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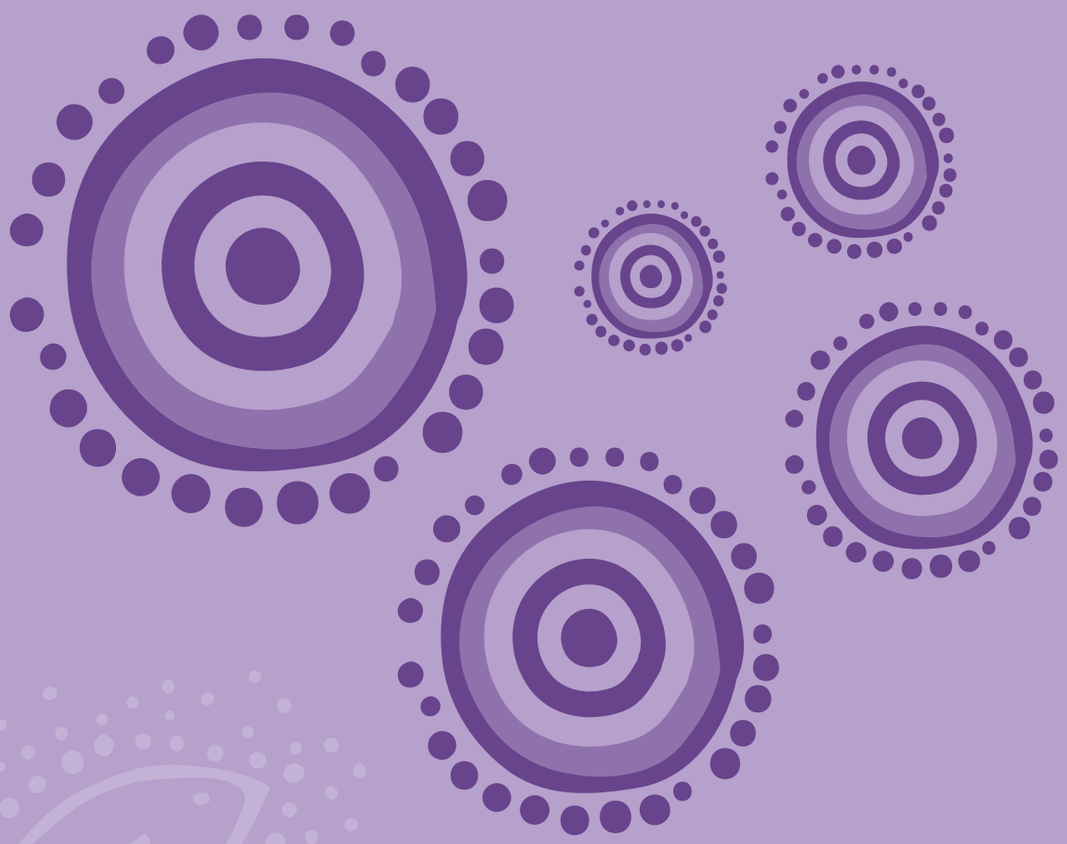
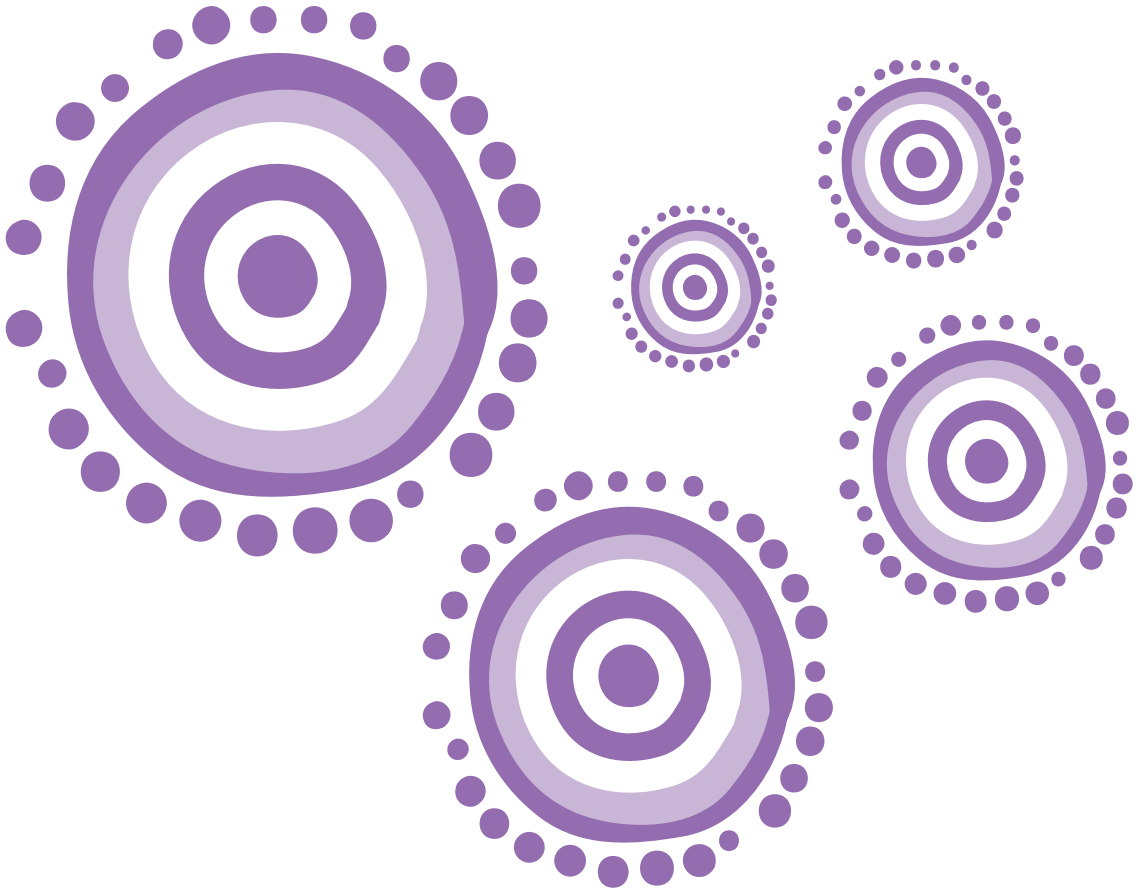
Cancer Australia

Gynaecological Cancers



A handbook for Aboriginal and Torres Strait Islander Health Workers and Health Practitioners

Gynaecological Cancers



A handbook for Aboriginal and Torres Strait Islander Health Workers and Health Practitioners

Helping health workers provide information and support to Aboriginal and Torres Strait Islander women with gynaecological cancers

Gynaecological cancers: a handbook for Aboriginal and Torres Strait Islander Health Workers and Health Practitioners resource was prepared and produced by:

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Contents

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- Professor Ian Hammond AO, Gynaecological Oncologist
- Ms Kim Hobbs, Social Worker
- Dr Pearly Khaw, Radiation Oncologist
- Professor Michael Quinn AM, Gynaecological Oncologist

Acknowledgement of country and cultural diversity

Cancer Australia acknowledges the traditional owners of country throughout Australia, and their continuing connection to land, sea and community. We pay our respects to them and their cultures, and to Elders both past and present.

Wording in this handbook

Cancer Australia recognises that 'Aboriginal and Torres Strait Islander people' is the preferred term for referring to Aboriginal peoples and Torres Strait Islanders collectively. This term recognises the distinct cultures, languages and homelands of Australia's Indigenous communities.

We use the term 'Health Workers' to refer to Aboriginal and/or Torres Strait Islander Health Workers and Health Practitioners.

Introduction

This handbook has been written to help Aboriginal and/or Torres Strait Islander Health Workers and Health Practitioners provide information and support to women in their community about gynaecological cancers.

The handbook may also be useful for Aboriginal Liaison Officers, nurses and other health professionals working with Aboriginal and Torres Strait Islander people.

Key information

This handbook contains information about:

Read the Chapter(s) that are most relevant for you and the women in your care.

Talking cancer

Women need clear information about gynaecological cancer, the tests and treatment options. It is okay if you don't know a lot about cancer or don't have all the answers to a woman's questions. You can let the woman know that you will find out the answer, for example from a doctor or nurse, and let her know at the next appointment.

The following tips may be useful when talking to a woman with gynaecological cancer.

- Explain that any information a woman shares with you and her healthcare team is confidential.
- Ask her if she would like you or a family member to be with her when she meets with her doctor or specialists.
- Encourage her to talk about how she feels and what she is worried about.
- Handle embarrrassing or worrying topics directly and sensitively.
- Check to see whether she has understood what her doctors have told her. Explain medical jargon, use diagrams and pictures and write out information for the woman and her family to take away if helpful.

Your role

Throughout this handbook, we have included tips to help you provide information, referral, support and guidance about gynaecological cancers for a woman, her family and your community.

You can help all women in your community understand what they can do to lower their risk, and encourage them to see a doctor if they have symptoms. For women with symptoms, you can explain the tests they might need. And if a woman in your community is diagnosed with a gynaecological cancer, you can talk about what treatment involves and provide practical and emotional support.

As the roles of Aboriginal and/or Torres Strait Islander Health Workers and Health Practitioners can be different in each workplace, it is best to check what the roles and responsibilities are in your workplace first and to use these tips in line with your local context.

A note about looking after yourself

Your role can be stressful and emotionally draining. It is important to look after your own health and seek support if needed.

Talking to your manager about how you are feeling can be a good place to start.

Many workplaces have employee assistance programs that can offer professional counselling services. The following organisations can also provide support.

- Cancer Council Helpline: 13 11 20
- Lifeline: 13 11 14

Chapter 1: Gynaecological cancers: the facts

Key points

- Gynaecological cancers are cancers that develop in the female reproductive system.
- Aboriginal and Torres Strait Islander women are more likely to be diagnosed with and die from gynaecological cancers than non-Indigenous women.[1,2] This is partly due to diagnosis at a more advanced stage.[2]
- The earlier gynaecological cancer is found, the better the chances of survival.[1]

What are gynaecological cancers?

Cancer is a disease in which the body's basic building blocks – the cells – change and grow in an uncontrolled way. The abnormal cells can grow into (invade) and damage the surrounding tissue, and can sometimes spread to other parts of the body, causing more damage.

There are more than 100 types of cancer. **Gynaecological cancers** are cancers that develop in the female reproductive system (see Figure 1.1).

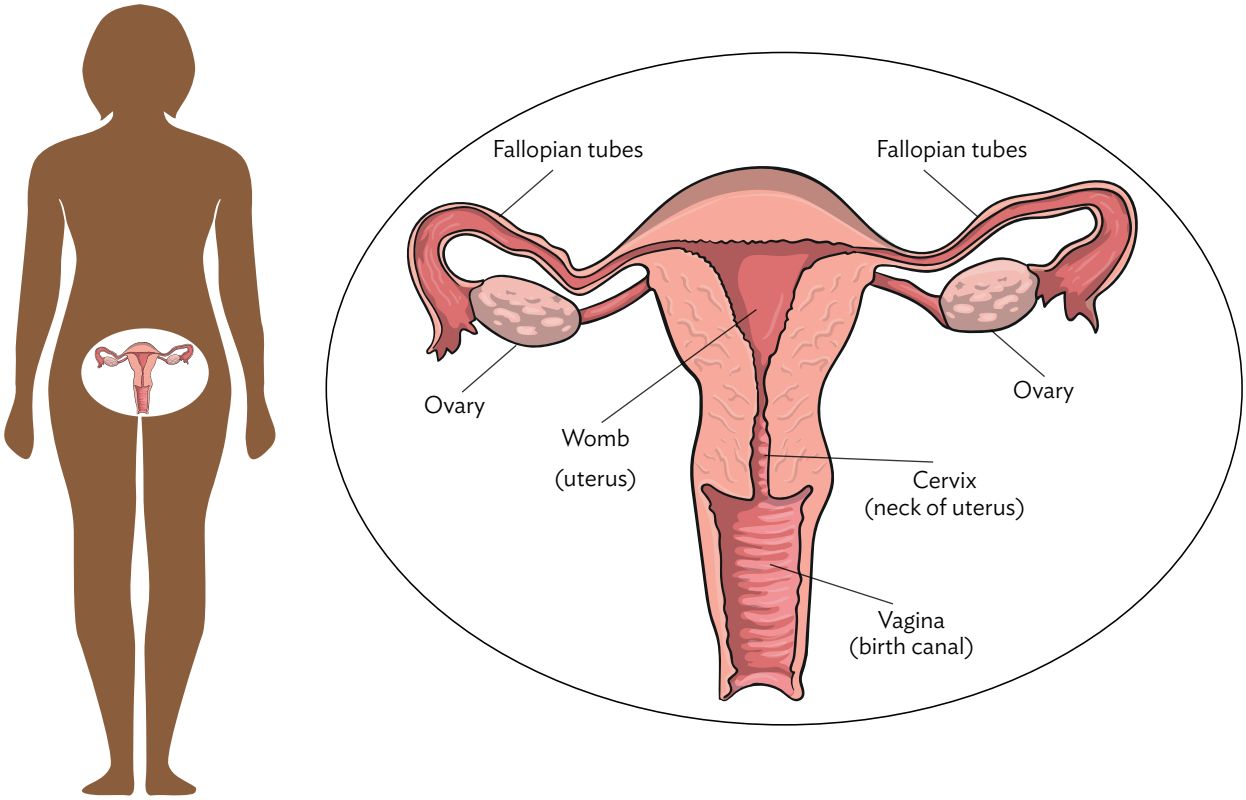
The three most common types of gynaecological cancer are:[1,2]

- **cervical cancer:** starts in the cells of the cervix
- **endometrial cancer:** starts in the womb (uterus) (also called cancer of the womb, or uterine cancer)
- **ovarian cancer:** starts in one or both ovaries, fallopian tubes or the peritoneum.

Less common types of gynaecological cancer include **vaginal cancer, vulval cancer**, and **placenta cancer** (a pregnancy-related cancer).[1]

This handbook contains information about the three most common types of gynaecological cancer.

Figure 1.1 The female reproductive system



How cancer spreads

When cells grow in an uncontrolled way, they form a **tumour**.

Not all tumours are cancer. **Benign tumours** do not spread to other parts of the body. Most benign tumours do not develop into cancer. However, if they continue to grow at the original site, they can cause a problem if they press on nearby organs.

A **malignant tumour** contains cancer cells that grow into the surrounding tissue and spread to other parts of the body. Gynaecological cancers are malignant tumours. They can damage the tissue and can stop the tissue or organ from working properly.

The place where the tumour first grows is called the **primary site** or **primary tumour**. Sometimes cancer cells break away and travel in the blood or lymph to another part of the body. This is called **metastasis**. When cancer grows in another part of the body this is called a **secondary cancer** or **advanced cancer**.

Gynaecological cancers in Aboriginal and Torres Strait Islander women

Aboriginal and Torres Strait Islander women are more likely to be diagnosed with and die from gynaecological cancers than non-Indigenous women.[1,2]

The incidence (number of new cancers diagnosed) of cervical and endometrial cancers in Aboriginal and Torres Strait Islander women is much higher than in non-Indigenous women.[2,4] This difference is likely due to higher rates of known risk factors such as obesity, lower participation in cervical cancer screening and diagnosis at a more advanced stage.[2]

Is it true? Sorting out beliefs from facts about cancer

Sometimes it can be hard to tell beliefs or stories from facts. Here are some important facts about gynaecological cancers.

Belief *"I'm young, I won't get gynaecological cancer."*

Fact Gynaecological cancers can affect women at any age.[1,3]

Belief *"I recently had a Cervical Screening Test that was clear, so I know I do not have any type of gynaecological cancer."*

Fact A Cervical Screening Test is used to look for the HPV virus or changes in the cells of the cervix that may lead to cervical cancer if left untreated. A Cervical Screening Test cannot detect other types of gynaecological cancer.

Belief: *If I have a Cervical Screening Test, I am being tested for all sexually transmitted infections (STIs).*

Fact A Cervical Screening Test is used to look for HPV infection, not other STIs.

Belief *"I have had the HPV vaccine, so I won't get gynaecological cancer."*

Fact The HPV vaccine can help reduce the risk of cervical cancer. It does not prevent all cervical cancers and does not protect against other types of gynaecological cancer.

Belief *"If I have cancer, nothing can be done about it anyway."*

Fact Treatments are available for gynaecological cancers and they are getting better all the time.

Belief *"If I have cancer it means I've done something wrong. So I don't deserve to get treatment"*

Fact No-one deserves to get cancer. Everyone deserves to have treatment.

Belief *"I need to be strong and face cancer alone."*

Fact Having help and support is important for everyone. It is important for women with gynaecological cancer to be open and honest with their family and health professionals so that they can get the help and support they need.

Chapter 2: Staying healthy and finding gynaecological cancers early

Key points

- All women can take steps to reduce their risk of developing gynaecological cancers.
- Cervical cancer is one of the most preventable cancers.[5] There are two ways to help reduce the risk of cervical cancer:
  - HPV vaccination
  - regular cervical screening.
- It is important that women see a doctor if they notice any signs and symptoms of gynaecological cancers.

Reducing the risk of gynaecological cancers

There are several things that can increase a woman's risk of developing gynaecological cancers – these are called risk factors. Some risk factors – like smoking and being overweight – can be changed. Others – such as increasing age and family history – cannot be changed.

There are different risk factors for different types of gynaecological cancer.

For more information about risk factors for cervical, endometrial and ovarian cancers, go to Chapters 4, 5 and 6.

Having one or more risk factors does not mean a woman will get gynaecological cancer. Many women have one risk factor but will never get gynaecological cancer. Some women with gynaecological cancers have none of the known risk factors. All women can take steps to improve their overall health and lower their risk of gynaecological cancer .

Reducing the risk of cervical cancer

The main risk factor for cervical cancer is an infection called the **human papillomavirus (HPV)**.

Cervical cancer is one of the most preventable cancers.[5] There are two ways to help reduce the risk of cervical cancer.

