

# Understanding Cancer of the Uterus

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



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

## Understanding Cancer of the Uterus

A guide for people with cancer, their families and friends

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*Understanding Cancer of the Uterus* is reviewed approximately every 2 years.

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

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### Note to reader

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

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

### Cancer Council

Cancer Council is Australia's peak non-government cancer control organisation. Through the 8 state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit [cancer.org.au](http://cancer.org.au) or call your local Cancer Council.



*Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past, present and emerging.*



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# About this booklet

This booklet has been prepared to help you understand more about cancer of the uterus – also called uterine cancer, endometrial cancer, womb cancer, or cancer of the lining of the womb.

Many people feel shocked and upset when told they have cancer of the uterus. We hope this booklet will help you, your family and friends understand how cancer of the uterus 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 cancer of the uterus. 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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More information



Alert



Personal story



Tips

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# What is cancer?

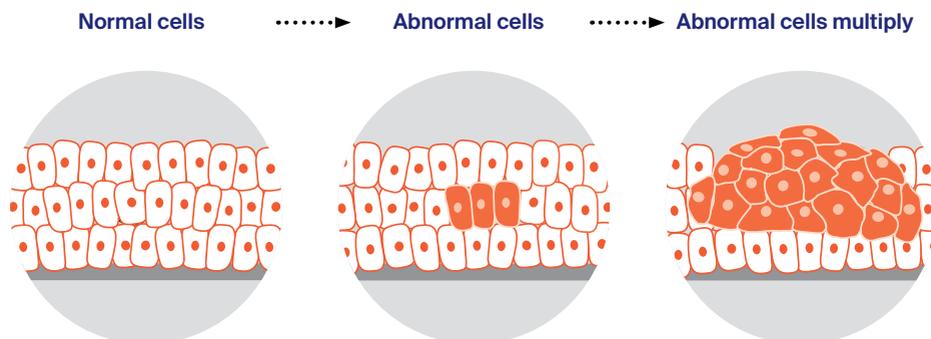
Cancer is a disease of the cells. Cells are the body's basic building blocks - they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

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 cancer of the uterus, 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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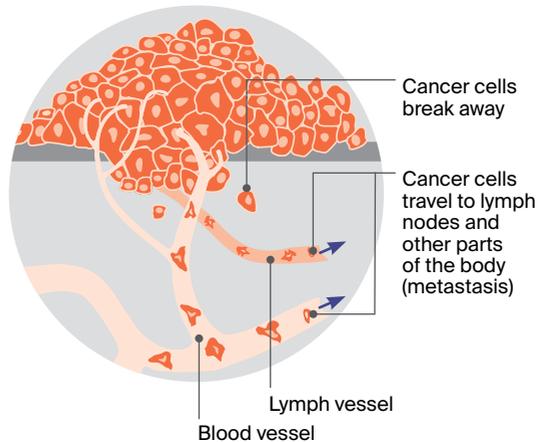
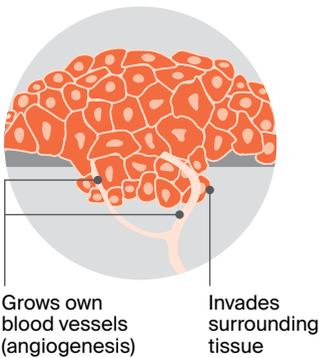


Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break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

The cancer that first develops in a tissue or organ 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, cancer of the uterus that has spread to the lungs is called metastatic cancer of the uterus, 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. The ovaries sit on either side of the uterus. The ovaries contain eggs (ova) and are connected to the uterus by the fallopian tubes.

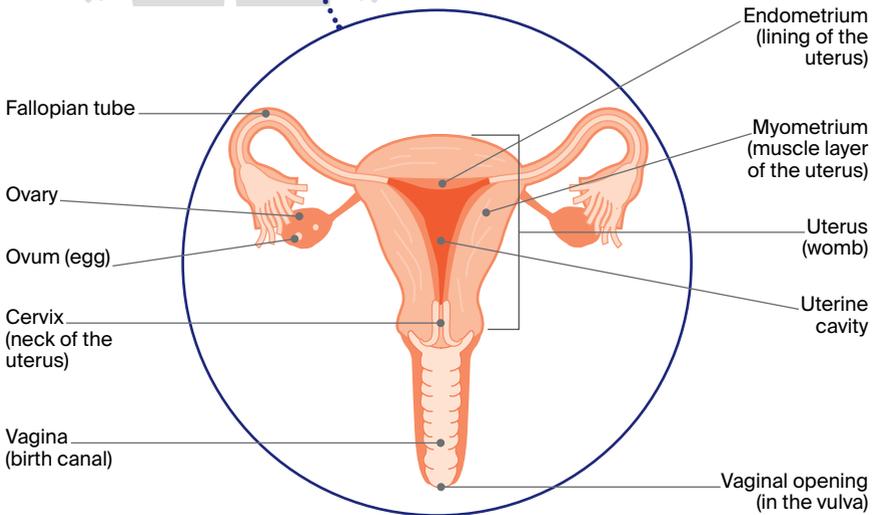
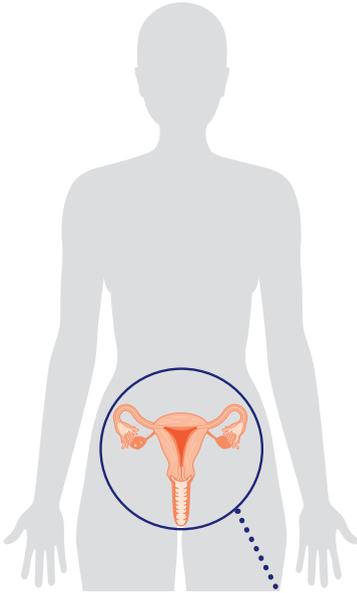
**Layers** – The uterus has 2 layers. The myometrium is the outer layer of muscle tissue and makes up most of the uterus. The endometrium is the inner layer or lining.

