

Endometrial cancer

Your guide to best cancer care



About this guide

Being told you have endometrial cancer (a cancer of the uterus) or could have endometrial cancer can be overwhelming. A lot can happen quickly, and you might have lots of questions. This resource can help to guide you and your family and friends through this experience.

Information and support

Cancer Council: For information and support, call Cancer Council on **13 11 20** to talk to an experienced healthcare professional or visit www.cancer.org.au.

For more information about endometrial cancer, look for Cancer Council's Understanding Endometrial Cancer booklet on your local Cancer Council website.

Counterpart: For patient support from a woman with lived experience of cancer, call Counterpart on **1300 781 500** or visit www.counterpart.org.au.

Translating and Interpreting Service (TIS): If you need a translator, call TIS on **13 14 50** or visit www.tisnational.gov.au.

Initial tests and referral

Symptoms

Your general practitioner (GP) should do a check-up to see if they can find what is making you unwell. They will ask you about any symptoms you might be having. For example, you might have unexpected bleeding from your vagina (after menopause or between periods) or pain or discomfort in your lower abdomen (pelvis).

Initial tests you may have

Pelvic examination (including a cervical screening test).

Your GP will look at your vagina, pelvis and abdomen to check for growths or lumps.

Transvaginal pelvic ultrasound. A gynaecological sonographer (healthcare professional with experience in this type of ultrasound) inserts a small ultrasound tool into your vagina. Soundwaves are used to make a picture of your uterus.

Referrals

If your GP has concerns, you will be referred to a specialist (gynaecologist or gynaecological oncologist) at a public hospital or in private practice for more tests.

Gynaecologists are doctors who are highly trained in a particular area of women's health and gynaecological oncologists are doctors who are highly trained in treating endometrial cancer.



You can bring a family member or friend with you to your appointments.



Timeframes

You should be referred to a specialist **within 4 weeks** of your first GP appointment.

If you can't get an appointment within this time, follow up with your GP.



Questions you might want to ask

- Can I choose whether I go to a public hospital or private practice?
- Can I choose the specialist I see?
- How much will appointments cost me?

Diagnosis and staging

The specialist will do more tests to see if you have endometrial cancer. This process of working out if you have a medical problem is called making a **diagnosis**.

You might have one test or a mix of tests:

Transvaginal pelvic ultrasound. If you have not already had one.

Blood test. A sample of your blood is collected to assess your general health.

Biopsy. A small sample of your endometrium (the lining of the uterus) is taken to check under a microscope. This can be done in a clinic. It can often be done with minimal discomfort, although sometimes the doctor may inject local anaesthetic into the cervix so you don't feel any discomfort.

Computed tomography (CT) scan. Computers and x-rays are used to make a detailed picture of the chest, abdomen and pelvis.

Magnetic resonance imaging (MRI). A scan where a powerful magnet and radio waves are used to make a detailed picture of the body.

These tests may give the specialist more information about the cancer such as where exactly it is in your body, if it is growing or if it has spread and what stage it is. This is called **staging**.

Staging helps to work out the best treatment for you.



Timeframes

Results should be available **within two weeks** from when you have the tests.



Questions you might want to ask

- What is endometrial cancer?
- What tests will I have?
- How much will tests/appointments cost?
- Where should I be treated? Do I have a choice?
- What stage is my cancer?
- What support services are available to me?

Treatment

There are several ways to treat endometrial cancer. Your specialist will talk to you about your treatment options.

You will be treated by a team of experts, and you may need more than one treatment type to get the best results. The team will work with you and your family or carer to plan your treatment.

You might have one treatment or a mix of treatments:

Surgery is where the cancer is cut out. It is the most common treatment for endometrial cancer.

Radiation therapy uses x-rays to kill cancer cells and stop the cancer growing. It might be used alone but more commonly after surgery, and sometimes with chemotherapy.

Chemotherapy or drug therapy uses drugs to kill cancer cells or stop the cancer growing. It might be used alone but more commonly after surgery, or with radiation therapy.

Hormone therapy stops your body making certain hormones or blocks the way the hormones work in your body. It helps to reduce the size and slow down the spread of the cancer. It might be used if you are a young woman and you want to have a baby in the future. It can also help with your symptoms.

For more information visit

www.cancer.org.au/cancer-information/treatment.

Supportive care (treatment or services that support you through a cancer experience) are also available.



Timeframes

Treatment should start **within four weeks** (surgery) or **six weeks** (other treatments) of agreeing to your treatment plan.



You can ask your GP for a referral to another specialist for a second opinion.

Risk of lymphoedema

Some treatments for cancer, commonly surgery, involving the lymph node areas such as the pelvis, may increase your risk of developing lymphoedema (swelling of a body region). Your specialist should discuss this risk with you and arrange for it to be managed appropriately.

