

# Epithelial Ovarian Cancer

Understanding  
your diagnosis and  
treatment



Australian Government  
Cancer Australia

# Epithelial ovarian cancer

Understanding your  
diagnosis and treatment

Epithelial Ovarian Cancer — Understanding your diagnosis and treatment  
was prepared and produced by:  
National Breast and Ovarian Cancer Centre\*.

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## Acknowledgments

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## Note to reader

While every effort has been made to ensure the information in this guide is as up-to-date as possible, new information about ovarian cancer risk factors, diagnosis, treatment and supportive care is constantly becoming available. Readers are advised to seek expert advice about specific problems. This booklet is intended as a guide only and should not be used as a substitute for professional advice.

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Every woman's situation and needs are different.

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Not all the information in this booklet will be relevant to you and your situation.

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We recommend that you read this booklet in sections, when you need to, rather than reading it from cover to cover.

## Introduction

If you have been diagnosed with epithelial ovarian cancer, this booklet aims to assist you in understanding your diagnosis and making decisions about your treatment and care. Your partner, family and friends might also find it useful.

The information is based on the evidence available at the time of publication. New treatments are continually being developed and might be introduced in the future. If you hear about any technologies and treatments that are not mentioned here, please ask your doctors for more information.

**If you are reading this book for a relative or friend who does not understand English very well, you can get a professional interpreter to help.**

**For more information, call the Translating and Interpreting Service (TIS) on 13 14 50.**

## Understanding epithelial ovarian cancer

This chapter explains:

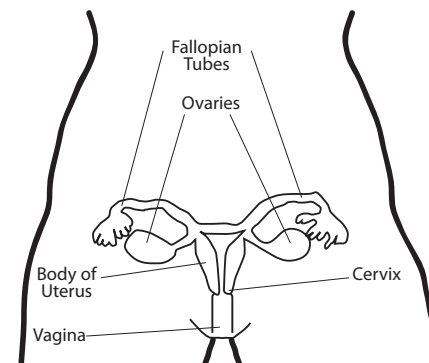
- what epithelial ovarian cancer is
- what causes it
- what reduces the risk of getting ovarian cancer
- the survival outlook.

### What is epithelial ovarian cancer?

Ovarian cancer occurs when cells in the ovaries grow abnormally and the body's natural defences can't stop them. The abnormal cells form growths called cancers. Epithelial ovarian cancer starts in the outer covering of the ovary. Other types of ovarian cancer include: germ cell (starts in the cells that mature into eggs) and sex-cord stromal (starts from the cells that release female hormones).

To understand what epithelial ovarian cancer is, it helps to know what your reproductive organs look like. The ovaries are two small organs near the uterus (womb), one on each side. The ovaries have an outer covering called the epithelium (skin) and are linked to the womb by two tubes called the Fallopian tubes.

### Female reproductive organs



# 1

**UNDERSTANDING  
EPITHELIAL  
OVARIAN  
CANCER**

**Ovarian cancer is the eighth most common cancer in women in Australia. It will affect around one in 100 women each year. Epithelial ovarian cancer is the most common type. Nine out of ten women with ovarian cancer have this type.**

**Genetic counselling services**  
**Familial cancer clinics provide information, counselling and advice for women with a family history of cancer.**  
**Genetic counsellors can also discuss genetic testing with you or your family.**  
**If you are concerned about your family history, talk to your GP to arrange a referral.**

## Why did I get ovarian cancer?

It is not known why some women get ovarian cancer and others don't.

There are some factors that can increase a woman's risk, but it is important to know that having some or all of the common risk factors for ovarian cancer does not mean that a woman will develop the disease.

## Risk factors for ovarian cancer

**Age:** The risk increases as women become older. Women who are over 50 years of age are more likely to develop ovarian cancer than younger women.

**Family history and genetic factors:** Having changes in a small number of ovarian cancer-related genes increases the risk of ovarian cancer. Having a family history of ovarian cancer, breast cancer or some other cancers, such as colorectal or endometrial cancer, also increases risk.

Only around 5-10% of all ovarian cancers are due to inherited factors.

Research suggests that the risk of ovarian cancer is slightly higher for women who:

- have medical conditions such as endometriosis
- use long-term hormone replacement therapy (HRT)
- smoke cigarettes
- are obese.

## Could I have done anything to prevent getting ovarian cancer?

There is currently nothing that can be done to prevent ovarian cancer.

## What reduces the risk of getting ovarian cancer?

Research has shown that the following are associated with a reduced risk of ovarian cancer:

- removal of the uterus (womb); removal of ovaries and having the Fallopian tubes tied
- having children
- using oral contraceptives.

## Should I have gone to a GP earlier?

Some women feel guilty that they did not go to the doctor earlier. However, going to a doctor earlier does not necessarily mean that you would have been diagnosed with earlier stage disease. The symptoms for ovarian cancer are very vague and are often like those of many other common illnesses. You may not have had any symptoms at all while the cancer was first developing.

## Your feelings

If you feel guilty about not seeking medical advice earlier, or angry that your illness was not discovered sooner, it may help to talk about this with your doctor, or a counsellor or similar professional.

Not all women diagnosed with epithelial ovarian cancer will have all of the listed symptoms, and most women who have these symptoms will not have epithelial ovarian cancer.

## What are the symptoms of epithelial ovarian cancer?

- a swollen abdomen (tummy)
- pain, pressure or discomfort in the abdomen
- change in bowel habit eg diarrhoea or constipation
- urinary changes eg frequency or urgency
- bleeding, apart from the normal monthly period
- a feeling of bloating or fullness
- indigestion or feeling sick
- gaining or losing weight
- lower back pain
- feeling unusually tired
- loss of appetite
- flatulence (wind)
- pain during sex



## How long will I live?

Every woman's case is different. Your prognosis depends on the type of ovarian cancer you have, the stage and grade of the cancer (*see page 13 for more details*), how the cancer develops and responds to treatment, and personal factors such as your age and general health. Most women, including those with advanced disease, respond to treatment. However it is not uncommon for the disease to recur and some women need a number of treatments.

The number of women surviving from all types of ovarian cancer is improving. From 1988-2002, 42% of women with ovarian cancer were living five years after their diagnosis, compared with 34% in 1982-1986. Survival is highest for younger women, as they are more likely to get the types of ovarian cancer which generally respond best to treatment.

*"I had bloating, not severe, but different from any other sort of bloating I have ever had. And because my body doesn't do peculiar things, I thought, I'll look into this."*

*"I was quite bloated. I looked pregnant, I think. Almost no appetite, and I always felt full."*

*"OK, this has happened to me. There's nothing that I did to cause this. Absolutely nothing that I did. It's not what I ate, it's not what I thought..."*

## Diagnosis

This chapter explains:

- how epithelial ovarian cancer is diagnosed.

### How was my epithelial ovarian cancer diagnosed?

You may have seen a number of doctors and had a number of tests before you were diagnosed. It's likely that you have had some of the following investigations.

**Physical examination** where the doctor checks for any masses or lumps by feeling your abdomen (tummy) and doing an internal examination.

**Imaging**, which uses various methods to provide images of the ovaries that can be seen on a screen. These images can show changes in the shape or size of the ovaries that may indicate ovarian cancer. Imaging of the chest and the abdomen can also be used to check for the spread of the cancer. Methods usually include ultrasound or computed tomography (CT) scans, but magnetic resonance imaging (MRI) scans or X-rays are sometimes used.

**Blood test** to measure levels of CA125, a protein which is a tumour marker. Raised levels of CA125 in the blood can indicate epithelial ovarian cancer.

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

## 2 DIAGNOSIS

*"I was nursing my mother who was dying of ovarian cancer and I had a bowel spasm. I went to see my GP who obviously felt the tumour. He thought it was in my bowel. I didn't have any idea I had cancer, I just thought I had something wrong with my bowel."*

*"My GP knew me quite well and she knew me to be a reasonably sensible sort of person. So she took me seriously and I think that was very useful. I told her what the symptom was and she said 'it's probably nothing' but she sent me for an ultrasound."*

*“I had no suspicion that I had ovarian cancer. I went to my GP because I was bloating and she sent me to my gynaecologist who scheduled an ultrasound.”*

*“My advice to other women is don’t ignore symptoms. Know your family history. Get symptoms checked out and make sure they rule out ovarian cancer.”*

*“I felt really relieved to find out there was something actually wrong. My GP had dismissed all my symptoms for a long time.”*

The only definite way to make sure of the diagnosis of epithelial ovarian cancer is with an operation and a biopsy of the tumour. This means that the treatment of ovarian cancer begins at the time of this diagnostic operation. It is important that you understand as much about the operation as possible before having surgery.

*See Chapter 4 for information about surgery for epithelial ovarian cancer.*

### ① Questions you can ask your doctor

- What does having epithelial ovarian cancer mean for me?
- What stage is my cancer at?
- Do you know if the cancer has spread? If so, where?
- What type of treatment might I need?
- What happens now?

## Deciding about treatment

This chapter explains:

- how epithelial ovarian cancer is treated
- who is involved in your treatment
- how to decide about your treatment.

### Treatment

The type of treatment you have depends on the stage of the cancer and your general health. Treatment for epithelial ovarian cancer usually involves surgery and chemotherapy. Sometimes radiotherapy might also be used. These treatments might be used alone or together.

### Who will be involved in your treatment?

Your treatment and follow-up will involve a number of doctors and other health professionals working as a team. Your treatment team may include some of the following:

- **a gynaecological oncologist**, who performs surgery and oversees all aspects of treatment of cancers of women’s reproductive organs (except breasts)
- **a gynaecological pathologist**, who examines the cells/tissue removed from your abdomen or ovaries under a microscope
- **a medical oncologist**, who manages chemotherapy, cancer pain and other symptoms
- **a radiation oncologist**, who manages radiotherapy
- **a radiation therapist**, who delivers radiotherapy
- **a radiologist**, who reads diagnostic images such as X-rays, ultrasounds, computed tomography (CT) scans and magnetic resonance imaging (MRI) scans
- **oncology nurses**, who can administer chemotherapy, assist with radiotherapy and provide care, information, counselling and support
- **a general practitioner (GP) or family doctor** who provides ongoing care and referrals to specialists.



*“One of the things that women need to know is that they are allowed to and should ask questions of their doctors and to actually ask who their care team is and who they can ask questions of when their doctor isn’t immediately available.”*

At different times in the treatment of the cancer, a different treatment team member might be the main co-ordinator of your care. This person might be your gynaecological oncologist, medical oncologist, GP or another member of your treatment team. This role will change over time, so make sure you know who to contact regarding any concerns.

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There is evidence that women with epithelial ovarian cancer do better when their care is managed by a group of professionals, each specialising in a different aspect of treatment and supportive care (multidisciplinary care team). Centres where all aspects of treatment and care are available are ideal.

