



Understanding Cancer of the Uterus

A guide for women with cancer,
their families and friends

Cancer
information

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13 11 20



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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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About this booklet

This booklet has been prepared to help you understand more about cancer of the uterus – also called uterine cancer, endometrial cancer, womb cancer, or cancer of the lining of the womb. 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 cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, this information may answer some of your questions and help you think about what to ask your treatment team (see page 59 for a question checklist).

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary (see page 60). You may also like to pass this booklet to family and friends for their information.

How this booklet was developed

This information was developed with help from a range of health professionals and people affected by uterine cancer. This booklet is based on Australian and international clinical practice guidelines.¹⁻³

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. You can also visit your local Cancer Council website (see back cover).



**Cancer
Council
13 11 20**

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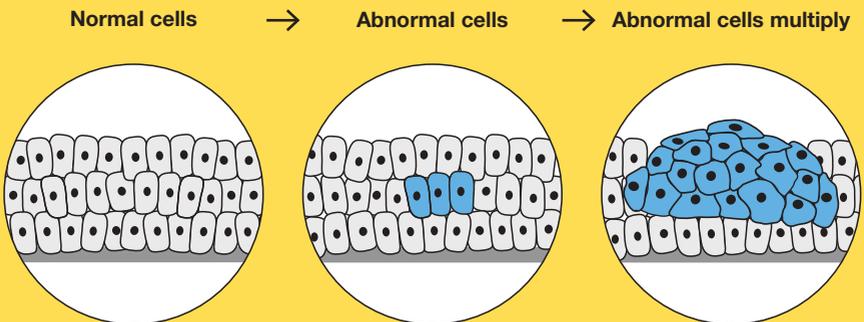
What is cancer?

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

Normally, cells multiply and die in an orderly way, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. In solid cancers, such as uterine cancer, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into

How cancer starts

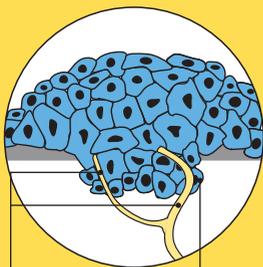


cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

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

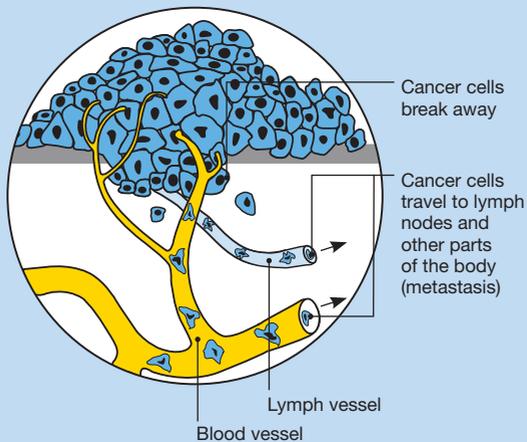
How cancer spreads

→ Malignant cancer



Grows own
blood vessels
(angiogenesis)

Invades
surrounding
tissue





The uterus

The uterus, or womb, is where a baby grows during pregnancy. It is part of the female reproductive system, which also includes the ovaries, fallopian tubes, cervix (neck of the uterus) and vagina (birth canal).

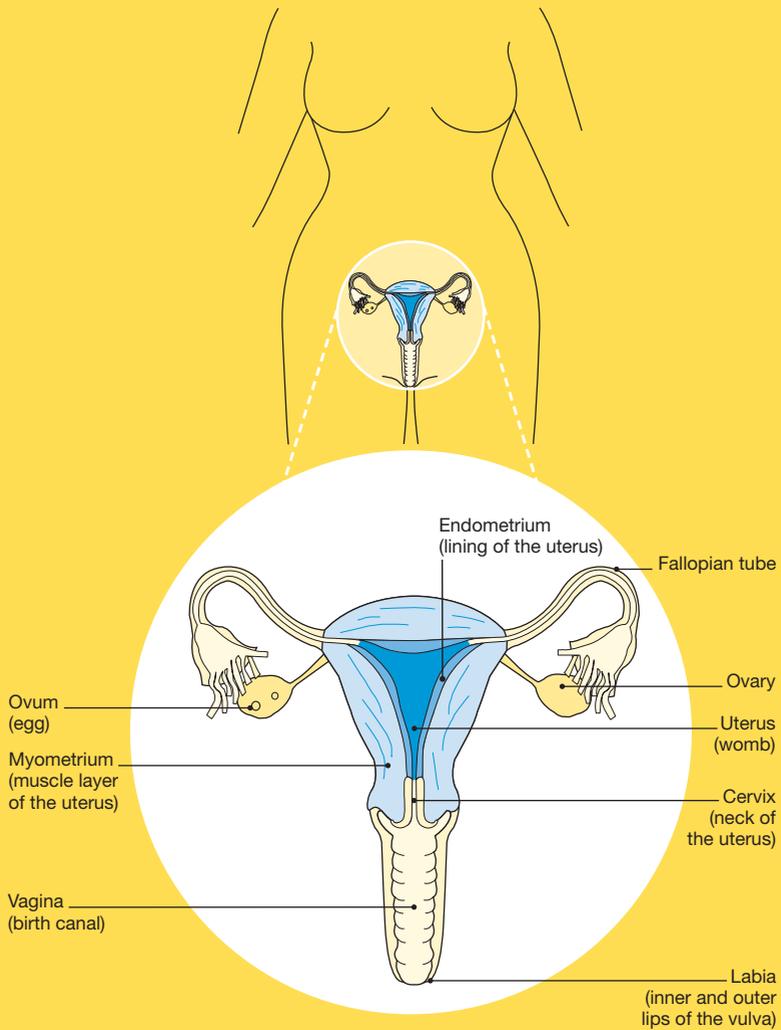
The position of the uterus – About the size and shape of a hollow, upside-down pear, the uterus sits low in the abdomen between the bladder and rectum. It is joined to the vagina by the cervix. On either side of the uterus are the ovaries, which contain the woman's eggs (ova). The ovaries are connected to the uterus by the fallopian tubes.

The layers of the uterus – The uterus has two layers. The myometrium is the outer layer of muscle tissue and makes up most of the uterus. The endometrium is the inner layer or lining.

Menstruation – In a woman of child-bearing age, the endometrium becomes thicker each month to prepare for pregnancy. If no pregnancy occurs, the endometrium is shed and flows out of the woman's body through the vagina. This flow is known as a woman's period (menstruation).

Menopause – The ovaries produce oestrogen and progesterone, the hormones that control the release of eggs (ovulation) and menstruation. During menopause, the levels of these hormones decreases. This means the woman's ovaries no longer release eggs, her periods stop and she is not able to become pregnant. The uterus becomes smaller and the endometrium becomes thinner.

