Understanding Ovarian Cancer
A guide for people with cancer, their families and friends

For information & support, call 131120
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.
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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

- **Normal cells**
- **Abnormal cells**
- **Abnormal cells multiply**
- **Malignant or invasive cancer**
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.
The ovaries

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

The ovaries are two small, grape-shaped organs. 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 made up of:

- **epithelial cells** – found on the outside of the ovary in a layer known as the epithelium
- **germinal (germ) cells** – found inside the ovaries, these cells eventually mature into eggs (ova)
- **stromal cells** – form connective (supporting) tissue within the ovaries, and produce the female hormones oestrogen and progesterone.

Each month, the ovaries release an egg (ovum) in a process called ovulation. The egg travels down the fallopian tube into the uterus. If the egg is fertilised by a sperm, it will implant itself into the lining of the uterus and grow into a baby. If the egg is not fertilised by a sperm, the lining is shed and flows out of the body through the vagina. This flow is known as a woman’s period (menstruation).

Oestrogen and progesterone cause ovulation and menstruation. As a woman gets older, the ovaries gradually produce less of these hormones. When the levels of oestrogen and progesterone fall low enough, a woman’s periods will become irregular and finally stop. This is known as menopause. After menopause, it is no longer possible to conceive a child. The ovaries also become smaller.
The female reproductive system

- Egg (ovum)
- Fallopian tube
- Vagina (birth canal)
- Labia (inner and outer lips of the vulva)
- Cervix (neck of the uterus)
- Ovary
- Uterus (womb)
- Endometrium (uterus lining)

The ovaries
**Key questions**

**Q: What is ovarian cancer?**

**A:** Ovarian cancer is a malignant tumour in one or both ovaries. It can start in any of the three cell types found in the ovary (see table opposite).

Epithelial ovarian, fallopian tube and peritoneal cancers all develop in the same type of cell and are very similar. Recent research suggests that many epithelial ovarian cancers start in the fallopian tubes. Ovarian cancer often spreads from the ovaries to the diaphragm, the lining of the abdomen (peritoneum), and the sheet of fatty tissue that hangs inside the abdomen (omentum).

**Q: What types are there?**

**A:** There are many types of ovarian cancer. The table on the opposite page lists the three most common types. Some women (usually younger women) are diagnosed with a borderline ovarian tumour. This is not considered to be cancer because, although it can spread, it does not usually invade other organs. For this reason, borderline tumours are also known as low malignant potential tumours.

**Q: How common is it?**

**A:** Each year, about 1400 Australian women are diagnosed with ovarian cancer. The average age at diagnosis is 63. It is the eighth most common cancer in women in Australia. Ovarian cancer is more commonly diagnosed in women over 50.2,3
## Most common types of ovarian cancer

<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
</tr>
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</table>
| **epithelial**     | • starts in the fallopian tubes, on the surface of the ovary (epithelium) or in the peritoneum  
                      • most common type of ovarian cancer (about 9 out of 10 cases)  
                      • subtypes include serous, mucinous, endometrioid and clear cell cancers  
                      • usually develops in women over 60                                                                                                       |
| **germ cell**      | • starts in the egg-producing (germinal) cells  
                      • rare type of ovarian cancer (about 4% of cases)  
                      • usually develops in adolescents and women under 40                                                                                     |
| **stromal cell**   | • rare cancer that starts in the cells that produce the female hormones oestrogen and progesterone  
                      • usually occurs in women between 40 and 60  
                      • may produce extra hormones, such as oestrogen                                                                                         |
| **(or sex cord-stromal tumours)** |                                                                                                                                                                 |

For an overview of what to expect during all stages of your cancer care, visit [cancerpathways.org.au/optimal-care-pathways/ovarian-cancer](http://cancerpathways.org.au/optimal-care-pathways/ovarian-cancer). This is a short guide to what is recommended, from diagnosis to treatment and beyond.
Q: What are the symptoms?

A: In its early stages, ovarian cancer usually has no symptoms. This means it is typically diagnosed when the cancer is more advanced.

If symptoms occur, they may include: pressure, pain or discomfort 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 more often, increased flatulence); indigestion 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, are severe or continue for more than a few weeks, keep a record of how often they occur and make an appointment to discuss them with your general practitioner (GP).

These symptoms can also occur in many other conditions and do not necessarily mean you have cancer, but it is best to have a check-up.
How important are genetic factors?

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

Some 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, and not all women with an inherited faulty gene have a family history of cancer.

The main genetic condition known to increase the risk of ovarian cancer is hereditary breast/ovarian cancer, usually caused by a fault in the BRCA1 and BRCA2 genes. Less commonly, Lynch syndrome is associated with ovarian cancer. About 15–20% of women with ovarian cancer are found to have a fault in one of the BRCA genes or other similar genes.

Other genetic conditions continue to be discovered and are often included in genetic tests for cancer risk. Genetic testing aims to detect faulty genes that may increase the risk of developing cancer.

Many women diagnosed with ovarian cancer are eligible for a Medicare rebate for a genetic test. Your specialist or a familial cancer centre will assess your eligibility and, with your permission, order a blood test to check whether you have the BRCA1, BRCA2 or another similar mutation. Knowing whether you have a particular faulty gene may help determine suitable treatment options (see Targeted therapy on page 38).

