Understanding Ovarian Cancer
A guide for women with cancer, their families and friends
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Note to reader
Always consult your doctor before beginning any health treatment. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your doctor’s or health professional’s advice. However, you may wish to discuss issues raised in this booklet with them. All care is taken to ensure that the information in this booklet is accurate at the time of publication.

Cancer Council New South Wales
Cancer Council is the leading cancer charity in NSW. It plays a unique and important role in the fight against cancer through undertaking high-quality research, advocating on cancer issues, providing information and services to the public and people with cancer, and raising funds for cancer programs. This booklet is funded through the generosity of the people of NSW. To make a donation to help defeat cancer, visit Cancer Council’s website at www.cancercouncil.com.au or phone 1300 780 113.

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Introduction

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

Many people feel understandably shocked and upset when told they have ovarian cancer. We hope this booklet will help you understand how the disease is diagnosed and treated. We also include information about support services.

We cannot advise you 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 questions you want to ask your doctors or other health carers.

You may like to pass this booklet to your family and friends for their information.

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.

How this booklet was developed

The information in this booklet was developed with help from medical experts and people who have been diagnosed with ovarian cancer. The booklet is based on clinical practice guidelines for ovarian cancer.
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What is cancer?

Cancer is a disease of the cells, which are the body’s basic building blocks. Our bodies constantly make new cells: to help us grow, to replace worn-out cells, or to heal damaged cells after an injury.

Normally, cells grow and multiply in an orderly way, but sometimes something goes wrong with this process and cells grow in an uncontrolled way. This uncontrolled growth may result in abnormal blood cells or may develop into a lump called a tumour.

A tumour can be benign (not cancer) or malignant (cancer). A benign tumour does not spread outside its normal boundary to other parts of the body. However, if a benign tumour continues to grow at the original site, it can cause problems by pressing on nearby organs.

A malignant tumour is made up of cancerous cells that grow
out of control and are able to spread to other parts of the body. When it first develops, a malignant tumour may not have invaded nearby tissue. This is known as a cancer in-situ (carcinoma in-situ) or localised cancer. As the tumour grows, it may invade surrounding tissue, becoming invasive cancer.

Cancers grow their own blood vessels in a process known as angiogenesis. This allows the cancer cells to get a direct supply of oxygen and other nutrients.

Sometimes cells move away from the original (primary) cancer site and spread to other organs and bones. When these cells reach a new site, they may continue to grow and form another tumour at that site. This 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 liver is still called ovarian cancer, even though the person may be experiencing symptoms caused by cancer cells in the liver area.
The ovaries

The ovaries are part of the female reproductive system.

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

Each ovary has an outer covering made up of a layer of cells called the epithelium. Inside are germ cells, which will eventually mature into eggs (ova).

In a woman of childbearing age, a mature 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 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 contain cells that release the female hormones oestrogen and progesterone. These cells are called sex-cord stromal cells.

As a woman gets older, the ovaries gradually produce less oestrogen and progesterone. At the same time, the production of eggs also decreases and the woman’s periods become irregular and eventually stop. This is known as menopause and usually happens between the ages of 45 and 55. After menopause, it is no longer possible to have a child by natural means.
Ovarian cancer – key questions

Q: What is ovarian cancer?
A: Ovarian cancer is a malignant tumour in one or both ovaries.

Q: What types are there?
A: There are two types of ovarian cancer.

- **Epithelial ovarian cancer:** Cancer that starts in the surface of the ovary (epithelium). This makes up 90% of all ovarian cancers. Types of epithelial ovarian cancer include serous, mucinous and endometriod cancers.

- **Non-epithelial cancers:** These types of cancer, which start in different parts of the ovary, are uncommon. Types include:
  - germ cell ovarian cancer – starts in the egg-producing cells, usually affecting women younger than 30
  - sex-cord stromal cancer – develops in the cells that release the female hormones.

Some younger women are diagnosed with a borderline tumour. Borderline tumours are not considered to be cancer as there is little risk they will spread. For this reason, borderline tumours are often said to have low malignant potential.

Q: How common is it?
A: Each year in NSW, there are about 450 new cases of ovarian cancer. It is the tenth most common cancer in women. The average age at diagnosis is 63.
Q: What are the causes?
A: The causes of ovarian cancer are unknown. However, the following factors increase the chance of developing ovarian cancer:

- **Age** – Ovarian cancer is most common in women over 50 and in women who have stopped menstruating (have been through menopause). The risk increases with age.

- **Child-bearing history** – Women who haven’t had children, or who were unable to have children, may be slightly more at risk.

- **Hormonal factors** – This includes early puberty or late menopause, or using oestrogen-only hormone replacement therapy (HRT).

Women who have taken the contraceptive pill for a number of years seem to have a lower risk. There is also limited evidence suggesting that breastfeeding may protect against ovarian cancer. The exact reasons why are uncertain. It could be that ovarian cancer is more likely to develop when the ovaries do not have a break from ovulation during a woman’s lifetime.

There is no proven link between ovarian cancer and a high-fat diet, using talcum powder around the genital area, or the mumps virus. Most women who have proven risk factors do not develop ovarian cancer.

**The importance of family history**

In about 5–10% of women diagnosed with ovarian cancer there may be an inherited faulty gene in their family. This fault increases the risk of developing the disease. There are two genetic conditions known to cause an increased risk of ovarian cancer: hereditary breast/ovarian cancer and Lynch syndrome. Lynch syndrome is also known as hereditary non-polyposis colorectal cancer (HNPCC).
You may want to talk to your doctor or get a referral to a family cancer clinic if you have one or more of the following risks:

- two or more people diagnosed with breast or ovarian cancer on the same side of the family (mother’s or father’s side)
- a family member who has had breast cancer before the age of 40
- a family member who has had breast cancer in both breasts
- a family member who has had breast and ovarian cancer
- Jewish ancestry
- a male relative who has been diagnosed with breast cancer.