The female reproductive system





Key questions

Q: What is cancer of the uterus?

A: Cancer of the uterus occurs when cells become abnormal and start growing and multiplying out of control. It is also known as uterine cancer and can begin in cells in the:

- lining of the uterus (endometrium)
- muscle tissue (myometrium)
- connective tissue (stroma) that supports the endometrium.

The table opposite provides more information about the different types of uterine cancer.

Q: How common is it?

A: Uterine cancer is the fifth most common cancer in women and the most commonly diagnosed gynaecological cancer in Australia. Each year, about 2700 Australian women are diagnosed with uterine cancer, and most are over 50. About one in 60 women is likely to have uterine cancer by the age of 75.⁴

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. In rare cases, symptoms include abdominal pain, unexplained weight loss, difficulty urinating or a change in bowel habit.

Any of these symptoms can happen for other reasons, but it is best to check with your doctor if you are concerned.

Types of cancer of the uterus

Uterine cancer can be either endometrial cancer (around 95% of all uterine cancers) or the less common uterine sarcoma.

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 endometrial cancers. In most cases, they are adenocarcinomas, which start in the glandular cells of the endometrium. Type 1 cancers 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 carcinomas and clear cell carcinomas. They grow faster than type 1 cancers and are more likely to spread. Treatment usually involves more extensive surgery followed by radiation therapy and chemotherapy.

Uterine sarcomas

These are rare soft tissue sarcomas that develop in the muscle of the uterus (myometrium) or the connective tissue (stroma) that supports the endometrium. There are three types: endometrial stromal sarcoma is a low-grade, slow-growing tumour, while leiomyosarcoma and undifferentiated sarcoma are usually faster growing and may be more likely to spread to other parts of the body.

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 (see box opposite)
- never having children or being unable to have children
- starting periods early (before age 12)
- reaching menopause late (after age 55)
- being overweight or obese and/or having diabetes
- having high blood pressure (hypertension)
- a family history of uterine, ovarian or bowel cancer
- inheriting a 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 for breast cancer (talk to your doctor if you are concerned about this risk).

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



For an overview of what to expect during all stages of your cancer care, visit cancerpathways.org.au/optimal-care-pathways/endometrial-cancer. This is a short guide to what is recommended for endometrial cancer, from diagnosis to treatment and beyond.

Other uterine conditions

Other conditions can affect the uterus and cause abnormal vaginal bleeding and pain. They may be found during tests for uterine cancer.

Polyps – Small, soft growths attached to the inner wall of the uterus. Polyps are usually benign (non-cancerous), although some may eventually turn into cancer. These can be removed during a hysteroscopy (see page 15) and sent to a laboratory for testing.

Fibroids – Benign (non-cancerous) tumours that begin in the muscle layer of the uterus (myometrium). Some women with fibroids choose to have surgery to remove the uterus (hysterectomy, see pages 24–25).

Endometrial hyperplasia – Thickening of the lining of the uterus (endometrium) caused by too much oestrogen. It is usually benign, but in some cases can lead to cancer so may be treated with hormones or minor surgery.

Endometriosis – When endometrial tissue grows outside the uterus, e.g. in the abdomen or ovaries. Endometriosis doesn't lead to cancer, but many women with endometriosis also have endometrial hyperplasia. It may be treated with hormones or surgery.

Q: Which health professionals will I see?

A: Your general practitioner (GP) will arrange the first tests to assess any symptoms. If these tests do not rule out cancer, you will be referred to a gynaecological oncologist or gynaecologist for more tests. If uterine cancer is diagnosed, the specialist will consider treatment options. Often these will be discussed with other health professionals at what is known as a multidisciplinary team (MDT) meeting. During and after treatment, you'll see a range of health professionals for various aspects of your care (see next page).

Health professionals you may see

gynaecological oncologist*	diagnoses and performs surgery for cancers of the female reproductive system, e.g. uterine, cervical, ovarian, vulvar and vaginal cancers
gynaecologist*	specialises in diseases of the female reproductive system; may diagnose cancer of the uterus and then refer you to a gynaecological oncologist
radiation oncologist*	treats cancer by prescribing and overseeing a course of radiation therapy
medical oncologist*	treats cancer with chemotherapy and other drug therapies
cancer care coordinator	coordinates care, liaises with other members of the MDT and supports you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)
nurse	administers drugs and provides care, information and support throughout treatment
women's health physiotherapist	assists with physical problems associated with gynaecological cancers, such as bladder and bowel issues, sexual issues and pelvic pain
dietitian	recommends an eating plan to follow during and after treatment
social worker	links you to support services and helps you with emotional, practical or financial issues
psychologist, counsellor	help you manage your emotional response to diagnosis and treatment

** Specialist doctor*



Diagnosis

If your doctor suspects that you have cancer of the uterus, you may have some of the following tests, but you are unlikely to need all of them. Your doctor will usually start with a physical examination and ultrasound of the pelvic area, but a diagnosis of uterine cancer can only be made by checking a sample of tissue (biopsy). Cervical screening tests and Pap tests are not used to diagnose uterine cancer.

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. 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 cervical screening test or Pap test.

Pelvic ultrasound

A pelvic ultrasound uses soundwaves to create a picture of the uterus and ovaries. The soundwaves echo when they meet something dense, like an organ or tumour, then a computer creates a picture from these echoes. A technician called a sonographer performs the scan. It can be done in two ways, often at the same appointment.

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 abdomen.

Transvaginal ultrasound – You don't need a full bladder for this procedure. The sonographer covers a transducer wand with gel and inserts it into your vagina. Some women find a transvaginal ultrasound uncomfortable, but it should not be painful.

If you feel embarrassed or concerned about having a transvaginal ultrasound, talk to the sonographer beforehand. 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. Even if you have had an abdominal ultrasound, the transvaginal ultrasound will usually still be needed as it provides a clearer picture of the uterus.

A pelvic ultrasound appointment usually takes 15–30 minutes. The pictures can show if any masses (tumours) are present in the uterus. If anything appears unusual, your doctor will suggest you have a biopsy.

Endometrial biopsy

This type of biopsy can be done in the specialist's office and takes just a few minutes. A long, thin plastic tube called a pipelle is inserted into your vagina and through the cervix to gently suck cells from the lining of the uterus. This may cause some discomfort similar to period cramps. Your doctor may advise you to take a non-steroidal anti-inflammatory drug (e.g. ibuprofen) before the procedure to reduce this discomfort. The sample of cells will be sent to a specialist doctor called a pathologist for examination under a microscope. If the results are unclear, you may need another type of biopsy taken during a hysteroscopy.

