



“Ovarian Cancer Australia was my safe place when I was diagnosed at the age of 29. It is a wonderful organisation — full of information to help you, full of people who do not judge you, full of people going through or who have been through what you are going through. Lean on them for help.”  
— Meghan

# Finding out

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## You have ovarian cancer.

You may not even believe that right now. Perhaps someone has made a mistake with your diagnosis?

Or it may be beginning to sink in and you are angry, shocked, anxious and confused.

You didn't deserve this, there's probably no good reason why it happened to you, you are going to beat this, you don't want to die, you are worried about your family and your finances, you hate hospitals ...

There are so many thoughts racing around in your head and tugging at your heart. *And every one of them is normal.* It's also normal for your reaction and your feelings to change from day to day and to feel like you are on an emotional roller coaster.

There is no right or wrong way to respond to a diagnosis of ovarian cancer. But after many years of talking to women and their families, we know that there are some helpful things you can do soon after your diagnosis to help you feel a little less overwhelmed and to cocoon yourself with the support you need.

## What do I do next?

### Share your feelings and build support

**Talking to other people about your diagnosis, your feelings and your fears can really help to ease anxiety and help you to find ways of coping.**

Ovarian cancer is too big to live with by yourself. Sharing your feelings with the people you are closest to helps lighten the emotional load. The love and support of your family and friends is usually the most important support network for women and will form part of your healing process. These are the people who can cry and laugh with you and don't need apologies and explanations when you get angry and frustrated (and can handle being yelled at from time to time).

Some women are used to talking about their feelings, but for other women, it can be a more difficult experience. When you are able to be open and honest with family and friends it helps everyone to understand that your cancer is not a taboo subject and that it's positive for all of you to talk about how you feel. That can be a big relief for others too.

Ask for professional support when you need it. It's often helpful to talk to someone who is outside your immediate support circle to give you a different perspective and to help you work out practical ways of coping.

Just as you would at work and in social situations, learn to rely on the skills and experience of different people for different needs — no one person can offer everything you need.

Good people to talk to might include:

- Your family GP.
- Other doctors or your specialist.
- An oncology nurse.
- A social worker, psychologist or counsellor.
- Your family minister, priest or other spiritual advisor.
- Members of a cancer support group. Please see the *Support* section for details.

Ovarian Cancer Australia's online forum at [www.ovariancancer.net.au](http://www.ovariancancer.net.au) gives you access to a community of compassionate and supportive women who have been touched by ovarian cancer.

The Cancer Council's Helpline 13 11 20 provides information and support, and may be able to put you in touch with other women who have lived with ovarian cancer.

Section 7: *Support* in this guide provides more information on support networks and groups.

**No matter how tough this journey may become, you never have to travel it alone.**

### Telling others

Tell other people about your diagnosis when you are ready to. You can ask your family, close friends or your doctor to help you.

People may ask a lot of questions, so be ready to share a level of information that you feel comfortable with.

You may need to draw some boundaries: not everyone needs to know every little detail. You will find information about talking to children later in this section.

### Look after yourself and be 'selfish' when you need to

YOU are the most important person right now. You need to look after yourself, conserve your energy and sometimes make choices that may have felt a little selfish in the past.

**A good night's sleep** helps you to cope physically and emotionally. But slowing down your mind for sleep may not be so easy, especially in the early days and weeks after being diagnosed. If you are having problems sleeping, ask your doctor for suggestions to help.

**Listen to your body.** Rest when you need to, and enjoy gentle physical activity when you can. Immerse yourself in enjoyable activities like reading, listening to music and good conversations with friends. Take your time to work out the balance that's right for you and accept that it may be different every day.

**Eating a variety of nutritious foods** will help keep your body as healthy as possible and to deal with surgery, chemotherapy and their side effects. Many women lose their appetite when they are first diagnosed, so choose simple, appealing foods that are easy to digest.

**Placing a message on your answering machine** or using a message bank service can be really useful when you are first home from hospital, when you are adjusting to chemo, or at times when you just don't need any more phone calls (other people's concern and support is wonderful, but the phone calls can sometimes be exhausting). You can update your message when you feel like it so callers know what's happening and how you are doing. Let callers know in your message that you'll do your best to call back when you are able.

**You may like to use Facebook to create or update a page** that keeps family and friends updated on your progress.

You may like to ask a family member or close friend to visit [www.imthinkingofyou.com.au](http://www.imthinkingofyou.com.au) to create a free, personalised webpage for you called a 'Care Zone'. You can then use the zone to post updates about your situation and list practical ways that others can help. You can also send SMS updates about your progress to people in your Care Zone network.

