



Understanding Cancer of the Uterus

A guide for women with cancer,
their families and friends

Cancer
information

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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.



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Introduction

This booklet has been prepared to help you understand more about cancer of the uterus – also called uterine cancer, womb cancer, cancer of the lining of the womb or endometrial cancer. In this booklet, we use the terms “cancer of the uterus” and “uterine cancer”.

Many women feel shocked and upset when told they have uterine cancer. We hope this booklet will help you, your family and friends understand how uterine 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. You may also like to pass this booklet to your family and friends for their information.

How this booklet was developed

This information was developed with help from a range of health professionals and people affected by uterine cancer. This booklet is based on Australian and international clinical practice guidelines.^{1,2}

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



**Cancer
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13 11 20**

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What is cancer?

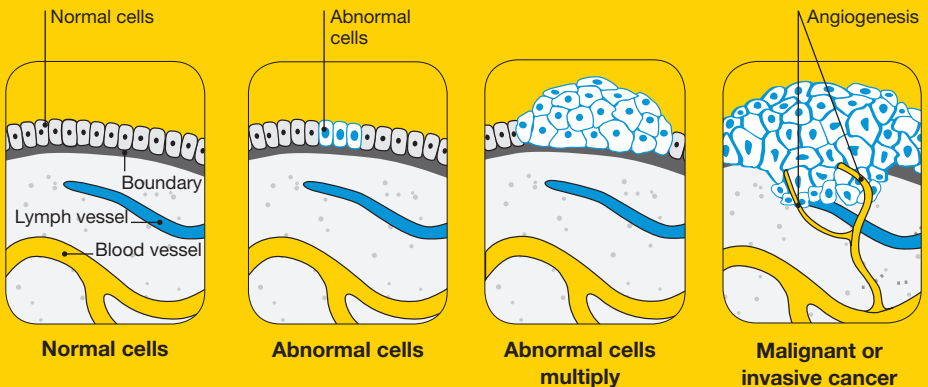
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

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 (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, uterine cancer that has spread to the lungs is called metastatic uterine cancer, even though the person may be experiencing symptoms caused by problems in the lungs.

How cancer spreads

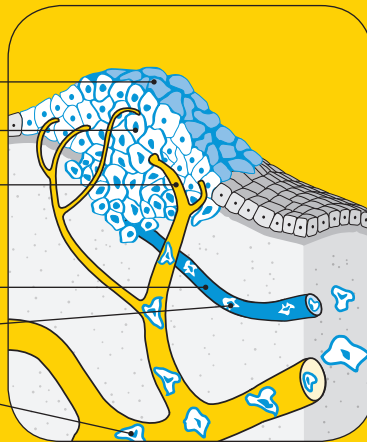
Primary cancer

Local invasion

Angiogenesis –
tumours grow their
own blood vessels

Lymph vessel

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





The uterus

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

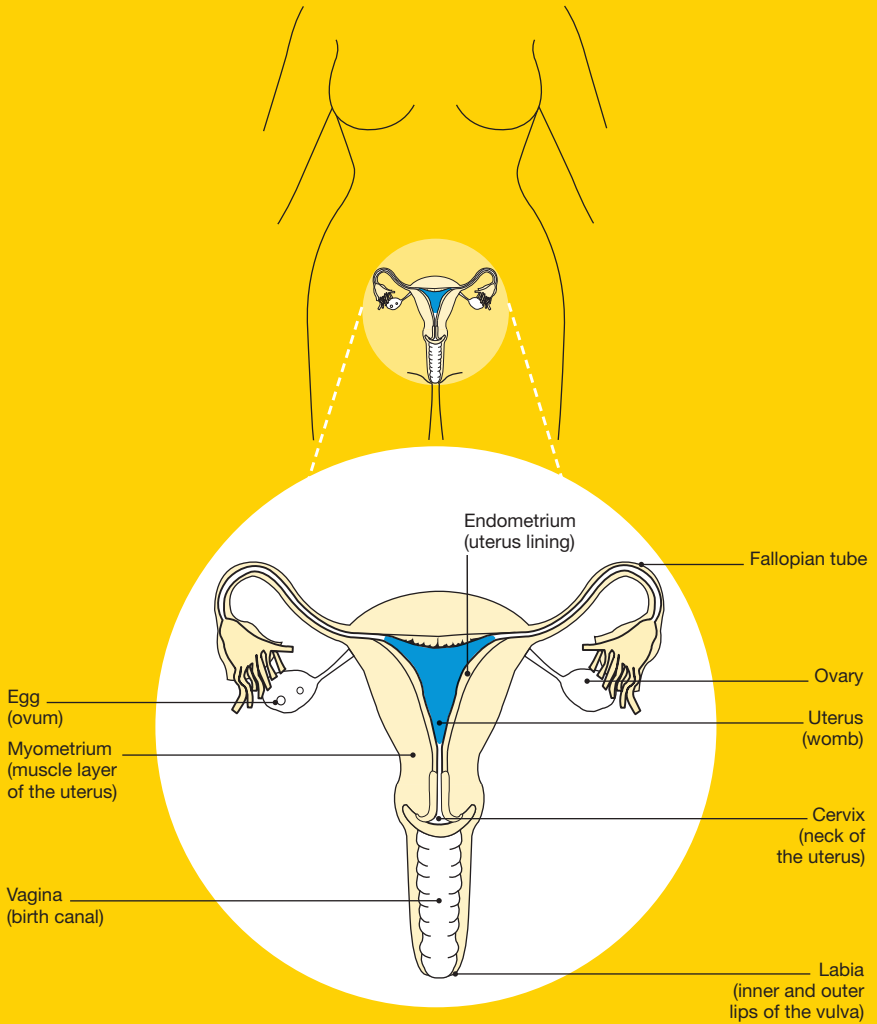
The uterus is about the size and shape of a hollow, upside-down pear. It sits low in the abdomen between the bladder and rectum, and is held there by muscle. It is joined to the vagina by the cervix, which is the neck of the uterus. The uterus is where a foetus grows during pregnancy. It is made up of two layers:

- **Myometrium** – the outer layer of muscle tissue. This makes up most of the uterus.
- **Endometrium** – the inner layer or lining. In a woman of child-bearing age, the hormone oestrogen causes the endometrium to become thicker each month to prepare for pregnancy.

Each month, the ovaries release an egg (ovum) in a process called ovulation. The egg travels down the fallopian tube into the uterus. If the egg is fertilised by a sperm, it will implant itself into the lining of the uterus and grow into a baby. If the egg is not fertilised by a sperm, the lining is shed and flows out of the body through the vagina. This flow is known as a woman's period (menstruation).

The ovaries produce the hormones oestrogen and progesterone that cause ovulation and menstruation. Menopause occurs when the levels of these hormones decrease. A menopausal woman's periods stop and she is not able to become pregnant. The uterus becomes smaller, and the endometrium becomes thinner and inactive.

The female reproductive system





Key questions

Q: What is cancer of the uterus?

A: Cancer of the uterus begins from abnormal cells in the lining of the uterus (endometrium), the muscle tissue (myometrium), or the connective tissue supporting the endometrium (stroma).

Q: How common is it?

A: Each year, about 2500 Australian women are diagnosed with uterine cancer.³ The majority of these women are over 50. It is the fifth most common cancer diagnosed in Australian women and the most commonly diagnosed gynaecological cancer in Australia. One in 60 women is likely to be diagnosed with uterine cancer by the age of 75.

Q: What are the symptoms?

A: The most common symptom of cancer of the uterus is unusual vaginal bleeding, particularly any bleeding after menopause. Some women experience a smelly, watery discharge. Other symptoms include abdominal pain, unexplained weight loss, or difficulty urinating. These symptoms can happen for other reasons, but it is best to check with your doctor.

Q: What types are there?