**Q: What are the symptoms?**

**A:** Ovarian cancer is often a silent disease in its early stages, which means many women have no symptoms. If symptoms do appear, they are usually vague and may include:

- a swollen abdomen
- pressure, discomfort or pain in the abdomen
- heartburn, nausea and bloating
- changes in toilet habits (e.g. constipation, diarrhoea, frequent urination due to pressure)
- tiredness and loss of appetite
- unexplained weight loss or weight gain
- changes in your menstrual pattern or postmenopausal bleeding
- pain during sex.

Having these symptoms doesn’t mean you have ovarian cancer. Only tests can confirm the diagnosis.

“I was well but my tummy started to blow up, making me really uncomfortable. It was as if I was seven months pregnant! I knew I needed to see a doctor.”
Diagnosis

Most ovarian cancer tumours are present for some time before they are diagnosed. Sometimes ovarian cancer is found unexpectedly during an operation such as a hysterectomy.

Physical examination
The doctor will check for any masses or lumps by feeling your abdomen and doing a vaginal examination.

If there is a build-up of fluid in the abdomen, a fluid sample may be taken by a needle passed through the skin (paracentesis). The fluid is checked under a microscope for cancer cells.

Blood tests
Chemicals that are produced by cancer cells as proteins are found in the blood. They are called tumour markers.

The most common tumour marker for ovarian cancer is called CA125. The level of CA125 may be higher in women with ovarian cancer. However, CA125 can also be raised in women who have other common gynaecological conditions, such as endometriosis or fibroids.

Your doctor can explain more to you about tumour markers, or you can call the Helpline on 13 11 20 for more information.
Imaging and scans

Your doctor may use one of these scans to see if you have ovarian cancer, and if it has spread.

- **Abdominal ultrasound:** A hand-held device called a transducer is passed over your abdominal area. Echoes from soundwaves are turned into a picture by a computer.

- **Transvaginal ultrasound:** A transducer is inserted into your vagina. Some women find the procedure a little embarrassing and uncomfortable, but it should not feel painful. Discuss the procedure with your doctor and the person performing the ultrasound (sonographer) if you have any concerns.

- **CT scan:** The CT (computerised tomography) scan uses x-ray beams to take pictures of the inside of your body. You will be asked not to eat or drink anything before the scan, except for a liquid dye. The dye makes your organs appear white on the scans, so anything unusual can be seen more clearly. You will be asked to lie on a table while the scanner, which is large and round like a doughnut, moves around you.

- **MRI scan:** The MRI (magnetic resonance imaging) scan uses magnetism and radio waves to build up cross-section pictures of your body. You will need to lie in a narrow metal cylinder while the scan is done. Tell your doctor if you feel scared in confined spaces, as you may be able to take medicine to make you feel less anxious.

- **X-rays:** You may have chest and abdominal x-rays to locate the cancer. A bowel x-ray called a barium enema may also be done. In this procedure, a white chalky liquid is put into your bowel through your anus and rectum and x-rays are taken. The barium enema is not painful, but it can be uncomfortable.
Prognosis

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

For women with epithelial ovarian cancer, the outcome depends on the stage of the disease (see next page). Women diagnosed with stage I cancer have a good outlook and the cancer can usually be cured. Many women with advanced cancer may respond well to treatment, but the cancer often comes back at a later time.

Non-epithelial cancers can usually be treated successfully.

Borderline tumours have a good prognosis regardless of whether they are diagnosed early or late.

Assessing prognosis

Test results, the type of ovarian cancer you have, the rate and depth of tumour growth, how well you respond to treatment, and other factors such as age, fitness and your medical history are all important factors in assessing your prognosis.
Stages of ovarian cancer
The results of the blood tests and various scans can help the doctor determine how far the cancer has spread. This is called staging.

Staging the cancer helps your health care team decide what treatment is best for you.

A commonly used staging system is described below:

**Stage I** – Cancer is in one or both ovaries.

**Stage II** – Cancer is in one or both ovaries and has spread to other organs near the pelvis.

**Stage III** – Cancer is in one or both ovaries and has spread beyond the pelvis to the lining of the abdomen, the intestines or lymph nodes in the abdomen or pelvis.

**Stage IV** – Cancer has spread outside the abdomen, for example, to the liver, lungs or distant lymph nodes.

You may have an operation (an exploratory laparotomy – see page 16) so the doctor can accurately stage the cancer. The tissue will be examined under a microscope.

Which health professionals will I see?
Your GP (general practitioner) 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, a specialist in treating women with ovarian cancer. 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 multidisciplinary team will probably include:

- **medical oncologist** – prescribes and coordinates the course of chemotherapy
- **radiation oncologist** – prescribes and coordinates the course of radiotherapy
- **nurses** – help administer chemotherapy and provide care, information and support throughout your treatment
- **dietitian** – recommends an eating plan to follow while you are in treatment and recovery
- **social worker** – helps provide emotional support and practical assistance to patients and carers
- **psychologists and counsellors** – help you manage your feelings and cope with changes to your life as a result of cancer or its treatments
- **physiotherapist and/or occupational therapist** – help you resume normal activities
- **palliative care doctor** – provides support and symptom relief.
The treatment for ovarian cancer depends on what type of cancer you have, the stage of cancer, your general health and fitness, your doctors’ recommendations, and your wishes.