**When you are resting or sleeping**, it's a good idea to take the phone off the hook and place a note on the door so you are not disturbed.

## Don't delay in asking for help

Ovarian Cancer Australia's Information and Referral Line on **1300 660 334** can refer you to specialised counselling services.

If you need urgent help at any time of the day or night call the Lifeline 24-hour telephone counselling service on **13 11 14**.

## Express yourself

The emotional roller coaster that begins with learning you have ovarian cancer prompts many women to find new ways of expressing themselves. As well as sharing your feelings with others, you may want to start keeping a journal — a place where you can rant, rave and swear as well as record the joyful moments in each day. Writing in

## If things get really tough ...

It is very normal to experience a wide range of emotions when you have been diagnosed with ovarian cancer. Most women will experience anger, sadness, anxiety and grief. Over time, and with love, support and the opportunity to talk about how you feel, these intense feelings of distress usually begin to ease.

But if your feelings are overwhelming, don't seem to be settling down, or are making it difficult for you to sleep and live, please talk to your doctor or another member of your healthcare team.

There are many effective treatments for depression and anxiety — and there are also simple ways you can help yourself. Most women find that when their depression or anxiety is treated, they are much better able to cope with other aspects of living with ovarian cancer.

a journal can be a very useful way of dealing with feelings that seem overwhelming.

Or you may find that painting, writing poetry or baking provides an expressive outlet for your emotions. Experiment and work out what feels right for you. When you are first diagnosed, writing in a journal may seem too intense, but it may be something that has more relevance as you continue your journey.

“*Those initial days were the worst in my life. Your whole existence crumbles. I thought constantly of death and unbearable loss, and not being there for my much loved daughter — I felt alienated from everyone round me. They all had a future and I felt I had none. However, once the full situation was known, and a treatment for the cancer had been drawn up, things improved radically. Once you know exactly where you are and have a plan, you are in control, and this helps hugely.*”  
— Jan



## Ovarian cancer in the family.

Many women are eager to find out if their cancer may be hereditary. Knowing this may affect your treatment and can provide helpful information for other family members.

A woman is said to have a potentially significant family history of ovarian cancer if she has one or more blood relatives who has had either or both breast or ovarian cancer, or alternatively, a family history of bowel cancer that was diagnosed under 50 years.

You may have a family history of ovarian cancer by chance, because family members have been exposed to similar environmental or lifestyle risk factors, or because there is an inherited faulty gene that has increased the risk of ovarian cancer.

At least 15% of epithelial ovarian cancers are thought to be the result of inheriting a faulty gene from either your mother's or father's side of the family. The women who are most likely to have inherited a faulty gene are those with a strong family history of ovarian or breast cancer — although it is possible to inherit a faulty gene without having a clear family history of these cancers.

### Inherited gene faults

Inheriting a faulty **BRCA1** or **BRCA2** gene is involved in most cases of hereditary ovarian cancer. These gene faults are named for their connection to breast cancer: **BR**east **C**ancer genes 1 and 2 — but are also associated with inherited ovarian cancer as well as fallopian tube, prostate, peritoneal, pancreas and male breast cancer.

These genes normally help to prevent cancer, but when a woman inherits a damaged version of either gene, she is less protected against cancer. Women who inherit a faulty BRCA1 gene have approximately a 40–60% lifetime risk of developing ovarian cancer, while women who inherit a faulty BRCA2 gene have approximately a 10–27% risk of developing ovarian cancer.



“ I do not know if I carry an inherited gene fault, but I am aware of all of my options and am doing what I can to prevent my chances of developing ovarian cancer. ”  
— Sonja, daughter of woman with ovarian cancer



# Treatment

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## Every woman with ovarian cancer will have an individual treatment plan.

Your plan will depend on the type and stage of ovarian cancer you have, on your general health, and may include other personal factors such as whether you want to have children in the future.

For most women, treatment for ovarian or primary peritoneal cancer involves a combination of surgery and chemotherapy (chemo).

Ideally, a gynaecological oncologist will perform your surgery and your treatment will be managed by a team of healthcare professionals.

Each member of your team will have specialised skills to provide you with the best possible care as well as the information and support you need during this journey. You can ask your doctor for a referral to any member of your healthcare team at any time.