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Other professionals who might be involved in your care include:

- a **counsellor, psychologist or psychiatrist**, who provides emotional support and/or help in managing anxiety and depression, and help in coping with pain
- a **palliative care consultant, palliative care nurse and palliative care volunteers**, who provide support and symptom relief
- a **social worker** who provides support and can arrange practical and financial assistance
- a **dietitian** who provides information about diet
- a **physiotherapist or occupational therapist**, who provides exercise programs and other support to assist with recovery from surgery
- a **pastoral carer or religious representative**, who can discuss meaning of life issues with you.

Talk to your doctor for a referral to one of these professionals if you feel you would benefit from the services they provide. In rural and remote areas you might not have local access to the services of some of these professionals. Links to larger treatment centres by telephone or through visiting health professionals are possible.

## ? Questions you can ask your treatment team

- Will my care be provided by a multidisciplinary care team?
- What role does each person play in my care?
- Will you keep my GP informed of what is happening?
- Will I get information about test results and treatment?
- How often will my treatment team members meet?
- How do they discuss my progress if they are not all in the same location?
- Who should I call if I have a problem or am worried about symptoms or pain?
- Who should I contact out of regular hours if I need to?

## How do I decide about treatment?

It’s up to you how much you want to be involved in making decisions about your treatment. You might want to be actively involved, or you might want your doctors to make decisions for you. Discuss any decisions you make about treatment with your doctor and any others you may care to consult. Your wish to be involved in deciding about your treatment may change over time, so it is best to keep your doctor informed about any change in your preferences.



**Your feelings**  
Being told you have epithelial ovarian cancer might make you feel overwhelmed, shocked and anxious and you might feel a sense of injustice. You might feel more in control if you receive a lot of information, or you might not want to know very much at all. The amount of information you feel you need might also change at different times. See Chapter 14.

*“Every three weeks I’d have a list of questions based on my doctor’s last answer to me, which at the time I just accepted at face value.”*

*“My personal view is that you need to find out as much as you think you can put up with.”*

*“I was not given a lot of information so I went into a bookstore and looked up books about ovarian cancer, but it was a pessimistic outlook and I decided I’d wait and see what they found after the surgery.”*

## Can I get a second opinion?

You have the right to ask for a second opinion at any time. Having a second opinion can help clear up any questions, and can help you decide which doctor you prefer to manage your treatment, and which course of treatment to follow. You can be referred by your GP or by one of the clinicians on your treatment team.

You might decide, after seeing another doctor for a second opinion, that you want your initial doctor to manage your treatment.



### Tips for talking to your doctors

You need good quality information to help you make decisions about your treatment.

You might find it helps to:

- ask for as much information as you need, even if you have asked for it before
- write down a list of questions to ask your doctor as they come to mind
- ask a relative or a friend to come with you when you visit your doctor, especially the first time
- read pamphlets, notes, booklets and websites - your doctor will be able to help you with these
- if your doctor agrees, tape record all discussions so you or your family can later go through what the doctor said
- ask your doctor to give you a written summary of your treatment plan.

## Using a professional interpreter

If you are reading this booklet for a family member or friend who does not understand English very well, you can get a professional interpreter to help. A qualified interpreter can make sure that your relative or friend understands everything the doctor says.

Interpreters are available free of charge in both the public and private hospitals, although they must be booked before any consultation. To book an interpreter:

- ask your doctor about the hospital’s interpreter services, or
- call the Translating and Interpreting Service on 13 14 50, or
- call the Cancer Council Helpline on 13 11 20.

## ? Questions you can ask your doctor

- What treatments are available to me?
- What treatment do you recommend for me and why?
- What are the benefits, risks and side effects of each treatment?
- What will my out-of-pocket expenses be?
- If I choose not to have treatment, now or in the future, what services are there to help me?
- How much time do I have to make a decision - will taking some time to think about my options make any difference?

*“The surgeon would sit down and answer my questions and also the oncologist went through the whole thing with me. He wrote his recommendations out for me and handed me his notes. He was really good.”*

*“The important thing is not to hold back. No question is silly, so don’t be afraid to ask.”*

*“I had a very sharp learning curve to take back control and learn as much as I could. I thought I’ve got to know about this and take responsibility for my decisions, so since then I’ve been fairly proactive.”*

## Surgery

This chapter explains:

- what is involved in the surgery
- stage and grade of the cancer
- what to expect after surgery.

The first treatment for epithelial ovarian cancer is usually cytoreduction (surgery to remove as much of the cancer as possible). The surgery needed depends on the type of cancer and whether it has spread from the ovaries. Removing as much of the cancer as possible allows other treatments, such as chemotherapy and radiotherapy, to be more effective.

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Research shows the best results in removing epithelial ovarian cancer occur when the surgery is done by a gynaecological oncologist.

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### What might happen during surgery for epithelial ovarian cancer?

The surgeon will make a long cut starting from near the navel (bellybutton) down to the pubic area. This is called a laparotomy.

If the cancer has spread it is necessary to remove not only the ovary itself (oophorectomy) but also other tissues or organs. This surgery usually means removing the uterus (hysterectomy), both ovaries and Fallopian tubes (bi-lateral salpingo-oophorectomy) and the fatty tissue around the organs in the abdomen (omentectomy).

Sometimes it is necessary to remove cancer that has spread to the lining of the abdomen or the bowel. If the bowel is affected, the surgeon may need to remove part of the bowel and rejoin the two ends. The lymph nodes, or lymph glands (small, bean-shaped organs that filter harmful agents from the blood stream) may also be removed.

During the surgery, the surgeon will also take samples of any fluid in the abdomen. This fluid, the tumour and any organs removed by the surgeon, will be sent to the pathologist to determine what type and grade of ovarian cancer is present and whether it has spread. This will help the doctor to determine the stage of the cancer and whether more treatment is needed.

### What does staging of epithelial ovarian cancer mean?

The stage describes how advanced your cancer is and how far it has spread at the time of diagnosis. The earlier the stage of ovarian cancer, the better the survival outlook.

The stage of the tumour is determined to help the specialist decide whether further treatment with chemotherapy is needed. It also gives a guide to the chances of the cancer coming back.

### Stages of epithelial ovarian cancer

There are four main stages of epithelial ovarian cancer:

**Stage I:** the cancer is only in the ovary

**Stage II:** the cancer is found in one or both ovaries and has spread to other areas in the pelvis such as the uterus (womb), Fallopian tubes, bladder or bowel.

**Stage III:** the cancer is found in one or both ovaries and has spread outside the pelvis to the omentum (the fatty tissue around the organs in the abdomen), the intestines or to lymph nodes in the pelvis or abdomen.

**Stage IV:** the cancer is found in one or both ovaries and has spread outside the abdomen (usually in the outer lining of the lung) or has spread to inside the liver.

If you have been diagnosed as Stage I, the outlook is good. This stage responds very well to surgery alone and between 80-100% of women who are diagnosed as Stage I survive for more than five years.

If your cancer is diagnosed as Stage II, III or IV, the cancer is advanced. The cancer usually responds well to initial treatment

## SURGERY

*"I didn't know much about ovarian cancer, but my surgeon discussed it with me and explained that it was going to be major surgery, and based on what was found they were probably going to do a full hysterectomy and the treatment team would discuss whether to do follow-up chemotherapy."*

*"I had radical surgery - oophorectomy and hysterectomy. The oncologist said he thought I had Stage IV cancer and I began chemotherapy immediately."*

**You should feel free to ask questions before surgery so that you have all the information you need to help you understand what will happen.**

**"My doctor said, 'You'll need an operation, you'll need chemotherapy but until I open you up I won't know the extent of it'."**

*"I didn't know anything about ovarian cancer so I didn't know about stages. I found that out as I went along because I started to get curious about it. Every time I saw my doctor I would ask her something more. And she'd tell me."*

but often recurs at a later time. About 20-25% of women diagnosed when the cancer is advanced survive for more than five years. This figure is, however, improving all the time with more effective testing, better surgery, and better chemotherapy.

**Recurrent** or **relapsed** epithelial ovarian cancer is when the cancer comes back after treatment.

### What is the grade of epithelial ovarian cancer?

The grade describes how close your cancer cells are to your normal cells. The lower the grade or the more like normal cells, the better the chance of treatment being successful. There are three grades of epithelial ovarian cancer. Grade 1 is the lowest and Grade 3 is the highest.

### What is 'residual disease'?

The amount of cancer remaining at the end of surgery is called 'residual disease'. Surgery aims to remove all signs of the cancer but sometimes this is not possible. Your surgeon will probably tell you about any residual disease you may have and suggest what can be done to treat it.

### What can I expect after the operation?

Every woman's situation is different and it's not possible to say exactly what will happen after your surgery. Discuss this with your surgeon before your operation. However, it's likely that when you wake up after the operation, you will be in a special ward so that the nursing staff can check on how you respond to the anaesthetic, check your blood pressure and provide you with pain relief.

After the operation you might have a number of tubes in place:

- a nasogastric tube (a tube down your nose and into your stomach). This is not always necessary but it is sometimes used to suck fluid out from the stomach to prevent vomiting
- a drip into a vein in your arm to provide you with fluid, and through which medication and pain relief can be given

- tubes (drains) from your abdomen to take away fluid from the operation
- a catheter (tube) into your bladder to remove urine.

The tubes will be removed over the first two to five days.

### Pain after surgery

You will feel sore around the site of the surgery but the pain can be controlled. You should let your treatment team know if you are in pain, so that the medication levels can be changed. Pain relief is usually given through an epidural, rectal suppositories or patient-controlled analgesia (PCA), which enables you to give yourself pain medication. Your treatment team will explain to you how to use the PCA.

It will be uncomfortable to move around at first but getting out of bed when you feel able and walking a little bit can also help to relieve the pain caused by wind (gas) in the abdomen.

You might stay in hospital for about a week.

### Recovering from the surgery

To make sure that your body has a chance to recover from the surgery, there are some things that you should avoid. Before you leave hospital your doctor, or a member of your treatment team, will probably speak to you about what you should do during recovery. In general:

- you should avoid lifting heavy things for about six weeks, to allow your body to heal. It's a good idea to leave tasks such as vacuuming or cleaning to someone else until you feel able to do them. If you live alone or need assistance with work around the house this may be able to be arranged. *See Chapter 15 for information about practical support services.*
- you should not drive a car until given clearance to do so by your doctor
- sexual intercourse is usually best avoided for about six weeks, but you should discuss this with the doctor or treatment team.

## How you might feel

**You might feel angry, depressed or sad after your surgery. For some women it is hard to adjust to having a sudden menopause due to the surgery. Some women feel that they have lost their femininity. Others mourn that they can no longer have children. It is natural to have these feelings and it might help to talk them through with someone. See Chapter 14: Coping with your diagnosis.**

## Is it possible to have children after surgery for epithelial ovarian cancer?

If the cancer has not spread or if it is found to be a borderline tumour (a type of less aggressive ovarian cancer), it may be possible to just remove the affected ovary, leaving the other ovary and the uterus. This means that a woman may still fall pregnant. Removing both ovaries, Fallopian tubes or uterus means that it is no longer possible to become pregnant.

