

# **Understanding Cervical Cancer**

A guide for women with cancer, their families and friends

Cancer information

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131120

#### **Understanding Cervical Cancer**

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Understanding Cervical Cancer is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.

Editor: Jenny Mothoneos. Designer: Paula Marchant. Printer: SOS Print + Media Group.

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The illustration on page 7 has been adapted from *An abnormal Pap smear result – what this means for you* (National Cervical Screening Program, 2006). Used by permission of the Australian Government.

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



#### **Cancer Council Australia**

Level 14, 477 Pitt Street, Sydney NSW 2000

**Telephone** 02 8063 4100 **Facsimile** 02 8063 4101 **Email** info@cancer.org.au **Website** cancer.org.au ABN 91 130 793 725

# Introduction

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

Many women feel shocked and upset when told they 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, we hope this information will answer some of your questions and help you think about other questions to ask your treatment team.

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

#### How this booklet was developed

This information was developed with help from a range of health professionals and women affected by cervical cancer. It is based on international clinical practice guidelines for cervical cancer.<sup>1</sup>

If you or your family have any questions, call Cancer Council 13 11 20. We can send you more information and connect you with support services in your area. Turn to the last page of this book for more details.



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# **What is cancer?**

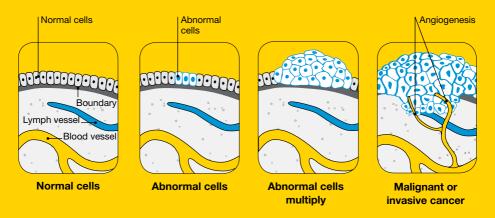
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

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

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

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

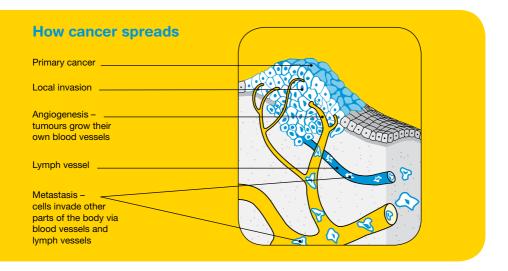
#### How cancer starts



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

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

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





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

Also called the neck of the uterus, the cervix connects the uterus to the vagina. It has an outer surface that opens into the vagina and an inner surface that faces into the uterus.

The functions of the cervix include:

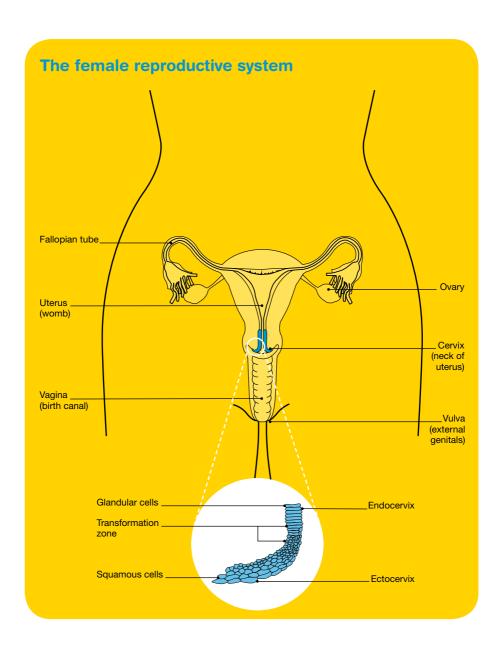
- producing moisture to lubricate the vagina, which keeps the vagina healthy
- producing mucus that helps sperm travel up the fallopian tube to fertilise an egg that has been released from the ovary
- holding a developing baby in the uterus during pregnancy
- widening to enable a baby to be born via the vagina.

The cervix is covered by two kinds of cells:

**Squamous cells** – flat, thin cells that cover the outer surface of the part of the cervix that opens into the vagina (ectocervix). Cancer of the squamous cells is called squamous cell carcinoma (see page 10).

**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 10).

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



#### **Cervical cell changes**

Sometimes the squamous cells and glandular cells in the cervix start to change and no longer appear normal when they are examined under a microscope. These early cell changes may be precancerous. This means there is a lesion (area of abnormal tissue) that is not cancer but may lead to cancer.

Cervical cell changes are often caused by certain types of the human papillomavirus (HPV).

There are two main types of cervical cell changes:

**Abnormal squamous cells** – These are called squamous intraepithelial lesions (SIL), and they can be classified as either low-grade (LSIL) or high-grade (HSIL).

SIL used to be called cervical intraepithelial neoplasia (CIN) and was graded according to how deep the abnormal cells were within the surface of the cervix.

- LSIL, previously graded as CIN 1, usually disappear without treatment.
- HSIL, previously graded as CIN 2 or CIN 3, are precancerous. This means that although they do not usually cause symptoms, high-grade abnormalities have the potential to develop into early cervical cancer over about 10–15 years if they are not detected and treated. HSIL will require treatment (see *Finding and treating precancerous abnormalities*, pages 19–21).

Only some women with precancerous changes of the cervix will develop cervical cancer.

**Abnormal glandular cells** – These abnormalities always require further testing, as glandular cell changes can be harder to interpret than squamous cell changes. Adenocarcinoma refers to glandular cells that are cancerous.

These cervical cell changes may be found during a routine screening test (see pages 16–17). For most women, mild cervical cell changes will go away on their own without treatment. Moderate to severe cell changes can be treated before they develop into cervical cancer. Your doctor will recommend one of the following options depending on the grade of the changes:

- a follow-up test in 6–12 months to monitor the cells
- a colposcopy to have a magnified look at the cervix using an instrument called a colposcope (see pages 17–18)
- a biopsy taken from the cervix at the time of the colposcopy (see page 18).



### Q: What is cervical cancer?

A: Cervical cancer is the growth of abnormal cells in the lining of the cervix.

Cancer most commonly begins in the area of the cervix called the transformation zone (see page 6), but it may spread to tissues around the cervix, such as the vagina, or to other parts of the body, such as the lungs or liver.

# Q: What types are there?

A: There are two main types of cervical cancer, which are named after the cells they start in:

**Squamous cell carcinoma (SCC)** – the most common type, accounting for about 7 out of 10 (70%) cases.

Adenocarcinoma – a less common type (about 25% of 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 recognise.

A small number of cervical cancers 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 and cervical sarcoma.

### Q: How common is it?

A: About 800 women in Australia are diagnosed with cervical cancer every year. Cervical cancer accounts for about 2 out of 100 of all cancers diagnosed in women. It is more common in women over 40, but it can occur at any age.<sup>2,3</sup>
About one in 200 women will develop cervical cancer before the age of 75.

The incidence of cervical cancer in Australia has decreased significantly since a national screening program was introduced in the 1990s.

# Q: What are the symptoms?

A: In its early stages, cervical cancer usually has no symptoms. The only way to know if there are abnormal cells in the cervix, which may develop into cervical cancer, is to have a cervical screening test (see pages 16–17).

If symptoms are present, they usually include:

- vaginal bleeding between periods, after menopause or during or after sexual intercourse
- pain during sexual intercourse
- an unusual vaginal discharge
- heavier periods or periods that last longer than usual.

These symptoms can also be caused by other conditions. See your general practitioner (GP) if you are worried or the symptoms are ongoing.

# Q: What are the causes and risk factors?

A: Most cases of cervical cancer are caused by an infection called human papillomavirus (HPV). There are also other known risk factors (see pages 13–14).

