compiles them into a detailed, 3-dimensional picture.

When you make the appointment for the scan, you will be told if there are any special instructions to follow. Before the scan, you may be given a drink, or have an injection of a dye (called contrast) into one of your veins. The contrast may make you feel hot all over for a few minutes. You may also be asked to insert a tampon into your vagina. The dye and the tampon make the pictures clearer and easier to read.

During the scan, you will need to lie still on a treatment table that moves in and out of the CT scanner, which is large and round like a doughnut. The scan is painless and takes 5-10 minutes.

**MRI scan** – An MRI (magnetic resonance imaging) scan uses a powerful magnet and radio waves to create detailed cross-sectional pictures of the inside of your body. Let your medical team know if you have a pacemaker or any other metal implant, as some may affect how an MRI works.

Sometimes gel is placed in the vagina before the MRI scan to better show the cervix or vagina. During the scan, you will lie on a treatment table that slides into a large metal cylinder that is open at both ends.

The test is painless but the noisy, narrow machine can make some people feel anxious or claustrophobic. If you are concerned, talk to your medical team before the scan. You may be given medicine to help you relax, and you will usually be offered headphones or earplugs. Most MRI scans take between 30 and 90 minutes.

**PET-CT scan** – A PET (positron emission tomography) scan combined with a CT scan is a specialised imaging test. It provides more detailed information about the cancer than a CT scan on its own. Not all people need to have a PET-CT scan.

Before having the scan, you will be injected with a glucose (sugar) solution containing a small amount of radioactive material. Cancer cells show up brighter on the scan because they take up more glucose than normal cells do. The radioactive material will leave your body within a few hours.

You will be asked to lie still for 30–60 minutes while the solution spreads through your body, then you will have the scan. Let your doctor know if you are claustrophobic, as you need to be in a confined space for the scan. It may take a few hours to prepare for a PET-CT scan, but the scan itself usually takes about 30 minutes.

## **Examination under anaesthetic**

Another way to check whether the cancer has spread is for the doctor to examine your cervix, vagina, uterus, bladder and rectum. This is done in hospital under general anaesthetic.



If the doctor sees any abnormal areas of tissue during the procedure, they will usually take a biopsy (see pages 16-17). The area examined will depend on where the cancer may have spread to and may include:

**Pelvic examination** – The doctor will put a speculum into your vagina and spread the walls of the vagina apart so the doctor can check the cervix and vagina for cancer.

**Uterus** – The cervix will be dilated (gently opened) and some of the cells in the lining of the uterus (endometrium) will be removed and sent to a laboratory for examination. This is called a dilation and curettage (D&C).

**Bladder** – To examine the bladder, the doctor will insert a thin viewing instrument with a camera and light on the end (a cystoscope) into your urethra. The urethra is the tube that drains urine (wee) from the bladder.

**Rectum** – The doctor will wear gloves and use a finger to feel for any abnormal growths inside your rectum. To examine your rectum more closely, the doctor may insert an instrument called a sigmoidoscope, which is a tube with an attached camera.

For people who will be having radiation therapy (see pages 36-41), the doctor may implant small markers into the cervix or vagina to show the size and position of the cancer. The markers (called fiducials) are made of gold and are about the size of a grain of rice. They can be seen on x-ray and CT scans and are used to guide radiation therapy treatment.

You can usually go home from hospital on the same day after an examination under anaesthetic. You may have some light bleeding and cramping for a few days afterwards. Your doctor will talk to you about any other side effects you may have.

## Staging cervical cancer

The tests and procedures described on pages 16–23 help the doctors work out how far the cancer has spread. This is called staging. Knowing the stage of the cancer helps your health care team recommend the best treatment for you.

Cervical cancer is usually staged using the International Federation of Gynecology and Obstetrics (FIGO) staging system. FIGO classifies cervical cancer into 4 stages. Each stage is further divided into sub-stages such as A, B and C, which indicate increasing amounts of tumour.

### Stages of cervical cancer

<b>stage 1</b>	<b>early or localised cancer</b>	Cancer is found only in the cervix.
<b>stage 2</b>	<b>locally advanced cancer</b>	Cancer has spread outside the cervix to the upper two-thirds of the vagina or other tissue next to the cervix.
<b>stage 3</b>	<b>locally advanced cancer</b>	Cancer has spread to the lower third of the vagina and/or the tissue on the side of the pelvis (pelvic wall). The cancer may also have spread to lymph nodes in the pelvis or abdomen, or caused a kidney to stop working.
<b>stage 4</b>	<b>metastatic or advanced cancer</b>	Cancer has spread to the bladder or rectum (stage 4A) or beyond the pelvis to the lungs, liver or bones (stage 4B).



Clinical practice guidelines set out the tests and treatment recommended at each stage of cervical cancer. You can ask your doctors what guidelines they are using.

## Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your doctor, but it is not possible for anyone to predict the exact course of the disease. Instead, your doctor can give you an idea about the general outlook for people with the same type and stage of cervical cancer.

To work out your prognosis, your doctor will consider:

- your test results
- the type of cervical cancer
- the size of the cancer and how far it has grown into other tissue
- whether the cancer has spread to the lymph nodes or other organs
- other factors such as your age, fitness and overall health.

In general, the earlier cervical cancer is diagnosed and treated, the better the outcome. Most early-stage cervical cancers have a good prognosis with high survival rates. Even if cancer is found after it has spread beyond the cervix (locally advanced cancer), it may still respond well to treatment and good outcomes are possible. In recent years, clinical trials have led to new treatments that continue to improve the prognosis for people with metastatic cervical cancer.

Discussing your prognosis and thinking about the future can be challenging and stressful. It may help to talk with family and friends. You can also call Cancer Council 13 11 20 if you or your family or friends need more information or emotional support.

## Key points about diagnosing cervical cancer

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### Cervical screening test

- A cervical screening test checks for HPV, the virus that causes almost all cervical cancers.
- If HPV is found, a pathologist will check a sample of cells from the cervix to look for abnormal cell changes.
- HPV usually goes away on its own, but if your cervical screening test shows you are at higher risk of precancerous cell changes, you will usually have further tests.

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### Diagnostic tests

- If you are at higher risk of significant cervical abnormalities, the first test is a colposcopy to look for cell changes in the cervix and vagina.
- The person doing the colposcopy may take a tissue sample (biopsy) from the cervix to see whether any cell changes are precancerous or cancerous.

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### Treating precancerous cell changes

Precancerous cell changes can be checked and treated in several ways including large loop excision of the transformation zone (LLETZ; also called loop electrosurgical excision procedure or LEEP), cone biopsy or laser surgery.

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### Follow-up tests

You may have further tests or imaging scans to find out whether the cancer has spread to other parts of the body.

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### Staging and prognosis

- The stage shows how far the cancer has spread through the body. Early cervical cancer is stage 1. Locally advanced cervical cancer is stage 2 or 3. Advanced (metastatic) cervical cancer is stage 4.
- The earlier cervical cancer is found, the easier it is to treat.



# Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast, or you might be anxious to get started.

Check with your specialist how soon treatment should begin, as it may not affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as you can before making a decision.