Some women need chemotherapy following surgery (*see page 18*). When an ovary remains after surgery, having chemotherapy can mean that a woman goes through menopause early. Women who have gone through menopause are no longer able to become pregnant.

If having children in the future is an issue for you, it is important that you discuss the possibility of preserving fertility with your doctor, before surgery.

## Will I still have periods after the surgery?

If you were still having your monthly period and you needed to have both your ovaries removed as part of your surgery for epithelial ovarian cancer, you will no longer have periods. You will have gone through surgically-induced menopause (menopause due to the surgery). You should talk to your doctor or treatment team about the options available for you to manage menopausal symptoms such as hot flushes and to reduce the risk of osteoporosis.

If your uterus was removed but you still have one ovary, you will no longer have periods but you will not get menopausal symptoms such as hot flushes.

## What will happen if there is damage to my bowel?

A small number of women may need to have part of the bowel removed due to the spread of the cancer. Usually the bowel ends can be sewn together again but if the disease is low in the pelvis and the rectum is removed, some patients will have a stoma (an

opening) made in the abdominal wall to allow for removal of bowel waste. A nurse who is specially trained in this area will be able to help you as you adjust to this change.

## Will I need more surgery?

You might need further surgery, depending on how your cancer responds to initial treatment. In some cases, secondary cytoreduction (more surgery) might be done if the cancer comes back some years after the initial treatment.



For early epithelial ovarian cancer that might spread or where the cancer has started to grow outside the ovary, there is research to show that adjuvant chemotherapy (having chemotherapy soon after surgery to kill remaining cancer cells) can improve survival and reduce the chance of the cancer coming back. However, chemotherapy can also affect fertility (see page 16). Women with early epithelial ovarian cancer who still want to have children should discuss the effect of chemotherapy on fertility with their doctor.

## Chemotherapy

This chapter explains:

- what chemotherapy is
- when it is used
- what to expect from chemotherapy.

Chemotherapy uses a drug or a combination of drugs to attack the cancer cells and slow or stop their growth. Epithelial ovarian cancer cells can be quite sensitive to chemotherapy, and most women with epithelial ovarian cancer will be offered chemotherapy as part of their treatment.

### When is chemotherapy used?

#### Early stage epithelial ovarian cancer

Women with borderline epithelial ovarian cancer and some Stage 1 cancer that has not spread outside the ovaries do not usually have chemotherapy.

#### Advanced epithelial ovarian cancer

Once as much of the cancer as possible has been removed by surgery, women with epithelial ovarian cancer that has spread outside the ovaries usually receive chemotherapy using platinum-based chemotherapy drugs. Platinum drugs may be used by themselves or combined with other drugs. Some of the platinum drugs that your doctor may mention are carboplatin and cisplatin. A different agent often used with the platinum drugs is paclitaxel.

### How will having chemotherapy help me?

Chemotherapy reduces your risk of the cancer returning, particularly if it hasn't spread too much. For most women it causes the cancer to subside and the symptoms to stop.

## What can I expect during chemotherapy?

### How is chemotherapy given?

Chemotherapy for epithelial ovarian cancer is usually given intravenously (through a drip into a vein in your arm). Some types of chemotherapy can be given in tablet form. You might also have heard about intraperitoneal chemotherapy (putting the chemotherapy drugs directly into the abdominal cavity using a tube). This method is not yet standard treatment but might be offered to some women. *See Chapter 9 for more information about clinical trials.*

### How soon after surgery will I start chemotherapy?

Chemotherapy will not stop your body from healing after surgery, so it can usually be started once your bowels have started to work again after your surgery.

### Who will manage my chemotherapy?

Your gynaecological oncologist or medical oncologist will explain which chemotherapy drugs are recommended for your situation and their side effects, how long you may need to take chemotherapy drugs and where you can have chemotherapy.

### Where will I go to have my chemotherapy?

If you are receiving chemotherapy into your vein, this may be done as an outpatient or day patient, or you may need to stay in hospital for a short while. If you are taking chemotherapy by mouth this can usually be taken by you at home.

If you live in an area where there is no medical oncologist or where chemotherapy services are not available, you will need to discuss with your treatment team who will provide your chemotherapy and where your treatment will occur. You may need to travel to the nearest large regional centre or city for treatment managed by a medical oncologist.

*"I made an appointment to speak to my oncologist about chemotherapy to ask him up front, what are my chances here? He sat and we chatted about it."*



## How long will the chemotherapy continue?

The times during which chemotherapy is given are called 'cycles'. The standard treatment for women with advanced epithelial ovarian cancer is to receive six cycles of chemotherapy, with one cycle every three weeks. Women with early stage disease may be given three to six cycles and some women with advanced disease receive more than six cycles. You have chemotherapy for a period of time, followed by a rest period so that your body has a chance to rebuild healthy cells and regain its strength. The treatment might be given on one day or over a number of days. The time it takes to give the drugs depends on the type of drug - it may be 30 minutes, or three to 24 hours.

## Common side effects of chemotherapy

Chemotherapy kills cancer cells but can also damage normal cells. The main areas in your body where normal cells are damaged are the mouth, stomach, bowel, skin, hair and bone marrow. The side effects of chemotherapy are caused by the damage to normal cells.

Each woman will have a different reaction to the chemotherapy used. The side effects also depend on the type of drug or combination, how much is given, by which method and how often. Ask your doctor about side effects you can expect from the chemotherapy recommended to you.

Your doctor might be able to adjust your chemotherapy treatment according to your side effects and how well your cancer is being controlled. Some of these side effects might only occur if the drug is used over an extended period of time.

The following are some of the side effects that you are likely to have with chemotherapy. It is not a complete list and not all women will have these side effects.

## Nausea and vomiting

As around half of women receiving chemotherapy will have some nausea or vomiting, you will be given drugs called anti-emetics with your chemotherapy to help prevent and to relieve

these side effects. These drugs are very effective in relieving nausea and vomiting but can cause constipation. Your doctor or oncology nurse can advise you about how to prevent and relieve constipation.

You can discuss other ways to manage nausea and vomiting with your treatment team but some things that may help include:

- having small meals at frequent intervals
- not lying down flat immediately after eating
- avoiding fatty or fried foods.

## Hair loss

Not all chemotherapy drugs cause hair loss. Your doctor can tell you whether you are likely to lose your hair from the chemotherapy that is recommended to you and whether other options are available.

Hair loss from chemotherapy can range from mild thinning of the hair to total hair loss (including body hair). If you do lose some of your hair, it will usually grow back within weeks or months of ending chemotherapy. It can start to grow back while you are still having chemotherapy. You might want to wear a scarf, hat or wig to cover your head while your hair is growing back. When it does grow back it may be a different texture from before. *See Chapter 15 for information about practical support.*

## Effect on blood cells

Chemotherapy can increase your risk of getting an infection. This happens because the chemotherapy drugs can reduce the white blood cells that fight infections. Your doctor will regularly check your white blood cell count during chemotherapy treatment.

Any infection you get during your chemotherapy treatment can be treated effectively with antibiotics, so contact your treatment team immediately if you have a fever (temperature greater than 38°C), chills, or severe sweats. Other possible symptoms of infection may include loose bowels, a burning sensation when you urinate, a severe cough or sore throat, flu-like symptoms,

*"I knew I was very likely to lose my hair, so I went off to a wig shop and bought a very nice wig, got some scarves and some big earrings and looked around for false eyelashes and things."*

*"I thought losing all my hair would be the worst thing that could happen to you and it isn't. It's not good but you get used to it."*

*"Turbans worked for me. One to match every outfit and sparkly ones for parties."*

*"When my hair grew back after chemotherapy it was curly. I'd always wanted curly hair. All my life I'd put up with long, straight, lifeless, boring, no fun, brown hair. But now... it was go, go, go in chemo!"*

unusual vaginal discharge or itching, and redness, swelling or tenderness around a wound, sore, pimple, boil, or the needle site where you receive your treatment.

### Bleeding or bruising

Chemotherapy can, rarely, make you more likely to bleed or bruise easily. This happens because the chemotherapy drugs reduce the platelets that make the blood clot. Your doctor will check your platelet count during chemotherapy treatment.

Tell your doctor if you have any signs or symptoms of reduced platelets - such as bruising more easily than usual, bleeding from gums or nose, reddish urine, and black or bloody bowel movements.

### Peripheral neuropathy (nerve damage)

Some of the drugs used in ovarian cancer chemotherapy can cause numbness and tingling in the hands and feet. This occurs gradually over time. If it occurs it may get worse with each treatment. It can lead to difficulty walking or buttoning clothes in severe cases. The symptoms will usually improve after the treatment has stopped. Your doctor will monitor you for this unwanted side effect.

### Other effects of chemotherapy

Other side effects reported by women undergoing chemotherapy are:

- feeling tired
- skin problems such as redness, itching, dryness, skin breakouts
- feeling anxious, distressed or teary
- weight gain or weight loss
- feeling vague or 'in a fog'
- kidney and bladder problems
- brittle or cracked nails
- mouth ulcers.

If you develop any of these side effects, tell your medical oncologist or treatment team. Allergic reactions to a chemotherapy drug do occur but are considered to be rare. Such reactions occur at the time that you are receiving your chemotherapy and can be treated very effectively. The possibility of an allergic reaction is one of the reasons why chemotherapy is given in a specialist oncology unit by experienced nursing staff.

### ? Questions you can ask your doctor or treatment team

- How will chemotherapy benefit me?
- When will I start chemotherapy?
- What chemotherapy drugs will I be having?
- How long will I need to have chemotherapy?
- How will it be given?
- Will the drugs make me sick? Will my hair fall out?
- What are the other possible side effects? Are they permanent or temporary?
- Will chemotherapy affect my fertility? Will I still be able to have children?
- Will I still be able to work?
- What things can I do/not do while I am having chemotherapy treatment?
- If chemotherapy doesn't work, are there any other treatments that might help?

*"I couldn't work, my hair all fell out and my head didn't leave the pillow for four days. My husband knew I was coming good when I insisted we go out for a spicy laksa."*

## Radiotherapy

This chapter explains:

- when radiotherapy is used
- what to expect with radiotherapy.

### What is radiotherapy?

Radiotherapy uses X-rays (controlled doses of radiation) to destroy cancer cells. Radiotherapy can reduce the size of the cancer and relieve pain or discomfort and other symptoms.

### When is radiotherapy used for epithelial ovarian cancer?

Radiotherapy used initially to treat women with epithelial ovarian cancer is called Whole Abdominal Radiotherapy (WART). Not all women with epithelial ovarian cancer will have radiotherapy. Your treatment team will discuss whether radiotherapy is recommended for you, based on things such as the stage and grade of your cancer, your response to surgery and other treatments like chemotherapy, and your symptoms.

