

# Understanding Cancer of the Uterus

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



For information & support, call **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](http://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.

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

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, this information may answer some of your questions and help you think about what to ask your treatment team (see page 60 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 61). 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.<sup>1-2</sup>



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



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### **Key to icons**

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More information



Alert



Personal story



Tips

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# What is cancer?

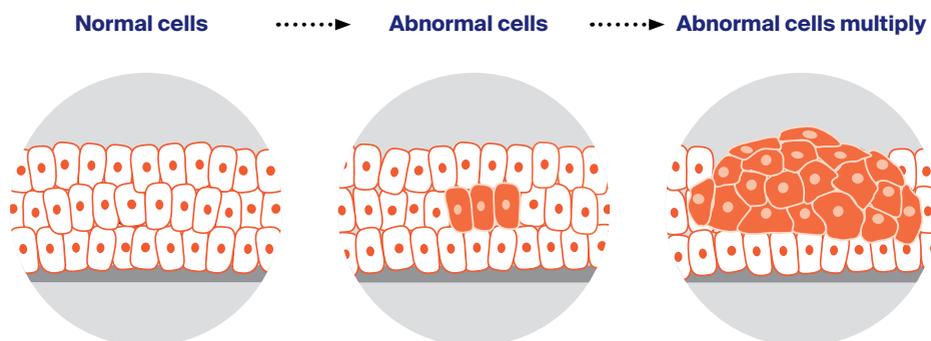
Cancer is a disease of the cells. Cells are the body's basic building blocks - they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

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

In solid cancers, such as 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.

## How cancer starts

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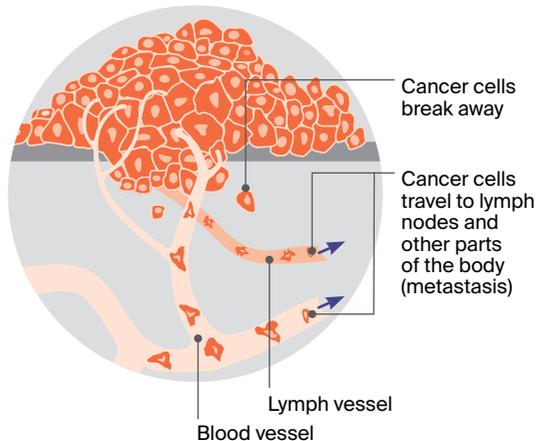
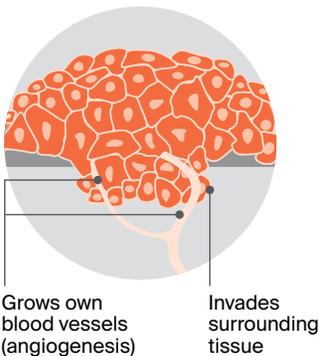


Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break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

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





# 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), vagina (birth canal) and vulva (external genitals).

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

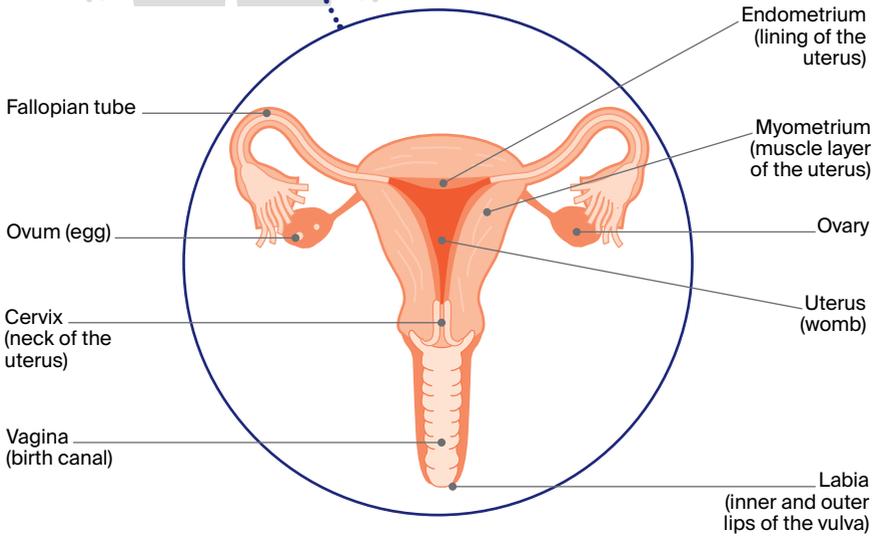
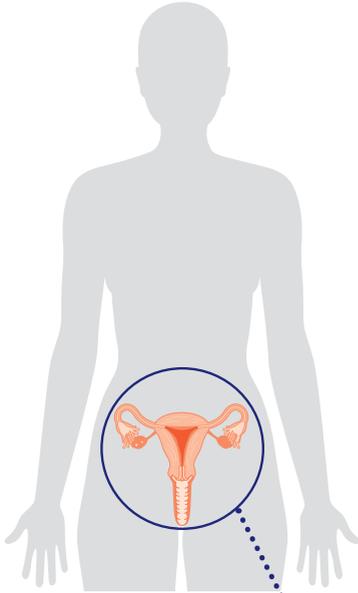
**Layers** – The uterus has two layers. The myometrium is the outer layer of muscle tissue and makes up most of the uterus. The endometrium is the inner layer or lining.

**Menstruation** – Each month, from puberty to menopause, the endometrium becomes thicker to prepare for pregnancy. If no pregnancy occurs, some of the lining is shed and flows out of the body through the vagina. This flow is known as a monthly period (menstruation).