- **Epithelial ovarian cancer** is commonly treated with surgery, chemotherapy and/or radiotherapy. Borderline tumours are usually treated with surgery.

- **Non-epithelial ovarian cancer** is usually treated with surgery and/or chemotherapy.

### Surgery

Your doctor will discuss the most appropriate type of surgery with you.

The first treatment for ovarian cancer is usually an operation to look inside the abdomen. This is called a laparotomy. The surgeon will make a long cut from the bellybutton to the pubic bone.

If there is obvious spread of cancer, you will need an operation to remove as much of the cancer as possible. This is called surgical debulking. Surgical debulking allows chemotherapy treatment to be more effective.

Surgery may cause infertility. If having children is important to you, talk to your doctor before surgery. You may be able to store eggs before treatment.
You may have one or more of the following procedures:

- **total abdominal hysterectomy** – removal of the uterus and cervix
- **bilateral salpingo-oophorectomy** – removal of both ovaries and both Fallopian tubes
- **omentectomy** – removal of the fatty protective tissue (omentum) covering the abdominal organs
- **colectomy** – removal of all or part of the bowel and the rejoining of the two ends of the bowel or the creation of a new opening called a stoma (colostomy or ileostomy)
- **lymphadenectomy** – removal of the small bean-shaped organs that help filter toxins from the blood stream (lymph nodes).

The surgeon will also take samples of the tumour, the organs that are removed and fluid in the abdomen. Samples will be sent to a pathologist to determine the type of ovarian cancer and its stage. This information will help the doctor know the stage of the cancer and whether more treatment is needed.

**After the operation**

After surgery, you may have several tubes in place.

- A drip inserted into a vein in your arm (intravenous drip) will give you fluid, medications 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 suck out stomach fluid to prevent vomiting.

- You may have tubes in your abdomen to drain fluid from the operation site.

As you recover from the operation, the tubes will be removed gradually over 2–3 days. You will be in hospital for 5–7 days.
Some women also have inflatable leg casts to keep the blood in their legs circulating. Once you are mobile, these leg casts will be removed so you can get out of bed.

It is common to feel some pain after an operation, but this will be controlled with medication. Medication may be given by an intravenous drip or through an injection in the spine called an epidural. Some patients have a patient controlled analgesic system (PCA system). This is a machine that allows the patient to get a dose of pain relief medication by pressing a button.

Let your doctor or nurse know if you are in pain so they can adjust your medication. Don’t wait until the pain is severe.

**Taking care of yourself after surgery**

Most women feel better within six weeks, but it may take longer, depending on the type of surgery you had.

- **Rest:** Recovery time varies from woman to woman. Take things easy and do only what is comfortable. Cancer Council has relaxation and meditation CDs that you may like to listen to. Call the Helpline on 13 11 20 for free copies.

- **Sex:** Penetrative sexual intercourse should be avoided for about six weeks after the operation to give your wound time to heal.

  For more information, call the Helpline for a free copy of *Sexuality, Intimacy and Cancer*.

- **Driving:** Avoid driving for about four weeks after surgery.
Further treatment
A few days after the operation, your doctor should have all the test results and will discuss any further treatment options with you.

It can help to have a close friend or relative with you when you talk to your medical team. This person can listen or participate in the conversation.

Further treatment will depend on the type of cancer, the stage of the disease and the amount of any remaining cancer. Most women have chemotherapy treatment but radiotherapy may also be an option.

• Lifting and exercise: Heavy lifting should be avoided for at least six weeks. If you have a partner or children, ask them to do more around the house. Services are also available to help – see Seeking support, page 38).
Chemotherapy

Chemotherapy is the treatment of cancer with anti-cancer (cytotoxic) drugs.

Women with epithelial ovarian cancer that has spread outside the ovaries usually receive a combination of two chemotherapy drugs. Most women are prescribed a drug called carboplatin and another drug called paclitaxel. However, a single chemotherapy drug may be prescribed for frail or elderly women.

Chemotherapy is usually given through an intravenous drip. Your first treatment may be given while you are recovering from surgery, or a few days after you leave hospital.

About 6–8 treatments will be given every 3–4 weeks over about six months. You will probably be treated as a day patient, but some women need to stay in hospital overnight.

Blood tests will be taken before each treatment to ensure your body’s healthy cells have had time to recover.

During your chemotherapy you will have regular blood tests to check your tumour markers, such as CA125. The level should drop if treatment has worked.

You may also have heard about intraperitoneal chemotherapy. This is a type of chemotherapy that is delivered directly into the abdominal cavity through a tube. Intraperitoneal chemotherapy is not commonly used in Australia, but it may be offered to some women.

Women with stage I epithelial ovarian cancer and women with borderline tumours don’t usually have chemotherapy.
who participate in a clinical trial. Some side effects may be more severe such as nausea, a rash, and abdominal discomfort.

**Side effects**
The side effects of chemotherapy vary according to the drugs used.

- **Tiredness:** Your red blood cell level may drop, which can cause you to feel tired and breathless. Travelling to and from treatment can also be exhausting.

- **Nausea:** Some chemotherapy may make you feel sick or vomit. Anti-sickness drugs can prevent or reduce nausea and vomiting.

- **Temporary thinning or loss of hair:** Your hair will grow back when treatment is done.

- **Risk of infections:** Chemotherapy drugs lower the number of white blood cells that fight infection. Infections can be treated with antibiotics.

- **Joint and muscle pain:** Pain may occur in women treated with the chemotherapy drug called paclitaxel. These symptoms usually disappear after a few days.