Hysteroscopy and biopsy

This type of biopsy is taken during a hysteroscopy, which allows the specialist to see inside your uterus and examine the lining for abnormalities. It will usually be done in hospital under a general anaesthetic.

The doctor inserts a thin tube with a tiny light and camera (known as a hysteroscope) through your vagina into the uterus. To take the biopsy, the doctor uses surgical instruments to gently widen (dilate) the cervix and then remove some tissue from the uterine lining. This is known as a dilation and curettage (D&C). You will stay in hospital for a few hours and are likely to have period-like cramps and light bleeding for a few days afterwards.

Further tests

After uterine cancer is diagnosed, you may have blood tests to check your general health. Your doctor may also arrange one or more of the imaging tests below to see if the cancer has spread outside the uterus.

X-rays – You may have a chest x-ray to check your lungs and heart.

CT scan – A CT (computerised tomography) scan uses x-ray beams to take many pictures of the inside of your body and then compiles them into one detailed picture. However, it is not able to detect very small (less than 1 cm) tumours.

You will be asked not to eat or drink anything (fast) before the CT scan. You may need to have an injection of or drink a special dye

(the contrast) that makes your organs appear white in the pictures, so anything unusual can be seen more clearly. You will lie on a table that moves in and out of the scanner, which is large and round like a doughnut. The test is painless and takes about 15 minutes.

MRI scan – MRI (magnetic resonance imaging) is not covered by Medicare for uterine cancer, so check with your doctor what costs are involved. This scan uses a powerful magnet and radio waves to create detailed cross-sectional pictures of the inside of your body.

If you are having an MRI scan, let your medical team know if you have a pacemaker or any other metallic object in your body. The magnet can interfere with some pacemakers, but newer pacemakers are often MRI-compatible. You will usually be asked to fast for four hours before the scan. As with a CT scan, a dye may be injected into a vein to help make the pictures clearer.

For the scan, you will lie on a treatment table that slides into a metal cylinder. The test is painless, but the noisy, narrow machine makes some people feel anxious or claustrophobic. If you think you may become distressed, mention it beforehand to the medical team. You may be given medicine to help you relax, and you will usually be offered headphones or earplugs. This test can take 30–90 minutes.



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

PET scan – Medicare covers the cost of PET (positron emission tomography) scans only for uterine sarcomas. PET scans are not routine for endometrial cancers, but may be recommended in particular cases – ask your doctor what costs are involved.

Before a PET scan, you will be injected with a small amount of a glucose (sugar) solution containing some radioactive material. You will rest for about 30–60 minutes while the solution spreads throughout your body, and you will then be scanned. 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 only about 15 minutes. The radioactive material in the glucose solution is not harmful and will leave your body within a few hours.

Genetic tests after surgery

In most cases, uterine cancer will be removed by surgery (see pages 23–30) and sent to a laboratory for further testing. For endometrial cancer, some of these tests will check whether you have particular signs in the cancer cells that may indicate a genetic cause for the cancer. For example, less than 5% of women with endometrial cancer have a fault (mutation) in the mismatch repair (MMR) genes, a problem known as Lynch syndrome. If you have Lynch syndrome, you are at increased risk of developing other cancers and it is important for you, your family and your doctors to know about this.

Staging and grading uterine cancer

Staging is a way to describe the size of the cancer and whether it has spread to other parts of the body. In some cases, the scans listed on pages 15–17 can show if the cancer has spread, but it is often not possible to be sure of the stage until after surgery (see pages 23–25). Grading describes how the cancer cells look under a microscope compared to normal cells and how aggressive they may be.

The stage and grade help your doctors work out the risk of the cancer returning and if you need further treatments (see pages 32–38). The table opposite shows how endometrial cancers are staged and graded. Uterine sarcomas are staged differently, so discuss this with your specialist.

Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your oncologists. However, it is not possible for anyone to predict the exact course of the disease in an individual person. Instead, your doctor can give you an idea about the general outlook for people with the same type and stage of cancer. You will also have tests to check how the cancer is responding to treatments.

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 all important in assessing your prognosis. As for most types of cancer, the outcomes tend to be better when uterine cancer is found and treated early.

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 lymph nodes in the pelvis or abdomen.	regionalised cancer
stage IV	The cancer has spread further, to the bladder or rectum, throughout the abdomen, to other parts of the body such as the bones or lung, or to lymph nodes in the groin.	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.



Key points about diagnosing uterine cancer

Main tests

If you have symptoms of uterine cancer, initial tests may include:

- pelvic examination – your doctor feels the abdomen and examines the vagina
- vaginal or cervical examination using a speculum
- pelvic ultrasound – abdominal and/or transvaginal ultrasound
- endometrial biopsy – your doctor takes a sample of cells from the uterus using a thin plastic tube (pipelle)
- hysteroscopy and biopsy – allows your doctor to see inside your uterus and remove a sample of tissue.

Other tests

Other tests can give more information about the cancer and often help guide treatment. These tests may include:

- blood tests
- x-rays
- CT, MRI and PET scans
- genetic tests on the cancer (after surgery).

Staging and prognosis

- The cancer will be given a stage (after surgery) and grade (before surgery). The stage describes how far it has spread, and the grade describes how fast it is growing. This helps your doctor work out the risk of the cancer returning after treatment.
- Prognosis means the expected outcome of a disease. If uterine cancer is diagnosed early, it can usually be successfully treated.



Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast, or you might be anxious to get started. Check with your specialist how soon treatment should begin – often it won't affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as you can before making a decision.

Know your options – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see page 11) and if the treatment centre is the most appropriate one for you – you may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

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

Ask questions – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 59 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

Consider a second opinion – You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or reassure you that you have explored all of

your options. Specialists are used to people doing this. Your GP or specialist can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the second specialist.

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

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

Should I join a clinical trial?

Your doctor or nurse may suggest that you take part in a clinical trial.

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

and led to better outcomes for people diagnosed with cancer.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time.

For more information, visit australiancancertrials.gov.au.

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



Treatment

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 needed. If cancer has spread beyond the uterus, radiation therapy, chemotherapy or hormone therapy may also be used.

Surgery

Cancer of the uterus is usually treated with an operation that removes the uterus and cervix (total hysterectomy), along with both fallopian tubes and ovaries (bilateral salpingo-oophorectomy). If the cancer has spread beyond the cervix, the surgeon may also remove a small part of the upper vagina and the ligaments supporting the cervix.

For more advanced or higher-grade tumours, the surgeon may suggest removing some nearby lymph nodes at the same time. This is called a pelvic lymphadenectomy, lymph node dissection or lymph node sampling and helps show whether cancer has spread outside the uterus.