**Menopause** – The hormones oestrogen and progesterone control the release of eggs (ovulation) and the timing of menstruation. As you get older, the ovaries gradually produce less of these hormones. When the levels of oestrogen and progesterone fall low enough, periods become irregular and finally stop. This is known as menopause. After menopause, you can't conceive a child naturally. The uterus also becomes smaller and the endometrium becomes thinner.

# The female reproductive system

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# Key questions

## Q: What is cancer of the uterus?

**A:** Cancer of the uterus occurs when cells in any part of the uterus become abnormal, grow out of control and form a lump called a tumour. Cancer of the uterus can be either endometrial cancer or the less common uterine sarcoma.

## Types of cancer of the uterus

### Endometrial cancers (around 95% of all uterine cancers)

Cancers that begin in cells in the lining of the uterus (endometrium) are called endometrial cancers. There are two main types:

#### type 1 cancers (linked to an excess of oestrogen)

- type 1 cancers are the most common endometrial cancers and are usually called endometrioid cancers
- most are adenocarcinomas, which start in glandular cells
- usually grow slowly and are less likely to spread

#### type 2 cancers (not linked to oestrogen)

- type 2 cancers are much less common
- include uterine carcinosarcomas (also known as malignant mixed Müllerian tumours), serous carcinomas and clear cell carcinomas
- grow faster and are more likely to spread

### Uterine sarcomas (around 5% of all uterine cancers)

These are rare soft tissue sarcomas that develop in the cells in the muscle of the uterus (myometrium) or the connective tissue (stroma) that supports the endometrium. There are three types:

- **endometrial stromal sarcoma** – mostly low-grade, slow-growing tumours
  - **leiomyosarcoma** – faster-growing and more likely to spread
  - **undifferentiated sarcoma** – faster-growing and more likely to spread.
- ▶ See our *Understanding Soft Tissue Sarcoma* fact sheet.

## Q: How common is it?

**A:** Each year, about 3200 Australian women are diagnosed with uterine cancer, and most are over 50.<sup>3</sup> Uterine cancer is the fifth most common cancer in women and the most commonly diagnosed gynaecological cancer in Australia. (Cancers that affect the female reproductive system are known as gynaecological cancers.)

The number of women diagnosed with uterine cancer has increased in recent years, and includes younger women. This increase is likely to be due to rising rates of obesity and diabetes.

Anyone with a uterus can get uterine cancer – women, transgender men and intersex people. For information specific to your situation, speak to your doctor.

## Q: What are the symptoms?

**A:** The most common symptom of cancer of the uterus is unusual vaginal bleeding. This may include:

- a change in your periods
- heavier than usual periods
- bleeding between periods
- constant bleeding (periods that continue without a break)
- bleeding or spotting after menopause.

A less common symptom is a smelly, watery vaginal 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 see your doctor for a check-up.

## Q: What are the risk factors?

**A:** The exact cause of cancer of the uterus is unknown, but factors that can increase the risk include:

- **age** – uterine cancer is most common in women over 50 and in women who have stopped having periods (postmenopausal)
- **body weight** – being overweight or obese is a major risk factor; the higher your body mass index (BMI), the greater the risk
- **medical factors** – having diabetes; having previous pelvic radiation therapy for cancer; having endometrial hyperplasia (see box opposite)
- **family history** – having one or more close blood relatives diagnosed with uterine, ovarian or bowel cancer; or inheriting a genetic condition such as Lynch syndrome or Cowden syndrome
- **reproductive history** – not having children
- **hormonal factors** – starting periods before the age of 12; going through menopause after the age of 55; taking some types of oestrogen-only menopause hormone therapy (MHT), previously called hormone replacement therapy (HRT); or taking tamoxifen, an anti-oestrogen drug used for breast cancer.

Many women who have risk factors don't develop cancer of the uterus, and some women who get this cancer have no risk factors. If you are concerned about any risk factors, talk to your doctor. Maintaining a healthy body weight and being physically active are the best ways to reduce the risk of developing cancer of the uterus.



For an overview of what to expect at every stage of your cancer care, visit [cancer.org.au/cancercareguides/endometrial-cancer](https://cancer.org.au/cancercareguides/endometrial-cancer). This is a short guide to what is recommended for endometrial cancer, from diagnosis to treatment and beyond.

## Other uterine conditions

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Some 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 (not cancer), 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 tumours that begin in the muscle layer of the uterus (myometrium). They may be treated with surgery to remove the uterus (hysterectomy, see pages 23–30).
  - **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. It doesn't lead to cancer, but many people also have endometrial hyperplasia. Endometriosis 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. To ensure the best outcome, it is recommended that you are treated in a specialist centre for gynaecological cancer.

Treatment options will often 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

<b>gynaecological oncologist*</b>	diagnoses and performs surgery for cancers of the female reproductive system, e.g. uterine, cervical, ovarian, vulvar and vaginal cancers
<b>gynaecologist*</b>	specialises in diseases of the female reproductive system; may diagnose cancer of the uterus and then refer you to a gynaecological oncologist
<b>radiation oncologist*</b>	treats cancer by prescribing and overseeing a course of radiation therapy
<b>medical oncologist*</b>	treats cancer with drug therapies such as chemotherapy, hormone therapy, targeted therapy and immunotherapy (systemic treatment)
<b>cancer care coordinator</b>	coordinates your 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)
<b>nurse</b>	administers drugs and provides care, information and support throughout treatment
<b>fertility specialist*</b>	diagnoses, treats and manages infertility and reproductive hormonal disorders
<b>women's health physiotherapist</b>	assists with physical problems associated with gynaecological cancers, such as bladder and bowel issues, sexual issues and pelvic pain
<b>lymphoedema practitioner</b>	educates people about lymphoedema prevention and management, and provides treatment if lymphoedema occurs; often a physiotherapist
<b>dietitian</b>	recommends an eating plan to follow during and after treatment
<b>social worker</b>	links you to support services and helps you with emotional, practical or financial issues
<b>psychologist, counsellor</b>	help you manage your emotional response to diagnosis and treatment

\* *Specialist doctor*

# Diagnosis

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 removing a tissue sample for checking (biopsy). Cervical screening tests and Pap tests are not used to diagnose uterine cancer.