A: Uterine cancer can be either endometrial cancer (around 95% of all uterine cancers) or the less common uterine sarcoma (around 4% of all uterine cancers). The table on the opposite page provides more information about the different types.

Endometrial cancers

Most cancers of the uterus begin in the lining of the uterus (endometrium) and are called endometrial cancers. There are two main types:

Type 1 cancers (linked to an excess of oestrogen)

Usually called endometrioid cancer, Type 1 cancers are the most common types of endometrial cancer. Subtypes include adenocarcinoma, adenoacanthoma and secretory carcinoma. They are usually slow growing and less likely to spread. They typically require less intensive treatment.

Type 2 cancers (not linked to oestrogen)

Type 2 cancers are much less common. They include uterine carcinosarcomas (also known as malignant mixed Müllerian tumours), serous carcinoma and clear cell carcinoma. They grow faster than type 1 cancers and are more likely to spread. Treatment usually involves more extensive surgery followed by radiotherapy and chemotherapy.

Uterine sarcomas

These soft tissue sarcomas develop in the muscle of the uterus (myometrium) or the connective tissue supporting the endometrium, which is called the stroma. There are three types:

- leiomyosarcoma
- undifferentiated sarcoma

These types are rare and may be more likely to spread to other parts of the body.

- endometrial stromal sarcoma

Rare, low-grade, slow-growing tumour.

Q: What are the risk factors?

A: The exact cause of cancer of the uterus is unknown, but some factors seem to increase a woman's risk:

- being over 50
- being postmenopausal
- having endometrial hyperplasia, a benign condition in which the endometrium thickens because of too much oestrogen
- never having children or being infertile
- starting periods early (before age 12)
- reaching menopause late (after age 55)
- having high blood pressure (hypertension)
- having diabetes
- being overweight or obese
- a family history of ovarian, uterine, breast or bowel cancer
- having an inherited genetic condition such as Lynch syndrome or Cowden syndrome
- previous ovarian tumours or polycystic ovary syndrome
- taking oestrogen hormone replacement without progesterone
- previous pelvic radiation for cancer
- taking tamoxifen, an anti-oestrogen drug used to treat breast cancer (talk to your doctor about the risks and benefits if you are concerned).

Many women who have risk factors don't develop cancer of the uterus, and some women who get cancer have no risk factors.



Diagnosis

If your doctor suspects you have uterine cancer, you may have some of the following tests, but you are unlikely to need all of them. The main tests for diagnosing cancer of the uterus are transvaginal ultrasound (see page 12), examination of the lining of the uterus (hysteroscopy) and tissue sampling (biopsy). A Pap test is not used to diagnose uterine cancer.

Physical examination (pelvic examination)

The doctor will feel your abdomen to check for swelling and any masses. To check your uterus, they will place two fingers inside your vagina while pressing on your abdomen with their other hand. This is called a bimanual examination. You may also have a vaginal or cervical examination using a speculum, an instrument that separates the walls of the vagina. This is the same instrument used when you have a Pap test.

Pelvic ultrasound

A pelvic ultrasound uses soundwaves to create a picture of your uterus and ovaries. A computer creates an image based on the echoes produced when soundwaves meet something dense, like an organ or tumour. A technician called a sonographer performs the scan. It can be done in two ways:

Abdominal ultrasound – To get good pictures of the uterus and ovaries during an abdominal ultrasound the bladder needs to be full, so you will be asked to drink water before the appointment. You will

lie on an examination table while the sonographer moves a small handheld device called a transducer over your abdominal area.

Transvaginal ultrasound – If you have had an abdominal ultrasound, you will be able to empty your bladder between procedures. The sonographer will insert a transducer wand into your vagina. The wand will be covered with a disposable plastic sheath and gel to make it easier to insert. Some women find the transvaginal ultrasound procedure uncomfortable, but it should not be painful. Talk to the sonographer before the ultrasound if you feel embarrassed or concerned. You can ask for a female sonographer or to have someone in the room with you (e.g. your partner or a female relative) if that makes you feel more comfortable.

Many women will have both procedures. The transvaginal ultrasound is often the preferred type of ultrasound, as it provides a clearer picture of your uterus.

The ultrasound pictures can show the size of your ovaries and uterus, any masses (tumours) present in the uterus, and the thickness of the endometrium. If anything appears unusual, your doctor may suggest you have a biopsy.

Hysteroscopy and biopsy

You may have a hysteroscopy and biopsy if your doctor suspects cancer is present. A hysteroscopy is a procedure that allows the gynaecologist or gynaecological oncologist to see inside your uterus and examine the lining for abnormalities.

During a hysteroscopy, your doctor will insert a telescope-like device called a hysteroscope through your vagina into your uterus. Your doctor will remove some tissue from the uterine lining (biopsy) and send it to a tissue specialist (pathologist) for examination. The tissue sample can be taken in different ways:

- Part of the uterine lining is lightly scraped out. This is called a dilation and curettage (D&C), and is the most common and accurate way to remove tissue for a biopsy.
- A long, thin plastic tube (Pipelle) is used to gently suck cells from the womb. This is called an endometrial biopsy and is often performed in the doctor's surgery.

Some women may have an endometrial biopsy as an outpatient under a local anaesthetic. If you have a D&C, you may need a general anaesthetic and to stay in hospital for a few hours. These tests can cause you to have period-like cramps and light bleeding for a few days afterwards.

Blood and urine tests

You might have blood and urine tests to assess your general health. The test results can help you and your doctor to make treatment decisions. In some cases you might be asked to have a test for a marker in the blood called CA125 (a protein that can be produced by uterine cancer cells). If the level is abnormal, it might be used for monitoring later on during treatment or to decide on more imaging tests before surgery.

Further imaging tests

Most cancers of the uterus are found early and do not require further tests. If the initial tests show you have uterine cancer, you may have additional imaging to see if the cancer has spread. Each scan can take about an hour, and most people can go home as soon as the scans are done.

X-rays

You may have a chest x-ray to check that your lungs and heart are healthy. This will usually happen before surgery.

CT scan

A CT (computerised tomography) scan uses x-ray beams to take pictures of the inside of your body. It is used when the doctor suspects the cancer may have spread outside of the uterus.

You will be asked not to eat or drink anything before the scan, except for a liquid dye. This makes your organs appear white in the pictures, so anything unusual can be seen more clearly. You may also receive a separate injection of dye, which makes blood vessels easier to see. The CT scan machine is large and round like a doughnut. You will lie on a table that moves in and out of the scanner. The test is painless but can be noisy.



The dye used in a CT scan can cause allergies in some people. If you have had an allergic reaction to iodine or dyes during a previous scan tell the medical team beforehand.

MRI scan

The MRI (magnetic resonance imaging) scan uses a powerful magnet linked to a computer to take pictures of areas inside the body. It can be helpful to confirm if the cancer has spread from the uterus to the cervix or deeply invades the muscle of the uterus.

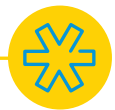
You will lie on a treatment table that slides into a metal cylinder. The test is painless, but some people find lying in the cylinder noisy and confined. You will be given headphones to protect your hearing and to make you more comfortable. This test can take 40–45 minutes.

PET scan

During a PET (positron emission tomography) scan you will be injected with a glucose (sugar) solution containing a small amount of radioactive material. The PET scan detects increased amounts of radioactive glucose in areas of the body where there are cancer cells, because these cells cannot eliminate this glucose in the way that normal cells do.

PET scans are usually used for particular types of uterine cancer, such as sarcoma. They are sometimes also used to help with staging some cases of endometrial cancer. (However, Medicare only covers the cost for PET scans for uterine sarcomas.)

The radiation that's absorbed into your body during a PET scan is generally not harmful and will leave your body within a few hours. Talk to your doctor before the scan if you are concerned.