**Know your options** – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see page 14) and if the treatment centre is the most appropriate one for you – you may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

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

**Ask questions** – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 63 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

**Consider a second opinion** – You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this. Your GP or specialist can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the second specialist.

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

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

## Should I join a clinical trial?

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

led to better outcomes for people diagnosed with cancer.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit [australiancancertrials.gov.au](http://australiancancertrials.gov.au).

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

# Treatment

The treatment recommended by your doctors will depend on the stage of the cancer; your age and general health; and whether you would like to have children in the future. You may have more than one treatment, and treatments may be given in different orders and combinations.

The treatment options by stage are:

- **early** – usually treated with surgery to remove the cancer; may have radiation therapy combined with chemotherapy (chemoradiation) or internal radiation therapy (brachytherapy) after surgery. See pages 36–39.
- **locally advanced** – usually treated with chemoradiation followed by brachytherapy; surgery is not usually used
- **advanced** – may be treated with radiation therapy, chemotherapy, targeted therapy, immunotherapy, chemoradiation and/or surgery. Other drug therapies may also be available through clinical trials.

## Surgery

For some people, surgery may be the only treatment needed. Surgery is usually recommended when the tumour is in the cervix only. The type of surgery you have will depend on how far within the cervix the cancer has spread. See pages 30–31 for more information about the main types of surgery used. Your gynaecological oncologist may also remove some lymph nodes during surgery (see page 32).

- ▶ See our *Understanding Surgery* booklet.

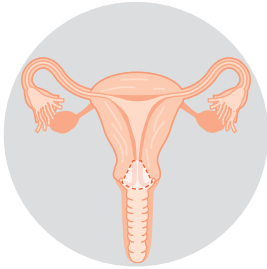


If becoming a parent is important to you, talk to your doctor before starting treatment and ask for a referral to a fertility specialist. For more information, see page 51.

## Types of surgery

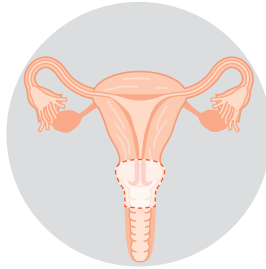
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Depending on how far the cancer has spread and your age, you may have one or more of the procedures listed below.



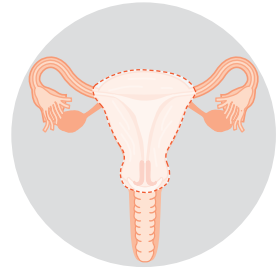
### Cone biopsy

Removes a cone-shaped piece of tissue around the cancer, including a margin of healthy tissue. A cone biopsy is used to treat very early cervical cancers. You may have this if you would like to have children. See page 19 for more information.



### Trachelectomy

Removes part or all of the cervix, along with the upper part of the vagina. The uterus, fallopian tubes and ovaries are left in place. This is not a common procedure, but it may be used if you have early-stage cancer and would like to have children. See also page 51.



### Total hysterectomy

Removes the uterus and cervix. This surgery can be used for early cervical cancers. The fallopian tubes are also commonly removed (see *Bilateral salpingectomy*, opposite). You may be able to keep your ovaries if you are premenopausal.

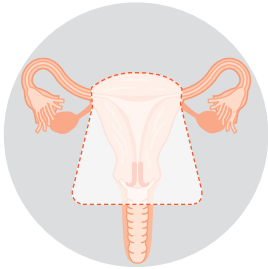
## How the surgery is done

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The surgery will be performed under a general anaesthetic. Research has shown that outcomes for larger cervical cancers are better with open surgery (laparotomy). This means that the surgery is performed through a cut in the abdomen. The cut is usually made from the pubic area to the bellybutton. Sometimes the cut is made

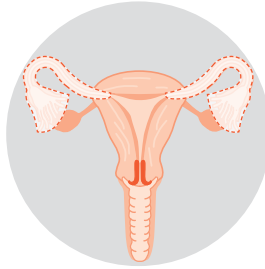
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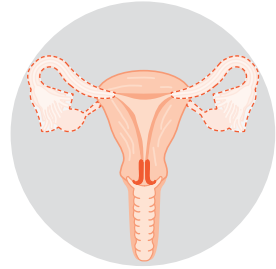
### **Radical hysterectomy**

Removes the uterus, cervix, and soft tissue around the cervix and top of the vagina. This is the standard operation for most cervical cancers treated with surgery. The fallopian tubes are also commonly removed (see next column). You may be able to keep your ovaries if you are premenopausal.



### **Bilateral salpingectomy**

Removes both fallopian tubes. A bilateral salpingectomy may be recommended if you are having a total or radical hysterectomy.



### **Bilateral salpingo-oophorectomy**

Removes both fallopian tubes and ovaries. This may be considered for those who are having a hysterectomy when there is a risk that the cancer may have spread to the ovaries, which may happen with adenocarcinoma. This procedure may be recommended before or after menopause.

across the pubic hair line instead. The uterus and other organs are then removed through the cut. Keyhole surgery (laparoscopy or robotic surgery) is usually only used for very early cervical cancer. Your surgeon will talk to you about the most suitable surgery for you, as well as any risks.

## **Surgery to remove lymph nodes**

You may have one of the following procedures to check if the cancer has spread from the cervix to lymph nodes in the pelvis. If cancer is found in the lymph nodes, your doctors may recommend additional treatment.

**Lymphadenectomy (lymph node dissection)** – The surgeon will remove a number of lymph nodes from the pelvic and/or abdominal areas to see if the cancer has spread beyond the cervix.

**Sentinel lymph node biopsy** – This procedure may be used for early cervical cancer but is only performed in some treatment centres. It helps to find the lymph node that the cancer is most likely to spread to first (the sentinel lymph node). While you are under anaesthetic, your surgeon will inject a dye into the cervix. The dye will flow to the sentinel lymph node and the surgeon will remove it for testing. If it contains cancer cells, the surgeon may remove the remaining nodes in the area (lymphadenectomy, see above). Alternatively, your doctors may decide you need other treatments such as chemoradiation (see page 36). A sentinel lymph node biopsy can help avoid the removal of more lymph nodes than necessary and minimise side effects such as lymphoedema (see page 52).

## **What to expect after surgery**

When you wake up from surgery, you will be in a recovery room near the operating theatre. Once you are fully conscious, you will be taken to your bed on the hospital ward.

**Tubes and drips** – You may have an intravenous (IV) drip to give you fluid and medicine (such as pain medicine or antibiotics to prevent infection), a tube in your abdomen to drain fluid from the operation site, and a small plastic tube (catheter) in your bladder to drain urine (wee). These tubes will be removed before you go home.

After the catheter is removed from your bladder, the nurses will check that your bladder is emptying properly. This is called a bladder scan. It is a quick, painless scan that is done on the hospital ward.

**Pain and discomfort** – After a major operation, it is common to feel some pain. You will be given pain medicine as a tablet (orally), through a drip (intravenously) or through a catheter inserted in the spaces in the spine (epidural). If you still have pain, let your doctor or nurse know so they can change your medicine to one that provides more relief.

