



Ovarian Cancer

For women with cancer,
their family and friends



Ovarian cancer

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Interpreting service: Deaf or hearing or speech impaired

If you use text-based communication, call the Cancer Council Helpline (13 11 20) through the National Relay Service (NRS) 13 3677. If you can hear and still use your voice, but have a speech impairment, call the Cancer Council Helpline through NRS 1300 555 727.

Generous Victorians who fundraise to fight cancer make many Cancer Council services, including the publication of this booklet, possible. For information on how you can help, visit www.cancervic.org.au or call 1300 65 65 85.

Introduction

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

Many women feel understandably shocked and upset when they are told that they have ovarian cancer. This booklet aims to help you understand how ovarian cancer is diagnosed and treated. We also include information about support services you may use.

We cannot tell you what is the best treatment for you. You need to discuss this with your doctors. However, we hope this booklet will answer some of your questions and help you think about the questions you want to ask your doctors.

You may like to pass it on to your family and friends for their information.

The booklet does not need to be read from cover to cover, but can be read in sections according to your needs or interest. The words in **bold** are explained in the glossary.

Rarely, cancer develops in the fallopian tubes. These cancers are very similar to epithelial ovarian cancer and are treated in much the same way.

★ Are you reading this for someone who does not understand English? Tell them about the Multilingual Cancer Information Line. See the inside back cover for details.

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What is cancer?

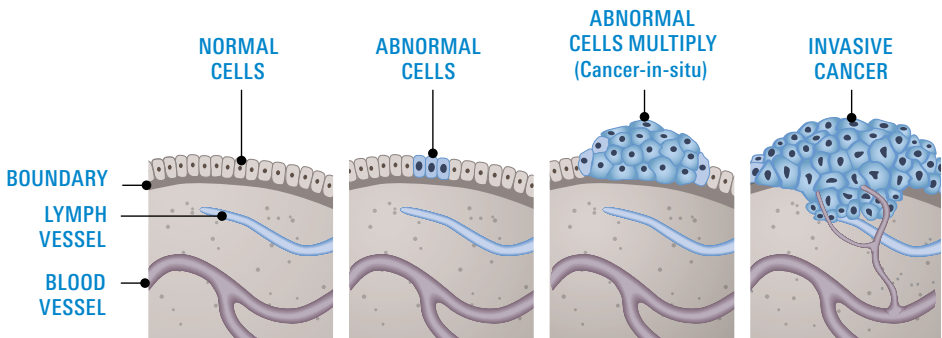
Cancer is a disease of the body's cells. Our bodies are always making new **cells**: so we can grow, to replace worn-out cells, or to heal damaged cells after an injury. This process is controlled by certain **genes**. All cancers are caused by changes to these genes. Changes usually happen during our lifetime, although a small number of people inherit such a change from a parent.

Normally, cells grow and multiply in an orderly way. However, changed genes can cause them to behave abnormally. They may grow into a lump. These lumps can be **benign** (not cancerous) or **malignant** (cancerous).

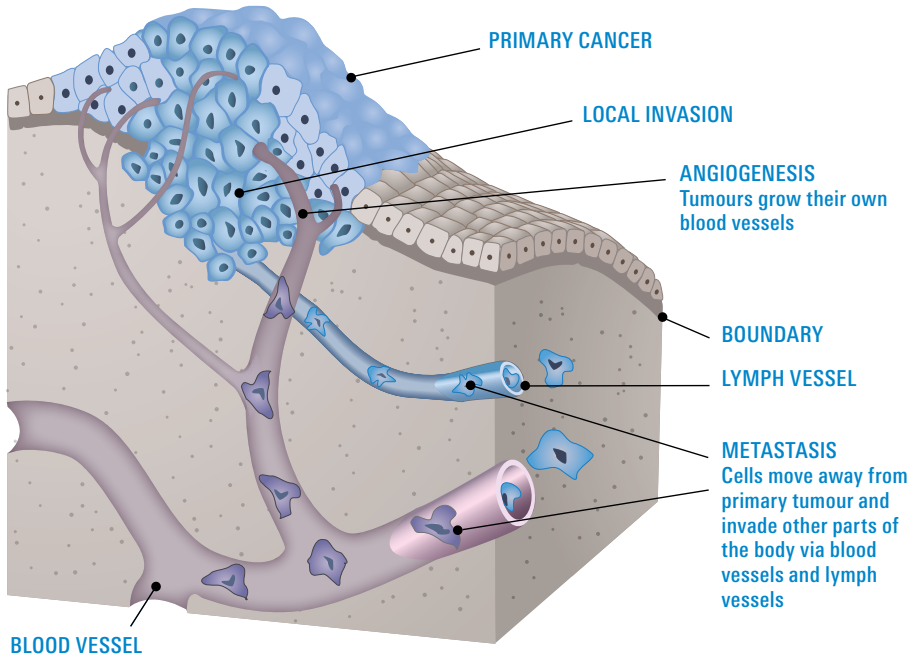
Benign lumps do not spread to other parts of the body.

A malignant lump (more commonly called a malignant tumour) is made up of cancer cells. When it first develops, this malignant tumour may be confined to its original site. If these cells are not treated they may spread into surrounding **tissue** and to other parts of the body.

The beginnings of cancer



How cancer spreads



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**.

For a cancer to grow bigger than the head of a pin, it must grow its own blood vessels. This is called angiogenesis.

The ovaries

The ovaries are part of the female reproductive system. They contain the eggs (ova), which can make a new human life when fertilised. In women of childbearing age, a mature egg is released from one of the ovaries each month (ovulation) and travels down the **fallopian tubes** to the **uterus** (womb).

The ovaries are oval-shaped organs, each about 3 cm long and 1 cm thick. They are found inside the pelvic cavity, one on each side of the uterus, and are very close to the end of the fallopian tubes.

Each ovary is covered by a layer of cells called **epithelium**. Inside are **germ cells** that eventually mature into eggs. The eggs travel to the outside of the ovary to be released into the fallopian tubes. If the egg is not fertilised by sperm, it passes out of the uterus with the monthly period (menstruation).