**Infection with HPV** – Human papillomavirus is the name for a group of viruses. HPV is a common infection that affects the surface of different areas of the body, such as the cervix, vagina and skin.

There are more than 100 different types of HPV, including more than 40 types of genital HPV. Some other types of HPV cause common warts on the hands and feet.

Genital HPV is usually spread via the skin during sexual contact. About four out of five people will become infected with genital HPV at some time in their lives.

Most people will not be aware they have HPV as it is usually harmless and doesn't cause symptoms. In most women, the virus is cleared quickly by the immune system and no treatment is needed.

Approximately 15 types of genital HPV cause cervical cancer. Screening tests are used to detect these types of HPV or the precancerous cell changes caused by the virus. See pages 16–17 for more information on screening tests. There is also a vaccination against HPV (see box opposite).

#### **National HPV Vaccination Program**

The HPV vaccine provides protection against two strains of HPV, 16 and 18, that are known to cause 70–80% of cervical cancers. The vaccine also offers some protection against other less common cancers associated with HPV, including vaginal, vulvar and anal cancers.

As part of the National HPV Vaccination Program, the vaccine is free for girls and boys aged 12–13. (The vaccine helps to protect males against penile and anal cancers.)

People who are already sexually active may still benefit from the HPV vaccine. Ask your GP for information.

The HPV vaccine cannot be given to treat precancerous changes or cervical cancer.

If you've been vaccinated, you will still need regular screening tests as the HPV vaccine does not provide protection against all types of HPV.

For more information, visit **hpvvaccine.org.au**.

**Smoking and passive smoking** – Chemicals in tobacco can damage the cells of the cervix, making cancer more likely to develop in women with HPV.

Having a weakened immune system – The immune system helps rid the body of HPV. Women with a weakened immune system are at increased risk of developing cervical cancer. This includes women with the human immunodeficiency virus (HIV) and women who take medicines that lower their immunity. Ask your doctor if this applies to you.

#### Long-term use of oral contraceptive (the pill) -

Research has shown that women who have taken the pill for five years or more are at increased risk of developing cervical cancer. The reason for this is not clear. However, the risk is small and the pill can also help protect against other types of cancer, such as uterine and ovarian cancers. Talk to your doctor if you are concerned.

**Exposure to diethylstilbestrol (DES)** – This is a synthetic (artificial) form of the female hormone oestrogen. DES was prescribed to pregnant women from the 1940s to the early 1970s to prevent miscarriage. Studies have shown that the daughters of women who took DES have a small but increased risk of developing a rare type of cervical adenocarcinoma.

# Q: Which health professionals will I see?

A: Your GP will arrange the first tests to assess your symptoms or investigate the results of an abnormal screening test. If these initial tests do not rule out cancer, you will be referred to a gynaecologist or gynaecological oncologist for more tests and treatment.

You will be cared for by a range of health professionals who are part of a multidisciplinary team (MDT). The table on the following page describes the roles of the people who may be in your MDT.

Health professional	Role
gynaecologist*	specialises in treating diseases of the female reproductive system
gynaecological oncologist*	treats women with cancers of the reproductive system, e.g. cervical, ovarian, uterine, vulvar and vaginal cancers
radiation oncologist*	prescribes and coordinates the course of radiotherapy
medical oncologist*	prescribes and coordinates the course of chemotherapy
radiologist*	reads and interprets x-rays and diagnostic scans, e.g. CT, MRI and PET scans
cancer nurse coordinator, cancer care coordinator	support patients and families throughout treatment and liaise with other members of the treatment team
nurses	care for you during and after surgery; help administer drugs; and provide care, information and support throughout treatment
dietitian	recommends an eating plan to follow during treatment and recovery
social worker, psychologist	link you to support services; help with emotional and practical problems associated with cancer and treatment
physiotherapist, occupational therapist	help with any physical or practical problems associated with cancer and treatment

<sup>\*</sup> Specialist doctor



If your screening test results (see below) suggest that you have a higher risk of developing cervical cancer, or you have symptoms of cancer, you will be referred to a specialist for tests to confirm the diagnosis of precancerous changes or cervical cancer.

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.

# **Screening test for cervical cancer**

Screening is the process of looking for cancer or precancerous changes in people who don't have any symptoms.

For several decades, the Pap test (also called a Pap smear) has been used as a screening test for cervical cancer. While this has helped decrease cervical cancer significantly, scientific evidence has found that screening women for HPV – the virus that causes cervical cancer – is a more effective way of preventing cervical cancer.

In December 2017, a Cervical Screening Test will replace the Pap test as part of the National Cervical Screening Program. The new Cervical Screening Test will detect cancer-causing HPV types in a sample of cells taken from the cervix.

During both the old Pap test and the new Cervical Screening Test, the doctor gently inserts an instrument called a speculum into the vagina to get a clear view of the cervix. The doctor uses a brush or



The current screening program recommends two-yearly Pap tests for women aged 18–69 who are or have ever been sexually active. Under the new program, women aged 25–74 will be tested for HPV every five years.

spatula to remove some cells from the surface of the cervix. This can feel slightly uncomfortable, but it usually takes only a minute or two. The sample is placed into liquid in a small container (a vial) and then sent to a laboratory for further testing.

The results of the screening test are used to predict your level of risk for precancerous cell changes or cervical cancer. If the results show a higher risk, your GP will refer you to a specialist (gynaecologist) to discuss whether you need further tests or treatment and how you will be monitored. Monitoring may include a follow up test (usually for HPV) or more frequent screening tests in the future.

For more information about screening tests, call Cancer Council 13 11 20 or visit cancerscreening.gov.au.

# Colposcopy

A colposcopy is a way of looking closely at the cervix to help see where abnormal or changed cells are and what they look like. While you are lying on your back, the doctor will use an instrument called a speculum to open up the vagina so they can look at your cervix through a colposcope. The colposcope is a magnifying instrument that has a light and looks like a pair of binoculars on a large stand. It doesn't touch you or go inside your body. The doctor may coat your cervix and vagina with a fluid to highlight any abnormal areas. The colposcopy takes 10–15 minutes.

**Side effects of a colposcopy** – You may feel some mild discomfort during the procedure.

# **Biopsy**

A biopsy is when the doctor removes some tissue from the surface of the cervix and sends it to a laboratory for examination under a microscope. A biopsy may be done during the colposcopy. During a biopsy, you may feel uncomfortable for a short time while the tissue sample is taken.

You will be able to go home once the colposcopy and biopsy are over. The results will be available in about a week.

Side effects of a colposcopy with biopsy – After the procedure, it is common to experience cramping that feels similar to menstrual pain. You can ask for medicine to relieve any pain. You may also have some light bleeding or other vaginal discharge for a few hours.

To allow the cervix to heal and to reduce the risk of infection, your doctor will probably advise you not to have sexual intercourse or use tampons for 2–3 days after a biopsy.

# Finding and treating precancerous abnormalities

#### Large loop excision of the transformation zone (LLETZ) -

Also called loop electrosurgical excision procedure (LEEP), this is the most common way of removing cervical tissue for examination and treating precancerous changes of the cervix. The abnormal tissue is removed using a thin wire loop that is heated electrically. Sometimes the doctor can remove all visible abnormal cells.

A LLETZ is usually done under a local anaesthetic in the doctor's office or, sometimes, under a general anaesthetic in hospital. It takes about 10 minutes. Sometimes it is done at the same time as a colposcopy, but this is uncommon (see pages 17–18). The tissue sample will be sent to a laboratory for examination under a microscope. The results will be available in about a week.