**Blood clot prevention** – You will usually have injections of a blood-thinning drug to reduce the risk of blood clots. While you are in bed, you may have to wear compression stockings on your lower legs. These stockings help the blood in your legs circulate and prevent blood clots forming in the deep veins of the legs or pelvis (deep vein thrombosis). You will be encouraged to walk around as soon as you can and you may be asked to continue injecting blood-thinning drugs for several weeks after returning home.

**Recovery** – You will usually spend up to 5 days in hospital after surgery. The recovery time depends on the type of surgery, your fitness and whether you have any complications. You will be able to go home when the treatment team is satisfied with your recovery and the results of your bladder scans.

## **Side effects after surgery**

After surgery for cervical cancer, you may have some side effects.

**Problems with how the bladder works** – Some of the nerves to the bladder may be affected by a hysterectomy. You may feel that you're not able to empty your bladder completely or that you're emptying your

bladder very slowly. These problems usually improve with time. You may also find that you leak some urine after surgery. This is called urinary incontinence. For more information, see page 46.

**Constipation** – The pain medicines used during and after surgery can cause constipation (difficulty having bowel movements). Your treatment team may suggest medicines to help prevent or relieve constipation. Once your surgeon says you can get out of bed, walking around can also help. For more information, see page 47.

**Impact on sexuality** – The physical and emotional changes you have after surgery may affect how you feel about sex, but surgery doesn't change the ability to feel pleasure. See pages 48–49 for more information.

**Lymphoedema** – Sometimes removing lymph nodes in the pelvic area can stop or slow the natural flow of lymphatic fluid from the legs. This may cause lymphoedema – a build-up of fluid in the soft tissues under the skin – in the legs or genital area. See page 52 for more information.

**Menopause** – If your ovaries are removed and you have not been through menopause, removal will cause sudden menopause. After menopause, you will stop having periods and you will not be able to become pregnant. If you are finding it hard to manage the symptoms of menopause, you may be able to take menopausal hormone therapy (MHT). For more information, see pages 52–53.

**Internal scar tissue (adhesions)** – Scar tissue in the pelvis may stick together. Sometimes these adhesions, particularly to the bowel or bladder, may cause abdominal pain or discomfort. Rarely, adhesions may need to be treated with surgery.

## Taking care of yourself at home after surgery

Your recovery time after surgery will depend on the type of operation you had, your age and general health. In most cases, you will feel better within 6 weeks.

### Rest up



Take things easy for the first few weeks after the surgery. Ask family or friends to help you with household chores so you can rest as much as you need to.

### Activity and exercise



Walk regularly if your doctors say it is okay to do so. Gentle exercise can help speed up recovery. Speak to your doctor about when you can start more vigorous exercise or go swimming.

### Work



Depending on the type of work you do, you will probably need up to 4–6 weeks leave from your job.

### Lifting



Avoid heavy lifting for 6 weeks, maybe more depending on the type of surgery you've had.

### Sex



You'll need to avoid sexual intercourse for at least 6 weeks after surgery to give the vaginal wound time to heal properly.

## Radiation therapy

Also known as radiotherapy, radiation therapy uses a controlled dose of radiation to kill or damage cancer cells. The radiation is usually in the form of x-ray beams. It is targeted at the parts of the body with cancer or at areas the cancer cells might have spread to. Treatment is carefully planned to do as little harm as possible to healthy tissues.

Radiation therapy may be given in combination with chemotherapy as the main treatment for cervical cancer (chemoradiation) or after surgery to help destroy any remaining cancer cells and reduce the chance of the cancer coming back (adjuvant therapy).

There are 2 main ways of delivering radiation therapy: externally or internally. It is common to have both types to treat cervical cancer.

► See our *Understanding Radiation Therapy* booklet.

## Chemoradiation

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When radiation therapy is given at the same time as chemotherapy, it is known as chemoradiation. The chemotherapy drugs make the cancer cells more sensitive to radiation therapy.

If you have chemoradiation, you will usually receive chemotherapy once a week a few hours before the radiation therapy appointment.

Side effects of chemoradiation include fatigue; diarrhoea; needing

to pass urine more often or in a hurry; cystitis (irritation of the bladder); dry and itchy skin in the treatment area; and nausea.

Chemoradiation can also affect blood cells, and weekly blood tests may be needed during treatment to monitor your blood cell levels.

Talk to your treatment team about ways to manage the side effects of chemoradiation.

## **External beam radiation therapy**

In external beam radiation therapy (EBRT), a machine precisely directs radiation beams from outside the body to the cervix, lymph nodes and other organs that need treatment. You will have a planning session, including a CT scan, to work out where to direct the radiation. To help direct the treatment, up to 4 small tattoos the size of a freckle may be applied to the skin on your pelvis. These marks are usually permanent. See page 23 for information about other markers that may be used.

You may be asked to empty your bowels and/or drink some water so that your bladder is comfortably full before the CT scan and treatments. This helps to ensure that organs in the pelvic area – including the cervix and uterus – are in the same position for each treatment and the radiation beams are delivered to the targeted area.

You will probably have EBRT as daily treatments, Monday to Friday, over 4–6 weeks as an outpatient. You will lie on a table and the radiation therapy machine will move around you. It is important that you lie still and breathe normally. The radiation therapist will leave the room during treatment, but will be able to talk to you through an intercom and watch you on a screen. The EBRT session may take up to 45 minutes, but the actual treatment takes about 15 minutes and is painless.

## **Internal radiation therapy**

Also known as brachytherapy, internal radiation therapy delivers radiation directly to the tumour from inside your body (usually through the vagina). It allows a higher radiation dose to be delivered to the tumour, while reducing the amount of radiation delivered to nearby organs such as the bowel and bladder. Brachytherapy is usually given after the course of EBRT is finished. The main type of internal radiation therapy used for cervical cancer is high-dose-rate (HDR) brachytherapy.

With HDR brachytherapy, only a few treatments are needed to receive the required radiation dose. Your treatment team will develop a personalised treatment plan to suit your body and target the cancer while limiting the radiation dose to other organs.

You will have treatment as a day patient or may stay in hospital overnight. You will probably have 3–4 sessions over 2–3 weeks, and will be given a general or spinal anaesthetic at each session.

**During treatment** – Devices called applicators are used to deliver the radiation source to the cancer. They are available in different sizes. Your radiation oncologist will examine you to choose suitable applicators for your situation. Applicators are placed into the cervix under ultrasound guidance to make sure they are in the right place. To hold the applicators in place, you will have gauze padding put into your vagina, and may have a stitch placed in the vulva.

You will also have a small tube (catheter) inserted to empty your bladder of urine during treatment. You will have a CT or MRI scan to check the position of the applicator. If you have a general anaesthetic, you may be woken after the applicator is put in place and given patient-controlled pain medicine for the rest of the procedure.

The radiation dose is delivered from a shielded container through cables to the applicator. The radiation stays in the applicator for about 10–20 minutes and is then taken out.



External beam radiation therapy and HDR brachytherapy will not make you radioactive. It is safe for you to be with both adults and children after your treatment sessions.