**Menstruation** – Each month, from puberty to menopause, the endometrium becomes thicker to prepare for pregnancy. If a pregnancy does not occur, some of the lining is shed and flows out of the body through the vagina. The flow is called a monthly period or 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, it is not possible to 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 (also called uterine cancer) occurs when cells in any part of the uterus become abnormal, grow out of control and form a lump (tumour).

It can be either endometrial cancer (which accounts for about 95% of cancers of the uterus) or the less common uterine sarcoma (which accounts for about 5%).

### Endometrial cancer

This cancer begins in the cells in the lining of the uterus (called the endometrium).

Endometrial cancer was traditionally categorised as type 1 (linked to excess oestrogen) or type 2 (not linked to oestrogen). With advances in testing and treatment, however, endometrial cancer is increasingly being categorised according to 4 subtypes based on the particular gene changes in the cancer cells.

Tests on tissue samples collected during surgery look for gene changes and help the doctor to work out the subtype of endometrial cancer (see pages 16 and 18) and what treatment may be needed after surgery. Talk to your doctor about these tests.

### Uterine sarcoma

These rare soft tissue cancers develop in the cells in the muscle of the uterus (myometrium) or connective tissue (stroma). There are 3 types: endometrial stromal, leiomyosarcoma and undifferentiated.

## Q: How common is it?

**A:** Each year, about 3300 Australian women are diagnosed with cancer of the uterus, and most are over 50 years of age.<sup>3</sup> Cancer of the uterus is the fifth most common cancer in women and the most commonly diagnosed gynaecological cancer (cancer affecting the female reproductive system).

The number of women diagnosed with cancer of the uterus has increased in recent years, including in younger women. This is likely to be linked to rising rates of obesity and diabetes, as well as more people living to older ages.

Anyone with a uterus can get cancer of the uterus – women, transgender men, non-binary people and people with intersex variations. For information specific to you, speak to your doctor.

▶ See also our *LGBTQI+ People and Cancer* booklet.

## Q: What are the symptoms?

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

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

A less common symptom is a smelly, watery vaginal discharge. In rare cases, symptoms include abdominal (belly) pain, unexplained weight loss, difficulty urinating (weeing) or a change in bowel habit (pooping). 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** – cancer of the uterus is most common in women aged over 50 and in women who have stopped having periods (postmenopausal)
- **body weight** – carrying extra body weight (overweight or obese) is a major risk factor
- **medical factors** – having diabetes; having previous radiation therapy for cancer in the pelvic area; having endometrial hyperplasia (see box opposite)
- **family history** – having an inherited change in a gene (mutation) linked with endometrial cancer (e.g. Lynch syndrome or Cowden syndrome), or having one or more close blood relatives diagnosed with cancer of the uterus or ovarian cancer
- **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 menopausal hormone therapy (MHT, previously called hormone replacement therapy or HRT); or taking tamoxifen, an anti-oestrogen drug used for breast cancer.

Many people who have risk factors don't develop cancer of the uterus, and some people 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 conditions of the uterus

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

- **Polyps** – Small, soft growths attached to the inner wall of the uterus. Polyps are usually benign (not cancer), but some may turn into cancer. They can be removed during a hysteroscopy (see page 15) and tested for cancer.
  - **Endometrial hyperplasia** – Thickening of the uterus lining (endometrium) caused by too much oestrogen. Usually benign, but can lead to cancer, so may be treated with hormones, minor surgery or, in some cases, hysterectomy.
  - **Fibroids** – Benign tumours that begin in the muscle layer of the uterus (myometrium). Surgery may be used to reduce the size of the fibroid (myomectomy) or remove the uterus (hysterectomy, see pages 23–25).
  - **Endometriosis** – When endometrial tissue grows outside the uterus (e.g. in the abdomen). Does not usually lead to cancer, but people with endometriosis may also have endometrial hyperplasia. May be treated with surgery or hormones.
- 

## 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 cancer of the uterus is diagnosed, the specialist will consider treatment options. To ensure the best outcome, it is recommended that you are treated by a specialist gynaecological cancer team.