If the faulty gene causing the cancer is found, Medicare-funded testing can be offered to other family members who have no signs of cancer. For more information about genetic testing, talk to your specialist or local familial cancer centre, or call 13 11 20.
Q: What are the risk factors?
A: The causes of most ovarian cancers 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

• **genetic factors** – up to 20% of serous ovarian cancers (the most common subtype) are linked to an inherited faulty gene, and a smaller proportion of other types of ovarian cancer are also related to genetic faults (see box on page 11)

• **family history** – having one or more close blood relatives diagnosed with ovarian, breast, bowel or uterine cancers, or having Ashkenazi Jewish ancestry

• **reproductive history** – women who have not had children or who had children over the age of 35 may be slightly more at risk

• **lifestyle factors** – such as smoking and being overweight

• **hormonal factors** – including early puberty or late menopause, or using oestrogen-only hormone replacement therapy (HRT) for five years or more.

Some factors 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) or removed.
Diagnosis

There is currently no effective screening test for ovarian cancer. If your doctor suspects you have ovarian cancer, you may have some of the tests and scans described in this chapter. These tests can show if there are any abnormalities that need to be followed up with a biopsy.

The only way to confirm a diagnosis of ovarian cancer is by taking a tissue sample (biopsy) and looking at the cells under a microscope. This is usually done during surgery (see page 28), which means that the cancer is diagnosed and treated at the same time.

Pelvic examination

The doctor will check for any masses or lumps by feeling your abdomen. To check your uterus and ovaries, they will place two fingers inside your vagina while pressing on your abdomen with their other hand. You may also have a vaginal examination using a speculum, an instrument that separates the walls of the vagina.

An internal examination is not painful but may be uncomfortable. The doctor may also perform a digital rectal examination, placing a gloved finger into the anus to feel the tissue behind the uterus where cancer cells may grow.

The Cervical Screening Test (which has replaced the Pap test) does not diagnose ovarian cancer. It looks for human papillomavirus (HPV), which causes most cases of cervical cancer but not ovarian cancer.
CA125 blood test

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

The level of CA125 may be higher in some 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 not used for screening for ovarian cancer in women who do not have any symptoms. It can be used:

**At diagnosis** – A CA125 test is more accurate in diagnosing ovarian cancer in 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 opposite).

**During treatment** – If you are found to have ovarian cancer that produces CA125, the blood test may be used to check how well the treatment is working. Falling CA125 levels may mean it’s working, and rising CA125 may mean the treatment is not working effectively, but the CA125 level is only one item used by the treating team to assess a woman’s response to treatment.

**After treatment** – CA125 blood tests are sometimes included in follow-up tests. See pages 56–57 for more information.
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.

Pelvic ultrasound

A pelvic ultrasound uses echoes from soundwaves to create a picture of your uterus and ovaries 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 small transducer wand into your vagina. It will be covered with a disposable plastic sheath and gel to make it easier to insert. Some women find this procedure uncomfortable, but it should not be painful. Talk to your doctor and the sonographer if you feel distressed or concerned. You can ask for a female sonographer if that makes you feel more comfortable.

The transvaginal ultrasound is often the preferred type of ultrasound, as it provides a clearer picture of the 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 take pictures of the inside of the body. It is used to look for signs that the cancer has spread, but a CT scan may not be able to detect all ovarian tumours. CT scans are usually done at a hospital or 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 may make you feel hot all over and leave a bitter taste in your mouth. You may also feel the need to pass urine. These side effects usually ease quickly, but tell the person carrying out the scan if they don’t go away.

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.

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.
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 help with planning before surgery, and to check on how the treatment is working. Medicare only covers the cost of PET scans for ovarian cancer that has returned, so they are not often used for the initial diagnosis.

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.

Any 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.

Colonoscopy

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

Before the test, you will have to change your diet and take prescribed laxatives to clean out your bowel completely (bowel
preparation). The process varies for different people and between hospitals. Your doctor will give you specific instructions and talk to you about what to expect. On the day, you will probably be given an anaesthetic so you don’t feel any discomfort.

A colonoscopy usually takes about 20–30 minutes. You will need to have someone take you home afterwards, as you may feel drowsy or weak.

**Staging and grading ovarian cancer**

The tests described on pages 13–18 help show whether you have ovarian cancer and whether it has spread to other parts of the body. This process is called staging and it helps your health care team recommend the best treatment for you.

In most instances, your doctor will not have enough information to work out the stage of the ovarian cancer until after surgery (see page 28 for more information).

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, which indicate increasing amounts of tumour.

Stages I–II mean that it is early ovarian cancer. Stages III–IV mean the cancer is advanced. About 7 out of 10 women with ovarian cancer are diagnosed at stages III or IV.
### Stages of ovarian cancer (FIGO system)

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

### Grades of ovarian cancer

Grading describes how the cancer cells look compared to normal cells. It helps work out how aggressive the cancer cells may be. Treatment has a greater chance of success if the grade is lower.

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grade 1</td>
<td>The cancer cells look similar to normal cells and are probably growing relatively slowly.</td>
</tr>
<tr>
<td>Grade 2</td>
<td>The cancer cells appear slightly abnormal and might grow more rapidly.</td>
</tr>
<tr>
<td>Grade 3</td>
<td>The cancer cells look very different from normal cells and may grow quickly.</td>
</tr>
</tbody>
</table>
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 in an individual person.

**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** – These can usually be treated successfully.

**Borderline tumour** – This 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.

Your doctor will consider many factors in assessing your prognosis. These include: test results; the type of ovarian cancer you have; the grade; genetic factors (see page 11); your response to treatment; and other factors such as your age, fitness and overall health.
Emma’s story

Although I had a long history of gynaecological problems, my diagnosis of ovarian cancer at age 36 was a complete surprise.

During an emergency operation to fix a twisted ovary, the doctors took a biopsy from an ovarian cyst. Five days later I got a call to say I had ovarian cancer.