Clinical trials

You may be offered to take part in a clinical trial. Clinical trials are used to test whether new treatments are safe and work better than current treatments. Many people with cancer are now living longer, with a better quality of life, because of clinical trials.

For more information visit www.australiancancertrials.gov.au.

Complementary therapies

Speak to your healthcare team about any complementary therapies (including dietary supplements like vitamins) you use or would like to use. Something as common as vitamins might not work well with your treatment.



Questions you might want to ask

- What treatment do you recommend?
- Where will I have to go to have treatment?
- What will treatment cost and how much of the cost will I have to pay myself?
- What activities/exercise will help me during and after treatment?
- Can I still work?
- How will the treatment affect my day-to-day life?
- Who are the people in my team and who is my main contact person?
- What side effects could I have from treatment?
- Who do I contact if I am feeling unwell or have any questions?
- Will treatment affect my ability to have a child?



Decisions about cost

You may have to pay for some appointments, tests, medications, accommodation, travel or parking.

Speak with your GP, specialist or private health insurer (if you have one) to understand what is covered and what your out-of-pocket costs may be.

If you have concerns about costs talk to your healthcare team or a social worker about:

- being bulk-billed or being treated in the public system
- help with accommodation during treatment
- the possible financial impact of your treatment.

You can call Cancer Council on **13 11 20** to speak to a healthcare professional about financial support.

For more information about costs, visit www.cancer.org.au/support-and-services/practical-and-financial-assistance and www.cancer.org.au/support-and-services/practical-and-financial-assistance/what-will-i-have-to-pay-for-treatment.

Recovery

Cancer treatment can cause physical and emotional changes.

Treatment for endometrial cancer sometimes results in hormonal changes and, in some cases, early menopause. This can lead to side effects such as night sweats, hot flushes and reduced sex drive. Fortunately, there are many ways to reduce or manage the side effects of treatment.

Follow-up care plan

Your healthcare team will work with you to make a plan for you and your GP. This plan will explain:

- who your main contact person is after treatment
- how often you should have check-ups and what tests this will include
- understanding and dealing with side effects of treatment
- how to get help quickly if you think the cancer has returned or is worse.

Many people worry that the cancer will return. Your specialist and healthcare team will talk with you about your needs and can refer you to other healthcare professionals and community support services.

Other information you may get:

- signs and symptoms to look out for if the cancer returns
- late effects of treatment and the specialists you may need to see
- how to make healthy lifestyle choices to give you the best chance of recovery and staying well.

For more information visit www.cancer.org.au/cancer-information/after-a-diagnosis/after-cancer-treatment.



Questions you might want to ask

- Who should I contact if I am feeling unwell?
- What can I do to be as healthy as possible?
- Where can I get more help?

Living with advanced cancer

If cancer returns

Sometimes cancer can return after treatment. It can come back in the same place or can appear somewhere different in your body.

If cancer returns, you may be referred to the specialist or the hospital where you were first treated, or to a different specialist.

Treatment will depend on how far the cancer has spread, how fast-growing it might be and the symptoms you are experiencing.



Questions you might want to ask

- Where is the cancer and has it spread?
- What are my treatment options?
- What are the chances that the treatment will work this time?
- Is there a clinical trial available?
- Where else can I get support?

Advance care planning

Your GP or healthcare team may talk with you, your family and carer about your future treatment and medical needs.

Advance care directive

Sometimes known as a living will, an advance care directive is a legally binding document that you prepare to let your family and healthcare team know about the treatment and care you might want or not want in case you become too unwell to make those decisions yourself. For more information visit www.advancecareplanning.org.au.

Palliative care

Your specialist may refer you to palliative care services, but this doesn't always mean end-of-life care. Today people can be referred to these services much earlier if they're living with cancer or if their cancer returns. Palliative care can help you to live as well as you can including managing pain and symptoms. This care may be at home, in a hospital or at another location you choose.

Speak to your GP or specialist or visit www.palliativecare.org.au.

Making treatment decisions

You may decide not to have treatment at all, or to only have some treatment to reduce pain and discomfort. You may want to discuss your decision with your healthcare team, GP, family and carer. For more information visit www.cancer.org.au/cancer-information/treatment/advanced-cancer-treatment.



Questions you might want to ask

- What can you do to reduce my symptoms?
- What extra support can I get if my family and friends care for me at home?
- Can you help me to talk to my family about what is happening?
- What support is available for my family or carer?
- Can I be referred to a community support service?

Disclaimer: Always consult your doctor about matters that affect your health. This guide is intended as a general introduction and is not a substitute for professional medical, legal or financial advice. Information about cancer is constantly being updated and revised by the medical and research communities. While all care is taken to ensure accuracy at the time of publication, 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 above.

Published in September 2021.

This resource is based on information from the optimal care pathway for women with endometrial cancer (2nd edition), available at www.cancer.org.au/OCP.