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 may 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. cancer of the uterus, or 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 genetics specialist</b>	specialises in understanding cancers that have occurred as a result of inherited risk
<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; may be an obstetrician, gynaecologist or reproductive endocrinologist
<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 or occupational therapist
<b>psychologist, counsellor</b>	help you manage your emotional response to diagnosis and treatment

# Diagnosis

Your doctor will usually start with a physical examination and ultrasound of the pelvic area, but cancer of the uterus can only be diagnosed by removing a tissue sample for checking (biopsy). Cervical screening tests (formerly called Pap smears or tests) are not used to diagnose this cancer.

## Pelvic examination

The doctor will feel your abdomen (belly) to check for swelling and any masses. To check your uterus, they will place 2 fingers inside your vagina while pressing on your abdomen with their other hand. You may also have a vaginal or cervical examination where a speculum is inserted into your vagina. A speculum separates the walls of the vagina; it is the same instrument used in 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 2 ways, and often you have both types at the same appointment.

**Abdominal ultrasound** – The bladder needs to be full to get a clear picture of the uterus, so you will be asked to drink water before the appointment. For the ultrasound, 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 type of ultrasound. The sonographer inserts a transducer wand into your vagina. It will be covered with a disposable plastic cover 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 about 10–15 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 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

A hysteroscopy allows the specialist to see inside your uterus, examine the lining for abnormalities and take tissue samples (biopsy). It will usually be done under a general anaesthetic as day surgery in hospital.

The doctor will look inside the uterus by inserting a thin tube with a tiny light and camera (called a hysteroscope) through your vagina into the uterine cavity. Your cervix will also be gently widened (dilated) and some tissue will be removed from the uterine lining (called a dilation and curettage or 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 cancer of the uterus it is.

## Further tests

After diagnosis, you may have blood tests to check your general health. Your doctor may also arrange for you to have one or more imaging tests to see if the cancer has spread outside the uterus. These may include a CT (computerised tomography) scan; MRI (magnetic resonance imaging) scan; and/or PET-CT scan (this combines positron emission tomography with a CT scan). Check with your doctor or medical imaging provider if, and how much, you will have to pay for these tests.



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

## Staging and grading cancer of the uterus

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 page 15 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 compared with 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 doctor.

## Tests after surgery

Cancer of the uterus is often removed with surgery (see pages 23–30). The removed tissue is then sent to a laboratory for further testing to find out more about the type and features of the cancer. Some people may also have genetic tests (see page 18) to help doctors decide if any treatment is needed after surgery.

## Pathology assessment

The pathologist will check the sample to assess: how deeply the tumour is growing into the uterine wall (myometrial invasion); how quickly the cells are growing (grade); the type of cells that make up the cancer; and whether any lymph nodes contain cancer cells. They will also use special chemicals (called stains) to look for any gene changes in the cancer cells. The results of these tests help your doctors to work out what types of treatment may be helpful and if further genetic tests may be needed (see page 18).

## Stages of endometrial cancers

The 4 stages of endometrial cancers 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 and are slow growing.
<b>grade 2 (moderate grade)</b>	The cancer cells look moderately abnormal and are growing at a moderate rate.
<b>grade 3 (high grade)</b>	The cancer cells look more abnormal and tend to be faster growing than lower-grade cancers.

## Genetic tests

For endometrial cancer, the tissue sample may be checked for inherited gene changes. For example, a small number of endometrial cancers are caused by Lynch syndrome. This is linked to an inherited fault in the genes that help the cell's DNA repair itself (called deficient mismatch repair or dMMR). People with Lynch syndrome are at increased risk of other cancers, so it's important for you, your family and your doctors to know about this.

Also, knowing if the tumour contains a faulty gene will help your treatment team decide if further treatment may be needed after surgery.

## 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 cancer of the uterus.

To work out your prognosis, your doctor will consider test results, the type of cancer of the uterus, 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 prognosis. Most early-stage cancers of the uterus have 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 or continuing to grow.

## 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 vagina
- vaginal or cervical examination – your doctor uses a speculum to help see inside the vagina or cervix
- pelvic ultrasound – you may have an abdominal ultrasound 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 – this 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, CT, MRI and PET-CT scans.

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### Staging and tests after surgery

- 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.
- After surgery, the removed tissue will undergo pathology assessment and, sometimes, genetic testing. The results will guide further treatment.

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### Prognosis

Prognosis means the expected outcome of a disease. If cancer of the uterus is diagnosed early, it can usually be successfully treated.

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# 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. If you would like to record the discussion, ask your doctor first. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

**Ask questions** – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 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.