I had surgery to remove my remaining ovary, along with the uterus and some lymph nodes. Luckily the cancer was found early and it hadn’t spread outside the ovary.

As they found a clustering of cells in my abdomen during the surgery, the medical oncologist recommended I have a course of chemotherapy to help prevent the cancer coming back.

Even though I was young and fit, I found the chemotherapy very difficult. I had treatment weekly for 16 weeks and had a lot of side effects, including fatigue, nausea, diarrhoea and constipation, numbness in the hands and feet, and hair loss. I also had an adverse reaction to the first drug, which meant I had to take medicines before each infusion to try to prevent this.

Although some people bounce right back, once treatment was over I questioned my values and reasons for being here. Attending support groups and seeing an oncology psychologist really helped me come to grips with the experience of having had ovarian cancer, and my emotions are now in a much better place.

My body also needed time to recover after treatment. Although I’m still dealing with lymphoedema and fatigue, I’m happy to be getting back to work and my usual activities.

I now realise how important it is to build a relationship with my health care professionals and to actively look after my 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.

### Health professionals you may see

<table>
<thead>
<tr>
<th>Role</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>gynaecological oncologist*</td>
<td>diagnoses and performs surgery for cancers of the female reproductive system, e.g. ovarian, cervical, uterine, vulvar and vaginal cancers</td>
</tr>
<tr>
<td>gynaecological pathologist*</td>
<td>examines tissue removed from the abdomen or ovaries under a microscope</td>
</tr>
<tr>
<td>medical oncologist*</td>
<td>treats cancer with drug therapies including chemotherapy and targeted therapy</td>
</tr>
<tr>
<td>radiation oncologist*</td>
<td>treats cancer by prescribing and coordinating a course of radiation therapy</td>
</tr>
<tr>
<td>radiation therapist</td>
<td>plans and delivers radiation therapy</td>
</tr>
<tr>
<td>radiologist*</td>
<td>reads and interprets diagnostic scans (e.g. x-rays, CT and PET scans)</td>
</tr>
<tr>
<td>nurse</td>
<td>administers drugs and provides care, information and support throughout treatment</td>
</tr>
</tbody>
</table>

* Specialist doctor
The gynaecological oncologist may arrange further tests, advise you about treatment options and perform any recommended surgery. 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).

<table>
<thead>
<tr>
<th>Health professional</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>cancer nurse/ cancer care coordinator</strong></td>
<td>coordinates your care, liaises with other members of the MDT and supports you and your family throughout treatment</td>
</tr>
<tr>
<td><strong>dietitian</strong></td>
<td>recommends an eating plan to follow while you are in treatment and recovery</td>
</tr>
<tr>
<td><strong>physiotherapist, occupational therapist</strong></td>
<td>assist with physical and practical problems, including restoring mobility after treatment, and recommending aids and equipment</td>
</tr>
<tr>
<td><strong>social worker</strong></td>
<td>links you to support services and helps you with emotional, practical or financial issues</td>
</tr>
<tr>
<td><strong>counsellor, clinical psychologist</strong></td>
<td>help you manage your emotional response to diagnosis and treatment</td>
</tr>
<tr>
<td><em><em>palliative care specialists</em> and nurses</em>*</td>
<td>work closely with the GP and oncologist to help control symptoms and maintain quality of life</td>
</tr>
<tr>
<td><em><em>familial cancer specialist</em>, genetic counsellor</em>*</td>
<td>provide advice about genetic conditions; perform and interpret genetic test results for you and your family</td>
</tr>
</tbody>
</table>

*Specialist doctor
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 internal vaginal and rectal examinations 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 looks for signs that the cancer has spread. It may not detect all tumours.

- Results of the diagnostic tests and biopsy help the doctors determine whether and 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 expected outcome of a disease. Women with early-stage cancer have the best prognosis.

- You will be treated by a gynaecological oncologist and other health professionals, who will work together in a multidisciplinary team (MDT).

- Genetic testing is available on Medicare for many women who are diagnosed with ovarian cancer. It can be organised by your cancer specialists.
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 for further explanation – see page 63 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 ovarian 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.
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 type of ovarian cancer

<table>
<thead>
<tr>
<th>Type</th>
<th>Treatment</th>
</tr>
</thead>
</table>
| **Epithelial**   | 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.  
  - **Stage I** ovarian cancer is usually treated with surgery alone. Some women will be offered chemotherapy after surgery if there is a high risk of the cancer coming back.  
  - **Stages II, III and IV** are usually treated with a combination of surgery and chemotherapy. New targeted therapy drugs are being offered to women with a BRCA mutation. In some cases, radiation therapy is offered. |
| **Germ cell**    | This is usually treated with surgery and/or chemotherapy.                  |
| **Stromal cell** | This is usually treated with surgery, sometimes followed by chemotherapy or targeted therapy. |
| **Borderline tumour** | This is usually treated with surgery only. |
Surgery

Your gynaecological oncologist will talk to you about the most suitable type of surgery, as well as the risks and any possible complications. These 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.

Ovarian cancer is staged surgically. This means that the surgery will help the doctor work out how far the tumour has spread within the pelvic cavity.

You will be 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). The type of surgery you have will depend on how certain the gynaecological oncologist is that cancer is present and how far they think the cancer has spread. A laparoscopy may be used to see if a suspicious mass is cancerous; however, most women with advanced cancer will have a laparotomy.

The gynaecological oncologist will look inside your pelvis and abdomen for signs of cancer, and take tissue and fluid samples (biopsy). During the operation, the samples are usually sent to a specialist called a pathologist, who immediately examines them for signs of cancer. This is called a frozen section analysis or biopsy.