1. Vaccination against HPV infection

- The best time to be vaccinated is before a person becomes sexually active as this gives the best protection.
- The HPV vaccine is provided free in schools to all girls and boys aged 12–13 years through the National HPV Vaccination Program.
- The vaccine is given through a course of injections. It is important to complete the full course to give the best protection.

2. Cervical screening through the National Cervical Screening Program

- Regular screening can help find HPV infection and cervical changes that may lead to cervical cancer, so that they can be treated before cervical cancer develops.
- The Cervical Screening Test should be done very five years from the age of 25 years to 74 years.
- Women should have the Cervical Screening Test even if they have had the HPV vaccine.

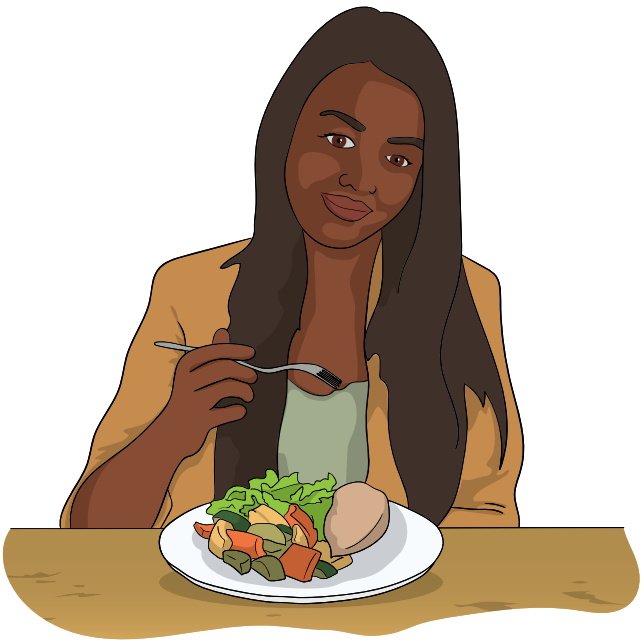
For more information about the HPV vaccination and cervical cancer screening, including why the cervical screening program has changed from a 2 yearly Pap test to a 5 yearly HPV test, go to Chapter 4.

Your role: promoting a healthy lifestyle and healthy behaviours

It is important that women understand what they can do to reduce their risk of gynaecological cancers. Some of these things will also reduce the risk of other diseases.

You can help by:

- promoting messages about gynaecological cancer and other women's cancers to all Aboriginal and Torres Strait Islander women in your community
- encouraging women to have a healthy lifestyle and reduce risky behaviours (stop smoking, eat a healthy diet, keep a healthy weight, limit alcohol intake, use protection during sexual activity)
- encouraging women to take part in the National Cervical Screening Program
- advising parents that it is very important for children to take part in the National HPV Vaccination Program and get the HPV vaccine before they are sexually active.



Talking about signs and symptoms

Treatment for gynaecological cancers is most effective if the cancer is found and treated early.[1]

Signs and symptoms of gynaecological cancers are like symptoms of many other health conditions. Some women may not seek advice from a doctor because they do not realise that the symptoms could be due to cancer.

Some women are embarrassed to visit their doctor to talk about women's business. They may be ashamed because they think their sexual activity may have caused the cancer. Or they may see no point seeing a doctor because they think there are no effective treatments.

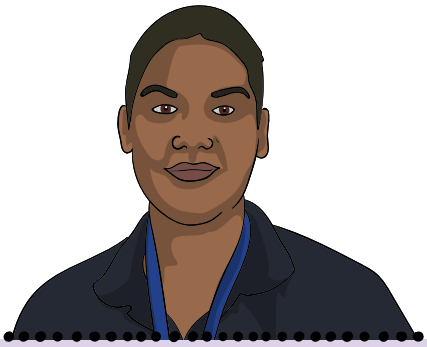
Signs and symptoms – when should a woman see a doctor?[6]

If a woman notices any of the following symptoms, she should visit her doctor straight away, regardless of her age:

- abnormal or persistent vaginal bleeding – between periods, after sex, after menopause
- unusual vaginal discharge
- persistent pain, pressure or discomfort in the abdomen
- swelling of the abdomen
- change in bowel or bladder habits
- pain during sex
- itching, burning or soreness
- lumps, sores or wart-like growths.

Having one or more of these symptoms does not mean a woman has gynaecological cancer. However, if a woman notices these symptoms, she should see her doctor to have the symptoms checked.

For more information about symptoms of cervical, endometrial and ovarian cancer, go to Chapters 4, 5 and 6.



Your role: encouraging women to report symptoms

It is important that women know the signs and symptoms of gynaecological cancer and that they see a doctor if they have any symptoms.

You can help by:

- telling women in your community about signs and symptoms to look for
- encouraging women to report symptoms to a doctor – even if they feel embarrassed or ashamed
- reassuring women that having symptoms does not mean it is cancer
- explaining that finding and treating cancer early gives the best chance of effective treatment.

Investigating symptoms

If a woman has symptoms of gynaecological cancer, her doctor will arrange some tests. If these do not rule out cancer, the woman will usually be referred to a **gynaecological oncologist** (a doctor who specialises in diagnosing and treating gynaecological cancer) to confirm the diagnosis.

If it is gynaecological cancer, other tests and examinations may be done to find out whether cancer has spread to other parts of the body.

Table 2.1 lists the main tests used to investigate symptoms of gynaecological cancer.

Table 2.1 Tests to investigate symptoms of gynaecological cancer

Test	What's involved?
Physical examination	Feeling the abdomen (tummy) to check for swelling Internal vaginal examination including looking at the cervix with a speculum
Internal scoping tests	Using a device like a telescope to have a closer look at the area(s) that may be affected; the test may be used in combination with a **biopsy** Examples include **colposcopy** (to look at the cervix, vulva or vagina), **hysteroscopy** (to look inside the womb), **cystoscopy** (to look inside the bladder) and **laparoscopy** (to look inside the tummy) Scoping tests may require a woman to have a local or sometimes a general anaesthetic

Imaging tests	Taking pictures of the part(s) of the body affected by symptoms and/or other areas of the body to check for signs of cancer Examples include: **X-rays, ultrasound, computerised tomography (CT) scans, magnetic resonance imaging (MRI)** or **positron emission tomography (PET)**
Biopsy	Removal of a small piece of tissue to check for abnormal cells or signs of cancer under a microscope
Blood tests	Blood tests may be used to help diagnose ovarian cancer; they may also be done to check a woman's general health and to help inform treatment recommendations for other gynaecological cancers

For more information about the tests used to diagnose cervical, endometrial and ovarian cancer, go to Chapters 4, 5 and 6.

To find out more about what is involved in each test, go to Chapter 10.

Your role: supporting women when they are having tests

Women may be confused by the medical language used by doctors while they are having tests. Some women may not want tests because they are embarrassed to talk about women's business with their doctor.

Women from regional, rural or remote communities may need to travel to a city for testing if the tests used are not available locally.

You can help by:

- explaining the different tests and what they involve
- explaining that a woman can ask for a female doctor to do the tests or bring someone with her for support
- going to specialist appointments with the woman, if possible
- providing help with travel and accommodation (see page 63)
- reassuring the woman that if it is cancer, effective treatments are available.

Chapter 3: If it's cancer – what next?

Key points

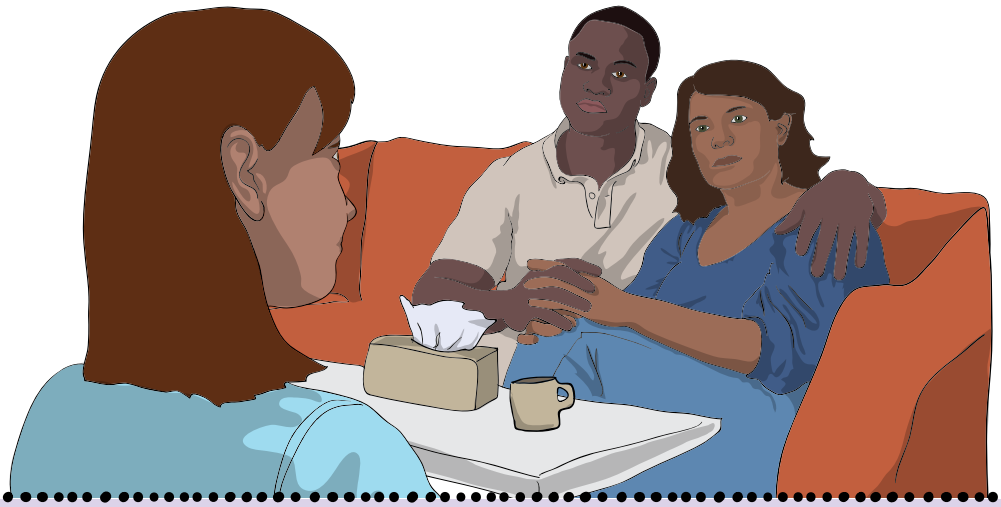
- Pathology reports and imaging reports contain important information about a woman's diagnosis of gynaecological cancer.
- Decisions about treatment for gynaecological cancer will depend on the woman's history, test results, general health, her individual preference, family and kinship obligations or cultural and community issues.
- The most common treatments for gynaecological cancers include surgery, radiotherapy and chemotherapy.
- Complementary therapies, including some bush medicine, can be used alongside conventional treatments, but it is important to check with the treating doctor to make sure they will not interfere with treatment.
- Providing information about treatments will enable a woman to make an informed choice about her treatment.
- It is important to respect a woman's choice about her treatment.

Explaining test results

When a woman is diagnosed with gynaecological cancer, test results are provided to the doctor in **pathology reports** and **imaging reports**. The reports include information about the:

- **type** of cancer
- **size** and **location** of the cancer
- **grade** of the cancer – which describes how similar the cancer cells are to normal cells, and how fast they are likely to grow
- **stage** of the cancer – which describes whether cancer cells have spread to other parts of the body:
  - stage I describes cancer that is only in the primary site
  - stages II and III describe cancer that has spread to areas nearby
  - stage IV describes cancer that has spread to other parts of the body.

Information in the pathology and imaging reports helps the healthcare team make treatment recommendations.



Your role: supporting women at diagnosis

A diagnosis of gynaecological cancer is a shock for any woman and this can be a worrying time for the woman, her family and community. Medical jargon can be confusing. It is important for the woman and her family to understand what the test results mean and how they can be used to help make decisions about treatment.

You can help by:

- explaining what the test results mean and why there may be a need for further tests
- encouraging the woman to go for further tests if they are recommended
- explaining that a woman can ask for a female doctor to do the tests or bring someone with her for support
- going to specialist appointments with the woman, if possible
- providing help with travel and accommodation (see page 63)
- reassuring the woman and her family that effective treatments are available for gynaecological cancer and they are getting better all the time.

Overview of treatments for gynaecological cancers

Treatments recommended for a woman with gynaecological cancer will depend on the woman's history, her test results, her general health and her preference.

Table 3.1 lists the main treatments for gynaecological cancers.

Table 3.1 Treatments for gynaecological cancers

Treatment	What is it?
Surgery	Physical removal of the tumour/cancer cells May be used to test for cancer in other parts of the body
Radiotherapy	Uses X-rays to destroy cancer cells and stop them growing

Chemotherapy	Uses medicines to destroy cells that are rapidly dividing, such as cancer cells Medicines are usually given intravenously (into a vein in the arm, hand or chest)
Hormonal therapy	Medicines that help the body reduce the production of hormones that the cancer needs to grow Can be given as a tablet, an injection by a doctor or nurse, or a device fitted into the womb
Targeted therapy	Uses medicines that stop certain types of cancer cells from growing, usually given by an injection by a doctor or nurse

The following video shows an Aboriginal woman having radiotherapy and chemotherapy treatments and is designed for Aboriginal and/or Torres Strait Islander Health Workers and patients.

It was made by Albury/Wodonga Health Unit in the Murrumbidgee Local Health District as part of the Aboriginal Cancer Partnerships Project network, funded by NSW Ministry of Health.

Beginning the journey: Introduction to radiotherapy and chemotherapy treatment (video - 14mins)
www.cancerinstitute.org.au/how-we-help/programs-we-support/aboriginal-cancer-partnership-project

To find out more about treatments for cervical cancer, endometrial cancer and ovarian cancer, go to Chapters 4, 5 and 6.

To find out more about what is involved in different treatments, go to Chapter 10.

Complementary therapies and bush medicine

Complementary therapies are treatments or therapies that can be used alongside conventional treatments to improve quality of life and overall wellbeing. Examples include relaxation therapy and meditation. Aboriginal and Torres Strait Islander women may wish to use bush medicine alongside conventional treatments.

Some complementary therapies and bush medicine can reduce the effectiveness of conventional treatments provided by the doctors. That is why it is important that the doctors are aware of any bush medicines or complementary therapies that the woman is taking or thinking about taking.

Alternative therapies are treatments that are used instead of conventional treatments. Most alternative therapies have not been assessed for their effectiveness or safety in treating women with gynaecological cancer and are not recommended.

Clinical trials and research

Some treatments for gynaecological cancers are still being tested in a clinical trial or research project. Clinical trials and other types of research are used to find out how well a treatment works, and to see whether there are better ways to help control symptoms and improve a woman's wellbeing.

Clinical trials and research are not available in every hospital. It can be useful to know about trials and research that may be available for women in your region. You can find out more by asking the healthcare team in the hospital where the woman is receiving treatment.

Making decisions about treatment

A lot of things are likely to affect a woman's treatment decisions. Giving clear and simple information and developing trust with women, their families and community will be helpful in supporting women as they make decisions about treatment.

Involving family and/or community members in decision-making can be important for some women and can benefit the family and the treatment team.

Your role: supporting women during treatment

Women may be confused about treatment options and worried about potential side effects. They may feel uncomfortable being away from home, being in hospital, or being treated by an unfamiliar health professional. Concerns about treatment can lead to women not having or completing treatment.

A woman's preferences about treatment might be influenced by where she lives, her beliefs and her community.

You can help by:

- explaining the different types of treatment and what they involve
- providing practical support for women and their families if the woman needs to travel for treatment
- helping women manage side effects of treatment
- encouraging women and their families to talk to their doctors about any bush medicines they may be using
- talking to women about what is important to them and their family, and providing guidance to the healthcare team about any cultural issues
- answering questions from women about research and clinical trials and finding out more information from the healthcare team if needed.

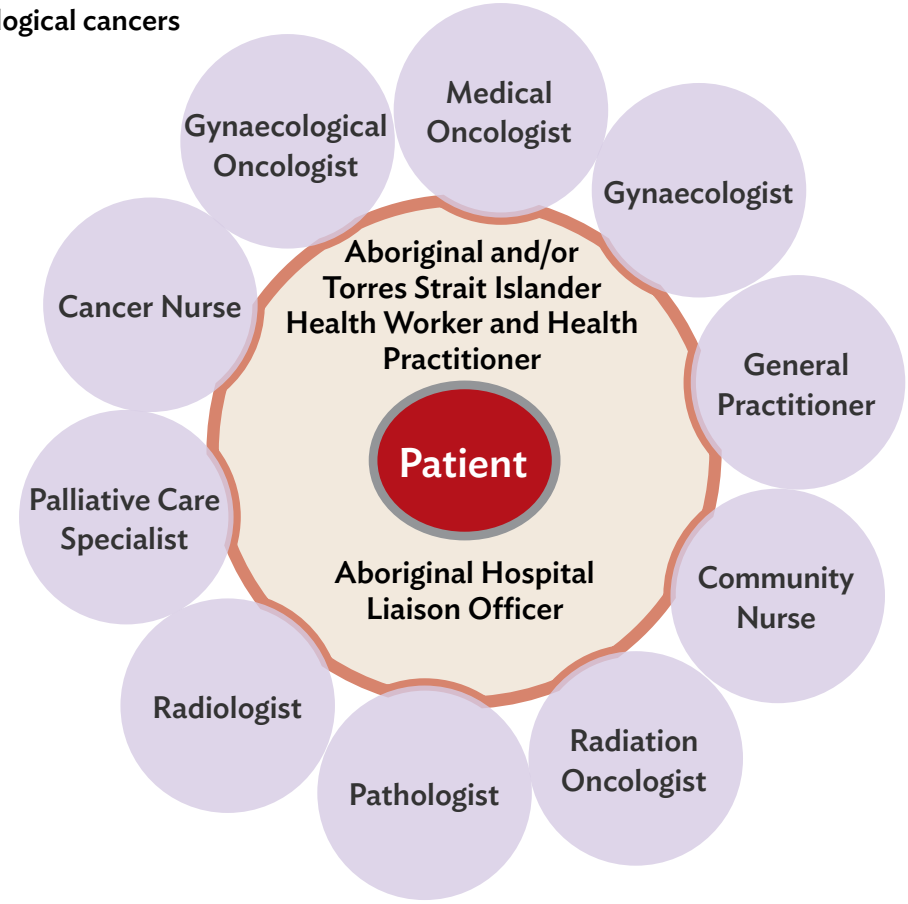
Multidisciplinary care

Treatment and care for women with gynaecological cancers involves a team of medical, nursing and allied health professionals. This is called multidisciplinary care. Multidisciplinary care helps to make sure that treatment recommendations for a woman consider all her physical and supportive care needs.

The multidisciplinary team includes health professionals who are involved in treatment planning (the core team), and other health professionals who may be involved in a woman's treatment and care at different times.

As an Aboriginal and/or Torres Strait Islander Health Worker, you are an important member of this team.

Figure 3.1 The core team of health professionals involved in the care of women with gynaecological cancers



To find out more about the different health professionals involved and what they do, go to Chapter 10.

Multidisciplinary team meetings

Multidisciplinary team meetings are meetings of health professionals who recommend a treatment plan for people diagnosed with cancer. Meetings may be face-to-face, or via teleconference or videoconference if health professionals are in different locations.

During a multidisciplinary team meeting, health professionals will talk about each woman who has recently been diagnosed in the hospital or region. They will review the woman's history and general health, her cancer test results and her supportive care needs. They will then recommend a treatment plan to be discussed with the woman by her treating doctor.