*“For me, the hardest part of cancer and treatment is the ongoing emotional side. My doctors have told me to be vigilant about everything abnormal, such as any vaginal bleeding or pain. Sometimes I panic when I feel unwell and rush to my doctor for reassurance. Mostly now, it feels like it was a bad dream, and I focus on living my life to the full.”* ANNE

**After treatment** – As several sessions are needed, you may stay in hospital with the applicator in place (and no radiation inside) so that a second treatment can be given. Otherwise, the applicator may be taken out after the radiation dose is delivered and then reinserted before each session.

After brachytherapy, you may feel uncomfortable in the vaginal region or have a small amount of bleeding. Pain medicines can help.

### **Radiation therapy after surgery (adjuvant therapy)**

If you’ve had surgery, your doctor may recommend that you also have additional radiation therapy. Usually, about 4–6 weeks after surgery, you will have EBRT (see page 37) in combination with chemotherapy. Occasionally, some women will have brachytherapy to deliver radiation to the top of the vagina.

This brachytherapy is done as an outpatient procedure and does not require anaesthetic. A cylinder-shaped applicator is inserted into the vagina, then removed after each session. You may need to have 2–4 sessions to deliver the right amount of radiation to treat the cancer. Each treatment session takes about 30 minutes.

## Short-term side effects of radiation therapy

The side effects you have will vary depending on the dose of radiation and the length of the treatment. Many will be short-term side effects that occur during treatment or within a few weeks of finishing. Side effects can take several weeks to get better.

**fatigue**  
(see also page 50)

Your body uses a lot of energy dealing with the effects of radiation on healthy cells. Tiredness usually builds up slowly during the course of the treatment, particularly near the end. It may last for some time after treatment ends.

**bladder and bowel changes**  
(see also pages 46–47)

You may pass urine more often or with more urgency, or feel a burning sensation. Try to drink plenty of water to dilute your urine. Bowel movements may be more frequent, urgent or loose (diarrhoea), or you may pass more wind than normal. Less commonly, there may be some blood in the faeces (poo or stools). Your treatment team will prescribe medicines to reduce these side effects.

**skin redness, soreness and swelling**

Radiation therapy may make the skin in the treatment area dry and itchy. Occasionally, your skin may look red and peel, like sunburn. The treatment team will recommend creams to use to make you more comfortable.

**hair loss**

When radiation therapy is aimed at your pelvic area, you may lose your pubic hair. This hair may grow back after the treatment ends, but it will usually be thinner. The radiation therapy will not cause you to lose hair from your head or other parts of your body.

**vaginal discharge**

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

## Long-term or late effects of radiation therapy

Some side effects may continue for longer. Other side effects from radiation therapy may not show up until many months or years after treatment. These are called late effects.

<b>lymphoedema</b> (see also page 52)	Radiation can scar the lymph nodes and vessels and stop them draining lymph fluid properly. This may lead to swelling of the legs or genital area. This can occur months or years after radiation therapy.
<b>bladder and bowel changes</b> (see also pages 46–47)	Bladder and bowel changes can also be late effects, appearing months or years after radiation therapy finishes. You may pass urine or stools (poo) more often or need to go in a hurry. Sometimes, changing your diet and avoiding spicy and fatty foods can help. Let your doctor know if you have any bleeding or have pain in the abdomen and cannot open your bowels.
<b>narrowing of the vagina</b> (see also pages 48–49)	The vagina may become drier, 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 using vaginal dilators.
<b>menopause</b> (see also pages 52–53)	If your ovaries have not been removed, radiation therapy will stop the ovaries producing hormones, which leads to early menopause. Your periods will stop, you will no longer be able to become pregnant and you may have menopause symptoms.
<b>pelvic fracture</b>	Rarely, radiation therapy to the pelvic area can weaken bones and cause a fracture. Pelvic fractures are the most common. This may not happen until 2–4 years after treatment. The risk is higher after menopause and if you have low bone density (osteoporosis, see page 53).

# Chemotherapy

Chemotherapy uses drugs to kill cancer cells or slow their growth while causing the least possible damage to healthy cells. It may be given:

- in combination with radiation therapy as the main treatment for cervical cancer (chemoradiation, see page 36)
- on its own or combined with targeted therapy (see opposite page).

The drugs are usually given through a vein (intravenously) during day visits to a hospital or clinic. Chemotherapy is usually given as a period of treatment followed by a break. This is called a cycle. The number of cycles you have depends on the type of cervical cancer and any other treatments you may be having. If you have chemotherapy without radiation therapy, you are likely to have up to 6 cycles (with a cycle every 3–4 weeks), though it may continue for longer.

**Side effects of chemotherapy** – The possible side effects vary according to the drugs given, how often you have treatment, your general health, and whether you have chemotherapy alone or chemoradiation. You may have nausea or vomiting; feel tired; or lose some hair from your body or head. Temporary or permanent menopause may also occur (see pages 52–53).

Chemotherapy may reduce the number of blood cells in your body, so you will have regular blood tests during treatment to monitor this. Depending on the type of blood cells affected, you may feel very tired and be more likely to get infections. If your temperature rises to 38°C or above, go to the nearest hospital emergency department immediately.

Most side effects of chemotherapy are temporary, and your treatment team can help you to prevent or reduce them.

- ▶ See our *Understanding Chemotherapy* booklet.

## Targeted therapy

Targeted therapy is a drug treatment that attacks specific features of cancer cells to stop the cancer growing and spreading. It is used to treat cervical cancer that has spread to other parts of the body or has come back and cannot be treated by surgery or radiation therapy.

Bevacizumab is a type of targeted therapy that can be used to treat advanced cervical cancer. It is given with chemotherapy every 3 weeks through a drip into a vein (infusion). The total number of infusions you receive will depend on how you respond to the drug.

**Side effects of targeted therapy** – The most common side effects of taking bevacizumab include high blood pressure, feeling tired and loss of appetite. Less common side effects include bleeding, blood clots and problems with wound healing. Rarely, bevacizumab has the potential to cause other more serious side effects, such as damage to the bowel (perforation) or the development of an abnormal opening between the vagina and another part of the body (fistula). Your doctor will discuss these possible side effects with you.

- ▶ See our *Understanding Targeted Therapy* fact sheet and listen to our “New Cancer Treatments” podcast episode.

## Immunotherapy

Immunotherapy is a type of drug treatment that helps the body’s own immune system to fight cancer.

Pembrolizumab is an immunotherapy drug that may be offered to certain people with cervical cancer that has not responded to treatment, has spread or has come back. Pembrolizumab is given with chemotherapy drugs and sometimes with bevacizumab (see above).

**Side effects of immunotherapy** – Immunotherapy can have a range of side effects. Because this therapy is given with chemotherapy there may also be side effects related to the chemotherapy. Common side effects of pembrolizumab include fatigue, diarrhoea, itching and joint pain.

Rarely, pembrolizumab can affect other organs including the heart, lungs, bowel or thyroid gland and these side effects can sometimes be life-threatening. It's important to let your treatment team know about any new or worsening side effects during or after treatment. Don't try to treat side effects yourself.

## Palliative treatment

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

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

As well as slowing the spread of cancer, palliative treatment can relieve any pain and help manage other symptoms. Treatment may include radiation therapy, chemotherapy, targeted therapy or other medicines such as hormone therapy.