## Christine's story

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*At 50 I was having some heavy bleeding during my periods, so my GP sent me for an ultrasound. The ultrasound technician told me that everything looked okay, so 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 4 days later I was told I had cancer of the uterus and booked in to see a gynaecological oncologist.*

*The gynaecological oncologist recommended a hysterectomy to remove the uterus, cervix and ovaries, as well as some of the nearby lymph nodes.*

*After the surgery, my gynaecological oncologist informed me that the*

*cancer hadn't spread, but it was well advanced into the walls of the uterus. He recommended that I have radiation therapy to reduce the risk of the cancer coming back.*

*With the support of my family and workplace, I was able to schedule the radiation therapy sessions 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 about what I eat.*

*I've just passed the 5-year mark and have had my final appointment with my oncologist – this was a big relief.*

*In the last year, I've become involved as a volunteer offering telephone peer support with Cancer Council's Cancer Connect service. 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.*

# Treatment

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

## How cancer treatment affects fertility

If you have not yet been through menopause, having a hysterectomy or radiation therapy for cancer of the uterus 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. It may be helpful to talk with a psychologist or counsellor if possible changes to fertility are worrying you.

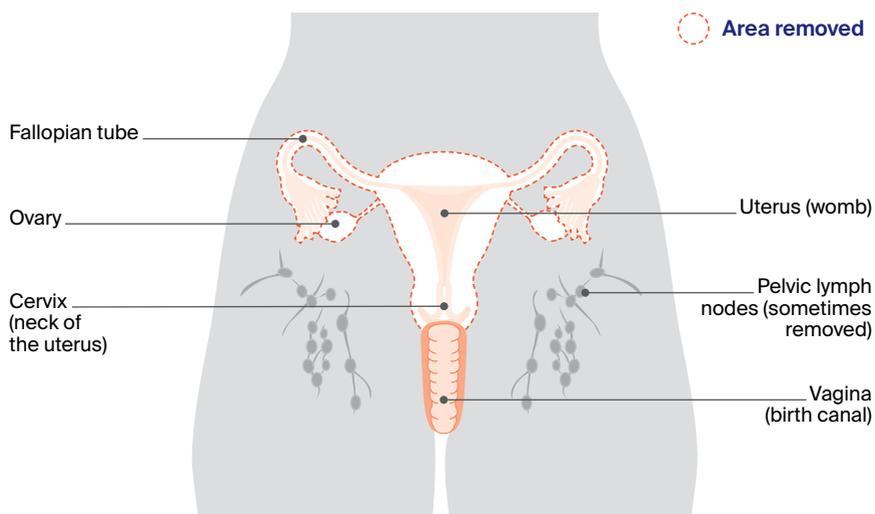
A small number of women with early-stage, low-grade cancer of the uterus choose to wait until after they have had children to have a hysterectomy. These women may be offered hormone therapy (see page 37) and carefully monitored while waiting to have surgery.

▶ 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



Most people with cancer of the uterus 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 are also removed to help with staging.

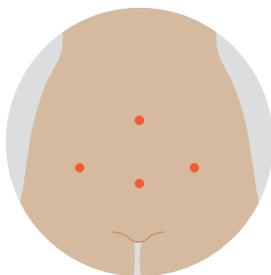
A pathologist examines all removed tissue and fluids. The results will help confirm the type of cancer of the uterus, if it has spread (metastasised), and its stage and grade. The cancer may also be tested for particular gene changes (see pages 16 and 18).

The surgery will be performed under a general anaesthetic. Your surgeon will discuss the most appropriate surgery for you, and explain the risks and benefits.

The type of hysterectomy you have depends 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.

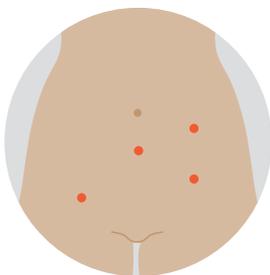
See the opposite page for more information about the different types of surgery you might have.

### Keyhole surgery



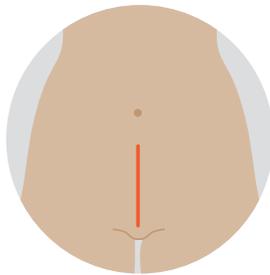
Also called a laparoscopic hysterectomy, a surgeon inserts a laparoscope (thin tube with light and camera) and instruments through about 4 small cuts in the abdomen. The uterus and other organs are removed through the vagina.

### Robotic-assisted hysterectomy



This is a special form of keyhole surgery. The instruments and camera are inserted through about 4 small cuts, and controlled by robotic arms guided by the surgeon, who sits next to the operating table.

### Open surgery



This surgery (also called abdominal hysterectomy or laparotomy) is done through the abdomen. A cut is usually made from the pubic area to the bellybutton. The uterus and other organs are then removed.

## Treatment of lymph nodes

Cancer cells can spread from the uterus to the pelvic lymph nodes. If this occurs, your doctor may recommend you have additional treatment after surgery, such as chemotherapy or radiation therapy. Lymph nodes may be checked in 2 ways:

- **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. 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 (catheter) in your bladder 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 had and how quickly you recover. Most people who have keyhole 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 medicine to swallow. 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 medicine as needed.

**Wound care** – You can expect some light vaginal bleeding after the surgery, which should stop within 2 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 4 weeks to help the blood in your legs circulate well and prevent 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 more treatment is necessary will depend on the type, stage and grade of the disease, and the amount of remaining cancer, if any. 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.

### 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.

### Work



You will probably need 4–6 weeks of leave from work, depending on the type of surgery and nature of your job. People who have had keyhole 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 you are able to move freely without pain. 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.