Localised radiotherapy can also be used to treat the cancer if it comes back.

The pain and symptoms caused by the cancer may also be managed using radiotherapy.

### Who will manage my radiotherapy treatment?

A **radiation oncologist** manages radiotherapy treatment. He/she will tell you about the benefits and risks of radiotherapy and answer your questions.

A **radiation therapist** and an **oncology nurse** will also be part of the team that handles your treatment.

Radiotherapy is given in a hospital radiotherapy department. If this is not available in your area, discuss your options with your treatment team.

## Common side effects of radiotherapy

The treatment itself is painless but you might have some side effects at the time of radiotherapy treatment. These are usually only temporary and include:

- feeling tired
- diarrhoea
- vomiting
- nausea.

Other side effects, depending on the strength of the radiotherapy dose and how long you need to have the treatment, include: chronic diarrhoea, changes to liver function, inflammation of the lung and bladder and bowel obstruction.

### Questions you can ask your doctor or treatment team

- Why do I need to have radiotherapy?
- How will radiotherapy benefit me?
- Where will I go for the treatment?
- How long will I need to have radiotherapy?
- What can I do to help manage the side effects of radiotherapy?
- How long will I take to recover from the side effects?
- What happens if I decide not to continue with the treatment?

*For information about financial assistance for travel and accommodation expenses see page 57.*

*"My treatment was in the city and I had to fly back home to the country on the weekends, exhausted."*

*"She had a strong will and a strong constitution and that got her through it."*

*"They said it would knock me around and they could lower the dose. It did knock me around but it was only for four weeks so I thought I could put up with it."*

## Follow-up

This chapter explains:

- why follow-up is important
- what follow-up involves.

### Why follow-up is important

While follow-up is important to monitor your health, manage symptoms and to provide support, there is no evidence that you will live longer if your doctor finds that the cancer has come back sooner rather than later.

After discussion with your treatment team you may decide that you don't wish to have a regular scheduled follow-up program. If that is your decision, you can still arrange to contact your gynaecological oncologist or other member of your treatment team if you have symptoms or concerns that you need to discuss.

### What does follow-up involve?

After you complete your initial treatment you will need to discuss follow-up with your gynaecological oncologist/treatment team.

Follow-up visits might include a physical examination, including a pelvic examination, a blood test for CA125 (*see page 5*) or other cancer markers, and a discussion about any symptoms, effects of surgery or chemotherapy, concerns or problems. Your doctor will discuss whether you need to have any other tests such as a computed tomography (CT) scan or an ultrasound.

### Who will do my follow-up?

You may see your gynaecological oncologist, medical oncologist or another member of the treatment team for follow-up. For example, you may work out a program where you see the gynaecological oncologist at one visit and the medical oncologist at the next, if that is convenient for you. For women who have had surgically-induced menopause, follow-up might

be shared with your referring gynaecologist or GP to help you manage menopausal symptoms.

### How often will I need to have follow-up?

How often you see your treatment team member for follow-up will be worked out between you and your doctor. Your doctor may want to see you for follow-up visits every 2-3 months or every 3-4 months for the first two years after your initial treatment. The timing of the visits can be reviewed as time goes on and depending on your progress.

### ? Questions you can ask your doctor or treatment team

- How often should I have a follow-up visit?
- What happens if my CA125 levels have gone up between visits?
- Do I need further tests?
- If I decide not to have regular follow-up visits, who should I contact if I have any concerns about my health?

## FOLLOW-UP

*"I had quarterly CA125 tests and when they came back between 9 and 14, I used to do cartwheels around the hospital."*

*"She used to dread getting results of her CA125 tests. She got very anxious waiting for the results."*

*"The stress level builds as a check-up approaches. I tend to sleep a bit less. I tend to be more on edge and feel anxious coming up to my examination."*

*"I actually tell people that if I'm a bit short with them or not concentrating on what they're saying that I'm due for my test. Please excuse me."*

## Your feelings

Follow-up visits can be stressful. Having a physical examination, having tests done and waiting for the results can all make you feel worried or anxious. You may worry that the test will show that the cancer has come back. If you find that the visits are making you feel anxious or worried you should talk to the member of the treatment team doing your follow-up.

*"Relaxation was always important. One of the registrars asked me if I was Buddhist because of how calm and relaxed I was."*

*"I have acupuncture three times a week. I believe this helps with relaxation, speeds up my recovery, helps me sleep and encourages energy into the muscles where I've lost muscle tone."*

## Complementary and alternative therapies

This chapter explains:

- what complementary therapies are
- what alternative therapies are
- why it is important to tell your doctors about complementary or alternative therapies that you are taking.

### What are complementary therapies?

A complementary therapy is any treatment or therapy that is not part of the conventional medical treatment for cancer. Conventional treatments include surgery, chemotherapy and radiotherapy.

Some complementary therapies are:

- acupuncture
- relaxation therapy/meditation
- yoga
- Tai Chi
- positive imagery
- faith/spiritual healing
- laughter
- music
- art
- massage
- aromatherapy
- dietary therapies.

Some women use these therapies together with conventional treatments. For example, meditation or relaxation therapy may be used to help relieve pain.

There is evidence to show that:

- muscle relaxation and imagery can reduce distress in women with mild anxiety
- relaxation therapy can ease cancer pain
- acupuncture can ease pain.

### What are alternative therapies?

An alternative therapy is any treatment or therapy that is used as an alternative to conventional treatments.

Some alternative therapies include:

- naturopathy
- immune therapy
- homeopathy
- Chinese herbs
- megavitamins



Although these therapies are called alternative therapies, research has shown that most women who use alternative therapies also use conventional treatments.

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There is no evidence that alternative therapies can cure epithelial ovarian cancer.

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It is important to discuss with your doctor any complementary therapies or alternative therapies that you are using, as some treatments may be harmful or work against the benefit of conventional treatments, such as chemotherapy.

### ? Questions you can ask your alternative health practitioner

- What is the evidence for success of this treatment?
- Will this therapy affect other treatments I am having?
- How much will this therapy cost?
- What side effects may occur?
- How commonly do side effects occur?

## Clinical trials

This chapter explains:

- what clinical trials are
- the advantages and disadvantages of participating in clinical trials.

### What are clinical trials?

During the course of your treatment you may be asked if you would like to take part in a clinical trial. Each clinical trial must be approved by an ethics committee established by each hospital and health service.

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A clinical trial is research that aims to find better ways to prevent, diagnose, or treat diseases.

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### What are the advantages and disadvantages of participating in a clinical trial?

The advantage of participating in a clinical trial is that you may receive newer treatments that are not yet available to the general public and may be more effective. By participating in a clinical trial you will also be helping other women who are diagnosed with cancer in the future. The disadvantage of participating in a clinical trial is that the newer treatments may not be more effective than standard treatments and might have more side effects. The trial might involve more tests, X-rays or paperwork, but this will be explained to you by your doctor or the researcher.

Many clinical trials have a control group, which means that you may not receive the newer form of treatment during your participation in a trial. You will not be able to choose whether you are in the group that receives the newer treatment or in the control group. However, in the control group you will always receive the best proven care and will be looked after by a member of the clinical trial team, usually an oncology nurse.

## How do I decide whether to participate in a clinical trial?

You may hear about a clinical trial for epithelial ovarian cancer and be interested in taking part. You need to discuss this with your treatment team. Clinical trials usually have a set of criteria that need to be met and your doctor can discuss whether you may be eligible. If you are invited by your doctor to enter a clinical trial, you should ask for as much information as possible so that you can weigh up the risks and benefits of this decision.

If you decide not to accept an offer to be part of a clinical trial, this will not affect your treatment in any way. If you join a clinical trial and then decide not to continue you are able to leave the trial at any time without affecting your ongoing treatment. The consent form you sign ensures this.

### ? Questions you can ask your doctor

- Are there any clinical trials for epithelial ovarian cancer that may be suitable for me?
- What aspect of epithelial ovarian cancer does the clinical trial cover?
- Who can I contact if I have questions or concerns about the trial?
- What will I have to do as part of the clinical trial?
- Will I need to go back into hospital for the trial?
- What are the possible side effects?
- Are there any risks involved?
- How long will the trial last?



### For more information about clinical trials you can:

- speak to your doctor
- visit the Australian Clinical Trials Registry at [www.actr.org.au](http://www.actr.org.au)
- ring the Cancer Council Helpline (13 11 20) for a copy of *Understanding Clinical Trials* or visit the website of the Cancer Council in your state or territory (see Appendix *Resources for women with epithelial ovarian cancer and their families*).

*"I was asked to participate in a clinical trial. I found it gave another dimension and purpose to my treatment."*



## Controlling symptoms and side effects

This chapter explains:

- some of the symptoms and side effects you might experience
- how to manage symptoms and side effects.

You might experience symptoms caused by the cancer. The treatment you have may also cause some side effects.

Some of the symptoms reported by women with epithelial ovarian cancer are listed below. You might only experience some of these symptoms. Your doctor should tell you about any side effects of drugs or other treatments that are recommended.

Tell your doctor if you have any of these symptoms or if they do not get better with treatment. Always tell your doctor about any new symptoms or if your symptoms get worse.

### Nausea and vomiting

Might be caused by:

- bowel obstruction (a complication of epithelial ovarian cancer)
- treatment using chemotherapy or radiotherapy
- the effects of not being able to eat properly
- drugs for pain or symptom relief
- constipation
- the cancer.

Your doctor can prescribe medication to help control nausea and vomiting. Depending on how bad the nausea and vomiting become, the causes and the impact on your quality of life, your doctor can also discuss other options that are available to you.

### Loss of appetite

Might be caused by:

- treatment such as chemotherapy or radiotherapy
- constipation or bowel obstruction
- drugs for pain or symptom relief
- decreased physical activity
- nausea and vomiting.

You might feel uncomfortable eating normal-sized meals, crave certain foods or find that some foods upset you. Your treatment team can give you some practical suggestions to help treat loss of appetite.

### Pain

Might be caused by:

- the cancer or its spread into other parts of the body
- bowel blockage or obstruction caused by the cancer
- ascites (a build-up of fluid in the abdomen).

*See Chapter 12 for more information about managing pain.*

### Distended (swollen) abdomen

Might be caused by:

- ascites
- obstruction of the bowel from cancer
- constipation
- the spread of the cancer into the liver
- inflammation of the bowel due to chemotherapy or radiotherapy.

If you experience a build-up of fluid in your abdomen, your doctor can advise you about how this may be slowed or how the fluid can be removed.