## Pelvic examination

The doctor will feel your abdomen (belly) 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. You can ask for a family member, friend or nurse to be present during the examination.

## 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, and often you have both types 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 inserts a transducer wand into your vagina. It will be covered with a disposable plastic sheath and gel to make it easier to insert. You may 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, a friend or relative) if that makes you feel more comfortable.

If you have had an abdominal ultrasound, you will usually also need a transvaginal ultrasound 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 some pain-relieving medicine 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 of an endometrial biopsy 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 under a general anaesthetic as day surgery in hospital.

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.

The tissue sample will be sent to a laboratory, and a specialist doctor called a pathologist will look at the cells under a microscope. The pathologist will be able to confirm whether or not the cells are cancerous, and which type of uterine cancer it is.

## 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** – You will usually have a CT (computerised tomography) scan of your chest, abdomen and pelvis. A CT uses x-rays and a computer to create a detailed picture of the inside of the body. 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 scan. You may need to have an injection of or drink a special dye. This dye is called contrast and it 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 you will have to pay. 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 and it will slide into a large metal tube that is open at both ends. 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 between 30 and 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 if you are pregnant or breastfeeding.

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

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 30–60 minutes while the solution spreads throughout your body, then you will have the scan. 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 15–30 minutes. The radioactive material in the glucose solution is not harmful and will leave your body within a few hours.

## **Genetic tests after surgery**

Uterine cancer is usually removed surgically (see pages 23–30) and the removed tissue is sent to a laboratory for further testing. For endometrial cancer, some of these tests will check whether the cancer cells have features that indicate a genetic cause for the cancer. Knowing whether the tumour has one of these features may help your treatment team decide on suitable treatment options.

For example, a small number of endometrial cancers are caused by Lynch syndrome. This syndrome is characterised by a fault in the genes that helps the cell's DNA repair itself (called mismatch repair or MMR genes). 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 23–30). Grading describes how the cancer cells look under a microscope compared to normal cells and estimates how fast the cancer is likely to grow.

Knowing the stage and grade helps your doctors recommend the best treatment for your situation. The table on the opposite page 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 with your doctor, but it is not possible for anyone to predict the exact course of the disease. Instead, your doctor can give you an idea about the general outlook for people with the same type and stage of uterine cancer.

To work out your prognosis, your doctor will consider 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.

In general, the earlier cancer of the uterus is diagnosed, the better the outcome. Most early-stage endometrial cancers have a good prognosis with high survival rates. If cancer is found after it has spread to other parts of the body (advanced cancer), the prognosis is not as good and there is a higher chance of the cancer coming back after treatment.

## Stages of endometrial cancers

The four stages of endometrial cancer may be divided into sub-stages, such as A, B and C, which indicate increasing amounts of tumour.

<b>stage 1</b>	The cancer is found only in the uterus.	early or localised cancer
<b>stage 2</b>	The cancer has spread from the uterus to the cervix.	regionalised cancer
<b>stage 3</b>	The cancer has spread beyond the uterus/cervix to the ovaries, fallopian tubes, vagina, or lymph nodes in the pelvis or abdomen.	regionalised cancer
<b>stage 4</b>	The cancer has spread further, to the bladder, bowel 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

## Grades of endometrial cancers

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

## Key points about diagnosing cancer of the uterus

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### Main tests

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

- pelvic examination – your doctor feels the abdomen (belly) and examines the vagina
- vaginal or cervical examination using a speculum
- pelvic ultrasound – you may have an abdominal or transvaginal ultrasound, or both
- endometrial biopsy – your doctor takes a sample of cells from the uterus using a long, thin plastic tube called a pipelle
- hysteroscopy and biopsy – allows your doctor to see inside your uterus and remove a sample of tissue from the uterine lining.

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### 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).

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### Staging and prognosis

- Endometrial cancer will be given a stage and grade, which will be confirmed after surgery.
- The stage describes how far the cancer has spread. The grade describes how fast the cancer is growing.
- Prognosis means the expected outcome of a disease. If cancer of the uterus 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, as it may not affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as you can before making a decision.

**Know your options** – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see page 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 says you have cancer, you may not remember everything you are told. Taking notes can help, or you might like to ask if you can record the discussion. 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 60 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

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

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

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

## Should I join a clinical trial?

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

led to better outcomes for people diagnosed with cancer.

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

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

# Treatment

Cancer of the uterus is often diagnosed early, before it has spread, and can be treated surgically. In many cases, surgery will be the only treatment needed. If cancer has spread beyond the uterus, radiation therapy, hormone therapy or chemotherapy may also be used.

## How cancer treatment affects fertility

If you have not yet been through menopause, having a hysterectomy or radiation therapy for uterine cancer will mean you won't be able to become pregnant. If having children is important to you, discuss the options with your doctor before starting treatment and ask to see a fertility specialist.

A small number of women with early-stage, low-grade uterine cancer choose to wait until after they have had children to have a hysterectomy. These women are offered hormone therapy instead (see page 38). This is not standard treatment and they need to be monitored closely.