Your role: contributing to the multidisciplinary team

It is important that treatment plans for Aboriginal and Torres Strait Islander women consider the woman's family as well as any kinship obligations or cultural and community issues.

You can help to inform the treatment plan by:

- talking to the other health professionals in the team about the woman, her family and community
- providing guidance and information to the team on social and cultural issues.

You can also help women understand the job of each health professional involved in their care. You may also be a central contact person for the woman at different times during her treatment and care.

Chapter 4: Cervical cancer

Key points

- Cervical cancer is one of the most preventable cancers.[5]
- The main cause of cervical cancer is infection with the human papillomavirus (HPV).[7]
- HPV vaccination is a very important step in reducing the risk of cervical cancer.
- The best time to be vaccinated is before a person becomes sexually active as this is when it is most effective.
- The HPV vaccine is provided free in schools to all girls and boys aged 12–13 years through the National HPV Vaccination Program.
- The best way to prevent cervical cancer or find it early is for women to take part in the National Cervical Screening Program.
- Cervical cancer is more common in women older than 35 years of age.[3]
- Treatment for cervical cancer usually involves surgery, and/or a combination of chemotherapy and radiotherapy.

What causes cervical cancer?

Almost all cases of cervical cancer are caused by infection with the **human papillomavirus (HPV)**.[7] HPV viruses can affect the surface of any part of the body, including the skin, vagina and cervix. There are about 100 types of HPV; only some of these can cause cervical cancer.

HPV is spread through skin-to-skin contact during sex. The virus does not usually have symptoms, so many people don't know they have the virus or that they are passing it to a sexual partner.

HPV infection is very common. Around four out of five people will have HPV at some point in their lives. In most women, the infection is cleared quickly by the immune system. If the virus stays in a woman's body for several years, it can cause cervical cancer.

Other things that increase the risk of cervical cancer include:

- **smoking**: chemicals in tobacco may damage the cells of the cervix and make cancer more likely to develop
- **lack of regular Cervical Screening Tests**: cervical cancer is more common among women who don't have regular Cervical Screening Tests
- **getting older**: cervical cancer occurs mainly in women older than 35 years [3]
- **using the contraceptive pill for five or more years**: the risk decreases quickly when women stop taking the contraceptive pill
- **a history of abnormal cervical cells detected by screening:** women who have HPV detected on the Cervical Screening Test may be at a higher risk of cervical cancer and women who have had an abnormality on a previous Pap test should discuss their ongoing management with their doctor

- **a previous diagnosis of cervical cancer**: these women should talk to their specialist or doctor about ongoing monitoring/treatment
- **giving birth to five or more children**: may slightly increase the risk of cervical cancer
- **previous use of diethylstilbestrol (DES)**: prescribed to pregnant women in the 1940s to 1970s to prevent miscarriage.

Reducing the risk of cervical cancer

National HPV Vaccination Program [8,9]

The HPV vaccine protects against the types of the HPV virus that are known to cause cervical cancer. The HPV vaccine is provided free in school to all girls and boys aged 12-13 years under the National HPV Vaccination Program. In addition, adolescents up to the age of 19 years can receive free catch up vaccinations through their GP, Aboriginal Medical Service or school based vaccination provider.

HPV vaccination does not prevent cervical cancer completely. Women who have received the vaccine should still have regular cervical screening.

The vaccine is given through a course of injections. It is important to complete the full course to give the best possible protection.

Catch up doses are available for individuals aged 20 years or older. There may be a cost involved.

The HPV vaccine works best if given before sexual activity commences. It cannot be given to treat cancer once a woman has already been diagnosed with precancerous cells or cervical cancer.

Your role: encouraging HPV vaccination

HPV vaccination is an important step in reducing the risk of cervical cancer. The National HPV Vaccination Program has dramatically reduced the incidence of HPV in Australian women.

You can help by:

- encouraging parents to have their children vaccinated through the National HPV Vaccination Program
- explaining that the HPV vaccine is most effective before a person becomes sexually active.

Cervical Screening Test

Cervical screening involves checking for signs of cell changes that can lead to cervical cancer so that they can be treated before cervical cancer develops. Since the introduction of the National Cervical Screening Program in 1991, the number of cervical cancers diagnosed and the number of people who have died from cervical cancer has halved.[10]

Cervical screening has changed in Australia[11]

On 1 December 2017, the National Cervical Screening Program changed from a 2-yearly Pap test to a 5-yearly HPV test.

Why has the Cervical Screening Test changed?[12]

The Pap test has been replaced with a new Cervical Screening Test every five years.

The Cervical Screening Test is more accurate at detecting human papillomavirus (known as HPV). The Pap test looked for cell changes in the cervix, whereas the new Cervical Screening Test looks for HPV which can lead to cell changes in the cervix.

Why does screening start at 25?[9, 12]

Research shows that beginning cervical screening at age 25 years is safe.

The change in the starting age for cervical screening is because evidence shows that:

- cervical cancer in young women (under the age of 25 years) is rare
- screening has not changed the rates of incidence or mortality from cervical cancer in this age group
- starting screening at age 25 will reduce the investigation and treatment of common cervical abnormalities that would usually resolve by themselves in women under the age of 25
- treatment of these common abnormalities can increase the risk of pregnancy complications later in life
- in addition, the HPV vaccine has been shown to reduce cervical abnormalities in young women.

Who should have cervical screening?[12]

- The National Cervical Screening Program recommends that all women who have a cervix and have ever had sex have a regular Cervical Screening Test
- The test should be done every five years from the age of 25 years to 74 years
- If a woman has had sexual intercourse before the age of 14 years and had not received the HPV vaccine before this, a single Cervical Screening Test can be done between the ages of 20-24
- The Cervical Screening Test can be done in women who are pregnant
- Women can stop cervical screening if they have a Cervical Screening Test at age 70-74 years that does not find cancer-causing HPV
- Women should take part in the National Cervical Screening Program even if they have had the HPV vaccine
- If a woman has symptoms at any age, such as abnormal vaginal bleeding, pain or discharge, she should discuss these with her doctor straight away.

What does the Cervical Screening Test involve? [11]

Taking a sample for the Cervical Screening Test is the same as taking a sample for a Pap test. A health professional will use an instrument called a speculum to open the vagina and see the cervix. They will then collect some cells from the cervix. The test only takes a few minutes.
A Cervical Screening Test can be done through:

- a doctor's clinic
- a women's health clinic
- a family planning clinic
- a sexual health clinic
- a community health clinic or women's health centre
- an Aboriginal Medical Service.

Who can do a Cervical Screening Test?

Healthcare providers who can do a Cervical Screening Test include:

- General practitioners (GPs)
- nurses trained in cervical screening
- specialist doctors such as gynaecologists
- Aboriginal and Torres Strait Islander Health Practitioners.

Checking the results of the Cervical Screening Test [11]

What happens after a cervical screening test will depend on the test results.

- If HPV is not found in the sample, the woman will be due for her next Cervical Screening Test in 5 years time.
- If the test result is positive and shows signs of HPV, a woman will need to see her doctor for further tests.

Self collection [11]

All cervical screening participants now have the choice to self-collect their own Cervical Screening Test sample.

If you are eligible for a Cervical Screening Test, you now have the choice to either:

- do the test yourself using a thin, soft swab to collect a sample from your vagina; or
- have a doctor or a nurse take a sample using a speculum to access your cervix

Both options are safe and accurate at detecting HPV.

Self-collection is when a person collects their own vaginal sample for cervical screening.

Self-collection is available to all people eligible for a Cervical Screening Test – that is people who:

- are aged between 25 and 74
- have had any type of sexual contact
- are a woman / person with a cervix
- are due or overdue for routine cervical screening

If you are eligible and want to collect your own sample, your healthcare provider will give you a swab and instructions.

You will be given a private space, such as behind a medical curtain, or in a bathroom, to collect your sample.

You should speak to your doctor or nurse about whether self-collect is the right option for you.

Your role: encouraging cervical screening participation

Women may be reluctant to take part in regular cervical screening because it involves visiting an unfamiliar health professional, or because they are embarrassed about having the test.

Some women are fearful about the test and think it will be painful.

Others are worried about having the test because HPV is spread by sexual intercourse and they are ashamed about having the infection.

You can help by explaining:

- the importance of early detection through regular cervical screening
- that cervical screening is for healthy women and does not mean the woman has cervical cancer
- how the test is done
- that the test should not be painful and will only take a few minutes
- that four out of five people have HPV at some point in their life and a woman should not be embarrassed or ashamed if she has the virus
- suggesting that the woman can ask for a female health professional to do the test and that she can take someone to the appointment for support if needed.

Symptoms of cervical cancer

Early changes in the cells of the cervix rarely cause symptoms. The Cervical Screening Test is the best way to find out whether there are abnormal cells in the cervix that may develop into cervical cancer.

Some women may develop symptoms of cervical cancer even if they have had a negative Cervical Screening Test, but this will be very rare. Cervical cancer is more common in women who have not been screened. The most common symptoms include:

- vaginal bleeding (either between periods or after menopause)
- bleeding after intercourse
- pain during intercourse
- unusual vaginal discharge
- vaginal bleeding after menopause.

If cervical cancer has spread to other parts of the body before it is detected, symptoms may include:

- excessive tiredness
- leg pain or swelling
- lower back pain.

Having one or more of these symptoms does not mean that a woman has cervical cancer. However, if a woman notices these symptoms she should see her doctor to have the symptoms checked.

Tests for cervical cancer

Tests to investigate symptoms of cervical cancer may include:

- **physical examination** of the abdomen (tummy) and an internal vaginal examination
- **colposcopy:** a procedure where a doctor uses a large microscope (called a colposcope) to get a closer look at the cervix, vagina and vulva and, if needed, take a small sample of tissue to send to a laboratory for testing; this test can usually be done in a doctor's office
- **large loop excision of the transformation zone (LLETZ):** a procedure where some tissue is removed from the cervix for testing; this can be done in a doctor's office or hospital and is usually done under a local anaesthetic
- **cone biopsy:** a procedure where some tissue from the cervix is removed for examination or small cancers are removed; this is usually done under a general anaesthetic and involves a day or overnight stay in hospital.

If a diagnosis of cervical cancer is confirmed, other tests may be carried out to find out how much of the cervix is affected and whether cancer has spread to other parts of the body.

To find out more about what these tests involve, go to Chapter 10.

What the test results mean

Types of cervical cancer

There are two main types of cervical cancer, named after the cells the cancer affects.

- **Squamous cell carcinoma** is the most common type of cervical cancer.
- **Adenocarcinoma** is a less common type of cervical cancer and can be more difficult to diagnose.

Stages of cervical cancer

The four stages of cervical cancer are:

- **Stage I:** cancer cells are only in the cervix
- **Stage II:** cancer has spread to the vagina or other tissue next to the cervix
- **Stage III:** cancer has spread to tissue on the side of the pelvis (pelvic sidewall)
- **Stage IV:** cancer has spread to the bladder or rectum, or beyond the pelvis to the lung, liver or bones.

Treatments for cervical cancer

The aims of treatment for cervical cancer are to:

- remove the cancer
- destroy the cancer cells and slow growth of the cancer and/or
- manage the symptoms of cervical cancer.

The main treatment options for cervical cancer are **surgery**, or a combination of **chemotherapy** and **radiotherapy**.[13]

Surgery

Surgery is recommended for women with cervical cancer that has not spread to other parts of the body.

The type of surgery will depend on how much of the cervix is affected and whether the woman still wants to get pregnant and have children naturally.

Women who have a hysterectomy will no longer be able to get pregnant and have children naturally.

For more information about the effects of treatment on fertility and menopause, go to Chapter 7.

Types of surgery for cervical cancer include:

- **trachelectomy:** removal of the cervix only
- **hysterectomy:** removal of the womb and cervix (Figure 4.1). Depending on the size and type of the cancer, the surgeon may also remove:
  - a small part of the upper vagina
  - ligaments supporting the cervix
  - lymph nodes in the pelvis (pelvic lymphadenectomy).
- **lymph node dissection (pelvic lymphadenectomy):** removal of some lymph nodes in the pelvis to see whether cancer has spread beyond the cervix
- **bilateral salpingo-oophorectomy:** removal of both ovaries and fallopian tubes (uncommon for cervical cancer) (Figure 4.2).

Figure 4.1 Hysterectomy

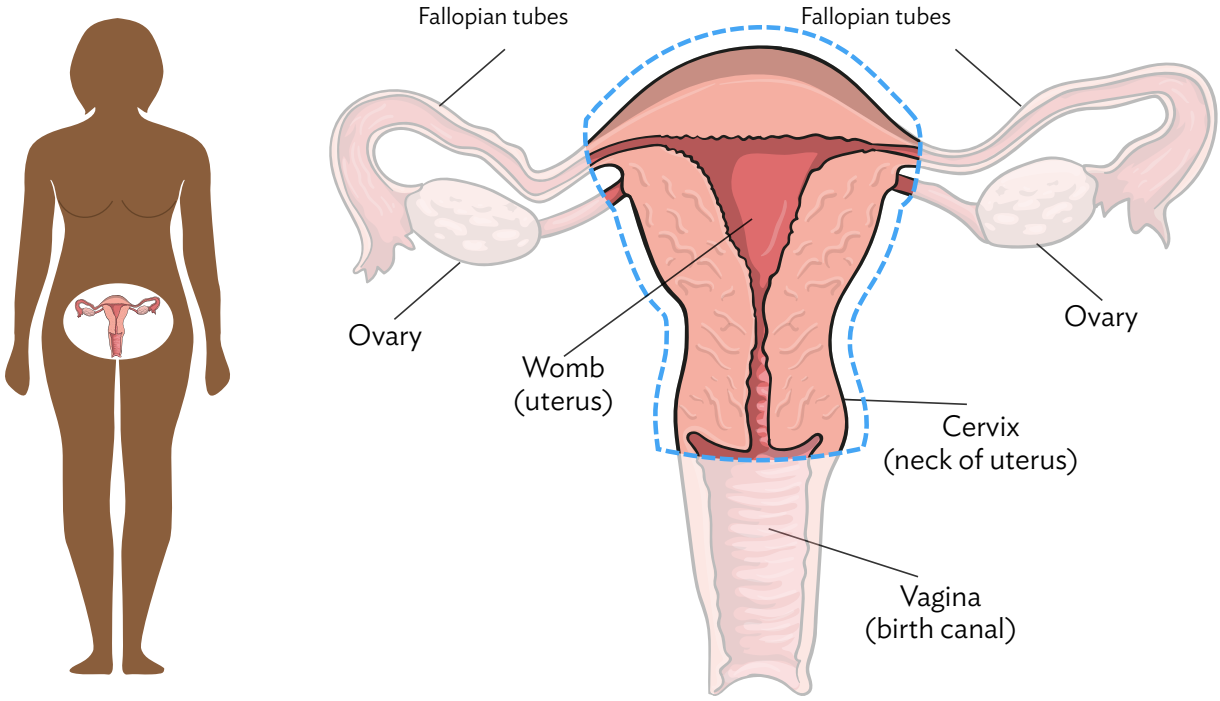
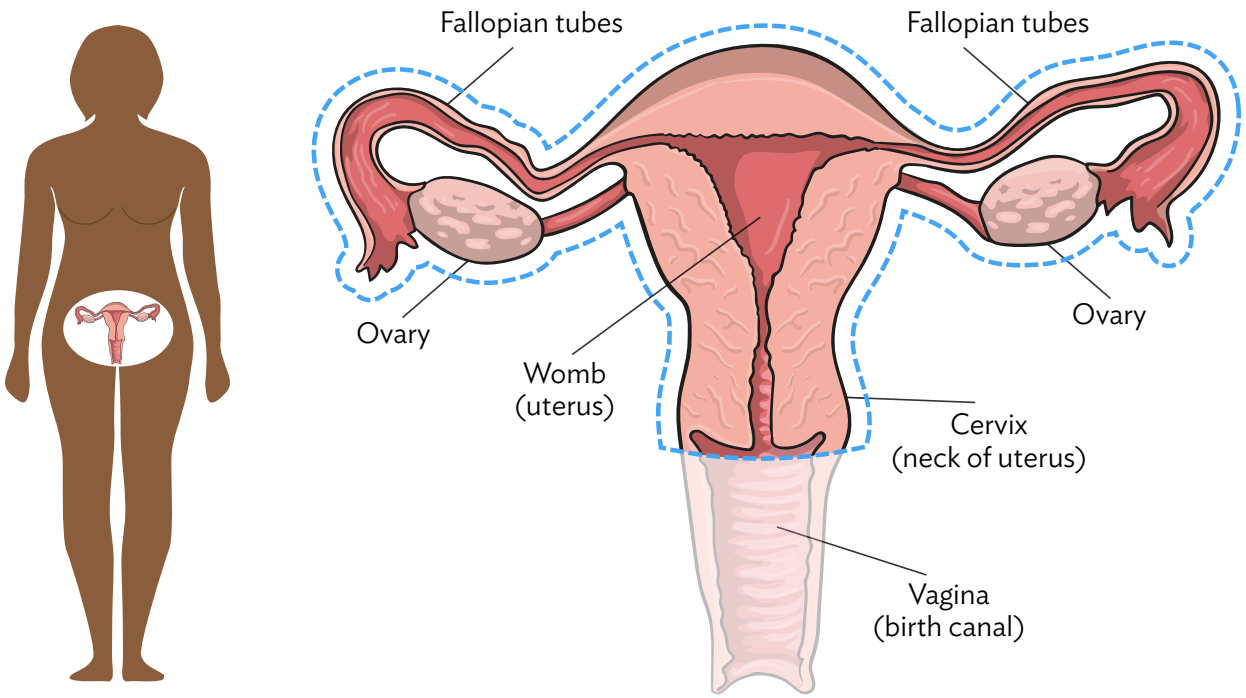
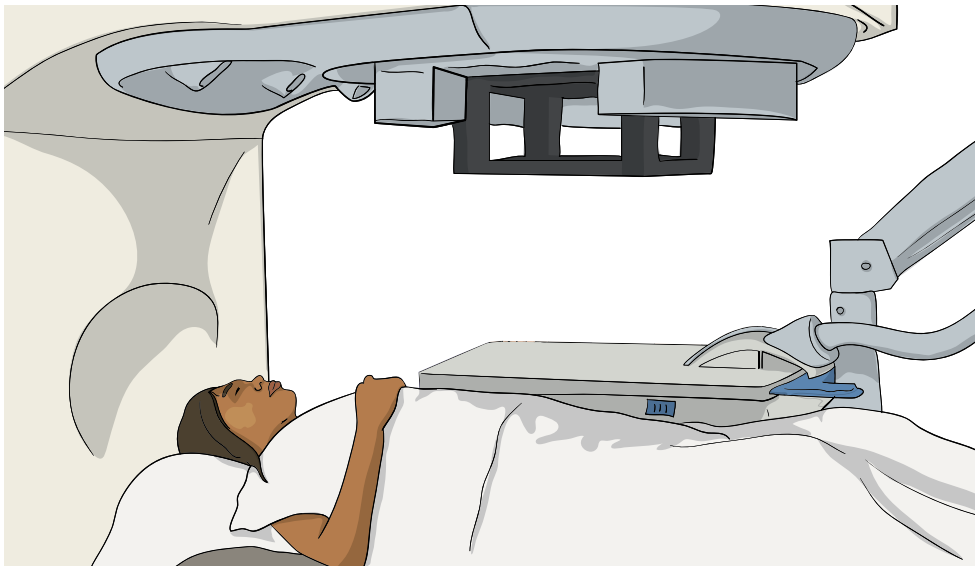


Figure 4.2 Hysterectomy and bilateral salpingo-oophorectomy





Radiotherapy

Radiotherapy uses high energy X-rays or other types of radiation to destroy cancer cells or stop them from growing.

