



Understanding Ovarian Cancer

A guide for people with cancer,
their families and friends

A blue circular callout containing the text "Cancer information". A thin orange line extends from the bottom of the circle, curving to the left and ending in a telephone handset icon.

Cancer
information

For information & support, call

13 11 20

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Understanding Ovarian Cancer is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.

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Note to reader

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

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

Cancer Council

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



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Introduction

This booklet has been prepared to help you understand more about ovarian cancer.

Many women feel shocked and upset when told they have ovarian cancer. We hope this booklet will help you, your family and friends understand how ovarian cancer is diagnosed and treated. We also include information about support services.

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, we hope this information will answer some of your questions and help you think about other questions to ask your treatment team.

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

How this booklet was developed

The information in this booklet was developed with help from a range of health professionals and women affected by ovarian cancer. It is based on clinical practice guidelines for ovarian cancer.¹

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. Turn to the last page of this book for more details.



**Cancer
Council
13 11 20**

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What is cancer?

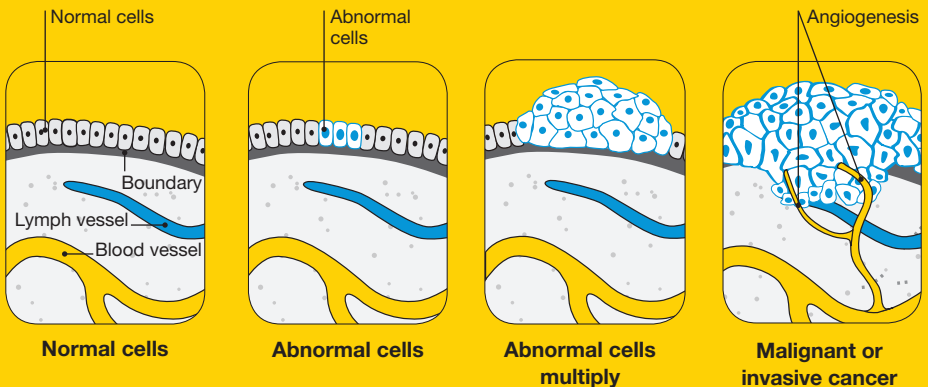
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

Sometimes cells don't grow, divide and die in the usual way. This may cause blood or lymph fluid in the body to become abnormal, or form a lump called a tumour. A tumour can be benign or malignant.

Benign tumour – Cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

Malignant tumour – This is made up of cancerous cells, which have the ability to spread by travelling through the bloodstream or lymphatic system (lymph fluid).

How cancer starts



The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell affected.

A malignant tumour that has not spread to other parts of the body is called localised cancer. A tumour may grow deeper into surrounding tissue and can grow its own blood vessels in a process called angiogenesis.

If cancerous cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, ovarian cancer that has spread to the abdomen is called metastatic ovarian cancer, even though the woman may be experiencing symptoms caused by problems in the abdomen.

How cancer spreads

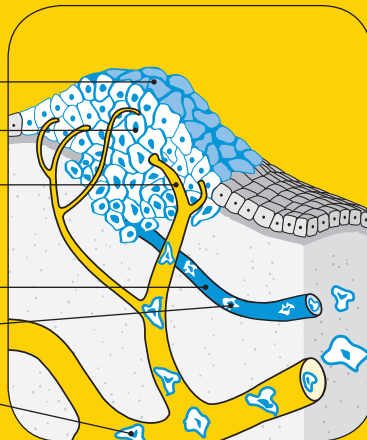
Primary cancer

Local invasion

Angiogenesis –
tumours grow their
own blood vessels

Lymph vessel

Metastasis –
cells invade other
parts of the body via
blood vessels and
lymph vessels





The ovaries

The ovaries are part of the female reproductive system. The female reproductive system also includes the fallopian tubes, uterus (womb), cervix (the neck of the womb) and vagina (birth canal).

The ovaries are two small, oval-shaped organs, each about 3 cm long and 1 cm thick in size. They are found in the lower part of the abdomen (the pelvic cavity). There is one ovary on each side of the uterus, close to the end of the fallopian tubes.

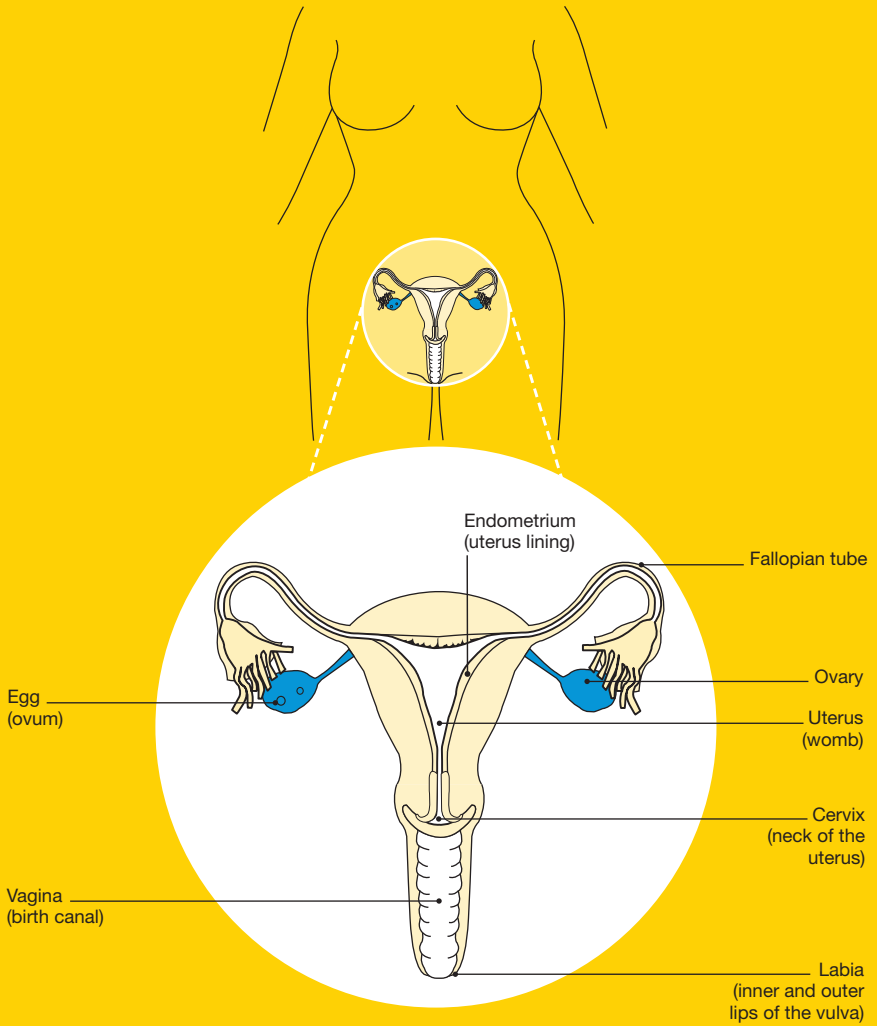
Each ovary is covered by a layer of cells called the epithelium. Inside the ovaries are cells called germ cells, which will eventually mature into eggs (ova).

An egg, called an ovum, is released from one of the ovaries each month (ovulation). The egg travels down the fallopian tube to the uterus. If the egg is fertilised by sperm, it can grow into a baby. If an egg is not fertilised by sperm, it disintegrates and – with the lining of the uterus – passes out of the vagina in the monthly period (menstruation).

The ovaries also release the female hormones oestrogen and progesterone from cells called stromal cells.

As a woman gets older, the ovaries gradually produce less of the hormones oestrogen and progesterone. The production of mature eggs also decreases and the woman's periods become irregular and finally stop. This is known as menopause, which usually happens between the ages of 45 and 55. After menopause, it is no longer possible to conceive a child naturally.

The female reproductive system





Key questions

Q: What is ovarian cancer?

A: Ovarian cancer is a malignant tumour in one or both ovaries. Recent research suggests that many ovarian cancers start in the fallopian tubes. This is different to fallopian tube cancer, which is rare.

Q: How common is it?

A: Each year, about 1400 Australian women are diagnosed with ovarian cancer. The average age at diagnosis is 64. It is the ninth most common cancer in women in Australia. Ovarian cancer is usually diagnosed in women over 50.²

Q: What are the symptoms?