### Constipation

Might be caused by:

- use of drugs such as codeine or morphine for pain relief or anti-emetics for nausea

When you talk to your doctor about your symptoms, be as exact as you can so that the appropriate treatment can be prescribed. You may find it helpful to keep a diary of how well your symptoms are being controlled. Take your diary with you when you see your doctor.

- lack of movement due to weakness or pain
- the cancer affecting the bowel
- not drinking enough fluids.

If you become constipated you should ask your doctor or treatment team about the best option for you. Your dietitian can advise you about ways in which you could benefit from a change of diet.

### Dyspnoea (shortness of breath)

Might be caused by:

- the muscles in the diaphragm becoming rigid in an effort to avoid painful movement
- ascites
- pleural effusion (a build-up of fluid in the lungs).

If you notice that you are short of breath, speak to your doctor about the ways in which this may be relieved. Women with recurrent epithelial ovarian cancer may experience a build-up of fluid in the lungs. If this happens your doctor will talk to you about ways of relieving the symptoms and removing the fluid.

### Lymphoedema

Lymphatic vessels run from the limbs towards the heart, usually beside veins. They collect normal tissue fluid and dead cells. Lymphoedema is swelling in an area of the body due to the lymphatic vessels being blocked. For example, lymphoedema may be experienced in the leg if the lymph nodes in your pelvis have been removed during surgery.

Lymphoedema might be caused by:

- surgery or radiotherapy to the area
- the cancer.

Lymphoedema can range from very mild to severe. There are specially trained nurses to help if lymphoedema occurs and the physiotherapist and occupational therapist on your treatment team can also provide advice and treatment.

### Discharge from the vagina

Might be caused by:

- the cancer
- lack of hormones
- infection.

### Thromboses (blood clots)

Caused by:

- an increase in the clotting properties of the blood as a result of the cancer.

### Feeling tired

Might be caused by:

- the side effects of treatment such as chemotherapy, radiotherapy and surgery
- anaemia (low amount of red blood cells in blood)
- coping with pain or other symptoms
- travelling for various treatments
- the stress of living with cancer
- the cancer
- poor sleep.

Your treatment team can give you some suggestions to help you conserve your energy, improve sleep and reduce tiredness.

### Mouth ulcers

Might be caused by:

- chemotherapy
- viral infections
- unknown reasons.

Washing your mouth out with a solution of sodium bicarbonate, keeping your teeth clean using a soft toothbrush and using an analgesic gel or mouth wash may help to relieve the discomfort. Speak to your oncology or community nurse for specific advice.

## Incontinence

Some women may lose control over their bladder and bowels, although this is rare. A community nurse can advise you on how to manage incontinence, and how to make yourself more comfortable.

You should let your doctor know immediately if you suddenly lose control of your bowels or bladder.

## Recurrence of epithelial ovarian cancer

This chapter explains:

- how the cancer recurs
- how it is discovered
- what can be done about it.

### How does epithelial ovarian cancer recur?

When epithelial ovarian cancer is at an advanced stage at first diagnosis, it has already spread or seeded to other areas within the pelvis or to areas and organs outside the pelvis, such as the liver, lungs or (in very rare circumstances) the brain. The cancer can then grow in these areas, even if the ovaries and other affected organs have been removed.

Even after a good response to the initial surgery and chemotherapy, it is likely that women with advanced epithelial ovarian cancer at first diagnosis will have the cancer recur. Generally, the longer the time between the end of the first-line treatment and the return of the cancer, 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 treatment.

### How will I know if the cancer has come back?

Your doctor may be alerted to the return of the cancer by an increase in the levels of CA125 in your blood or by changes found when you are examined, usually confirmed by an ultrasound or computed tomography (CT) scan. You may also notice symptoms or changes in your health. You should always mention these changes to your doctor.

### What can be done if the cancer comes back?

The most common treatment for recurrent epithelial ovarian cancer is more chemotherapy. The type of treatment used

# 11

## RECURRENCE OF EPITHELIAL OVARIAN CANCER

*“I had a recurrence and I had three lots of chemotherapy. I would tell somebody else in my position that the treatment was well worth it. I would advise her to fight it.”*

*“When I had a recurrence I found the Internet incredibly helpful, especially the chat sites where you got feedback from other women.”*

depends on how long it has been between the end of the first treatment and the cancer returning. Ask your doctor about the type of chemotherapy that will be best for you. While the cancer may respond to chemotherapy it is not likely to cure it.

### ? Questions you can ask your doctor

- Are there any particular symptoms that may tell me that the cancer has come back?
- What are the treatments for recurrent epithelial ovarian cancer?
- For how long will I need to continue treatment?
- How will you know if the treatment is working?
- Will I need treatment straight away if my CA125 level goes up?

## Pain Management

This chapter explains:

- why you need to discuss your pain with your doctor
- how the cancer pain can be managed
- coping with the pain.

### Cancer pain

Not everyone with cancer will suffer pain. For those women who do experience pain, improvements in drugs and a better understanding of the causes of pain mean that cancer pain can usually be effectively controlled. Pain management aims to relieve your pain during the night and the day, both at rest and on movement. It can involve drug and non-drug treatments.

Pain does not always get worse. The level of pain experienced may remain unchanged, or may increase or decrease. In any situation medication can be adjusted to ensure pain relief. Pain is not necessarily related to the extent of the cancer.

### Reporting your pain

It is important that you do not put up with pain. You should report any pain to your doctor, even if it is minor, so that your doctor can investigate the cause of your pain and recommend appropriate pain relief. There are various drugs to control different levels of pain. Always tell your doctor about any new or worsening pain. Do not change or start any pain relief medication without consulting with your doctor.

### Treating pain

#### Drug treatments for pain

There is a large range of effective drugs for pain of all types and severity. Drugs used to control pain include:

- aspirin and paracetamol
- codeine-based drugs
- anti-cholinergic drugs (drugs to relieve colicky pain)
- non-steroidal anti-inflammatory drugs (NSAIDs)
- morphine and other strong opioid drugs.

**Relaxation therapy and acupuncture have also been found helpful to manage pain. Your doctor or other members of your treatment team might also advise you about non-medical methods of pain relief, such as relaxation therapy.**

Women with epithelial ovarian cancer who take morphine or other strong opioid drugs may worry that they are addictive or that they have unpleasant side-effects. These drugs are safe and effective for moderate to severe pain. The dose of morphine can be increased or reduced according to the severity of your pain to give you pain relief.

The drugs can be used in a number of ways:

- patient-controlled analgesia (PCA) pumps
- patches worn on the skin
- injection into skin or muscle
- tablets or liquids
- suppositories.

If these measures do not control your pain ask your doctor about other ways to relieve pain.

### Side effects of morphine or other opioid drugs

Possible side effects of morphine or other opioid drugs include:

- drowsiness
- constipation
- a dry mouth
- nausea and vomiting
- itchiness (a less common side effect). If this occurs, inform your doctor.

These side effects often subside after the first two or three days.

### Other medical treatments for pain

Other medical treatments for pain include:

- antidepressants
- muscle relaxants
- radiotherapy
- steroids
- surgery.

Your doctor will discuss these options with you, if it is felt that any of them would be beneficial.

## How will I know which pain relief is best for me?

Choosing a drug or a combination of drugs for pain depends on the type and severity of pain. If one drug does not effectively help your pain, many other drugs or combinations of drugs can be used to give you pain relief. It might take time, in consultation with your doctor, to establish the drug or drug combination that is right for you.

While most pain relief drugs have some side effects, they are generally not serious. Not everyone experiences side effects. They can be reduced by treatment (for example using other drugs to treat side effects) or by changing to a different medication. Your doctor can advise you about any side effects that you should look for, and what to do if you experience them. You can also ask your pharmacist for a drug information printout.

### Coping with your pain emotionally

Any pain can be difficult to cope with. However, pain is more difficult to cope with if you are also experiencing anxiety or depression. Also, being in pain can make you more likely to be depressed or anxious. If you are concerned by the feelings you are experiencing, it is important that you talk to your doctor as soon as possible. Help is available. Support from friends, family, religious organisations, trained counsellors, psychologists or psychiatrists, or joining support groups with other women in a similar situation might help you cope with your pain. *See Chapter 14 for information about coping with a diagnosis of epithelial ovarian cancer.*

*"I'm a queen of the trivia and so I laughed through so many things."*

*"I find using a relaxation tape incredibly helpful. I have played it 300 times a year for four years. At the moment I'm doing it four times a day."*

*"I've had a lot of help from an 'aqua-recovery' course. Being a water baby it was just up my alley."*

**? Questions you can ask your doctor**

- What type of pain relief is best for me?
- How often will I need to take the medication?
- How bad does the pain have to be before I get some pain relief?
- What side effects can I expect?
- How can the side effects be relieved?
- What are the alternatives if this pain relief doesn't work?
- Can I drive if I am using pain relief?
- What effect will the pain relief have on other medication that I need to take?
- Are there any non-drug treatments that can help to relieve my pain?

**Palliative Care**

This chapter explains:

- what palliative care is
- when to think about getting palliative care.

**What is palliative care?**

Palliative care includes care at home or in hospitals, hospices or palliative care units for people whose disease cannot be cured. Any treatment that you have for advanced epithelial ovarian cancer that helps reduce your symptoms and improves your quality of life, such as radiotherapy or chemotherapy, can also be called palliative care.

Palliative care focuses not only on physical symptoms, but also on emotional wellbeing, relationships with others and spiritual needs.

A specialist palliative care service can provide:

- information about drugs used for pain and symptom relief
- practical support about how to cope with your symptoms
- emotional support for you and your family/carers.

**Who provides palliative care services?**

A specialist palliative care service may involve a palliative care consultant, a palliative care nurse, a palliative care social worker/counsellor and palliative care volunteers. The team works with your specialist, GP and community nurse and other members of your treatment team to provide you with the best possible care. Speak to a member of your treatment team (eg your GP) to find out how you can access palliative care services.

**When should I think about using palliative care services?**

There are benefits in establishing contact with a specialist palliative care service, even while you are relatively well. Contact with a specialist palliative care service does not stop you from having treatments and follow-up that your other doctors recommend.



## Will I have to go into a hospice or palliative care unit?

A member of the specialist palliative care team will visit you in your home, or if you are in a hospital, hospice or palliative care unit they can visit you there. They will assess your need for care by a specialist palliative care team.

### ? Questions to ask your doctor

- Who decides whether I should have palliative care services and when I need them?
- How can I access palliative care services?
- Will I be able to claim any of these services back from Medicare?
- Will my private health fund cover any of the costs of these services?
- If I can't afford the costs is there anywhere that I can get financial assistance?

*"We've had our house fitted out as a 'hospital in the home' with all whiz-bang gadgetry and they all work. I've set myself a goal to get to a rugby game."*

Palliative Care Australia is the national organisation for palliative care in Australia. For further information visit their website at [www.pallcare.org.au](http://www.pallcare.org.au) or telephone the national office in the ACT on 02 6232 4433.