If cancer is present, the gynaecological oncologist will continue the operation and remove as much of the cancer as possible. This is called surgical debulking.
Types of surgery
Depending on how far the cancer has spread, you may have one or more of the procedures listed below.

<table>
<thead>
<tr>
<th>Total hysterectomy and bilateral salpingo-oophorectomy</th>
<th>Unilateral salpingo-oophorectomy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most women with ovarian cancer will have an operation to remove the uterus and cervix, along with both fallopian tubes and ovaries.</td>
<td>If the cancer is found early and it is only in one ovary, some young women who still wish to have children may have only one ovary and fallopian tube removed.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Omentectomy</th>
<th>Lymphadenectomy</th>
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</thead>
<tbody>
<tr>
<td>The omentum is a sheet of fatty tissue attached to the stomach and bowel. It hangs down in front of the intestines. Ovarian cancer often spreads to the omentum and it may need to be removed.</td>
<td>The pelvis contains large groups of lymph nodes. Cancer cells can spread from your ovaries to nearby lymph nodes. Your doctor may suggest removing some in a lymphadenectomy (also called lymph node dissection).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Colectomy</th>
<th>Removal of other organs</th>
</tr>
</thead>
<tbody>
<tr>
<td>If cancer spreads to the bowel, some of the bowel may be removed. A new opening called a stoma may be created (colostomy or ileostomy). This is usually temporary. See page 49 for more details.</td>
<td>Ovarian cancer can spread to many organs in the abdomen. In some cases, parts of the liver, diaphragm, bladder and spleen may be removed if it is safe to do.</td>
</tr>
</tbody>
</table>
Surgery for ovarian cancer is complex. To ensure the best result, it is recommended that you are treated by a gynaecological oncologist at a specialist centre for gynaecological cancer. Call Cancer Council 13 11 20 for information about specialist centres in your area or to ask for a free copy of the *Understanding Surgery* booklet.

All tissue and fluids removed during surgery are examined for cancer cells by a pathologist. The results will help confirm the type of ovarian cancer you have, if it has spread (metastasised), and its stage. It may not be possible to remove all the cancerous tissue. Surgery is often followed by chemotherapy, which will shrink or destroy any remaining cancer cells.

**What to expect after surgery**

When you wake up from surgery, you will be in a recovery room near the operating theatre. Once you are fully conscious, 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 to collect urine in a bag
- a tube may be inserted down your nose into your stomach (nasogastric tube) to drain stomach fluid and prevent vomiting
- tubes may be inserted in your abdomen to drain fluid from the site of the operation.
**Pain** – After an operation, it is common to feel some pain, but this can be controlled. For the first day or two, you may be given pain medicine through a drip or via a local anaesthetic injection into the abdomen (a transverse abdominis plane or TAP block) or spine (an epidural). Some patients have a patient-controlled analgesia (PCA) system. This machine allows you to self-administer a measured dose of pain relief by pressing a button. Let your doctor or nurse know if you are in pain so they can adjust the medicine. Managing your pain will help you to recover and move around more quickly.

**Injections** – It is common to have daily injections of a blood thinner to reduce the risk of blood clots. These injections may continue for some time after the operation and while you’re having chemotherapy. A nurse will show you how to give this injection to yourself before you leave hospital.

**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 moving around, compression devices will be removed so you can get out of bed, but you may still wear the stockings for a couple of weeks.

**Wound care** – You can expect some light vaginal bleeding after the surgery, which should stop within two weeks. Your doctor will talk to you about how to keep the wound clean once you go home to prevent it becoming infected.

**Length of stay** – You will probably stay in hospital for 4–7 days for a big operation, less for a laparoscopy or smaller operation.
Taking care of yourself at home after surgery

Your recovery time will depend on the type of surgery you had, your general health, and your support at home. Most women are able to fully return to their usual activities after 4–8 weeks.

Rest
Take things easy and do only what is comfortable. You may like to try meditation or some relaxation techniques to reduce tension.

Lifting
Avoid heavy lifting (more than 3–4 kg), hanging out the washing, or vacuuming for at least six weeks. Use a clothes horse or dryer instead of hanging the washing on a line. If you have a partner or children, ask them to help around the house. You can also check with a social worker if it’s possible to get help at home.

Work
Depending on the nature of your work, you will probably need 4–6 weeks leave from work.

Driving
You will most likely need to avoid driving for a few weeks after the surgery. Check with your car insurer for any conditions regarding major surgery and driving.
Sexual intercourse should be avoided for about six weeks after the operation to give your wounds time to heal. Ask your doctor when you can resume sexual intercourse and explore other ways you and your partner can be intimate, such as massage.

Exercise
Your health care team will probably encourage you to start walking the day after the surgery. Exercise has been shown to help people manage some of the common side effects of treatment, speed up a return to usual activities and improve overall quality of life. Start with a short walk and go a little further each day. Speak to your doctor if you would like to try more vigorous exercise.

Bowel problems
You may have constipation following the surgery. It is important to avoid straining when passing a bowel motion, so you may need to take laxatives (see page 48).

Nutrition
To help your body recover from surgery, focus on eating a balanced diet (including proteins such as lean meats and poultry, fish, eggs, milk, yoghurt, nuts, seeds and legumes/beans).

Bathing
Take showers instead of baths, and avoid swimming for 4–6 weeks after surgery.
Further treatment

Your doctor should have all the test results within two weeks of surgery. Further treatment will depend on the type of ovarian cancer, the stage of the disease and the amount of any remaining cancer. If the cancer is advanced, it’s more likely to come back, so surgery will usually be followed by chemotherapy, and occasionally by targeted therapy. Radiation therapy is not often recommended.