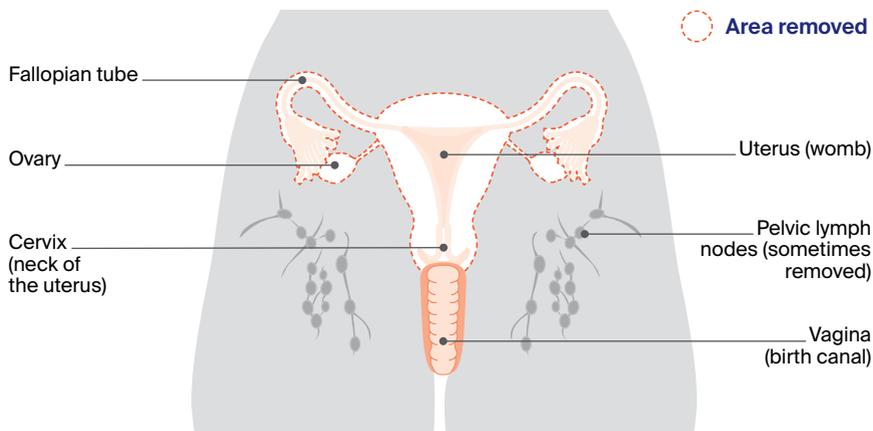
▶ See our *Fertility and Cancer* booklet.

## 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, see next page). If your ovaries appear normal, you don't have any risk factors, and it is an early-stage, low-grade cancer, you may be able to keep your ovaries. 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.

## Total hysterectomy and bilateral salpingo-oophorectomy

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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 to help with staging.

A pathologist examines all removed tissue and fluids. The results will help confirm the type of uterine cancer, if it has spread (metastasised), and its stage and grade. The cancer may also be tested for particular gene changes (see page 17).

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### How the surgery is done

The surgery will be performed under a general anaesthetic. The hysterectomy can be done in different ways.

**Laparoscopic hysterectomy (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 (belly). The uterus and other organs are removed through the vagina.

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

**Abdominal hysterectomy (open surgery or 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.

Your surgeon will discuss the most appropriate surgery for you, and explain the risks and benefits. The type of hysterectomy you have will depend on a number of factors, such as your age and build; the size of your uterus; the tumour size; and the surgeon's specialty and experience.

## **Treatment of lymph nodes**

Cancer cells can spread from the uterus to the pelvic lymph nodes. If cancer is found in the lymph nodes, your doctor may recommend you have additional treatment, such as chemotherapy or radiation therapy.

**Lymphadenectomy (lymph node dissection)** – For more advanced or higher-grade tumours, the surgeon may remove some lymph nodes from the pelvic area to see if the cancer has spread beyond the uterus.

**Sentinel lymph node biopsy** – This test helps to identify the pelvic lymph node that the cancer is most likely to spread to first (the sentinel node). While you are under anaesthetic, your doctor will inject a dye into the cervix. The dye will flow to the sentinel lymph node, which will be removed for testing. If it contains cancer cells, this will guide additional treatment, such as chemotherapy and radiation therapy. Sentinel lymph node biopsies are available only in some treatment centres.

## What to expect after surgery

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 (wee). These will usually be removed the day after the operation.

**Length of stay** – You will stay in hospital for about 1–4 days. How long you stay will depend on the type of surgery you have had and how quickly you recover. Most people who have laparoscopic surgery will be able to go home on the first or second day after the surgery (and occasionally on the day of surgery).

**Pain** – As with all major surgery, you will have some discomfort or pain. The level of pain will depend on the type of operation. After keyhole surgery, you will usually be given pain-relieving tablets. If you have open surgery, you may be given pain medicine in different ways:

- through a drip into a vein (intravenously)
- 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.

While you are in hospital, 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. After you go home, you can continue taking pain-relieving tablets as needed.

**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 up to four weeks to help the blood in your legs to circulate well and avoid clots.

**Constipation** – The medicines used during and after surgery can cause constipation (difficulty having bowel movements). Talk to your treatment team about how to manage this – they may suggest medicines to help prevent or relieve constipation. Once your surgeon says you can get out of bed, walking around can also help.

**Test results** – Your doctor will have all the test results about a week after the operation. Whether additional 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 further 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 the type of surgery you had, your age and general health. In most cases, you will feel better within 1–2 weeks and should be able to fully return to your usual activities after 4–8 weeks.

### Rest up



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 as much as you need to.

### Lifting



Avoid heavy lifting (more than 3–4 kg) for 4–6 weeks, 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 of leave from work. People who have laparoscopic surgery and have office jobs that don't require heavy lifting can often return to work after 2–4 weeks.

### Driving



You will need to avoid driving after the surgery until pain in no way limits your ability to move freely. Discuss this issue with your doctor. Check with your car insurer for any exclusions regarding major surgery and driving.

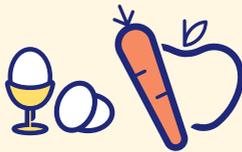
If you don't have support from family, friends or neighbours, ask your nurse or a social worker at the hospital whether it is possible to get help at home while you recover.

## Bowel problems



It is important to avoid straining during bowel movements. Continue to manage constipation as advised by your treatment team (see pages 46–47).

## Nutrition



To help your body recover from surgery, eat a well-balanced diet that includes a variety of foods. Include proteins such as lean meat, fish, eggs, milk, yoghurt, nuts, and legumes/beans.

## Bathing



Your doctor may advise taking showers instead of baths for 4–5 weeks after surgery.

## Exercise



Your treatment team will probably encourage you to walk the day of the surgery. Exercise has been shown to help people manage some treatment side effects and speed up a return to usual activities. Speak to your doctor about suitable exercise. To avoid infection, it's best to avoid swimming for 4–5 weeks after surgery.

## Sex



Sexual intercourse should be avoided for up to 8 weeks after surgery. Ask your doctor or nurse when you can have sex again, and explore other ways you and your partner can be intimate, such as massage.

## Side effects after surgery

**Menopause** – If your ovaries are removed and you have not been through menopause, removal will cause sudden menopause. For ways to manage menopausal symptoms, see pages 41–42. If you are concerned about fertility, see page 42.