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

► See our *Understanding Palliative Care* booklet.

## Key points about treating cervical cancer

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### Treatment choice

- The treatments you are offered will depend on the stage of the cancer, your age and general health.
  - If having children is important to you, talk to your doctor before starting treatment.
- 

### Surgery

- Surgery is commonly used to remove early cervical cancer.
  - If you have early-stage cervical cancer and still want to have children, you may have a cone biopsy or a trachelectomy to remove the cervix and some surrounding tissue.
  - Other operations include a hysterectomy to remove the uterus and cervix, and a bilateral salpingo-oophorectomy to remove the fallopian tubes and ovaries.
  - Sometimes the lymph nodes in the pelvic region are removed (lymphadenectomy or sentinel lymph node biopsy).
- 

### Radiation therapy and chemoradiation

- Radiation therapy may be given with chemotherapy (chemoradiation) as the main treatment for some cervical cancers.
  - Radiation therapy may also be used after surgery to help get rid of any remaining cancer cells and reduce the risk of the cancer coming back.
- 

### Drug therapies

- Chemotherapy may be used on its own to treat advanced cervical cancer or cancer that has come back after treatment.
  - Targeted therapy or immunotherapy drugs may be given with chemotherapy to treat advanced cervical cancer.
  - New drug therapies may be available through clinical trials or other programs. Ask your doctor if these might be an option for you.
-

# Managing side effects

It will take some time to recover from the physical and emotional changes caused by treatment for cervical cancer. Some people have many side effects, while others don't have any. Side effects may last from several weeks to a few months or, less commonly, many years or permanently. This chapter includes ways to reduce or manage the discomfort that side effects cause.

## Bladder changes

Bladder control may change after surgery or radiation therapy. You may find that you need to pass urine (wee) more often or in a hurry. Or you may leak a few drops of urine when you cough, sneeze, laugh, strain or lift. This is called urinary incontinence and there are ways to manage it, including strengthening your pelvic floor muscles. You can find a guide to exercising the pelvic floor muscles in our *Exercise for People Living with Cancer* booklet.

Using continence pads and special underwear can help you manage leakage. You may be eligible for help with the cost of these products. Visit [servicesaustralia.gov.au/continence-aids-payment-scheme](http://servicesaustralia.gov.au/continence-aids-payment-scheme). You might also find it helpful to see a continence nurse or physiotherapist for a bladder training program – ask your doctor for a referral or contact the National Continence Helpline on 1800 33 00 66 or at [continence.org.au](http://continence.org.au).



The blood vessels in the bowel and bladder can break more easily after radiation therapy. This can cause blood to appear in urine or faeces (poo), even months or years after treatment. Let your doctor know if this occurs so the problem can be treated.



## Bowel changes

After surgery or radiation therapy, you may notice changes in your bowel habits. You may have constipation or diarrhoea, or feel pain in your abdomen from trapped wind.

**Radiation proctitis** – Radiation therapy can damage the lining of the rectum, causing inflammation and swelling known as radiation proctitis. The risk of developing radiation proctitis is low and your treatment team will try to reduce this risk. Radiation proctitis is usually a short-term side effect but may be ongoing in a small number of people. It can cause a range of symptoms including: blood in bowel movements; diarrhoea; the need to empty the bowels urgently; and loss of control over the bowels (faecal incontinence).

You may develop some of these symptoms for other reasons. Let your treatment team know if you develop any of these symptoms. If you have ongoing bowel problems, you may be referred to a gastroenterologist.



### Tips for managing bowel changes

- Drink peppermint or chamomile tea to reduce abdominal or wind pain.
- Drink plenty of water to replace fluids lost through diarrhoea or to help soften stools if you're constipated.
- Avoid alcohol and cut down on coffee, cola and other drinks that contain caffeine.
- Avoid spicy and fatty foods.
- See a women's health physiotherapist for information about exercises to strengthen your pelvic floor and anal muscles. Also see our *Exercise for People Living with Cancer* booklet.
- Talk to your doctor or a dietitian about what to eat, or ask about suitable medicines.

## Impact on sexuality and intimacy

Having cervical cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many things, such as the treatments you have and any side effects, whether you have a partner, and your overall self-confidence.

**Low libido** – A lack of interest in sex or loss of desire is common during and after treatment. This may be because of the worry of having cancer and the side effects of treatment. If you do not feel like having sex, or if you find it uncomfortable, let your partner know. See the table opposite for some suggestions on managing sexual changes.

**Vaginal changes** – The main side effect of treatment for cervical cancer will be to the vagina. If the ovaries have been affected by surgery or radiation therapy, they will no longer produce oestrogen. This will cause your vagina to become very dry and it may not expand easily during sexual intercourse. Radiation therapy to the pelvic area can also cause vaginal tissue to lose its elasticity and shrink, narrowing the vagina. This is called vaginal stenosis. If vaginal changes make sexual penetration difficult or painful, you may have to explore different ways to enjoy sex. Even if you don't plan to have sex, your doctor will need to do regular pelvic examinations after treatment, so it's important to prevent vaginal stenosis. See the table opposite for ways to manage this.

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

*“Using vaginal dilators helped. The plastic vaginal dilators the hospital gave me were sturdy, white and horrible...so I bought my own. Buying pretty, silicone dilators gave me a sense of control, and they were a lot more comfortable to use.”* JANE

## Managing changes in your sex life

### Sexual changes

- Give yourself time to get used to any physical changes.
- Talk to your doctor about ways to manage side effects that change your sex life. They may suggest using hormone creams and vaginal moisturisers to help with vaginal discomfort and dryness. You can get a prescription for hormone creams from your doctor or buy vaginal moisturisers over the counter from pharmacies.
- Discuss changes to your libido with your partner so they understand how you're feeling.
- Consider touching, hugging and kissing. This is a chance to feel close to your partner without expectations of sexual penetration.
- Explore other ways to experience sexual pleasure, such as caressing the breasts, thighs, feet or buttocks.
- Use water- or silicone-based vaginal lubricants (without perfumes, oils or glycerines) to make penetration comfortable.
- If you need more support, ask your doctor for a referral to a sex therapist or psychologist.

### Changes to the vagina

- Keeping the vagina open and supple will make sexual intercourse more comfortable. Even if you don't plan to be sexually active, it also makes it easier for your doctor to do regular vaginal examinations to check whether the cancer has come back.
- Your doctor or nurse may suggest you use a vaginal dilator to help keep the walls of the vagina open and supple.
- Dilators are tube-shaped devices made from plastic or silicone. They are designed to gently stretch the vagina. They come in different sizes – it is important to seek advice from a health professional about the correct size.
- Wait until any soreness has settled before you start using a dilator. This is usually 2–6 weeks after your last session of radiation therapy.
- Used with lubricant, the dilator is inserted into the vagina for short periods of time.
- Using a dilator can be challenging. Your doctor, nurse or a physiotherapist can provide practical advice on how to use them.

# Fatigue

It is common to feel tired and lack energy during and after treatment, particularly if you've had both radiation therapy and chemotherapy. The tiredness may continue for several months, or even a year or two, after treatment has finished.