Radiotherapy is mainly used to treat cervical cancer:

- when the cancer has spread to the vagina or tissues outside the cervix (e.g. lymph nodes)
- if the woman is not able to undergo a major operation
- after surgery to destroy any cells that may not have been removed (this is not common in cervical cancer).

Radiotherapy for cervical cancer can be given in two different ways: external and internal.

External radiotherapy: uses a machine that beams radiation onto the tumour. It is usually given as an outpatient, every day for several weeks.

At each appointment, the woman will lie on a treatment table. The machine that gives out the radiotherapy will be positioned around her.

Each treatment only takes a few minutes. The treatment itself is painless, although the woman may be a bit uncomfortable, depending on the position she is lying in.

Internal radiotherapy: radiotherapy that is given internally is called brachytherapy. It involves giving radiation via a tube or needle into the body close to where the cancer cells are. It may involve a general anaesthetic for the insertion of the tube.

Each treatment only takes a few minutes. The woman will usually be able to leave the hospital at the end of each treatment and return to the hospital for the next treatment. Most women will have 3-5 treatments.

Chemotherapy

Chemotherapy, often called "chemo", uses medicines to destroy cancer cells.

Chemotherapy for cervical cancer is given intravenously (into a vein in the arm, hand or chest) through a drip or a plastic tube.

The number of chemotherapy treatments will depend on the type of cervical cancer the woman has and what other treatments she is receiving. Chemotherapy is usually combined with radiotherapy to make radiotherapy more effective in treating the cancer.

Your role: supporting women during treatment

You can help a woman with cervical cancer understand the treatments that are recommended for her and the possible side effects before she starts treatment.

You can also provide support to help the woman manage any side effects.

To find out more about what different treatments involve, go to Chapter 10.

For information about the possible side effects of treatment and how to manage them, go to Chapter 7.

Chapter 5: Endometrial cancer

Key points

- Endometrial cancer is the most common type of cancer of the womb (also called the uterus).
- Endometrial cancer is more common in women older than 50 years.[14]
- There is no screening test for endometrial cancer.
- If endometrial cancer is diagnosed early, it can usually be treated successfully.[15]
- The most common symptom of endometrial cancer is abnormal vaginal bleeding or discharge.
- Tests for endometrial cancer include physical examination, imaging tests and taking a biopsy to check for cancer cells.
- The most common treatment for endometrial cancer is surgery to remove the womb (hysterectomy). Radiotherapy and chemotherapy may sometimes be used.

What causes endometrial cancer? [14]

We do not know what causes endometrial cancer. Certain risk factors have been linked to the development of endometrial cancer, including:

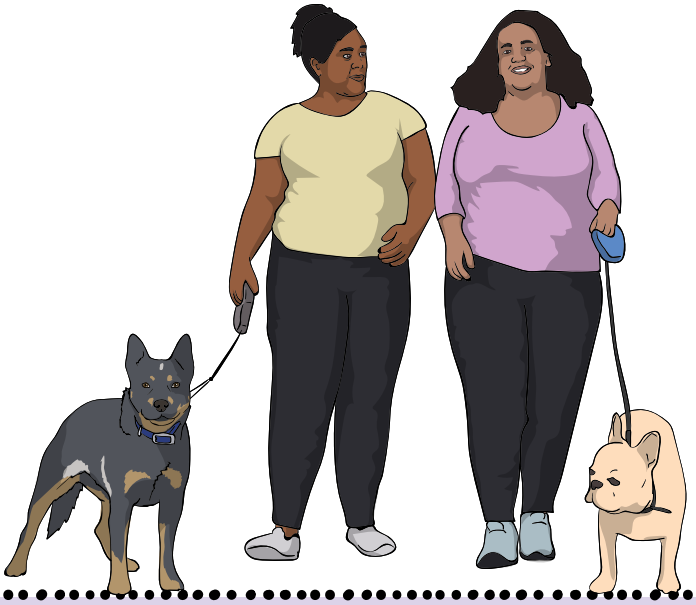
- **increasing age**: endometrial cancer is more common in women older than 50 years
- being **overweight** or **obese**
- **high blood pressure** (hypertension) or **diabetes**
- **polycystic ovary syndrome**
- taking **oestrogen hormone replacement therapy** without progesterone
- taking **tamoxifen to treat breast cancer**: the risk of endometrial cancer is usually outweighed by the benefits of treating breast cancer - women should speak to their doctor if they are concerned
- having a family history of **endometrial, ovarian or bowel cancer**
- never having children or being infertile.

Having one or more of these risk factors does not mean that a woman will develop endometrial cancer. Some women without any of these risk factors may still develop the disease.

Reducing the risk of endometrial cancer

Having a healthier lifestyle can help to reduce the risk of developing endometrial cancer.

There is no screening test for endometrial cancer.



Your role: encouraging healthy behaviours [15]

You can help by:

- encouraging women to maintain a healthy body weight by eating healthy foods, including fruit and vegetables
- encouraging women to be physically active – all exercise helps!
- explaining to women that taking the oral contraceptive pill (especially over a long period) may reduce their risk
- explaining to women who are using hormone replacement therapy (HRT) that including progesterone as well as oestrogen, instead of oestrogen alone, may reduce their risk.

Symptoms of endometrial cancer [15,16]

The most common symptom of endometrial cancer is **abnormal vaginal bleeding or discharge**, particularly in women who have been through menopause. The discharge can be watery or bloody, and may be smelly. Abnormal bleeding or discharge is usually not due to endometrial cancer. However, all women with unusual bleeding or discharge should see their doctor.

Other symptoms of endometrial cancer include:

- persistent pelvic discomfort or pain in the abdomen
- pain during sex
- unexplained weight loss.

Your role: encouraging women to talk about symptoms

If endometrial cancer is diagnosed early, it can usually be treated successfully.[15]

You can help by:

- increasing awareness of the risks and symptoms of endometrial cancer
- encouraging women to see a doctor if they notice new or unusual symptoms.

Tests for endometrial cancer

Tests to investigate symptoms of endometrial cancer may include:

- **physical examination**: feeling the abdomen (tummy) to check for swelling, or doing an internal vaginal examination
- **transvaginal ultrasound**: insertion of an ultrasound probe into the vagina to view the size of the womb and the thickness of the womb lining (endometrium); the doctor may recommend a biopsy to examine any unusual areas
- **hysteroscopy and biopsy**: insertion of a telescope-like device (hysteroscope) into the womb through the vagina, and taking a sample of tissue (biopsy) to examine under a microscope (this procedure is sometimes also called a dilation and curettage (D&C). This is usually done in a hospital.

If a diagnosis of endometrial cancer is confirmed, other tests will be carried out to find out how much of the womb is affected and whether cancer has spread to other parts of the body.

To find out more about what these tests involve, go to Chapter 10.

What the test results mean

Types of cancer affecting the womb (uterus)

There are two main types of cancer that affect the womb:

- most cancers that affect the womb usually begin in the lining of the womb (endometrium) and are called **endometrial cancers**
- some cancers begin in the muscle of the womb (myometrium); these are called **uterine sarcomas** and are less common.

Stages of endometrial cancer

The four stages of endometrial cancer are:

- **Stage I**: cancer is only in the womb
- **Stage II**: cancer has spread to the cervix
- **Stage III**: cancer has spread beyond the womb/cervix to the ovaries, fallopian tubes, vagina or nearby lymph nodes
- **Stage IV**: cancer has spread further, to the inside of the bladder or rectum, throughout the abdomen or to other parts of the body.

Treatments for endometrial cancer

The aims of treatment for endometrial cancer are to:

- remove the cancer
- destroy cancer cells and slow growth of the cancer and/or
- manage the symptoms of endometrial cancer.

The main treatment for endometrial cancer is **surgery**. Because endometrial cancer is often diagnosed before it has spread, many women will not need treatment other than surgery.

If cancer has spread beyond the womb, **chemotherapy, radiotherapy** and **hormonal therapy** may also be used.

Surgery

Surgery is recommended for women who have endometrial cancer that has not spread to other parts of the body.

Surgery for endometrial cancer usually involves a **hysterectomy** (Figure 5.1). This involves removing the womb and cervix. In most cases, the fallopian tubes and both ovaries will also be removed at the same time. This is called a **bilateral salpingo-oophorectomy** (Figure 5.2)

Depending on the size and type of the cancer, the surgeon may also remove:

- a small part of the upper vagina
- ligaments supporting the cervix
- lymph nodes in the pelvis **(pelvic lymphadenectomy)**.

Women who have a hysterectomy will no longer be able to get pregnant and have children naturally.

For more information about the effects of treatment on fertility and menopause, go to Chapter 7.

Figure 5.1: Hysterectomy

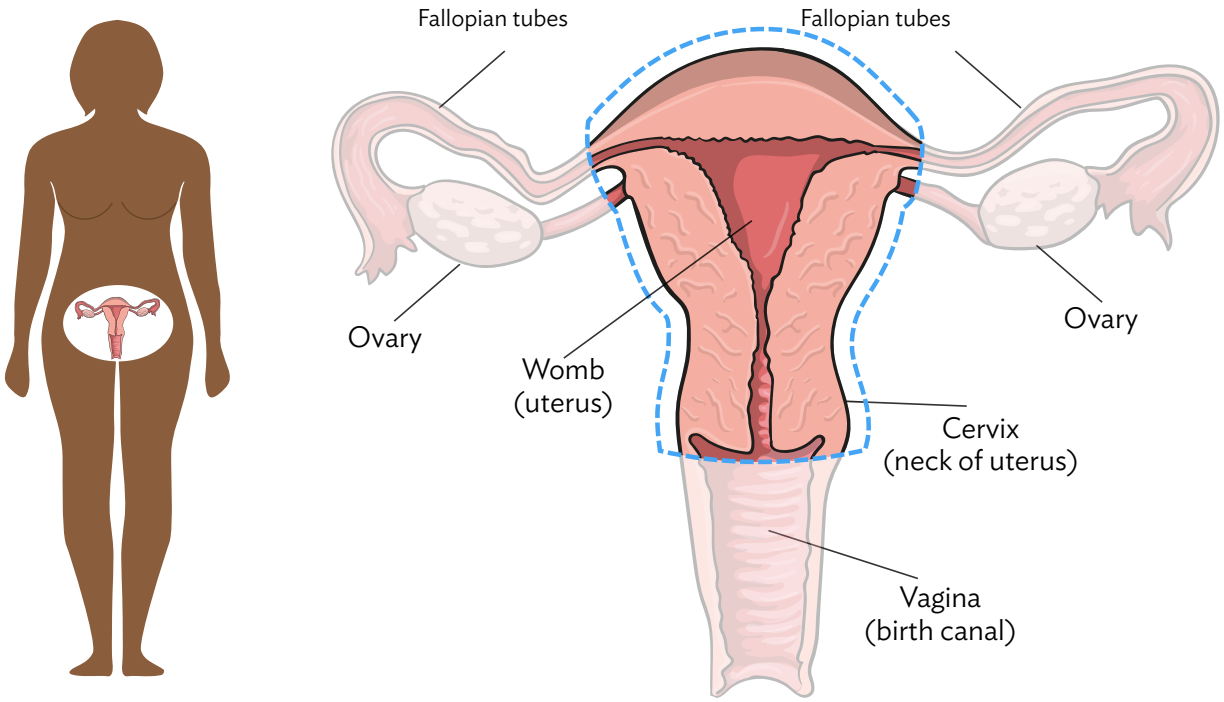
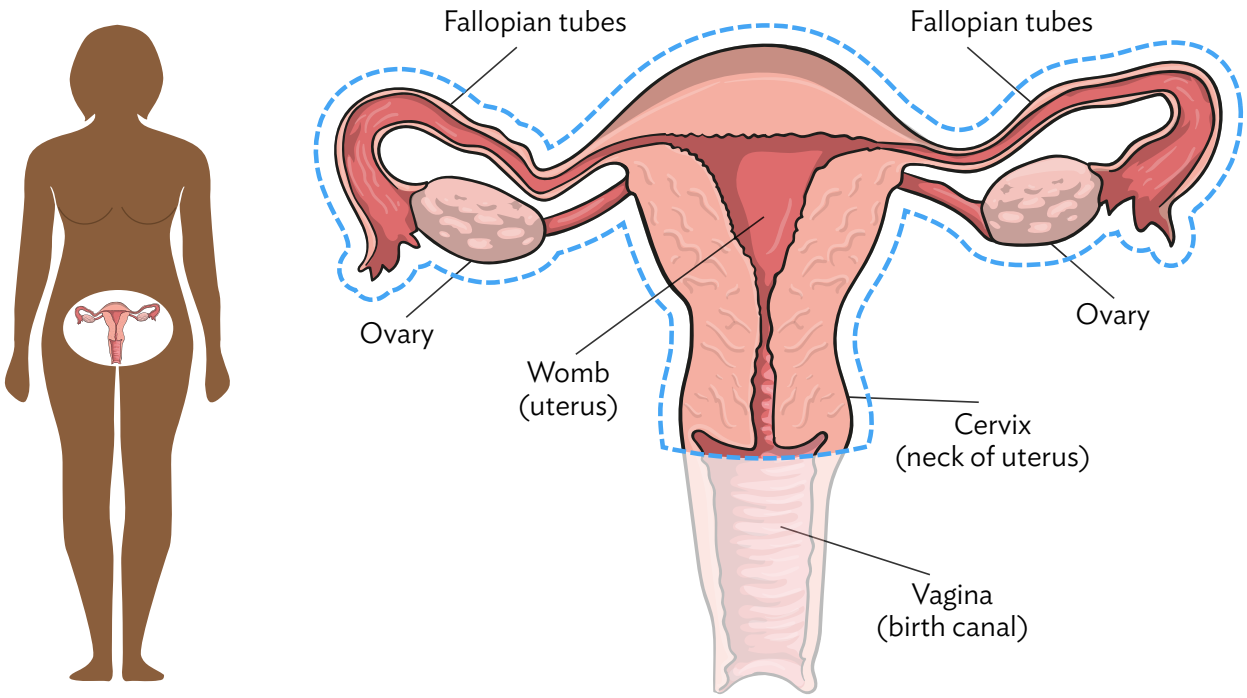
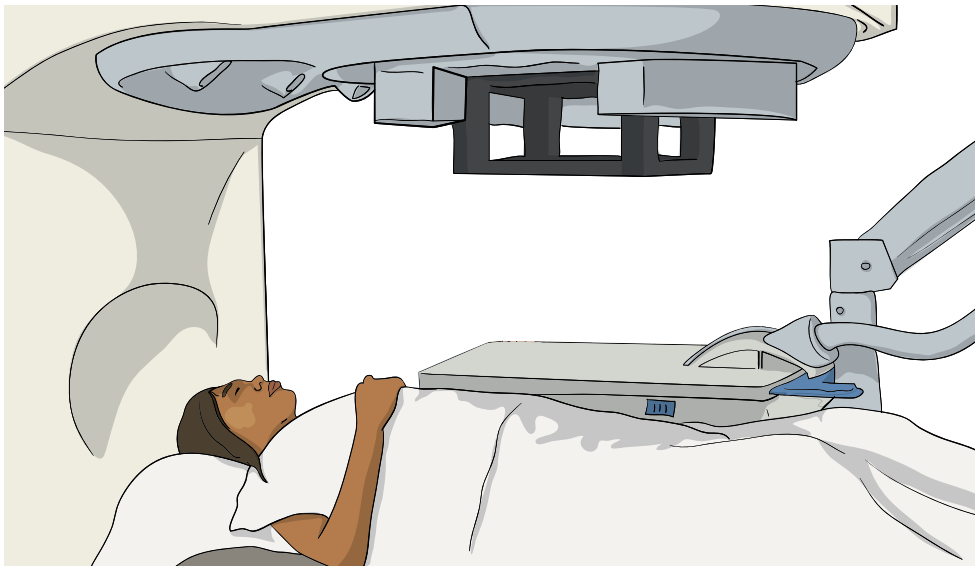


Figure 5.2: Hysterectomy and bilateral salpingo-oophorectomy





Radiotherapy

Radiotherapy uses high energy X-rays or other types of radiation to destroy cancer cells or stop them from growing.