Side effects of a LLETZ or LEEP – After a LLETZ or LEEP, you may have some vaginal bleeding and cramping. This will usually ease in a few days, but you may notice some spotting for 3–4 weeks. If the bleeding lasts longer than 3–4 weeks, becomes heavy or has a bad odour, see your doctor. To allow your cervix to heal and to prevent infection, you should not have sexual intercourse or use tampons for 4–6 weeks after the procedure.

After a LLETZ or LEEP procedure you can still become pregnant, however the procedure may slightly increase your risk of having the baby prematurely. Talk to your doctor before the procedure if you are concerned.

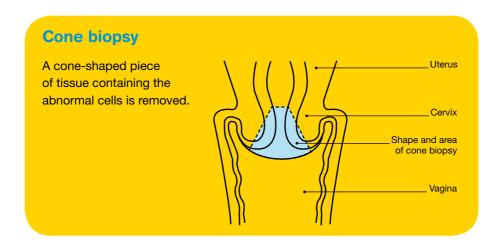
**Cone biopsy** – This procedure is similar to a LLETZ, and is used when there are abnormal glandular cells in the cervix or when early-stage cancer is suspected. In some cases, it is also used to treat very small, early-stage cancers.

A surgical knife (scalpel) is used to remove a cone-shaped piece of tissue from the cervix. The cone biopsy is usually done under a general anaesthetic and involves a day or overnight stay in hospital. Results are usually available in a week.

Side effects of a cone biopsy – You may have some light bleeding or cramping for a few days after the cone biopsy. 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 a bad odour, see your doctor. Some women notice a dark brown discharge for a few weeks, but this will ease.

To allow 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.

A cone biopsy may weaken the cervix. If you would like to become pregnant in the future, talk to your doctor before the procedure. It is usually still possible to become pregnant, but you may be at a higher risk of having a miscarriage or having the baby prematurely. Some women who become pregnant after a cone biopsy have stitches inserted into the cervix to strengthen it. These stitches are usually removed before the baby is born.



**Laser surgery** – This procedure uses a laser beam in place of a knife to burn away the abnormal cells or remove pieces of tissue for further study.

A laser beam is a strong, hot beam of light. The laser beam is directed through the vagina and the procedure is done under local anaesthetic. Laser surgery takes about 10–15 minutes, and you can go home as soon as the treatment is over.

Laser surgery is just as effective as LLETZ and may be a better option if the precancerous cells extend into the wall of the vagina or if the lesion on the cervix is very large.

**Side effects of laser surgery** – These are similar to those of LLETZ. Most women are able to return to normal activity within 2–3 days after laser surgery.

#### **Further tests**

If any of the tests described on pages 17–21 show that you have cervical cancer, you may need to have further tests to help the doctor work out whether the cancer has spread to other parts of your body. This is called staging (see page 25). You may have one or more of the tests described on the following pages.

#### Blood test and chest x-ray

You may have a blood test to check your general health and how well your kidneys and liver are working. You may also have an x-ray of your chest so the doctor can examine your lungs for signs of cancer.

#### **Imaging scans**

**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, three-dimensional picture. The scan can show whether the cancer has spread to lymph nodes in the abdomen or pelvis or to other organs in the body.

Before the scan, you may be given a drink or 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.

For the scan, you will need to lie still on a 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.



The dye used in a CT scan usually contains iodine. If you have had an allergic reaction to iodine or dyes, let the person performing the scan know in advance. You should also tell them if you're diabetic, have kidney disease or are pregnant.

MRI scan – An MRI (magnetic resonance imaging) scan uses a powerful magnet and radio waves to build up 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 interfere with an MRI.

During the scan, you will lie on a treatment table that slides into a large metal cylinder that is open at both ends. The noisy, narrow machine can make some people feel anxious or claustrophobic. If you think you may become distressed, mention it beforehand to your medical team. You may be given medication to help you relax, and you will usually be offered headphones or earplugs. MRI scans usually take 30–90 minutes.

**PET scan** – Before a PET (positron emission tomography) scan, you will be injected with a glucose (sugar) solution containing some radioactive material. You will be asked to lie still for 30–60 minutes while the solution spreads throughout your body.

Cancer cells show up brighter on the scan because they absorb more of the glucose solution than normal cells do. It may take a few hours to prepare for a PET scan, but the scan itself usually takes about 30 minutes.

#### **Examination under anaesthetic**

Another way for the doctor to check whether the cancer has spread is 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 take a biopsy (see page 18) and send the sample to a laboratory for examination.

**Pelvic examination** – The doctor will put a speculum into your vagina to check for cancer.

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

**Bladder** – A thin tube with a lens and a light called a cystoscope will be inserted into your urethra (the tube that carries urine from the bladder to the outside of the body) to examine your bladder.

**Rectum** – The doctor will use a gloved 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 flexible tube with a camera attached.

You will most likely be able to go home from hospital on the same day as the examination under anaesthetic. You may have some light bleeding and cramping for a few days afterwards. Your doctor will talk to you about side effects you may experience.

# Staging cervical cancer

The tests described on pages 17–24 help the doctors decide 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.

In Australia, cervical cancer is usually staged using the International Federation of Gynecology and Obstetrics (FIGO) staging system. It is often used for other cancers of the female reproductive organs. FIGO divides cervical cancer into four stages. Each stage is further divided into several sub-stages.

Cervical cancer staging		
Stage I	Cancer is found only in the tissue of the cervix.	
Stage II	Cancer has spread outside the cervix to the upper two-thirds of the vagina or other tissue next to the cervix (parametrium).	
Stage III	Cancer has spread to the tissue on the side of the pelvis (pelvic sidewall) and/or the lower third of the vagina.	
Stage IV	Cancer has spread to the bladder or rectum, or beyond the pelvis to the lungs, liver or bones.	

# **Prognosis**

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your doctor, but it is not possible for any doctor to predict the exact course of the disease.

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. If cancer is found after it has spread to other parts of the body (referred to as an advanced stage), the prognosis is worse and there is a higher chance of recurrence.

To work out your prognosis, your doctor will consider:

- your test results
- the type of cervical cancer you have
- the rate and depth of tumour growth
- other factors such as your age, fitness and medical history.



#### **Key points**

- Cervical cell changes may be detected by a screening test. Low-grade changes usually go away on their own; highgrade changes will require treatment.
- During a colposcopy, the doctor examines the cervix and vagina using a magnifying instrument called a colposcope.
- A biopsy is when a sample of tissue is removed from the cervix to be examined under a microscope.
- An examination of cervical tissue will show whether the cell changes are cancerous.
- Precancerous changes can be checked and treated in several ways including large loop excision of the transformation zone (LLETZ)/ loop electrosurgical excision procedure (LEEP); cone biopsy or laser surgery.

- Further tests or scans, including CT, MRI and PET scans, may be required to check whether the cancer has spread to other parts of the body.
- Staging describes how far the cancer has spread in the body. Knowing the stage of the cancer allows the doctor to recommend the best treatment for you.
- Prognosis is the expected outcome of a disease. If cervical cancer is diagnosed, early, it can usually be treated successfully.
- You will see many health professionals, including gynaecological oncologist, radiation oncologist and medical oncologist as necessary, who work together as a multidisciplinary team.