A: In its early stages, ovarian cancer usually has no symptoms or only vague ones. If symptoms occur, they may include: pressure, discomfort or pain in the abdomen or pelvis; swollen or bloated abdomen; appetite loss or feeling full quickly; changes in toilet habits (e.g. constipation, diarrhoea, passing urine often due to pressure, increased flatulence); heartburn and nausea; tiredness; unexplained weight loss or weight gain; changes in menstrual pattern or bleeding after menopause; or pain during sex.

If these symptoms are new for you or continue for a few weeks, make an appointment with your general practitioner (GP). Having these symptoms does not necessarily mean you have cancer, but it is best to have a check-up.

Q: What types are there?

A: There are many types of ovarian cancer. The table below lists the three most common types.

Types of ovarian cancer

Epithelial	<ul style="list-style-type: none">• starts in the surface of the ovary (epithelium)• most common type (about 9 out of 10 cases)• subtypes include serous, mucinous, endometrioid and clear cell cancers
Germ cell	<ul style="list-style-type: none">• starts in the egg-producing cells• rare type of ovarian cancer (about 4% of cases)• usually develops in women under 30
Stromal cell	<ul style="list-style-type: none">• rare cancer that starts in the cells that produce the female hormones oestrogen and progesterone• can occur at any age• may produce extra hormones, such as oestrogen

Some women (usually younger women) are diagnosed with a borderline tumour. This is not considered to be cancer because, although it can spread, it does not invade other organs. For this reason, borderline tumours are also known as low malignant potential tumours.



Ovarian Cancer Australia has produced a symptom diary to help women record any symptoms and talk about their health concerns with their doctor. Visit ovariancancer.net.au to order a copy or download a pdf by searching for 'symptom diary'.

Q: What are the risks?

A: The causes of ovarian cancer are unknown, but the risk factors include:

- **age** – ovarian cancer is most common in women over 50 and in women who have stopped menstruating (have been through menopause), and the risk increases with age
- **reproductive history** – women who have not had children, were unable to have children, or had children over the age of 30 may be slightly more at risk
- **having endometriosis** – a benign (non-cancerous) condition in which the tissue that lines the uterus (endometrium) is also found in other areas of the body
- **lifestyle factors** – such as being overweight or eating a high-fat diet
- **hormonal factors** – including early puberty or late menopause, or using oestrogen-only hormone replacement therapy (HRT) for five years or more.

Some factors may reduce the risk of developing ovarian cancer. These include having children, breastfeeding, using the combined oral contraceptive pill for several years, and having your fallopian tubes tied (tubal ligation).

How important is family history?

Most women diagnosed with ovarian cancer do not have a family history of the disease.

About one in 10 women have an inherited faulty gene that increases the risk of developing ovarian cancer. However, not all women who inherit a faulty gene develop ovarian cancer.

The two main genetic conditions known to increase the risk of ovarian cancer include hereditary breast/ovarian cancer (fault in the BRCA1 and BRCA2 genes) and, less commonly, Lynch syndrome (formerly known as hereditary non-polyposis colorectal cancer or HNPCC).

Certain factors may increase the chance of ovarian cancer being hereditary, including if:

- you or a family member were diagnosed with breast cancer
- you or a family member were diagnosed with bowel or uterine cancer
- you have Ashkenazi Jewish ancestry.

If you are concerned about your family history of cancer, visit a familial cancer centre to discuss the possibility of genetic testing. Often, these centres are located in major public hospitals. To find a family cancer clinic near you, visit the Cancer Council Australia website at cancer.org.au.

Cancer Australia has developed an online tool called the Familial Risk Assessment – Breast and Ovarian Cancer (FRA-BOC) to help health professionals assess your risk. You can find it by visiting canceraustralia.gov.au and searching for 'FRA-BOC'.

- family members were diagnosed with ovarian cancer



Diagnosis

The tests and scans described in this chapter can show if there are abnormalities, but they cannot provide a diagnosis of ovarian cancer. The only way to confirm a diagnosis is by taking a tissue sample (biopsy) and looking at the cells under a microscope. This is usually done during surgery (see page 26), which means that the cancer is diagnosed and treated at the same time.

Sometimes ovarian cancer is found unexpectedly during another operation, such as a hysterectomy (when the uterus and cervix are removed). In many cases, ovarian cancer is present for some time before it is diagnosed.

Physical examination

The doctor will check for any masses or lumps by feeling your abdomen and doing an internal vaginal examination. An internal examination is not painful but may be uncomfortable.

Removing fluid from the abdomen

Sometimes swelling or bloating is due to a build-up of fluid in the abdomen. This is known as ascites.

To check the fluid for cancer cells, your doctor will inject a local anaesthetic to the

abdomen area and pass a needle through your skin to take a sample. This is called paracentesis. The fluid is sent to a laboratory to be examined. To make you feel comfortable, the fluid will be removed.

Blood tests

You may have blood tests to check for proteins produced by cancer cells. These are called tumour markers. The most common tumour marker for ovarian cancer is CA125.

The level of CA125 may be higher in women with ovarian cancer. However, it can also rise for reasons other than cancer, including ovulation, menstruation, irritable bowel syndrome, liver or kidney disease, endometriosis or fibroids. The CA125 blood test is used during diagnosis and treatment and after treatment.

At diagnosis – A CA125 test is more accurate in diagnosing women who have been through menopause (postmenopausal) than those who haven't (premenopausal). Women with early stage ovarian cancer often have normal CA125 levels. This is why doctors will often combine CA125 tests with an ultrasound (see next page).

During treatment – If you are found to have ovarian cancer that produces CA125, the blood test is also used to check how well the treatment is working. Falling CA125 may mean it's working, and rising CA125 may mean the treatment is not working effectively.

After treatment – CA125 blood tests are sometimes included in follow-up tests. See page 53 for more information.

The Pap test does not diagnose ovarian cancer. It's used to look for abnormal cells on the cervix that may develop into cervical cancer.



Imaging and investigations

Your doctor may recommend a number of imaging scans and investigations to determine the extent and stage of the disease. You may also have chest x-rays to check the lungs for cancer or fluid.

Ultrasound

An ultrasound uses echoes from soundwaves to create a picture of your organs on a computer. A technician called a sonographer performs the scan. It can be done in two ways:

Abdominal ultrasound – You will lie on an examination table while the sonographer moves a small handheld device called a transducer over your abdominal area.

Transvaginal ultrasound – The sonographer will insert a transducer about the size of a tampon into your vagina. The transducer will be covered with a gel to make it easier to insert. Some women find the transvaginal ultrasound procedure uncomfortable, but it should not be painful. Talk to your doctor and the sonographer if you feel embarrassed or concerned.

The transvaginal ultrasound is often the preferred type of ultrasound, as it provides a clearer picture of your ovaries and uterus.

“ I went in to have minor surgery. Afterwards the doctor said, ‘I’m sorry, but it looks like ovarian cancer.’ It certainly changed my life. ” *Louisa*

CT scan

A CT (computerised tomography) scan uses x-ray beams to create a detailed three-dimensional picture of the inside of the body. It is used to look for signs that the cancer has spread, but the CT scan may not be able to detect all ovarian tumours.

CT scans are usually done at a hospital or a radiology clinic. You will be asked not to eat or drink for several hours (fast) before the scan. A liquid dye, sometimes called the contrast, may be injected into one of your veins to help make the pictures clearer. The contrast makes your organs appear white on the scan, so anything unusual can be seen more clearly.



The dye used in a CT scan usually contains iodine. If you have had an allergic reaction to iodine or dyes during a previous scan, tell the medical team beforehand. You should also let them know if you're diabetic, have kidney disease or are pregnant.

The dye may make you feel hot all over, leave a bitter taste in your mouth, and you may feel the need to pass urine. Symptoms usually ease quickly, but tell the person carrying out the scan if they don't.

The CT scanner is a large, doughnut-shaped machine. You will lie on a table that moves in and out of the scanner. The scan takes 10–20 minutes, but it may take extra time to prepare and then wait for the scan. While a CT scan can be noisy, it is painless. Most women can go home as soon as the CT scan is over.

PET scan

A PET (positron emission tomography) scan highlights abnormal tissues in the body, and it can be more accurate than a CT scan.

The results are often used to decide what combination of treatment is most likely to work, to help with planning before surgery, and to check on how the treatment is working.