Radiotherapy for endometrial cancer can be given in two different ways: external and internal.

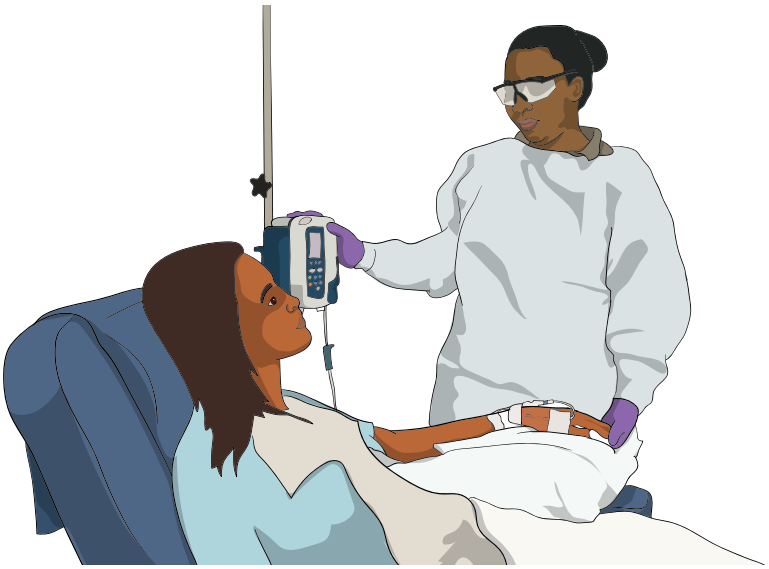
External radiotherapy: uses a machine that beams radiation onto the lower abdominal area and the pelvis, and any other parts of the body where the tumour may have spread.

It is usually given every day for several weeks.

At each appointment, the woman will lie on a treatment table. The machine that gives out the radiotherapy will be positioned around her.

Each treatment only takes a few minutes. It is painless, although the woman may be a bit uncomfortable, depending on the position she is lying in.

Internal radiotherapy: radiotherapy that is given internally is called brachytherapy. It involves giving radiation via a tube or needle into the body close to where the cancer cells are. It may involve a general anaesthetic for the insertion of the tube. Each treatment only takes a few minutes. The woman will usually be able to leave the hospital at the end of each treatment and return to the hospital for the next treatment. Most women will have 3-5 treatments.



Chemotherapy

Chemotherapy, often called “chemo”, uses medicines to destroy cancer cells.

Chemotherapy may be used to treat certain types of endometrial cancer:

- if cancer comes back after surgery or radiotherapy to try to control the cancer and relieve symptoms
- if the cancer does not respond to hormonal therapy
- if the cancer has spread beyond the pelvis when the cancer is first diagnosed, so that surgery is not possible.

Chemotherapy for endometrial cancer is usually given intravenously (into a vein in the arm, hand or chest) through a drip or a plastic tube. The number of chemotherapy treatments will depend on the type of cancer the woman has and what other treatments she is receiving.

Hormonal therapy

Some cancers of the womb depend on hormones (such as oestrogen) to grow. Hormonal therapies are medicines that help the body reduce the production of hormones that the cancer needs to grow.

Hormonal therapy may be used to treat endometrial cancer:

- as the main treatment if surgery is not an option or may be considered for women with early cancers who wish to keep their womb to retain their fertility
- if the cancer has spread or if the cancer has come back (recurred).

The main hormonal therapy for women with endometrial cancer is **progesterone**. Progesterone may be given as a tablet or in an injection given by a doctor or nurse. Some women with early endometrial cancers receive hormonal therapy through a device implanted into the womb and thus avoid surgery.

Your role: supporting women during treatment

You can help a woman with endometrial cancer understand the treatments that are recommended for her and the possible side effects before she starts treatment.

You can also provide support to help the woman manage any side effects.

To find out more about what different treatments involve, go to Chapter 10.

For information about the possible side effects of treatment and how to manage them, go to Chapter 7.

Chapter 6: Ovarian cancer

Key points

- Ovarian cancer is most common in women older than 60 years.
- We do not know exactly what causes ovarian cancer. A family history of ovarian cancer or breast cancer can increase the risk of developing the disease.
- There is no screening test for ovarian cancer.
- Symptoms of ovarian cancer can include bloating, pain in the abdomen or pelvis, loss of appetite, changes in urinary and bowel habits, unexpected weight gain, and tiredness.
- Tests to diagnose ovarian cancer include a physical examination, blood tests, imaging tests and a biopsy to look for cancer cells.
- Treatment for ovarian cancer usually involves surgery and chemotherapy. Some treatments are also being tested in clinical trials.

What causes ovarian cancer?[17]

We do not know what causes ovarian cancer. Certain risk factors have been associated with the development of ovarian cancer:

- **increasing age**: ovarian cancer is more common in women older than 50 years; 6 out of 10 women with ovarian cancer in Australia are older than 60 years
- **family history and inherited factors**: having a family history of ovarian cancer, breast cancer and some other cancers can increase the risk of ovarian cancer.

Other risk factors that may increase the risk of developing ovarian cancer include:

- a history of **endometriosis**: a benign (non-cancerous) condition where the tissue that lines the womb is also found in other areas of the body
- lifestyle factors, including **smoking cigarettes, being overweight**
- hormonal factors, including long-term use of hormone replacement therapy (HRT).

Questions to ask about family history

To find out if a woman might have a higher risk of developing ovarian cancer due to a family history, ask her if she has:

- other blood relatives with ovarian cancer
- family members diagnosed with cancer at a young age
- blood relatives with both breast and ovarian cancer
- blood relatives with breast cancer in both breasts
- breast cancer in a male blood relative.

Cancer Australia has an online tool to assess family history of breast and ovarian cancer in women who have not been diagnosed with breast or ovarian cancer: canceraustralia.gov.au/clinical-best-practice/gynaecological-cancers/familial-risk-assessment-fra-boc

What do we mean by 'inherited factors'?

Some women with a family history may have inherited one of two faulty genes – BRCA1 or BRCA2 that increase the risk of ovarian cancer. It is possible to have a blood test to check for the faulty BRCA1 and BRCA2 genes.

Around 15% of women with ovarian cancer carry an inherited faulty gene. Inheriting a faulty gene may increase a woman's risk but does not mean that she will develop ovarian cancer.[17]

Your role: ask a woman about her family history

You can help by:

- helping a woman assess her family history
- encouraging a woman who is worried about her family history to speak to her doctor.

Reducing the risk of ovarian cancer

There is no screening test for ovarian cancer.

Some things are known to reduce the risk of ovarian cancer, including:

- having children
- use of oral contraceptives
- gynaecological surgery, such as removal of the womb or tubal ligation (having your tubes tied).

Surgery for women at high risk of ovarian cancer

Women at high risk of ovarian cancer due to an abnormal BRCA1 or BRCA2 gene can have surgery to reduce their risk of developing ovarian cancer in the future. Surgery involves removal of the ovaries and fallopian tubes. This is usually done after a woman has finished having children.

Symptoms of ovarian cancer [18]

Many symptoms of ovarian cancer are vague and are like symptoms of other conditions. This means that women may not visit their doctor to discuss symptoms, and this can delay a diagnosis of ovarian cancer.

Symptoms of ovarian cancer can include:

- bloating and increased size of the abdomen (tummy)
- persistent pain in the abdomen or pelvis
- loss of appetite, feeling full quickly or indigestion
- changes in urinary habits, including needing to urinate more often or more urgently
- changes in bowel habits, such as constipation
- unexplained weight loss or weight gain
- unexplained fatigue (tiredness).

Having one or more of these symptoms does not necessarily mean that a woman has ovarian cancer. However, if any of these symptoms are unusual or persistent, it is important for the woman to see a doctor for advice.

Your role: encouraging women to talk about symptoms

Finding ovarian cancer early increases the chance of survival.

You can help by:

- increasing awareness of the risks and symptoms of ovarian cancer
- encouraging women to see a doctor if they notice new, unusual or persistent symptoms.

Tests for ovarian cancer [19]

Women should be referred to a doctor as soon as possible if they have any symptoms of ovarian cancer.

Tests to investigate symptoms of ovarian cancer may include:

- **history and physical examination**: asking questions about the woman's symptoms, general health and family history; feeling the abdomen to check for any swelling or lumps; doing an internal vaginal examination
- **blood tests**: may be used to look for certain proteins in the blood that are produced by ovarian cancer cells
- **transvaginal ultrasound:** insertion of an ultrasound probe into the vagina to view the womb and ovaries; the doctor may recommend a biopsy to examine any unusual areas
- **CT scan**: may be used to look for signs that ovarian cancer has spread beyond the ovaries.

If the results of tests performed by the doctor suggest that a woman may have ovarian cancer, she will be urgently referred to a specialist doctor, a gynaecological oncologist.

Tests to look at the extent and spread of ovarian cancer may include:

- **X-rays**: a chest X-ray may be done to check that the woman's lungs and heart are healthy; sometimes special X-rays using dyes are used to test the kidneys
- **positron emission tomography (PET) or magnetic resonance imaging (MRI) scan**: may be used to see whether ovarian cancer has spread to other parts of the body
- **biopsy**: a biopsy is the only way to confirm a diagnosis of ovarian cancer
  - a biopsy for ovarian cancer is most commonly done by removing the tumour and testing the tissue that is removed
  - less commonly a biopsy can be done by inserting a needle into the abdomen and guiding it to the tumour using a CT scan or ultrasound or doing a laparoscopy to view the ovaries.

To find out more about what these tests involve, see Chapter 10.

What the test results mean

Types of ovarian cancer

There are three main types of ovarian cancer, named after the type of cells the cancer affects:

- **epithelial ovarian cancer**: the most common type of ovarian cancer
- **germ cell ovarian cancer**: a rare cancer that usually affects younger women
- **sex-cord stromal cancer**: generally respond very well to treatment.

Stages of ovarian cancer

The four stages of ovarian cancer are:

- **Stage I**: cancer is in one or both ovaries
- **Stage II**: cancer is in one or both ovaries and has spread to other organs in the pelvis
- **Stage III**: cancer is in one or both ovaries and has spread beyond the pelvis to the lining of the abdomen, the bowel, or lymph nodes in the abdomen or pelvis
- **Stage IV**: cancer has spread to the inside of the bladder or rectum, throughout the abdomen or to other parts of the body.

Treatments for ovarian cancer [19]

The aims of treatment for ovarian cancer are to:

- remove the cancer
- destroy cancer cells and slow growth of the cancer and/or
- manage the symptoms of ovarian cancer.

Surgery

The first treatment for ovarian cancer is usually an operation called a **laparotomy**.

This type of surgery is usually used to confirm whether ovarian cancer is present. The surgeon will do a **biopsy** at the start of the operation to confirm the diagnosis. If ovarian cancer is confirmed, the surgeon will continue with the operation and will look to see if the cancer has spread.

If the cancer has spread, it is likely that chemotherapy will also be used. The surgeon will remove as much of the cancer as possible. This is called **surgical debulking** and helps make the chemotherapy more effective.

The type of surgery will depend on how far the cancer has spread but may involve:

- **hysterectomy**: removal of the womb and cervix
- **bilateral salpingo-oophorectomy**: removal of both ovaries and fallopian tubes
- **omentectomy**: removal of the fatty protective tissue (omentum) covering the abdominal organs
- **bowel surgery**: removal of part of the bowel; the ends of the bowel may be rejoined or a new opening called a stoma may be created (colostomy or ileostomy)
- **lymphadenectomy**: removal of some lymph nodes.

Chemotherapy

Chemotherapy, often called “chemo”, uses medicines to destroy cancer cells.

Chemotherapy may be given as a treatment for ovarian cancer:

- before surgery, to reduce the size of the cancer and make the operation easier (**neoadjuvant treatment**)
- after surgery, to reduce the chance of the cancer coming back (**adjuvant treatment**)
- as the main treatment for women who have not had surgery
- as palliative treatment, to reduce symptoms, improve quality of life or extend life for women whose ovarian cancer has spread.

Radiotherapy

Radiotherapy is not often used to treat ovarian cancer.

Radiotherapy may be used:

- to relieve symptoms that are not responding to chemotherapy
- to treat ovarian cancer that has spread to the pelvis or other parts of the body.

Targeted therapies

Targeted therapies (or ‘biological therapies’) may be used instead of, or together with, chemotherapy to target particular types of cancer cells.

Examples of targeted therapies for ovarian cancer are medicines that attack the cancer’s blood supply. These medicines, known as **anti-angiogenesis drugs**, work by starving the cancer of its blood supply.

Currently, clinical trials are being done to look at whether targeted therapies are safe and effective for ovarian cancer.

Your role: supporting women during treatment

You can help a woman with ovarian cancer understand the treatments that are recommended for her and the possible side effects before she starts treatment.

You can also provide support to help the woman manage any side effects.

To find out more about what different treatments involve, go to Chapter 10.

For information about the possible side effects of treatment and how to manage them, go to Chapter 7.

Chapter 7: Wellbeing and practical support

Key points

- Women with gynaecological cancer may experience physical, emotional and practical issues before, during and after their diagnosis and treatment for cancer.
- 'Supportive care' describes the services that can help with the physical, emotional and practical challenges of cancer.
- Supportive care should consider the physical, social, emotional, cultural and spiritual wellbeing of the woman, community and the environment.
- Emotional care and social support are important for women with gynaecological cancers.
- Although emotional and practical support may be the role of family members, there is a lot you can do to help in your role as an Aboriginal and/or Torres Strait Islander Health Worker and Health Practitioner.

Physical issues

Women with gynaecological cancer may need support to help with their symptoms and the side effects of treatment.

Some of the most common physical issues are described below, together with tips on what can help.

To find out more about the side effects of treatment for gynaecological cancers, got to Chapter 10.

Tiredness/fatigue

Fatigue is a common side effect of radiotherapy and chemotherapy. It is different from normal tiredness because it often does not go away after rest. Women may feel exhausted and lack energy for day-to-day activities. This can continue for several months, or even a year after treatment.

Tiredness can also be caused by the physical and emotional impact of diagnosis and treatment, including travelling to hospital for tests and treatment.

Things that can make tiredness and fatigue worse include poor nutrition, sleep disorders and menopause.

Your role: helping women with fatigue

Whatever the cause, tiredness and fatigue can be distressing and affect a woman's quality of life. Fatigue can be linked to depression in some women.

You can help by:

- encouraging women to do some light exercise, such as walking, to help boost energy levels and reduce fatigue
- suggesting that women spread out their daily activities and limit activities that bring on tiredness
- referring women who may be depressed to a health professional to talk about available treatments.

Pain

Pain may be caused by the symptoms of cancer or may be a side-effect of surgery. It is important to find out the cause of the pain to decide the best treatment.

Treatment may include pain-relieving medicines, relaxation therapy, massage and educational programs to help with pain control. Severe pain that is difficult to control using these methods will require specialist pain management from a doctor.

Your role: helping women with pain

Pain can be distressing and can affect a woman's quality of life. Effective treatments are available.

You can help by:

- explaining that treatments are available to manage pain
- encouraging women to talk about any pain they are experiencing
- encouraging women and their families to talk to their doctors about any bush medicines they may be using to manage pain
- referring women to a doctor for advice about how to manage severe pain symptoms.

Infertility

If a woman has surgery to remove her ovaries and/or womb (hysterectomy), she will no longer be able to get pregnant and have children naturally. Infertility can also be caused by radiotherapy or chemotherapy.

If a woman diagnosed with gynaecological cancer hopes to have children in the future, it is important for her to talk to her doctor before starting treatment. She may be referred to a fertility clinic to talk about her options.

If a woman is uncomfortable talking about fertility with you, you could arrange for a nurse or health professional from outside the community to talk to her.

The woman's partner should also be provided with opportunities to talk about this. You could arrange for a male doctor or Health Worker to talk to a woman's husband or male partner.

Your role: helping women talk about infertility

Infertility can be emotionally difficult for a woman. Feelings of sadness, grief and low self-esteem are common.

You can help by:

- encouraging women who hope to have children to talk to their doctor about fertility options
- referring women who become infertile due to treatment to a counsellor for support.

Early menopause

Early menopause can be caused by surgery to remove the ovaries. Radiotherapy and chemotherapy can also cause menopause.

The symptoms can occur quite quickly, and may be more severe than in natural menopause. Symptoms include hot flushes, mood swings, trouble sleeping, tiredness and vaginal dryness.

Medicines are available that can help manage the symptoms of menopause.

Your role: helping women with symptoms of early menopause

The sudden onset of menopause can be physically and emotionally difficult. Loss of menstruation at a younger age can lead to feelings of sadness, grief and low self-esteem. Women may feel 'old before their time' or less feminine.

You can help by:

- suggesting that women tell their doctor about any menopausal symptoms so that they can find out about treatments that can help
- encouraging women to talk about how they are feeling
- referring women who are experiencing feelings of sadness or depression to a counsellor for support.

Vaginal narrowing and dryness

Radiotherapy or surgery to remove the ovaries can cause the vaginal tissue to shrink and stiffen. This can cause the vagina to become narrow and dry, which can make sex painful.