## Coping with your diagnosis

This chapter explains:

- how you might feel after being diagnosed
- the impact your diagnosis and treatment might have on your partner, children, family and friends, and on other aspects of your life, including your sexuality
- how to find support to help you cope with your diagnosis and treatment.

### Your feelings

Being diagnosed with epithelial ovarian cancer is a very personal experience to which each woman brings her own beliefs, strengths and coping strategies. Your diagnosis may have made you feel shocked, angry or afraid. Perhaps you felt relieved to find out what was actually wrong. Coping with your diagnosis is an ongoing adjustment process.

### Depression, sadness and grief

Many women experience sadness, grief or some level of depression. Depression can be brought about by the physical effects of the cancer and its treatment, as well as the psychological effects. You might feel a sense of loss from the removal of your ovaries and uterus and the resulting infertility, from being ill, experiencing financial hardship, changes in relationships and from losses associated with your change in circumstances.

Working through loss is an ongoing process. Allow yourself the opportunity to experience your grief and sadness. This is an important part of the process of coping with the cancer. Over time, most women find the distress lessens. For some women, however, the sadness is more severe and long-lasting, and specific treatment might be needed.

If you are experiencing any sadness, grief or depression that feels overwhelming, it is important that you talk to your doctor or another member of your treatment team as soon as possible to discuss the treatment options available for you.

*"I woke up from surgery and my husband was crying. I thought, 'I'm only 43. I'm fit. I'll beat this bloody thing!' And I did."*

***“This experience brought my partner and I closer together. We realised that we are not immortal or invulnerable and it made us realise that we need to make the most of our life.”***

## Fear and anxiety

Women with epithelial ovarian cancer face many fears as they try to come to terms with their diagnosis. Feeling anxious or fearful is a common reaction to a very distressing situation. It is normal to fear the unknown and to be anxious about test results, whether the treatment is working and how you will cope. Anxiety might also have a physical cause such as pain or certain drugs.

You might find it helpful to talk to someone with whom you feel comfortable - your partner, a friend or family member or your religious representative. You might prefer to seek help from a health professional or from someone who has been through a similar experience. Relaxation or meditation techniques might also be helpful.

If your anxiety or fear feels overwhelming, treatment can help. Most women find that they are much better able to cope with their physical symptoms when their depression or anxiety is effectively treated. Ask your treatment team as soon as possible about the treatment options available for you.

## Finding strength through difficult times

Throughout the difficult times you may also discover your strengths and weaknesses. You might deepen your relationships with others, or form new friendships and explore your spirituality. Although difficult, it might be a time of great learning.

Women with epithelial ovarian cancer find that hope helps them to get through each day, as it comes. Some women hope for a cure or that the cancer will not return. What is hoped for may change over time, for example, it may turn to hope that you will be as comfortable as possible and enjoy the best quality of life as you deal with the disease.

## The impact of your diagnosis and treatment

### The impact on your sexuality

The physical changes of having epithelial ovarian cancer, and its treatments, often have a profound impact on how women feel about themselves and their sexuality, whether they have a partner or not.

The changes to your body, your level of energy and your mood will affect how you feel about yourself, your sexual desire and your ability to be sexual with others. Coping with these changes will involve an ongoing adjustment process as your situation changes.

You might experience sexual difficulties due to the cancer, treatment, or treatment side effects, and these could include:

- feeling less attractive because of hair loss, body changes, treatments, and illness
- feeling that you are an incomplete woman as a result of surgery or the inability to have children
- lower libido due to feeling unwell, tired, worried, being in pain, having cancer treatment or taking medication
- vaginal dryness due to chemotherapy, medication or to menopause brought about by surgery
- difficulty being physically active due to pain or disability.

Although it might be difficult, it is important to communicate with your partner about your respective fears and needs. This might help you find creative ways to adapt to your situation and help you feel closer to one another.

If sexual intercourse is difficult or not what you feel you want to do, explore being sexual in other ways. You might find it helpful to discuss the effects on your sexuality with a counsellor, psychologist, psychiatrist, social worker or oncology nurse.

***“I’m someone who has always been extremely competent but I lost some confidence in my body image. I was a bit frustrated that I lost my confidence.”***

***“The issue of sexuality after surgery for ovarian cancer needs to be addressed. My partner and I used a checklist that helped us talk about our likes and dislikes.”***

## Issues for lesbian women

You might feel that a lot of attention is placed on heterosexual couples or that lesbian sexuality is not mentioned when talking about the effect of the diagnosis on sexuality. Some partners also feel invisible, or even feel discriminated against.

You need to feel comfortable with your doctor and other members of your treatment team. You do not need to disclose your sexuality to your treatment team. However, if you feel comfortable with your treatment team, disclosure might help you feel more supported.

*For further information about useful contacts or resources see Appendix: Resources for women with epithelial ovarian cancer and their families.*

## The impact on your family and friends

The news of your diagnosis with epithelial ovarian cancer will affect your partner, family and friends. Everyone reacts differently. Some relationships or friendships break up, while others grow and are deepened by the experience. For your family, partners or friends, coping with your diagnosis is an ongoing adjustment process. Women with epithelial ovarian cancer sometimes remark that it seems harder for family and friends as they often feel helpless or don't know what to do.

Some of the feelings that a partner, your family and close friends may have after your diagnosis, as experienced by others in a similar situation, include:

- denial
- sadness and depression
- anger and resentment
- feeling closer to you
- feeling powerless
- fear and anxiety
- shock
- guilt.



Good communication between yourself and others is essential in adjusting to your changing circumstances and resolving any problems. There may be times when you want to be left alone to sort out your thoughts and emotions. This can be hard for your family and friends who want to share this difficult time with you, but you should feel free to tell them when you need some personal time.

You may want to involve your family and friends in treatment. For example, someone whom you feel is supportive - a family member, a close friend or a partner - may attend discussions with your doctor or other members of your treatment team.

Women who live alone or who do not have family or friends close by might find coping especially difficult. Some women find support through their church or through community groups, social clubs or sporting clubs to which they belong.

While you should make time for family and friends, you might also encourage them to have time away from you. Their own needs are important and some time out might help them to have more energy to support you.

Talk with your doctor if you are concerned about any of your relationships. Your doctor, oncology nurse or the social worker on your treatment team may be able to talk with a family

***“Some of my friends just couldn't cope and they don't come to see me anymore. But some people I barely knew have stepped in and become much closer. They became wonderful and helped me get through some really bad patches.”***

***“My husband was very supportive. I could not have gone through the first chemotherapy and the recurrence without my husband being there every day.”***

**The National Breast and Ovarian Cancer Centre website [www.breasthealth.com.au/boysdocry](http://www.breasthealth.com.au/boysdocry) is a useful source of information and support for the male partners of women with breast cancer. Much of this information is also relevant for the partners of women with epithelial ovarian cancer.**

***“We had to really make time for us.”***

***“My family was terrific. They were sympathetic and supportive. They were not pessimistic.”***

member, partner or close friend during your next consultation, or a separate appointment can be made to discuss any issues of concern.

### **The impact on your children**

Children and teenagers in your family will be affected by your diagnosis of epithelial ovarian cancer. It is important that you talk to them about your situation, so that they understand what is going on. There is evidence that talking with your children about your illness helps them to cope better.

Children are often concerned about changes in the family and are worried that the well parent may also get sick. Children might also worry that they have caused your illness.

Children might have a range of responses to your diagnosis, such as:

- being angry at you for being sick
- withdrawing from you
- clinging to you
- resenting that they need to help you
- behaving badly to cover up real feelings
- wanting to get sick to get attention
- going through the stages of grief you are going through
- being afraid that they will get cancer too.

Teenagers might feel particularly vulnerable as they try to cope with their own problems and with the situation of you having cancer. Daughters might worry whether they will also get ovarian cancer. It might be difficult for teenagers to talk about these issues.

Teenagers in the family might need to take on more household chores or care for you. Disruption to their social outings or leisure activities can be issues for them. Sometimes this can make them feel that their needs are not being met. They might have an intense desire for life to return to ‘normal’ and feel resentful at the disruption to their lives and the change of roles within the family.

Teenagers might have a range of issues to face at this time, including:

- worry about the effect of the cancer on your marriage and the stability of the family
- feeling stigmatised because their mother has cancer
- fear about whether your treatment will be effective
- concern about their relationship with the other parent
- dealing with any unresolved issues with you
- anxiety about the well parent
- feeling isolated from friends
- wanting to be closer to you.

Encourage them to communicate honestly about their needs and about their feelings. It is important that they are allowed to talk about death and their feelings of loss and resentment. If they cannot talk to you there may be a relative or friend with whom they can let out their feelings. Many young people who have friends or relatives with cancer find CanTeen helpful. *See page 68 for more details.*

You could talk to your doctor or the social worker on your treatment team about how you can help children and teenagers close to you to cope with your diagnosis. If you are worried about your children you can ask your doctor to refer them to a trained counselling specialist such as a counsellor, psychologist or psychiatrist, or the whole family can see a family therapist.

**The National Breast and Ovarian Cancer Centre website [www.myparentscancer.com.au](http://www.myparentscancer.com.au) is designed primarily for teenagers with mothers who have breast cancer. However, much of the information is relevant generally for teenagers with a parent who has cancer.**

***“My daughter hasn’t coped with my diagnosis and she’s left home. It’s a lot of responsibility to put on a kid to be the prime carer of a person with cancer.”***

## Making a decision about continuing to work

Some women who are feeling well, and who are employed at the time of their diagnosis, find that continuing to work is helpful. For these women, continuing to work makes them feel valued and provides them with the comfort of being around people with whom they are familiar.

Other women who are employed at the time of their diagnosis want to make changes in their work life. They may stop work so that they can have more time to enjoy the things they have always wanted to do, or they might change jobs, work part-time, work flexible hours or do volunteer work.

Deciding about whether to continue working will depend on your health, your financial situation and your priorities. If you feel you need more support (other than the support you receive from your family and friends) in making decisions about work, talk to your doctor or ask your doctor for a referral to a health professional who is experienced in counselling.

## Finding support

### Cancer Council Helpline

Contact the Cancer Council Helpline on 13 11 20. The Cancer Council Helpline provides telephone and written information about cancer and related issues. Each call is confidential and remains anonymous.

### Support groups

Support groups are regular meetings for people to talk about their experiences and share their concerns and fears with other women in similar circumstances. Support groups might be run by health professionals or by women diagnosed with cancer ('self-help' groups).

Some support groups are for women with ovarian cancer, while others are for women with any type of gynaecological cancer or people with any type of cancer.

Some groups are for family and friends of women with ovarian cancer.