Staging and grading uterine cancer

The tests described on pages 11–15 help show whether you have uterine cancer and whether it has spread to other parts of the body. This testing process is called staging and it helps your health care team recommend the best treatment for you.

It is often not possible to work out the stage of uterine cancer until after the examination of any tissue removed during surgery (see page 24).

Grading describes how the cancer cells look compared to normal cells and helps work out how aggressive the cancer cells may be. This is determined by a pathologist who looks at the biopsy sample under a microscope.

The tables on the opposite page show how endometrial cancers are staged and graded. Uterine sarcomas are staged differently – to find out more talk to your specialist.

Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with any of your oncologists (gynaecological, radiation or medical). However, it is not possible for any doctor to predict the exact course of the disease in an individual person. Instead, your doctor can give you an idea about the general prognosis for people with the same type and stage of cancer. You will also have tests throughout your treatment that show how well the treatment is working.

Staging endometrial cancers

Stage I	The cancer is found only in the uterus.	Early or localised cancer
Stage II	The cancer has spread from the uterus to the cervix.	Regionalised cancer
Stage III	The cancer has spread beyond the uterus/cervix to the ovaries, fallopian tubes, vagina or nearby lymph nodes.	
Stage IV	The cancer has spread further, to the inside of the bladder or rectum, throughout the abdomen, to other parts of the body such as the bones or lung, or to distant lymph nodes.	Metastatic or advanced cancer

Grading endometrial cancers

Grade 1 (low-grade)	The cancer cells look slightly abnormal.
Grade 2 (moderate-grade)	The cancer cells look moderately abnormal.
Grade 3 (high-grade)	The cancer cells look more abnormal. These cancers tend to be more aggressive than lower-grade cancers.

As for most types of cancer, the results of treatment for uterine cancer tend to be better when the cancer is found and treated early. Most endometrial cancers, especially type 1 (endometrioid), 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.



Test results, the type of uterine cancer, the rate and depth of tumour growth, the likelihood of response to treatment, and factors such as your age, level of fitness, and medical history are important in assessing your prognosis. These factors will also help your doctor advise you on the best treatment options.

Which health professionals will I see?

Your general practitioner (GP) or gynaecologist will arrange the first tests to assess your symptoms. If you do have uterine cancer you will be referred to a gynaecological oncologist who specialises in treating women with uterine cancer.

The gynaecological oncologist will discuss your test results and treatment options with you, and perform surgery if you need it.

You will be cared for by a range of health professionals who specialise in different aspects of your treatment. This is often referred to as a multidisciplinary team (see table opposite).

Health professional	Role
gynaecological oncologist*	specialises in treating women with cancers of the reproductive system (for example, uterine, ovarian, cervical, vulvar and vaginal cancers)
radiation oncologist*	prescribes and coordinates the course of radiotherapy and advises about side effects
medical oncologist*	prescribes and coordinates the course of chemotherapy/hormonal therapy/clinical trials of experimental therapies
radiologist*	reads and interprets diagnostic scans (for example, CT, MRI and PET scans)
cancer care coordinator	supports patients and families throughout treatment and liaises with other staff
oncology nurse	administers drugs including chemotherapy, help treats any radiotherapy-induced reactions, and provides care, information and support throughout treatment
dietitian	recommends an eating plan to help you manage nutrition-related symptoms and help you stay well during treatment and recovery
social worker and clinical psychologist	link you to support services and help you with any emotional problems associated with cancer and treatment, including financial concerns, insurance and superannuation claims
women's health physiotherapist	treats physical problems associated with treatment for gynaecological cancers, such as bladder and bowel issues, sexual issues and pelvic pain

* *specialist doctor*



Key points

- If your doctor suspects you have uterine cancer, you will need to have several tests.
- Your doctor will feel your abdomen to check for swelling or masses (pelvic examination). You may also have a vaginal or cervical examination using a speculum.
- You will usually have a pelvic ultrasound, which uses soundwaves to create a picture of the inside of your uterus and ovaries. The sonographer may pass a small device called a transducer over the abdomen or insert it into the vagina.
- If anything looks unusual on the ultrasound, you will normally have a hysteroscopy and biopsy. This allows your doctor to see inside your uterus and remove some tissue for examination (biopsy).
- Blood and urine samples enable your doctor to assess your general health and help determine what treatment is best for you.
- Further tests, including x-rays and CT, MRI and PET scans, may be required to check whether the cancer has spread from the uterus.
- A stage and grade will be assigned to the cancer to describe how far it has spread and how fast the cancer cells are growing.
- Prognosis means the expected outcome of a disease. If uterine cancer is diagnosed early, it can usually be treated successfully.
- You will be treated by a gynaecological oncologist and other health professionals who will work together in 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 people with more advanced cancer choose treatment even if it offers only a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so they have the best possible quality of life.

Talking with doctors

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

If you are confused or want clarification, you can ask questions – see page 59 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 the first doctor. You might decide you would prefer to be treated by the doctor who provided the second opinion.

Taking part in a clinical trial

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

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

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

Treatment

The treatment recommended by your doctor will depend on the results of your tests, the type of cancer, where the cancer is, whether it has spread, your age and your general health. Cancer of the uterus is often diagnosed early, before it has spread, and can be treated surgically. For many women, surgery will be the only treatment they need. If the cancer has spread beyond the uterus, radiotherapy, hormone treatment or chemotherapy may also be used.

Surgery

Cancer of the uterus is usually treated by an operation to remove the uterus and cervix (a total hysterectomy), along with both fallopian tubes and ovaries (a bilateral salpingo-oophorectomy). The ovaries are usually removed as they produce oestrogen, a hormone that may cause the cancer to grow. Removing them reduces the risk of the cancer coming back.

The surgery will be performed under a general anaesthetic. The type of hysterectomy offered to you will depend on a number of factors, including your age and build, the size of your uterus, the size of the tumour, and the surgeon's specialty and experience. Your surgeon will talk to you about the risks and complications of your procedure.

If you are pre-menopausal, the removal of the ovaries will bring on menopause. If your ovaries appear normal and you don't have any risk factors, you may be able to keep your ovaries. Talk to your doctor about your particular situation.



How the surgery is done

Laparotomy – The surgery is performed through the abdomen. A cut is usually made from the pubic area to the bellybutton. Sometimes the cut is made along the pubic line instead. Once the abdomen is open, the surgeon washes out the area with fluid. The uterus, fallopian tubes and ovaries are then removed. If the cancer has spread to the cervix, the surgeon may also remove a small part of the upper vagina and the ligaments supporting the cervix.

Laparoscopic hysterectomy – This is sometimes called keyhole surgery. The surgeon will make 3–4 small cuts in the abdomen and use a thin telescope (laparoscope) to see inside the abdomen. The uterus and other organs are usually removed through the vagina. A robotic hysterectomy is a specialised form of laparoscopic hysterectomy where the surgical instruments are controlled by robotic arms guided by the surgeon, who sits next to the operating table.

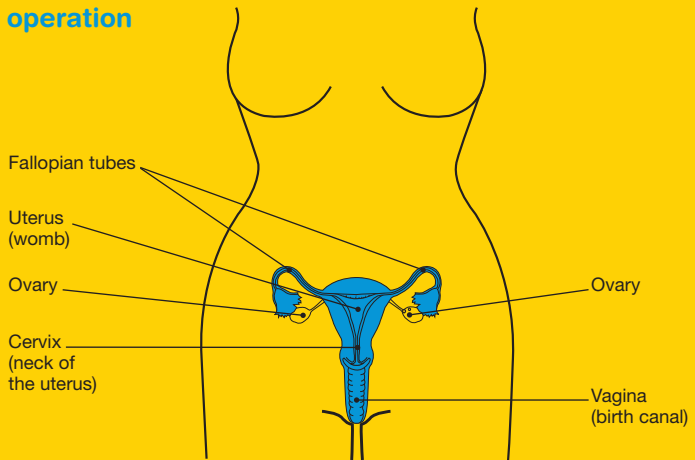
The lymph nodes in your pelvis may also be removed, depending on the size and type of cancer. This procedure is called a lymphadenectomy or lymph node sampling (see page 28). In certain cases, further biopsies or tissue might be taken depending on the type of tumour that you have. Your gynaecological oncologist will discuss this with you before the operation.