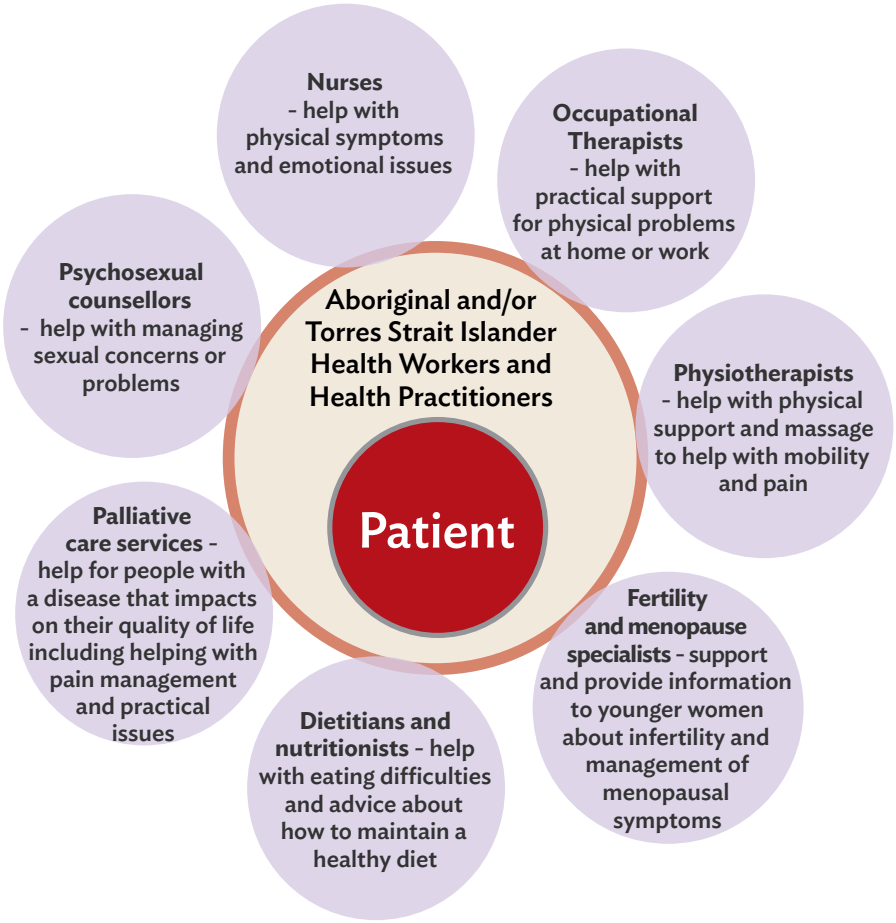
How long symptoms last varies between women. However, the changes are usually not permanent.

- Using a vaginal lubricant can help make sex more comfortable. Some women also find it helpful to use an instrument called a vaginal dilator to expand the vagina before sex.

Who can help with physical issues

Different members of the healthcare team can help with the physical issues of gynaecological cancer.

Figure 7.1 The main health professionals that can help with physical issues



Emotional issues

How a woman feels during diagnosis and treatment for cancer will depend on many things and can change at different times. A woman's feelings may be affected by:

- her experience – for example whether a family or community member has had cancer, her stage of life and her family and community role
- the physical burden of cancer and whether she has to travel away from home for tests or treatment
- whether cancer has been found early or late, and how likely it is that treatment will be effective.

Feelings of fear, distress, anger and disbelief are common. It can take time to accept the diagnosis. Some women feel they are losing control of their life.

Women may feel guilty, blaming themselves for their diagnosis. This is particularly the case for cervical cancer, because of the link between cervical cancer and HPV infection, which is transmitted sexually.

Loneliness can also be a problem. It is natural for a woman to think that no-one understands what she is going through, especially if family and community find it difficult to accept her cancer. She might feel too sick to work or enjoy usual social and community activities, which can add to feelings of isolation.

Depression

It is natural for a woman to feel sad when she is diagnosed with cancer. Sometimes feelings of sadness don't go away. This may be a sign of depression. Signs that a woman may be depressed include wanting to stay in bed, being irritable and not wanting to get involved with community or social activities.

Your role: helping women with depression

Women who are depressed or having suicidal thoughts need specialist care.
This may involve counselling and sometimes medicines like antidepressants.

You can help by:

- asking women regularly about how they are feeling
- looking out for signs of depression, such as irritability, social withdrawal, and difficulty coping
- referring women who may be depressed to a doctor for specialist help
- suggesting women contact:
  - Cancer Council Helpline: telephone 13 11 20. Open between 9am and 5pm, Monday to Friday, for the cost of a local call from anywhere in Australia (mobile calls charged at mobile rates). Cancer Council also provides online support through Cancer Connections, where you can ask questions and participate in groups, forums and blogs: **onlinecommunity.cancercouncil.com.au/**
  - Lifeline: telephone 13 11 14. Open 24 hours a day, every day of the year for the cost of a local call or free from your mobile. Online crisis Support Chat available 7.00pm – midnight (AEST). 7 days. **www.lifeline.org.au/get-help/online-services/crisis-chat**
  - beyondblue: telephone 1300 22 46 36. Open 24 hours a day, 7 days a week for the cost of a local call (mobile calls charged at mobile rates). Online support available 3pm – midnight (AEST), every day at: **www.beyondblue.org.au/get-support/get-immediate-support.** beyondblue's website has information for Aboriginal and Torres Strait Islander people: **www.beyondblue.org.au/who-does-it-affect/aboriginal-and-torres-strait-islander-people**

Relationships

A diagnosis of gynaecological cancer can change how a woman feels about herself. It can also affect how she relates to her family and community.

Sexuality and intimacy

Physical changes, such as scars from surgery or side effects of treatment can change how a woman feels about her body. This can affect the woman's body image, self-esteem and mood and can change how she feels about sexuality and intimacy.

A diagnosis can also put a strain on relationships. A cancer diagnosis can be as overwhelming and distressing for partners and other family members as it is for the woman diagnosed. A woman may also find it difficult to know how, when and how much to tell a new partner about her cancer.

While sexual intercourse may not always be possible during and immediately after treatment, closeness and sharing can still be part of a relationship. Counselling, either individually or with a partner, can provide ways to discuss cancer and how it affects a woman's relationship with her partner.

Your role: helping women with emotional issues

Some women may find it difficult to talk about how they feel.

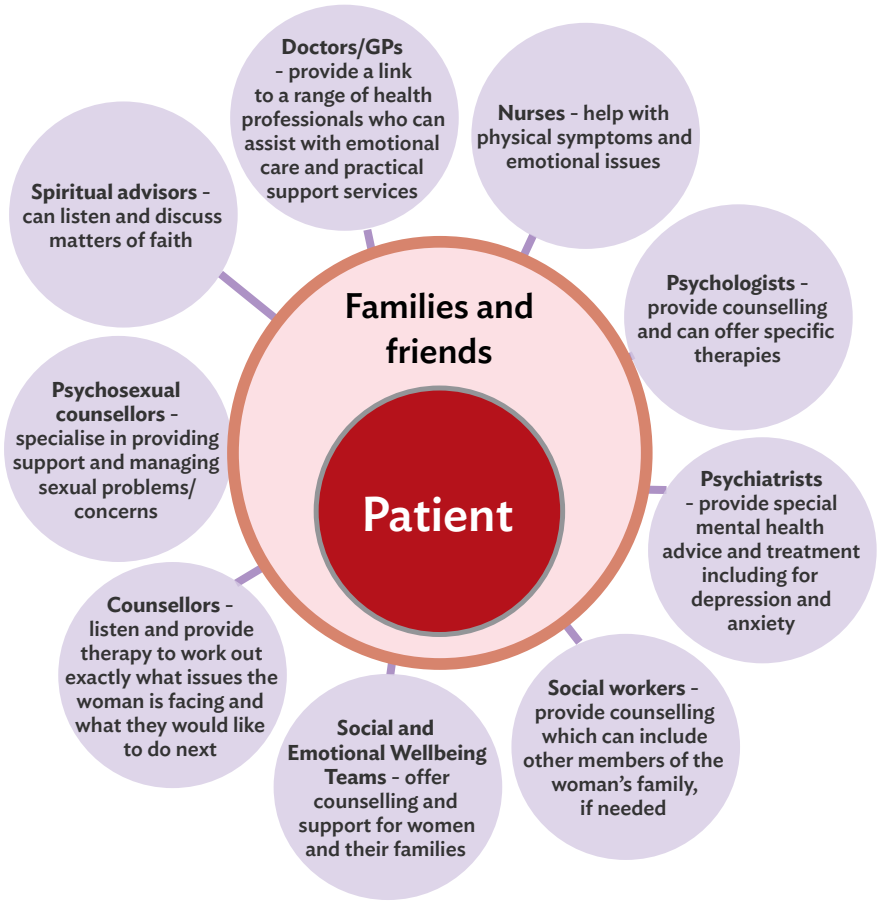
You can help by:

- providing accurate information to help women understand what to expect
- listening and encouraging women to share their concerns and feelings with you and with their family and community
- reassuring women that no-one deserves to get cancer
- referring women to other health professionals and organisations that may be able to help
- starting a support group for women in your community with gynaecological or other women's cancers to give women a chance to talk to each other and hear from people and services who can help.

Who can help with emotional issues

Different members of the healthcare team can also help with some of the emotional issues for women with gynaecological cancer.

Figure 7.2 The main people that can help with emotional issues



Practical issues

Practical issues to think about after a diagnosis of gynaecological cancer include:

- the cost of treatment and care
- support services
- travel and accommodation
- childcare and family support.

The costs associated with diagnosis and treatment can add to feelings of stress and anxiety. Diagnosis and treatment for gynaecological cancer can also affect a woman's ability to work.

Your role: helping women navigate the health system

Hospital visits and stays can be daunting for some women, especially if this means being away from home.

You can help by:

- describing what is likely to be involved during diagnosis and treatment for gynaecological cancer, and the health professionals involved
- making a list of practical and support services for women with cancer in your community
- preparing women and their families for what to expect.

Practical challenges can also affect family and community. A woman may feel guilty that her cancer treatment means the rest of the family must change the way they do things.

Practical and financial support for women who have to travel for treatment

Women from rural and remote communities are likely to have to travel for treatment and support services. If a woman needs to have treatment in a hospital away from home, she may be able to get help with the cost of accommodation and travel.

All States and Territories have patient accommodation and travel schemes (PATS) to help people that have to travel long distances for specialist medical treatment that is not available locally. Conditions vary between State and Territories so check with your nearest service or contact your local hospital.

Depending on the woman's situation and where she lives, she may also be able to get assistance with childcare, meals and general home help. Some women may also be eligible for a sickness allowance while having treatment.

Some hospitals allow consultations with doctors to be done using videoconference or teleconference. This can reduce the need for women and their families to travel.

Healthcare costs

The costs of diagnosis and treatment for gynaecological cancer will depend on whether the woman:

- lives in a rural or remote area and needs to travel for treatment
- has a health care card
- has private health insurance
- is treated in a public or private hospital.

Superannuation for people with a terminal illness

People with a terminal illness may be able to access their superannuation as a tax-free lump sum.

If a woman wants to do this, she will need to provide certificates from medical practitioners (one of whom must be a specialist) stating that she has a terminal illness with a life expectancy of 24 months or less. More details are available from the Department of Human Services website: www.humanservices.gov.au/customer/services/centrelink/early-release-superannuation

Your role: helping with practical and financial support

It is important that women have information about travel, accommodation and other financial assistance available to them.

You can help by:

- providing information about sources of financial and practical support available in your region
- helping women understand the likely costs of treatment and care so that they can plan for what might be needed
- referring women to local support groups or health professionals and organisations who may be able to provide advice and support.

Who can help with practical issues

Different members of the healthcare team and other services can help with some of the practical issues for women with gynaecological cancer.

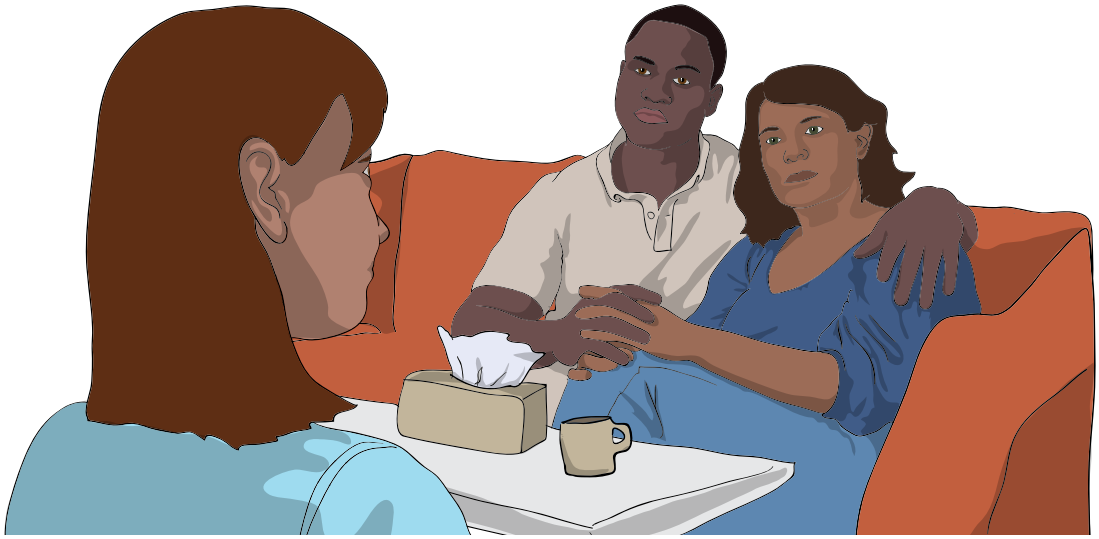
- **Cancer care coordinators and specialist rural nurses**: can be very helpful in providing a link between local services and the specialist doctors.
- **Social/welfare workers**: can provide information about financial and practical services available.
- **Local Medicare offices**: can provide information about the 'safety net' on costs of medicines and medical bills and other information about rebates and benefits.
- **Palliative care services** provide specialised symptom and practical support to manage issues faced by people with a disease that cannot be cured.

Support for family and community

Support for partners

Many partners are reluctant to seek help for themselves because they feel the need to be 'strong'.

Partners can accompany women to appointments to provide support and ask questions. Separate appointments can also be made for a woman's partner to discuss how they are feeling.



Support for children

Children are likely to be affected by their mother's cancer. It can be difficult for children to adjust, especially if their mother looks different or is in hospital and away from home. Children may play up to get attention or become insecure.

Helping families to have open and honest communication with their children, especially older children, is generally helpful. Here are some tips for talking to children about cancer.

- Ask children what they are worried about.
- Talk about feelings as well as facts.
- Answer questions honestly and simply and correct any misunderstandings.
- Try to explain what will happen next.
- Reassure them that cancer is not their fault – this is particularly important for young children.

Information and/or support for children and young people experiencing cancer is also available from the following:

- **Talking to kids about cancer** – available from Cancer Council Australia www.cancer.org.au/about-cancer/patient-support/talking-to-kids-about-cancer.html
- **Cancer in the school community** – available from Cancer Council Australia www.cancer.org.au/about-cancer/living-with-cancer/
- **CanTeen** – telephone: 1800 835 932 www.canteen.org.au
  Canteen provides counselling and support for people aged 12-25 living with cancer including cancer patients, their brothers and sisters and young people with parents or primary carers with cancer.

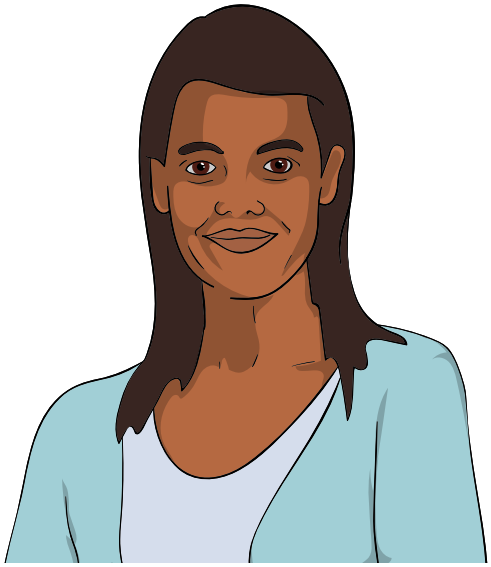
Your role: supporting family and community

A diagnosis of gynaecological cancer can affect family and community. It is important that partners, family and community can talk about how they are feeling and ask questions when they need to.

You can help by:

- giving family members the opportunity to discuss their feelings and experiences
- explaining support services available to family members, including how they can be accessed
- The woman's partner should also be provided with opportunities to talk about this. You could arrange for a male doctor or Health Worker to talk to a woman's husband or male partner
- referring family to a professional counsellor if more help is needed (where possible, it is important for people to talk to counsellors who are trusted by the community and who will respect confidentiality).

Chapter 8: Follow-up after treatment



Key points

- Follow-up after treatment for gynaecological cancer is important to check for signs that cancer has or hasn't come back and to help women manage the long-term side effects of treatment.
- The approach to follow-up will vary according the woman's individual needs.
- Typically, follow-up care is more frequent in the first two years after treatment. It may become less frequent after that.
- If a woman notices signs or symptoms in between follow-up appointments, she should see her doctor straight away.

Follow-up care after treatment for gynaecological cancer

Follow-up care for women who have finished treatment for gynaecological cancer is important to help:

- check for signs that cancer may have come back
- look for signs that cancer may have spread to other parts of the body
- manage the side effects of treatment, including menopause and infertility
- monitor physical and supportive care needs.

The approach to follow-up care after treatment for gynaecological cancer will vary according the woman's individual needs. Typically, follow-up care is more frequent in the first two years after treatment. It may become less frequent after that.

It is important that follow-up care for women is well coordinated. A follow-up plan will outline the frequency of follow-up appointments and who will see the woman at these times.

If a woman notices any symptoms between follow-up appointments, it is important that she sees her doctor or specialist as soon as possible. She does not need to wait until the next follow-up appointment.

Follow-up tests

Follow-up tests are usually done by one or more of the specialist doctors involved in a woman's diagnosis and treatment. The woman's local doctor may also be involved in follow-up appointments.

Follow-up tests are likely to include:

- a physical examination
- blood tests
- imaging tests, such as X-rays, ultrasounds and CT or MRI scans
- talking about the woman's physical and emotional wellbeing.

Follow-up visits also provide an opportunity for health promotion and wellness discussions, including:

- talking about symptoms to look for and the importance of reporting symptoms
- smoking status assessment (with an offer of medicines, counselling and referral for cessation, as needed)
- review of immunisation schedules, such as annual flu vaccinations.

How women feel when treatment is over

Many women look forward to finishing hospital-based treatment (surgery, radiotherapy or chemotherapy). However, for some women, the end of treatment can be a confusing and worrying time.