*For information about support groups and services see page 67. You might also like to talk to other women who are in a similar situation via 'chat' groups on the Internet.*

### Ovarian Cancer Australia Limited

Ovarian Cancer Australia Limited has stories written by women with ovarian cancer on their website. It also produces a free newsletter. The number is 1300 660 334 and its website address is [www.ovariancancer.net.au](http://www.ovariancancer.net.au)

### Gynaecological Cancer Psychosocial Support Services

This website provides information about social and emotional issues women face after being diagnosed with ovarian cancer. The website address is [www.gynaecancersupport.org.au](http://www.gynaecancersupport.org.au)

*"My greatest support was an online email mailing list of over 1000 women with ovarian cancer. I read this list every night and contribute to it very often. It's been my absolute lifeline. They're the mothers, the grandmother and the sisters I don't have."*

*"My advice is to ask your doctor or the senior nurse in charge if you can be put in touch with another woman with ovarian cancer."*



*"It's really important to keep everyone well informed. My partner and I made a decision to fully include friends and family in my day-to-day health management."*

*"I spent a lot of time caring for my wife through some unpleasant experiences and it brought us closer together. I won some 'brownie points' which is pretty hard for most husbands to do."*

## Practical and financial support

This chapter explains:

- how to get support
- what practical support services are available
- where you can find out about what financial assistance is available.

### Where can I get support?

There might be times when you need help to do all the things you would usually do in your home. This might happen when you are recovering from surgery or treatment, or if the cancer progresses. It can be difficult to accept the loss of some of your independence and have people look after you, but accepting help can allow you to conserve your energy for things that are really important to you.

Your family, partner, friends or neighbours might be able to give practical support. Although it is sometimes difficult to accept this support, remember that others might feel good if they can help.

As well as practical support from family, friends, partners or neighbours, outside help is available. Accepting outside help can put less strain on family and friends and allow you to spend more pleasurable time with those close to you. Remember, the sooner you ask for help for whatever type of care, the easier and quicker it will be to organise and receive it.

### What types of support services are available?

Support services can cover a number of areas - from accommodation while undergoing treatment, to assistance with a wig for hair loss during chemotherapy and practical help around the home. The social worker, discharge planner or community liaison nurse in the hospital or your GP will assess your need for care at home. They can inform you about the support services available in your area and make the necessary arrangements for your care at home.

### What types of services are available in my home?

A number of different people and organisations provide services to help women in their own homes. The support services available to you will depend on the state or territory and the region or town in which you live. You will need to check what is available in your local area.

The people involved in your care and types of services which might be available to you include:

- Your **general practitioner** might be responsible for your care once you have left hospital.
- **Community nurses** offer a variety of practical services, which may include assistance with bathing, changing dressings, giving medication and providing support to you and your carers.
- **Occupational therapists** can help in providing practical aids to assist your self-care. They can also arrange for minor changes to your home, such as the fixing of handrails in bathrooms. If you are having difficulty dressing they may be able to suggest and arrange alterations to clothing.
- **Physiotherapists** can help you keep mobile and help you with pain relief, specific treatments, massage and exercise programs.
- **Palliative care teams** might involve a palliative care consultant, a palliative care nurse, a counsellor or social worker and palliative care volunteers. The teams work with your specialist, GP and community nurse to help you with control of pain and other symptoms and give emotional support to you and your family or carers.
- **Private nursing agencies** can provide services extra to those of the community nurse. The time required can be

*"I've become expert at being a real bossy boots and I recommend it to everyone. Your garden will never look better, your fridge will never be so full, your carpet will never be so spotless and your laughter will never be so great."*

*"Because people really want to help and be part of the picture, I tell them what to do and they will do it... happily."*



negotiated with the nursing service and the cost will vary according to the type of care and the number of hours required. Some nursing services offer care 24 hours a day. If you have private health insurance you should check to see if this service is covered.

- **Home care service/domiciliary care services** can provide practical help in your home. They can provide services such as respite, basic domestic help and personal care; essential home and yard upkeep are sometimes available. You could be placed on a waiting list. The greater your need, the sooner you will receive help. The cost of the service is adjusted according to your ability to pay.
- **Private home care services** are also available, providing assistance with shopping, washing and cleaning. Charges apply.
- **Meals on Wheels** will deliver meals on weekdays to housebound people for a minimal charge. You can contact them directly, but you need a referral from your GP, social worker or community nurse.
- **Church or other religious groups** might offer support to their members, such as going shopping for you. Contact your local church to find out if any such help is available.
- **Volunteer respite carers** can come and visit you for a set time each week or fortnight to give your carer a break. They may visit for between half an hour to a few hours to chat, help with letter-writing, phone calls, reading or just to be there. Your local community or neighbourhood centre can give you information about these services.

### What services are available to provide care?

If your illness progresses, you might need to be looked after outside your home, such as in a hospital, palliative care unit or hospice, or you might go into respite care for a short period in order to give your carers a break. *For more information about palliative care see Chapter 13.*

There are a number of services available to give you care outside your home.

- **Day centres**, often attached to nursing homes, hospitals or hospices, offer specialist care in nursing, leisure activities, symptom control, counselling and an opportunity for social interaction. Open during the day they often provide a transport service.
- **Nursing homes** can offer short-term accommodation, and sometimes long stay care, to give your carers a break. Nursing homes will charge a fee.
- **Hospitals**, both public and private, have beds available for short- or long-term care. Access to public hospitals will depend on beds being available at the time and your level of need.

Ask your doctor or community nurse about these services.

### Financial support

Having epithelial ovarian cancer might have an impact on your financial situation. You might need to give up work, your partner might need to take time off to care for you and there might be additional costs such as medications, extra support services, travel and accommodation.

### Accommodation and travel assistance

State and territory health departments have travel and accommodation schemes for people from rural and regional areas who need to travel to receive treatment. For more information contact your state or territory health department.

### Program of Aids for Disabled People (PADP)

These programs are state-based and provide equipment and aids to help people live independently. Equipment such as wheelchairs, shower chairs and wigs for those women suffering

**To find out about where to go for financial assistance or practical help, start by asking your hospital or community social worker or your community nurse about benefits for which you might be eligible. He or she can also help you in claiming them.**

**You can also contact The Cancer Council Helpline on 13 11 20 for information. Some local councils also help with practical matters, such as child care, meals and general home help. Centrelink is also a useful source of information about your financial entitlements. Visit the Centrelink website at [www.centrelink.gov.au](http://www.centrelink.gov.au) or phone 132717**

hair loss from chemotherapy might be provided. PADP provides the equipment on indefinite loan for as long as it is needed, except for personal use items such as wigs, which are not required to be returned. You will need to get a letter from your doctor and your needs will be assessed by a health professional, such as an occupational therapist.

Your local hospital or community nurse will be able to tell you about other schemes that are available or places where you can get equipment cheaply.

## Putting your affairs in order

This chapter explains:

- what you might consider to prepare for dying
- how to decide about ending treatment
- legal issues to consider.

Reading this chapter does not mean that you are dying. Any woman who finds out that she has epithelial ovarian cancer goes through the process of wondering what will happen and whether the treatment will be successful. Putting your affairs in order, no matter what the expected outcome, can be a very useful thing to do and can provide some peace of mind for you and your loved ones.

However, if you find this chapter difficult to read just now, please read it when you feel you are able.

### Unfinished business

This might be a good time to think about the relationships or friendships that are important to you. You might not have been in contact with some of your friends for a while, or you might have had a 'falling out' with someone that you now want to repair. You might want to spend more time with particular people, or you might want to say something to someone that you feel you have always wanted to say. This can be a time of healing and strengthening the relationships and friendships that are important to you.

However, it is unrealistic to think that all the conflicts in your past or present relationships and friendships will be able to be resolved. It is a matter of prioritising those in your life who are important to you, those with whom you want to try to resolve any issues, and those with whom you want to spend time.

You might find yourself thinking about the past. You might want to visit the place where you were born, or go through your old photographs. This might be a good way to come to terms with the events in your life.

*"I feel fortunate  
to be able to say  
goodbye to my  
friends and people  
who love me and  
care for me."*

You might also want to write letters to people you are close to, or prepare a tape to be given to them after your death, or to be given to children or grandchildren at major events in their lives.

Whatever you do is a very personal experience, and you need to do what is right for you, at the time that feels right.



### Spiritual or religious comfort

Religious beliefs and the question of meaning can become increasingly important to women with epithelial ovarian cancer. You might find that your diagnosis has deepened your faith, or has made you question it. You might feel confused about what you believe and why this is happening to you. It might be useful to talk to a priest or religious representative about questions you have, even if you have not attended any services for a while.

### What if I decide not to have any more treatment?

It is difficult to decide when to stop cancer treatment. You need to get as much information as you can from your treatment team and weigh up the possible benefits and the side effects of each treatment. It is important to think about your quality of life.

Talk about your decision with your doctor or other members of your treatment or palliative care team, your family, partner and friends or a counsellor, psychologist or psychiatrist.

Ultimately, the decision to stop cancer treatment is your decision. You might feel that although you want to stop treatment, your family or your partner does not want you to. If this happens, you and your doctor or a counsellor or psychologist might need to talk to your family or your partner about their concerns.

### Fears about dying

Many people fear dying. This is natural, particularly in the Western world where we do not have much contact with people who are dying. Dying can be a very peaceful process, and health professionals working with people who are dying report that there is often a sense of calm surrounding the person who is dying.

The process of dying for women with epithelial ovarian cancer usually occurs over a period of time and as the body gets weaker over time, this can help women to let go.

Health professionals working with people who are dying say that most people know when they are dying. You can be reassured that when you are dying everything will be done to keep you as pain free and comfortable as possible, and that you can have family and friends with you.

Coming to terms with dying is an ongoing process. It can be helpful to express your fears and concerns about dying to your doctor, family and friends. This can also help them to express their fears and grief about you dying, and bring you closer together.

### Practical aspects of preparing for death

It is important to think about the practical aspects of preparing for death, although it can be difficult to do so. This can ensure that your wishes are acted upon. It can also prevent any painful decisions that your partner or family might need to make if you do not express your wishes.

Legal considerations differ in each state and territory. However, some things to consider include:

- **Living will or an Advanced Health Directive**

You may wish to discuss with your partner, family and/or a close friend and your doctor whether or not you wish to be kept alive by artificial means, or resuscitated if you stop breathing.

You might also write an Advanced Health Directive stating your wishes. An Advanced Health Directive is a document that states your wishes or directions regarding your future health care. It can be used to cover matters such as consent to future health treatment and the circumstances in which you want, or do not want, to have life-sustaining measures. The Advanced Health Directive only comes into effect when you are no longer capable of making decisions for yourself.

The requirements for an Advanced Health Directive may differ depending on the state or territory where you live. You should talk to your doctor about what you want and how to write an Advanced Health Directive. You should discuss the nature of life-saving treatments and their end results with your doctor, so that you are fully informed before you make any decisions.

Decisions in your Advanced Health Directive should be about specific situations rather than a general, 'do not resuscitate' statement.