- **Numbness or tingling in your hands and feet:** This can be a side effect of chemotherapy treatment. Let your doctor know if this happens to you.

These side effects are usually temporary and there are ways to prevent or reduce them. To learn more, call the Cancer Council Helpline on 13 11 20 for a free copy of *Understanding Chemotherapy.*
Radiotherapy uses x-rays to kill cancer cells or injure them so they cannot multiply. It is occasionally used to treat ovarian cancer, especially if the cancer is confined to the pelvic cavity.

You may receive radiotherapy to the whole abdomen (called whole abdominal radiotherapy or WART), or to one particular area of your abdomen.

You will lie on an examination table and a radiotherapy machine will be positioned above you. The radiation therapist will position you and the machine, then leave the room during treatment. You may be in the room for about 30 minutes, but treatment itself is painless and should only take a few minutes each time.

The number of radiotherapy treatments you have will depend on your situation. Most women have a treatment session daily, Monday to Friday for 3–4 weeks. Your doctor will tell you how often you will need to have treatment.

Side effects
The side effects of radiotherapy depend on the strength of the radiotherapy dose and how long treatment lasts. You may have:
• fatigue and tiredness
• diarrhoea
• cystitis (urinary tract infection)
• nausea or vomiting.

Some women who have a higher dose of radiotherapy have long-term side effects, like changes in their bowel habits.

For more information on radiotherapy and side effects, talk to your medical team or call the Helpline on 13 11 20 for a copy of Understanding Radiotherapy.
Palliative treatment

Palliative treatment helps to improve people's quality of life by alleviating symptoms of cancer without trying to cure the disease. It is particularly important for people with advanced cancer. However, it can be used at different stages of cancer.

Often treatment is concerned with pain relief and stopping the spread of cancer, but it can also involve the management of other physical and emotional symptoms. Treatment may include radiotherapy, chemotherapy or other medication.

For more information on palliative treatment or advanced cancer, call the Helpline for free copies of *Understanding Palliative Care* or *Living with Advanced Cancer*, or view them online at www.cancercouncil.com.au.
Managing side effects

Your recovery from treatment will take some time. As well as physical changes, you will have to cope with the emotional impact of treatment.

Treatment side effects can vary. Some women will experience a few side effects, others will have more. There are ways to reduce or manage the discomfort the side effects cause.

Tiredness

It is common to feel tired or fatigued during or after treatment.

Most women who have chemotherapy start treatment before they have had time to recover from their operation. Travelling to and from hospitals and clinics for treatment can be tiring.

If you start work again during the treatment, or if you have a home and family to care for, you will feel very tired. If you are on your own and have to do everything yourself, fatigue may be a problem.

Your tiredness may continue for a while after treatment has finished.

“I felt guilty since I couldn’t do much – it helped when I realised that this tiredness was normal.”

Some women find that it takes them up to 1–2 years to feel really well again. It may help to talk with your family and friends about how you feel and discuss ways in which they can help you. You may need to plan your day’s activities so that you get regular rest periods.
Early menopause
In women who are still having periods, an operation to remove the uterus or both ovaries (such as a hysterectomy or oophorectomy) will suddenly bring on menopause. This means that your periods will stop and it will no longer be possible to become pregnant.

The sudden onset of menopause can be both physically and emotionally difficult.

Menopausal symptoms include hot flushes, mood swings, trouble sleeping, tiredness and vaginal dryness. Symptoms may be more severe than a natural menopause because the body hasn’t had time to get used to the gradual loss of hormones.

Talk to your doctor about medication for relieving the symptoms of menopause. Cancer Council’s Sexuality, Intimacy and Cancer booklet has suggestions for dealing with vaginal dryness and fatigue.

Coping with infertility
Younger women and those who hope to have children may feel deeply upset after a hysterectomy.

For some women, having children is a long-held dream. You may feel devastated if you can’t have a child naturally. Even if you had not planned to have children or have finished having a family, the removal of your reproductive organs may make you feel less feminine.

These feelings are all understandable. Consider talking about how you feel with a counsellor or gynaecology oncology nurse, who can listen and provide support.
Bowel problems

After surgery, some women may have bowel problems such as diarrhoea, cramps or constipation. These can occur for some time after treatment. If you have had a colostomy or ileostomy, you will have a stoma bag, which will take some time to adjust to.

Try and avoid becoming constipated, as this will put more pressure on the bowel. Talk with your doctor, nurse or dietitian about ways to prevent constipation.

Surgery may sometimes cause the bowel to become blocked (bowel obstruction). However, this blockage can also occur because the cancer has come back. If you have symptoms such as feeling sick, vomiting, abdominal discomfort or pain you should see your doctor or specialist as soon as possible.

Often a bowel obstruction can be relieved with simple treatment in hospital. Occasionally, another operation may be needed to unblock the bowel.

Tips

- Prevent or manage constipation by eating more high-fibre foods, such as wholegrain bread and pasta, bran, fruit and vegetables.
- Drink plenty of fluids. This will help loosen the bowels if you are constipated and replace the fluids lost through diarrhoea. Warm and hot drinks work well.
- Eat small, frequent snacks instead of big meals.
- Read Cancer Council’s free booklet Food and Cancer, available in print or online at www.cancercouncil.com.au.
- If you have a stoma, talk to a stomal therapy nurse. The nurse can provide you with advice and written information.
**Fluid build-up**
Sometimes fluid can build up in the body.

*Ascites* is a collection of fluid in the abdomen. This can be uncomfortable because of swelling and pressure. If ascites becomes a problem, a procedure called a paracentesis can drain away the fluid and relieve discomfort. This may require an overnight stay in hospital.