# Making treatment decisions

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

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

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

# **Talking with doctors**

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

If you are confused or want clarification, you can ask for further explanation – see page 62 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

# A second opinion

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

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

# Taking part in a clinical trial

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

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

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



The most common treatment for cervical cancer is surgery and/or a combination of chemotherapy and radiotherapy (chemoradiotherapy). When cervical cancer has spread beyond the cervix, targeted therapy may also be used.

Your medical team will recommend treatment based on:

- the results of your tests
- the location of the cancer and whether it has spread
- your age and general health
- whether you would like to have children in the future. 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 pages 52–53.

# Surgery

Surgery is usually recommended for women who have a tumour that is confined to the cervix. The type of surgery you have will depend on how far within the cervix the cancer has spread.

The main type of surgery is called a hysterectomy. A hysterectomy is an operation to remove the uterus (womb) and sometimes other organs of the reproductive system. There are different types of hysterectomy, which are done under a general anaesthetic. See box on the opposite page.

A hysterectomy may also involve removing both ovaries and fallopian tubes (a bilateral salpingo-oophorectomy) and some pelvic lymph nodes (see page 32).

### **Types of hysterectomies**



Total hysterectomy
The uterus and cervix

are removed.



Radical hysterectomy
The uterus, cervix, soft tissue
around the cervix, top of the
vagina, ovaries and fallopian
tubes are removed.

## How the surgery is done

The hysterectomy can be done in two different ways. Your surgeon will talk to you about the most suitable method of surgery.

**Open surgery (laparotomy)** – This may involve an up and down (vertical) or crossways (transverse) cut on your tummy. Open surgery usually means a longer hospital stay and slower recovery.

**Keyhole surgery (laparoscopy)** – This technique is becoming more common. This involves 3–4 small cuts in your abdomen, and usually means a shorter hospital stay and faster recovery.

#### **Bilateral salpingo-oophorectomy**

Depending on how far the cancer has spread, and your age, you may also have the ovaries and fallopian tubes removed. This is called a bilateral salpingo-oophorectomy. With your consent, they will be taken out at the same time as the hysterectomy.

For some women, the ovaries will be left in place to prevent the onset of early menopause. Ask your doctor if this might be an option for you.

#### **Trachelectomy**

A trachelectomy involves removing part of the cervix and some surrounding tissue. The uterus is left in place. This is not a common procedure, but it may be used in young women with early-stage cancer (e.g. a cancer smaller than 2 cm) who would like the option of being able to have children in the future.

#### **Removing lymph nodes**

During a hysterectomy, your doctor may decide to remove some of the lymph nodes in the pelvic and/or abdominal area to see if the cancer has spread beyond the cervix. This is called a lymphadenectomy or lymph node dissection.

Before a lymphadenectomy, some women with early cervical cancer may have a sentinel lymph node biopsy. This test helps identify the lymph node most likely to be the first to have cancer spread to it. You will have an anaesthetic and an injection of radioactive dye near the site of the cancer. They dye will flow to this node, and the surgeon will remove it and determine whether

it's necessary to remove more lymph nodes. A sentinel lymph node biopsy can help the surgeon avoid removing all of the pelvic lymph nodes, which reduces the risk of lymphoedema (see page 35). If cancer is found in the lymph nodes, your doctor may recommend you have additional treatment, such as radiotherapy (see pages 37–41).

#### What to expect after surgery

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

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

After the catheter is removed, the nurses will perform a test to check that your bladder is emptying properly. This is done by measuring the amount of urine you pass each time you go to the toilet, then using an ultrasound scan to check that your bladder is empty. It is a quick, painless test 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 relief medicine through a drip (intravenously) or via a catheter inserted in the spaces in the spine (epidural) or as a tablet. If you still have pain, your doctor or nurse can change your medicine to one that is more effective.

Moving your legs – While you are in bed, you may have to wear "calf compressors" around your lower legs. These act like a constant massage to help the blood in your legs circulate and prevent deep vein thrombosis (DVT). You will be encouraged to get out of bed and walk around as soon as you can.

Recovery time – You will spend up to a week in hospital after a hysterectomy, depending on the type of surgery you have. The recovery time depends on the type of surgery and your fitness. You will be able to go home when the medical team is satisfied with your recovery and the results of your bladder function tests. The illustration on page 36 provides tips for recovering from surgery once you get home from hospital.



#### Anne's story

After the operation, I had radiation therapy daily for six weeks. The treatment made me feel very tired and also affected my bowels and bladder.

But for me, the hardest part of cancer and treatment is the ongoing emotional side of it. The physicality of having treatment is one thing, but the emotional roller-coaster was the worst part.

My doctors have told me to be vigilant about everything abnormal, such as any vaginal bleeding or pain. Even many years later, there is a lot of uncertainty.

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.

## **Side effects of surgery**

After surgery for cervical cancer, you may experience some of the following side effects. For more information about the side effects listed below, see the *Managing side effects* chapter (pages 46–54).

**Problems with bladder or bowel function** – Because some of the nerves to the bladder are removed, you may feel the sensation of not being able to empty your bladder completely, or emptying your bladder or bowel too slowly. These problems improve with time. Some women experience accidental leakage of urine after surgery. This is called urinary incontinence.

**Lymphoedema** – If you have a lymphadenectomy, you may develop lymphoedema, which is excess tissue fluid in the legs or pubic area. Symptoms of lymphoedema may appear straightaway or years after surgery.

**Menopause** – If you have a bilateral salpingo-oophorectomy and have not been through menopause, the removal of your ovaries will cause sudden menopause. This will affect your fertility.

**Impact on sexuality –** The physical and emotional changes you experience after surgery may affect how you feel about sex, but surgery doesn't change the ability to have sex or feel pleasure during sexual intercourse.

**Internal scar tissue (adhesions)** – Tissues in the body may stick together. In some rare cases, adhesions to the bowel or bladder may need to be treated with further surgery.

## What to expect when you get home

Most women say they feel better within six weeks of surgery, but recovery may take longer.



## Lifting

Avoid carrying heavy shopping bags, doing laundry or vacuuming for at least a month. The length of time will depend on the type of surgery you have.



#### Rest

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



#### Exercise

Walk regularly if your doctors say it is okay to do so. Speak to your doctor about when it is suitable to start more vigorous exercise.



#### **Driving**

Avoid driving for a few weeks. Check with your car insurer whether there are any exclusions on your policy regarding major surgery and driving.



#### Diet

Drink plenty of water and eat lots of fresh vegetables and fruit to avoid becoming constipated.

#### Sex

If you've had open surgery, you'll need to avoid sexual intercourse for at least 4–6 weeks to give the vaginal wound time to heal properly.

## **Radiotherapy**

Radiotherapy, also called radiation therapy, uses radiation such as x-rays to kill cancer cells or injure them so they cannot multiply. The radiation is targeted at parts of the body with cancer, and treatment is carefully planned to do as little harm as possible to healthy body tissues.

Most women who have radiotherapy for cervical cancer will have both external and internal radiotherapy.

Women with cervical cancer that has spread to the tissues or lymph nodes surrounding the cervix will usually have chemoradiotherapy to reduce the chance of the cancer coming back. See box below.

## Chemoradiotherapy

Chemoradiotherapy means having radiotherapy and chemotherapy together.
The chemotherapy drugs can make the cancer cells more sensitive to radiotherapy.

If you are treated with chemoradiotherapy, you will usually receive lowdose chemotherapy once a week a few hours before the radiotherapy appointment. The side effects of treatment include fatigue, diarrhoea, needing to pass urine more often or in a hurry, cystitis, dry and itchy skin in the treatment area, nausea, and a lowered number of white blood cells, which means you have an increased risk of infection. Talk to your treatment team about ways to manage the side effects of chemoradiotherapy.