Feeling tired is not only a side effect of the treatment itself. Travelling to hospitals and clinics for treatment can be exhausting. If you work during your treatment or if you have a family to care for, this can make you feel especially tired.

It may be frustrating if other people don't understand how you're feeling. See pages 60–61 for information about support services.

► See our *Understanding Fatigue and Cancer* fact sheet.



## Tips for managing fatigue

- Gentle exercise during and after treatment has been shown to boost energy levels and reduce fatigue. Ask your doctor about the amount and type of exercise that is right for you.
- Plan your day. Do things at the time of day when you have more energy.
- Rest regularly. Keep a journal to track your “good times” and pace your activities so you manage your energy over the day.
- Talk with your family and friends about how you're feeling and discuss things they can help you with (e.g. housework and shopping).
- Limit daytime naps to 30 minutes so you don't have trouble sleeping at night.
- Don't expect to be able to instantly do everything you used to do. Your body is still recovering and it will take some time for your energy levels to return.

## Fertility issues

If your uterus is removed or you have radiation therapy to the uterus and cervix, you will not be able to conceive children or carry a pregnancy. Before treatment starts, ask your doctor or a fertility specialist about what options are available to you.

Being told that your reproductive organs will be removed or will no longer work can be devastating. Even if your family is complete or you did not want children, you may still feel a sense of loss and grief. These reactions are common. Speaking to a counsellor or gynaecological oncology nurse about your feelings can be helpful.

▶ See our *Fertility and Cancer* booklet.

## Ways to preserve fertility

- Ovarian transposition (oophoropexy) is a type of surgery that moves one or both ovaries to limit the amount of radiation the ovaries receive. This can help to keep the ovaries working after treatment.
- If you have not already been through menopause, ask about ways to preserve your fertility. One option may be to store eggs or embryos for use in the future. These can be implanted in your body, if you still have a healthy uterus, or into a surrogate.
- Having a trachelectomy, where only the cervix is removed, may be an option (see page 30). It will still be possible to become pregnant after this procedure, but you will be at higher risk of miscarriage and having the baby prematurely. Your doctor can discuss these risks with you.

*“The first time I met my surgeon she said, ‘You should go and see a fertility specialist’. The only way to describe the process is that it was overwhelming. However, it’s better not to delay it.”* MACKENZIE

## Lymphoedema

Surgery or radiation therapy to the pelvic area can stop lymph fluid from draining normally, causing swelling in the legs or genital area. This is known as lymphoedema. Lymphoedema may appear during treatment or months or years later.

It is important to look after your skin, avoid injury or infection to the lower limbs, and manage lymphoedema symptoms as soon as possible. Mild lymphoedema is usually managed with exercise, skin care and a compression stocking or sleeve. A physiotherapist trained in lymphoedema management can give you further advice.

To find a practitioner who specialises in the management of lymphoedema, visit the Australasian Lymphology Association's website at [lymphoedema.org.au](http://lymphoedema.org.au) and click on "Find a Practitioner". You may also be able to visit a practitioner at your treatment centre.

▶ See our *Understanding Lymphoedema* fact sheet.

## Menopause

If your ovaries have been damaged by radiation therapy or chemotherapy, or they've been surgically removed, your body will no longer produce the hormones oestrogen and progesterone. When this happens, periods stop. This is called menopause. Menopause is a natural and gradual process that usually starts between the ages of 45 and 55.

The symptoms of menopause caused by cancer treatment are usually more severe than during a natural menopause because the body hasn't had time to adjust to a gradual decrease in the hormone levels. Symptoms can include hot flushes, mood swings, trouble sleeping (insomnia), tiredness and vaginal dryness (see page 48).

Menopause may cause other changes in the body over time, such as:

- **low libido** – you may be less interested in sex (see pages 48–49)
- **osteoporosis** – this is when your bones become weak and brittle and may break more easily
- **high cholesterol** – cholesterol is a fatty substance found in the blood; having high levels can increase your risk of heart disease and stroke.

Menopausal hormone therapy (MHT), previously known as hormone replacement therapy (HRT), is medicine that replaces the hormones usually produced by the ovaries. It has been shown to treat menopause symptoms and help prevent osteoporosis. There are also non-hormonal drugs that can help. Talk to your doctor about the risks and benefits of MHT, and other ways to deal with the symptoms of menopause.



## How to manage menopause symptoms

- Talk to your doctor about having a bone density test or taking medicines to prevent osteoporosis. Regular exercise can help keep your bones strong. Call 1800 242 141 or visit [healthybonesaustralia.org.au](http://healthybonesaustralia.org.au) for information.
- Ask your doctor to check your cholesterol levels. If levels are high, regular exercise and a balanced diet may help reduce them. If levels don't improve, talk to your doctor about cholesterol-lowering drugs.
- Your doctor can suggest dietary changes and suitable exercises.
- If you smoke, talk to your doctor about quitting or call the Quitline on 13 7848.
- Try meditation and relaxation techniques to help reduce stress and lessen symptoms. Listen to our *Finding Calm During Cancer* podcast series.
- If you have ongoing symptoms, ask your doctor for a referral to a specialist menopause clinic.

## Key points about managing side effects

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### Common side effects

- Some people have few side effects from treatment, while others have many.
  - Common side effects include bladder and bowel changes, sexual changes, fatigue, fertility issues, lymphoedema and menopause.
  - Talk to your treatment team about any symptoms or side effects you have. They can suggest ways to reduce or manage any discomfort.
- 

### Bladder and bowel changes

- Bladder and bowel control may change after treatment.
  - A continence nurse, physiotherapist or dietitian can help you manage any changes.
- 

### Sexuality

- Cancer and its treatment may affect sexuality in physical and emotional ways.
  - A sex therapist or psychologist may be able to help you find new strategies for expressing intimacy and enjoying sex.
  - A nurse or women's health physiotherapist can help you with pelvic floor relaxation and using vaginal dilators.
- 

### Lymphoedema

- Some people develop swelling in the legs or genital area. This is called lymphoedema.
  - A lymphoedema practitioner can show you ways to manage this.
- 

### Menopause and fertility

- Treatment may cause menopause. Your periods will stop, you will not be able to become pregnant and you will have menopause symptoms.
  - If fertility is a concern for you, discuss this with your medical team before treatment starts.
-



# Looking after yourself

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

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

▶ See our *Nutrition for People Living with Cancer* booklet.

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

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

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

▶ See our *Understanding Complementary Therapies* booklet.



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

**Work and money** – Cancer can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check whether any financial assistance is available to you by asking a social worker at your hospital or treatment centre or calling Cancer Council 13 11 20.

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

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

▶ See our *Emotions and Cancer* booklet.

**Contraception and fertility** – If you can have sex, you may need to use certain types of contraception to protect your partner or avoid pregnancy for a time. Your doctor will explain what precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, discuss the options with your doctor before starting treatment.

▶ See page 51 and our *Fertility and Cancer* booklet.

**Body image** – Changes to your body can affect the way you feel about yourself (your self-esteem) and make you feel self-conscious. You may feel less confident about who you are and what you can do. It can be helpful to think about all the parts of yourself – body, mind and personality – that make you who you are, rather than focusing only on what has changed.