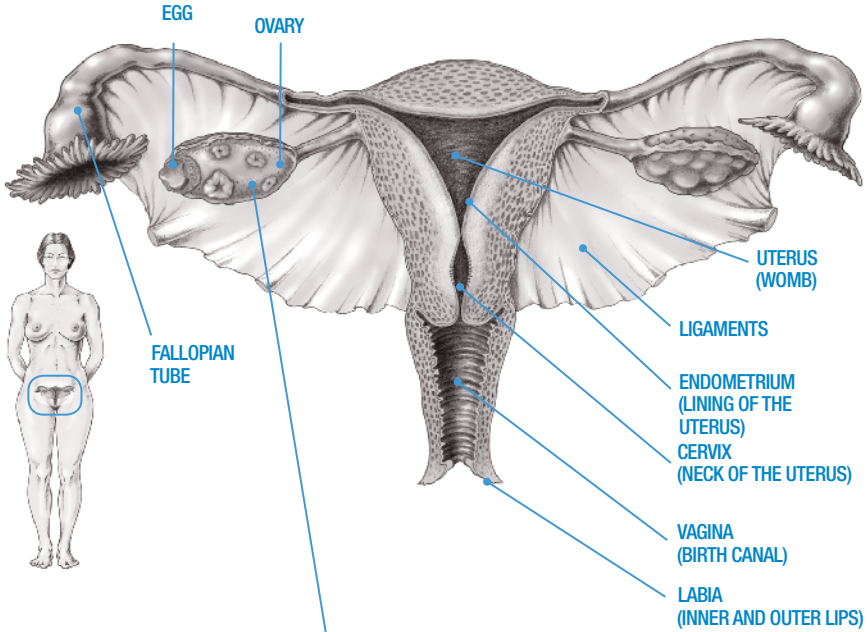
The ovaries also contain cells that release the hormones **oestrogen** and **progesterone**. These cells are called sex-cord stromal cells.

As women get older, the ovaries gradually produce less oestrogen and progesterone. The production of eggs also decreases and a woman's periods become irregular and eventually stop. This is known as **menopause**. It usually happens between the ages of 45 and 55. After menopause it is no longer possible to have a child.

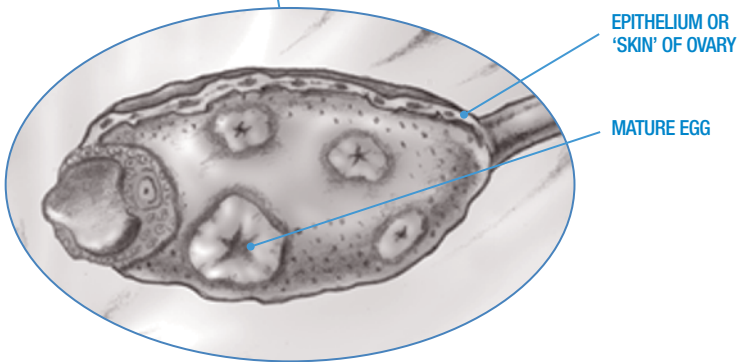
Ovarian cancer

Ovarian cancer is a **malignant** tumour in one or both ovaries. There are four main types of ovarian cancer, named after the part of the ovary that is affected. Knowing which type of cancer you have helps your doctor advise you on which treatment is best for you.

The female reproductive system



The ovary



Epithelial ovarian cancer

This type of ovarian cancer arises in the **epithelium**: the cells covering the ovary. It is the most common type of ovarian cancer. Eight out of 10 ovarian cancers are epithelial.

Germ cell and sex-cord stromal cell ovarian cancers

These two types of ovarian cancer are very uncommon.

Germ cell cancers arise in the cells that mature into eggs, and usually only affect women under the age of 30.

Sex-cord stromal cell cancers arise in the cells which release the female hormones. These cancers can occur at any age.

Germ cell and sex-cord stromal cell ovarian cancers usually respond very well to treatment and are often curable. If these cancers only affect one ovary, it may still be possible for younger women to have children after treatment.

Borderline tumours

Borderline tumours are epithelial tumours that are not as aggressive as other forms of ovarian cancer. Sometimes the words 'low malignant potential' are used to describe borderline tumours.

The **prognosis** for women with borderline tumours is generally very good, whether the disease is diagnosed early or late.

How common is ovarian cancer?

In Victoria around 360 women are diagnosed with ovarian cancer each year. About nine out of 10 ovarian cancers occur in women over the age of 40. Like most cancers, the risk of ovarian cancer increases with age.

Causes of ovarian cancer

The causes of most ovarian cancers are not known. However, some factors seem to put women at a higher risk of ovarian cancer. These are described below.

- Ovarian cancer is more common in Caucasian (white) women who live in western countries with a high standard of living.
- Women who have no or few pregnancies appear to be more at risk of ovarian cancer. Women who have taken the contraceptive pill for a number of years seem to be at less risk. The exact reason is uncertain. It could be that ovarian cancer is more likely to develop when the ovaries do not have a 'rest' from **ovulation** (release of eggs) during a woman's lifetime.
- Some types of ovarian cancer may be linked with a family history of cancers of the ovary, bowel, breast and lining of the uterus. A small number of ovarian cancers (approximately 5–10%) are caused by inheriting a damaged **gene** from a parent. If there are other people in your family with ovarian, breast, bowel or uterine cancer you should discuss this with your doctor.

Many women with ovarian cancer do not have these risk factors. It is also worth noting that many women who do have the risk factors do not develop ovarian cancer.

Diagnosis



The early symptoms of ovarian cancer are vague and can include discomfort in the abdomen or a bloated feeling or pressure. There may be a change in bowel habits and flatulence (wind). Indigestion can also occur and sometimes problems with the kidneys or bladder. Some women have abnormal vaginal bleeding. Occasionally pain is the first sign of ovarian cancer.

Symptoms such as these can be due to other things, so ovarian cancer is not always suspected. Sometimes ovarian cancer is found unexpectedly, for example during a scan for other reasons.

'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.'

As the cancer grows, your **abdomen** can become bigger. This is due to the cancer or a build-up of fluid called **ascites**, which is caused by the cancer. Women may also lose weight in spite of having a bigger abdomen.

There is no effective way to detect ovarian cancer early. The Pap test is very important for finding cancer of the **cervix** early, but it does not detect ovarian cancer.

Many women feel angry or upset that their cancer was not found earlier. You may even feel guilty that you did not go to a doctor sooner. It is quite normal to have these feelings. It may help you to talk about them with your doctor or nurse.

Researchers are looking for ways to find ovarian cancer early.

'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.'