Options for preserving fertility

If you have not yet been through menopause, the removal of the ovaries will bring it on. If your ovaries appear normal and you don't have any risk factors, you may be able to keep your ovaries.

A small number of women with early uterine cancer choose to wait until after they have had children to have a hysterectomy. These women are offered hormone therapy instead. This is not standard treatment and they need to be monitored closely. If having children is important to you, talk to your doctor about your particular situation.

Total hysterectomy and bilateral salpingo-oophorectomy

Most women with uterine cancer will have this operation, which removes the uterus, cervix, fallopian tubes and ovaries (as shown by the dotted line). Sometimes one or more pelvic lymph nodes (shown in grey) are also removed. A pathologist examines all removed tissue and fluids for cancer cells. The results will help confirm the type of uterine cancer you have, if it has spread (metastasised), and its stage and grade (see pages 18–19). The cancer may also be tested for particular gene changes (see page 17).

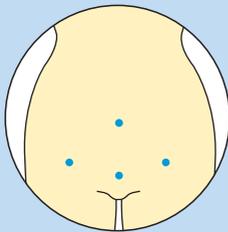
The surgery will be performed under a general anaesthetic. It can be done in different ways, as shown in the diagrams below. The type of hysterectomy offered to you will depend on a number of factors, including:

- your age and build
- the size of your uterus
- the size of the tumour
- the surgeon's specialty and experience.

Your surgeon will talk to you about the most appropriate surgery for you and explain the risks and benefits.

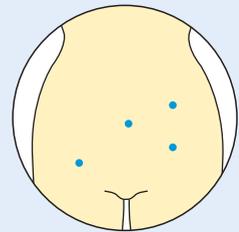
Laparoscopic hysterectomy

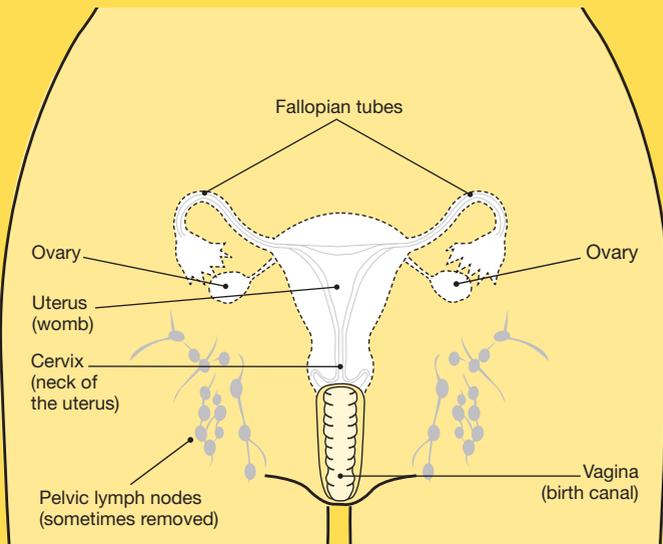
Also called keyhole surgery, this method uses a laparoscope, a thin tube with a light and camera. The surgeon inserts the laparoscope and instruments through 3–4 small cuts in the abdomen. The uterus and other organs are removed via the vagina.



Robotically assisted hysterectomy

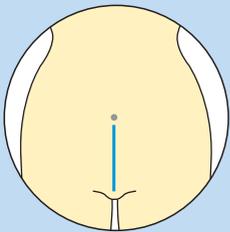
A robotically assisted hysterectomy is a special form of laparoscopic hysterectomy. The instruments and camera are inserted through 4–5 small cuts and then controlled by robotic arms guided by the surgeon, who sits next to the operating table.





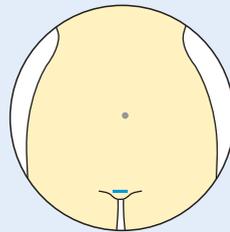
Abdominal hysterectomy (laparotomy)

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. The uterus and other organs are then removed.



Vaginal hysterectomy

The surgery is performed through a small cut at the top of the vagina. This method does not allow the surgeon to check whether the cancer has spread to other parts of the pelvis.



What to expect 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.

Tubes and drips – You will have an intravenous drip in your arm to give you medicines and fluid, and a tube in your bladder (catheter) to collect urine. These will usually be removed the day after the operation.

Pain – As with all major operations, you will have some discomfort or pain. For the first day or two, you may be given pain medicine. This may be delivered in different ways, such as:

- through a drip
- via a local anaesthetic injection into the abdomen (a transverse abdominis plane, or TAP, block)
- via a local anaesthetic injection into your back, either into spinal fluid (a spinal) or into the space around spinal nerves (an epidural)
- with a patient-controlled analgesia (PCA) system, a machine that allows you to press a button for a measured dose of pain relief.

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.

Wound care – You can expect some light vaginal bleeding after the surgery, which should stop within two weeks. Your treatment team will talk to you about how you can keep the wound/s clean to prevent infection once you go home.

Blood clot prevention – You will 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. You may also be advised to wear compression stockings for a couple of weeks to help the blood in your legs circulate.

Constipation – The medicines used during and after surgery can cause constipation (difficulty passing bowel motions). Talk to your treatment team about how to manage this – they may suggest a stool softener, fibre supplement, or another medicine. Once your surgeon says you can get out of bed, walking around can also help.

Length of stay – You will stay in hospital for about 1–4 days. The length of stay will depend on the type of surgery you have had and how quickly you recover.

Test results – 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.

“ I had a total hysterectomy and some of my lymph nodes were removed as well. Fortunately, the cancer hadn’t spread, but because it was grade 3 the doctor recommended I have chemotherapy and radiation therapy. ” Julie

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 usual activities after 4–8 weeks. In general, women do not need specific help to recover, but if you think you may 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.

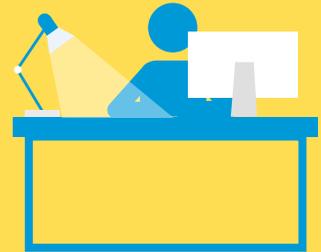


Lifting

Avoid heavy lifting (more than 3–4 kg) for 2–3 months, depending on the advice of your surgeon. This will depend on the method of the surgery.

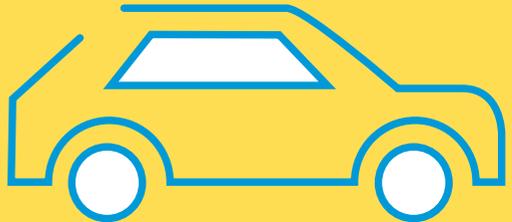
Work

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



Driving

You will need to avoid driving for about a month after the surgery. Check with your car insurer for any exclusions regarding major surgery and driving.