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. Chemotherapy may be used at different times:

**After surgery** – Most women will have chemotherapy after surgery (adjuvant chemotherapy) as there may be some cancer cells still in the body. Chemotherapy usually starts 2–4 weeks after surgery. The drugs you receive will depend on the stage of the cancer and your general health. For ovarian cancer, a combination of several drugs is usually given in repeating cycles spread over 4–5 months. Your treatment team will provide details about your specific schedule.

**Before surgery** – Some women with stage III or stage IV ovarian cancer have chemotherapy before surgery (neoadjuvant chemotherapy). The aim is to shrink the tumours to make them easier to remove. This usually involves three cycles of chemotherapy, followed by surgery, and then another three cycles.
Primary treatment – Chemotherapy may be recommended as the main treatment if you are not well enough for a major operation or when the cancer cannot be surgically removed.

Having chemotherapy
Chemotherapy is usually given as a combination of two drugs, or sometimes as a single drug. It’s delivered as a liquid drip into a vein (intravenous drip). To reduce the need for repeated needles, some women have a small medical appliance or tube placed beneath their skin through which they receive chemotherapy. This may be a port-a-cath, a peripherally inserted central catheter (PICC), or another type of catheter.

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, you will have blood tests 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 14). If the CA125 level was high before chemotherapy, it can be monitored to see if the treatment is working.

“I kept a notebook to record my chemotherapy symptoms and any questions I had. Ann”
**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 they will vary according to the drugs you are given. Your health care team will talk to you about what to expect and how to manage any side effects (see also *Managing side effects* on pages 43–53).

**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. You will generally be given anti-nausea medicines with each chemotherapy session to help prevent or reduce nausea and vomiting. Whether or not you feel sick is not a sign of how well the treatment is working.

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

**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 to ask about wig services in your area. If you have private health insurance, check with your
provider whether you are entitled to a rebate on a wig purchased because of hair loss associated with chemotherapy.

**Risk of infections** – Chemotherapy reduces your white blood cell level, making it harder for your body to fight infection. Colds and flu may be easier to catch and harder to shake off, and scratches or cuts may get infected more easily. You may also be more likely to catch a more serious infection and need to be admitted to hospital. Contact your doctor or go to the nearest hospital if you have a temperature of 38°C or over or other signs of infection.

**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.

**Numbness or tingling in your hands and feet** – This is called peripheral neuropathy, and it 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.

**Targeted therapy**
Targeted therapy drugs can get inside cancer cells and block particular proteins (enzymes) that tell the cancer cells to grow. These drugs are used to treat some types of ovarian cancer. They may also be used in certain situations (e.g. if chemotherapy has not been successful). Genetic testing (see page 11) will help determine if you have a particular faulty gene that may respond to targeted therapy drugs.
Bevacizumab is a targeted therapy drug used to treat advanced epithelial tumours. It works by stopping the cancer developing new blood vessels and growing. Bevacizumab is given with chemotherapy every three weeks as a drip into a vein (infusion). It is commonly given in repeating cycles.

Olaparib is a new treatment for women with high-grade epithelial ovarian cancer who have the BRCA1 or BRCA2 gene mutation. This drug is usually given after chemotherapy to help stop the cancer growing. It is taken as a tablet twice a day.

Other targeted therapy drugs may be available on clinical trials (see page 26). Talk with your doctor about the latest developments and whether you are a suitable candidate.

**Side effects of targeted therapy**
Although targeted therapy minimises harm to healthy cells, it can still have side effects. It is important to discuss any side effects with your doctor immediately. If left untreated, some can become life-threatening. Your doctor will monitor you throughout treatment.

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.

The most common side effects experienced by women taking olaparib include nausea, fatigue, vomiting, and low blood cell counts. More serious side effects include bone marrow or lung problems.
Radiation therapy

Radiation therapy (also known as radiotherapy) uses x-rays to damage cancer cells. The radiation is targeted at cancer sites in your body, with the aim of reducing the cancer’s growth and improving symptoms.

Radiation therapy for ovarian cancer may be used to treat the pelvis or other sites of cancer that have spread further away. It may be used after chemotherapy or on its own as a palliative treatment.

Before treatment starts, the radiation oncology team will explain the treatment schedule and the possible side effects. You will lie on a table under a machine that delivers radiation to the affected parts of the body. You will not feel anything during the treatment, which will take only a few minutes each time. You may be in the room for a total of 10–20 minutes for each appointment.

The number of radiation therapy sessions you have will depend on the type and size of the cancer. You may have a few treatments or daily treatment for several weeks.

Side effects of radiation therapy

The side effects of radiation therapy vary. Most are temporary and disappear a few weeks or months after treatment. Radiation therapy for ovarian cancer is usually given over the abdominal area, which can irritate the bowel and bladder.

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. For more information, call Cancer Council 13 11 20 for a free copy of Understanding Radiation Therapy, or visit your local Cancer Council website.

**Palliative treatment**

Palliative treatment helps to improve people’s quality of life by managing the symptoms of cancer without trying to cure the disease. It is best thought of as supportive care.

Many people think that palliative treatment is for people at the end of their life, but it may be beneficial for people at any stage of advanced ovarian cancer. 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 radiation therapy. 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 50).

Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, practical, emotional, spiritual and social 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, whether you have a faulty gene, and your overall health and fitness.

• Ovarian cancer is usually treated with surgery. In most women with ovarian cancer, surgery involves a total hysterectomy, as well as 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 biopsy.