Doctors and other health professionals you may see

Your doctor will refer you for tests to see if you have cancer. If the tests show you have cancer or may have cancer, your doctor will refer you to a specialist, who will examine you and may ask you to have more tests.

If you have cancer, one or more specialists will advise you about treatment options.

You should expect to be cared for by a team of health professionals from the relevant major fields (see following list). Ideally, all your tests and treatment will be available at your hospital; however, this may not be possible. Health professionals who care for people with ovarian cancer include:

- **gynaecological oncologists**, who diagnose and treat women with ovarian cancer
- medical oncologists, who specialise in using **chemotherapy** to treat cancer
- radiation oncologists, who specialise in using **radiotherapy** to treat cancer
- surgeons, who are responsible for some biopsies and other surgical procedures

- dietitians, who will recommend the best diets to follow during and after treatment
- nurses and general practitioners, who will help you through all stages of your cancer
- social workers, psychologists, physiotherapists and occupational therapists, who will advise you on support services and help you to get back to normal activities.

How ovarian cancer is diagnosed

If ovarian cancer is suspected or has been diagnosed, you should be referred to a doctor who specialises in treating women with ovarian cancer, who is known as a **gynaecological oncologist**. Your specialist will arrange for you to have some tests and examinations. These tests help the doctor decide whether your symptoms are due to ovarian cancer or to other causes.

Physical examination

This will include an internal **pelvic** examination, where the doctor checks for a mass or lump in the lower **abdomen**.

Blood tests

Your blood may be tested for **tumour markers** (for example, **CA 125**). These are proteins that are often higher than normal in women with ovarian cancer, because it is sometimes produced by ovarian cancer cells.

Testing blood for tumour markers is one way to help confirm a **diagnosis** of cancer in a woman with symptoms of ovarian cancer. These tests can be used later to check your progress.

Other blood tests may be done to help with diagnosis and check the effects of treatment.

Colonoscopy

You may have a colonoscopy of your bowel to make sure that your symptoms are not due to a bowel problem. The doctor will look at the large bowel using a thin flexible tube with a small camera and light at the end.

Computerised tomography (CT) scan

A CT scan is a type of x-ray. It gives a cross-sectional picture of the organs and other structures (including any **tumours**) in your body.

CT scans are usually done at a hospital or a radiology clinic. It takes about 30 to 40 minutes to complete this painless test.

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 that are taken, so anything unusual will show more clearly.

You will lie on a table while the CT scanner, which is large and round like a doughnut, moves around you. Most people are able to go home as soon as their scan is over. There is a small possibility of the injected dye causing an allergic reaction. You should tell your doctor if you are allergic to iodine or to contrast dyes, or if you are diabetic or have abnormal kidney function.

Magnetic resonance imaging (MRI)

This test is like a CT scan, but it uses magnetic fields instead of x-rays to build up pictures of the organs in your pelvic area, including your ovaries and other organs nearby.

MRI is painless, and the magnetism is harmless. You will lie still inside a large metal tube, which is open at both ends. The tube makes some people feel claustrophobic (afraid of being in a small space). You can usually take someone into the room with you to keep you company.

A probe may be placed in your vagina to get a better view of the ovaries. The test may take up to an hour. The machinery can be quite noisy.

If you have a metal device like a pacemaker or joint replacement you should not have an MRI. This test will help your doctor decide whether the cancer has spread beyond the ovaries. This will help you both decide which treatment is best for you.

Ultrasound scan

Ultrasound scans are very important in the **diagnosis** of ovarian cancer.

They are done in two ways. In an abdominal scan, the ultrasound specialist passes a hand-held device called a transducer over your **pelvic** area. This is used to build up pictures of your organs. The pictures can be seen on a screen. You may also have a trans-vaginal ultrasound, where the transducer is inserted into your vagina. This is because the ovaries sometimes cannot be imaged by the abdominal ultrasound. Some women find the procedure a little embarrassing and uncomfortable, although it is not painful. Discuss the procedure with your doctor and ultrasound specialist if you have any concerns.

Positron emission tomography (PET) scan

Like other scans, PET scans can be used to look for abnormalities in **tissues**, particularly whether there might be cancer. It can give valuable extra information to the CT or MRI scans. You will be injected with a glucose solution containing a very small amount of radioactive material. You will lie on a table, which moves through a large, ring-shaped scanner. The scanner can 'see' the radioactive material, which shows where the glucose is being used in the body. Cancer cells show up as areas where glucose is being used by actively growing cells.

This test can take up to two to three hours.

Unfortunately, none of these tests can definitely diagnose ovarian cancer. The only way this can be done is with an operation. This means that ovarian cancer is usually diagnosed and treated at the same time.

You need to make sure that you understand enough about your illness and the operation before you have surgery.

Treatment



Treatment for ovarian cancer usually involves surgery and chemotherapy. Sometimes, it includes **radiotherapy**.

Surgery

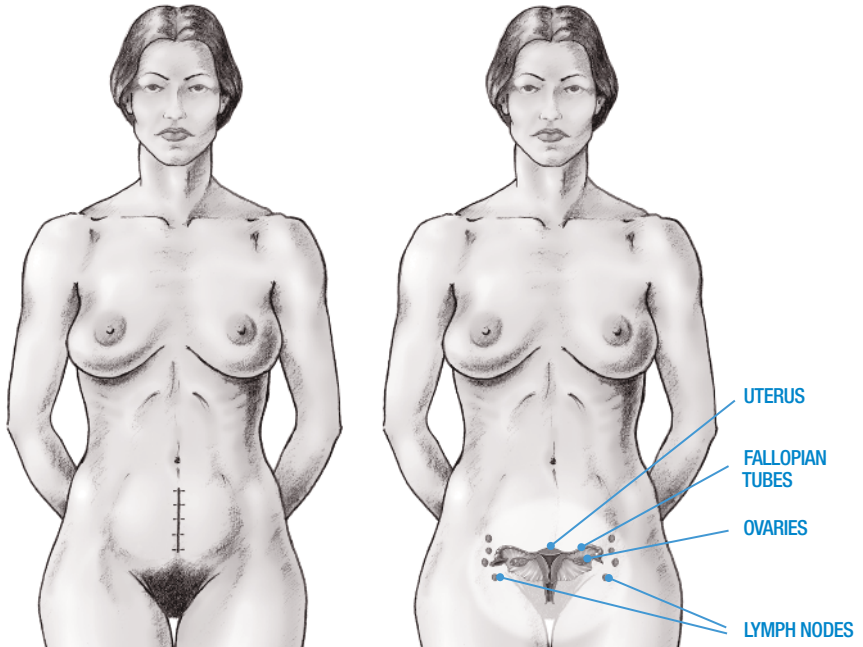
The first treatment for ovarian cancer is usually an operation called a **laparotomy**. In this operation a cut is made in your **abdomen**. This allows your doctor to find and remove as much cancer as possible.