Before the scan, you will be injected with a small amount of radioactive glucose solution. This makes cancer cells show up brighter on the scan because they take up more of the glucose solution than normal cells do. You will be asked to sit quietly for 30–90 minutes while the glucose solution moves around your body, then you will be scanned for high levels of radioactive glucose.

The radiation will leave your body within a few hours. Let your doctor know beforehand if you are diabetic, pregnant, think you might be pregnant, or are breastfeeding.

PET scans may not be available at your local hospital. Some women have to travel to a hospital or treatment centre where a PET scanner is located.



Resilience is a free information kit for women with ovarian cancer. It has been produced by Ovarian Cancer Australia and includes information on diagnosis, treatment and support. To order a copy, visit ovariancancer.net.au or call **1300 660 334**.

Colonoscopy

Some women have a bowel examination (colonoscopy) to make sure that symptoms are not due to a bowel problem. The doctor will insert a thin, flexible tube with a small camera and a light (colonoscope) into your bowel.

The day before the test, you may have to fast (no eating or drinking). On the day, you will probably be given an anaesthetic so you don't feel any discomfort. This will make you feel drowsy. Your doctor will talk to you about what to expect.

Staging and grading ovarian cancer

The tests described on pages 12–17 help the doctors decide how far the cancer has spread. This is called staging.

Knowing the stage helps your health care team recommend the best treatment for you. If you have difficulty understanding the stage of the cancer, ask your doctor to explain the stage in simple terms. It is often not possible to work out the stage of the ovarian cancer until after surgery (see page 26).

The staging system most commonly used for ovarian cancer is the International Federation of Gynecology and Obstetrics (FIGO) system. It divides ovarian cancer into four stages. Each stage is further divided into sub-stages, such as A, B, C. Stage I means it is early ovarian cancer. Stages II–IV mean the cancer has spread from the ovary and is advanced. About 7 out of 10 (70%) women with ovarian cancer are stage III or stage IV at diagnosis.

Staging: FIGO system

Each stage has a number of sub-stages.

Stage I	Cancer is in one or both ovaries only.
Stage II	Cancer is in one or both ovaries and has spread to other organs in the pelvis (uterus, fallopian tubes, bladder or bowel).
Stage III	Cancer is in one or both ovaries and has spread beyond the pelvis to the lining of the abdomen (peritoneum), the bowel or lymph nodes.
Stage IV	The cancer has spread further to distant organs such as the lung or liver.

Grading

The grade of ovarian cancer describes how similar the cancer cells are to normal cells. There are three grades of epithelial ovarian cancer. Treatment has a greater chance of success if the grade is lower.

Grade 1	The cancer cells look similar to normal cells and are probably growing slowly.
Grade 2	The cancer cells appear slightly abnormal and might grow more rapidly.
Grade 3	The cancer cells look very different from normal cells and may grow quickly.

Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your doctor, but it is not possible for any doctor to predict the exact course of the disease.

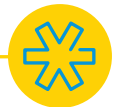
Epithelial cancer – The stage and grade of the cancer will influence the outcome. If epithelial ovarian cancer is diagnosed and treated before the cancer has spread outside the ovary (stage I), it has a good prognosis. Many women with more advanced cancer may respond well to treatment, but the cancer often comes back (recurs) and further treatment is needed.

Germ cell and stromal cell tumours – Can usually be treated successfully.

Borderline tumour – Usually has a good prognosis.

Discussing your prognosis and thinking about the future can be challenging and stressful. It may help to talk with family and friends. You can also call Cancer Council 13 11 20 if you need more information or emotional support.

There are many important factors in assessing your prognosis. These include: test results; the type of ovarian cancer you have; the grade; how well you respond to treatment; and other factors such as your age, fitness and overall health.



Which health professionals will I see?

Your GP will probably arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a gynaecological oncologist, who specialises in treating women with ovarian cancer.

MDT health professionals

gynaecological oncologist*	treats women with cancers of the reproductive system, e.g. ovarian, cervical, uterine, vulvar and vaginal cancers
gynaecological pathologist*	examines tissue removed from the abdomen or ovaries under a microscope
medical oncologist*	prescribes and coordinates the course of chemotherapy
radiation oncologist*	prescribes and coordinates the course of radiotherapy
radiologist*	reads and interprets diagnostic scans (e.g. CT and PET scans)
oncology nurses	administer drugs, including chemotherapy, and provide care and support throughout treatment

The gynaecological oncologist may arrange further tests and advise you about treatment options.

You will be cared for by a range of health professionals who specialise in different aspects of your treatment. This is often referred to as a multidisciplinary team (MDT).

cancer nurse coordinator or cancer care coordinator	coordinates your care, liaises with other members of the MDT and supports your family throughout treatment
dietitian	recommends an eating plan to follow during treatment and recovery
physiotherapist and occupational therapist	help with physical or practical issues, including any rehabilitation you may need
social worker	links you to support services
counsellor, clinical psychologist	provide emotional support and help manage anxiety and depression
palliative care specialists* and nurses	work closely with GP and oncologists to help control symptoms and manage quality of life when cancer is advanced
<i>*Specialist doctor</i>	



Key points

- Most ovarian cancers are present for some time before they are diagnosed.
- You will have many tests to check your health, but the only way to definitively diagnose ovarian cancer is by taking a tissue sample (biopsy) during surgery.
- The doctor will feel your abdomen and do an internal vaginal examination to check for masses or lumps.
- Blood tests may be done to look for tumour marker proteins made by cancer cells. The most common tumour marker for ovarian cancer is CA125.
- An ultrasound scan uses soundwaves to create a picture of the ovaries. The sonographer may pass a small device called a transducer over the abdomen or insert it into the vagina.
- A CT scan uses x-ray beams to take pictures of the inside of your body. It may not detect all tumours.
- Some women have other tests, such as a PET scan or a bowel examination (colonoscopy).
- Results of the diagnostic tests and biopsy help the doctors work out how far the cancer has spread. This is called staging. The grade describes how similar the cancer cells are to normal cells.
- Prognosis means the likely outcome of the disease. Women with early stage cancer have the best chance of long-term survival. Most women are diagnosed at a later stage.
- You will see a team of health professionals, including a gynaecological oncologist and oncology nurses, who will provide care and advice.



Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast. Check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that's based on your personal values. You may also want to discuss the options with your doctor, friends and family.

You have the right to accept or refuse any treatment offered. Some women with more advanced cancer choose treatment even if it offers only a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so they have the best possible quality of life.

Talking with doctors

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may help. Many women like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If you are confused or want clarification, you can ask questions for further explanation – see page 59 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

A second opinion

You may want to get a second opinion from another specialist to confirm or clarify your doctor's recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this.

Your doctor can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by the first doctor. You might decide you would prefer to be treated by the doctor who provided the second opinion.

Taking part in a clinical trial

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

Over the years, trials have improved treatments and led to better outcomes for women diagnosed with cancer.

It may be helpful to talk to your specialist or clinical trials nurse, or to get a second opinion. If you decide to take part, you can withdraw at any time. For more information, call Cancer Council 13 11 20 for a free copy of *Understanding Clinical Trials and Research*, or visit australiancancertrials.gov.au.



Treatment

The treatment for ovarian cancer depends on the type of ovarian cancer you have, the stage of the cancer, your general health and fitness, your doctors' recommendations, and whether you wish to have children.

Treatment options by types of ovarian cancer

Epithelial	<p>Surgery is the main treatment for all stages of epithelial ovarian cancer. The aim is to remove as much of the cancer as possible. Sometimes, additional treatment is needed.</p> <ul style="list-style-type: none">• Early stage ovarian cancer – Stages IA and IB are usually treated with surgery only. Women with stage IC cancer are usually offered chemotherapy after surgery as there is a high risk of the cancer coming back.• Advanced ovarian cancer – Stages II, III and IV are usually treated with a combination of surgery and chemotherapy. New targeted therapies are being offered to women with a BRCA mutation. In some cases, radiotherapy is offered.
Germ cell	<p>This is usually treated with surgery and/or chemotherapy.</p>
Stromal cell	<p>This is usually treated with surgery, sometimes followed by chemotherapy or targeted therapies.</p>
Borderline tumour	<p>This is usually treated with surgery only.</p>

Surgery

Your gynaecological oncologist will talk to you about the most suitable type of surgery, which will depend on how far the cancer has spread (the stage, see pages 17–18). Often information about the stage becomes available during surgery.

Your treating doctor will explain the risks of surgery. This may include infertility. If having children is important to you, talk to your doctor before surgery and ask for a referral to a fertility specialist. For more information, see page 44.