## Lifting



You may be advised to avoid heavy lifting (more than 3–4 kg) for 4–6 weeks. This will depend on the way the surgery was done.

## Bowel problems



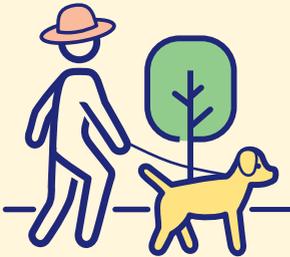
It is important to avoid straining during bowel movements (pooping). Talk to your treatment team about the best way to manage constipation (see pages 46–47).

## 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 about 8–12 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 immediate menopause. Menopause can cause significant emotional and physical changes. For ways to manage menopause symptoms, see pages 41–43. If you are worried 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. If you have concerns, you may find it helpful to talk to a psychologist or counsellor.

▶ See pages 49–50 and our *Sexuality, Intimacy and Cancer* booklet.

**Lymphoedema** – The removal of lymph nodes from the pelvis can stop lymph fluid draining normally, causing swelling in the legs or, sometimes, the vulva. This is known as lymphoedema. The risk of developing lymphoedema is low after most operations for cancer of the uterus, but the risk is higher if you have had a full lymphadenectomy (see page 25) followed by external beam radiation therapy (see pages 32). Symptoms may appear gradually, sometimes years after the treatment.

▶ See page 48 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. Doing pelvic floor exercises several times a day can help to prevent prolapse. Talk to your treatment team about doing these exercises.

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

## 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 (e.g. when other health conditions mean you are not well enough for a major operation).

There are 2 main ways of delivering radiation therapy: internally and 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 a small, radioactive seed (made of metal). Next, this seed moves from the machine into the applicator where it delivers a targeted dose of radiation to the area affected by cancer. After a few minutes, the seed is drawn back into the machine. The applicator is taken out of the vagina 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 abdomen and pelvis are treated, but if the cancer has spread (metastasised), other areas may also be treated.

Planning for EBRT may involve several visits to your doctor to have more tests, such as blood tests and scans. Your radiation therapy team will give you instructions on preparing your bowel and bladder before planning scans and treatment sessions.

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 2 pages).

If you are having EBRT, you will probably have daily treatments, Monday to Friday, for 5–6 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 have 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 ended. Short-term side effects usually get better within weeks of finishing treatment.

### 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.

**bladder  
and bowel  
changes**  
(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 usual. Less commonly, there may be blood in the faeces (poo or stools); talk to your treatment team if you notice this. You may also pass urine more often or with more urgency.

**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 or has blood in it. Do not wash inside the vagina with water or other fluids 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 loose-fitting, cotton underwear.

## Long-term or late effects of radiation therapy

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

<b>hair loss</b>	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.
<b>bladder and bowel changes</b> (see also pages 45–47)	Bowel changes, such as diarrhoea, wind or constipation, and bladder changes, such as frequent or painful urination, can arise 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. Let your doctor know about any bleeding or if you have pain in the abdomen and difficulty opening your bowels (pooing).
<b>lymphoedema</b> (see also page 48)	Radiation can scar the lymph nodes and vessels and stop them draining lymph fluid properly from the legs, making the legs swollen. This can occur months or years after radiation therapy. The earlier lymphoedema is found, the easier it is to treat. Look for early signs in the legs, including feelings of tightness or heaviness; tighter clothing; skin pitting; and swelling that comes and goes.
<b>narrowing of the vagina</b> (see also page 49)	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 ways to prevent this.
<b>menopause</b> (see also pages 41–43)	If you are premenopausal, radiation therapy to the pelvis can stop the ovaries producing hormones, causing early menopause. Your periods will stop, you will no longer be able to become pregnant and you may have menopause symptoms.

# 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 cancer of the uterus that are more aggressive
- 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 37)
- if the cancer has spread beyond the pelvis when first diagnosed
- during radiation therapy (called chemoradiation, see next page) or after radiation therapy.

Chemotherapy is usually given by injecting the drugs into a vein (intravenously), often through a drip. You will have a treatment session followed by a rest period. This is called a cycle. You will have up to 6 treatment cycles, with one every 3–4 weeks, so chemotherapy treatment can take 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.



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.

**Chemotherapy side effects** – These 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; hair loss; ringing or buzzing in the ears (tinnitus); 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.

## Chemoradiation

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High-grade endometrial cancer is often treated with EBRT in combination with chemotherapy. This is called chemoradiation and it is done to reduce the chance of the cancer coming back after treatment.

The chemotherapy drugs make the cancer cells more sensitive to radiation therapy.

If you have chemoradiation, you will usually receive chemotherapy in the first and last weeks of your radiation treatment. The chemotherapy will usually be given a few hours before the radiation therapy session.

Once the radiation therapy is over, you may have another 3–4 cycles of chemotherapy on its own.

Side effects of chemoradiation include: fatigue; diarrhoea; needing to pass urine more often or in a hurry; cystitis (a type of urinary tract infection); dry skin in the treatment area; numbness and tingling in the hands and feet (peripheral neuropathy); ringing or buzzing in the ears (tinnitus); low blood counts. Low numbers of blood cells may cause anaemia, infections or bleeding problems.