Bowel problems

It is important to avoid straining when passing bowel motions. Continue to manage constipation as advised by your treatment team (see page 27).



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 up to 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 side effects of treatment, speed up a return to usual activities, and improve overall quality of life. Start with a short walk and then 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.

Side effects after surgery

Menopause – If you had a bilateral salpingo-oophorectomy and had not been through menopause before the operation, the removal of your ovaries will cause menopause. For more about menopause, see pages 40–41. If you are concerned about fertility, see page 42.

Vaginal vault prolapse – After a hysterectomy, the top of the vagina can drop towards the vaginal opening because the structures that support it have weakened. To help avoid a prolapse, it is important to do pelvic floor exercises several times a day. Most women can start these exercises 1–2 weeks after surgery. Your treatment team may explain how to do these exercises. You can also consult a women's health physiotherapist – you may be able to see one at the hospital or you can ask your GP for a referral.

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

Impact on sexuality – The changes you experience after surgery may affect how you feel about sex and how you respond sexually.

➤ See page 49 and our *Sexuality, Intimacy and Cancer* booklet.

Lymphoedema – The removal of lymph nodes from the pelvis can stop lymph fluid from draining normally, causing swelling in the legs known as lymphoedema. The risk of developing lymphoedema is low following most operations for cancer of the uterus in Australia, but it is higher in women who had a lymphadenectomy (see page 23) followed by external beam radiation therapy (see pages 32–35).

Symptoms appear gradually, sometimes years after the treatment. Your treatment team will explain how to reduce your risk.

➤ See page 48 and our *Understanding Lymphoedema* fact sheet.



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, removing the uterus, cervix and ovaries, as well as some of the 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 radiation therapy 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 offering telephone peer support with Cancer Council's 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.

Radiation therapy

Also known as radiotherapy, radiation therapy is the use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams. Treatment is carefully planned to limit damage to the surrounding healthy tissues.

For cancer of the uterus, radiation therapy is commonly used as an additional treatment after surgery to reduce the chance of the disease coming back. This is called adjuvant therapy. In some cases, radiation therapy may be recommended as the main treatment if other health conditions mean you are not well enough for a major operation.

There are two main ways of delivering radiation therapy: internally or externally. Some women are treated with both types of radiation therapy. Your radiation oncologist will recommend the course of treatment most suitable for you.

Internal radiation therapy (brachytherapy)

Internal radiation therapy may be used after a hysterectomy to deliver radiation directly to the top of the vagina (vaginal vault) from inside your body. This is known as vaginal vault brachytherapy.

During each treatment session, a plastic cylinder (the applicator) is inserted into the vagina. The applicator is connected by plastic tubes to a machine that contains radioactive material in the form of a small metal seed. Next, this seed is moved from the machine through the tubes into your body. After a few minutes, the seed is returned to the machine. The applicator is taken out after each session.

Brachytherapy does not need any anaesthetic, and each treatment session usually takes only 20–30 minutes. You are likely to have 3–6 treatment sessions as an outpatient over 1–2 weeks.

If a hysterectomy has not been done and radiation is given as the main treatment, the internal radiation therapy may involve an applicator being placed inside the uterus. This is done under general anaesthetic or sedation, and may require a short hospital stay.

External beam radiation therapy

External beam radiation therapy (EBRT) directs the radiation 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 large machine known as a linear accelerator, which delivers the radiation.

The actual treatment takes only a few minutes each time and is painless (like having an x-ray). However, the planning may involve a number of visits to your doctor to have more tests, such as blood tests and scans.

You will probably have EBRT sessions from Monday to Friday for 4–6 weeks. You usually receive this treatment as an outpatient and won't need to stay in hospital. 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.

- ▶ See the next two pages for side effects, and our *Understanding Radiation Therapy* booklet for more information.

Side effects of radiation therapy

The side effects you experience will vary depending on the type of radiation, the dose of radiation and the areas treated. Brachytherapy tends to have fewer side effects than EBRT. Side effects often get worse during treatment and just after

Short-term side effects

fatigue

(see also page 43)

Your body uses a lot of energy to recover, and travelling to treatment can also be tiring. The fatigue may last for weeks after treatment ends. Exercise can help manage fatigue.

bowel and bladder problems

(see also pages 45–47)

Radiation therapy can cause inflammation and swelling of the bowel (radiation proctitis) and bladder (radiation cystitis). Bowel motions may be more frequent, urgent or loose (diarrhoea), or you may pass more wind than normal. Less commonly, there may be blood in the stools. You may also pass urine more often or with more urgency, or with a burning sensation. Your treatment team will prescribe medicines to reduce these side effects.

nausea and vomiting

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

vaginal discharge

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

skin redness, soreness and swelling

The vulva and the skin in the groin area may become sore and swollen. It may start by being pink or red and feeling itchy, and then peel, blister or weep. Your treatment team will recommend creams and pain relief to use. Wash the vulva with lukewarm water or weak salt baths, avoid perfumed products, and wear cotton underwear.

the course of treatment has ended. They usually get better within weeks, though some may continue for longer. Some side effects may not show up until many months or years after treatment. These are called late effects.

Long-term or late effects

hair loss

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

bowel and bladder changes

(see also pages 45–47)

Bowel changes, such as diarrhoea, wind or constipation, and bladder changes, such as frequent or painful urination, can also be late effects, appearing months or years after treatment. Bleeding from the bowel or bladder can also occur. In rare cases, women experience loss of bowel control (faecal incontinence) or blockage of the bowel. It is important to let your doctor know if you have any bleeding or if you have pain in the abdomen and cannot open your bowels.

lymphoedema

(see also page 48)

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

narrowing of the vagina

(see also page 44)

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

menopause

(see also pages 40–42)

In premenopausal women, radiation therapy to the pelvis can stop the ovaries producing hormones, and this causes early menopause. Your periods will stop, you will no longer be able to become pregnant and you may have menopausal symptoms. Talk to your radiation oncologist about these issues. You may be able to visit a menopause clinic.

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 of uterine cancer
- when cancer comes back after surgery or radiation therapy to try to control the cancer and to relieve symptoms
- if the cancer does not respond to hormone therapy
- if the cancer has spread beyond the pelvis when first diagnosed
- during radiation therapy (chemoradiation) and/or after radiation therapy.

Chemotherapy is usually given by injecting the drugs into a vein (intravenously). You may be treated as an outpatient or, very rarely, 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. Talk to your doctor 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, fatigue, some thinning and loss of body and head hair, and numbness and tingling in the hands and feet (peripheral neuropathy). Most side effects are temporary and steps can often be taken to prevent or reduce their severity.