## **External radiotherapy**

In external radiotherapy, a machine produces radiation (such as x-rays) and directs it to the cervix, lymph nodes and other organs that need treatment. The initial planning session will include a CT scan to work out where to direct the radiation beams. This may take up to 45 minutes, but the actual treatment takes only a few minutes each time.

You will probably have external radiotherapy as daily treatments, Monday to Friday, over 4–6 weeks as an outpatient. You will lie on a table under the radiotherapy machine. Before the machine is turned on, the radiation therapist will leave the room, but they will be able to talk to you through an intercom and they will watch you on a screen while you have treatment. The treatment itself is painless and will not make you radioactive.

## **Internal radiotherapy**

Internal radiotherapy is known as brachytherapy. For cervical cancer a radiation source is placed inside the body next to the cancer in the cervix. This reduces the effect radiation has on nearby organs such as the bowel and bladder.

The most common type of brachytherapy for cervical cancer is high-dose rate (HDR). Less commonly, pulsed-dose-rate (PDR) is offered. Ask your radiation oncologist for more details on PDR.

**During treatment** – At each HDR session, you will be given a general or spinal anaesthetic. Your radiation oncologist will examine you to choose a suitable applicator for your situation.

Applicators are used to deliver the radiation source to the cancer and they are available in different sizes. The applicator is placed through the cervix and into your uterus using ultrasound to make sure it is in the right place.

To hold the applicator in place, you may have gauze padding put into your vagina, and a stitch or two in the area between the vulva and the anus (perineum). 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 location and size of the cancer. This scan will help your doctor deliver the brachytherapy to the correct area. Once your doctor is happy with the treatment plan, the radiation source will be placed into the applicator for 10–20 minutes. If you have a general anaesthetic, this will happen while you are asleep.

If you've had surgery to remove the cervix and uterus (hysterectomy), your doctor may want to deliver some extra radiation to the top of the vagina. An applicator will be placed inside your vagina. You will not need to have a general anaesthetic or gauze padding.

At the end of each treatment, the radiation source is removed from the applicator. You will not be radioactive and you can safely interact with other people.

**After treatment** – The applicator is removed between treatments. You will probably have 3–4 sessions over 2–4 weeks.

## **Side effects of radiotherapy**

The side effects you experience vary depending on the dose of the radiotherapy and the length of the treatment. Many will be short-term side effects that occur during treatment or within a few weeks of finishing. Some side effects may be late effects, not appearing until some time after treatment.

**Tiredness** – During radiotherapy, your body uses a lot of energy dealing with the effects of radiation on healthy cells. Travelling to treatment can also be tiring. Tiredness usually builds up slowly during the course of the treatment, particularly towards the end. It may last for weeks after treatment ends.

**Hair loss** – If radiotherapy is aimed at your pelvis area, you may lose your pubic hair. This hair may grow back after the treatment ends, but it will usually be thinner. Radiotherapy will not cause you to lose hair from your head or other parts of your body.

**Diarrhoea** – Radiation can irritate the bowel and bowel motions may be more frequent or urgent or may become loose (diarrhoea). For suggestions on managing diarrhoea, see page 46.

Bladder problems – Radiation passes through the bladder to reach the treatment area, which can cause a burning feeling when passing urine (cystitis) and an urge to urinate more often (urinary urgency). You may need a urine test to rule out infection, so talk to your doctor about your symptoms. Drinking water and taking an over-the-counter urinary alkaliser (e.g. Ural) can help relieve symptoms of cystitis. You may also be given pain relief.

**Skin problems** – Radiotherapy may make the skin in the treatment area dry and itchy. Your skin may look red and peel. The treatment team will recommend creams to use to make you more comfortable.

**Swelling of the legs** – If the pelvic lymph nodes are treated with radiotherapy, this may lead to swelling in the leg. This is known as lymphoedema. See pages 48–49 for more details.

**Menopause** – If your ovaries have not been removed, radiotherapy will cause them to stop working permanently, causing menopause. See pages 49–50 for more information.

Narrowing of the vagina – Radiotherapy may cause internal scar tissue to form, which sometimes shortens and narrows the vagina. This is called vaginal stenosis and can be prevented or reduced with a vaginal dilator. See page 52 for suggestions on coping with vaginal side effects.

**Pelvic fracture** – Radiotherapy to the pelvic area can weaken the bones and cause a fracture. Hip fractures are the most common. This may not occur for 2–4 years after treatment.

For more information about radiotherapy and its side effects, call Cancer Council **13 11 20** for a free copy of *Understanding Radiotherapy*, or download a digital version from your local Cancer Council website.



## **Chemotherapy**

Chemotherapy is the use of drugs to kill or slow the growth of cancer cells. The aim is to destroy cancer cells while causing the least possible damage to healthy cells. However, some healthy cells in the body, such as hair and bone marrow cells, may be affected.

The drugs are usually given through a vein (intravenously). You may need to stay overnight in hospital, or you may be treated as an outpatient. The number of chemotherapy sessions you have will depend on the type of cervical cancer and any other treatment you may be having. If you have chemotherapy without radiotherapy, you will probably have treatment up to six times, and these will be scheduled every 3–4 weeks over several months.

## **Side effects of chemotherapy**

The side effects of chemotherapy vary according to the drugs given, how often you have treatment, and your general health and fitness. They will also depend on if you have chemotherapy alone, or as part of chemoradiotherapy. You may experience nausea or vomiting, feel tired, or lose some hair from your body or head. Chemotherapy can also cause temporary or permanent menopause (see pages 49–50).

Chemotherapy may also reduce the number of blood cells in your body. Depending on the type of blood cells affected, you may feel very tired and be more prone to infections, such as colds. If your temperature rises to 38°C or above, seek urgent medical attention. You will have regular blood tests during treatment to monitor the levels of blood cells.

Most side effects are temporary, and your treatment team can help you to prevent or reduce them. Cancer Council's booklet *Understanding Chemotherapy* has more information. Call 13 11 20 or download a digital version from your local website.

## **Targeted therapy**

A new type of drug treatment known as targeted therapy is being used to treat some women with cervical cancer that has spread to other parts of the body or has come back and cannot be treated by surgery or radiotherapy.

Cancers develop their own blood vessels to help them grow. This process is called angiogenesis. Some targeted therapy drugs are designed to stop this process. These are known as angiogenesis inhibitors.

Bevacizumab (Avastin) is an angiogenesis inhibitor that can be used to treat advanced cervical cancer. It is given with chemotherapy every three weeks as an infusion into a vein. The number of infusions you receive will depend on how you respond to treatment. For more information about targeted therapies, talk with your medical team.

## Side effects of targeted therapy

The most common side effects experienced by women taking bevacizumab include high blood pressure, feeling tired and loss of appetite. Less common side effects include bleeding and wound healing problems.

## **Palliative treatment**

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

Many people think that palliative treatment is for people at the end of their life: however it may be beneficial for people at any stage of advanced cervical cancer. It is about living 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 radiotherapy, chemotherapy or other medicines such as hormone treatment.

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

For more information or free booklets about *Understanding Palliative Care* or *Living with Advanced Cancer*, call 13 11 20 or download digital versions from your local Cancer Council website.