In many cases, your doctor will do a **biopsy** of the tumour at the beginning of the operation to make sure it is a cancer. This is called a 'frozen section'. If cancer is confirmed, the operation will continue. The operation usually removes the **ovaries** and **fallopian tubes**, the **uterus**, the **omentum** and some of the **lymph nodes** in the area. The appendix may also be removed. Sometimes part of the bowel or even the bladder needs to be removed.

It may sound as if a lot of your body parts or organs are removed in the operation. However, these organs are quite small compared with everything else in your abdomen and pelvis and their removal will not leave a space.

Some women may not need extensive surgery. For instance, a young woman with an early epithelial ovarian cancer, germ cell cancer or

borderline tumour may not need to have her uterus and both ovaries removed. In this case it may still be possible for her to have children.



In a laparotomy a long incision or cut is made either vertically or horizontally on the lower abdomen (left). The affected organs are removed (right).

‘Staging’ the disease

After the operation, samples of some of the organs that have been removed are sent to a laboratory for examination. The results, combined with some of your diagnosis test results, provide information about the type and extent of your cancer. This enables the doctors to ‘stage’ the disease so they can work out the best treatment for you. If the ovarian cancer you have is confined to the ovaries or very close to the ovaries, it may be called stage 1 or 2. If it has spread to other organs it may be

stage 3 or 4. Knowing the stage of the disease helps your doctor discuss treatment choices with you.

After the operation

When you wake up from the operation, you will have several tubes in place. An intravenous drip will give you fluid as well as medication. You may have one or two tubes in your **abdomen** to drain away fluid from the operation site. You will also have a **catheter** in your bladder to drain away urine. As you recover after the operation, these tubes will be removed, usually within three to five days.

As with all major operations, you will feel some discomfort or pain. You will have pain relievers to control this. They may be given through an intravenous drip or through an epidural tube into your spine. This epidural pain relief is similar to that given to women during childbirth. It is best to let your nurse know when you are starting to feel uncomfortable: don't wait until the pain becomes severe.

'Initially I was very upset about my scars. I've got more used to them now.'

This operation is a major one and you may be in hospital for about one week. Before you go home, your doctor will have the results of your biopsies and will discuss further treatment with you. This will depend on the type of cancer, the extent of disease and the amount of any remaining cancer.

Further treatment, usually **chemotherapy**, is almost always needed for ovarian cancer.

Chemotherapy

Chemotherapy is the treatment of cancer using anti-cancer drugs. The aim is to destroy cancer cells while causing the least possible damage to normal cells. The drugs destroy cancer cells by stopping them from growing and reproducing themselves.

Chemotherapy works best when the cancer is small and the cancer cells are actively growing. With ovarian cancer, even though most of the cancer may have been removed at the time of the operation, there may be some cancer cells left. For this reason, chemotherapy works best if it is started soon after the operation.

You will probably have chemotherapy through a vein. You will have a number of treatments, usually six, every three to four weeks over several months. It is usually a day procedure. Blood tests before each treatment will check that your body's normal cells have had time to recover. The standard chemotherapy is a combination of drugs.

During your chemotherapy you may have other blood tests to see if the treatment is working. For example, the doctor may check for the CA 125 tumour marker.

If your cancer does not respond to one type of chemotherapy, or if your disease comes back, other drugs can be tried.

Side effects of chemotherapy

The side effects of chemotherapy differ according to the drugs used. They may include feeling off-colour and tired, and some temporary thinning or loss of hair. Your hair will grow back when treatment is completed.

Many women fear feeling sick (nausea) while having **chemotherapy**. Nausea can be controlled with a variety of anti-nausea medications. Tell your doctor if nausea is troubling you, so they can prescribe treatment.

*'I tried two wigs but they weren't for me so I wore scarves.
I was afraid of what other people might think but they
accepted me for who I am, not what I look like.'*

Some women become constipated while on chemotherapy. Ask your doctor if this is likely to happen with your treatment. Beginning laxatives early in the treatment can help. Diarrhoea is another possible side effect. This can be treated. You may be more at risk of infections.

These side effects are usually temporary and measures can be taken to either prevent or reduce them.

If you are treated with paclitaxel, you may find that you have joint and muscle pain, rather like flu symptoms, for a few days after treatment. Simple pain relievers like paracetamol can help, and the symptoms usually disappear after a few days. You may also get numbness or tingling in your hands and feet after several treatments. Let your doctor know if this happens to you.

★ **The Cancer Council's booklet *Coping with Chemotherapy* discusses ways of managing side effects.**

Visit www.cancervic.org.au or telephone 13 11 20 for a copy.

Women who have chemotherapy are welcome to take part in a Look Good, Feel Better workshop. These workshops provide cosmetic tips and other useful information. Contact your hospital or the Cancer Council Helpline for information.

Further chemotherapy

You may need more chemotherapy if your cancer does not respond completely to your initial treatment. It may also be needed if your disease comes back some time in the future. The drugs you have will depend on what drugs you have previously had, as well as the aims of the treatment.

Radiotherapy

Radiotherapy (treatment using radiation) is occasionally used for women with ovarian cancer, especially if it is confined to the pelvic cavity. If radiotherapy is advised, your doctor will discuss it with you.

★ **The Cancer Council's booklet *Coping with Radiotherapy* provides more information. Visit www.cancervic.org.au or**

telephone 13 11 20 for a copy.

Complementary and alternative medicines

It's common for people with cancer to seek out complementary and alternative treatments. Many people feel that it gives them a greater sense of control over their illness, that it's 'natural' and low-risk, or that they just want to try everything that seems promising.

Complementary therapies include massage, meditation and other relaxation methods which are used along with medical treatments. Alternative therapies are unproven remedies, including some herbal and dietary remedies, which are used instead of medical treatment. Some of these have been tested scientifically and found to be not effective or even to be harmful.