➤ See our *Understanding Chemotherapy* booklet.

Targeted therapy for cancer of the uterus

Targeted therapy is a new kind of drug treatment that attacks specific features of cancer cells to stop the cancer growing and spreading. Your oncologist may discuss additional testing of the tumour to see whether any of these drugs might be an option, particularly for cancer that has

returned. Targeted therapy drugs are not yet standard treatment for cancer of the uterus, but you can ask your oncologist whether you may be able to access them through a clinical trial (see page 22).

➤ See our *Understanding Targeted Therapy* fact sheet.

Hormone therapy

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 oestrogen and/or progesterone to grow. These are known as hormone-dependent or hormone-sensitive cancers and can sometimes be treated with hormone therapy.

Hormone therapy may be recommended for uterine cancer that has spread or come back (recurred), particularly if it is a low-grade cancer. It is also sometimes offered as the first treatment if surgery has not been done (e.g. when a young woman with early, low-grade uterine cancer chooses not to have a hysterectomy because she wants to have children, or if a woman is too unwell for surgery).

The main hormone therapy for women with hormone-dependent cancer of the uterus is progesterone that has been produced in a

laboratory. Progesterone is available in tablet form (usually 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.

Palliative treatment

Palliative treatment helps to improve people's quality of life by managing symptoms of cancer without trying to cure the disease. Many people think that palliative treatment is for people at the end of their life, but it can help 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 radiation therapy, chemotherapy or hormone therapy. Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, practical, emotional, spiritual and social needs. The team also supports families and carers.

- ▶ See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets.



Key points about treating uterine cancer

Surgery

- The main treatment for cancer of the uterus is usually surgery to remove the uterus and cervix. This operation is called a total hysterectomy.
- In most cases, both fallopian tubes and ovaries will be removed at the same time. This is called a bilateral salpingo-oophorectomy. Lymph glands may also be removed.
- For many women, surgery will be the only treatment they need.

Radiation therapy

- Radiation therapy may be used as an additional treatment after surgery. It may also be used as the main treatment if other health conditions mean you are not well enough for a major operation.
- The radiation may be delivered directly to the tumour from inside your body (vaginal vault brachytherapy) and/or from outside the body by a large machine (external beam radiation therapy or EBRT).

Chemotherapy and hormone therapy

- Chemotherapy may be used if the cancer has spread beyond the uterus, or if the cancer comes back after surgery or radiation therapy.
- Hormone therapy targets cancers of the uterus that depend on hormones to grow. The main hormone therapy for uterine cancer is progesterone.



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.

Once cancer treatment finishes, many women worry about the cancer coming back. See page 54 for more information about recurrence or call Cancer Council 13 11 20 to talk through your concerns.

Menopause

The ovaries produce the hormones oestrogen and progesterone. If both ovaries have been removed or if you've had radiation therapy to 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, night sweats, dry or itchy skin, mood swings, trouble sleeping (insomnia), tiredness, vaginal dryness, weight gain, and bladder problems.

The symptoms of menopause caused by cancer treatment are usually more severe than during a natural menopause because the body hasn't had time to get used to the gradual decrease in hormone levels.

A loss of oestrogen at menopause may cause bones to weaken and break more easily. This is known as osteoporosis. Radiation therapy to the pelvis can also weaken the bones.

Cholesterol levels can change after menopause. This can increase your risk of heart disease, so these levels will need to be monitored.



Tips for managing menopausal symptoms

- Try vaginal moisturisers from pharmacies to help with vaginal discomfort and dryness.
- Ask your doctor if you need to avoid products containing oestrogen. They can suggest non-hormonal medicines for menopausal symptoms.
- If your menopausal symptoms are severe, talk to your gynaecological oncologist about the risks and benefits of taking hormone replacement therapy (HRT) to reduce the symptoms. HRT is not usually used in women with uterine cancer because oestrogen may cause the cancer to grow. If you were already on HRT when the cancer was diagnosed, you may need to consider stopping its use.
- 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**).
- Try to improve cholesterol levels with regular exercise and a balanced diet. You can also discuss cholesterol-lowering medicines with your doctor.
- Learn meditation and relaxation techniques, which may reduce stress and lessen some of the symptoms of menopause.
- Ask for a referral to a specialist menopause clinic if needed.

“ I now understand what they mean by ‘information means control’. Seeking accurate, reliable information was a huge coping strategy for me. ” Sonya

Infertility

Although most women are older and postmenopausal when they are diagnosed with uterine cancer, it does occasionally affect younger women who have not yet been through menopause. If premenopausal women have surgery or radiation therapy for uterine cancer, they will be unable to have children.

If you may want to have children in future, it is important to talk to your doctor before your treatment starts. It may be possible to preserve the ovaries and sometimes the uterus so you can still have children (see page 23). However, this is not standard treatment and is an option only in certain cases. If it is an option for you, your doctor will explain the risks and benefits.

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 helpful. You can also call Cancer Council 13 11 20 to talk to a health professional about your concerns.

► See our *Fertility and Cancer* booklet.

Fatigue

It is common to feel very tired and lack energy during and after treatment. This can be a side effect of the treatment itself or a symptom of menopause (see pages 40–41). 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 affect your ability to keep working 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, and allow yourself plenty of time to get to appointments.
- 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.
- Talk to your employer about taking time off, reducing your hours or working from home.
- Do some regular exercise – even a walk around the block can boost energy levels. Evidence shows that exercise reduces cancer-related fatigue, so talk to your specialist or GP about what activities are right for you. You can ask for a referral to an exercise physiologist or physiotherapist.
- Eat nutritious foods to keep your energy levels up, and limit your alcohol intake.
- ▶ Listen to our “Managing Cancer Fatigue” podcast.

Vaginal narrowing and dryness

Radiation therapy 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 uncomfortable or difficult, and may make it painful to have sex.

Your treatment team may recommend using a vaginal moisturiser or lubricant (available over-the-counter from pharmacies) or a hormone cream (available on prescription and safe with many uterine cancers). They may also advise you to start using vaginal dilators (or have regular sexual intercourse) some weeks after radiation therapy ends.



Tips for using vaginal dilators

- Vaginal dilators are tube-shaped devices made from plastic or silicone. They come in different sizes and may help keep the vaginal walls open.
- Ask your treatment team if they will provide the dilators or where you can buy them. Your team will explain when and how to start using the dilators.
- Make sure any soreness or inflammation has settled down before you start using dilators. This will usually be 2–6 weeks after your last session of radiation therapy.
- Start with the smallest dilator and move up sizes as each becomes more comfortable.
- Find a private place. Using a water-based lubricant, slowly insert a dilator into the vagina. Leave it for 5–10 minutes. Do this once or twice a day for the first few months, and then 2–3 times per week for several months after that, as advised by your team.