## **Key points**

- Surgery is a common treatment for cervical cancer.
   The type of surgery you have will depend on how far the cancer has spread.
- A hysterectomy is an operation to remove the cervix and uterus.
- Some women also need a bilateral salpingooophorectomy, which is an operation to remove the ovaries and fallopian tubes.
- A trachelectomy removes only the cervix. This is not a common procedure and is used more often for young women with early-stage cervical cancer.
- Sometimes the lymph nodes in the pelvic region are removed. This is called a lymphadenectomy.
- Radiotherapy uses x-rays to kill or damage cancer

- cells. You may have external or internal radiotherapy (brachytherapy), or both.
- Chemotherapy is the use of drugs to kill or damage cancer cells. Chemotherapy is usually given intravenously every 3–4 weeks, or weekly if combined with radiotherapy.
- Chemoradiotherapy
   is a combination of
   chemotherapy and
   radiotherapy. It is usually
   given to treat more advanced
   cervical cancer.
- Targeted therapy drugs work by stopping the cancer developing new blood vessels. The most commonly used drug for cervical cancer that has spread is bevacizumab.
- Palliative treatment can treat symptoms and side effects at any stage of advanced cancer.



## Managing side effects

It may take time to recover from treatment for cervical cancer. You may find the cancer affects you physically and emotionally.

Side effects of treatment vary from person to person. Some women may experience a few side effects; others don't experience any side effects. Side effects may last from several weeks to a few months or, less commonly, many years or permanently. Fortunately, there are ways to reduce or manage the discomfort that side effects cause.

## **Bowel changes**

After surgery or radiotherapy, some women notice changes in their bowel habits. You may experience constipation or diarrhoea, or feel pain in your abdomen. The following tips may help.

- Drink peppermint or chamomile tea to reduce abdominal or wind pain.
- Drink plenty of liquids (except alcohol and caffeinated drinks) to replace fluids lost through diarrhoea or to help soften stools if you are constipated.
- Limit spicy and greasy foods, as these can make diarrhoea and constipation worse.
- Talk to your doctor or a dietitian about making changes to your diet, or to ask whether taking medicine is an option.

For more information, call Cancer Council 13 11 20 for a free copy of the booklet *Nutrition and Cancer*, or download a digital version from your local Cancer Council website.

## **Tiredness**

Many women who are treated for cervical cancer find that tiredness is a major issue, particularly if they have radiotherapy 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 58–59 for information about support services.

## Tips for coping with tiredness

- Plan to do things at the time of day when you feel less tired. Keep a journal to track your "good times".
- Limit daytime naps to 30 minutes so they don't make it hard to sleep at night.
- Talk with your family and friends about how you're feeling and discuss things they can help you with, e.g. housework and shopping.
- Do some light exercise, such as walking or stretching, to help increase your energy levels. Ask your doctor if these activities are suitable for you.
- Read Cancer Council's booklet Living Well After Cancer for more tips.
   Call 13 11 20 or download a copy from your local Cancer Council website.



## **Bladder problems**

Bladder control may change after surgery or radiotherapy. Some women find they need to pass urine more often or in a hurry. Others may experience involuntary loss of urine when they cough, sneeze, laugh, strain or lift. This is called urinary incontinence.

Strengthening the muscles needed for urinary control can help manage urinary incontinence. You can find a guide to exercising the pelvic floor muscles in Cancer Council's *Exercise for People Living with Cancer* – call 13 11 20 for a copy or download it from your local website. You can also ask your doctor to refer you to a continence nurse or physiotherapist, or contact the National Continence Helpline on 1800 33 00 66 or at continence.org.au.



The blood vessels in the bowel and bladder can become more fragile after radiotherapy. This can cause blood to appear in urine or stools, even months or years after treatment. Let your doctor know if this occurs so you can be given the appropriate treatment.

## Lymphoedema

If lymph nodes have been damaged or removed during surgery, lymph fluid may not drain properly from your legs. This causes the fluid to build up and the legs to swell, which is called lymphoedema. Radiotherapy to the pelvic area may also cause swelling. Lymphoedema can occur during treatment or after treatment has finished, sometimes months or years later.

It is important to avoid pressure, injury or infection to the lower limbs, and to manage lymphoedema symptoms as soon as possible. Gentle exercise, compression stockings, and a type of massage called manual lymphatic drainage can all help to reduce the swelling. A physiotherapist trained in lymphoedema management will be able to give you further advice.

To find a practitioner who specialises in the management of lymphoedema, visit the Australasian Lymphology Association website at lymphoedema.org.au/the-register/find-a-practitioner. For more information, download a copy of Cancer Council's *Understanding Lymphoedema* from your local website.

## Menopause

If your ovaries have been damaged by radiotherapy or chemotherapy, or they've been surgically removed, your body will no longer produce the hormones oestrogen and progesterone. When these hormones are no longer made, women stop having periods. This is called menopause. For most women, menopause is a natural and gradual process that starts between the ages of 45 and 55.

Symptoms of menopause can include hot flushes, mood swings, trouble sleeping (insomnia), tiredness and vaginal dryness. The symptoms of sudden menopause are usually more severe than a natural menopause, because the body hasn't had time to get used to a gradual decrease in the levels of oestrogen and progesterone. For information about dealing with the symptoms of menopause, talk to your doctor or call Cancer Council 13 11 20.

### Osteoporosis and heart disease

Menopause may cause other changes in the body. For example, over time, your bones may become weak and brittle, and break more easily. This is called osteoporosis. Your cholesterol levels may rise, which can increase your risk of heart disease. The table below outlines ways to help prevent osteoporosis and heart disease. For more information, talk to your doctor, or visit osteoporosis.org.au and heartfoundation.org.au.



## How to manage effects of menopause

#### **Osteoporosis**

- Eat 3–5 serves of calciumrich food daily (e.g. yoghurt, milk, tofu, green vegetables).
- Vitamin D helps the body absorb calcium. The sun is a good source of vitamin D.
   Download the SunSmart app for safe times to go out in the sun. Ask your GP whether a calcium or vitamin D supplement might help you.
- Do weight-bearing exercise, such as walking, dancing or team sports. Ask your GP what is suitable for you.

#### **Heart disease**

- Ask your doctor to check your cholesterol levels. If they are high, ask about medication and/or dietary changes.
- Eat lots of fruit, vegetables and fibre.
- Reduce your saturated fat intake by limiting processed meats and takeaway foods.
- Exercise regularly. Your doctor can suggest exercises that are suitable for you.
- If you smoke, talk to your doctor about quitting or call the Quitline on 13 7848.

## **Sexuality issues**

Having cervical cancer can affect your sexuality in physical and emotional ways. The impact of these changes depend on many factors, such as your treatment and its 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 because of the physical and emotional effects of treatment. If you do not feel like having sexual intercourse, or if you find it uncomfortable, let your partner know. It normally takes some time for sex to be comfortable again. You can also explore other ways to be intimate, such as massage and cuddling.

**Vaginal changes** – The main side effect of treatment will be to the vagina. If the ovaries have been affected by surgery or radiotherapy, they will no longer produce oestrogen. This will cause your vagina to become very dry and it may not expand easily during sexual intercourse.

Radiotherapy to the pelvic area can also cause vaginal tissue to lose its elasticity and shrink, narrowing the vagina (vaginal stenosis). Although vaginal stenosis can make sexual intercourse uncomfortable, it should not affect your ability to reach orgasm. See the box on page 52 for ways to keep your vagina open and more elastic.

For more information about sexuality issues, call 13 11 20 for a free copy of the booklet *Sexuality, Intimacy and Cancer*, or download it from your local Cancer Council website.