Some complementary therapies are useful in helping people to cope with the challenges of having cancer and cancer treatment. However, some alternative therapies are harmful, especially if:

- you use them instead of medical treatment
- you use herbs or other remedies that make your medical treatment less effective
- you spend a lot of time and money on alternative remedies that simply don't work.

Be aware that a lot of unproven remedies are advertised on the Internet and elsewhere without any control or regulation. Before choosing an alternative remedy, discuss it with your doctor or a cancer nurse at the Cancer Council Helpline. Visit the Cancer Council website www.cancerciv.org.au or the US National Center for Complementary and Alternative Medicines nccam.nih.gov. Quackwatch at www.quackwatch.com is also a reliable website.

*** The Cancer Council has a booklet *Complementary and Alternative Cancer Therapies*. Visit www.cancerciv.org.au or telephone 13 11 20 for a copy.**

Prognosis

The **prognosis** for women with the less common types of ovarian cancer (for example, borderline tumours or germ cell tumours) is usually very good. For women with the more common epithelial ovarian cancer, it is not so easy to predict the outcome.

Epithelial ovarian cancer can sometimes be cured, especially for those diagnosed at an early stage. Even **advanced** epithelial cancers usually respond very well to initial treatment.

‘People often say “Be positive”. Sometimes I just can’t be. When I’m low I think that I will scream if one more well-meaning person says it to me. I just take each day as it comes.’

There is more chance that the cancer will come back (recur) if it was advanced to begin with. If the cancer does come back, although it may not be curable, further treatment (usually with **chemotherapy**) can sometimes shrink the cancer and help you maintain a good quality of life.

A diagnosis of cancer can make your future seem very uncertain: it may help to think of it as a chronic illness. This means that even if your cancer cannot be cured it can still be treated. You can then return to a near-normal life for periods of time.

If you would like information about your own prognosis, speak to your specialist, who is familiar with your medical history.

If any repeat of your symptoms occurs, consult your specialist, as you may need more treatment.

When cancer can’t be cured

If your cancer has spread and it is not possible to cure it by surgery, your doctor may still recommend treatment. In this case, treatment may help relieve any symptoms, can make you feel better and may allow you to live longer.

Whether or not you choose to have anti-cancer treatment, symptoms can still be controlled. For example, if you have pain, there are effective treatments for this.

General practitioners, specialists and palliative care teams in hospitals all play important roles in helping people with cancer. For further information, contact the Cancer Council Helpline on 13 11 20 or Palliative Care Victoria on (03) 9662 9644.

*** The Cancer Council has a booklet for people with cancer and a booklet for carers of people with advanced cancer. Visit www.cancervic.org.au or telephone 13 11 20.**

Making decisions about treatment



Sometimes it is hard to decide which is the right treatment for you. You may feel that everything is happening too fast, that you don't have time to think things through.

While some women feel they have too much information, others may feel that they don't have enough. You need to make sure that you understand enough about your illness, the possible treatment and side effects to make your own decisions.

For some women with ovarian cancer, treatment will result in a cure. However, treatment often means that women can no longer have children. This may be a blow for many women, even if they already have a family. For other women who have not yet had children, it can be devastating. If fertility is really important for you, talk with your doctor about what other choices are available. This will depend on the type of ovarian cancer you have.

'Everything moved so fast: I was so shocked I felt that I was in a whirl. It was only really after the operation and my first chemotherapy that I began to really absorb everything that I had been told.'

For women with **advanced** ovarian cancer, treatment may be aimed at controlling symptoms rather than curing the cancer. Sometimes, the best way to control the symptoms is to treat the cancer – which may carry a small chance of a cure. Some women in this situation want all possible treatments, while others want to make sure that the possible benefits of treatment will outweigh the possible side effects. Still others will choose the option they consider offers them the best quality of life.

Talking with doctors

If it is suspected that you have ovarian cancer, you may find that things move very rapidly. This makes it very hard for you to make your decisions. It is also very difficult to take everything in, and you may need to ask the same questions more than once. You may find it helpful to talk not only with your doctor(s), but also with the nurses who will be caring for you during your treatment. You have the right to find out what a suggested treatment means for you and the right to accept or refuse it.

*** Before you see the doctor, it may help to write down your questions. The list of questions at the end of this booklet may help you. The cancer nurses on the Cancer Council Helpline can also help you tailor questions for your doctor to suit your individual needs. Call 13 11 20. Taking notes during the session 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. Some people find it is helpful to tape record the discussion, but ask your doctor first.**

Talking with others

Once you have discussed your treatment options with your doctor, you may want to talk them over with your partner, family or friends,

nurses, the hospital social worker, or your own spiritual or religious adviser. Talking it over can help to sort out what course of action is right for you. You may also like to speak to a woman who has been through a similar experience. See page 37 for more information.

You may be interested in looking for information about ovarian cancer on the Internet. While there are some very good websites, you need to be aware that some websites provide wrong or biased information. We recommend that you begin with the Cancer Council's site (www.cancervic.org.au) and use our links to find other good cancer websites.

I talked with the nurses on the ward – they went through things again and again with me – that helped a lot.

A second opinion

You may want to ask for a second opinion from another **gynaecological oncologist**. This is okay and can help you make your decision. Your specialist or local doctor can refer you to another specialist and you can ask for copies of your results to be sent to the second-opinion doctor. You can still ask for a second opinion even if you have already started treatment or still want to be treated by your first doctor.

Taking part in a clinical trial

Cancer Council Victoria supports participation in clinical trials. They are the most accurate way to determine the effectiveness of promising new treatments or new ways of combining cancer treatments. Always discuss treatment options with your doctor.

If your doctor suggests taking part in a clinical trial, make sure that you fully understand the reasons for the trial and what it means for you. Before deciding whether or not to join the trial, you may wish to ask your doctor:

- What is the standard (best available) treatment for my cancer if I don't go in the trial?
- Which treatments are being tested and why?
- Which tests are involved?
- What are the possible risks or side effects?
- How long will the trial last?
- Will I need to go into hospital for treatment?
- What will I do if any problems occur while I am in the trial?

If you decide to join a randomised clinical trial, you will have either the best existing treatment or a promising new treatment. You will be allocated at random to receive one treatment or the other. In clinical trials, people's health and progress are carefully monitored.

If you do join a clinical trial, you have the right to withdraw at any time. Doing so will not affect your treatment for cancer.