Women may feel nervous or upset at the thought of no longer seeing members of their health care team regularly. They may worry about cancer coming back. Or they may feel pressure to return to 'normal life', but they don't want life to return to how it was before cancer.

Women may need support and reassurance when treatment is over. Follow-up care is an important part of providing supportive care to women after their treatment for gynaecological cancer.

Sex after treatment

The time that a woman should wait before having sex after treatment for gynaecological cancers will vary depending on the treatment she has had and how quickly she is healing.

The woman's doctor will be able to give advice on how long she needs to wait before having sex.

If a woman is uncomfortable talking about sex with you, you could arrange for a nurse or health professional from outside the community to talk to her.

The woman's partner should also be provided with opportunities to talk about this. You could arrange for a male doctor or Health Worker to talk to a woman's husband or male partner.

Your role: talking to women about follow-up

Follow-up appointments are a good opportunity for women to talk to their doctor about their feelings once treatment is over. They can also ask about any side effects or symptoms they are having.

You can help by encouraging women to:

- keep their follow-up appointments
- continue to take any prescribed medicines for as long as required
- tell the doctor about any side effects or symptoms
- talk about any worries they have about their follow-up.

In between follow-up appointments, if you see a woman who has had gynaecological cancer, you can help by:

- asking how she is feeling now treatment is over
- providing information about relevant support services
- coordinating and liaising with local health professionals and specialists who are providing follow-up care and who may be in different locations.

Chapter 9: If cancer comes back or spreads

Key points

- If gynaecological cancer comes back or spreads to other parts of the body, a woman will need further tests to decide on the best treatments.
- Some women might decide not to have more treatment.
- It is important to respect a woman's choice about her treatment.
- Early introduction of palliative care is important to help women manage symptoms, control pain and help with practical and emotional issues.
- Advance care planning can help a woman decide who will take control of decisions that affect her care, if she can no longer make those decisions herself.
- The transition to end-of-life care should be coordinated between the palliative care team and the woman's specialist doctors.
- It is important that the woman and her family feel well supported during this time.

If cancer comes back

Women who are diagnosed and treated for gynaecological cancer have a lifelong risk that cancer will come back and spread to other parts of the body. If cancer comes back, this is called a **recurrence**.

If cancer comes back, women may be offered further treatment to remove or slow down the spread of the cancer.

The woman and her family will also be asked about what is important for them in any future treatment. Treatment plans are usually decided in the same way as the first treatment.

Treatments offered will depend on the location and extent of the cancer, and what treatments the woman had before.

If gynaecological cancer comes back after treatment, this can be very challenging and upsetting for a woman, her family and community.

The woman, her family and carers should be fully informed and counselled about the likely outcome of any further treatment, and should be helped to think through the benefits of treatment and its side effects as well as the effect of treatment on survival and quality of life.

Treatment when cancer has spread

Some people with cancer that has spread to other parts of the body may choose to have treatment even if it only offers benefit for a short period. Others may choose not to have treatment at all. A woman's choice about her treatment should be respected.

It is important that a woman who chooses not to undergo treatment is still offered supportive care to relieve her symptoms.

The importance of palliative care

Palliative care is care for people with a life-limiting illness and their families. Women can have palliative care at any time. It is not just for the last weeks of life.

The aim of palliative care for a woman whose gynaecological cancer cannot be cured is to improve her quality of life by preventing and relieving symptoms. Palliative care can also help with other physical, emotional and practical issues.

Medical treatment is an important part of palliative care. Some of the treatments used to cure cancer can also be used to help relieve symptoms and slow the growth and spread of the cancer.

Palliative care is not just for people who are near the end of their life. Managing symptoms is important at all stages of the disease. Palliative care is likely to be helpful for many women who have gynaecological cancer that has spread to other parts of the body. Early referral to palliative care can improve the quality of life, and in some cases survival, for women with gynaecological cancer.

Who provides palliative care?

Palliative care is delivered by many different services and people. Some parts of palliative care need input from a specialist doctor or nurse. Others can be provided by the woman's doctor, Aboriginal and/or Torres Strait Islander Health Worker or Health Practitioner, Hospital Liaison Officer, health and community care worker, or by a spiritual healer. Family and community can also be involved.

Your role: palliative care

Palliative care services can be provided at home, in a hospital or at a hospice (palliative care unit). Patients can move between these places if their needs change.

You can help by:

- explaining to the woman what palliative care services are available
- helping doctors and nurses understand what care and support the woman and her family need and would like
- providing community-based care and liaising with the palliative care team and other services for women who want to be cared for at home.

Advance care planning

An advance care plan is a written plan that details a woman's preferences for important healthcare and personal decisions, in case they lose their ability to make decisions for themselves in future. Advance care planning can provide a woman, her family and community the opportunity to talk about who will take control of decisions that affect her care, if she can no longer make those decisions herself.

While advance care planning relates to care at the end of life, it is helpful to talk with the woman about her situation. The woman needs to have the mental and physical capacity to make the advance care plan; so it is better for this to be done while she is still feeling well.

An advance care plan can be as simple or detailed as the woman wants it to be. It can include religious or cultural beliefs that may affect their care decisions.

Advance care planning may involve:

- discussing the woman's prognosis (how she is expected to respond to treatment) and possible future scenarios
- appointing someone who will make decisions when the woman is unable to, and involving this person in ongoing discussions
- deciding on the goals of care, now and in future
- discussing the woman's choice for place of care
- writing the plan down in a way that everyone understands.

Getting things in order

When a woman is diagnosed with advanced gynaecological cancer, it can be useful to talk about the importance of getting things in order.

This might include:

- organising relevant paperwork
- making decisions about ongoing medical care
- making a will
- appointing a substitute decision maker
- creating an advance care directive
- planning a funeral
- personal affairs, such as saying goodbye to loved ones.

Although this can be difficult, it can also bring a sense of control and relief for women and allow them to focus on treatment and living.

If appropriate, women should be encouraged to talk to a lawyer or a financial planner about their legal and financial situation, as rules and regulations differ for each State and Territory.

Organising paperwork

It is a good idea for a woman to get all her paperwork in one place. This will make it easier if, for example, she needs to be in hospital for a long time and a family member has to help with financial and legal matters. This might include key documents such as her birth certificate, marriage or divorce certificate and passport, as well as Centrelink and Medicare details. Other things may include bank and credit card details, other financial information like superannuation or insurance, and any rental or house title documents. It is also important to have her will and any funeral details in one place.

It is also important that someone else – a lawyer, family member or community Elder – knows where all the information is.

The transition to end-of-life care

As a woman nears the end of life, the specialist palliative care team may become the main specialist service involved in her care, working alongside a doctor and other primary care providers.

The physical burden faced by a woman at the end of life can have a major effect on her emotional wellbeing, and the emotional wellbeing of her family and carers.

The transition to care led by the specialist palliative care team should be coordinated between the specialist groups, so the woman and her family understand the reason for the transition and how it will happen. It is important that the woman and her family feel well supported during this time.

Your role: end-of-life care

A woman with gynaecological cancer may feel distressed at being separated from family at the end of her life. She may want to be cared for by family and community.

You can help by:

- helping communication between the treatment team, the woman and her family about preferences for end-of-life care
- explaining to family why the healthcare team might recommend that she stays in hospital or in a hospice for pain and symptom control
- explaining to healthcare teams the cultural and spiritual significance of the place of dying for Aboriginal and Torres Strait Islander people, and the importance that a woman may place on her need to return to country at the end of her life
- providing community-based care and liaising with the palliative care team and other services for women who want to be cared for at home
- working with the healthcare team and hospital or hospice services to help family and community see the woman at the end of her life, for example by finding a space for large family meetings or relaxing the rules around visitor numbers.

Chapter 10: More information

More information can be found here about:

- Tests for gynaecological cancers
- Treatments for gynaecological cancer
- Side effects of treatments for gynaecological cancer
- The main health professionals involved in diagnosing and treating gynaecological cancer
- Glossary
- Additional resources
- Other useful contacts
- Useful materials
- References

Tests for gynaecological cancer: what's involved?

Table 10.1 provides some more information about what's involved with different types of tests a woman may have to investigate symptoms of gynaecological cancer and confirm a diagnosis.

Table 10.1 Tests to investigate gynaecological cancers

Test	Used for	What's involved?
Physical examination	All gynaecological cancers	Feeling the abdomen (tummy) to check for swelling, masses or lumps Internal vaginal examination including speculum examination
Colposcopy	Cervical cancer	Uses a large microscope to get magnified view of the cervix, vagina and vulva A biopsy may be taken at the same time to remove tissue for examination Women may feel slight discomfort during the colposcopy
Large loop excision of the transformation zone (LLETZ)	Cervical cancer	May be done under local anaesthetic in the doctor's office or in hospital under a general anaesthetic The doctor uses a loop of wire to cut a small sample of abnormal tissue from the cervix Women may experience some light vaginal bleeding and cramping afterwards

Cone biopsy	Cervical cancer	Usually done under a general anaesthetic and involves a day or overnight admission to hospital The doctor removes a cone-shaped piece of tissue containing abnormal cells from the cervix Can be used to treat very early and very small cancers, including precancerous abnormalities Women may experience some light vaginal bleeding and cramping afterwards
Transvaginal ultrasound	Endometrial cancer/Ovarian cancer	An ultrasound probe is inserted into the vagina so that the doctor can look at the lining of the womb on a screen If anything looks unusual, a biopsy may be done
Hysteroscopy and biopsy Sometimes called a dilation and curettage (D&C)	Endometrial cancer	Usually done in hospital or as a day procedure The procedure is done under a light general anaesthetic and usually takes a few hours The doctor stretches the cervix open and inserts a telescope-like device (hysteroscope) to look inside the womb A biopsy is taken for examination under a microscope Bleeding for a few days is common after a biopsy

Table 10.2 provides more information about the tests used to see whether gynaecological cancers have spread to other parts of the body.

Table 10.2 Tests to see whether gynaecological cancers have spread

Test	What's involved?
X-ray	An X-ray may be done of the chest to check whether the cancer has spread to the lungs Sometimes special X-rays using a dye are used to test the kidneys, bladder or bowel
Computed tomography (CT) scan	A type of X-ray that takes pictures of inside the body to check if the cancer has spread
Magnetic resonance imaging (MRI) scan	Uses a powerful magnet linked to a computer to take detailed pictures of areas inside the body Pictures are taken while the woman lies on a table that slides into a metal cylinder An MRI scan is painless, but some women may find it noisy and claustrophobic inside the cylinder The scan takes less than an hour A woman can ask to have someone in the room for company or can ask for medicines to ease feelings of discomfort

Positron emission tomography (PET)	A whole-body scan that takes detailed pictures inside the body using a radioactive substance to show where cancer cells are The woman will be injected with a radioactive sugar fluid before the scan It takes about 30 to 90 minutes for the fluid to go through the body
Examination under general anaesthetic	A more detailed examination under a general anaesthetic might include looking inside the vagina, bladder and rectum A biopsy may be taken if necessary
Blood tests	Blood tests may be done to check the woman's general health and help inform treatment decisions
Laparoscopy (also called keyhole surgery)	A thin telescope inserted through a small cut in the tummy may be used for diagnosis

Treatments for gynaecological cancer: what's involved?

Surgery

Surgery for gynaecological cancer is done under a general anaesthetic. Depending on the type of operation, surgery may require an open cut (laparotomy), or may be done using a small incision (**laparoscopy** or **keyhole surgery**).

Surgery for ovarian cancer often requires a long, vertical cut from the belly button to the public bone hairline. Surgery for endometrial and cervical cancer is commonly performed using keyhole surgery.

When a woman wakes after surgery, she may have several tubes coming out of her abdomen. The tubes help to drain fluid from the operation site. The tubes will be removed after a few days.

The woman may need to spend anywhere from one day to one week in hospital, depending on the type of operation.

External radiotherapy

External radiotherapy is usually given as an outpatient. It is usually given every day for several weeks.

At each appointment, the woman will lie on a treatment table. The machine that delivers radiotherapy will be positioned around her. She will need to keep very still while the radiotherapy is being given.

Each treatment only takes a few minutes. The treatment itself is painless, although the woman may be uncomfortable, depending on the position she is lying in.

Internal radiotherapy

Radiotherapy that is given internally is called brachytherapy. It involves giving radiation via a tube or needle into the body close to where the cancer cells are. It may involve a general anaesthetic for the insertion of the tube. Each treatment only takes a few minutes. The woman will usually be able to leave the hospital at the end of each treatment and return to the hospital for the next treatment.

Chemotherapy

Chemotherapy is usually given intravenously (into a vein in the arm, hand or chest) through a drip or a plastic tube.

Each chemotherapy treatment is called a 'cycle'. Each cycle involves a short period of treatment followed by a rest period in which the woman does not receive treatment.

The number of chemotherapy treatments will depend on the type of cancer the woman has and what other treatments she is receiving.

Hormonal therapy

Hormonal therapy may be given as:

- a tablet
- an injection by a doctor or nurse
- a device that is fitted into the womb that releases the hormone.

Side effects of treatments for gynaecological cancer

Treatments for gynaecological cancers have different side effects. Most side effects can be managed and made more tolerable. It is important for a woman to tell her healthcare team about any side effects she is experiencing.

Infertility and early menopause

In women who are still having periods, treatment for gynaecological cancer may affect their ability to get pregnant and have children naturally.

If a woman hopes to have children in future, it is important for her to talk to her doctor before starting treatment. She may be referred to a fertility clinic to talk about her options.

Some types of surgery, chemotherapy and radiotherapy can result in early menopause for younger women. This can be physically and emotionally challenging.

Symptoms of menopause include:

- hot flushes
- mood swings
- trouble sleeping
- tiredness
- vaginal dryness.

A woman with menopausal symptoms should talk to her healthcare team about how to best manage symptoms.

Other side effects of surgery

Table 10.3 lists some of the known side effects of surgery for gynaecological cancers.

Table 10.3 Side effects of surgery for gynaecological cancer

Side effect	Details	What can help
Pain, discomfort	Can occur around the operation site	Pain relief medicines
Problems with bladder function	Some types of surgery can damage nerves in the pelvic area This can mean a woman may not be able to empty the bladder completely or may need to empty the bladder frequently	Usually improves with time or medicine Some women may need to use a small tube (catheter) inserted into the urethra to help empty their bladder, although this is rare
Lymphoedema	Removal of lymph nodes in the pelvic area can cause one or both legs to swell due to a build-up of fluid Can occur at the time of treatment or months later	Gentle leg exercises or receiving treatment such as massage from a qualified lymphoedema practitioner can help
Vaginal changes	If the ovaries are removed, a woman will no longer produce the hormone oestrogen This can cause dryness in the vagina and pain during sex	Vaginal lubricant or an instrument to expand the vagina (vaginal dilator) can make sexual intercourse more comfortable

Side effects of radiotherapy

Table 10.4 lists some of the known side effects of radiotherapy for gynaecological cancers. The side effects of radiotherapy depend on the strength of the dose and the part of the body being treated.

Table 10.4 Side effects of radiotherapy for gynaecological cancer

Side effect	Details	What can help
Fatigue / tiredness	Tiredness can build up slowly during treatment and may last for a few months after treatment finishes	Light exercise, such as walking, can help to boost energy levels and reduce fatigue It can help to spread out daily activities and limit activities that bring on tiredness
Diarrhoea	Radiotherapy can irritate the lining of the bowel Diarrhoea often begins during the third or fourth week of treatment and usually improves over time	Medicines can be prescribed to help relieve diarrhoea Avoiding high-fibre and spicy foods can help It is important to drink a lot of clear liquids to avoid dehydration
Skin reaction	Radiotherapy can cause the skin in the treatment area to become dry and itchy Skin may peel and appear red, sunburnt or darker Things that can make skin reactions worse include: • having other health problems, such as diabetes • smoking	Washing with a mild soap or cleanser and using light moisturising cream Avoiding irritation from chemicals (e.g. perfumes, deodorants) and very hot water
Burning when passing urine (cystitis)	Radiotherapy passes through the bladder to reach the cervix and this can cause cystitis	Drinking water, cranberry juice or medicines that reduce the acidity of urine can help relieve cystitis
Vaginal changes	Radiotherapy can cause the vagina to feel dry, itchy or burning Treatment can also cause pain during sexual intercourse	Vaginal lubricant or an instrument to expand the vagina (vaginal dilator) can make sexual intercourse more comfortable

Side effects of chemotherapy

Most medicines used in chemotherapy can cause side effects. Most side effects are temporary and can be managed. Women should talk to their health care team if they have side effects during or after chemotherapy.

Sometimes chemotherapy can cause side effects that are rare but can be quite serious. If a woman has any unusual symptoms, like high fever or bleeding or bruising, she should talk to her healthcare team straight away.

Table 10.5 lists some of the known side effects of chemotherapy for gynaecological cancers. The side effects of chemotherapy depend on the medicines being used.

Table 10.5 Side effects of chemotherapy for gynaecological cancer

Side effect	Details	What can help
Infection	Chemotherapy temporarily weakens the immune system Women are at risk of infections while they are receiving treatment Any infection during chemotherapy can be serious and potentially life-threatening	Women should contact their doctor immediately if they experience symptoms of infection such as: • fever (a temperature above 38°C) • chills • severe sweats **If symptoms of infection develop, women should seek immediate medical advice, as strong antibiotics may be required**
Nausea and/or vomiting	Common side effects of chemotherapy Nausea usually starts a few hours after treatment and may last for a few days	Anti-nausea medicines can help most women Medicines can be taken before, during or after treatment Drinking plenty of fluid, and having small frequent snacks instead of large meals can also help
Changes to bowel habits	Some chemotherapy medicines, pain-relief medicines and anti-nausea medicines can cause constipation or diarrhoea	Medicines can be prescribed to help with constipation or diarrhoea Drinking lots of clear liquids can also help

Hair loss	Can range from mild thinning to total hair loss, including body hair Usually starts 2-3 weeks after the first treatment	Using a large comb or hairbrush with soft bristles can help Cutting the hair short before it falls out may be less upsetting Suggest the woman considers using a wig or scarf Cancer Council Helpline (13 11 20) can help women find a wig
Numbness or tingling in the hands and feet	This is a side effect of some chemotherapy medicines	Women should tell their health care team if this happens The dose of chemotherapy may need to be adjusted

Side effects of hormonal therapies

The most common side effects of progesterone treatment include:

- tender breasts
- tiredness
- nausea
- swollen legs (fluid retention).