*Pleural effusion* is fluid that collects in the lining of the lungs. This may make you feel short of breath and cause some pain. Draining the fluid using a procedure called a thoracentesis or pleural tap can provide relief.

**Lymphoedema**
Removing lymph glands in the pelvic area (lymphadenectomy) may cause one or both of your legs to swell because of a build-up of lymph fluid. This may make movement and some activities difficult.

**Tips**
- Gently exercise the swollen leg to move the fluid out to other lymph channels.
- Wear special bandages, stockings or a compression garment to help remove fluid. Talk to your health care team for more information.
- Avoid infection by caring for your skin and nails.
- Avoid injections in your legs.
- See a qualified manual lymphatic drainage therapist who does specialised massage to remove fluid build-up. See www.lymphoedema.org.au
- Ask if your hospital has a physiotherapist or nurse who can tell you how you can reduce your risk of lymphoedema or give you limb exercises to reduce it.
Making treatment decisions

Sometimes it is difficult to decide on the right treatment. You may feel that everything is happening so fast you don’t have time to think things through, but there is usually time to consider what sort of treatment you want.

Waiting for test results and for treatment to begin can be difficult. While some people feel overwhelmed by information, others want as much information as they can find. Making sure you understand enough about your illness, the treatment and its side effects will help you make your own decisions.

- If you are offered a choice of treatments, you need to weigh up their advantages and disadvantages. Consider how important any side effects are to you, especially those that affect your lifestyle.

- If you have a partner, you may want to talk about treatment options with them. You can also talk to friends and family.

- If only one type of treatment is recommended, ask your doctor to explain why other treatment choices have not been offered.

You have the right to accept or refuse any treatment.

Some people with more advanced cancer choose treatment, even if it only offers a small chance of cure. Others want to make sure the benefits of treatment outweigh any side effects so they have the best possible quality of life. Some people choose options that don’t try to cure the cancer but make them feel as well as possible.
Talking with doctors
When your doctor first tells you that you have cancer, it is very stressful and you may not remember much. You may want to see the doctor a few times before deciding on treatment.

If your doctor uses medical terms you don’t understand, it’s okay to ask for a simpler explanation. You can also check a word’s meaning in the glossary (see page 46).

Before you see the doctor, it may help to write down your questions. Taking notes or recording the discussion can also help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

A second opinion
Getting a second opinion from another specialist may be a valuable part of your decision-making process. It can confirm or clarify your doctor’s recommendations and reassure you that you have explored all of your options. Some people feel uncomfortable asking their doctor for a second opinion, but specialists are used to patients doing this.

Your doctor can refer you to another specialist and send them your initial results. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You may decide you would prefer to be treated by the doctor who provided the second opinion.
Taking part in a clinical trial

Your doctor may suggest you consider taking part in a clinical trial. Doctors conduct clinical trials to test new or modified treatments to see if they are better than current treatments.

If you are unsure about joining the trial, ask for a second opinion from an independent specialist.

If you decide to join a randomised clinical trial, you will be given either the best existing treatment or a promising new treatment. You will be chosen at random to receive one treatment or the other.

Being in a trial gives you important rights. You have the right to withdraw at any time; doing so will not jeopardise your treatment for cancer.

For more information about clinical trials – such as questions to ask your doctor and how to find a trial that may be suitable for you – call the Helpline on 13 11 20 for a free copy of *Understanding Clinical Trials*. 
Looking after yourself

Cancer can cause physical and emotional strain. Eating well, exercising and relaxing may help reduce stress and improve well-being. Addressing changes in your emotions and relationships early on is also very important.

Healthy eating
Eating nutritious food will help you keep as well as possible and cope with cancer and treatment side effects. Depending on your treatment, you may have special dietary needs. A dietitian can help you to plan the best meals for your situation – ones that you find tempting, easy to eat and nutritious.

The Cancer Council Helpline can send you information about nutrition, including the free booklet *Food and Cancer*.

Being active
You will probably find it helpful to stay active and to exercise regularly if you can. Physical activity – even if gentle or for a short duration – helps to improve circulation, reduce tiredness, decrease joint or muscle pain, and elevate mood. The amount and type of exercise you do will depend on what you are used to, how well you feel and what your doctor advises.

If you aren’t used to exercise or haven’t exercised for a while, make small changes to your daily activities. You could walk to the shops, take the stairs, or do some gardening. To do more vigorous exercise or weight-bearing exercise, ask your doctor what is best for you.
Complementary therapies

Complementary therapies may help you cope better with side effects such as pain. They may also increase your sense of control over what is happening to you, decrease your stress and anxiety, and improve your mood.

There are many types of complementary therapies, including acupuncture, massage, hypnotherapy, relaxation, meditation, yoga, herbal medicine and nutrition. While some cancer treatment centres offer complementary therapies as part of their services, you may have to go to a private practitioner. Ask what’s available at your hospital. Self-help CDs or DVDs can also guide you through some different techniques.

Let your doctor know about any complementary therapies you are using or thinking about trying. This is important, as some therapies may not be appropriate, depending on your conventional treatment. For example, some herbs and nutritional supplements may interact with your medication, resulting in harmful side effects. Massage and exercise therapies may also need to be modified.

Call the Helpline for a free copy of Cancer Council’s CD Relaxation for People with Cancer and the publications Understanding Complementary Therapies and Massage and Cancer: an introduction to the benefits of touch.