**Impact on sexuality** – The changes you experience after surgery may affect how you feel about sex and how you respond sexually. You may notice changes such as vaginal dryness and loss of libido.

▶ 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 full lymphadenectomy (see page 25) followed by external beam radiation therapy (see pages 33 and 35). Symptoms appear gradually, sometimes years after the treatment. Your treatment team will explain how to reduce your risk.

▶ See page 50 and our *Understanding Lymphoedema* fact sheet.

**Vaginal vault prolapse** – This is when the top of the vagina drops towards the vaginal opening because the structures that support it have weakened. Having a hysterectomy does not appear to increase the risk of vaginal vault prolapse in women without pelvic floor issues. Prolapse is more commonly caused by childbirth and weak pelvic floor muscles. To help prevent 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 or you can see a women's health physiotherapist.

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



## 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 that I saw my GP again. 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 uses a controlled dose of 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 people 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.

This type of brachytherapy does not need any anaesthetic. 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 you are having radiation therapy as the main treatment and haven't had a hysterectomy, the internal radiation therapy may involve placing an applicator inside the uterus. This is done under 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.

Planning for EBRT may involve a number of visits to your doctor to have more tests, such as blood tests and scans. You will also be told about any special bladder or bowel preparations you have to take before each treatment.

Each EBRT session lasts about 30 minutes, with the treatment itself taking only a few minutes. You will lie on a treatment table under a large machine known as a linear accelerator, which delivers the radiation. The treatment is painless (like having an x-ray), but may cause side effects (see next two pages).

You will probably have EBRT as daily treatments, Monday to Friday, for 4–6 weeks as an outpatient. It's very important that you attend all of your scheduled sessions to ensure you receive enough radiation to make the treatment effective.

► See our *Understanding Radiation Therapy* booklet.

## Side effects of radiation therapy

The side effects you experience will vary depending on the type and 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 the course of treatment has

### Short-term side effects

**fatigue**  
(see also page 44)

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 movements may be more frequent, urgent or loose (diarrhoea), or you may pass more wind than normal. Less commonly, there may be blood in the faeces (poo or stools). You may also pass urine (wee) 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 the discharge 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. The area may look pink or red and feel 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.

ended. They usually get better within weeks, through 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. Sometimes, 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, there may be loss of bowel control (faecal incontinence) or blockage of the bowel. It is important to let your doctor know about any bleeding or if you have pain in the abdomen and difficulty opening your bowels.

### lymphoedema (see also page 50)

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. Look for early signs that you are developing lymphoedema to make treating it easier.

### narrowing of the vagina (see also page 48)

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 using vaginal dilators.

### menopause (see also pages 41–43)

If you are premenopausal, 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.

## Chemoradiation

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High-risk endometrial cancer is often treated with EBRT in combination with chemotherapy to reduce the chance of the cancer coming back after treatment is over.

When radiation therapy is combined with chemotherapy, it is known as chemoradiation. The chemotherapy drugs make the cancer cells more sensitive to radiation therapy.

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

Once the radiation therapy is over, you may have another four cycles of chemotherapy on its own.

Side effects of chemoradiation include fatigue; diarrhoea; needing to pass urine more often or in a hurry; cystitis (see page 45); dry and itchy skin in the treatment area; numbness and tingling in the hands and feet (peripheral neuropathy); and low blood counts. Low numbers of blood cells may cause anaemia, infections or bleeding problems.

Talk to your treatment team about ways to manage any side effects.

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## 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 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 (see page 38)
- if the cancer has spread beyond the pelvis when first diagnosed
- during radiation therapy (chemoradiation) or after radiation therapy.

Chemotherapy is usually given by injecting the drugs into a vein (intravenously). You will usually have several treatment sessions, with rest periods in between. Together, the session and rest period are called a cycle. 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.

Treatment is usually given to you during day visits to a hospital or clinic as an outpatient or, very rarely, you may need to stay in hospital overnight. Let your oncologist know if you are taking nutritional or herbal supplements as these can interact with chemotherapy and may affect how the drugs work.

## Side effects of chemotherapy

The side effects of chemotherapy vary greatly 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
- 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.



Chemotherapy can affect your immune system, increasing the risk of infection. If you develop a temperature over 38°C, contact your doctor or go immediately to the emergency department at your nearest hospital.

## Hormone therapy

Hormone therapy may also be called endocrine therapy or hormone-blocking 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 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 woman with early-stage, low-grade uterine cancer chooses not to have a hysterectomy because she wants to have children, or if a person is too unwell for surgery).

The main hormone therapy for hormone-dependent cancer of the uterus is progesterone that has been produced in a laboratory. High-dose progesterone is available in tablet form (usually medroxyprogesterone) or through a hormone-releasing intrauterine device (IUD) called a Mirena, which is placed into the uterus by your doctor (if you have not had a hysterectomy). Other hormone drugs may be available on clinical trials (see page 22). Talk to your doctor about the risks and benefits of the different methods.

## Side effects of hormone therapy

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.

## New drug treatments

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Some targeted therapy and immunotherapy drugs are being tested in clinical trials for people with endometrial cancer that has come back or not responded to treatment.

Targeted therapy is a drug treatment that attacks specific features of cancer cells to stop the cancer growing and spreading. Your medical oncologist may discuss testing the tumour to see whether there are any suitable targeted therapy drugs available through clinical trials.

Immunotherapy is a type of cancer treatment that uses the body's own immune system to fight cancer. It may be an option for some endometrial cancers that have a fault in the mismatch repair (MMR) genes.

Ask your doctor about recent developments in drugs for uterine cancer and whether a clinical trial may be an option for you.

► See our *Understanding Targeted Therapy* and *Understanding Immunotherapy* fact sheets.