## **Coping with vaginal side effects**

- Your doctor may suggest you use a vaginal dilator to help keep the walls of the vagina open and supple. A dilator is a tube-shaped device that is designed to gently stretch the vagina. Used with lubricant, it is inserted into the vagina for short periods of time.
   Ask your nurse or radiation
- therapist for more information about vaginal dilators.
- Having regular gentle sexual intercourse can also help widen the vagina.
- Ask your doctor about shortterm hormone replacement therapy (HRT), which may help with vaginal dryness.

## **Fertility issues**

Surgery and radiotherapy for cervical cancer will affect the reproductive organs and cause infertility. This means it is no longer possible to become pregnant.

Many women experience a sense of loss when they learn that their reproductive organs will be removed or will no longer function. You may feel devastated if you are no longer able to have children, and may worry about the impact of this on your relationship or future relationships. Even if your family is complete or you were not planning to have children, you may feel some distress.

If you have a partner, talk to them about your feelings. Speaking to a counsellor or gynaecological oncology nurse may also help.

For some women, there may be options for having children after treatment. Before treatment starts, ask your doctor or a fertility specialist about what options are available to you.

## **Fertility options**

The following list outlines some ways you may be able to have children after treatment for cervical cancer.

- 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.
- If you require radiotherapy but your ovaries do not need to be treated, one or both of the ovaries may be moved higher in the abdomen and out of the field of radiation. This is called ovarian transposition (oophoropexy), and it may help the ovaries keep working properly.
- Having a trachelectomy, where only the cervix is removed, is an option for some women with early-stage cervical cancer (see page 32). It will still be possible to become pregnant after this procedure, but you will be at higher risk of having a miscarriage and having the baby prematurely. Your doctor can discuss these risks with you.

You can find more information in Cancer Council's booklet *Fertility and Cancer*. Call 13 11 20 for a free copy, or download a digital version from your local Cancer Council website.



## **Key points**

- Many women experience side effects following treatment.
   There are ways to reduce or manage the discomfort that side effects may cause.
- Bowel and bladder problems may occur after treatment.
   Your doctor can refer you to a continence nurse or physiotherapist to help you manage these problems.
- Tiredness is a common side effect. Try to plan activities around your energy levels, and talk to your family and friends about ways they can help you.
- If fluid builds up in the legs (lymphoedema), try gentle exercise, compression stockings or visit
   lymphoedema.org.au to find a specialised practitioner.
- Surgery or radiotherapy to the ovaries can cause menopause.
   Chemotherapy may also cause temporary or permanent

- menopause. The symptoms of menopause include hot flushes, mood swings and insomnia. Talk to your doctor about ways to help reduce these symptoms.
- Menopause increases the risk of osteoporosis and heart disease. Ask your doctor for advice on reducing your risk or ways to manage these issues. Making some changes to your diet and lifestyle can help.
- Sexuality issues following treatment are common.
   Addressing any challenges early can help you adjust.
   It can be helpful to talk to a counsellor.
- If you are unable to have children as a result of treatment (infertility), you may feel very distressed. If you would like to have children, speak to your doctor before treatment starts about options for preserving your fertility.

# **C** Looking after yourself

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

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

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

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

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

## **Relationships with others**

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

Give yourself time to adjust to what's happening, and do the same for others. People may deal with the cancer in different ways, for example, by being overly positive, playing down fears, or keeping a distance. It may be helpful to discuss your feelings with each other or with a health professional, such as a nurse or a counsellor. See pages 51–53 for more information about coping with sexuality issues after treatment, and options for preserving fertility.

### **Dealing with feelings of sadness**

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

This is quite common among people who have had cancer.

Talk to your GP, as counselling or medicines – even for a short time – may help. Some people are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Your local Cancer Council may also run a counselling program.

The organisation beyondblue has information about coping with depression and anxiety. Go to **beyondblue.org.au** or call **1300 22 4636** to order a fact sheet.

## Life after treatment

For most women, 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 if every ache and pain means the cancer is coming back.

Some women say they feel pressure to return to "normal life", but they don't want life to return to how it was before cancer. Take some time to adjust to the physical and emotional changes, and re-establish a new daily routine at your own pace. Cancer Council 13 11 20 can help you connect with other women who have had cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

## Follow-up appointments

After your treatment, you will need regular check-ups to confirm that the cancer hasn't come back. At these appointments, you may have a follow-up HPV test or liquid-based cytology test, blood tests, x-rays, a CT scan or PET scan. Your doctor will discuss your follow-up schedule with you.

### What if cervical cancer returns?

For some women, cervical cancer does come back after treatment, which is known as a recurrence. This is why it's important to have regular check-ups. If cervical cancer does return, you will usually be offered treatment with chemotherapy, radiotherapy or surgery. You may not be able to have further radiotherapy if you had it the first time you had treatment.

# **Seeking support**

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

## **Practical and financial help**

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

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

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

## Talk to someone who's been there

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

Women often feel they can speak openly and share tips with others who have gone through a similar experience. In a support group, you may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some women say they can be even more open and honest in these support settings because they aren't trying to protect their loved ones.

## **Types of support**

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

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

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

■ I felt really alone when treatments were finished, and I worried about the cancer coming back. I found talking to other people who'd been through the same thing so important. ■ Amanda



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

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

Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can also find local support services, as well as practical information and resources, through the Carer Gateway. Visit carergateway.gov.au or call 1800 422 737.

There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Visit carersaustralia.com.au or call 1800 242 636 for more information and resources.

You may also call Cancer Council 13 11 20 to find out more about carers' services and to get a free copy of the *Caring for Someone* with Cancer booklet, or download it from your local Cancer Council website.



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

## **Australian**

Cancer Council Australia	cancer.org.au
Cancer Australia	. canceraustralia.gov.au
Cancer Council Online Community ca	ncercouncil.com.au/OC
Carer Gateway	carergateway.gov.au
Carers Australia	.carersaustralia.com.au
Department of Health	health.gov.au
Department of Human Services	humanservices.gov.au
healthdirect Australia	healthdirect.gov.au
beyondblue	beyondblue.org.au
Australian Cervical Cancer Foundation	accf.org.au
Gynaecological Cancer Society	gcsau.org
HPV Vaccine	hpvvaccine.org.au
Cancer Screening	cancerscreening.gov.au
National HPV Vaccination Program Register	hpvregister.org.au
Continence Foundation of Australia	continence.org.au
Australasian Lymphology Association	lymphoedema.org.au
International	
American Cancer Society	cancer.org
Macmillan Cancer Support (UK)	macmillan.org.uk
Cancer Research UK	cancerresearchuk.org
National Cancer Institute (US)	cancer.gov
HysterSisters: Woman-to-Woman	
Hysterectomy Support	hystersisters.com

# **Question checklist**

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

- What type of cervical cancer do I have?
- Has the cancer spread? What stage is it?
- What treatment do you recommend and why?
- Do I have more than one treatment option? If not, why not?
- What are the risks and possible side effects of each treatment?
- Are the side effects temporary or permanent?
- How will the treatment affect my sex life and fertility?
- Will I still be able to get pregnant after treatment?
- What options are available to help preserve my fertility?
- How long will treatment take? Will I have to stay in hospital?
- How much will treatment cost?
- Will I have a lot of pain with the treatment? What will be done about this?
- Are the latest tests and treatments for this type of cervical cancer available in this hospital?
- Are there any clinical trials or research studies I could join?
- How frequently will I need check-ups after treatment?
- Who should I go to for my check-up appointments?
- Are there any complementary therapies that might help me?
- Should I change my diet during or after treatment?
- If the cancer comes back, how will I know?