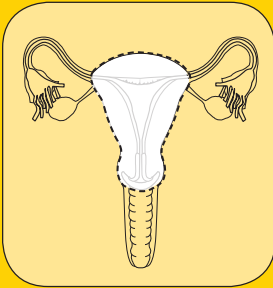
Laparoscopy or laparotomy – This is often recommended as a first step if ovarian cancer is suspected, and it will help provide more information about the stage. You are given a general anaesthetic and will have either a laparoscopy (with 3–4 small cuts in your abdomen) or a laparotomy (with a long, vertical cut from your bellybutton to your bikini line).

Tissue samples (biopsy) and fluid samples may then be taken from the abdomen. During the operation, the samples are sent to a specialist called a pathologist, who examines them for signs of cancer. This is called a frozen section analysis. If the pathologist confirms that cancer is present, the surgeon will continue the operation to remove all the cancer.

Debulking – If the cancer has spread, the gynaecological oncologist will remove as much of the cancer as possible. This is called surgical debulking. It's often followed by chemotherapy, which will shrink any remaining cancer cells.

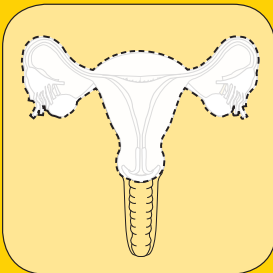
Types of surgery for ovarian cancer

Following the debulking surgery, you will have one or more of the procedures listed below.



Total abdominal hysterectomy

The uterus and the cervix are removed.



Total hysterectomy with bilateral salpingo-oophorectomy

The uterus, both ovaries and fallopian tubes are removed.

Omentectomy

Removal of the omentum (sheet of fatty tissue that is attached to the stomach and bowel and hangs down in front of the intestines).

Lymphadenectomy

Some lymph nodes are removed. Lymph nodes are small, bean-shaped organs that filter toxins, including cancer cells, from the bloodstream.

Colectomy

If cancer spreads to the bowel, the part of the bowel with cancer is cut out and the healthy parts are sewn back together. Sometimes a new opening called a stoma is created (colostomy or ileostomy). This is usually temporary. See page 46 for more details.

What to expect after surgery

When you wake up from surgery, you will be in a recovery room near the operating theatre, then you will be taken back to your bed on the hospital ward.

Tubes and drips – You will have several tubes in place, which will be removed as you recover:

- A drip inserted into a vein in your arm (intravenous drip) will give you fluid, medicines and pain relief.
- A small plastic tube (catheter) may be inserted into your bladder, and urine will be collected in a bag.
- A tube down your nose into your stomach (nasogastric tube) may drain your stomach fluid to prevent you vomiting.
- Tubes may be inserted in your abdomen to drain fluid from the site of the operation.

Compression devices and stockings – Some women have to use compression devices or wear elastic stockings to keep the blood in their legs circulating. Once you are mobile, compression devices will be removed so you can get out of bed, but you can still wear the stockings.

Pain – After an operation, it is common to feel some pain, but this can be controlled. Medicine may be given by an intravenous drip or through an injection close to the spine (epidural). This is similar

to what may be given to women during childbirth. Some patients have a patient controlled analgesia (PCA) system. This machine allows you to self-administer pain relief by pressing a button.

Let your doctor or nurse know if you are in pain so they can adjust your medicine. Do not wait until the pain is severe. Everyone's pain tolerance is different and medicine will be used to make you as comfortable as possible. Managing your pain will help you to recover and move around more quickly.

Injections – It is common to have daily anticoagulant injections in the abdomen to decrease the risk of developing a blood clot. These injections may continue for some time after the operation and while you're having chemotherapy. A nurse will show you how to administer the injection before you leave hospital.

Length of hospital stay – You will probably need to stay in hospital for 5–7 days.

Further treatment

Within a week of surgery, your doctor should have all the test results and will discuss any further treatment options with you. Further treatment will depend on the type of cancer, the stage of the disease and the amount of any remaining cancer. If ovarian cancer is advanced, it's more likely to come back, so surgery will usually be followed by chemotherapy, and occasionally by targeted therapies. Radiotherapy is not often recommended.

What to expect when you get home

Some women say they start to feel better within six weeks of surgery, but recovery may take longer. How long it takes to recover depends on the type of surgery you had, other treatment or medical conditions you have had, and your support at home.

Rest

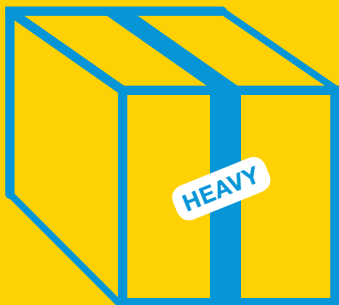
Take things easy and do only what is comfortable. You may like to try some meditation or relaxation techniques to reduce tension. You can also check with a social worker if it's possible to get help at home.



Sex

Penetrative sex should be avoided for about six weeks after the operation to give your wounds time to heal. For more information about sexuality, intimacy and cancer, see page 51, speak to your medical team, or call Cancer Council **13 11 20**.





Lifting and exercise

Avoid heavy lifting or vacuuming for at least six weeks. If you have a partner or children, ask them to help around the house. You may be able to access home help – see page 55.

Talk to your doctor about starting to exercise. You should begin with gentle exercise and build up to more vigorous exercise, depending on how active you were before your surgery.

Driving

Your medical team will tell you how long you should avoid driving, which is usually a few weeks.



Other side effects

You may have bowel problems, such as constipation or diarrhoea. Some women go through menopause if their ovaries have been removed and they were still having periods before surgery. See pages 42–49 for tips on managing side effects.

Chemotherapy

Chemotherapy is the treatment of cancer with anti-cancer (cytotoxic) drugs. The aim is to destroy cancer cells while causing the least possible damage to normal, healthy cells.

Women with epithelial ovarian cancer classified as stage IC or above are likely to need chemotherapy. Those with stage IA or IB epithelial ovarian cancer or borderline tumours may not need chemotherapy. However, chemotherapy may be recommended for stage IA or IB cancer with a high grade.

Chemotherapy may be used at different times:

After surgery – Chemotherapy is most commonly given after surgery (adjuvant chemotherapy) as there may be some cancer cells still in the body. Recent research shows that giving the drugs weekly improves the way they work³; however, in some hospitals, chemotherapy is given every 3–4 weeks over 5–6 months.

Before surgery – Some women with stage III or stage IV ovarian cancer have chemotherapy before surgery (neo-adjuvant chemotherapy). This usually involves three cycles of chemotherapy (see below) followed by surgery and then another three cycles.



Each chemotherapy treatment is called a cycle and is followed by a rest period to give your body time to recover. Ask your doctor about the treatment plan recommended for you.

Having chemotherapy

Chemotherapy is usually given as a combination of two drugs, or sometimes as a single drug. It's delivered through an intravenous drip. To reduce the need for repeated needles, some women have a small medical appliance called a port-a-cath or catheter placed beneath their skin through which they receive chemotherapy. Others may have a peripherally inserted central catheter (PICC).

You will usually have chemotherapy as an outpatient (also called a day patient), but some women need to stay in hospital overnight.

Let your oncologist know if you are taking nutritional or herbal supplements as these can interact with chemotherapy and may lessen the effect.

For more information, call Cancer Council 13 11 20 for a free copy of the booklet *Understanding Chemotherapy*, or download a digital version from your local Cancer Council website.

Blood tests during chemotherapy

Before each chemotherapy session, blood tests will be taken to ensure your body's healthy cells have had time to recover. If your blood count has not recovered, your doctor may delay treatment.

Some women also have blood tests during treatment to check their tumour markers, such as CA125 (see page 13). If the CA125 level was high before chemotherapy, it can be monitored to see if the treatment is working.

Intraperitoneal chemotherapy

This is a way of giving chemotherapy directly into the space between the abdominal organs and the abdominal – called the abdominal cavity.

The drugs are given through a tube (catheter) that is put in place during surgery and removed once the course of chemotherapy ends.

Intraperitoneal chemotherapy is used only in specialised units in Australia. It may be offered to women with stage III disease with less than 1 cm of tumour remaining after surgery.

Ask your doctor for more information about this treatment and the advantages and side effects.

Side effects of chemotherapy

Chemotherapy can affect healthy cells in the body, which may cause side effects. Not all women will have side effects, and effects will vary according to the drugs you are given. Often they are temporary. Talk to your medical team about what to expect.