It is always your decision to take part in a clinical trial. If you do not want to take part, your doctor will discuss the best current treatment choices with you.

The Victorian Cooperative Oncology Group and Clinical Trials Office have developed a clinical trial database to make it easier for people affected by cancer and health professionals to find suitable clinical trials. This database was funded by the Victorian Cancer Agency. Visit www.cancervic.org.au/trials for more about clinical trials for ovarian cancer.

Recovery and follow-up care

Recovering from treatment is different for each woman. It depends on the type and stage of ovarian cancer you have and also the amount of treatment you have needed.

You will need to have regular check-ups with your specialist. These may include blood tests and physical examinations. Talk with your doctor about how often these may be.

I'm very independent so I tried to do as much as I could myself. But I was so tired I had to ask for help.'

It may take some time for you to recover from the various types of treatment. You will find that there are physical changes as well as many emotional changes to cope with. It is important that you, your partner (if you have one) and family are prepared for this. You may also need to talk with your employer about how the treatment may affect your work. If you would like some help to prepare for this task, speak to a cancer nurse on the Cancer Council Helpline.

Life after treatment

Many people are surprised to discover that life after treatment presents its own challenges.

During treatment, 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. Regular check-ups and talking to your doctor about what to expect if the cancer comes back may reassure you.

Some people feel pressure from their family and friends to get back to their 'normal life.' Everyone will eventually re-establish a daily routine, but it will be at their own pace and may be different from how things were in the past. Some people call this a 'new normal'.

Give yourself time to adjust to physical and emotional changes. You may not be fit enough to do your usual activities around the house. If you're returning to work, ease back into it slowly, rather than rushing back the week after leaving hospital.

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

Talking to someone who has had ovarian cancer may help you deal with the changes in your life. Call 13 11 20 and ask to speak to a Cancer Connect volunteer.

*** The Cancer Council has a booklet about life after cancer for people who have finished treatment.**

Visit www.cancervic.org.au or call 13 11 20 for a copy.

Research into ovarian cancer

Research for ovarian cancer is ongoing. Some recent clinical trials may involve risk reduction, targeted therapy, gene therapy and immunotherapy. These may not be approved or available as standard treatments. Always discuss diagnostic and treatment options with your doctor. For more information about clinical trials research in Victoria visit www.cancervic.org.au/trials

Coping with side effects



It may take some time to recover from treatment. You will find that there are physical and emotional changes. This section discusses ways to cope with these changes.

Tiredness

Many women say that tiredness (or fatigue) is a major problem. This is not surprising, as most women start chemotherapy soon after their operation. Travelling to and from hospitals and clinics for treatment is also very tiring. If you start work again during the treatment and/or you have a home and family to care for, you will almost certainly find that you are very tired. If you are on your own and have to do everything yourself, tiredness will be a major problem.

'I felt so guilty because I couldn't do much – it helped when I realised that this tiredness was normal.'

Your tiredness may continue for quite a while even after treatment has finished. Recovery is different for everyone. Many women feel 'normal' within a couple of months of finishing chemotherapy; for others, it can take longer. It may help to talk with your family and

friends about how you feel. Talk about how they can help you. You may need to plan your activities during the day so that you get regular periods of rest.

★ **The Cancer Council has information on cancer treatment-related fatigue. Visit www.cancervic.org.au or telephone 13 11 20 for a copy.**

Premature menopause

If you have had both your **ovaries** and your **uterus** removed, you will no longer have your periods and it will not be possible to become pregnant. If you have not been through **menopause** already, you may experience premature menopause. Because your ovaries have been removed, menopausal symptoms such as hot flushes, mood swings and vaginal dryness could be more sudden than they would be with a natural menopause. You will need to talk with your doctor about the need for hormone replacement therapy.

Hormone replacement therapy may be taken to control the symptoms of menopause. Oestrogen, a hormone normally produced by the ovaries, is taken to replace your natural oestrogen. Hormone replacement therapy can also reduce the risk of **osteoporosis** (thinning of the bones).

Using hormone replacement therapy for more than five years increases the risk of some diseases including some cancers. However it also decreases the risk of some other diseases and cancers.

You will need to discuss the issues with your doctor and weigh up the benefits and possible risks for yourself. There are also many useful books about menopause that may help you with your decisions.

Feeling low or depressed

It isn't uncommon to feel very low or depressed after a cancer diagnosis. Don't be too surprised if you do feel fed up and unhappy at certain

times. It may help to think about why you feel like you do. Some people feel sad or depressed because of the changes that their cancer has caused. Others become very down because they are frightened about the future. Whatever it is that is causing you to feel down, you need to get support.

There is a difference between feeling down and sad for a while and feeling very depressed for long periods. Depression can go on for a long time if you don't get the right help. If you have had one or more of these signs for a few weeks or more you should see your GP:

- feeling very sad and low most of the time
- not being able to enjoy life as you usually do
- having negative thoughts about yourself a lot of the time
- changes in eating habits: eating much more or less than usual
- weight gain or loss
- feeling very tired a lot of the time
- loss of concentration
- loss of interest in sex
- changes in sleeping habits: not being able to get to sleep, waking in the early hours of the morning or sleeping more than usual
- feeling very anxious and often upset
- feeling like you want to die or end your life.

If you have some of these signs or think you may be depressed, you must get some help. Be honest with your doctor about how bad you feel. This will help your doctor advise you about the type of support and care you need.

Bowel problems

It is common to have bowel problems after surgery for ovarian cancer. These can occur for some time after treatment. They may include diarrhoea, cramps or constipation. In particular, it is important not to become constipated. Talk with your doctor, nurse or dietitian about ways you can prevent constipation, and relieve any other symptoms.

Sometimes the bowel becomes blocked because of the surgery you have had. It may also occur because the cancer has come back. This blockage is called a bowel obstruction. If you have symptoms such as nausea (feeling sick), vomiting, abdominal discomfort or pain you should see your doctor or specialist as soon as possible. Quite often a bowel obstruction can be relieved with simple treatment in hospital. Occasionally you may need another operation to relieve your symptoms.

Lymphoedema

Lymphoedema is swelling of a part of the body, usually the arms or legs. It may occur after treatment for ovarian cancer if you have had some of the **lymph nodes** in your **pelvis** removed (lymph node dissection). Removal of the nodes may prevent normal draining of the fluid from the legs. As a result fluid can build up in one or both legs, causing swelling. This usually does not occur until some time after the operation.