• It will take time to recover from an operation. Recovery times vary depending on the type of surgery you have. You will need to take things easy when you first get home from hospital.

• After surgery, you may have further treatment. Most women have chemotherapy, but they may also have radiation therapy or targeted therapy.

• Chemotherapy is usually given soon after an operation for 4–5 months. Side effects may include tiredness, nausea and vomiting, and hair loss.

• Newer treatments for ovarian cancer include targeted therapy drugs, which can help stop the cancer growing. You may need a genetic test to see if you are likely to respond to these drugs.

• Radiation therapy uses x-rays to damage cancer cells. You may have treatment to your pelvis, but it can also be given to other parts of the body if the cancer has spread.

• 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 are temporary but some may be permanent. This chapter explains ways to manage the discomfort that side effects may cause.

Fatigue

It is common to feel very tired and lack 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. Fatigue may continue for a while after chemotherapy has finished, but it is likely to gradually improve over time. For some women, it may take up to 1–2 years to feel well again.

Tips for managing fatigue

- Plan your day. Set small manageable goals 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. It may help to see a dietitian.
- Regular light exercise has been shown to reduce fatigue. Even a walk around the block can help.
- Talk to your doctor about the amount and type of exercise suitable for you or ask for a referral to a physiotherapist or exercise physiologist.
Infertility

Surgery or radiation therapy for ovarian cancer will mean you are unable to conceive children. 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 the uterus and one ovary in place. They will, however, need to avoid pregnancy while on chemotherapy.

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 cannot 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 a sense of loss and grief.

If you have a partner, you may find it helpful to 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 visit your local Cancer Council website.

Menopause

If you were still having periods (menstruating) before surgery, having your ovaries removed will mean you no longer produce the hormones oestrogen and progesterone, and you will stop menstruating. 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, dry or itchy skin, mood swings, trouble sleeping (insomnia), tiredness and vaginal dryness. These symptoms are usually more severe after surgery than during a natural menopause, because the body hasn’t had time to get used to the gradual decrease in hormone levels.

Tips for managing the symptoms of menopause

- Vaginal moisturisers available over-the-counter from chemists can help with vaginal discomfort and dryness.
- Talk to your doctor about the benefits and risks of hormone replacement therapy (HRT). If taken after natural menopause, HRT containing oestrogen may increase the risk of some diseases. If you were already on HRT when the cancer was diagnosed, you will need to weigh up whether to continue.
- Menopause can increase your risk of developing thinning of the bones (osteoporosis). Talk to your doctor about having a bone density test or taking medicines to prevent your bones becoming weak. Regular exercise will help keep your bones strong. Osteoporosis Australia has more information – visit osteoporosis.org.au or call 1800 242 141.
- Cholesterol levels can change after menopause, which can increase your risk of heart disease. Regular exercise and a balanced diet may help improve cholesterol levels. If not, talk to your doctor about cholesterol-lowering drugs.
- Meditation and relaxation techniques may help reduce stress and lessen symptoms.
- Talk to your doctor or call Cancer Council 13 11 20 about ways to relieve the symptoms of menopause.
Impact on sexuality and intimacy

Ovarian 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 whether you have a partner.

Treatment can cause physical side effects such as vaginal dryness, scarring, internal scar tissue (pelvic adhesions, see page 50), and narrowing of the vagina. These side effects can make sexual penetration painful, and you may have to explore different ways to orgasm or climax. The experience of having cancer can also reduce your desire for sex (libido).

For most women, sex is more than arousal, intercourse and orgasms. It involves feelings of intimacy and acceptance, as well as being able to give and receive love. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

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

Look Good Feel Better runs workshops to help people manage the appearance-related effects of cancer treatment – go to lgfb.org.au or call 1800 650 960.
Tips for managing sexual changes

• Give yourself time to get used to any physical changes. Let your partner know if you don’t feel like having sex, or if you find penetration uncomfortable.

• Show affection by touching, hugging, massaging, talking and holding hands.

• Talk to your doctor about ways to manage side effects that change your sex life. These may include using vaginal dilators, lubricants and moisturisers.

• If vaginal dryness is a problem, take more time before and during sex to help the vagina relax and become more lubricated.

• Extra lubrication may make intercourse more comfortable. Choose a water-based or silicone-based gel without perfumes or colouring.

• Spend more time on foreplay and try different ways of getting aroused.

• Try different positions during sex to work out which position is the most comfortable for you.

• If you can’t enjoy penetrative sex, explore other ways to climax, such as oral and manual stimulation.

• Talk about your feelings with your sexual partner or doctor, or ask your treatment team for a referral to a sexual therapist or psychologist.

• Do some physical activity to boost your energy and mood. Talk to your GP if your low libido is caused by depression.

• Call 13 11 20 for a free copy of Sexuality, Intimacy and Cancer, or visit 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 (see canceraustralia.gov.au).
Bowel changes

After surgery or during chemotherapy or radiation therapy, some women notice bowel problems. You may experience diarrhoea, constipation or stomach 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

- 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 suitable medicines to relieve symptoms of diarrhoea or constipation.
- Eat small, frequent meals instead of three big ones.
- Drink peppermint or chamomile tea to reduce stomach or wind pain.
- If you have diarrhoea, rest as much as possible as diarrhoea can be exhausting.
- If you are constipated, do some gentle exercise such as walking.
- Call Cancer Council 13 11 20 for a free copy of the Nutrition and Cancer booklet.
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 (faeces) cannot pass through the bowel easily, symptoms may include feeling sick, vomiting, or stomach discomfort and pain.

To relieve the symptoms, you may have a small tube (stent) put in that helps 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 may be reversed when the obstruction is cleared or it may be permanent.