Alternative therapies are commonly defined as those used instead of conventional treatments. These therapies may be harmful if people with cancer delay or stop using conventional treatments in favour of them. Examples include high-dose vitamin supplements, coffee enemas and magnet therapy.
Strengthening your relationships

The strong emotions you experience as a result of cancer may affect your relationships. Your experiences may cause you to develop a new outlook on your values, priorities and life in general. Sharing those thoughts and feelings with your family, friends and work colleagues may strengthen your relationships.

If you feel uncomfortable talking about your feelings, take your time and approach others when you are ready. People usually appreciate insight into how you are feeling and guidance on providing support during and after treatment.

While you are giving yourself time to adjust to living with cancer, do the same for your friends and family. Everyone will react in a different way – by putting on a happy face, playing down your anxiety, or even ignoring you. They are also adjusting in their own way to changes. If someone’s behaviour upsets you, it will probably help to discuss how you both feel about the situation.

Sexuality, intimacy and cancer

Having cancer can affect your sexuality in both physical and emotional ways. The impact of these changes depends on many factors, such as your treatment and its side effects, the way you and your partner communicate, and your self-confidence. Knowing the potential challenges and addressing them will help you adjust to these changes.

Sexual intercourse may not always be possible, but closeness and communication are vital to a healthy relationship.

Call the Cancer Council Helpline on 13 11 20 for a free copy of the booklet Sexuality, Intimacy and Cancer.
Changing body image

Cancer treatment can change the way you feel about yourself (your self-esteem). You may feel less confident about who you are and what you can do. This is common whether your body has changed physically or not.

Give yourself time to adapt to any changes. Try to see yourself as a whole person (body, mind and personality) instead of focusing only on the parts of you that have changed.

For practical suggestions about weight changes and other physical changes, call the Helpline.

Look Good...Feel Better Program

This free program teaches techniques to help restore appearance and self-esteem during treatment. Call 1800 650 960 or visit www.lgfb.org.au.
Life after treatment

You may be surprised to find out that life after cancer treatment can present its own challenges. You will need to take some time to adjust to physical and emotional changes.

You may have mixed emotions. Beforehand, you may have been busy with appointments and focused on treatment, but afterwards you may feel anxious rather than secure. You might worry about every ache and pain and wonder if the cancer is coming back.

Some people say that after cancer they have changed priorities and see life with a new clarity. For example, you may decide to travel, spend more time with family, or do volunteer work.

Although you might feel pressure to return to normal life, it’s important to remember that your life may not return to how it was before cancer.

You might find it helpful to:
• take time to adjust to physical and emotional changes
• re-establish a new daily routine at your own pace
• maintain a healthy diet and lifestyle
• schedule regular checkups with your doctor
• share your concerns with family and friends and tell them how to support you
• call the Helpline on 13 11 20 to connect with other people who have had cancer, or to request a free copy of the booklet *Living Well After Cancer*.

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, talk to your doctor. You may be clinically depressed, and counselling or medication may help you.
Living Well After Cancer Program
Living Well After Cancer is a free community education program run by Cancer Council NSW and trained cancer survivors. It is held throughout NSW.

The program includes practical information and open discussion for people who are cancer survivors, their carers, family, friends and work colleagues.

Participants can:
• discuss changes, challenges and opportunities they may face after completing treatment
• learn how to connect with others
• share tips and ideas about living well after cancer.

Call 1300 200 558 or email livingwellaftercancer@nswcc.org.au for more information.

After treatment: follow-up
After your treatment, you will need regular checkups to confirm that the cancer hasn’t come back.

You may have scans or tests at your checkups, including physical examinations, blood tests, x-rays, ultrasounds and CT scans.

Checkups will be necessary on a regular basis even if you haven’t had any sign of cancer for some time. Your checkups will become less frequent if you have no further problems, and you may have fewer scans and tests at your follow-up appointments.

If you have any health problems between follow-up appointments, let your doctor know immediately.
If you are worried about the cancer coming back, ask your doctor about how often checkups will be needed. You can ask if there are any symptoms to look for.

**What if ovarian cancer returns?**

For some women, ovarian cancer does come back after treatment and a period of recovery. This is known as a relapse or 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 relapses with long intervals in between where they don't 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 given, the length of remission and the aims of the treatment.

If other types of treatment are an option, your doctor will discuss these with you.
When you are first diagnosed with cancer, and throughout the different stages of your treatment and recovery, it is normal to experience a range of emotions, such as fear, sadness, anxiety, anger and frustration. If sadness or anxiety is ongoing or severe, talk to your doctor.

It may help to talk about your feelings. Your partner, family members and friends can be a good source of support or you might prefer to talk to:
- members of your treatment team
- a counsellor, social worker or psychologist
- your religious or spiritual adviser
- a support group – see page 40
- the Cancer Council Helpline.

If you need assistance, such as help around the house, it may be hard to tell people what would be useful. Some people prefer to ask a family member or friend to coordinate offers of help.

You may find that while some people you know are supportive, others may not even know what to say to you. Cancer Council’s booklet *Emotions and Cancer* may help if this happens to you.

If you have children, the prospect of telling them that you have cancer can be frightening and unsettling. The booklet *Talking to Kids About Cancer* can help you prepare for this conversation.
Practical and financial help
A serious illness often causes practical and financial difficulties. This can add to the stress and anxiety you may already be feeling about having cancer and going through treatment.

Many services are available to help so you don’t have to face these difficulties alone:

- Financial assistance, through benefits and pensions, can help pay for prescription medicines and travel to medical appointments.
- Home nursing care is available through community nursing services or local palliative care services.
- Meals on Wheels, home care services, aids and appliances can make life easier.

To find out more, talk to the hospital social worker, occupational therapist or physiotherapist, or the Cancer Council Helpline. Cancer Council’s booklet Understanding Your Rights may also be useful.