It is not possible to predict whether you will have problems with lymphoedema. You should seek advice from your doctor or nurse. You may be given special stockings to wear after your operation.

★ For further information about lymphoedema contact the Cancer Council Helpline on 13 11 20.

Some hospitals have a specialist physiotherapist or nurse who can advise you on how you may be able to reduce your risk of lymphoedema. They can also help you manage if lymphoedema does occur in the future.

Fluid build-up (ascites)

Ascites is a collection of fluid in the **abdomen**. This can be uncomfortable because of swelling and pressure. If it becomes a problem there is a simple procedure to drain away the fluid and relieve discomfort. This is called a paracentesis. It is usually done on the hospital ward and you may need to stay overnight.

Sometimes fluid collects in the lining of the lungs. You may feel short of breath and have some pain. This fluid can be drained away to give you relief.

Seeking support



When you are first told you have cancer, you may feel a range of emotions, such as fear, sadness, depression, anger or frustration. It may be helpful to talk about your feelings with your partner, family members or friends, or with a hospital counsellor, social worker, psychologist or your religious or spiritual adviser.

Sometimes you may find that your friends and family do not know what to say to you. They may have trouble dealing with their feelings too. Some people may feel so uncomfortable that they avoid you. This can make you feel very lonely. You may feel able to approach your friends directly and tell them what you need. You may prefer to ask a close family member or a friend to talk with other people for you.

★ You can telephone the Cancer Council Helpline on 13 11 20, for information and support. Call Monday to Friday 8.30 am to 6 pm, and speak to one of our experienced and understanding cancer nurses.

Practical and financial help

A serious illness may cause practical and financial problems. You do not need to face these alone. Apart from offering emotional support,

a social worker may be able to suggest useful tips to help. Ask at your hospital, your community health centre, or ring the Cancer Council Helpline.

Many services are available, including:

- financial assistance, which may be available for transport costs to medical appointments, prescription medicines, or through benefits or pensions. Contact the social worker at your hospital.
- home nursing care, which is available through district nursing, or through the local palliative care service – your doctor or hospital can arrange this.
- meals on wheels, home care services, and aids and appliances, which can make life easier – contact the hospital social worker, occupational therapist or physiotherapist, or your local council.

Wigs

If you lose your hair during chemotherapy, you may want to wear a wig, scarf or hat while it's growing back. You can borrow a wig; some hospitals and cancer care units have wig libraries where wigs are available for a small fee. You can buy a wig, though they can be expensive. Ask your treating hospital or call the Cancer Council Helpline on 13 11 20 to find out more. Some private health funds cover part of the cost of wigs – check with your health fund.

Diet

A healthy diet will help you to keep as well as possible and cope with the cancer and any side effects of treatment. Depending on the kind of treatment you have had, you may have special dietary needs. A dietitian can help to plan the best foods for your situation – ones that you find tempting, easy to eat and good for you.

★ For Cancer Council information on diet and exercise, visit www.cancervic.org.au or telephone 13 11 20.

Exercise

You will probably find it helpful to stay active and exercise regularly if you can. Exercise can help with fatigue. The amount and type of exercise you do will depend upon what you are used to and how well you feel. Talk with your doctor about what will be best for you.

Relaxing

Some people find relaxing or meditating helps them to feel better. The hospital social worker or nurse will know whether the hospital runs any programs, or may be able to advise you on programs in your area. Your local community health centre may also be able to help.

★ For Cancer Council information on relaxing and coping with anxiety, visit www.cancervic.org.au or telephone 13 11 20.

Sexuality and cancer

Cancer treatment and the emotional effects of cancer may affect people with cancer and their partners in different ways.

Some people may withdraw through feelings of being unable to cope with the effects of treatment on themselves or their partner. Others may feel an increased need for sexual and intimate contact for reassurance.

It is important to talk about your feelings with your partner. If you have trouble continuing with your usual sexual activities, discuss this with your doctor or with a trained counsellor.

Some people can feel sad about going through a cancer diagnosis and treatment without a partner. Sharing these feelings with a counsellor or a trusted friend or family member can make a big difference to how you feel.

★ For Cancer Council information on sexuality and cancer, visit www.cancervic.org.au or telephone 13 11 20.

Cancer Council Helpline

The Cancer Council Helpline is a confidential service where you can talk about your concerns and needs with cancer nurses for the cost of a local call. They can send you information and can put you in touch with support services in your area. Telephone 13 11 20.

'I think one of the most important things is that although you feel you're on your own, you don't have to do it on your own. You need to ask questions and not try to be too stoic. There's a lot of help available. We have to find out where it is and what sort of help suits us.'

Multilingual Cancer Information Line

The Multilingual Cancer Information Line is a confidential Cancer Council service. You can call and speak to a specially trained nurse with the help of an interpreter for the cost of a local call. It is for people with cancer, and people who are close to them. People who speak any language can use the service. See the inside back cover for details.

Talk to someone who has been there

Getting in touch with other people who have been through a similar experience can be very helpful. 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.

Support services available for patients, carers and family members include:

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

Ask your nurse or social worker to tell you about support groups in your area. Visit www.cancervic.org.au or call the Cancer Council Helpline on 13 11 20 to access the Cancer Services Directory and find out how you can connect with others.

Joining a consumer advocacy group can also be rewarding for people who would like to use their experience to make a difference for others. Visit www.cancervoicesvic.org.au for more information.

Living with Cancer Education Program

The Cancer Council's Living with Cancer Education Program provides information on cancer and ways of coping with it. The program runs over one day or several weeks. Groups are small, with plenty of time for talking. Courses are held at hospitals and community organisations throughout Victoria. Contact your hospital social worker or the Cancer Council Helpline.

'It's good to talk to other people if you're afraid, and try to look at ways to overcome the things you're frightened about.'

Caring for someone with cancer



A carer is anyone, whether family or friend, who is helping to look after someone with cancer. Caring for someone with cancer can be very stressful, particularly when it is someone you care about very much. The person with cancer may be experiencing distressing emotions about their cancer diagnosis, side effects from treatment and mood changes from the effects of drugs.

Look after yourself during this time. Give yourself some time out, enjoy a cup of coffee with a friend, and share your worries and concerns with someone not involved. Make a list of 10 things you like to do and make sure that you do one each day.