Fatigue – Your red blood cell level (haemoglobin) may drop, which can cause you to feel tired and short of breath. Travelling to and from treatment can also be exhausting.

Nausea – Some chemotherapy drugs may make you feel sick or vomit. Whether or not you feel sick is not a sign of how well the treatment is working. Anti-sickness drugs can be given to prevent or reduce nausea and vomiting.

Changed bowel habits – Many women become constipated while on chemotherapy. This may be caused by anti-nausea drugs or because food intake changes. Your doctor will talk to you about taking laxatives. Diarrhoea (loose, watery bowel movements) is another possible side effect.

Risk of infections – Chemotherapy drugs lower the number of white blood cells that fight infection, so you may become more susceptible to colds and the flu. Let your doctor know if you have any signs of infection, which can be treated with antibiotics.

Joint and muscle pain – This may occur after your treatment session. It may feel like you have the flu, but the symptoms should disappear within a few days. Taking paracetamol may help.

Hair loss – It is likely that you will lose your head and body hair, depending on the chemotherapy drug you receive. The hair will grow back after treatment is completed, but the colour and texture may change. For more details, call Cancer Council 13 11 20 for a free copy of the *Hair Loss* fact sheet, or download it from your local Cancer Council website.

Numbness or tingling in your hands and feet – This is called neuropathy and can be a side effect of certain chemotherapy drugs. Let your doctor know if this happens, as your dose of chemotherapy may need to be adjusted.

For ways to prevent or reduce the side effects of chemotherapy, see the *Managing side effects* chapter on pages 42–49.

Radiotherapy

Radiotherapy uses x-rays to kill or damage cancer cells. It is used less often than chemotherapy for ovarian cancer. Doctors sometimes recommend radiotherapy to ease symptoms that are not responding to chemotherapy or when chemotherapy can no longer be given (palliative treatment – see page 40). If the cancer has spread, you will usually receive radiotherapy to the pelvis, or other affected parts of your body.

Before treatment starts, the radiation oncology team will plan your treatment, and will explain the treatment schedule and the possible side effects.

During radiotherapy, you will lie on an examination table, and a radiotherapy machine will be moved around you depending on the body part being treated. The radiation therapist will position you and the machine and then leave the room.

You will not feel anything during the treatment, which will only take a few minutes each time. You may be in the room for a total of 10–20 minutes for each appointment. The number of radiotherapy sessions you have will depend on the type and size of the cancer. You may have treatment for a week or daily treatment for several weeks.



For more information about radiotherapy treatment and its side effects, talk to your doctor and nurses, or call Cancer Council **13 11 20** for a free copy of *Understanding Radiotherapy*.

Side effects

The side effects of radiotherapy vary. Most are temporary and disappear within a few weeks or months after treatment. Common side effects include feeling tired, diarrhoea, needing to pass urine more often and burning when you pass urine (cystitis), and a slight burn to the skin around the treatment site.

More rarely, you may have some nausea or vomiting. If this occurs, you will be prescribed medicine to control it.

Targeted therapies

New types of drugs known as targeted therapies are being used to treat certain types of ovarian cancer, such as recurrent epithelial tumours or stromal tumours, or in certain situations (for example, when chemotherapy has not been successful).

One of these new treatments is called bevacizumab (Avastin). It works by stopping the cancer developing new blood vessels and growing. Bevacizumab is given with chemotherapy every three weeks as an infusion into a vein.

The most common side effects experienced by women taking bevacizumab include wound healing problems, bleeding, high blood pressure and kidney problems. In very rare cases, small tears (perforations) may develop in the bowel wall.

For more information about targeted therapies, talk with your medical team.

'Force of life', Susan Renouf's story

Extract from *Good Weekend*, 16 November 2013

Author: Jane Cadzow

Lady Susan Renouf was home alone, dozing on the sofa, when her GP rang with the results of her scans. The way she remembers it, "He said, 'It's the doctor here. You've got cancer. Masses. Everywhere in your body.'" The news was difficult to absorb. "I put the phone down and I think I went back to sleep for a while," she says. "I woke up and I thought, 'This is a terrible dream. I dreamt the doctor rang and told me I had cancer!'"

When Renouf thinks about it, she realises that for much of last year she lacked some of her usual oomph. "It was my 70th birthday, so I thought, 'I've got to make a special effort', because a lot of friends were planning a few little festivities. But I just wasn't feeling great. Very listless. If I didn't have to get out of bed in the morning, I didn't."

When she returned to Australia after three months in the UK and Europe, "a couple of girlfriends said to me, 'Gosh, you've got a funny colour.' I said, 'Well, I've been in the English summer.'"

By last November, she had become accustomed to an odd sensation in her abdomen: "Funny little jabbing pains." She went to her doctor, but for one reason or another it was January before the scans were done. The cancer had spread. "The prognosis was less than five months to live," she says with a tight, bright smile.

She had three months of chemotherapy, followed by surgery to remove as much of the cancer as possible. "When I went under, I thought, 'Well, I don't know if I'm coming out of it,'" she says. In the event, she was on the



table longer than expected: “It had invaded the lower part of my bowel and wrapped itself around my appendix. So that was another 2½ hours under anaesthetic. It was an 11-hour operation.” Then she had a second course of chemotherapy. “Luckily, I didn’t find the chemo as traumatic as I thought it would be,” she says. “I didn’t have the nausea or the vomiting. I lost my hair, of course.”

Wigs felt hot and itchy, and scarves kept slipping out of place, so she preferred to go bareheaded most of the time. When two of her grandsons arrived to visit her, her skull was as smooth as a billiard ball.

“Totally bald,” she says cheerfully, remembering their gasps when she opened the front door. “I said, ‘It’s a long story, boys. Come in.’”

Susan’s mother, Joan Rossiter, died in 1979 at 64. She had a brain tumour, which Renouf has only recently learnt was metastatic.

“It turns out that my mother had ovarian cancer,” she says. Tests have shown that Renouf has inherited faults in one of the two genes – BRCA1 and BRAC2 – that act as gynaecological tumour suppressors. Her daughters and a niece have subsequently undergone genetic testing, and to her great relief all the results so far have been normal.

She hasn’t forgotten that she briefly considered refusing treatment for her cancer. She sees now that quietly putting an end to it all would have been wildly out of character. “If I’m going,” she says, “I’m going with a bang.”

But she hopes to be around for a long time yet. She says she was touched by a get well message from her youngest grandson, Woody, then aged 10. “He said, ‘I know you will get better, Granny, because for me you are irreplaceable.’ I’m reading this. ‘Irreplaceable? Woody! I’ve got to live for you!’”

Palliative treatment

If the cancer is more advanced when it is first diagnosed or returns after treatment, your doctor will discuss palliative treatment for symptoms caused by the cancer, such as pain.

Palliative treatment aims to manage symptoms without trying to cure the disease. It can be used at any stage of advanced ovarian cancer to improve quality of life. It is not just for people who are about to die and does not mean giving up hope. Rather, it is about living for as long as possible in the most satisfying way you can.

As well as slowing the spread of cancer, palliative treatment can relieve pain and help manage other symptoms. The treatment may include chemotherapy and radiotherapy. If you are experiencing swelling and are uncomfortable, you may have a procedure called paracentesis or ascitic tap to drain the extra fluid from your abdomen (see page 47).

Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, emotional, practical and spiritual needs. For more information, visit your local Cancer Council website or call 13 11 20 for free copies of *Understanding Palliative Care* and *Living with Advanced Cancer*.



Key points

- Your treatment will depend on many factors, including the type of ovarian cancer, its stage, whether you wish to have children and your overall health and fitness.
- Ovarian cancer is usually treated with surgery. In most women with ovarian cancer, surgery involves a total abdominal hysterectomy, including the removal of both fallopian tubes and ovaries, and the omentum (fatty tissue).
- During the operation, the doctor may take tissue samples to check for signs of cancer. This is called a frozen section analysis or biopsy.
- It will take some time to recover from an operation. Most women start to feel better within six weeks, but it may take longer.
- After surgery, you may have further treatment. Most women have chemotherapy, but they may also have radiotherapy or targeted therapies.
- Chemotherapy is the treatment of cancer with anti-cancer drugs. It is usually given soon after an operation for 5–6 months. Side effects may include tiredness, nausea and vomiting, and hair loss.
- Radiotherapy uses x-rays to kill cancer cells or damage them. You may have treatment to your pelvis, but it can also be given to other parts of the body if the cancer has spread. Side effects may include fatigue, diarrhoea and nausea.
- Palliative treatment aims to improve your quality of life by relieving the symptoms of cancer.