All tissue and fluids removed are examined for cancer cells by a pathologist. The results will help confirm the type of uterine cancer you have, if it has spread (metastasised), and its stage (see pages 16–17).

Total hysterectomy and bilateral salpingo-oophorectomy

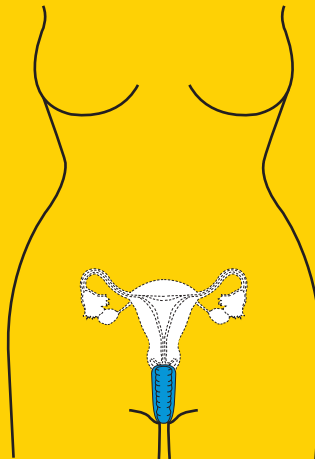
Most women with uterine cancer will have this operation. However, your case may be different. Talk to your doctor.

Before the operation



After the operation

The dotted outline shows the organs removed during surgery.



After the operation

When you wake up after the operation, you will be in a recovery room near the operating theatre. Once you are fully conscious, you will be transferred to the ward where you will stay for around one to four days until you can go home. Your length of stay will depend on the type of surgery (laparoscopy or laparotomy) you have had.

You will have an intravenous drip in your arm to give you medicines and fluid. There may also be a tube in your abdomen to drain the operation site and a tube in your bladder (catheter) to collect urine. These will usually be removed the day after the operation.

As with all major operations, you will have some discomfort or pain. For the first day or two, you may be given pain medicine through a drip or via a local anaesthetic injection into the abdomen (a TAP block) or spine (an epidural). Let your doctor or nurse know if you are in pain so they can adjust your medicines to make you as comfortable as possible. Do not wait until the pain is severe.

You can also expect some light vaginal bleeding after the surgery, which should stop within two weeks. Your doctor will talk to you about how to keep the wound clean once you go home to prevent it becoming infected.

You will have to wear compression stockings for a couple of weeks to help the blood in your legs to circulate. You will also be given a daily injection of a blood thinner to reduce the risk of blood clots. Depending on your risk of clotting, you may be taught to give this injection to yourself, so you can continue it for a few weeks at home.

Your doctor will have all the test results about a week after the operation. Whether further treatment is necessary will depend on the type, stage and grade of the disease, and the amount of any remaining cancer. If the cancer is at a very early stage, you may not need additional treatment.

Side effects

After surgery, some women experience side effects, such as:

Menopause – If you had a bilateral salpingo-oophorectomy and were not menopausal before the operation, the removal of your ovaries will cause menopause. For more details about menopause, see pages 40–41. If you have not been through menopause and are concerned about how surgery will affect your fertility, see page 43.

Vaginal vault prolapse – After a hysterectomy, the top of the vagina can drop towards the vaginal opening because the structures that support the top of the vagina have weakened. Talk to the hospital physiotherapist about pelvic floor exercises that can help strengthen the pelvic floor muscles to try to avoid a prolapse. They can usually be commenced one to two weeks after surgery.

Internal scar tissue (adhesions) – Tissues in the abdomen may stick together, which can sometimes be painful or cause bowel problems such as constipation (see page 46). Rarely, adhesions to the bowel or bladder may need to be treated with further surgery.

Impact on sexuality – The physical and emotional changes you experience after surgery may affect how you feel about sex and

how you respond sexually. See pages 51–52 for more information, or call 13 11 20 for a free copy of *Sexuality, Intimacy and Cancer*.

Lymphoedema – If you have a lymphadenectomy (see box below), you may develop lymphoedema. Removing lymph nodes from the pelvis may prevent lymph fluid from draining, causing swelling in the legs. The risk of lymphoedema following most operations for cancer of the uterus in Australia is low. The risk is higher in women who had a lymphadenectomy followed by radiotherapy. Symptoms appear gradually, sometimes years after the treatment. See page 48 for symptoms and tips on dealing with lymphoedema.

Lymphadenectomy

Lymph nodes are an important part of the lymphatic system. Cancer cells can travel from the uterus through the lymphatic system to other parts of the body. As they pass through the lymph nodes, some cancer cells are destroyed, some move through to grow in another part of the body, and some get stuck, forming tumours (known as lymph node spread).

There are large groups of lymph nodes in the pelvis. Your doctor

may suggest removing some pelvic lymph nodes to find out whether the cancer has spread. This procedure is called a pelvic lymphadenectomy, lymph node dissection or lymph node sampling. The lymph nodes will be examined to see if they contain cancer. As the risk of cancer spreading to the lymph nodes is low for early stage endometrial cancers, this procedure will usually only be offered for more advanced or higher grade tumours.



Christine's story

At 50 I was having some heavy bleeding during my periods, so my GP sent me for an ultrasound. As the ultrasound technician told me that everything looked okay, I put the heavy bleeding down to the menopause and didn't go back to my GP to check on the results. It wasn't until a year later when I saw my GP again that she told me that the ultrasound had shown I had fibroids and referred me to a gynaecologist.

The gynaecologist performed a dilation and curettage for the fibroids and to help with the heavy bleeding. As a matter of course the tissue was sent for testing, and four days later I was told I had uterine cancer and booked in to see an oncologist.

The oncologist recommended a hysterectomy. I chose to have robotic surgery to remove the uterus, cervix and ovaries, as well as some nearby lymph glands. After the surgery, my oncologist informed me that

the cancer hadn't spread, but it was very aggressive and well advanced into the walls of the uterus. He recommended that I have radiotherapy to reduce the risk of a recurrence.

With the support of my family and workplace, I was able to schedule the appointments before work. I found the sessions easier than I expected, although I got very tired at the time. I have also been left with some scar tissue around the bowel, which means I have to be careful with what I eat.

I've just passed the five year mark and have had my final appointment with my oncologist – this has been a big relief. In the last year I've become involved as a volunteer providing telephone peer support with Cancer Connect. I didn't connect with any services when I was diagnosed, and I now realise how helpful it would have been to speak to people in similar situations.

Taking care of yourself at home after a hysterectomy

Your recovery time will depend on your age, general health and the type of surgery that you had. Most women feel better within 1–2 weeks and should be able to fully return to normal activities after 4–8 weeks. The overwhelming majority of women do not need specific help to recover but if you think you will need home nursing care, ask hospital staff about services in your area.

Rest

When you get home from hospital, you will need to take things easy for the first week. Ask family or friends to help you with chores so you can rest.

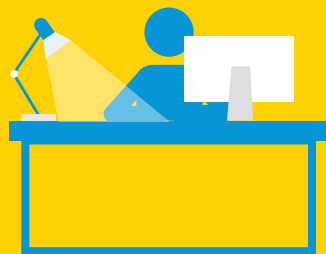


Lifting

Avoid heavy lifting (more than 3–4 kilograms) for about a month, although this will depend on the method of the surgery.

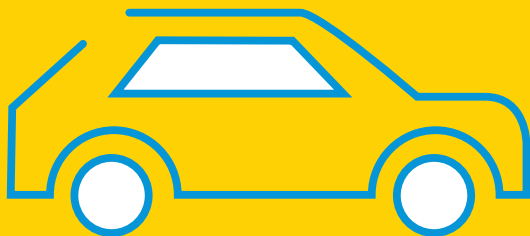
Work

Depending on the nature of your work, you will probably need 4–6 weeks leave from work.