Some side effects are temporary, but others can be permanent.

Talk to your treatment team about ways to manage any side effects. Also, see the *Managing side effects* chapter on pages 41–51.

## 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 they can sometimes be treated with hormone therapy.

Hormone therapy may be recommended for cancer of the uterus 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 someone with early-stage, low-grade cancer of the uterus chooses not to have a hysterectomy because they want to have children, or if someone 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, if you have not had a hysterectomy, through a hormone-releasing intrauterine device (IUD) called a Mirena. A Mirena is placed into the uterus by your doctor.

Other hormone drugs may be available on clinical trials (see page 21). Talk to your doctor about the risks and benefits of the different methods.

**Hormone therapy side effects** – 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.

## Immunotherapy

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

An immunotherapy drug called pembrolizumab (used in combination with the targeted therapy drug lenvatinib, see below) may be an option for some people with endometrial cancer that has spread (metastatic disease) or is no longer responding to treatment with chemotherapy.

**Immunotherapy side effects** – Common side effects include: fatigue; being or feeling sick (nausea); skin rash and itching; joint pain; diarrhoea; dry eyes; and joint pain.

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

▶ See our *Understanding Immunotherapy* fact sheet.

## Targeted therapy

Targeted therapy is a drug treatment that attacks specific features of cancer cells to stop the cancer growing and spreading.

A targeted therapy drug called lenvatinib may be used to treat endometrial cancer that has spread or come back, or to boost the effectiveness of immunotherapy.



Ask your doctor about other recent developments in drugs for cancer of the uterus and whether a clinical trial (see page 21) may be an option for you.

**Targeted therapy side effects** – Common side effects include: fatigue; being or feeling sick (nausea); diarrhoea; constipation; sore mouth; blood pressure changes; appetite loss; bleeding and bruising; skin problems; joint aches; and headache. Less common side effects, such as heart problems and stroke, can also occur. It's important to tell your doctor about any new or worsening side effects.

► See our *Understanding Targeted Therapy* fact sheet.

## 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 only for people at the end of their life, but it can help at any stage of advanced cancer of the uterus. It is about living as long as possible in the most satisfying way you can. Being referred to palliative treatment does not necessarily mean that you are at the final stages of life.

As well as slowing the spread of cancer, palliative treatment can help to relieve pain and manage other symptoms, such as bowel problems. Treatment may include radiation therapy, chemotherapy, hormone therapy, or immunotherapy (alone or in combination with targeted 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 nodes 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 (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.
- Hormone therapy targets cancers of the uterus that depend on hormones to grow. The main hormone therapy used for cancer of the uterus is high-dose progesterone.
- Immunotherapy and targeted therapy may be used together for certain types of endometrial cancer, or for cancer that has not responded to treatment or has come back.

# 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 you've had radiation therapy to the pelvic area, your body 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.

Menopause 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 50).

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 cancer of the uterus 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 if you were hoping to have a baby.

It may be possible to preserve the ovaries (e.g. if you are 45 years or under) and sometimes the uterus, so you can still have children (see page 23). However, this is an option only in certain cases, and 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 normal. Speaking to a counsellor, psychologist, social worker 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 menopause symptoms

- Vaginal moisturisers available over the counter from pharmacies can help with vaginal discomfort and dryness. Talk to your nurse for suggested products.
- 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 menopause symptoms are severe, talk to your doctor about the risks and benefits of taking menopausal hormone therapy (MHT). Previously called hormone replacement therapy (HRT), MHT is not usually used if you have cancer of the uterus, but may be considered in some cases if other treatments fail to manage symptoms. If you were on MHT when the cancer was diagnosed, your doctor will usually advise stopping its use as oestrogen can cause these cancers to grow.
- Talk to your doctor about having a bone density test or taking medicine to prevent your bones from weakening. Call 1800 242 141 or visit [healthybonesaustralia.org.au](http://healthybonesaustralia.org.au) for more information.
- Ask your doctor for a referral to a menopause clinic if needed.
- Have your cholesterol levels checked. If they are high, regular exercise and a balanced diet may help, or talk to your doctor about cholesterol-lowering drugs.
- Learn meditation and relaxation techniques. These may be helpful in reducing stress and some menopause symptoms.
- Several types of psychological therapies have been shown to help with menopause-related anxiety, low mood, sleep troubles and the impact of hot flushes. Talk to a psychologist about the best approach for you.
- Exercise can also help with mood changes and energy levels. Ask your doctor about suitable exercises or see an exercise physiologist or physiotherapist.

# 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 41–43). 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

- Do some light exercise, such as walking or stretching, to help increase your energy levels. Check with your doctor if these activities are suitable for you. You can also ask for a referral to an exercise physiologist or physiotherapist.
  - Plan your day. Set small, manageable goals so you can rest regularly, and allow yourself plenty of time to get to appointments.
  - Ask for and accept offers of help from family and friends (e.g. with shopping, housework, meals and driving). Contact your local council to see what support services they offer.
  - Learn to recognise signs of tiredness before you feel exhausted.
  - Talk to your employer about taking time off work, 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 fact sheet on fatigue and our *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.