Managing side effects

Treatment will cause some physical and emotional changes. Some women experience many side effects, while others have few.

Most side effects go away in time, but some may be permanent. This chapter includes ways to reduce or manage the discomfort that side effects may cause.

Fatigue

It is common to feel very tired and lacking energy during or after treatment. Fatigue for people with cancer is different from tiredness as it doesn't always go away with rest or sleep.

Most women who have chemotherapy start treatment before they have had time to fully recover from their operation. Travelling to and from hospitals and clinics for treatment can be tiring. Fatigue may continue for a while after treatment has finished. For some women, it may take up to 1–2 years to feel well again.



Tips for managing fatigue

- Set small manageable goals for the day and rest before you get too tired.
- Ask for and accept offers of help with tasks such as cleaning and shopping.
- Eat nutritious food to keep your energy levels up.
- Plan to exercise, with your doctor's approval. Even a walk around the block can boost your energy levels.

Menopause

If you were still having periods before surgery, having your ovaries removed will mean you no longer produce the hormones oestrogen and progesterone and you will stop menstruating (having periods). This is called menopause. For most women, menopause is a natural and gradual process that starts between the ages of 45 and 55.

Symptoms of menopause can include hot flushes, mood swings, trouble sleeping (insomnia), tiredness and vaginal dryness. Sudden menopause causes more severe symptoms than natural menopause, because the body has not had time to get used to a gradual decrease in the levels of oestrogen and progesterone.

The following tips may help you manage the symptoms of menopause:

- Ask your doctor about suitable moisturisers to relieve vaginal dryness. You may need to avoid products containing oestrogen.
- Use extra lubrication to make intercourse more comfortable. To reduce irritation, choose a water- or silicone-based gel without perfumes or colouring.
- Talk to your gynaecological oncologist about the benefits and risks of hormone replacement therapy (HRT). HRT containing oestrogen may increase the risk of some diseases, such as breast cancer. If you were already on HRT when the cancer was diagnosed, you will need to weigh up the risks of continuing it.
- Talk to your doctor or call Cancer Council 13 11 20 for details about medicine to relieve the symptoms of menopause.

Infertility


Treatments that affect the reproductive organs, such as hysterectomy and radiotherapy, will cause infertility. This means it is no longer possible to become pregnant.

Before treatment starts, ask your doctor or fertility specialist about what options are available to you. Women under 40 who have stage I ovarian cancer may be able to have surgery that leaves their uterus and one ovary in place.

Many women experience a sense of loss when told that their reproductive organs will be removed or will no longer function. You may feel extremely upset if you are no longer able to have children, and may worry about the impact of this on your relationship or future relationships. Even if your family is complete or you were not planning to have children, you may feel some distress.

If you have a partner, talk to them about your feelings. Speaking to a counsellor or gynaecological oncology nurse may also help.

You can find more information in Cancer Council's booklet *Fertility and Cancer*. Call 13 11 20 for a free copy, or download a digital version from your local Cancer Council website.

“My advice to other women is: be kind to yourself, this is really tough. Don't feel like you have to be strong all the time. It is okay to be sad at times. You don't always have to 'keep it together'.”  Patricia

Bowel changes

After surgery or during chemotherapy or radiotherapy, some women have bowel problems, such as diarrhoea, constipation or cramps. Pain relief medicines may also make you feel constipated. Diarrhoea and constipation can occur for some time, but often these bowel changes are temporary.

Ask your doctor, nurse or dietitian for advice about eating and drinking, and see the tips below for suggestions on preventing or relieving these side effects.



Tips for managing bowel changes

- Prevent or manage constipation by eating more high-fibre foods, such as wholegrain bread and pasta, bran, fruit and vegetables.
- Drink plenty of liquids to replace fluids lost through diarrhoea or to help soften stools if you are constipated. Warm and hot drinks work well, but avoid alcohol and caffeinated drinks.
- Avoid fried, spicy or greasy foods, which can cause pain and make diarrhoea and constipation worse.
- Ask your pharmacist or doctor about medicines to relieve symptoms of diarrhoea or constipation.
- Eat small, frequent meals instead of three big ones.
- Rest as much as possible as diarrhoea can be exhausting.
- Call Cancer Council **13 11 20** for a free copy of the booklet *Nutrition and Cancer*, or download a digital version from your local Cancer Council website.

Treating a blockage in the bowel

Surgery for ovarian cancer sometimes causes the bowel to become blocked (bowel obstruction). A bowel obstruction can also occur if the cancer comes back. Because waste matter cannot pass through the bowel easily, symptoms may include feeling sick, vomiting, or abdominal discomfort and pain.

To relieve the symptoms, you may have a small tube (stent) put in to help keep the bowel open. The stent is inserted through the rectum using a flexible tube called an endoscope.

Occasionally, the blockage in the bowel is treated with a stoma. A stoma is a surgically created opening in the abdomen that allows faeces to leave the body. Part of the bowel is brought out through the opening and stitched onto the skin. A small bag is worn on the outside of the body to collect the waste. This is called a stoma bag or appliance. The stoma is usually temporary and is later reversed.

There are two types of stomas for a bowel obstruction:

- **colostomy** – made from part of the colon (large bowel)
- **ileostomy** – made from the ileum (part of the small bowel).

People often have many questions after a stoma. A specially trained stomal therapy nurse can show you how to look after the stoma. For more information, contact the Australian Association of Stomal Therapy Nurses at stomalthrapy.com, visit the website of the Australian Council of Stoma Associations at australianstoma.com.au, or call Cancer Council 13 11 20.

Fluid build-up

Sometimes fluid can build up in the body.

Ascites – This is when fluid collects in the abdomen. It causes swelling and pressure, which can be uncomfortable. A thin needle is inserted into the abdomen to drain the fluid and relieve discomfort. This is called paracentesis or ascitic tap.

Pleural effusion – For some women, fluid may build up in the area between the lung and the chest wall (pleural space), which can cause pain and breathlessness. The fluid can be drained using a procedure called thoracentesis or pleural tap. You will have a local anaesthetic and a needle will be inserted into the pleural space to drain the fluid.

Lymphoedema

If lymph nodes in the pelvic area have been removed during surgery (lymphadenectomy), lymph fluid may not drain properly from your legs. This causes the fluid to build up and the legs to swell, which is called lymphoedema. Radiotherapy to the area may also cause lymphoedema. It can occur at the time of treatment or months or years later.

Lymphoedema may make movement and some activities difficult. It is important to manage lymphoedema symptoms as soon as possible. Gentle exercise, compression stockings, and a type of massage called manual lymphatic drainage can all help to reduce the swelling.

A physiotherapist trained in lymphoedema management will be able to give you further advice.

To find a practitioner who specialises in the management of lymphoedema, visit the Australasian Lymphology Association website at lymphoedema.org.au. Cancer Australia's booklet *Lymphoedema - what you need to know* is also a good source of information. To download a copy, visit canceraustralia.gov.au and click on 'Publications & Resources'.

Feeling low or depressed

It is natural to feel low or depressed after a cancer diagnosis, during treatment or when you are recovering. Some women feel sad or depressed because of the changes the cancer has caused. Others are frightened about the future.

There is a difference between feeling down and feeling depressed. If you have continued feelings of sadness, have trouble getting up in the morning, or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression.

Talk to your GP, as counselling or medication – even for a short time – may help. Some women are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Your local Cancer Council may also run a counselling program. The organisation [beyondblue](http://beyondblue.org.au) has information about coping with depression and anxiety. Go to beyondblue.org.au or call 1300 22 4636 to order a fact sheet.