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 stomaltherapy.com, visit the website of the Australian Council of Stoma Associations at australianstoma.com.au, or call Cancer Council 13 11 20.
**Internal scar tissue (pelvic adhesions)**

Tissues in the pelvis may stick together after a hysterectomy (known as an adhesion). These can be painful or cause bowel problems such as constipation. Rarely, adhesions to the bowel or bladder may need to be treated with further surgery.

**Fluid build-up**

Sometimes ovarian cancer can cause fluid to build up in the body.

**Ascites**

This is when fluid collects in the abdomen. It causes swelling and pressure, which can be uncomfortable and make you feel breathless. Your doctor will inject a local anaesthetic into the abdomen and then insert a needle to take a sample of the fluid. This is called paracentesis or ascitic tap. The fluid sample is sent to a laboratory to be examined for cancer cells.

Sometimes, to make you feel more comfortable, the doctor will remove the remaining fluid from your abdomen. It will take a few hours for all the fluid to drain into a drainage bag.

**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**

Some women who have lymph nodes removed from the pelvis (a lymphadenectomy, see page 29) may find that one or both legs become swollen. This is known as lymphoedema. It can happen if lymph fluid doesn’t drain back into circulation properly and builds up in the legs. Radiation therapy in the pelvic area may also cause lymphoedema. Lymphoedema may appear at the time of treatment or months or years later.

Lymphoedema may make movement and some types of activities difficult. It is important to seek help with lymphoedema symptoms as soon as possible. Early diagnosis and treatment lead to better outcomes. Though lymphoedema may be permanent, it can usually be managed. Gentle exercise, compression stockings, and a type of massage called manual lymphatic drainage can all help to reduce the swelling.

To find a practitioner who specialises in managing lymphoedema, visit the Australasian Lymphology Association website at lymphoedema.org.au. For tips on preventing and managing lymphoedema, download Cancer Council’s *Understanding Lymphoedema* fact sheet from your local Cancer Council website.

If your GP refers you to a lymphoedema practitioner, you may be eligible for a Medicare rebate. Talk to your GP about developing a Chronic Disease Management Plan or Team Care Arrangement to help you manage the condition.
Feeling low or depressed

It is common and understandable to feel low or anxious after a cancer diagnosis, during treatment or when you are recovering. Some women feel sad because of the changes the cancer has caused. Others are frightened about the future. If you often feel irritable, tense or on edge, experience frequent worries, find it hard to wind down, or have difficulty sleeping, you may be experiencing anxiety.

There is a difference between feeling down and experiencing depression. If you have continued feelings of sadness or emotional numbness on most days for two weeks, 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 has information about coping with depression and anxiety at beyondblue.org.au. If you would like to talk to someone about how you are feeling, call Lifeline on 13 11 14 or beyondblue on 1300 22 4636.

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
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 you are unable to have children (infertility) as a result of treatment for ovarian cancer, you may feel very distressed. Talking about your feelings with your family, friends or a counsellor may be helpful.

- 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.

- Treatment for ovarian cancer can have an impact on sexuality and self-esteem. There are things you can do to manage these changes.

- After treatment, some women have bowel problems such as diarrhoea, cramps or constipation. Surgery can also cause a blocked bowel (bowel obstruction).

- Sometimes fluid can build up in your abdomen, lungs or chest wall. Your medical team will drain the fluid.

- If fluid builds up in the legs (lymphoedema), try gentle exercise and compression stockings, or visit lymphoedema.org.au to find a specialised practitioner.

- Some women feel anxious or depressed during or after cancer treatment. Speak to your GP for support.
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.

**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.

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

Some 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. You may want or need to make changes to your life. Take some time to adjust to the physical and emotional changes, and establish a new daily routine at your own pace. Your family and friends may also need time to adjust.

Cancer Council 13 11 20 can help you connect with other women who have had cancer, and provide you with information about the emotional and practical aspects of living well after cancer.
Follow-up appointments
After your treatment, you will usually have regular check-ups to confirm that the cancer hasn’t come back or spread, and to manage any long-term side effects of treatment.

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

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. Check with your doctor if you are unsure of your follow-up plan.

It’s common to worry before 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.
Having CA125 blood tests
Your specialist will also talk to you about the advantages and disadvantages of having regular CA125 blood tests.

This test is optional – research has found that waiting until symptoms develop before starting treatment is just as effective as starting treatment earlier. This means that quality of life is improved as side effects of further treatment are delayed.

What if ovarian cancer returns?
For many women, ovarian cancer does come back after treatment and a period of improvement (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 recurrence, 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 or targeted therapy. The drugs used will depend on what drugs you were initially given, the length of remission and the treatment aims. The drugs used the first time may be given 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 therapy are offering new treatment options for women with ovarian cancer. Talk with your doctor about the latest developments that may be available through clinical trials (see page 26).

**Tips for dealing with uncertainty**

- Talk with other women who have had ovarian cancer. You may find it reassuring to hear about their experiences. See page 60 for information about support groups.
- Keep a symptom diary to track how you’re feeling.
- Explore different ways to relax, such as meditation or yoga, to deal with stress and anxiety.
- Talking to a psychologist or counsellor about how you are feeling might help. They may be able to teach you some strategies to help you manage your fears.
- Practise letting your thoughts come and go without getting caught up in them.
- Try to exercise regularly. Exercise has been shown to help women cope with the side effects of treatment.
- Focus on making healthy choices in areas of your life that you can control, such as what you eat.
- Set yourself some goals – as you achieve each one, set some new goals.
- For more information, see Cancer Council's *Emotions and Cancer* booklet.
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 Cancer Council Online Community at cancercouncil.com.au/OC.