# Life after treatment

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

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

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

► See our *Living Well After Cancer* booklet.

## Dealing with feelings of sadness

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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, because counselling or medication – even for a short time – may help. Some people can

get a Medicare rebate for sessions with a psychologist. Cancer Council may also run a counselling program in your area.

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

## Follow-up appointments

After treatment ends, you will have regular appointments with your specialists to monitor your health, manage any long-term side effects and check that the cancer hasn't come back (recurred) or spread.

During check-ups, you will usually have a pelvic examination, and you may have a follow-up HPV and liquid-based cytology (LBC) tests, blood tests, and imaging scans. Your doctor will discuss your follow-up schedule with you. For the first few years, you will probably have a check-up every 3–6 months. Check-ups will become less frequent (once a year) if you have no further problems.

When a follow-up appointment is approaching, many people feel anxious. Talk to your treatment team or call Cancer Council 13 11 20 if you are finding it hard to manage this anxiety.

## What if cervical cancer returns?

While the risk of most cervical cancers coming back is very low, it does return for some people (called a recurrence). This is why it is important to have regular check-ups and to report any symptoms immediately, rather than waiting for your next follow-up appointment.

If the cancer does recur, you will usually be offered further treatment to remove the cancer or help control its growth. If you had radiation therapy the first time you had treatment, you may not be able to have further radiation therapy.

New drug treatments to treat the recurrence may be available through clinical trials (see page 28). Ask your doctor about recent developments and whether a clinical trial may be an option for you.

# Caring for someone with cancer

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

It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20. There is a wide range of support available to help you with the practical and emotional aspects of your caring role.

**Support services** – 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 information and resources, through the Carer Gateway. Call 1800 422 737 or visit [carergateway.gov.au](http://carergateway.gov.au).

**Support groups and programs** – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

**Carers Australia** – Carers Australia provides information and advocacy for carers. Visit [carersaustralia.com.au](http://carersaustralia.com.au).

**Cancer Council** – You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services.

▶ See our *Caring for Someone with Cancer* booklet.

# Seeking support

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

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

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

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

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



If your GP refers you to an allied health practitioner such as a dietitian, physiotherapist or lymphoedema practitioner, you may be eligible for a Medicare rebate. You may also be eligible for a Medicare rebate for some visits to a psychologist. Talk to your GP about these programs.

## Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary by location.

### Cancer Council 13 11 20



Our experienced health professionals will answer any questions you have about your situation and link you to local services (see inside back cover).

### Information resources



Cancer Council produces booklets and fact sheets on more than 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call 13 11 20 or visit your local Cancer Council website.

### Legal and financial support



If you need advice on legal or financial issues, we may be able to refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. To find out more, call Cancer Council 13 11 20.

### Practical help



Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access accommodation and transport services.

### Peer support services



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

## Useful websites

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

### Australian

Cancer Council Australia	<a href="http://cancer.org.au">cancer.org.au</a>
Cancer Council Online Community	<a href="http://cancercouncil.com.au/OC">cancercouncil.com.au/OC</a>
Cancer Council podcasts	<a href="http://cancercouncil.com.au/podcasts">cancercouncil.com.au/podcasts</a>
Cervical Screening	<a href="http://cervicalscreening.org.au">cervicalscreening.org.au</a>
Clinical Practice Guidelines	<a href="http://cancer.org.au/clinical-guidelines">cancer.org.au/clinical-guidelines</a>
Optimal Care Pathways	<a href="http://cancer.org.au/health-professionals/optimal-cancer-care-pathways">cancer.org.au/health-professionals/optimal-cancer-care-pathways</a>
Australasian Lymphology Association	<a href="http://lymphoedema.org.au">lymphoedema.org.au</a>
Australasian Menopause Society	<a href="http://menopause.org.au">menopause.org.au</a>
Australian Cervical Cancer Foundation	<a href="http://accf.org.au">accf.org.au</a>
Australia New Zealand Gynaecological Oncology Group (ANZGOG)	<a href="http://anzgog.org.au">anzgog.org.au</a>
Australian Physiotherapy Association	<a href="http://australian.physio">australian.physio</a>
Cancer Australia	<a href="http://canceraustralia.gov.au">canceraustralia.gov.au</a>
Carer Gateway	<a href="http://carergateway.gov.au">carergateway.gov.au</a>
Continence Foundation of Australia	<a href="http://continence.org.au">continence.org.au</a>
Inside Radiology	<a href="http://insideradiology.com.au">insideradiology.com.au</a>
Radiation Oncology: Targeting Cancer	<a href="http://targetingcancer.com.au">targetingcancer.com.au</a>

### International

American Cancer Society	<a href="http://cancer.org">cancer.org</a>
Cancer Research UK	<a href="http://cancerresearchuk.org">cancerresearchuk.org</a>
HysterSisters: Woman-to-Woman Hysterectomy Support	<a href="http://hystersisters.com">hystersisters.com</a>



# Question checklist

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

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## Diagnosis

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

## Treatment

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

## Side effects

- What are the risks and possible side effects of each treatment?
  - Will I have a lot of pain? What will be done about this?
  - Can I work, drive and do my normal activities while having treatment?
  - Will the treatment affect my sex life?
  - Will the treatment affect my ability to have children? What options do I have to preserve my fertility?
  - Should I change my diet or physical activity during or after treatment?
- 

## After treatment

- How often will I need check-ups after treatment? Who should I go to?
  - If the cancer returns, how will I know? What treatments could I have?
-

# Glossary

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## **abdomen (the belly)**

The part of the body between the chest and hips, which contains the stomach, bowel, bladder and kidneys. The lower abdomen (pelvic cavity) contains the uterus and other female reproductive organs.

## **adenocarcinoma**

Cancer that starts in the glandular cells of the body, such as those found in the inner surface of the cervix.

## **adenosquamous carcinoma**

A rare type of cervical cancer that features both squamous cells and glandular cells. Also called mixed carcinoma.

## **anaesthetic**

A drug that stops a person feeling pain during a medical procedure. Local and regional anaesthetics numb part of the body; a general anaesthetic causes temporary loss of consciousness.

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## **biopsy**

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

## **brachytherapy**

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

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## **cervical screening test**

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

## **cervix (neck of the uterus)**

The lower part of the uterus that connects the uterus to the vagina.

## **chemoradiation (chemoradiotherapy)**

Combined chemotherapy and radiation therapy treatment.

## **chemotherapy**

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

## **colposcopy**

Examination of the cervix, vulva and vagina from outside the body with a colposcope (a magnifying instrument).

## **cone biopsy**

The removal of a cone-shaped piece of the cervix for examination in a laboratory under a microscope.

## **CT scan**

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

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## **ectocervix**

The outer surface of the part of the cervix that opens into the vagina.

## **endocervix**

The inner surface of the cervix. Also called the cervical canal.

## **external beam radiation therapy (EBRT)**

Radiation therapy delivered to the cancer from outside the body.

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## **fallopian tubes**

Two thin tubes that form part of the female reproductive system. The fallopian tubes carry sperm from the uterus to the ovaries, and eggs from the ovaries to the uterus.