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## 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 aims to meet your physical, emotional, cultural, social and spiritual needs. The team also supports families and carers.

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

## Key points about treating cancer of the uterus

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### 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.
- Surgery is often the only treatment needed.

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### 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).
- Radiation therapy may be used in combination with chemotherapy (chemoradiation) to treat more advanced cancer of the uterus.

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### Drug therapies

- 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 used for uterine cancer is high-dose progesterone.
  - New drug treatments may be available through clinical trials.
-

# 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 people 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.

Some treatment side effects may not show up for many months or years. These are called late effects. Before treatment starts, talk to your doctor about whether you are at risk of developing late effects from your treatment and what you can do to help prevent them. After treatment, make sure to see your GP for regular health checks.

## 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, aching joints, vaginal dryness, weight gain and bladder problems. You may also have a decreased interest in sex (low libido, see page 49).

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.

Menopause may cause other changes in the body. For example, your cholesterol levels may rise, which can increase your risk of heart disease. Over time, your bones may become weak and brittle, and break more easily. This is called osteoporosis. Radiation therapy to the pelvis can also weaken the bones.

## Fertility issues

Surgery or radiation therapy for uterine cancer may mean you are unable to become pregnant. Before treatment starts, ask your doctor or a fertility specialist about what options are available to you.

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 a cancer 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.



## Managing menopausal symptoms

- Vaginal moisturisers available over the counter at pharmacies can help with vaginal discomfort and dryness.
- Ask your doctor if you need to avoid products containing oestrogen. They can suggest non-hormonal medicines to relieve the symptoms of menopause.
- If your menopausal symptoms are severe, talk to your doctor about the risks and benefits of taking menopause hormone therapy (MHT), previously called hormone replacement therapy (HRT). MHT is not usually used for uterine cancer because oestrogen may cause the cancer to grow. If you were already on MHT 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](http://osteoporosis.org.au)).
- Have your cholesterol levels checked. If they are high, regular exercise and a balanced diet may help. If not, talk to your doctor about cholesterol-lowering drugs.
- Learn meditation and relaxation techniques, which may reduce stress and lessen some of the symptoms of menopause.
- Ask your doctor for a referral to a specialist menopause clinic if needed.
- Cognitive behaviour therapy (CBT) has been shown to help with many of the effects of menopause, including anxiety. Exercise can also help with mood changes and energy levels.
- You can also call Cancer Council 13 11 20 to talk to a health professional about your concerns.

# 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 41–42). 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.



## Managing fatigue

- Plan your day. Set small, manageable goals so you can rest regularly, and allow yourself plenty of time to get to appointments.
  - Do some light exercise, such as walking or stretching, to help increase your energy levels. Ask your doctor if these activities are suitable for you. You can also ask for a referral to an exercise physiologist or physiotherapist.
  - Ask for and accept offers of help from family and friends, e.g. with shopping, housework and driving.
- Contact your local council to see what services they offer.
- Learn to recognise signs of tiredness before you feel exhausted.
  - Talk to your employer about taking time off, reducing hours or working from home.
  - Don't expect to be able to instantly do everything you used to do. Your body is still recovering and it will take time for your energy levels to return.
- See our *Fatigue and Cancer* fact sheet and *Living Well After Cancer* booklet.

## Bladder changes

Treatment for cancer of the uterus can cause bladder problems. Most bladder side effects are temporary or can be managed. Talk to your treatment team for more information.

**Urinary incontinence** – This is when urine (wee) leaks from your bladder without your control. Some people find they need to pass urine more often or feel that they need to go in a hurry. Others may leak a few drops of urine when they cough, sneeze, strain or lift. The pelvic floor muscles control the flow of urine, so strengthening them can help manage urinary incontinence. You can find a guide to exercising the pelvic floor muscles in our *Exercise for People Living with Cancer* booklet. Using continence pads can help you manage any leakage and prevent any embarrassing accidents. A continence nurse or women's health physiotherapist can develop a bladder training program – ask your doctor for a referral or contact the National Continence Helpline on 1800 33 00 66 or at [continence.org.au](http://continence.org.au).

**Radiation cystitis** – Radiation therapy can irritate the lining of the bladder. You may feel like you want to pass urine often or have a burning sensation when you pass urine. This is known as radiation cystitis. Try to drink plenty of water to make your urine less concentrated. Urinary alkalisers 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. Keep in mind that it may not be related to your treatment.

## Bowel changes

Surgery, radiation therapy and medicines can cause changes to the way the bowels work. These changes are usually temporary, but for some people, 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 having a bowel movement 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 faeces (poo) from the bowels. A dietitian can suggest changes to your diet to reduce the number of bowel movements.

**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 movements; frequent passing of loose, watery faeces (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.

**Blood in bowel movements** – Blood vessels in the bowel can become more fragile after radiation therapy. This can cause blood to appear in your faeces, even months or years after treatment. Always seek advice from your specialist or GP if you notice any new or unusual bleeding.



## Managing bowel changes

### 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.
- Avoid drinking alcohol.
- Do some gentle exercise, such as walking. Check with your doctor about the amount and type of exercise that is right for you.
- 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.

### Diarrhoea

- Drink plenty of fluids such as water, herbal teas, sports drinks and electrolyte-replacing fluids. Avoid alcoholic drinks.
- Eat fewer high-fibre foods, e.g. wholegrain breads and cereals, raw fruits and vegetables, legumes.
- Eat more low-fibre foods, e.g. white rice, white pasta, white bread, potatoes.
- Limit spicy, fatty and greasy foods, as these can make diarrhoea worse.
- Cut down on coffee, cola and other drinks that contain caffeine.
- 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.

## 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 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 sexual intercourse regularly) some weeks after radiation therapy ends.