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

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I found talking to other people who’d been through the same thing so important. *Amanda*
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 Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local support services, as well as practical information and resources, through the Carer Gateway. Visit carergateway.gov.au or call 1800 422 737.

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. Visit carersaustralia.com.au or phone 1800 242 636 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 a digital version 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
- Cancer Australia .................................................. canceraustralia.gov.au
- Carer Gateway .................................................. carergateway.gov.au
- Carers Australia ............................................... carersaustralia.com.au
- Department of Health .............................................. health.gov.au
- Healthdirect Australia ....................................... healthdirect.gov.au
- Australasian Lymphology Association .......... lymphoedema.org.au
- Australia New Zealand Gynaecological Oncology Group .................. anzgog.org.au
- Australian Gynaecological Cancer Foundation ........ agcf.org.au
- beyondblue .................................................. beyondblue.org.au
- Centre for Genetics Education ..................... genetics.edu.au
- Ovarian Cancer Australia .................. ovariancancer.net.au
- Ovarian Cancer Research Foundation .......... ocrf.com.au

**International**
- American Cancer Society ................................ cancer.org
- Cancer Research UK ........................................ cancerresearchuk.org
- Macmillan Cancer Support (UK) .................. macmillan.org.uk
- National Cancer Institute (US) ................... cancer.gov
- Ovarian Cancer Research Fund Alliance (US) ...... ocrfa.org
You may find this checklist helpful when thinking about the questions you want to ask your doctor about the 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?
- Are the side effects temporary or permanent? How can any side effects be managed?
- 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?
- If I have to travel for treatment, is there any government funding available to help with the cost?
- 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?
- Should I exercise? When should I start? How much should I do?
- If the cancer comes back, how will I know?
- What are my treatment options if the cancer comes back?
abdomen
The part of the body between the chest and hips, which contains the stomach, spleen, pancreas, bowel, bladder and kidneys. The lower part of the abdomen (pelvic cavity) contains the ovaries and other female reproductive organs.

advanced cancer
Cancer that is unlikely to be cured. It may be limited to its 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.

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 main parts: the small bowel and the large bowel.

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

bowel preparation
The process of cleaning out the bowel before a test or scan to allow the doctor to see the bowel more clearly.

BRCA1 and BRCA2 mutations
Gene changes that increase the risk of getting breast or ovarian cancer.

CA125
A protein found in the blood that is often 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
A cancer treatment that uses drugs to kill cancer cells or slow their growth.

collectomy
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
A surgically created opening (stoma) in the abdomen to the outside of the body. It is made from the colon (part of the large bowel).

CT scan
Computerised tomography scan. This scan uses x-rays to create a detailed cross-sectional picture 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.
endoscope
A flexible tube with a light and camera on the end. It is used during diagnostic tests to look inside the body.

epithelial ovarian cancer
Cancer that starts in the surface of the ovary (epithelium).

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

fallopian tubes
The two thin tubes that extend from the ovaries to the uterus. The tubes carry sperm to the egg, and a fertilised egg from the ovaries to the uterus.

familial cancer centre
Provide genetic counselling and other services for people with a family history of cancer.

genes
The microscopic units that determine how the body’s cells grow and behave. Genes are found in every cell of the body and are inherited from both parents.

genetic testing
Genetic testing aims to detect faulty genes that may increase the risk of developing certain cancers. There are a number of genetic conditions included in genetic tests for ovarian cancer.

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

germinai (germ) cells
Cells that produce eggs in females and sperm in males.

grade
A number that describes how similar cancer cells look to normal cells.

gynaecological oncologist
A gynaecologist who specialises in treating women diagnosed with cancer of the reproductive organs.

hysterectomy
The surgical removal of the uterus. See also total hysterectomy.

ileostomy
A surgically created opening (stoma) in the abdomen to the outside of the body. It is 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.

laparoscopy
Surgery done through small cuts in the abdomen using a viewing instrument called a laparoscope.

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

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

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.

**lymph nodes**
Small, bean-shaped structures that collect and destroy bacteria and viruses. Also called lymph glands.

**lymphoedema**
Swelling caused by a build-up of lymph fluid. This happens when lymph vessels or nodes can’t drain properly because they have been removed or damaged.

**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). This can happen naturally, from treatment, or because the ovaries have been removed.

**metastasis (plural: metastases)**
Cancer that has spread from a primary cancer in another part of the body. Also called secondary cancer.

**oestrogen**
A 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 oestrogen and progesterone.

**ovulation**
The release of an egg during the menstrual cycle.

**palliative treatment**
Medical treatment for people with advanced cancer to help them manage pain and other physical and emotional 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 measured 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.

**peritoneum**
The lining of the abdomen.

**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.

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

**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 therapy**
Treatment that attacks specific particles (molecules) within cells that allow cancer to grow and spread.

**total hysterectomy**
The surgical removal of the uterus and cervix. See also hysterectomy.

**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. Markers can be found by blood tests or by testing tumour samples.

**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**
A hollow muscular organ in a woman’s lower abdomen in which a fertilised egg (ovum) grows and a foetus is nourished until birth. Also called the womb.

References
How you can help

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

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

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

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

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

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

To find out more about how you, your family and friends can help, please call your local Cancer Council.
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, you can contact us through the National Relay Service. www.relayservice.gov.au
Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council Queensland
cancerqld.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council NSW
cancercouncil.com.au

Cancer Council SA
cancersa.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Tasmania
cancerntas.org.au

Cancer Council Australia
cancer.org.au

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