**Urinary incontinence** – This is when you have trouble controlling your bladder and you leak urine (wee). Strengthening the pelvic floor muscles can help control the flow of urine. A women’s health physiotherapist or continence nurse can develop a bladder training program – ask your doctor for a referral or contact the National Continence Helpline on 1800 33 00 66 or visit [continence.org.au](http://continence.org.au). You can also find a guide to exercising the pelvic floor muscles in our *Exercise for People Living with Cancer* booklet. Using continence pads or special types of absorbent underwear can help you manage leakage.

**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. Called radiation cystitis, it usually gets better after treatment. Try to drink plenty of water or use a urinary alkaliser (e.g. Ural) to help reduce the burning sensation. You can buy urinary alkalisers from your pharmacy. 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.



If you have ongoing incontinence, you may be eligible for subsidised incontinence products through the continence aids payment scheme. For details, visit [servicesaustralia.gov.au/continence-aids-payment-scheme](http://servicesaustralia.gov.au/continence-aids-payment-scheme).

## Bowel changes

Treatment for cancer of the uterus can affect the way the bowels work. These changes are usually temporary, but for some people, they can be permanent and can have a significant impact on quality of life. Talk to your treatment team if you are finding bowel issues hard to manage.

**Constipation** – Constipation is when you have difficulty having a bowel movement (pooping) 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 constipated.

**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; diarrhoea; the need to empty the bowels urgently; and loss of control over the bowels (faecal incontinence). Radiation proctitis usually gets better after treatment has finished, but it can develop some time after treatment (called a late effect). 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 to drink 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 drinking alcohol.
- 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 (eating small amounts of cheese and yoghurt is usually okay).
- Ask your doctor about suitable medicines for diarrhoea. Take as directed.

## Lymphoedema and cellulitis

After surgery or radiation therapy to the pelvic area, one or both legs, and/or the vulvar area, may become swollen. Called lymphoedema, this occurs when lymph fluid doesn't circulate properly and builds up. 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 on the legs may become infected more easily after lymph nodes are removed. A common skin infection is called cellulitis. Signs of cellulitis include redness, painful swelling, warm skin and fever. If you have any symptoms, see your GP as soon as possible.

To reduce the risk of infection, keep the skin healthy and unbroken, 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 (such as a physiotherapist) as part of a chronic disease management plan, you may be eligible for a Medicare rebate for up to 5 visits each year. Ask your GP for more details.

## 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 dry. These side effects may make it painful to have sex or pelvic examinations. Even if you don't plan to have sex again, your doctor will need to do regular pelvic examinations after treatment, so it is important to prevent these side effects. Your treatment team may recommend using a vaginal moisturiser or lubricant or a hormone cream (available on prescription and safe with many cancers of the uterus). They may also advise you to use vaginal dilators.

### Using vaginal dilators

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Vaginal dilators can help keep your vagina open and flexible after treatment. They are made from plastic or silicone and come in a range of sizes. You usually start with the smallest dilator, and as each one becomes more comfortable, you can

move on to using the larger dilators. Make sure any soreness has settled down before you start using dilators (usually 4–6 weeks after your last radiation therapy session).

To use the dilator, find a private space. Apply a water-based lubricant to the dilator, slowly insert it into the vagina, then gently rotate it. Leave the dilator in for 5–10 minutes. You can 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 treatment team. You may also like to see a women's health physiotherapist. If you have a history of sexual trauma, speak with a psychologist or counsellor.

## Impact on sexuality

Cancer of the uterus can affect your sexuality in both physical and emotional ways. Some treatments can cause dryness and narrowing of the vagina, which can make sexual penetration difficult or painful. Also, removal of the uterus, cervix and ovaries can change how you experience sexual pleasure and orgasm.

Your treatment team may advise using vaginal dilators, lubricants, moisturisers or hormone creams (see page 49). It may be helpful to explore ways to orgasm (climax) without penetration or to use masturbation to see what might work for you.

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.

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 psychologist or sexual therapist.

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

## Key points about managing side effects

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### Menopause and fertility

- If you have not yet been through menopause, surgery or radiation therapy for cancer of the uterus will cause your periods to stop. You will experience symptoms of menopause.
- Even if you have been through menopause, you may find that menopause symptoms return.
- Treatment may affect your ability to get pregnant. If you are concerned about fertility, 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.
- Consider seeing a physiotherapist, exercise physiologist or joining a specialised cancer exercise program.

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### Other side effects

- If you lose control of your bladder and you leak urine (urinary incontinence), pelvic floor exercises can help.
- Constipation or diarrhoea can often be managed with changes to your diet.
- Some people develop swelling in the legs and/or vulva (lymphoedema). See your doctor about this; 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.
- 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.

# Looking after yourself

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

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

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

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

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

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

▶ See our *Understanding Complementary Therapies* booklet.