#### abdomen

The part of the body between the chest and hips, which contains the stomach, spleen, pancreas, liver, gall bladder, bowel, bladder and kidneys.

#### adenocarcinoma

A cancer that starts in the glandular cells of the cervix.

#### adenosquamous carcinoma

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

#### advanced cancer

Cancer that is unlikely to be cured. It may be limited to its original site (primary cancer) or may have spread to other parts of the body (secondary or metastatic cancer).

#### 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 a temporary loss of consciousness.

#### applicator

A tool that is used to insert a radiation source into the body for brachytherapy.

#### benian

Not cancerous or malignant. bilateral salpingo-oophorectomy

Surgical removal of both ovaries and fallopian tubes.

#### biopsy

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

#### brachytherapy

A type of internal radiotherapy in which radioactive material is placed into or near cancerous cells.

#### cells

The basic building blocks of the body. A human is made of billions of cells that are adapted for different functions. cervical intraepithelial neoplasia (CIN)

Abnormal changes found in cells on the surface of the cervix. Now called squamous intraepithelial lesion.

#### cervical screening test

Cervical cells are taken from the cervix using a brush or spatula and are placed in a liquid and tested for HPV. Replaced the Pap test.

#### cervix

The lower part of the uterus that connects the uterus to the vagina. Also called the neck of the uterus.

#### chemoradiotherapy

Combined chemotherapy and radiotherapy treatment. Also called chemoradiation.

#### chemotherapy

A cancer treatment that uses drugs to kill cancer cells or slow their growth. May be given alone or in combination with other treatments.

#### colposcope

An instrument that enables the doctor to see a magnified view of the cervix and vagina from outside the body.

#### colposcopy

Examination of the cervix with a colposcope.

#### cone biopsy

The removal of a cone-shaped piece of the cervix.

#### CT scan

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

Inflammation of the bladder lining. cystoscope

A thin viewing instrument with a light and camera that is inserted into the urethra to examine the bladder.

#### deep vein thrombosis (DVT)

A blood clot that forms in the deep veins of the legs or pelvis. diethylstilbestrol (DES)

#### diethyistlibestroi (DES)

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

#### dilation and curettage (D&C)

A procedure where the cervix is dilated and the lining of the uterus (endometrium) is scraped out.

#### 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.

#### endometrium

The lining of the uterus (womb). **epidural** 

An injection of anaesthetic drugs into the spinal column.

#### fallopian tubes

The two thin tubes that extend from

the ovaries to the uterus. The tubes carry sperm to the egg and a fertilised egg from the ovaries to the uterus.

#### glandular cell

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

#### grade

A score that describes how quickly a tumour is likely to grow.

#### gynaecological oncologist

A doctor who specialises in treating women diagnosed with cancer of the reproductive organs.

#### gynaecologist

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

#### hormone replacement therapy (HRT)

Drug therapy that supplies the body with hormones that it is no longer able to produce naturally.

#### **hormones**

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

#### **HPV** test

A test that can detect HPV (human papillomavirus) in cervical cells.

#### human papillomavirus (HPV)

A group of viruses that can cause infection in the skin surfaces of different areas of the body, including the genitals.

#### hysterectomy

The surgical removal of the uterus and cervix.

#### internal radiotherapy

See brachytherapy.

#### keyhole surgery

See laparoscopy.

#### laparoscope

A thin viewing instrument with a light and camera that is inserted through a cut in the abdomen to look inside the abdomen and pelvis.

#### **laparoscopy**

Surgery done through small cuts in the abdomen using a laparoscope. Also called keyhole 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.

#### laser surgery

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

#### lesion

An area of abnormal tissue.

## loop electrosurgical excision procedure (LEEP)

A procedure to remove cervical tissue for examination and to test some precancerous changes of the cervix.

#### lymphadenectomy

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

#### lymphatic system

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

#### lymph nodes

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

#### lymphoedema

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

#### malignant

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

#### menopause

When a woman stops having periods (menstruating).

#### metastasis (plural: metastases)

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

#### MRI scan

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

#### oestrogen

The female sex hormone produced mainly by the ovaries.

#### oophoropexy

See ovarian transposition.

#### osteoporosis

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

#### ovarian transposition or relocation

The surgical relocation of one or both ovaries from the pelvis into the abdomen. Also called oophoropexy. **ovary** 

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

#### palliative treatment

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

#### Pap test

A test that can detect changes in cervical cells. Also called Pap smear.

### pelvic sidewall

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** scan

Positron emission tomography scan. A scan in which a person is injected with a small amount of radioactive glucose solution to find cancerous areas.

#### precancerous

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

A female sex hormone made by the

ovaries that prepares the lining of the uterus (endometrium) for pregnancy. **prognosis** 

The likely outcome of a person's disease.

#### radical hysterectomy

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

#### radiotherapy

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

#### recurrence

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

#### screening tests

Help to detect cancer in people who don't have any symptoms. sentinel lymph node biopsy

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

#### speculum

An instrument used to hold the vagina open during an internal examination 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 the cervix. squamous intraepithelial lesion (SIL)

Abnormal growth of squamous cells

on the surface of the cervix. The changes are described as low grade (LSIL) or high grade (HSIL).

#### staging

Performing tests to determine how far a cancer has spread.

#### targeted therapy

Treatment that attacks specific particles (molecules) within cells that allow cancer to grow and spread. total hysterectomy

The surgical removal of the uterus and cervix. See also hysterectomy. **trachelectomy** 

The surgical removal of the cervix and some surrounding tissue.

#### transformation zone

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

#### tumour

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

#### 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.

#### uterus

A hollow organ in which a fertilised egg (ovum) grows and a foetus is nourished until birth. Also called the womb.

#### vagina

A muscular canal extending from the entrance of the uterus to the vulva.

#### vaginal dilator

A cylinder-shaped device that is inserted into the vagina to keep the walls of the vagina open and supple.

#### vaginal stenosis

Narrowing of the vagina.

#### vulva

The external sexual organs (genitals) of a woman.

#### womb

See uterus.

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

For more cancer-related words, visit:

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

#### References

- N Colombo et al., "Cervical cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up", *Annals of Oncology*, vol. 23, suppl. 7, 2012, pp. vii27–vii32.
- Australian Institute of Health and Welfare (AIHW), Australian Cancer Incidence and Mortality (ACIM) books: Cervical cancer, AIHW, Canberra, 2017.
- Australian Institute of Health and Welfare (AIHW), Australian Cancer Incidence and Mortality (ACIM) books: All cancers combined, AIHW, Canberra, 2017.

# 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.



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

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

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

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

Cancer Council services and programs vary in each area.

13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



If you need information in a language other than English, an interpreting service is available. Call 13 14 50. If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. www.relayservice.gov.au



For information and support on cancer-related issues, call Cancer Council **13 11 20**. This is a confidential service.

## Visit your local Cancer Council website

Cancer Council ACT acteancer.org

Cancer Council NSW cancercouncil.com.au

Cancer Council NT nt.cancer.org.au

Cancer Council Queensland cancerald.org.au

Cancer Council SA cancersa.org.au

Cancer Council Tasmania cancertas.org.au

Cancer Council Victoria cancervic.org.au

Cancer Council WA cancerwa.asn.au

Cancer Council Australia cancer.org.au

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To support Cancer Council, call your local Cancer Council or visit your local website.