Understanding Cancer program
If you want to learn more about cancer and ways to cope with it, you may find the Cancer Council’s Understanding Cancer program helpful. The program offers practical information and discussions about many issues people experience after diagnosis.

Topics covered include what cancer is, cancer symptoms and side effects, treatment, palliative care, diet, exercise and complementary therapies.

Understanding Cancer programs are held frequently at hospitals and community centres throughout NSW. Call the Helpline for more information.
Talk to someone who’s been there

Getting in touch with other people who have been through a similar experience can be beneficial. There are many ways to contact others for mutual support and to share information.

In these support settings, most people feel they can speak openly, share tips with others, and just be themselves. You will probably find that you feel comfortable talking about your diagnosis and treatment, your relationships with friends and family, and your hopes and fears about the future.

Ask your nurse or social worker to tell you about support groups in your area. Go to www.cancercouncil.com.au or call the Helpline to access the Cancer Services Directory and find out how you can connect with others.

Support services available for patients, carers and family members

- **Face-to-face support groups**, which are often held in community centres or hospitals
- **Online discussion forums** where people can connect with each other any time – see www.cancerconnections.com.au
- **Telephone support groups** for certain situations or types of cancer, which trained counsellors facilitate
- **Cancer Council Connect**, a program that matches you with a volunteer who has been through a similar cancer experience, and who understands how you’re feeling.
Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. Being a carer can be very stressful. 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 are open to carers as well as people with cancer. A support group can offer a valuable opportunity 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 organisations and groups that can provide you with information and support, such as Carers NSW. To contact Carers NSW, call 1800 242 636 or visit www.carersnsw.asn.au.

Call the Cancer Council Helpline to find out more about different services or to request a free copy of the booklet Caring for Someone with Cancer.
The Cancer Council Helpline is a telephone information service provided by Cancer Council NSW for people affected by cancer.

For the cost of a local call, you can talk about your concerns and needs confidentially with oncology health professionals. Helpline consultants can send you written information and put you in touch with appropriate services in your area. You can also request services in languages other than English.

You can call the Cancer Council Helpline, Monday to Friday, 9am to 5pm.

If you have difficulty communicating by phone, contact the National Relay Service, a Government initiative to assist people who are hearing and/or speech impaired (www.relayservice.com.au). This service will help you to communicate with a Cancer Council Helpline consultant.
The Internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of information.

**Australian**
- Cancer Council NSW ....................... www.cancercouncil.com.au
- Cancer Council Australia .................. www.cancer.org.au
- Cancer Institute NSW ...................... www.cancerinstitute.org.au
- Health Insite .................................. www.healthinsite.gov.au
- NSW Health ................................... www.health.nsw.gov.au
- Commonwealth Department
  of Health and Ageing ...................... www.health.gov.au
- Gynaecological
  Cancer Support ............................. www.gynaecancersupport.org.au
- Lymphoedema Association
  of Australia ................................. www.lymphoedema.org.au
- National Breast and Ovarian
  Cancer Centre .............................. www.nbocc.org.au
- Ovarian Cancer Australia ................. www.ovariancancer.net.au

**International**
- American Cancer Society ................ www.cancer.org
- Macmillan Cancer Support ............... www.macmillan.org.uk
- Ovarian Cancer National Alliance ...... www.ovariancancer.org
Following a cancer diagnosis, many people look for information about new types of treatment, the latest research findings, and stories about how other people have coped.

The Cancer Council Library has more than 3,000 resources in the collection, including books, CDs, DVDs, videos and a large range of medical journals.

You can visit the library at 153 Dowling Street, Woolloomooloo (Monday to Friday, 9am to 5pm), borrow by post or ask your local librarian to organise an inter-library loan. Contact the librarian on 13 11 20 or email library@nswcc.org.au.

**Related publications**

You might also find the following free Cancer Council publications relevant:

- *Emotions and Cancer*
- *Food and Cancer*
- *Understanding Chemotherapy*
- *Understanding Complementary Therapies*
- *Sexuality, Intimacy and Cancer*
- *Understanding Palliative Care*
- *Talking to Kids About Cancer*
- *Living Well After Cancer*.

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

- What type of ovarian cancer do I have?
- How extensive is my cancer?
- What treatment do you recommend and why?
- Are there other treatment choices for me? 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 much will treatment cost?
- Will I have a lot of pain with the treatment? What will be done about this?
- Will I still be able to have children?
- Are the latest tests and treatments for my type of cancer available in this hospital?
- Are there any clinical trials of new treatments?
- How frequently will I have checkups?
- Are there any complementary therapies that might help me?
You may come across new terms when reading this booklet or talking to health professionals. You can also check the meaning of other health-related words on Cancer Council’s website, www.cancercouncil.com.au.

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

**barium enema**
An examination of the bowel area. In this test, a barium-filled tube is inserted into the rectum and x-rays are taken.

**benign**
Not cancerous or malignant. Benign lumps are not able to spread to other parts of the body.

**bilateral salpingo-oophorectomy**
Surgical removal of both ovaries and Fallopian tubes.

**biopsy**
The removal of a small 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. This type of tumour tends to occur in young, premenopausal women.

**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 large bowel.

**bowel obstruction**
Blockage or clogging of the large bowel.

**CA125**
A protein found in the blood. This protein is often higher than normal in women with ovarian cancer. High levels may also occur in women with common gynaecological conditions such as endometriosis or fibroids.