Key points

- Some women experience few side effects from treatment, while others have many. There are ways to reduce or manage the discomfort that side effects may cause.
- The most common side effect is fatigue. This may continue for a while after treatment has finished. It may help to plan your activities so you can take regular rest breaks.
- If your ovaries have been removed, you will go through menopause. This means that your periods will stop and it will no longer be possible to become pregnant.
- If you are unable to have children as a result of treatment (infertility), you may feel very distressed. Talking about your feelings with your family, friends or a counsellor may be helpful.
- After treatment, some women have bowel problems such as diarrhoea, cramps or constipation. Surgery can also cause the bowel to become blocked (bowel obstruction).
- Sometimes fluid can build up in your abdomen, lungs or chest wall. Your medical team will drain the fluid.
- If fluid build ups in the legs (lymphoedema), try gentle exercise, compression stockings or visit **lymphoedema.org.au** to find a specialised practitioner.
- Some women feel sad or depressed during or after cancer treatment. Depression is when you are in a low mood for most of the time, or if your sadness lasts two weeks or more. If you are depressed, speak to your doctor for support and/or treatment.



Looking after yourself

Cancer can cause physical and emotional strain. It is important to try to look after your wellbeing as much as possible.

Nutrition – Eating healthy food can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation. Call Cancer Council 13 11 20 for a free copy of the *Nutrition and Cancer* booklet, or download a digital version from your local Cancer Council website.

Staying active – Physical activity may help to reduce tiredness, improve circulation and lift your mood. The amount and type of exercise you do depends on what you are used to, how you feel, and your doctor's advice. Cancer Council's *Exercise for People Living with Cancer* booklet provides more information about the benefits of exercise, and outlines simple exercises that you may want to try.

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

Alternative therapies are used instead of conventional medical treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful. For more information, call 13 11 20 for a free copy of the *Understanding Complementary Therapies* booklet, or visit your local Cancer Council website.

Relationships with others

Having cancer can affect your relationships with family, friends and colleagues. This may be because cancer is stressful, tiring and upsetting, or as a result of more positive changes to your values, priorities or outlook on life.

Give yourself time to adjust to what is happening, and do the same for others. People may deal with the cancer in different ways, for example, by being overly positive, playing down fears, or keeping a distance. It may be helpful to discuss your feelings with each other or with a health professional, such as a nurse or a counsellor.

Sexuality and intimacy

Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

If you have not had your ovaries removed, you may be advised to avoid pregnancy while you are on chemotherapy. Your doctor will talk to you about the precautions to take.

Call 13 11 20 for a free copy of *Sexuality, Intimacy and Cancer* or download it from your local Cancer Council website. Cancer Australia's booklet *Intimacy and sexuality for women with gynaecological cancer - starting a conversation* is a good source of information. Download a copy at canceraustralia.gov.au.

Life after treatment

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

Some women say that they feel pressure to return to 'normal life', but they don't want life to return to how it was before cancer. Take some time to adjust to the physical and emotional changes, and re-establish a new daily routine at your own pace.

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



Living with uncertainty

- Talk with other women who have had ovarian cancer. You may find it reassuring to hear about their experiences. See pages 55–56 for details on support groups.
- Explore different ways to relax, such as meditation, yoga or relaxation, to deal with stress and anxiety.
- Try to exercise regularly. Research shows that exercise helps women cope with the side effects of treatment.⁴
- Keep a symptom diary to track how you're feeling.
- Focus on making healthy choices in areas of your life that you can control, such as what you eat.

Follow-up after treatment

After treatment, women usually have regular check-ups to confirm that the cancer hasn't come back, and to manage any long-term side effects of treatment.

These appointments may be with your gynaecological oncologist or medical oncologist. There is no set follow-up schedule for ovarian cancer, but women commonly see their specialist every three months for the first two years, and every four to six months for the next two years. Some women prefer not to follow a schedule but to see their specialist if they experience symptoms. Discuss the follow-up schedule with your doctor.

Follow-up appointments may include a physical examination, discussion about any side effects or other concerns, and scans, including ultrasounds and CT scans.

Having CA125 blood tests

Your specialist will also talk to you about the advantages and disadvantages of having regular CA125 blood tests. Research has been looking at how useful this test is as part of follow-up for ovarian cancer. Results have found that waiting until symptoms develop before starting treatment is just as effective as starting treatment earlier.⁵ This means that quality of life is improved as side effects of further treatment are delayed.

It's common for women to worry before their follow-up appointments. To help ease your concerns, you may want to talk to your doctor or nurse about what to expect during check-ups.

What if ovarian cancer returns?

For some women, ovarian cancer does come back after treatment and a period of remission. This is known as a recurrence.

Even after a good response to initial surgery and chemotherapy, it is likely that cancer will recur in women who were first diagnosed with advanced epithelial ovarian cancer. Usually the longer the time between the end of the first course of treatment and the relapse, the better the response will be to further treatment.

Many women have a number of recurrences, with long intervals in between when they do not require any cancer treatment.

The most common treatment for epithelial ovarian cancer that has come back is more chemotherapy. The drugs used will depend on what drugs you were initially given, the length of remission and the aims of the treatment. Often the drugs that were given the first time will be used again if you had a good response to them and the cancer stayed away for six months or more.



New drugs are constantly being developed. Genetic screening and targeted therapies are offering new treatment options for women with ovarian cancer.



Seeking support

Cancer may cause you to experience a range of emotions, such as fear, sadness, anxiety, anger or frustration. It can also cause practical and financial problems.

Practical and financial help

There are many services that can help deal with practical or financial problems caused by the cancer. Benefits, pensions and programs can help pay for prescription medicines, transport costs or utility bills. Home care services, aids and appliances can also be arranged to help make life easier.

Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

If you need legal or financial advice, you should talk to a qualified professional about your situation. Cancer Council offers free legal and financial services in some states and territories for people who can't afford to pay – call 13 11 20 to ask if you are eligible.

Talk to someone who's been there

Coming into contact with other women who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone.

Women often feel they can speak openly and share tips with others who have gone through a similar experience.

In a support group, you may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some women say they can be even more open and honest in these support settings because they aren't trying to protect their loved ones.

Types of support

There are many ways to connect with others for mutual support and to share information. These include:

- **face-to-face support groups** – often held in community centres or hospitals
- **telephone support groups** – facilitated by trained counsellors
- **peer support programs** – match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums** – such as cancerconnections.com.au.

Talk to your nurse, social worker or Cancer Council 13 11 20 about what is available in your area.

“ I felt really alone when treatments were finished, and I worried about the cancer coming back. I found talking to other people who'd been through the same thing so important. ” *Amanda*



Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. Being a carer can be stressful and cause you much anxiety. Try to look after yourself – give yourself some time out and share your worries and concerns with somebody neutral, such as a counsellor or your doctor.

Many cancer support groups and cancer education programs are open to carers, as well as people with cancer. Support groups and programs can offer valuable opportunities to share experiences and ways of coping.

Support services such as Home Help, Meals on Wheels or visiting nurses can help you in your caring role. There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Phone 1800 242 636 or visit carersaustralia.com.au for more information and resources.

Call Cancer Council 13 11 20 to find out more about carers' services and to get a copy of the *Caring for Someone with Cancer* booklet, or download it from your local Cancer Council website.



Useful websites

The internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of support and information.

Australian

Cancer Council Australia.....	cancer.org.au
beyondblue.....	beyondblue.org.au
Cancer Australia.....	canceraustralia.gov.au
Carers Australia.....	carersaustralia.com.au
Department of Health.....	health.gov.au
healthdirect Australia.....	healthdirect.gov.au
Australasian Lymphology Association.....	lymphoedema.org.au
Ovarian Cancer Australia.....	ovariancancer.net.au
Ovarian Cancer – Cancer Australia.....	ovarian-cancer.canceraustralia.gov.au
Ovarian Cancer Research Foundation.....	ocrf.com.au
Centre for Genetics Education.....	genetics.edu.au

International

American Cancer Society.....	cancer.org
Macmillan Cancer Support (UK).....	macmillan.org.uk
National Cancer Institute (US).....	cancer.gov
Ovarian Cancer National Alliance (US).....	ovariancancer.org



Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don't understand, ask for clarification.

- What type of ovarian cancer do I have?
- Has the cancer spread? What stage is it?
- What treatment do you recommend and why?
- Do I have more than one treatment option? If not, why not?
- What are the risks and possible side effects of each treatment?
- How long will treatment take? Will I have to stay in hospital?
- How will the treatment affect my sex life and fertility?
- What are my fertility options?
- What sort of genetic testing can I have?
- Am I entitled to receive genetic counselling?
- Are the latest tests and treatments for ovarian cancer available in this hospital?
- Are there any clinical trials or research studies I could join?
- How frequently will I need check-ups after treatment?
- Who should I go to for my follow-up appointments?
- Are there any complementary therapies that might help me?
- Should I change my diet during or after treatment?
- If the cancer comes back, how will I know?
- What are my treatment options if the cancer comes back?