Bladder problems

After treatment for cancer of the uterus, some women experience bladder problems. Most bladder side effects are temporary or can be managed.

Urinary incontinence – 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 information about how to manage accidental or involuntary loss of urine (urinary incontinence), talk to the hospital continence nurse or a women's health physiotherapist. They will explain how to do 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.

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

Radiation cystitis – Radiation therapy 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 known as radiation cystitis. Try to drink plenty of water to make your urine less concentrated. Urinary alkalisers (e.g. Ural) are available over-the-counter from pharmacies and can help by making the urine less acidic. Your doctor may also prescribe medicine to treat cystitis.

Blood in urine – The blood vessels in the bladder can become more fragile after radiation therapy. This can cause blood to appear in your urine, even months or years after treatment. Always let your doctor know if you notice new or unusual bleeding.

Bowel problems

Surgery, radiation therapy and medicines can cause changes to the way the bowels work. These changes are usually temporary, but for some women, they are permanent and can have a significant impact on quality of life. It is important to talk to your treatment team if you are finding bowel issues difficult to manage.

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.

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 number of bowel motions.

Radiation proctitis – Radiation therapy can damage the lining of the rectum, causing inflammation and swelling known as radiation proctitis. This can cause a range of symptoms including blood in bowel motions; frequent passing of loose, watery stools (diarrhoea); the need to empty the bowels urgently; and loss of control over the bowels (faecal incontinence).

Talk to your treatment team about your risk of developing radiation proctitis. If you have any ongoing bowel problems, they may refer you to a gastroenterologist.



Tips to manage bowel changes

For 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, fruits, nuts and seeds.
- Reduce your alcohol intake.
- Do some gentle exercise, such as 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 for constipation as directed by your doctor.

For 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 coffee, cola and other caffeinated drinks.
- Choose low lactose or soy-based dairy products; small amounts of cheese and yoghurt are usually okay.
- Ask your doctor about suitable medicines for diarrhoea. 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 by radiation therapy or removed during surgery, it may prevent lymph fluid from draining properly. This causes fluid build-up and swelling. In some cases, the swelling can take months or years to develop, and some women who are at risk never develop lymphoedema. Although 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, see your GP as soon as possible.



How to prevent and manage lymphoedema

- Ask for a referral to a lymphoedema practitioner, who can suggest ways to help lymph fluid circulate, such as self-massage, exercises, and compression bandages or stockings. To find a practitioner, visit lymphoedema.org.au.
 - Move lymph fluid out of the affected area by doing leg exercises and gently massaging the swollen leg towards your heart. Elevate your legs when resting.
 - Keep the skin healthy and unbroken to reduce the risk of cellulitis. Use moisturiser and sunscreen, and avoid scratches, cuts, burns, insect bites, and injections in your legs. Keep your feet clean and dry to avoid fungal infections.
 - Talk to your GP about ways to stay or become a healthy weight for your height.
- See our *Understanding Lymphoedema* fact sheet.

Changes to sexuality and intimacy

Cancer of the uterus can change your body and how you feel about yourself, and both can affect sexuality.

Some treatments for cancer of the uterus can cause dryness and narrowing of the vagina. If this makes sexual penetration difficult or painful, you may have to explore different ways to orgasm or climax. Your treatment team may also advise using vaginal dilators, lubricants, moisturisers or hormone creams (see page 44). Other physical and emotional factors may affect your desire for sex (libido). These include the hormonal changes of menopause, the stress of the cancer experience, the fatigue caused by treatment, and changes in how you feel about your body (body image).

It may help to remember that for most people, sex is more than arousal, intercourse and orgasm. It involves feelings of intimacy and acceptance, as well as being able to give and receive love. Give yourself time to get used to any physical or emotional changes. If you have a partner and do not feel like having sexual intercourse, or if you find it uncomfortable, talk openly with them about how you're both feeling, and take things slowly by starting with hugs or a massage rather than penetrative sex. You may both need to be patient – things often improve with time and practice.

If you have ongoing concerns about how treatment has affected your sexuality, you can talk to your GP or gynaecological oncologist or ask for a referral to a sexual therapist.

- ▶ See our *Sexuality, Intimacy and Cancer* booklet and listen to our “Sex and Cancer” podcast.



Key points about managing side effects

Menopause and fertility

- If you are not already menopausal, surgery or radiation therapy for uterine cancer will mean your periods will stop. You will experience symptoms of menopause.
- If fertility is a concern for you, discuss this with your doctor before treatment starts.

Fatigue

- It is common to feel very tired during and after cancer treatment.
- Plan your daily activities, do some regular exercise, and ask for help around the house.

Other side effects

- Some treatments can make the vagina narrow and dry. Vaginal dilators, moisturisers, lubricants and hormone creams may help.
- Some women have accidental or involuntary loss of urine (urinary incontinence), but pelvic floor exercises can help. You may also be prone to bladder irritation (cystitis).
- Constipation, diarrhoea or pain in the lower abdomen can often be managed with changes to your diet.
- Exercises, massage and compression stockings may help to reduce any swelling in the legs (lymphoedema).
- See your doctor quickly if your legs become red or swollen or if you have a fever, as this may indicate an infection called cellulitis.
- You may feel less interested in sex because of physical or emotional changes. Take things slowly and communicate with your partner.



Looking after yourself

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

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

➤ See our *Nutrition and Cancer* booklet.

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

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

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

➤ See our *Understanding Complementary Therapies* booklet.



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

Work and money – Cancer can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check with a social worker or Cancer Council whether any financial assistance is available to you.

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

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

➤ See our *Emotions and Cancer* booklet.

Sexuality – Cancer can affect your sexuality in 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. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

➤ See page 49 and our *Sexuality, Intimacy and Cancer* booklet.

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

➤ See page 42 and our *Fertility and Cancer* booklet.



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 that every ache and pain means the cancer is coming back.

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

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

► See our *Living Well After Cancer* booklet.

Dealing with feelings of sadness

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

This is quite common among people who have had cancer.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people

can get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Cancer Council may also run a counselling program in your area.

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

Follow-up appointments

After treatment ends, you will have regular appointments with your specialists to monitor your health, manage any long-term side effects and check that the cancer hasn't come back or spread. During these check-ups, you will usually have a pelvic examination and may have blood tests, x-rays and imaging scans. You can also discuss how you're feeling and mention any concerns you may have.

Many women will have check-ups every 3–6 months for the first two years and then every 6 months for a few years after that. This may vary depending on the type and stage of the cancer, so check your follow-up plan with your specialists. Check-ups will become less frequent if you have no further problems. Between follow-up appointments, let your doctor know immediately of any symptoms or health problems.