### 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 one becomes more comfortable.
- Find a private place. Apply a water-based lubricant, then 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 a week for several months after that, as advised by your team.

## Impact on sexuality

Cancer of the uterus can affect your sexuality in both physical and emotional ways.

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 (climax). Your treatment team may also advise using vaginal dilators, lubricants, moisturisers or hormone creams.

You may lose interest in intimacy and sex (low libido) because of 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. Closeness and sharing can still be part of your relationship.

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.

Give yourself time to get used to any changes. If you have ongoing concerns about how treatment has affected your sexuality, 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.

## Lymphoedema and cellulitis

After surgery or radiation therapy to the pelvic area, you may find that one or both legs become swollen. This is known as lymphoedema. It can happen if lymph fluid doesn't circulate properly and builds up in the legs. The swelling may appear during treatment or months or years later.

Lymphoedema can make movement and some types of activities difficult. It is important to maintain a healthy body weight, avoid pressure, injury or infection to the legs, and manage lymphoedema symptoms as soon as possible.

Mild lymphoedema is usually managed with exercise, skin care and a compression stocking. To find a health professional who specialises in the management of lymphoedema, speak to your treatment team or visit the Australasian Lymphology Association at [lymphoedema.org.au](http://lymphoedema.org.au).

The skin of the legs may become infected more easily after lymph glands are removed. A common skin infection is called cellulitis. Signs of cellulitis include redness, painful swelling in the legs, warm skin and fever. If you have any symptoms, see your GP as soon as possible.

Keep the skin healthy and unbroken to reduce the risk of infection. Exercise regularly and avoid tight-fitting clothing. Use moisturiser and sunscreen, and avoid scratches, cuts, burns, insect bites, and injections in your legs. Also keep your feet clean and dry to avoid fungal infections.

► See our *Understanding Lymphoedema* fact sheet.



If your GP refers you to an allied health professional as part of a Chronic Disease Management Plan, you may be eligible for a Medicare rebate for up to five visits each year. Ask your GP for more details.

## Key points about managing side effects

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### Menopause and fertility

- If you are not already menopausal, surgery or radiation therapy for cancer of the uterus 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.
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### 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

- Constipation, diarrhoea or pain in the lower abdomen can often be managed with changes to your diet.
  - If you find that urine leaks without your control (urinary incontinence), pelvic floor exercises can help. You may also experience bladder irritation (cystitis).
  - Some treatments can make the vagina narrow and dry. Vaginal dilators, moisturisers, lubricants and hormone creams may help.
  - You may feel less interested in sex because of physical or emotional changes. Take things slowly and talk openly with your partner.
  - Some people develop swelling in the legs (lymphoedema). Exercises, massage and compression stockings may help.
  - See your doctor quickly if your legs become red or swollen or if you have a fever, as these may be signs of an infection called cellulitis.
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# 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.

**Maintaining a healthy body weight and staying active** – Obesity is a risk factor for endometrial cancer. A healthy body weight is important for general health and reducing the risk of cancer coming back. Physical activity can reduce tiredness, improve circulation and lift mood. The right exercise for you depends on 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. They can increase your sense of control, decrease stress and anxiety, and improve your mood. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

▶ See our *Understanding Complementary Therapies* booklet.



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

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

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

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

► See our *Emotions and Cancer* booklet.

## Effect on your emotions

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Changes to your body can affect the way you feel about yourself (your self-esteem) and make you feel self-conscious. You may feel less confident about who you are and what you can do. Try to see yourself as a whole person (body, mind and personality), instead of focusing on the parts that have changed.

It is normal to experience a wide variety of emotions after treatment,

including anger, fear and resentment. These feelings may become stronger over time as you adjust to the physical side effects of treatment.

Everyone has their own ways of coping with their emotions. There is no right or wrong way. It is important to give yourself and those around you time to deal with the emotions that cancer can cause. Call Cancer Council 13 11 20 for help and support.

# Life after treatment

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

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

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

► See our *Living Well After Cancer* booklet.

## Dealing with feelings of sadness

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If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression. This is quite common among people who have had cancer.

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

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

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

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## **Follow-up appointments**

After treatment ends, you will have regular appointments with your specialists to monitor your health, manage any long-term side effects and check that the cancer hasn't come back (recurred) or spread. If you have a low risk of recurrence, your follow-up care may be shared between your cancer specialist and GP.

During check-ups, you will usually have a pelvic examination and you may have imaging scans. Taking a sample of cells from the vagina after a hysterectomy has not been shown to help identify a return of uterine cancer, so this is no longer done. You will often have check-ups every 3-4 months for the first year and then every 6-12 months for the next few years. This may vary depending on the type and stage of the cancer, so check your follow-up plan with your doctors.

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

## **What if the cancer returns?**

For some people, 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 any symptoms (e.g. vaginal bleeding, pain in the abdomen, swelling, unexpected weight loss, unexplained cough) immediately, rather than waiting for your next follow-up appointment.

Most uterine cancers that come back do so in the first 2-3 years after treatment. If you have had a hysterectomy, cancer of the uterus usually comes back in the vagina or pelvic lymph nodes. If the cancer does recur, you will usually be offered further treatment to remove the cancer or help control its growth.

# 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 by location.

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

### Legal and financial support



If you need advice on legal or financial issues, we 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.