Your solicitor can prepare the document for you, or you could purchase a standard form from your newsagent. In some states you need to sign the document in the presence of your doctor or have the doctor provide a certificate to say that you had the necessary decision-making capacity at the time you made the directive.

To ensure that your wishes are carried out, a copy of your Advanced Health Directive should be held in your medical

file and given to your treatment team. Your file should also be marked to indicate that it contains your Advanced Health Directive. You should plan to review your decision at regular intervals, but particularly if your health changes significantly.

An Advanced Health Directive does not replace a protected or enduring Power of Attorney, which enables the holder to manage your personal or business affairs when you can no longer do so.

- **Power of Attorney**

A Power of Attorney is a document given from one person to another to act on their behalf should they not be able to manage their own affairs.

Your partner can have your Power of Attorney or you can choose another adult, such as a close and trusted friend. The nominated person, known legally as the donee, can also manage your financial or practical arrangements, if you are not able to do this for yourself.

An ordinary Power of Attorney applies only while the donor is capable of making her own decisions. If, for any reason, she loses her own decision-making power, the ordinary Power of Attorney is no longer valid. An Enduring Power of Attorney enables the donor to give another person the legal authority to manage her affairs on her behalf immediately, or in the future, if she loses the capacity to make her own decisions.

You should talk to a solicitor about how to nominate a Power of Attorney.

- **Writing a will**

A will outlines who should receive your possessions and property after your death. If you do not write a will, a government body will decide this for you. This might not be in accord with your wishes and can also be very costly. A will can also contain instructions for funeral and burial arrangements.

**Your thoughts may change over time, so it is good to keep others informed of any changes. You should tell your partner, family and/or a close friend about where you keep legal documents and how to contact your solicitor.**

***"Just hang in there. There are some people who survive for decades. There is hope."***

You might also need to discuss with your partner, family and/or close friends:

- how any children you have under 18 years will be cared for
- your wishes about your funeral and burial arrangements
- your preference about dying at home or in a hospice, palliative care unit or hospital.

Talk to a solicitor about drawing up a will or making changes to any existing will. It is better to do this when you are feeling well.

## Resources for women with epithelial ovarian cancer and their families

### General ovarian cancer support

#### The Cancer Council Helpline

Telephone **13 11 20**

The Cancer Helpline provides general information as well as information on local resources. This service can be accessed from anywhere in Australia for the cost of a local call, connecting to local cancer organisations.

#### Ovarian Cancer Program -

#### National Breast and Ovarian Cancer Centre (NBOCC)

Telephone **02 9357 9400**

Email **directorate@nbocc.org.au**

Website **www.ovariancancerprogram.org.au**

The Ovarian Cancer Program aims to improve outcomes for women with ovarian cancer by providing the most accurate, evidence-based information available to both women and health professionals.

#### Cancer Council Australia

Telephone **02 8063 4100**

Email **info@cancer.org.au**

Website **www.cancer.org.au**

Cancer Council Australia works together with its state and territory member organisations to undertake and fund cancer research, prevent and control cancer and provide information and support for people affected by cancer.

### State and territory cancer organisations

State and territory Cancer Councils provide information and educational resources on all types of cancers. To find out about cancer support groups and other local services, contact state or territory cancer organisations and the Cancer Council Helpline.

### **Cancer Council ACT**

Telephone **02 6257 9999**  
Email **reception@actcancer.org**  
Website **www.actcancer.org**

### **Cancer Council New South Wales**

Telephone **02 9334 1900**  
Email **feedback@nswcc.org.au**  
Website **www.cancercouncil.com.au**

### **Cancer Council Northern Territory**

Telephone **08 8927 4888**  
Email **admin@cancernt.org.au**  
Website **www.cancercouncilnt.com.au**

### **Cancer Council Tasmania**

Telephone **03 6233 2030 and 03 6233 2088**  
Email **infotas@cancer.org.au**  
Website **www.cancer.org.au/tas**

### **Cancer Council Victoria**

Telephone **03 9635 5000**  
Email **enquiries@cancervic.org.au**  
Website **www.cancervic.org.au**

### **Cancer Council South Australia**

Telephone **08 8291 4111**  
Email **tcc@cancersa.org.au**  
Website **www.cancersa.org.au**

### **Cancer Council Western Australia**

Telephone **08 9212 4333**  
Email **inquiries@cancerwa.asn.au**  
Website **www.cancerwa.asn.au**

### **Cancer Council Queensland**

Telephone **07 3258 2200**  
Email **info@cancerqld.org.au**  
Website **www.cancerqld.org.au**

## **Action and support groups**

### **Ovarian Cancer Australia Limited**

Telephone **1300 660 334**  
Email **info@ovariancancer.net.au**  
Website **www.ovariancancer.net.au**

Ovarian Cancer Australia is a national consumer organisation which works to increase awareness of ovarian cancer, whilst providing support and quality resources to women and their families.

### **The Lymphoedema Association of Australia**

Telephone **08 8271 2198**  
Email **casley@internode.on.net**  
Website **www.lymphoedema.org.au**

These groups provide information on lymphoedema, local services and resources and support. Some states and territories also have regional and special interest support groups.

### **Australian Council of Stoma Associations (ACSA)**

Website **www.australianstoma.org.au**

ACSA provides patients who have undergone stomal surgery access to local associations and support groups, and information and advice about locally available resources.

### **Palliative Care Australia**

Telephone **02 6232 4433**  
Email **pcainc@pallcare.org.au**

Palliative Care Australia is the national peak body for palliative care, which aims to work toward the relief of pain and suffering of dying people and the provision of the care they, and their families, need. State and territory contact details can be obtained from the national body.

### **Continence Foundation of Australia**

Telephone **03 9347 2522**  
Email **info@continence.org.au**  
Website **www.continence.org.au**

The Continence Foundation of Australia provides information and advice and promotes education, support and research.



### National Continence Helpline

Telephone **1800 330 066** (Freecall)

The National Continence Helpline provides free, professional and confidential advice about any continence issue to people with incontinence, their families and carers. The Helpline also provides supplementary information for medical and allied health professionals.

### Look Good... Feel Better

National helpline **1800 650 960** (Freecall)

Website **www.lgfb.org.au**

A community service sponsored by the Cosmetic, Toiletry and Fragrance Association of Australia Inc, to help women undergoing cancer treatment restore their appearance and self-image during chemotherapy and radiotherapy.

### CanTeen

Australia wide **1800 226 833** (Freecall)

Website **www.canteen.org.au**

A national organisation that supports people aged 12-24 with cancer, or who have relatives or friends with cancer.

### Services for lesbian women

Peer-based counselling about sexual health/health-related issues is available over the telephone through the Gay and Lesbian Community Services of Australia.

NSW, Qld, Vic and WA **1800 184 527** (Freecall)

SA **1800 182 233** (Freecall)

Tasmania **1800 184 527** (Freecall)

NT **1800 184 527** (Freecall -  
call will be  
re-directed  
to SA contact)

### Services for people from culturally and linguistically diverse backgrounds

#### The Translating and Interpreting Service (TIS)

Telephone **13 14 50** (24 hours a day, 7 days a week -  
anywhere in Australia for the cost of a  
local call)

The Translating and Interpreting Service offers both telephone and face-to-face interpreting. If an interpreter is needed to attend an appointment, this will need to be booked a few days in advance. There may be charges involved.

### Reading

Margaret Heffernan and Professor Michael Quinn. 'The Gynaecological Cancer Guide: Sex, sanity and survival.' Melbourne: Michelle Anderson Publishing Pty Ltd, 2003

### Recommended Internet sites

This is not a complete list but gives some indication of what is available.

#### Australian

##### Gynaecological Cancer Psychosocial Support Services

**www.gynaecancersupport.org.au**

This site provides information about supportive care available to women with ovarian cancer.

#### HealthInsite

**www.healthinsite.gov.au**

This site offers a wide range of up-to-date and quality assessed information on important health topics, including cancer.

#### OvCare

**http://www.womenscancerfoundation.org**

OvCare is a national initiative focusing on ovarian cancer research and education. The website has general information on ovarian cancer, research projects and links to other cancer sites.

### **Ovarian Cancer Research Foundation**

**[www.ocrf.com.au](http://www.ocrf.com.au)**

The Ovarian Cancer Research Foundation (OCRF) fosters research into ovarian cancer. The website provides general information on ovarian cancer, research projects, news and fund raising events.

### **GO Fund Gynaecological Oncology**

**[www.gofund.org.au](http://www.gofund.org.au)**

The GO Fund raises funds to support research into the prevention, early detection and treatment of gynaecological cancer and to create awareness within the community of gynaecological cancer. The website provides general information on ovarian cancer, stories of survivors, research projects, news and fund raising events.

### **Peter MacCallum Cancer Centre**

**[www.petermac.org](http://www.petermac.org)**

Peter MacCallum Cancer Institute provides cancer services in Melbourne and throughout Victoria and is a partner in the Australian Ovarian Cancer Study. The website includes information about the institute's services, research and cancer library.

### **Australian Society of Gynaecologic Oncologists (ASGO)**

**<http://www.asgo.net.au>**

This website lists current practising Gynaecological Oncologists and Gynaecological Oncology Departments.

### **Gynaecological Cancer Society**

**[www.gcsau.org](http://www.gcsau.org)**

Information on this website is for patients, their carers and families, professionals and students. The information is holistic, authoritative and cancer specific, covering the full range of gynaecological cancers.

Emotional Support Hotline **1800 700 288**

### **Clinical Trials Centre (NHMRC)**

**[www.ctc.usyd.edu.au](http://www.ctc.usyd.edu.au)**

This website provides details of clinical trials and other research conducted in Australia.

### **International websites**

Please note that some of the information on websites from other countries might only apply to people in that country.

### **National Cancer Institute**

**[www.cancer.gov](http://www.cancer.gov)**

This website contains information developed by the US National Cancer Institute for health professionals, the general public, and cancer researchers from a variety of sources.

### **American Cancer Society**

**[www.cancer.org](http://www.cancer.org)**

This useful site provides information about cancer, including information about the American Cancer Society, its publications, programs and local offices.

### **Cancerbackup**

**[www.cancerbackup.org.uk](http://www.cancerbackup.org.uk)**

The UK's leading cancer information service provides information about specific cancer types, including ovarian cancer.

### **Institute of Cancer Research**

**[www.icr.ac.uk](http://www.icr.ac.uk)**

Information about the Institute, plus information for patients and families.

**National Comprehensive Cancer Network (NCCN)  
and American Cancer Society (ACS) Cancer Treatment  
Guidelines for patients**

**[www.nccn.org](http://www.nccn.org)**

The NCCN and ACS have translated the NCCN Oncology Practice Guidelines into easy-to-understand information that can assist patients and families in making medical decisions. The site also provides information about cancer-related physical symptoms such as fatigue, pain, and nausea and vomiting.