When a follow-up appointment or test is approaching, many people find that they think more about the cancer and may feel anxious. Talk to your treatment team or call Cancer Council 13 11 20 if you are finding it hard to manage this anxiety.

What if the cancer returns?

For some women, uterine cancer does come back after treatment, which is known as a recurrence. This is why it's important to have regular check-ups and to report symptoms (e.g. vaginal bleeding, pain in the abdomen, swelling, unexpected weight loss, unexplained cough) straightaway rather than waiting for your next appointment. Most uterine cancers that come back do so in the first three years after treatment. If the cancer does come back, you will usually be offered further treatment.



Seeking support

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

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

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

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

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

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

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

Cancer Council 13 11 20

Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).



Information resources

Cancer Council produces booklets and fact sheets on over 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call **13 11 20** or visit your local Cancer Council website (see back cover).

Practical help

Your local Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation services.



Legal and financial support

If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council **13 11 20** to ask if you are eligible.

Peer support services

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



Useful websites

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

Australian

Cancer Council Australia	cancer.org.au
Cancer Australia	canceraustralia.gov.au
Cancer Council Online Community	cancercouncil.com.au/OC
Optimal Care Pathways	cancerpathways.org.au
<i>The Thing About Cancer</i> podcast	cancercouncil.com.au/podcasts
Carer Gateway	carergateway.gov.au
Carers Australia	carersaustralia.com.au
Department of Human Services	humanservices.gov.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
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



Caring for someone with cancer

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

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

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

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

Carers Associations – Carers Australia works with the Carers Associations in each state and territory to provide information and services to carers. Call 1800 242 636 or visit carersaustralia.com.au.

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

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



Question checklist

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

Diagnosis

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

Treatment

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

Side effects

- What are the risks and possible side effects of each treatment?
- Will I have a lot of pain? What will be done about this?
- Can I work, drive and do my normal activities while having treatment?
- Will I still be able to have children? Should I see a fertility specialist?
- Will the treatment affect my sex life?
- Should I change my diet or physical activity during or after treatment?
- Are there any complementary therapies that might help me?

After treatment

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



Glossary

abdomen

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

adenocarcinoma

Cancer that starts in the mucus-producing (glandular) cells that form part of the lining of internal organs.

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 radiation therapy in which radioactive material is placed into or near the tumour.

cervical screening test

A test that checks cells taken from the cervix 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.

chemotherapy

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

clear cell carcinoma

A less common endometrial cancer.

CT scan

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

dilation and curettage (D&C)

A procedure that involves opening (dilating) the cervix and using a surgical instrument called a curette to scrape out the lining of the uterus (endometrium).

endometrial biopsy

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

endometrial cancer

Cancer that begins in the lining of the uterus (endometrium). It is the most common type of cancer of the uterus.

endometrial hyperplasia

An abnormal increase in the number of cells in the lining of the uterus (endometrium).

endometrial stromal sarcoma

A type of uterine sarcoma.

endometrioid cancer

The most common type of endometrial cancer.

endometriosis

A condition that causes endometrial tissue to grow outside the uterus, e.g. in the abdomen or ovaries.

endometrium

The lining of the uterus (womb).

external beam radiation therapy (EBRT)

Radiation therapy delivered to cancer from outside the body.

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.

fibroids

Benign (non-cancerous) growth in the muscle layer of the womb.

glandular cells

Cells that release mucus, hormones or other substances.

gynaecological oncologist

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

gynaecologist

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

hormone replacement therapy (HRT)

Drug therapy that supplies the body with hormones that it can no longer make naturally. Often used to treat the symptoms of menopause, but usually not recommended after uterine cancer.

hormones

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

hormone therapy

A treatment that blocks the body's natural hormones. It may be used when the cancer is growing in response to hormones. Also called endocrine therapy.

hysterectomy

Surgical removal of the uterus. A total hysterectomy also removes the cervix.

hysteroscopy

A procedure to look inside the uterus using a hysteroscope, a long tube with a tiny light and camera.

laparoscopic surgery

Surgery done through small cuts in the abdomen using a thin viewing instrument with a light and camera known as a laparoscope. Also called keyhole surgery or minimally invasive surgery.

laparotomy

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

leiomyosarcoma

A less common 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 makes immune cells.

lymph nodes

Small structures that 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.

Lynch syndrome

A disease that increases the risk of developing uterine, ovarian and bowel cancer. Previously called hereditary non-polyposis colorectal cancer (HNPCC).

malignant

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

malignant mixed Müllerian tumour

See uterine carcinosarcoma.

menopause

When a woman stops having periods (menstruating). This can happen naturally; because of chemotherapy, radiation therapy or hormone therapy; 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. A scan that uses magnetism and radio waves to take detailed, cross-sectional pictures of the body.

myometrium

Smooth muscle tissue that makes up most of the uterus.

oestrogen

The primary female sex hormone. It is made mainly by the ovaries and helps regulate the female reproductive cycle.

osteoporosis

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

ovary

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

ovulation

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

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 that causes the ovaries to produce too many male hormones, which affects the development and release of the eggs.

polyp

A projecting growth from a surface in the body, such as the inner lining of the uterus. Most polyps are benign, but they can become malignant.

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. Progesterone can be produced artificially to help shrink some cancers and control symptoms.

radiation therapy

The use of targeted radiation (usually x-ray beams) to kill or damage cancer cells so they cannot grow, multiply or spread. Also called radiotherapy. See also brachytherapy and external beam radiation therapy (EBRT).

robotic hysterectomy

A form of laparoscopic surgery where the instruments are controlled by robotic arms guided by the surgeon.

serous carcinoma

A type of endometrial cancer.

stroma (endometrial)

The connective tissue that supports the lining of the uterus (endometrium).

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 an internal part of the body.

undifferentiated sarcoma

An aggressive type of uterine sarcoma.

uterine carcinosarcoma

A less common endometrial cancer. Also known as a malignant mixed Müllerian tumour.

uterine sarcoma

A cancer affecting the muscle tissue (myometrium) or the connective tissue (stroma) of the uterus.

uterus

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

vagina

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

vaginal dilator

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

vulva

The external sexual organs (genitals) of a woman.

Can't find a word here?

For more cancer-related words, visit:

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

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3. N Colombo et al., "ESMO-ESGO-ESTRO Consensus Conference on Endometrial Cancer: diagnosis, treatment and follow-up", *Annals of Oncology*, vol. 27, 2016, pp. 16–41.
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How you can help

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

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

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

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

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

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

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



Cancer Council 13 11 20

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

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

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



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.*