**catheter**
A hollow, flexible tube through which fluids can be passed into the body or drained from it.

**cells**
The basic organisational unit of all living things. A human is made of millions of cells, which are adapted for different functions.
**chemotherapy**
The use of cytotoxic drugs to treat cancer by killing cancer cells or slowing their growth.

**colectomy**
A surgical procedure in which cancerous areas of the colon are cut out and the healthy parts of the colon are sewn back together.

**colostomy**
An operation in which the colon is attached to an opening in the abdomen.

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

**epidural**
Anaesthetic drugs are injected directly into the spinal column. Also known as epidural anaesthesia.

**epithelial ovarian cancer**
Cancer that starts in the epithelium of the ovary.

**epithelium**
The cells that make up the internal and external surfaces of the body, for example, skin, inside of the lungs or the ovaries.

**Fallopian tubes**
The two long, finger-like tubes that extend from the uterus to the ovaries. The Fallopian tubes carry fertilised eggs from the ovary to the uterus.

**germ cells**
Cells that produce eggs in females and sperm in males. Germ cell cancers can occur in the ovaries or testicles.

**gynaecological oncologist**
A gynaecologist who has completed specialist training in treating women diagnosed with cancer of the reproductive organs.

**hormones**
Chemical messengers in the body that transfer information between cells.

**hysterectomy**
The surgical removal of the uterus and cervix.

**ileostomy**
An operation that connects the small bowel to a surgically created opening (stoma) in the abdomen.
intraperitoneal chemotherapy
A technique of administering chemotherapy into the abdominal cavity via injection into the perineum.

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

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

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

lymphoedema
Swelling caused by a build-up of lymph fluid. This happens when lymph vessels or nodes don’t drain properly.

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

menopause
When a woman stops having periods (menstruating). This can happen naturally (usually around the age of 52 years), because of chemotherapy or hormone treatment, or because the ovaries have been removed.

metastasis
A cancer that has spread from another part of the body. Also known as secondary cancer.

non-epithelial ovarian cancer
A type of ovarian cancer that does not start in the lining of the ovary. Types include germ cell ovarian cancer and sex-cord stromal 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.

oophorectomy
The removal of one or both ovaries.

ovarian cancer
Cancer that starts in the ovaries. There are several different types of ovarian cancer such as epithelial and non-epithelial cancers.
ovary
A hormone-producing female reproductive organ that is located near the uterus. It also produces eggs (ova).

ovulation
The release of an egg during the menstrual cycle.

ovum/ova
The female egg/s produced by the ovary.

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.

patient-controlled analgesic system
An intravenous system that allows a person to administer a dose of pain relief by pressing a button. Also known as a PCA system.

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
An abnormal build-up of fluid in the pleural cavity (lung area).

pleural tap
See thoracentesis.

progesterone
A hormone produced by the ovaries that prepares the lining of the uterus (endometrium) for pregnancy.

prognosis
The likely outcome of a person’s disease.

radiotherapy
The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply.

sex-cord stromal cells
Ovary cells that release the female hormones.

thoracentesis
A procedure in which doctors insert a hollow needle between the ribs in order to drain excess fluid. Also called a pleural tap.

tissue
A collection of cells that make up a
part of the body.

tumour
A new or abnormal growth of tissue on or in the body. A tumour may be benign or malignant.

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. An ultrasound scan can be used to measure the size and position of a tumour.

uterus
The hollow muscular organ in which a fertilised egg (ovum) grows and a foetus is nourished until birth. Also known as the womb.
How you can help

At Cancer Council NSW we're dedicated to defeating cancer. As well as funding more cancer research than any other charity in the state, we advocate for the highest quality of care for cancer patients and their families, and create cancer-smart communities by empowering people with knowledge about cancer, its prevention and early detection. We also offer direct financial assistance for those people in hardship as a result of having cancer. These achievements would not be possible without community support, great and small.

Join a Cancer Council event: Join one of our community fundraising events like 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 donation, whether large or small, will make a meaningful contribution to our fight to defeat cancer.

Buy sun protection products from our website or retail stores: Every purchase you make helps you prevent cancer and contributes financially to our work.

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

Join a research study: Cancer Council does research to investigate the causes, management, outcomes and impacts of different cancer types. To register online visit www.cancercouncil.com.au/joinastudy.

To find out more about how you or your family and friends can help, please call 1300 780 113.
Regional Offices

Central and Southern Sydney Region
153 Dowling Street
Woolloomooloo
NSW 2011
(PO Box 572
Kings Cross NSW 1340)
Ph: (02) 9334 1900
Fax: (02) 9334 1739

Far North Coast Region
101-103 Main Street
Alstonville
NSW 2477
Ph: (02) 6627 0300
Fax: (02) 6628 8659

Hunter Region
22 Lambton Road
Broadmeadow
NSW 2292
Ph: (02) 4923 0700
Fax: (02) 4961 0955

Mid North Coast Region
121 High Street
Coffs Harbour
NSW 2450
Ph: (02) 6659 8400
Fax: (02) 6652 1530

North West Region
Shop 2
218 Peel Street
Tamworth
NSW 2340
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622-650 Terrigal Drive
Erina
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Ph: (02) 4336 4500
Fax: (02) 4367 5895

South West Region
1/37 Tompson Street
Wagga Wagga
NSW 2650
Ph: (02) 6937 2600
Fax: (02) 6921 3680

Southern Region
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Western Sydney Region
43 Hunter Street
Parramatta
NSW 2150
Ph: (02) 9354 2000
Fax: (02) 9687 1118
Call the Cancer Council Helpline for support and information on cancer and cancer-related issues. This is a free and confidential service. Our website also has many resources. Please visit www.cancercouncil.com.au.