Some health professionals may not be permanently located in rural or regional areas, but you may be able to access visiting health professionals or access advice through linked phone and internet services.

*“Being treated for ovarian cancer is both emotionally and physically challenging and can be debilitating for many women, but the effects can be minimised if you look after yourself and be kind to yourself.”*  
— Debbie

## Your healthcare team.

Whenever possible, it is best if you can have surgery for ovarian cancer performed by a gynaecological oncologist. It is also ideal if your care is managed by a group of health professionals, where each member specialises in a different area of care and that care is coordinated between each member.

This approach to managing ovarian cancer is called a multidisciplinary team. Multidisciplinary teams within a gynaecological cancer centre provide women with ovarian cancer the best possible care available.

If it is not possible for your care to be provided by a gynaecological cancer centre (especially if you live in a rural or regional area), asking for referrals to other health professionals will provide you with the range of care you need.

## Your gynaecological oncologist

A gynaecological oncologist is a specialist who did their initial specialty training in obstetrics and gynaecology, and then completed a further 3 years of training in managing gynaecological cancer. Because gynaecological oncologists only look after women with reproductive tract cancers, they are very specialised in the surgery for these cancers and have the skills needed to remove as much cancer as possible.

A gynaecological oncologist is often the first specialist you will see in the process of being diagnosed and having your initial treatment. They then play a part in your ongoing treatment, care and follow-up.

*Ovarian cancer is sometimes diagnosed unexpectedly during surgery — where the surgeon did not expect to find cancer or may have expected to find a different problem. In these cases, a general surgeon may have performed the surgery and it is then important to see a gynaecological oncologist after this initial surgery to discuss the best options for further treatment.*

“Feeling comfortable with and being able to trust your medical team is imperative. After the initial shock of diagnosis, you want to know that you are getting the best and most up-to-date medical treatment.”  
— Debbie

## Finding a gynaecological oncologist and healthcare team

You will find an up-to-date listing of the multidisciplinary treatment centers in each state and territory, including the services available at each centre on [www.ovariancancer.net.au](http://www.ovariancancer.net.au). Choose the ‘Treatment & Support’ tab, then ‘How is ovarian cancer treated?’ and then click on the link ‘Directory of Gynaecological Oncology Services’.

To find the names of individual gynaecological oncologists (many of whom work in multidisciplinary treatment centres), visit the Australian Society of Gynaecologic Oncologist’s website at [www.asgo.net.au](http://www.asgo.net.au) and choose ‘Contact members’ to see a full list of members and their contact details.

*If you would like to talk to someone about specialists and treatment centres, or if you don’t have access to the internet, call Ovarian Cancer Australia’s Information and Referral Line on 1300 660 334.*

## Can I ask for a second opinion?

You may wish to ask for a second opinion from another gynaecological oncologist at any time during your diagnosis or treatment. You can ask your GP or a specialist to refer you to another doctor and to send copies of any test results to the second-opinion doctor.

Getting a second opinion can help to clear up questions and concerns and allows you to choose which doctor you would prefer to manage your treatment.

After receiving a second opinion, you may decide that you prefer to be treated by your original doctor or the second-opinion doctor — this is your right and your choice.





## Managing your symptoms and the side effects of treatment.

Both ovarian cancer itself and the treatment for it can result in various symptoms and side effects. These vary from woman to woman, at different times of the illness and from one cycle of chemo to another.

This section includes many practical tips from other women and health professionals to help you deal with symptoms and side effects that may affect you.

Always let your doctor know if you develop any new symptoms or side effects, if they are severe, or if they are not improving.

### Fatigue

Fatigue is a very common problem, both during treatment and beyond. Fatigue is a complex thing and can have many different causes: it is often a side effect of chemo, radiotherapy or medicines, can be caused by the cancer itself, or may result from difficulty sleeping or eating, pain, infection, emotional distress, anaemia and being less active. Travelling to and from chemo, going back to work and caring for a house and family can all eat up your available energy.

Many women expect to feel very tired during treatment, but may be surprised when that weary, worn-out feeling continues. Some women find that it takes 1–2 years to feel really well again.

Realising that this tiredness is normal and asking for help are important first steps in coping with it. If ongoing fatigue is a problem, it's important to talk to your doctor: there may be some causes that you haven't thought of that you can address.