Driving

You will most likely need to avoid driving for a few weeks after the surgery. Check with your car insurer for any exclusions regarding major surgery and driving.



Bowel problems

You may have constipation following the surgery and may need to take laxatives to avoid straining when passing a bowel motion.



Nutrition

Focus on eating a balanced diet (including proteins such as lean meats and poultry, fish, eggs, milk, yoghurt, nuts, seeds, and legumes/beans), to help your body recover from surgery.



Sex

Sexual intercourse should be avoided for 4–8 weeks after surgery. Ask your doctor when you can resume sexual intercourse, and explore other ways you and your partner can be intimate, such as massage.



Exercise

Your health care team will probably encourage you to walk the day after the surgery. Exercise has been shown to help people manage some of the common side effects of treatment, speed up a return to usual activities, and improve overall quality of life. Start with a short walk and go a little further each day. Speak to your doctor if you would like to try more vigorous exercise.



Bathing

Take showers instead of baths for 4–6 weeks after surgery.

Radiotherapy

Radiotherapy (also known as radiation therapy) uses x-rays to kill or damage cancer cells so they cannot multiply. The radiation is targeted at cancer sites in your body. Treatment is carefully planned to do as little harm as possible to your healthy body tissues.

Radiotherapy for cancer of the uterus is commonly used as an additional treatment after surgery to reduce the chance of the disease coming back. This is called adjuvant therapy. Alternatively, radiotherapy may be recommended as the main treatment if you are not well enough for a major operation.

There are two main ways of delivering radiotherapy: internally (see below) or externally (see page 33). Some women are treated with both types of radiotherapy. Your radiation oncologist will recommend the course of treatment most suitable for you.

Internal radiotherapy (vaginal brachytherapy)

Internal radiotherapy is a way of delivering targeted radiotherapy directly to the tumour from inside your body. For cancer of the uterus, a cylinder containing radioactive material is inserted into the vagina. This cylinder is connected to a machine using plastic or metal tubes. These tubes move the radiation from the machine into your body.

You will usually have 4–5 treatment sessions, 2–3 times a week, as an outpatient. Each session will last from 5–10 minutes, but it takes much longer to set up the equipment. The applicator is taken out after each dose of radiation is delivered.

Which radiotherapy treatment will I have?

The type of radiotherapy offered depends mostly on the type of cancer, how far it has spread, your general health and your age. But it can also depend on where you live and what services are available. For more information on radiotherapy treatments, call **13 11 20** and ask for a copy of the *Understanding Radiotherapy* booklet or visit your local Cancer Council website.

External radiotherapy (external beam radiotherapy)

External radiotherapy directs the treatment at the cancer and surrounding tissue from outside the body. For cancer of the uterus, the lower abdominal area and pelvis are treated, but if the cancer has spread (metastasised), other areas may also be treated. You will lie on a treatment table under a machine called a linear accelerator, which delivers high energy x-rays.

You will probably have external radiotherapy treatment from Monday to Friday for 4–6 weeks. Weekend rest breaks allow the normal cells to recover. You usually receive this treatment as an outpatient (at a radiotherapy centre) and you will not need to stay in hospital.

The actual treatment takes only a few minutes each time, but a lot of planning is required to make sure the treatment is right for you. This may involve a number of visits to your doctor to have more tests (e.g. blood tests) and undergo special planning scans such as a PET scan.

The machine used for external radiotherapy is large and kept in an isolated room. This can be confronting or frightening, especially when you have treatment for the first time. You may find you feel more at ease with each session you attend.

It's very important that you attend all of your scheduled sessions to ensure you receive enough radiation to kill the cancer cells or relieve symptoms.

Side effects

Radiotherapy can cause both temporary and long-term side effects. This is because radiotherapy can damage healthy cells as well as cancer cells. The most common side effects occur during or soon after treatment. Most are temporary and steps can often be taken to prevent or reduce them. When you're having radiotherapy, try to rest as much as possible. Drinking lots of water and eating small, frequent meals will also help.

Different women may have different side effects even if the dose and frequency of the radiotherapy are the same. Before your treatment starts, talk to your radiation oncologist about possible side effects. You may experience some of the following side effects:

Lethargy and loss of appetite – Radiotherapy can make you feel tired and you may lose your appetite. See page 42 for some tips on managing fatigue.

Skin problems – Radiotherapy may make your skin dry and itchy in the treatment area.

Hair loss – Radiotherapy to your abdomen and pelvis can cause you to lose your pubic hair. This may be permanent.

Reduced vaginal size – Radiotherapy to the pelvic area can affect the vagina, which will become tender during treatment and for a few weeks afterwards. In the long term, radiotherapy can make the vagina drier and cause vaginal scarring. This can lead to the vagina becoming shorter, narrower and less flexible (vaginal stenosis). This may make vaginal examinations painful and sexual intercourse difficult or uncomfortable. Your doctor may recommend the use of a vaginal dilator – see page 44 for more information.

Menopause – see pages 40–41.

Cystitis – Radiotherapy to the pelvic area can cause a burning sensation when passing urine (cystitis). See page 45 for some suggestions on dealing with cystitis.

Diarrhoea – Having radiotherapy to your lower abdomen or pelvis may irritate the bowel and cause diarrhoea. Symptoms include loose and watery stools, abdominal cramps and frequent bowel movements. For some ways to reduce diarrhoea, see page 47 and consult your doctor or dietitian.

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



Hormone treatment

Hormones such as oestrogen and progesterone are substances that are produced naturally in the body. They help control the growth and activity of cells. Some cancers of the uterus depend on hormones (like oestrogen) to grow.

Hormone treatment can be given if the cancer has spread or if the cancer has come back (recurred), particularly if it is a low grade cancer. It is also sometimes offered in the first instance if surgery is not an option, for example, for young women who still want to have children. The main hormone treatment for women with oestrogen-dependent uterine cancer is progesterone.

Progesterone

Progesterone occurs naturally in women and can also be produced in a laboratory. High doses of progesterone can help shrink some cancers and control symptoms. Progesterone is available in tablet form (commonly either medroxyprogesterone or megestrol); as an injection given by your GP or nurse; or through a hormone-releasing intrauterine device (IUD) called a Mirena, which is fitted into the uterus by your doctor (if you have not had a hysterectomy). Talk to your doctor about the risks and benefits of the different methods.

Side effects

The common side effects of progesterone treatment include breast tenderness, headaches, tiredness, nausea, menstrual changes, and bloating. In high doses, progesterone may increase appetite and cause weight gain. If you have an IUD, it may move out of place and need to be refitted by your doctor.

Chemotherapy

Chemotherapy uses drugs to kill or slow the growth of cancer cells. The aim is to destroy cancer cells while causing the least possible damage to healthy cells.

Chemotherapy for uterine cancer may be used:

- for certain types
- when cancer comes back after surgery or radiotherapy to try to control the cancer and to relieve symptoms
- if the cancer does not respond to hormone treatment
- if the cancer has spread beyond the pelvis when the cancer is first diagnosed
- in conjunction with radiotherapy.

Chemotherapy is usually given by injecting the drugs into a vein (intravenously). You may be treated as an outpatient or, very infrequently, you may need to stay in hospital overnight. You will have a number of treatments, sometimes up to six, every 3–4 weeks over several months. Your doctor will talk to you about how long your treatment will last.

Side effects

The side effects of chemotherapy vary greatly for each woman and depend on the drugs you receive, how often you have the treatment, and your general fitness and health. Side effects may include feeling sick (nausea), vomiting, feeling tired, and some thinning and loss of body and head hair. Most side effects are temporary and steps can often be taken to prevent or reduce their severity.

For more information about chemotherapy and tips for managing side effects, ask your doctor or nurse, or call 13 11 20 for a free copy of Cancer Council's *Understanding Chemotherapy* booklet. You can also download it from your local Cancer Council website.