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## **glandular cell**

A type of cell found in the inner surface of the cervix (endocervix).

## **grade**

A score that describes how similar cancer cells look to normal cells and how quickly they may grow.

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## **hormones**

Chemicals in the body that send information between cells. Some hormones control growth, others control reproduction.

### **HPV test**

A test that can detect the human papillomavirus (HPV).

### **human papillomavirus (HPV)**

A group of viruses that can cause infection in the skin surface of different body areas, including the genital area. HPV causes almost all cervical cancers.

### **hysterectomy**

Surgical removal of the uterus. See also total hysterectomy.

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## **laparoscopy**

Surgery done through small cuts in the abdomen using a viewing instrument called a laparoscope. Also called keyhole surgery or minimally invasive surgery.

### **laparotomy**

A type of open surgery in which a long cut is made in the abdomen to examine and remove internal organs.

### **large loop excision of the transformation zone (LLETZ)**

A procedure to remove cervical tissue for examination and to treat some precancerous changes of the cervix. Also called loop electrosurgical excision procedure (LEEP).

### **laser surgery**

Using a laser beam to remove tissue and treat some precancerous changes of the cervix.

### **lesion**

An area of abnormal tissue.

### **liquid-based cytology (LBC) test**

A test that looks for cervical cell abnormalities if the cervical screening test finds HPV. Similar to the Pap test.

### **loop electrosurgical excision procedure (LEEP)**

See large loop excision of the transformation zone (LLETZ).

### **lymphadenectomy**

Removal of the lymph nodes from a part of the body. Also called a lymph node dissection.

### **lymphatic system**

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

### **lymph nodes**

Small, bean-shaped structures found in groups throughout the body. They help protect the body against disease and infection. Also called lymph glands.

### **lymphoedema**

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

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## **malignant**

Cancerous. Malignant cells can spread (metastasise) and eventually cause death if they cannot be treated.

### **menopause**

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

### **metastasis (plural: metastases)**

Cancer that has spread from a primary cancer in another part of the body. Also called secondary or advanced cancer.

### **MRI (magnetic resonance imaging) scan**

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

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**oestrogen**

One of the two major sex hormones in females. It is produced mainly by the ovaries; helps regulate the female reproductive cycle.

**osteoporosis**

Thinning and weakening of the bones that can lead to bone pain and fractures.

**ovary**

A female reproductive organ that contains eggs (ova). It produces the hormones oestrogen and progesterone.

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**palliative treatment**

Medical treatment for people with advanced cancer to help them manage pain and other physical and emotional symptoms.

**Pap test**

A test that can detect changes in cervical cells. Replaced by the cervical screening test.

**pelvic wall**

A structure of bone and tissue on the side of the pelvis.

**pelvis**

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

**PET-CT scan**

Positron emission tomography scan combined with a CT scan. In a PET scan, a person is injected with a small amount of radioactive solution. This makes the cancerous areas show up brighter on the scan.

**precancerous**

A term used to describe a condition that may or is likely to become cancer.

**progesterone**

One of the two major sex hormones in females. Made mostly by the ovaries; prepares the lining of the uterus (endometrium) for pregnancy. Can be produced artificially to help shrink some cancers and control symptoms.

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**radiation therapy (radiotherapy)**

The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams.

**radical hysterectomy**

An operation that removes the uterus, cervix, and soft tissue around the cervix and top of the vagina.

**recurrence**

The return of a disease after a period of improvement (remission).

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**screening**

An organised program to identify disease in people before any symptoms appear.

**sentinel lymph node biopsy**

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

**speculum**

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

**squamous cell**

A type of cell found in the outer surface of the cervix (ectocervix).

**squamous cell carcinoma (SCC)**

A cancer that starts in the squamous cells of the body, such as those found in the outer surface of the cervix.

**squamous intraepithelial lesion (SIL)**

Abnormal growth of squamous cells on the surface of the cervix.

**staging**

Performing tests to work out how far a cancer has spread.

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**targeted therapy**

Drugs that attack specific features of cancer cells to stop a cancer growing and spreading.

### testosterone

The main sex hormone in males. It is made by the testicles. A small amount is also made in the ovaries and helps increase sexual desire in females.

### total hysterectomy

The surgical removal of the uterus and cervix.

### trachelectomy

Surgery to remove the cervix and some surrounding tissue.

### transformation zone

The area in the cervix where the squamous and glandular cells meet.

### tumour

A new or abnormal growth of tissue on or in the body. A tumour may be benign (not cancer) or malignant (cancer).

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### ultrasound

A scan that uses soundwaves to create a picture of part of the body.

### urethra

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

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### uterus

A hollow muscular organ in a female's lower abdomen in which a baby grows during pregnancy. Also called the womb.

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### vagina

A muscular canal that extends from the entrance of the uterus to the vulva.

### vaginal dilator

A cylinder-shaped device used to keep the vagina open and supple.

### vaginal stenosis

Narrowing of the vagina.

### vulva

A female's external sexual organs (genitals).

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### womb

See uterus.

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## Can't find a word here?

For more cancer-related words, visit:

- [cancercouncil.com.au/words](https://cancercouncil.com.au/words)
  - [cancervic.org.au/glossary](https://cancervic.org.au/glossary)
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## References

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2. Cancer Council Australia Cervical Cancer Screening Guidelines Working Party, *National Cervical Screening Program: Guidelines for the management of screen-detected abnormalities, screening in specific populations and investigation of abnormal vaginal bleeding*, Cancer Council Australia, Sydney, viewed 13 July 2023, available from: [cancer.org.au/clinical-guidelines/cervical-cancer/cervical-cancer-screening](https://cancer.org.au/clinical-guidelines/cervical-cancer/cervical-cancer-screening).
3. Australian Institute of Health and Welfare (AIHW), *Cancer data in Australia 2023*, viewed 3 October 2023, available from: [aihw.gov.au/reports/cancer/cancer-data-in-australia](https://aihw.gov.au/reports/cancer/cancer-data-in-australia).



# How you can help

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

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

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

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

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

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

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



# Cancer Council

## 13 11 20

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

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

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our experienced health professionals 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.



If you need information in a language other than English, an interpreting service is available. Call 131 450.



If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. [accesshub.gov.au](http://accesshub.gov.au)

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

For information & support  
on cancer-related issues,  
call **Cancer Council 13 11 20**

## Visit your local Cancer Council website

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**Cancer Council ACT**  
[actcancer.org](http://actcancer.org)

**Cancer Council Queensland**  
[cancerqld.org.au](http://cancerqld.org.au)

**Cancer Council Victoria**  
[cancervic.org.au](http://cancervic.org.au)

**Cancer Council NSW**  
[cancercouncil.com.au](http://cancercouncil.com.au)

**Cancer Council SA**  
[cancersa.org.au](http://cancersa.org.au)

**Cancer Council WA**  
[cancerwa.asn.au](http://cancerwa.asn.au)

**Cancer Council NT**  
[cancer.org.au/nt](http://cancer.org.au/nt)

**Cancer Council Tasmania**  
[cancer.org.au/tas](http://cancer.org.au/tas)

**Cancer Council Australia**  
[cancer.org.au](http://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.*