“Just do what is best for you. Try not to compare the experiences of others, everyone reacts to the treatment differently, just be guided by what feels right for you.”  
— Michelle



“ I coped by continuing to enjoy my favourite activities as much as I could. I gave myself permission to be a little selfish and took every opportunity to enjoy experiences — attending the races with my flame red wig under a big hat, dressing up for a party, taking off my shoes to walk on the grass. ”  
— Julie

## Living well

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**Having cancer and undergoing cancer treatment can be tough on just about every part of your body, mind and soul.**

This section will introduce you to some of the simple things that have helped other women to feel better along the way.

There's lots of cross-over between some of the ideas in these sections: because things that are good for your body (like healthy food and being active) are also good for your mind. And the relaxation and meditation techniques that help to calm your mind can also support your physical healing.

It's worth taking the time to explore what can help you to feel happier, stronger, calmer and more vital. This is how many women have discovered a lifestyle change, a hobby or a relaxing ritual that has stayed with them for life.



## Complementary therapies.

Many women with ovarian cancer are interested in trying **complementary therapies** — **natural therapies that are used together with mainstream medicine.**

Carefully chosen complementary therapies can help to:

- Manage symptoms and side effects — including nausea, pain and fatigue.
- Relieve stress, anxiety and sleeplessness.
- Support your immune system.
- Encourage an overall feeling of wellbeing.

Research shows that women with ovarian cancer can benefit in many ways from using complementary therapies. These therapies are not intended to cure cancer, but to help you feel as well as you can.

**Please seek expert advice from a qualified health professional when you are making choices about using any complementary therapy.**

**Integrative medicine** is another term that you may hear being used. Integrative medicine is a total approach to the care of a person's body, mind and spirit that combines standard medicine with lifestyle approaches and complementary medicines that have shown the most promise.

### Before you start ...

Before beginning any type of complementary therapy, have a chat to your GP or specialist and tell them about what you want to try. This is no time to be shy or embarrassed: it's not your doctor's job to judge your choices, but it IS their job to make sure that the therapy can work side-by-side with conventional treatments. Your doctor should also help you to access quality information and to understand information that you access for yourself.

Some natural therapies can interact with chemotherapy, preventing it from working properly or causing side effects. Think of your GP or specialist as the coordinator of your treatment who needs to be kept in the loop at all times.

## What about alternative therapies?

Alternative therapies are something quite different and are promoted as an *alternative* to conventional treatments such as chemotherapy, radiation and surgery. Alternative treatments are unproven, usually expensive and may be harmful. Be wary of any therapy that claims to cure cancer, is very expensive, requires you to stop conventional treatment or to not tell your doctor about the treatment. Examples of alternative therapies include mega doses of vitamins, shark cartilage and juice fasting.

## Which different therapies might help?

There are many different therapies that may help in different ways and at various stages of your illness and treatment.

We have included information about some of the more popular complementary therapies in the pages that follow. To learn more about any of these therapies and about other therapies not mentioned here, see 'More information' at the end of this section.

### Massage

The skin is your body's largest organ and is covered in sensors. Massage stimulates those sensors to produce endorphins and encephalins — your body's natural feel-good and pain-relieving chemicals. Benefits may include relief of muscle tension, improved sleep, reduced fatigue, pain relief, deep relaxation and immune support.

### Acupuncture

Acupuncture is an ancient form of traditional Chinese medicine that uses ultra-thin disposable needles or laser to stimulate the nervous system. Acupuncture has been well researched and it is known to help relieve pain, nausea, vomiting and other side effects of chemo and radiotherapy. It can also help with the sleeplessness that is often part of living with ovarian cancer.

*If your GP or specialist has limited knowledge about complementary therapies, ask an appropriately trained health professional for their opinion.*

## Meditation and relaxation

Meditation is simply a way of slowing down and observing your mind. There are many different types of meditation and you may wish to try a number of different types to see what suits you best. But it helps to remember that meditation doesn't have to be mystical or involve special techniques, and can be as simple as sitting in a quiet place and focusing on your breathing. By slowing down your body and mind, meditation helps you to relax and allows your body to focus its energy on getting well.

Mindfulness meditation is a popular type of meditation that has been widely used and can be very helpful for people living with long-term illnesses. This technique helps you to pay attention to the present moment in a non-judgemental way — accepting things as they are right now without worrying about the past or fearing the future.

Relaxation practise can be similar to meditation, and usually focuses on deliberately relaxing each of the major muscle groups in your body and often uses deep, conscious breathing.