You may have to make many decisions. You will probably have to attend many appointments with doctors, support services and hospitals. Many people have found it helpful to take with them another member of the family or a close friend. It also helps to write down questions before you go, and to take notes during the appointment.

Cancer Support Groups are usually open to patients and carers. A support group can offer the chance to share experiences and ways of coping. There is a range of support services such as home help, meals on wheels and visiting nurses that can help you cope with treatment at

home. These are provided by local councils, the Royal District Nursing Service and the palliative care services.

Call the Cancer Council Helpline on 13 11 20 to:

- be linked with another carer by telephone
- speak with a cancer nurse for further support and information
- be sent a carer's kit so that you can find out about financial assistance and other resources.

*** The Cancer Council has a booklet about caring for someone who has cancer. Visit www.cancervic.org.au or telephone 13 11 20 for a copy.**

Questions to ask your doctors

You may find the following list helpful when thinking about the questions you may want to ask about illness and treatment.

- 1 What type of cancer do I have?
- 2 How extensive is my cancer?
- 3 What treatment do you advise for my cancer and why?
- 4 Will my treatment (and surgery) be performed by a doctor who specialises in ovarian cancer?
- 5 Are there other treatment choices for me? If not, why not?
- 6 What are the risks and possible side effects of each treatment?
- 7 Will I have to stay in hospital, or will I be an outpatient?
- 8 How long will the treatment take? Will it affect what I can do?
- 9 How will I know if the treatment is working?
- 10 How much will it cost?
- 11 Will I have a lot of pain with the operation? What will be done about this?
- 12 If I need further treatment, what will it be like and when will it begin?
- 13 Will the treatment affect my sexual relationships?
- 14 How frequent will my check-ups be and what will they involve?
- 15 Are there any problems I should watch out for?
- 16 Can you refer me to someone else for a second opinion? (if you feel you want a second opinion)
- 17 Is my cancer hereditary?
- 18 What happens if I don't have treatment?
- 19 If I choose not to have treatment either now or in the future, what services are available to help me?
- 20 Will I still be able to have children?
- 21 Will I go through menopause?
- 22 How long will I need to take off work?
- 23 Will I be able to drive after treatment?

Glossary: what does that word mean?

Most of the words listed here are used in this booklet, others are words you are likely to hear used by doctors and other health professionals who will be working with you.

abdomen The part of the body between the chest and hips. The stomach, liver, bowel, bladder, kidneys, uterus, fallopian tubes, omentum and ovaries are in the abdomen.

advanced cancer Cancer that has spread (metastasised) and/or is unlikely to be cured.

ascites A build-up of fluid in the abdomen, making it swollen and bloated.

benign Not cancerous. Benign cells do not spread like cancer cells.

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

CA 125 A protein that is not specific to ovarian cancer but is sometimes produced by ovarian cancer cells. In women who have ovarian cancer, a rise in CA 125 usually means the disease has recurred or developed further. A decrease usually means the disease is responding to treatment. Levels can also be raised in women who have other non-cancerous conditions. CA 125 levels are measured through a blood test.

catheter A flexible tube inserted into a narrow opening so that fluids can be put into or removed from the body.

cells The 'building blocks' of the body. A human is made of billions of cells, which are adapted for different functions.

cervix The lower part of the uterus, which is at the top of the vagina.

chemotherapy The use of special drugs to treat cancer by destroying cancer cells or slowing their growth.

diagnosis The process of finding out about a person's illness by considering their signs and symptoms, medical background and results of diagnostic tests.

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

fallopian tubes The tubes that carry the ova (eggs) from the ovary to the uterus. Each woman has two fallopian tubes, one from each ovary.

genes The tiny factors that control the way the body's cells grow and behave. Each person has a set of many thousands of genes inherited from both parents.

germ cells Special cells in the ovary that can mature into ova (eggs).

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

laparotomy An operation in which a long cut is made in the abdomen.

lymph nodes Also called lymph glands. Small, bean-shaped structures that form part of the lymphatic system. Lymph is the fluid that flows through this system and carries cells that help to fight disease and infection. The lymph nodes filter the lymph to remove bacteria and other harmful agents, such as cancer cells.

lymphoedema Swelling caused by a build-up of fluid. Can occur sometimes after lymph nodes have been removed.

malignant Cancerous. Malignant cells can spread and can eventually cause death if not treated.

menopause The end of menstruation (periods). This marks a woman's transition from when reproduction is possible to the post-reproductive years. It usually occurs between the ages of 45 and 55.

metastasis Also known as 'secondaries'. Tumours or masses of cells that develop when cancer cells break away from the primary (original) cancer and are carried by the lymphatic and blood systems to other parts of the body.

oestrogen A hormone responsible for female characteristics and with a role in female reproduction, mainly produced by the ovaries.

omentum The 'apron' of fatty, protective tissue covering the abdominal organs.

osteoporosis A condition that affects bones, making them thinner and weaker than normal and more likely to fracture and break.

ovaries The female sex organs, which secrete important hormones and contain the ova.

ovulation The time in the menstrual cycle when ova are released from the ovary.

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

progesterone A hormone produced by the ovaries that has importance in menstruation and pregnancy.

prognosis An assessment of the possible future course and outcome of a person's disease.

radiotherapy The use of radiation, usually x-rays or gamma rays, to destroy cancer cells or injure them so they cannot grow and multiply. Radiotherapy can also harm normal cells, but they are able to repair themselves.

recurrent cancer A cancer that grows from the cells of a primary cancer despite previous treatment. Recurrent cancer may appear some years after the primary cancer was treated, depending on the type of cancer.

sex-cord stromal cells Cells of the ovary that release the female hormones.

tissue A collection of similar cells.

tumour An abnormal growth of tissue on or in the body.

tumour marker A substance sometimes produced by a tumour. The level of a tumour marker in the blood can be a useful way to determine whether a treatment is working.

uterus Also called the womb, this is the hollow muscular organ in which a fertilised egg can grow and the baby can be nourished until birth.

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Cancer information in other languages

خط معلومات السرطان باللغة العربية

إتصلوا بالخط
للتحدث الى ممرضة عن مرض السرطان
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请电 **9209 0164**

For other languages please call 9209 0169. Tell us which language you speak and an interpreter will help you talk to a nurse. To speak to a nurse in English, call 13 11 20.

INTERNET: For information in a range of languages please visit our multilingual website at: www.cancervic.org.au/other_languages



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