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

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

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

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

▶ See our *Emotions and Cancer* booklet.

## Effect on your emotions

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Changes to your body can make you feel self-conscious and affect the way you feel about yourself (your self-esteem). 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.

Everyone has their own ways of coping with their emotions. 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. You may also find it helpful to see the psychologist in your cancer centre about the impact of cancer on your mental health.

▶ See our *Emotions and Cancer* booklet.

# 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 of the uterus, 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, or you may be discharged to your GP with easy access back to your specialist if needed.

During check-ups, you will usually have a pelvic examination and you may have imaging scans. Follow-up appointments will start immediately after treatment, then become less frequent over time. How often you see your doctor will depend on the type and stage of the cancer.

When a follow-up appointment is approaching, many people find that they think more about the cancer and may feel anxious. If you are finding this hard to manage, talk to your doctor or call Cancer Council 13 11 20.

## What if the cancer returns?

For some people, cancer of the uterus does come back after treatment (called a recurrence). This is why it's important to have regular check-ups and to immediately report any symptoms (e.g. vaginal bleeding, pain in the abdomen, swelling, unexpected weight loss, unexplained cough), rather than waiting for your next follow-up appointment.

Most cancers of the uterus 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. It is also possible for the cancer to come back in another part of the body. 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



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

### Information resources



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

### Legal and financial support



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

### Practical help



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

### Peer support services



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

## Useful websites

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

### Australian

Cancer Council Australia	<a href="http://cancer.org.au">cancer.org.au</a>
Cancer Council Online Community	<a href="http://cancercouncil.com.au/OC">cancercouncil.com.au/OC</a>
Cancer Council podcasts	<a href="http://cancercouncil.com.au/podcasts">cancercouncil.com.au/podcasts</a>
Guides to Best Cancer Care	<a href="http://cancer.org.au/cancercareguides">cancer.org.au/cancercareguides</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>
Continence Foundation of Australia	<a href="http://continence.org.au">continence.org.au</a>
Healthdirect Australia	<a href="http://healthdirect.gov.au">healthdirect.gov.au</a>
Healthy Bones Australia	<a href="http://healthybonesaustralia.org.au">healthybonesaustralia.org.au</a>
Pelvic Floor First	<a href="http://pelvicfloorfirst.org.au">pelvicfloorfirst.org.au</a>
Services Australia	<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 menopause 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. The lower part of the abdomen (pelvic cavity) contains the uterus and other female reproductive organs. Also known as the belly.

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## **bilateral salpingo-oophorectomy**

Surgical removal of both ovaries and fallopian tubes.

## **biopsy**

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

## **brachytherapy**

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

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## **cellulitis**

An infection of the skin. It can occur after lymph glands have been removed.

## **cervix**

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

## **chemoradiation**

Treatment that combines chemotherapy with radiation therapy. Also called chemoradiotherapy.

## **chemotherapy**

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

## **CT scan**

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

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

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

## **endometrial biopsy**

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

## **endometrial cancer**

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

## **endometrial stromal sarcoma**

A type of uterine sarcoma.

## **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. They carry sperm from the uterus to the ovaries, and eggs from the ovaries to the uterus.

## **fibroid**

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 cancers**

Cancers of the female reproductive system.

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## **hormones**

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

## **hormone therapy**

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

### **hysterectomy**

The 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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### **immunotherapy**

Drugs that use the body's own immune system to fight cancer.

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### **keyhole surgery**

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

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### **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 produces immune cells.

### **lymph nodes (also called lymph glands)**

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

### **lymphoedema**

Swelling caused by a build-up of lymph fluid.

### **Lynch syndrome**

An inherited condition that increases the risk of developing cancer of the uterus, as well as ovarian and bowel cancer.

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### **menopause**

When periods (menstruation) stops. This can happen naturally; because of cancer

treatment; or because the ovaries have been removed.

### **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 of the uterus.

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### **oestrogen**

One of the two major sex hormones in females; helps regulate the female reproductive cycle.

### **open surgery**

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

### **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, extending from hip to hip and waist to groin.

### **PET-CT scan**

Positron emission tomography scan combined with a CT scan. In a PET scan, a person is injected with a small amount of radioactive solution to help show up any cancerous areas.

### **progesterone**

One of the two major sex hormones in females; 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.

### **robotic-assisted hysterectomy**

A form of keyhole surgery (also called 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.

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### **targeted therapy**

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

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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 sarcoma**

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

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### **uterus**

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

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### **vagina**

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

### **vaginal dilator**

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

### **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](https://cancercouncil.com.au/words)
  - [cancervic.org.au/glossary](https://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 2.2023.
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 2023*, AIHW, Canberra, viewed 17 May 2023, available from: [aihw.gov.au/reports/cancer/cancer-data-in-australia](https://aihw.gov.au/reports/cancer/cancer-data-in-australia).



# How you can help

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

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

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

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

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

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

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



# Cancer Council

## 13 11 20

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

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

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

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



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



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

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*Cancer Council services and programs vary in each area.*

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

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

## Visit your local Cancer Council website

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

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

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

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

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

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

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

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