### Practical help



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

### Peer support services



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

## Useful websites

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

### Australian

Cancer Council Australia	<a href="http://cancer.org.au">cancer.org.au</a>
Cancer Council Online Community	<a href="http://cancercouncil.com.au/OC">cancercouncil.com.au/OC</a>
Cancer Council podcasts	<a href="http://cancercouncil.com.au/podcasts">cancercouncil.com.au/podcasts</a>
Australasian Lymphology Association	<a href="http://lymphoedema.org.au">lymphoedema.org.au</a>
Australasian Menopause Society	<a href="http://menopause.org.au">menopause.org.au</a>
Australia New Zealand Gynaecological Oncology Group	<a href="http://anzgog.org.au">anzgog.org.au</a>
Australian Gynaecological Cancer Foundation	<a href="http://agcf.org.au">agcf.org.au</a>
Cancer Australia	<a href="http://canceraustralia.gov.au">canceraustralia.gov.au</a>
Carer Gateway	<a href="http://carergateway.gov.au">carergateway.gov.au</a>
Carers Australia	<a href="http://carersaustralia.com.au">carersaustralia.com.au</a>
Continence Foundation of Australia	<a href="http://continence.org.au">continence.org.au</a>
Guides to Best Cancer Care	<a href="http://cancer.org.au/cancercareguides">cancer.org.au/cancercareguides</a>
Healthdirect Australia	<a href="http://healthdirect.gov.au">healthdirect.gov.au</a>
Osteoporosis Australia	<a href="http://osteoporosis.org.au">osteoporosis.org.au</a>
Pelvic Floor First	<a href="http://pelvicfloorfirst.org.au">pelvicfloorfirst.org.au</a>
Services Australia (Centrelink and Medicare)	<a href="http://servicesaustralia.gov.au">servicesaustralia.gov.au</a>

### International

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

# 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 the practical and emotional aspects of your caring role.

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

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

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

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

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

# Question checklist

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

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## Diagnosis

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

## Treatment

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

## Side effects

- What are the risks and possible side effects of each treatment?
  - Will I have a lot of pain? What will be done about this?
  - Can I work, drive and do my normal activities while having treatment?
  - Will I still be able to have children? Should I see a fertility specialist?
  - What can I do to manage menopausal symptoms?
  - 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?
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## After treatment

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

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## **abdomen**

The part of the body between the chest and hips, which contains the stomach, bowel, bladder and kidneys. The lower abdomen contains the uterus and other female reproductive organs. Also known as the belly.

## **adenocarcinoma**

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

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## **bilateral salpingo-oophorectomy**

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; radioactive material is placed into or near the tumour.

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## **cervix**

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

## **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 type of endometrial cancer.

## **CT scan**

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

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

A procedure that widens (dilates) the cervix, then uses a surgical instrument called a curette to scrape out the endometrium.

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## **endometrial biopsy**

Removing cells from the lining of the uterus with a long, thin tube called a pipelle.

## **endometrial cancer**

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

## **endometrial stromal sarcoma**

A type of uterine sarcoma.

## **endometrioid cancer**

The most common type of endometrial cancer.

## **endometrium**

The lining of the uterus (womb).

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

Radiation therapy delivered to the cancer from outside the body.

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## **fallopian tubes**

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

## **fibroids**

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

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## **glandular cells**

Cells that release mucus, hormones or other substances.

## **gynaecological cancer**

Cancers of the female reproductive system. They include cervical, ovarian, uterine, vaginal and vulvar cancers.

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## **hormones**

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

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## **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 or hormone-blocking 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.

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## **laparoscopic surgery**

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

## **laparotomy**

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

## **leiomyosarcoma**

A type of uterine sarcoma.

## **lymphadenectomy**

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

## **lymphatic system**

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

## **lymph nodes**

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

## **lymphoedema**

Swelling caused by a build-up of lymph fluid.

## **Lynch syndrome**

A disease that increases the risk of developing uterine, ovarian and bowel cancer.

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## **malignant mixed Müllerian tumour**

See uterine carcinosarcoma.

## **menopause**

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

## **menopause hormone therapy (MHT)**

Drug therapy that supplies the body with hormones that it is no longer able to produce naturally. Previously known as hormone replacement therapy (HRT).

## **mismatch repair (MMR) genes**

Genes that help the cell's DNA repair itself.

## **MRI scan**

Magnetic resonance imaging scan. A scan that uses magnetic fields and radio waves to take cross-sectional pictures of the body.

## **myometrium**

Smooth muscle tissue that makes up most of the uterus.

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## **oestrogen**

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

## **ovary**

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

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## **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 solution to find cancerous areas.

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## progesterone

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

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## radiation therapy (radiotherapy)

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

## robotic-assisted hysterectomy

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

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## sentinel lymph node biopsy

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

## serous carcinoma

A type of endometrial cancer.

## stroma

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

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## tumour

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

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## ultrasound

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

## undifferentiated sarcoma

A 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 of the uterus (myometrium) or the connective tissue (stroma) supporting the uterus.

## uterus

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

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## vagina

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

## vaginal dilator

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

## vulva

A female's external sexual organs (genitals).

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## Can't find a word here?

For more cancer-related words, visit:

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

1. National Comprehensive Cancer Network (US), *NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines): Uterine Neoplasms*, Version 2.2020.
2. Gynaecological Oncology Network, *Gynaecological cancer: A guide to clinical practice in NSW*, Agency for Clinical Innovation, Chatswood, 2019.
3. Australian Institute of Health and Welfare (AIHW), *Cancer data in Australia*, AIHW, Canberra, 2020, viewed 16 September 2020, available from: [aihw.gov.au/reports/cancer/cancer-data-in-australia](http://aihw.gov.au/reports/cancer/cancer-data-in-australia).



# How you can help

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

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

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

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

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

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

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



# Cancer Council

## 13 11 20

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

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

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



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. [communications.gov.au/accesshub/nrs](https://communications.gov.au/accesshub/nrs)

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

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

## Visit your local Cancer Council website

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

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

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

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

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

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

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

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

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

*This booklet is funded through the generosity of the people of Australia.  
To support Cancer Council, call your local Cancer Council or visit your local website.*