When given at high doses, progesterone may increase appetite and cause weight gain.

Who's who in the treatment team?

Table 10.6 lists the main health professionals involved in the diagnosis and treatment of gynaecological cancer.

Table 10.6 Members of the gynaecological cancer multidisciplinary team

Health professional	Role
Aboriginal and/or Torres Strait Islander Health Worker and Health Practitioner	An Aboriginal and/or Torres Strait Islander person who provides specialised health care, and practical support and information in a culturally appropriate way
Aboriginal Hospital Liaison Officer	Helps Aboriginal and Torres Strait Islander communities to access mainstream health care services
General practitioner (doctor)	Provides ongoing care and works with other members of the treatment team
Cancer nurse	Specialises in providing information and support to people with cancer
Gynaecological oncologist	A specialist surgeon who diagnoses and treats gynaecological cancer
Medical oncologist	Specialises in cancer medicines such as chemotherapy and targeted therapies
Gynaecologist	Specialises in investigating and treating diseases of the female reproductive system
Pathologist	Examines cells, tissue and blood from the body
Radiologist	Examines scans, X-rays and other imaging tests
Radiation oncologist	Specialises in radiotherapy (X-ray treatment)
Palliative care physician	Specialises in providing practical support and symptom relief for people whose cancer has spread
Cancer care coordinator	Provides support and information to women and their families
Community/district nurse	Provides care and support for people at home
Community palliative care team	Provides practical support and symptom relief at home
Dietitian	Specialises in providing advice about what to eat
Fertility and menopause specialist	Specialises in providing support and information to women about infertility and menopause due to cancer treatment
Pharmacist	Specialises in supplying, dispensing and manufacturing medicines
Physiotherapist, occupational therapist, exercise physiologist	Assists with exercise, recovery from surgery and pain management

Psychologist, psychiatrist	Specialises in providing emotional support and managing anxiety and depression
Psychosexual counsellor	Specialises in providing support and managing sexual problems/ concerns
Radiation therapist	Assists in planning and giving radiotherapy
Radiographer	Assists in performing scans, X-rays and other imaging tests
Research nurse/clinical trials nurse	Assists in the planning and coordination of clinical research studies and clinical trials
Social worker	Specialises in providing emotional support, counselling and advice about some practical and legal matters
Spiritual advisor/religious representative	Provides spiritual support
Welfare worker	Provides practical support and advice

Glossary of terms

This glossary provides definitions for the medical terms used in this handbook.

You can use this list to explain medical terms to women in your community. Encourage them to ask if they do not understand something their health professional has said.

Medical term	What it means
A.	
Advanced cancer	Cancer that has spread deeply into the surrounding tissues or away from the primary site Advanced cancer is less likely to be cured
Alternative therapies	Treatments used instead of conventional treatments Alternative treatments are not recommended for gynaecological cancer
Anaesthetic	A medicine that stops a person feeling pain during a medical procedure See also 'general anaesthetic' and 'local anaesthetic'
Anti-emetic	A medicine used to control nausea and vomiting
B.	
Benign	A benign tumour does not invade the nearby tissue or spread to other parts of the body
Bilateral salpingo-oophorectomy	Surgery to remove both ovaries and fallopian tubes
Biopsy	Removal of a small sample of tissue from the body, for examination under a microscope to help diagnose a disease

Brachytherapy	A type of radiotherapy in which an implant containing highly concentrated radiation is placed inside the body close to an area of cancer
C.	
Cells	The body's building blocks The human body is made up of billions of cells
Cervical cancer	Cancer that starts in the cervix
Cervical Screening Test	A quick and simple test used to check for HPV infection in a sample taken from the cervix. If HPV is present, the test looks for signs of cell changes that can lead to cervical cancer
Cervix	The lower, cylinder-shaped part, or neck, of the womb The upper part of the cervix is connected to the womb and the lower part is connected to the vagina
Chemoradiation	A combination of chemotherapy and radiotherapy
Chemotherapy	A cancer treatment that uses cytotoxic medicines to destroy cancer cells or slow their growth
Clinical trial	A research study that compares new tests or treatments with standard treatments
Colposcopy	A procedure where a doctor uses a large microscope (colposcope) to get a magnified view of the cervix, vagina and vulva
Complementary therapies	Treatments or therapies that can be used alongside standard medical treatment
Cone biopsy	Removal of a cone-shaped piece of tissue containing abnormal cells from the cervix
CT (computed tomography) scan	A type of scan using X-rays to create a picture of the body
D.	
Dietician	A health professional who specialises in advice about human nutrition and healthy eating
Diethylstilbestrol (DES)	A drug used to prevent miscarriage in the 1940s to 1970s that can increase the risk of cervical cancer
Dilation and curettage (D&C)	A procedure to open the cervix and remove tissue from the womb (uterus)
E.	
Endometrial cancer	Cancer that begins in the lining of the womb
Endometrium	The lining of the womb

F.	
Fallopian tubes	Tubes that connect the womb with the ovaries, and prove a pathway for fertilisation of the female egg
Fertility	The ability to get pregnant
G.	
General anaesthetic	A medicine used during surgery to make a person lose consciousness and feel no pain
Grade	A way of describing how similar or different a cancer cell is from normal cells
Gynaecological cancers	Cancers that start in the female reproductive system
Gynaecological oncologist	A doctor who specialises in diagnosing and treating cancers of the female reproductive system
Gynaecologist	A doctor who specialises in diagnosing and treating diseases of the female reproductive system
H.	
Hormonal therapy (also called endocrine therapy)	Medicines that help the body reduce the production of hormones that the cancer needs to grow
Hormone replacement therapy (HRT)	Medicines used to replace hormones that the body can no longer produce Used to relieve symptoms of the menopause
HPV (human papillomavirus)	The name for viruses that can infect the surface of the skin in different areas of the body including the genital area Some virus strains are linked to cervical cancer
HPV vaccine	A vaccine that can prevent infection with some types of HPV, including some types that can cause cervical cancer
Hysterectomy (also called total abdominal hysterectomy)	Surgery to remove the womb and cervix See also 'Radical hysterectomy'
Hysteroscopy	A procedure to see into the womb, in which the cervix is stretched open and a telescope-like device (hysteroscope) is inserted
I.	
Intravenous	Inserted into a vein An intravenous drip gives medicines directly into a vein

L.	
Laparoscopy (also called keyhole surgery)	Surgery in which a surgeon makes a small cut in the abdomen and uses a thin telescope to look inside and remove tissue if required
Laparotomy (also called an exploratory operation)	Surgery in which a long cut is made in the abdomen to look at the internal organs and remove tissue or organs if required
LLETZ (large loop excision of the transformation zone)	A procedure to remove cervical tissue for examination, using a loop of wire carrying an electric current
Local anaesthetic	A medicine that blocks the feeling of pain in a specific location in the body
Lymph nodes (also called lymph glands)	Small, bean-shaped structures that form part of the lymphatic system and help the body fight infection
Lymph node dissection (also called pelvic lymphadenectomy)	Surgery to remove lymph nodes in the pelvic region to see if cancer has spread
Lymphatic system	A network of tissues, capillaries, vessels, ducts and nodes that remove excess fluid from tissues, absorb fatty acids, transport fat and produce cells to fight infection
Lymphoedema	Swelling in part of the body due to a build-up of fluid after removal of lymph nodes
M.	
Malignant	The name for cancer cells that can grow into the tissue and spread to other parts of the body
Menopause	When menstrual periods stop permanently After menopause, women are no longer able to have children naturally
Metastasis	When cancer spreads to another part of the body See also 'advanced cancer' and 'secondary cancer'
MRI (magnetic resonance imaging)	A scan that uses magnets and radio waves to take detailed cross-sectional pictures of the body
Multidisciplinary care	A team approach to cancer treatment and planning, involving medical, nursing and allied health professionals
N.	
Nausea	Feeling sick or wanting to be sick
O.	
Oestrogen	A female hormone

Omentectomy	Removal of the fatty protective tissue (omentum) covering the abdominal organs
Oncologist	A doctor who specialises in the study and treatment of cancer
Ovarian cancer	Cancer that affects the ovaries
Ovaries	Solid, oval-shaped organs attached to the womb that produce hormones and eggs (ova)
P.	
Palliative care	Holistic care of people with a life-limiting illness, their families and carers
Pap smear test	Cervical screening test used before December 2017 to check for changes to the cells of the cervix that can lead to cervical cancer. No longer used for cervical screening in Australia
Pathologist	A health professional who studies diseases to understand their nature and cause and examines tissue removed from the body to diagnose cancer and other diseases
Pathology	Tests that involve examining blood, tissue or cells from the body for signs of disease
Pelvis	The lower part of the trunk of the body (the area that extends from hip to hip and waist to groin)
Peritoneum	The membrane that lines the abdominal cavity The peritoneum covers and supports most of the intra-abdominal organs, and serves as a channel for their blood vessels, lymph vessels, and nerves
PET (positron emission tomography) scan	An imaging test that uses a radioactive solution to highlight cancer cells in the body
Placenta	The tissue that forms during pregnancy on the inside of the womb The placenta allows nutrition to be provided for the baby and removes waste products
Primary cancer	The site in the body where cancer first develops See also 'secondary cancer'
Progesterone	A female hormone
Prognosis	The likely outcome of a person's disease
Psychologist	A health professional who specialises in providing emotional support and managing anxiety and depression
Q.	
Quality of life	An individual's overall sense of wellbeing

R.	
Radiation oncologist	A doctor who specialises in treating cancer with radiotherapy
Radical hysterectomy	Surgery to remove the womb, and a small part of the upper vagina and the soft tissue around the cervix
Radiology	Taking scans or X-rays of different parts of the body
Radiotherapy	Use of radiation, usually X-rays or gamma rays, to destroy cancer cells or damage them so they cannot grow and multiply
Rectum	The last parts of the bowel, leading to the anus, through which the poo or faeces passes
Recurrence	When cancer comes back after treatment
Risk factor	Something that increases your chance of developing cancer
S.	
Screening	Organised programs to test for early signs of disease, such as cancer, so that treatment can be considered before symptoms appear
Side effect	Unwanted or unintended effects of a medicine or treatment
Stage	A way of describing the extent of a cancer and whether it has spread to other parts of the body
Staging	Tests to find out how far cancer has spread
Standard treatment	The current best proven treatment, based on results of research
Stoma	An artificial opening into the body created by surgery to act as an exit for body waste
Supportive care	Improving the comfort and quality of life for people with cancer
Surgeon	A doctor who performs surgery
Surgery	Treatment that involves an operation, for example to remove tissue or organs from the body
Surgical debulking	Removal of as much cancer as possible to make other treatments more effective
T.	
Tamoxifen	A medicine that blocks the effects of oestrogen in cells
Targeted therapy (also called biological therapy)	A medicine that stops the growth of particular types of cancer cells
Therapy	Another word for treatment
Tissue	A collection of cells that make up a part of the body

Tissue biopsy	Examination of tissue removed from the body under a microscope to look for changes in the cells
Trachelectomy	Surgery to remove the cervix
Transvaginal ultrasound	A procedure in which an ultrasounds probe is inserted into the vagina to build a picture of the inside of the vagina and womb
Tumour	Abnormal growth of tissue on or in the body See also 'benign' and 'malignant'
U.	
Ultrasound	An imaging test that uses soundwaves to build a picture of internal parts of the body
Uterus (also called the womb)	The uterus is the place in a woman's body where the baby grows. The uterus is made up of mostly muscle with an inner lining called the endometrium
V.	
Vagina (also called the birth canal)	A muscular tube-like channel that extends from the cervix to the vulva
Vulva	The outer part of the female reproductive system. It includes the opening of the vagina, the inner and outer lips (also called labia minor and labia majora), the clitoris and the mons pubis (soft fatty mound of tissue above the labia
W.	
Womb (also called the uterus)	The womb is the place in a woman's body where the baby grows. The womb is made up of mostly muscle with an inner lining called the endometrium
Woman-centred care	Care that considers a woman's cultural traditions, personal preferences, values, family situation and lifestyle when making decisions about treatment and care

Additional resources

In addition to the information provided by your health service or organisation you might find it helpful to get information from different sources.

Cancer Council Helpline

Call the Cancer Council Helpline on **13 11 20** for up-to-date, local information that is relevant for you, and the person with cancer that you are supporting. If your patient is not able to access the internet, the Cancer Council Helpline may be able to print out information from relevant websites and mail these to the patient.

Useful links

'Surfing' the internet can be a useful way to find information. However, keep in mind that the information you find may not always be accurate. If you are accessing information to use with your patients, use careful judgment and always check what type of organisation has provided the information.

Your patients may also be accessing information on the internet, via a personal computer or at local libraries and in internet cafes.

Australian websites that may be helpful

Cancer Australia www.canceraustralia.gov.au

Cancer Australia is the national authority on cancer control, funded by the Australian Government. The Cancer Australia website provides evidence-based information about a range of cancers, including gynaecological cancers. The website includes an **Aboriginal and Torres Strait Islander** specific page.

Cancer Council Australia www.cancer.org.au

This website provides information about cancer and resources available nationally and in each State and Territory. This includes facts sheets about cancer for **Aboriginal and Torres Strait Islander people**, including information on cancer types, treatment and common cancer terms.

Australian Indigenous Health Info Net www.healthinfonet.ecu.edu.au

This website is a 'one-stop info-shop' for people interested in information on health and wellbeing of Aboriginal and Torres Strait Islander people. There is information on cancer among **Aboriginal and Torres Strait Islander people** under the Chronic Conditions tab.

Optimal cancer care pathways www.cancer.org.au/health-professionals/optimal-cancer-care-pathways.html

Optimal cancer care pathways outline the best cancer care for specific tumour types. The pathways are designed to promote a full understanding of the patient journey in order to foster quality cancer care from the point of diagnosis. Both detailed and quick reference guides have been developed for a range of cancers including ovarian and endometrial.

Patient versions can be accessed through www.cancerpathways.org.au

Ovarian Cancer Australia www.ovariancancer.net.au

This website has a range of ovarian cancer information and resources for women and their families, including the *Resilience Kit* for women newly diagnosed with ovarian cancer. Links are also provided for information and support programs available nationally and within each State and Territory.

Palliative Care Australia www.palliativecare.org.au

Palliative Care Australia is the national peak body for palliative care, which aims to work towards high quality palliative care for all Australians. The website provides information for patients, health professionals and carers and a national directory of palliative care services.

Caresearch www.caresearch.com.au

CareSearch provides trustworthy information about palliative care for patients, carers and families as well as for the health professionals providing their care. Comprehensive information to support the health care workforce and carers in providing palliative care for **Aboriginal and Torres Strait Islander people** is available through the 'Information For' tab.

National Cervical Screening Program www.cancerscreening.gov.au

This website provides information about the *National Cervical Screening Program* including frequently asked questions.

Carers Australia www.carersaustralia.com.au

This website provides information and links to a network of State and Territory Carers Associations to deliver a range of essential national carer services, including specific services and resources for **Aboriginal and Torres Strait Islander carers**.

CanTeen www.canteen.org.au

This website provides support services to young people aged 12–24 living with cancer, including young people who have an immediate family member with cancer. This website has links to upcoming support programs in each State and Territory.

Other useful contacts

Centrelink www.humanservices.gov.au

Disability, sickness and carers: telephone **13 27 17**

Provides information about government support and financial assistance.

Medicare www.humanservices.gov.au

Aboriginal and Torres Strait Islander Access line: telephone **1800 556 955**

General enquiries: telephone **13 20 11**

Provides information about Medicare claims.

Department of Veterans Affairs www.dva.gov.au

General enquiries: telephone **13 32 54**

Provides information about support and assistance available to Veterans.

Useful materials

Aboriginal cancer Journeys – Our stories of kinship, hope and survival

A collaboration between Aboriginal Health & Medical Research Council and the Cancer Council NSW, this booklet contains stories and experiences from Aboriginal people affected by cancer. It includes personal insights and words of wisdom so Aboriginal people can get an insight into other people's experience of cancer.

www.cancercouncil.com.au/aboriginalcancer/stories-from-the-community

Cancer treatment side effects – A guide for Aboriginal Health Workers

Developed by Cancer Institute NSW in collaboration with Aboriginal Health Workers, this booklet provides important and practical information to help you support your patients during their cancer treatment.

www.cancerinstitute.org.au/patient-support/aboriginal-resources/diagnosis-and-treatment/cancer-treatment-side-effects

Aboriginal and Torres Strait Islander Discussion Starter

Developed by Palliative Care Australia, this is a series of resources to support health care workers open conversations with their patients around end-of-life care in a culturally safe way. They include a culturally appropriate step-by-step guide to make difficult discussions about death that bit easier and a set of cards that can be used as a tool to start the conversations.

www.dyingtotalk.org.au/aboriginal-torres-strait-islander-discussion-starter

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The artwork ‘Our Journeys’ represents the experience of Aboriginal and Torres Strait Islander people with cancer. The white dots are the journey of each individual; the patterned areas are the different landscapes and regions of Australia; and the colours are the different cancer types. Cancer Australia, as the leading agency shaping cancer control in Australia, is depicted by the central ochre meeting place which draws stakeholders together to share ways to improve cancer outcomes. The kangaroo prints and the fish leading to and from the meeting place represent the flow of information and engagement between Cancer Australia and Aboriginal and Torres Strait Islander people.

Artist: Jordan Lovegrove, Ngarrindjeri, Dreamtime Public Relations, www.dreamtimepr.com