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 uterine 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

- The main treatment for cancer of the uterus is surgery to remove the uterus and cervix. This operation is called a total hysterectomy.
- In most cases, the fallopian tubes and both ovaries will also be removed at the same time. This is called a bilateral salpingo-oophorectomy.
- You will be given pain relief during and after the operation as there will be some pain or discomfort.
- Recovery times vary depending on the type of surgery you have.
- You will need to take things easy when you first get home from hospital. Ask family or friends to help with chores so you can recover.
- You will probably need to avoid driving for a few weeks after surgery. Check whether your car insurance policy has any exclusions from driving after major surgery.
- Avoid heavy lifting for a few weeks after surgery.
- Sexual intercourse should be avoided for 4–8 weeks to give your wounds time to heal.
- Radiotherapy may be offered as the main treatment if you are not well enough for a major operation. It can also be used as an additional treatment after surgery.
- Hormone therapy targets cancers of the uterus that depend on oestrogen to grow. The main hormone treatment for women with uterine cancer is progesterone.
- Chemotherapy may be used if the cancer has spread beyond the uterus, or if the cancer comes back after surgery or radiotherapy.



Managing side effects

It will take some time to recover from the physical and emotional changes caused by treatment. Treatment side effects can vary – some women experience many side effects, while others have few.

Side effects may last from a few weeks to a few months or, in some cases, years or permanently. This chapter includes ways to reduce or manage the discomfort that side effects may cause.

For a free copy of *Living Well After Cancer*, call Cancer Council 13 11 20, or visit your local Cancer Council website.

Menopause

The ovaries produce the hormones oestrogen and progesterone. If both ovaries have been removed or if you've had radiotherapy in the pelvic area, you will no longer produce these hormones and you will 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. If you have not already entered menopause, these treatments will cause sudden menopause. If you have already been through menopause, the symptoms of menopause may come back.

Menopausal symptoms include hot flushes, dry or itchy skin, mood swings, trouble sleeping (insomnia), tiredness and vaginal dryness. The symptoms are usually more severe than during a natural menopause because the body hasn't had time to get used to the gradual decrease in hormone levels.

While hormone replacement therapy (HRT) can help reduce symptoms of menopause, this treatment is not usually used in women with uterine cancer because oestrogen may cause the cancer to grow. If your menopausal symptoms are severe, talk to your gynaecological oncologist about the risks and benefits of taking HRT. If you were already on HRT when the cancer was diagnosed, you may need to consider stopping its use.



Tips for managing the symptoms of menopause

- Vaginal moisturisers available over-the-counter from chemists can help with vaginal discomfort and dryness.
- You may need to avoid products containing oestrogen. Talk to your doctor about non-hormonal medicines that may help you deal with menopausal symptoms such as hot flushes and night sweats.
- A loss of oestrogen at menopause may cause bones to weaken and break more easily. Talk to your doctor about having a bone density test or taking medicine to prevent your bones from becoming weak. Regular exercise will also help keep your bones strong. For more information see Osteoporosis Australia (call **1800 242 141** or visit **osteoporosis.org.au**).
- Cholesterol levels can change after menopause and this can increase your risk of heart disease. Regular exercise and a balanced diet may help improve cholesterol levels. If not, talk to your doctor about cholesterol-lowering medicines.
- Meditation and relaxation techniques may help reduce stress and lessen some of the symptoms associated with menopause.

Fatigue

It is common to feel very tired and lack energy during and after treatment. This is not only a side effect of the treatment itself.

Travelling to hospitals and clinics for treatment and appointments can be exhausting. Dealing with your emotions can also cause fatigue. Your tiredness may continue for a while after treatment has finished.

Fatigue may impact on your ability to continue to work during your treatment or care for your home and family. It may help to talk with your family and friends about how you feel, and discuss ways they can help you.



Tips for managing fatigue

- Plan your day. Set small, manageable goals so you can rest regularly.
- Ask for and accept offers of help from family and friends, e.g. with shopping, housework and driving.
- Learn to recognise signs of tiredness before you feel exhausted.
- Leave plenty of time to get to appointments.
- Sit down whenever you can.
- Try not to feel you must please others all the time.
- Talk to your employer about taking time off, reducing your hours or working from home.
- Do some light exercise, with the approval of your doctor. Even a walk around the block can boost your energy levels.
- Eat nutritious foods to keep your energy levels up and limit your alcohol intake.
- Do some things that you enjoy.

Infertility

Surgery or radiotherapy for uterine cancer will mean you are unable to have children. Although most women are older and postmenopausal when they are diagnosed with uterine cancer, it does occasionally affect younger, premenopausal women.

If fertility is a concern for you, it is important to discuss this with your doctor before your treatment starts. There may be options available in certain cases to preserve the uterus so you can still have children. If appropriate, your doctor will discuss the risks and benefits of these options with you.

Learning that your reproductive organs will be removed or will no longer function and that you won't be able to have children can be devastating. Even if your family is complete or you did not want children, you may still experience a sense of loss and grief. These reactions are not unusual.

Speaking to a counsellor or an oncology nurse about your feelings and individual situation can be very beneficial. You can also call 13 11 20 for a free copy of *Fertility and Cancer*, or download it from your local Cancer Council website.

Call Cancer Council for information about wig services in your area. If you have private health insurance, check with your provider whether you are entitled to a rebate on a wig for hair loss associated with chemotherapy.



Vaginal narrowing and dryness

Radiotherapy to the pelvic area can cause vaginal tissue to lose its elasticity and shrink, narrowing the vagina (vaginal stenosis). If your ovaries were removed, your vagina may also become very dry. These side effects may make vaginal examination by a doctor difficult or uncomfortable, and may make it painful to have sex.

If you experience any of these problems, talk to your health care team as the symptoms can usually be relieved. They may advise you to use a device called a vaginal dilator to expand the vagina or a vaginal moisturiser or lubricant. Vaginal moisturisers are available over-the-counter from pharmacies or can be bought online.



Tips for using vaginal dilators

- Vaginal dilators can help keep the vaginal walls open and supple, and prevent vaginal narrowing, particularly if you are no longer sexually active.
- They are tube-shaped devices made from plastic or rubber.
- They come in different sizes. Begin with the smallest dilator and progress to larger ones as each size becomes more comfortable.
- Find a quiet, private place.
- Start using 4–6 weeks after you've finished radiotherapy, once any inflammation has settled down.
- Use a water-based lubricant and slowly insert a dilator into the vagina. Leave it there for 5–10 minutes.
- You will need to do this 3–5 times a week, usually for many months.
- Talk to your health care team for more detailed instructions.

Bladder problems

Urinary incontinence – Bladder control may change after treatment. Some women find they need to pass urine more often, or feel that they need to go in a hurry. Others may leak urine when they cough, sneeze, strain or lift.

For ways to manage accidental or involuntary loss of urine (urinary incontinence), talk to the hospital continence nurse or women's health physiotherapist. They may suggest exercises to strengthen your pelvic floor muscles. You could also visit the Australian Government's bladder and bowel website at bladderbowel.gov.au or contact the Continence Foundation of Australia at continence.org.au or on 1800 33 00 66.

Cystitis – Radiotherapy can irritate the lining of the bladder causing a burning sensation when you urinate and the need to pass urine more often than usual. This is called cystitis. Try to drink plenty of water to make your urine less concentrated. Over-the-counter urinary alkalisers (e.g. Ural) can help by making the urine less acidic. Your doctor may also prescribe medicine to treat cystitis.



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

Bowel problems

After surgery and radiotherapy, some women notice bowel changes. You may experience constipation or diarrhoea, faecal incontinence, or feel pain in your lower abdomen. If you experience any of these problems, talk to your GP, specialist doctor, dietician or women's health physiotherapist, as they may be able to help with these issues.