Glossary

abdomen

The part of the body between the chest and hips, which contains the stomach, spleen, pancreas, liver, gall bladder, bowel, bladder and kidneys.

adjuvant treatment

A treatment given with or shortly after the primary treatment to enhance the effectiveness of the primary treatment.

advanced cancer

Cancer that is unlikely to be cured. It may be limited to the original site (primary cancer) or may have spread to other parts of the body (secondary or metastatic cancer).

ascites

Fluid build-up in the abdomen, making it swollen and bloated.

benign

Not cancerous or malignant.

bilateral salpingo-oophorectomy

Surgical removal of both ovaries and fallopian tubes.

biopsy

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

borderline tumour

A type of ovarian tumour that is not considered cancerous.

bowel

The long, tube-shaped organ in the abdomen that is part of the digestive tract. The bowel has two parts: the small bowel and the large bowel.

bowel obstruction

When the bowel is blocked and waste matter cannot pass through easily.

BRCA1 and BRCA2 gene

People who inherit faults in these genes are at increased risk of getting ovarian, breast or prostate cancer.

CA125

A protein found in the blood that may be higher than normal in women with ovarian cancer.

cervix

The lower part of the uterus that connects the uterus to the vagina. Also called the neck of the uterus.

chemotherapy

The use of cytotoxic (anti-cancer) drugs to treat cancer by killing cancer cells or slowing their growth.

colectomy

An operation in which cancerous areas of the colon are cut out and the healthy parts are sewn back together.

colonoscopy

An examination of the large bowel with a camera on a flexible tube (endoscope), which is passed through the anus.

colostomy

An opening (stoma) in the abdomen made from the colon (part of the large bowel).

CT scan

A computerised tomography scan. This scan uses x-rays to create a picture of the inside of the body.

debulking

Surgery to remove as much of a tumour as possible. This makes it easier to treat the cancer that is

left and increases the effectiveness of other treatments, such as chemotherapy.

endometrium

The lining of the uterus.

endoscope

A flexible tube with a light and camera on the end. It is used during diagnostic tests to look inside the body.

epidural

An injection of anaesthetic drugs into the spinal column.

epithelial ovarian cancer

Cancer that starts in the epithelium of the ovary.

epithelium

Layers of cells covering internal and external surfaces of the body.

fallopian tubes

The two long tubes that extend from the uterus to the ovaries. The fallopian tubes carry fertilised eggs from the ovaries to the uterus.

fibroids

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

genes

The microscopic units that determine how the body's cells grow and behave. Genes are inherited from both parents.

germ cell ovarian cancer

Ovarian cancer that begins in the cells that eventually develop into eggs.

grade

A number that describes how close cancer cells look to normal cells.

gynaecological oncologist

A doctor who specialises in treating women diagnosed with cancer of the reproductive system.

hormones

Chemicals in the body that send information between cells to bring about changes in the body.

hysterectomy

The surgical removal of the uterus and cervix.

ileostomy

An opening (stoma) in the abdomen made from the ileum (part of the small bowel).

infertility

The inability to conceive a child.

intraperitoneal chemotherapy

A technique of administering chemotherapy into the abdominal cavity via injection into the peritoneum.

laparotomy

An operation in which a long cut is made in the abdomen to examine and remove internal organs.

lymphadenectomy

Removal of the lymph glands from a part of the body.

lymphatic system

A network of tissues, capillaries, vessels, ducts and nodes that removes excess fluid from tissues, absorbs fatty acids, transports fat and produces immune cells. Includes the bone marrow, spleen, thymus and lymph nodes.

lymph nodes

Small, bean-shaped structures that form part of the lymphatic system. Also called lymph glands.

lymphoedema

Swelling caused by a build-up of lymph fluid.

lynch syndrome

A disease that increases the risk of developing ovarian cancer.

malignant

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

menopause

When a woman stops having periods (menstruating).

metastasis

A cancer that has spread from a primary cancer in another part of the body. Also called secondary cancer.

neo-adjuvant treatment

A treatment given before the primary treatment to enhance the effectiveness of the primary treatment.

oestrogen

The female sex hormone produced mainly by the ovaries.

omentectomy

Surgical removal of the omentum.

omentum

A protective apron of fatty tissue over the abdominal organs.

ovary

A female reproductive organ that contains eggs (ova). It produces the

hormones oestrogen and progesterone.

ovulation

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

ovum (plural:ova)

A female egg that is released from an ovary at ovulation.

palliative treatment

Medical treatment for people with advanced cancer to help them manage pain and other symptoms of cancer.

paracentesis

The drainage of excess fluid from the abdomen. Also called an ascitic tap.

patient-controlled analgesia system (PCA)

An intravenous system that allows a person to administer a dose of pain relief by pressing a button.

pelvis

The lower part of the trunk of the body; roughly, the area that extends from hip to hip and waist to groin.

pleural effusion

A collection of fluid between the two sheets of tissue that cover the lungs.

progesterone

A female sex hormone made mostly by the ovaries that prepares the uterus lining (endometrium) for pregnancy.

radiotherapy

The use of radiation, such as x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply. Also called radiation therapy.

recurrence

The return of a disease after a period

of improvement (remission).

remission

When the symptoms and signs of the cancer reduce or disappear.

stage

The extent of a cancer and whether the disease has spread from an original site to other parts of the body.

stromal cell cancer

Ovarian cancer that begins in the cells that release female hormones.

targeted therapies

Treatments that attack specific weaknesses of cancer cells while minimising harm to healthy cells.

thoracentesis

A procedure in which a hollow needle is inserted between the ribs to drain excess fluid. Also called a pleural tap.

tumour

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

tumour markers

Chemicals produced by cancer cells and released into the blood. These may suggest the presence of a tumour in the body.

ultrasound

A non-invasive scan that uses soundwaves to create a picture of part of the body. Can be either an abdominal or transvaginal ultrasound.

uterus

The organ in which a fertilised egg (ovum) grows and a foetus is nourished until birth. Also called the womb.

Can't find a word here?

For more cancer-related words, visit:

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

References

1. National Comprehensive Cancer Network (US), NCCN Clinical practice guidelines in oncology (NCCN Guidelines): Ovarian cancer including Fallopian Tube Cancer and Primary Peritoneal Cancer, Version 2.2015.
2. Australian Institute of Health and Welfare (AIHW), Australian Cancer Incidence and Mortality (ACIM) books: Ovarian cancer, AIHW, Canberra, 2016.
3. Cancer Australia, First-line chemotherapy for the treatment of women with epithelial ovarian cancer, Cancer Australia, Sydney, 2014.
4. D Mizrahi et al., 'An exercise intervention during chemotherapy for women with recurrent ovarian cancer: a feasibility study', International Journal of Gynecological Cancer, vol. 25, no. 6, 2015, pp. 985–92.
5. Cancer Australia, Follow up of women with epithelial ovarian cancer, Cancer Australia, Sydney, 2012.



How you can help

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

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

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

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

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

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

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



Cancer Council 13 11 20

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

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

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

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

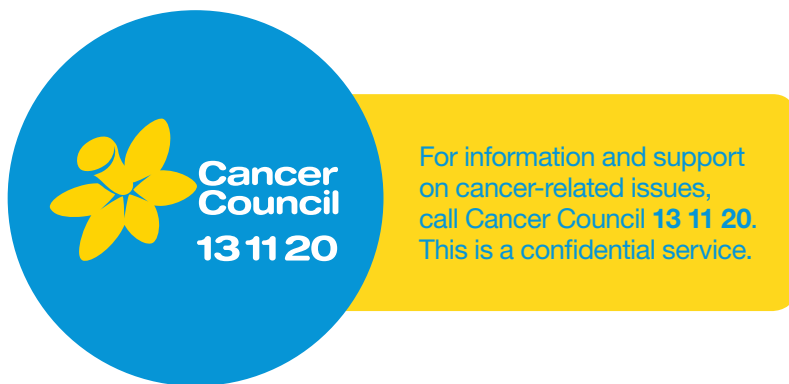
Cancer Council services and programs vary in each area.
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



If you need information in a language other than English, an interpreting service is available. Call 13 14 50.



If you are deaf, or have a hearing or speech impairment, contact us through the National Relay Service.
www.relayservice.gov.au



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

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To support Cancer Council, call your local Cancer Council or visit your local website.*