Constipation

Constipation is when you have difficulty passing a bowel motion regularly or often. It is important to avoid constipation, especially in the days after surgery, because it may lead to more discomfort or cause you to strain when you're sitting on the toilet. Talk to your dietitian or doctor about making changes to your diet or taking medicines if you are experiencing constipation.



Tips that may reduce constipation

- Drink more water – aim for at least 8 glasses during the day.
- Eat regular meals throughout the day.
- Try to eat more fibre-rich foods, e.g. wholegrain breads and cereals, legumes such as beans and lentils, vegetables, fruit, nuts and seeds.
- Reduce your alcohol intake.
- Do some gentle exercise like walking.
- Cut down on sweets, soft drinks, takeaway food, fried foods, potato chips and other savoury snacks.
- Limit foods containing added sugars and salts.
- Take medicines as directed by your doctor.

Diarrhoea

Diarrhoea is the frequent passing of loose, watery stools (faeces) from the bowels. A dietitian can suggest changes to your diet to reduce the frequency of your bowel movements. Once your bowels have returned to normal you should resume a balanced diet that includes fresh fruits, vegetables, dairy foods and wholegrain cereals.



Tips to help you manage diarrhoea

- Drink plenty of fluids such as water, herbal teas, sports drinks and electrolyte-replacing fluids. Avoid alcohol.
- Eat fewer high-fibre foods such as wholegrain breads and cereals, raw fruits and vegetables, and legumes.
- Cut down on caffeine drinks.
- Choose low lactose or soy-based dairy products; small amounts of cheese and yoghurt are usually okay.
- Ask your doctor about suitable medicines. Take as directed.

Lymphoedema and cellulitis

Lymphoedema is a swelling of part of the body, usually a leg in the case of uterine cancer. If lymph nodes have been damaged during surgery or removed in a lymphadenectomy, it may prevent lymph fluid from draining properly. This causes fluid build-up and swelling. Sometimes the swelling can take months or years to develop and some women who are at risk never develop lymphoedema. Though lymphoedema may be permanent, it can usually be managed.

The skin of the legs is more susceptible to infection after removal of the lymph glands. This inflammation is called cellulitis. Signs of cellulitis include redness, painful swelling in the legs, warm skin and fever. If you have any of these symptoms, you should see your GP as soon as possible. Symptoms are better managed if treated early.

For more information on managing lymphoedema and cellulitis, ask for a referral to a specialist physiotherapist or nurse; download a copy of Cancer Australia's booklet *Lymphoedema – what you need to know* from canceraustralia.gov.au; or call Cancer Council 13 11 20.



How to prevent and/or manage lymphoedema

- Keep the skin healthy and unbroken to reduce the risk of infection.
- Gently massage the swollen leg towards your heart to move the fluid to other lymph channels. Elevate your legs when resting.
- Do leg exercises to move fluid out of the affected area and into other lymph channels.
- Talk to a lymphoedema practitioner about wearing compression bandages or stockings, or other ways to improve the circulation of lymphatic fluid. Visit lymphoedema.org.au to find a practitioner and to learn more about lymphoedema.
- Avoid cuts, scratches, burns, insect bites, sunburn and injections in your legs.
- Moisturise your skin to prevent dryness and irritation. Use sunscreen to protect your skin from sunburn.
- Keep your feet clean and dry, especially between the toes, to avoid fungal infections.



Key points

- Every woman will experience side effects differently. Some will have none and others will have several. There are often ways to reduce or manage side effects.
- If you are not already menopausal, having surgery or radiotherapy will mean your periods will stop.
- Tiredness is common during and after treatment. Plan your daily activities, and ask family and friends for help around the house, so you can rest regularly.
- If fertility is a concern for you, discuss this with your doctor before treatment starts. After surgery or radiotherapy you will be unable to have children.
- Radiotherapy can cause your vagina to narrow and become dry, which can make vaginal examinations by a doctor and sexual intercourse difficult or painful. There are ways to reduce the discomfort of vaginal narrowing and dryness.
- Bladder control may change after treatment. There are ways to manage or prevent accidental or involuntary loss of urine (urinary incontinence). You may also be more prone to bladder infections (cystitis).
- After surgery, some women experience constipation, diarrhoea or pain in the lower abdomen. These can often be managed with changes to your diet.
- You may experience swelling in your legs (lymphoedema). Exercises or compression stockings may help to reduce the swelling. See your doctor as soon as possible if you have symptoms of an infection in your legs, such as redness, swelling and fever.



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.

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.

Sexuality, intimacy and fertility

Uterine cancer can affect your sexuality in both physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner.

Treatment can cause physical side effects such as tiredness, and soreness and narrowing of the vagina (see page 44). These side effects can make sexual penetration painful, and you may have to explore different ways to orgasm or climax. Talk to your doctor about ways to manage side effects that change your sex life. This may include using vaginal dilators, lubricants and moisturisers.

The experience of having cancer can also reduce your desire for sex (libido). However, for most women, sex is more than arousal, intercourse and orgasms. It involves feelings of intimacy and acceptance, as well as being able to give and receive love.

Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

Give yourself time to get used to any physical changes. Talk openly with your partner about how you're feeling, and take things slowly by starting with hugs or a massage if you're not ready to have sexual intercourse.

Your doctor will tell you if treatment will affect your fertility. If having children is important to you, talk to your doctor before starting treatment. See *Infertility* on page 43 for more information.



Call **13 11 20** for free copies of *Sexuality, Intimacy and Cancer* and *Emotions and Cancer*, or download the booklets from the website.

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. Most women find they need time to reflect on what has happened. You may have mixed feelings when treatment ends, and worry that 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.

🗨️🗨️ When my treatment finished, I couldn't wait to get back to work. I wanted to return to something normal. I went back part-time and that helped me take my mind off things. 🗨️🗨️ *Kate*

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

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](http://beyondblue.org.au) has information about coping with depression and anxiety. Go to beyondblue.org.au or call 1300 22 4636 to order a fact sheet.

Follow-up appointments

After your treatment, you will need regular check-ups to confirm that the cancer hasn't come back and to manage any long-term side effects of treatment. These appointments may be with any of your specialists, for example, your gynaecological oncologist

or medical oncologist. It's common for women to worry before their follow-up appointments. To help ease your concerns, you may want to talk to your doctor or nurse about what to expect.

There is no set follow-up schedule for uterine cancer – how often you will need to see your doctor will depend on the level of monitoring needed for the type and stage of the cancer. Check with your doctor if you are unsure of your follow-up plan.

Follow-up appointments may include a pelvic examination, blood tests, discussion about any side effects or new symptoms, and imaging tests. Women who have had cancer of the uterus are at an increased risk of breast and colon cancer – talk to your doctor about how often to conduct breast examinations and undergo screening.

Check-ups will become less frequent if you have no further problems. Between follow-up appointments, let your doctor know immediately of any health problems.

What if the cancer returns?

For some women, uterine cancer does come back after treatment, which is known as a recurrence. The majority of uterine cancers that recur do so in the first three years after treatment.

Recurrence can be locally in the uterus (if you didn't have a hysterectomy), in the lymph nodes or further away in other body sites, like the bladder, bones or lungs. If the cancer recurs you may be offered further treatment to try to control the cancer.



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

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 people 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 Cancer Council Online Community at cancercouncil.com.au/OC.

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

“ I found that my support group was a useful, safe place to express my emotions and experiences without having to censor myself to protect the feelings of other people. ” Pam



Caring for someone with cancer

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

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

Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local 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 phone 1800 242 636 for more information and resources.

Call Cancer Council 13 11 20 to find out more about carers' services. You can also ask for a copy of the *Caring for Someone with Cancer* booklet, or download a digital version from your local Cancer Council website.



Useful websites

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

Australian

Cancer Council Australia	cancer.org.au
Cancer Australia	canceraustralia.gov.au
Cancer Council Online Community	cancerCouncil.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
Dietitians Association of Australia	daa.asn.au
healthdirect Australia.....	healthdirect.gov.au
Australasian Lymphology Association.....	lymphoedema.org.au
Australian Gynaecological Cancer Foundation	agcf.org.au
Australia New Zealand Gynaecological Oncology Group	anzgog.org.au
beyondblue.....	beyondblue.org.au
Heart Foundation.....	heartfoundation.org.au
Osteoporosis Australia	osteoporosis.org.au
Pelvic Floor First.....	pelvicfloorfirst.org.au

International

American Cancer Society.....	cancer.org
Cancer Research UK.....	cancerresearchuk.org
Macmillan Cancer Support (UK).....	macmillan.org.uk
Memorial Sloan Kettering Cancer Center (US).....	mskcc.org
National Cancer Institute (US).....	cancer.gov



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 uterine cancer do I have?
- How far has the cancer spread? How fast is it growing?
- Do I have a choice of treatments?
- What treatment do you recommend in my case? What is the aim of the treatment?
- What are the risks and possible side effects of each treatment? Are the side effects temporary or permanent?
- How can any side effects be managed?
- Will I still be able to have children?
- Should I see a fertility specialist?
- How long will treatment take? Will I have to stay in hospital?
- How much will treatment cost?
- Are the latest tests and treatments for uterine cancer available in this hospital?
- Are there any clinical trials or research studies I could join?
- How will I know if the treatment is working?
- How frequently will I need check-ups after treatment?
- Who should I go to for my follow-up appointments?
- Are there any complementary therapies or other things I can do that will help me cope with treatment?
- Should I exercise? When should I start? How much should I do?
- If the cancer comes back, how will I know?
- Are there any local support groups for women with cancer of the uterus?



Glossary

abdomen

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

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.

benign

Not cancerous or malignant. Benign tumours are not able to spread to other parts of the body.

bilateral salpingo-oophorectomy

Surgical removal of both ovaries and fallopian tubes.

biopsy

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

brachytherapy

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

CA125

A protein found in the blood that may be higher than normal in women with uterine cancer.

carcinoma

A cancer that starts in the tissue lining the skin and internal organs of the body.

cervix

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

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.

clear cell carcinoma

A type of endometrial cancer.

CT scan

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

dilation and curettage (D&C)

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

endometrial biopsy

Removing cells from the lining of the uterus with a thin tube.

endometrial hyperplasia

An abnormal increase in the number of cells in the lining of the uterus.

endometrial stromal sarcoma

A type of uterine sarcoma.

endometrioid cancer

The most common type of endometrial cancer.

endometrium

The lining of the uterus (womb).

epidural

An injection of anaesthetic drugs directly into the spinal column.

fallopian tubes

The two thin tubes that extend from the uterus to the ovaries. The tubes carry sperm to the egg, and a fertilised egg from the ovaries to the uterus.

gynaecological oncologist

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

gynaecologist

A specialist doctor who treats 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.

hysterectomy

The surgical removal of the uterus. See also total hysterectomy.

hysteroscopy

A procedure to look inside the uterus using a telescope-like device called a hysteroscope.

keyhole surgery

See laparoscopic surgery.

laparoscope

A thin viewing instrument with a light and camera used to look inside the abdomen and pelvis during laparoscopic surgery.

laparoscopic surgery

Surgery done through small cuts in the abdomen using a tiny telescope called a laparoscope. Also called laparoscopy, keyhole surgery or minimally invasive surgery.

laparotomy

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

leiomyosarcoma

A type of uterine sarcoma.

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

lymph nodes

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

lymphoedema

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

Lynch syndrome

A disease that increases the risk of developing cancer of the uterus. Previously called hereditary non-polyposis colorectal cancer (HNPCC).

malignant

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

malignant mixed Müllerian tumour

A less common type of endometrial cancer, containing elements of both carcinoma and sarcoma.

menopause

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

metastasis (plural: metastases)

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

MRI scan

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

myometrium

Smooth muscle tissue that makes up the bulk of the uterus.

oestrogen

The primary female sex hormone produced mainly by the ovaries that helps mature and regulate the female reproductive cycle.

osteoporosis

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

ovary

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

ovulation

The release of an egg (ovum) during a woman's menstrual cycle.

ovum (plural: ova)

A female egg that is produced by the ovary and released during ovulation.

Pap test

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

pathologist

A specialist doctor who interprets the results of blood tests and biopsies.

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.

polycystic ovary syndrome (PCOS)

A hormonal disorder causing the ovaries to produce too many male hormones, which affects the development and release of eggs during ovulation.

primary cancer

The original cancer. Cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form.

progesterone

A female sex hormone made mostly by the ovaries that prepares the lining of the uterus (endometrium) for pregnancy. It can also be produced artificially to help shrink some cancers and control cancer symptoms.

radiotherapy

The use of radiation to kill cancer cells or injure them so they cannot grow and multiply. Also called radiation therapy.

robotic hysterectomy

A form of keyhole surgery where the instruments used are controlled by robotic arms guided by the surgeon, who sits next to the operating table.

serous carcinoma

A type of endometrial cancer.

stroma

The connective tissue supporting the lining of the uterus (endometrium).

TAP (transverse abdominis plane) block

An injection of anaesthetic drugs into the abdominal wall to block pain.

total hysterectomy

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

transducer

A small device used in an ultrasound. It can be passed over the surface of the body or inserted into an opening like the vagina or rectum.

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 non-invasive scan that uses soundwaves to create a picture of an internal part of the body.

undifferentiated sarcoma

An aggressive type of uterine sarcoma.

uterine sarcoma

A cancer affecting the smooth muscle of the uterus or the stroma.

uterus

A hollow muscular organ in a woman's lower abdomen 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 used to keep the vaginal walls open and supple.

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

1. Cancer Council Australia Endometrial Cancer Guidelines Working Party, *Clinical practice guidelines for the treatment and management of endometrial cancer*, Cancer Council Australia, Sydney. Available from: http://wiki.cancer.org.au/australia/Guidelines:Endometrial_cancer/Treatment/Early_stage (accessed 18 November 2016).
2. N Colombo et al. on behalf of the ESMO Guidelines Working Group, 'Endometrial cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up', *Annals of Oncology*, vol. 24, suppl. 6, 2013, pp. vi33–vi38.
3. Australian Institute of Health and Welfare (AIHW), *Australian Cancer Incidence and Mortality (ACIM) books: Uterine cancer*, 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 Pink Ribbon Day, or hold your own fundraiser or become a volunteer.

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

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

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

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

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



Cancer Council 13 11 20

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

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

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

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

Cancer Council services and programs vary in each area.

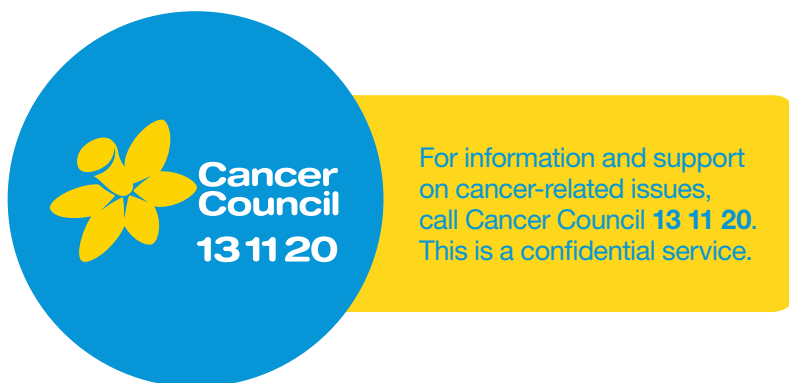
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



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



If you are deaf, or have a hearing or speech impairment, contact us through the National Relay Service.
www.relayservice.gov.au



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

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