Both meditation and relaxation can help with pain management, anxiety and depression, as well as improving immunity. Many people notice they have a greater feeling of general wellbeing and begin to sleep better when they practise meditation or relaxation exercises regularly. You can also use guided meditation and relaxation recordings that are specifically designed to help you enter into a deep, relaxing sleep.

There are many meditation and relaxation CDs available from libraries, bookstores, support groups and health professionals — you can also download guided meditations from the internet onto your computer or iPod. Some women prefer to join a class. There may be classes available at your cancer treatment centre or at a local community centre.

**Cancer Council NSW has two helpful CDs:** *Mindful Meditation — For People With Cancer* and *Relaxation — For People With Cancer*. To download the CDs, go to [www.cancercouncil.com.au](http://www.cancercouncil.com.au) and enter 'meditation' or 'relaxation' into the search box. To have a free CD sent to you, call 13 11 20 in NSW or (02) 9334 1900 outside NSW.

## A simple meditation

Settle yourself in a comfortable armchair, on a mat on the floor, or on your bed. Close your eyes and take several long, slow, deep, calming breaths.

Now imagine that with each breath IN you are drawing a stream of golden healing light into your body, allowing every cell to absorb and be rejuvenated by the light.

With each breath OUT, feel every cell in your body release any tension, negativity and toxicity.

Keep breathing in this way: drawing in the healing golden light and then releasing all tension and negativity.

Some people find it helpful to use a word like 'revive' or 'refresh' on their in breath, and then 'release' on their out breath. Experiment and see what feels right for you.

When you are ready, become aware of the sounds around you, wiggle your fingers and toes, and slowly come back to everyday consciousness.

## Tai chi, qi gong and yoga

Tai chi, qi gong and yoga are all types of exercise that are based on ancient Eastern philosophies and combine gentle movement, focused breathing and elements of meditation. These types of exercise are sometimes called moving meditation and help to encourage flexibility, balance and a deep sense of calm. They are very popular with people recovering from illness. Joining a class at your local community centre or treatment centre is an ideal way to learn and using a DVD at home is a good way to keep up regular practice.

“ Every day in every way, I'm getting better and better.  
I'm healing now. ”  
— Soula — daily affirmation



“ I found it helpful to meditate whilst the chemo was going in, and after initially calming myself through letting go of muscle tension, to visualise the chemo killing the remaining cancer, but not causing damage to the rest of my body. ”  
— Maggie

## Positive imagery

Positive imagery uses the power of your mind to remember and imagine all kinds of positive experiences. It may be as simple as remembering a time when you felt happy, energised and well and then bringing those feelings back into your body.

Use any opportunity to bring positive thoughts and experiences into your life. It's just another way to get your body producing those feel-good and pain-killing chemicals — and we can all do with plenty more of those!

## Herbal medicine

Some naturopaths may recommend herbal medicines to help with symptoms and chemo side effects. When prescribed carefully by a naturopath who specialises in this area, these medicines can be helpful, but it's vitally important that you talk to your GP or oncologist before starting to take any herbs or vitamins, as some of these can interact with conventional cancer treatments.

## Homeopathy

Homeopathy is a system of medicine that uses tiny doses of substances that support your body during illness. A natural therapist that specialises in homeopathy may prescribe remedies to help with nausea, sleeplessness, anxiety and energy levels.

## Art and music therapy

Even if you think you haven't got a creative bone in your body, you could be pleasantly surprised if you give art or music therapy a go. These are fantastic ways to 'lose yourself' in activity that is totally removed from your illness — helping you to relax and distract you from pain.

## Inspirations — by Petera

*Mother Nature has many wonders to impart,  
new buds, new offspring;  
a brand new start;  
A single flower, to amaze and inspire  
the forest regenerated,  
after a fire;  
Open your eyes,  
Look around and admire.*

*Music is soothing and good for the soul,  
brings peace and serenity,  
from fear and turmoil;  
Feel the passion, the pulse, in solos or symphonies,  
the quickness the softness,  
the words full of meaning;  
Open your heart,  
You're not really dreaming.*

“ When my concentration was with me, I treated my own and others' poetry with calligraphy. I found music and calligraphy a great source of support and strength on many, many occasions. ”  
— Petera



# Facing forward

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## When your initial treatment is complete you enter a new phase of your journey.

After the full-time job of dealing with surgery, chemo and side effects, your treatment is complete.

Most women will go into remission after their initial treatment and begin a period of surveillance or follow-up care.

This can be a time of great relief where you find new and positive ways to channel your time and energy. You may also feel a little abandoned! All those hospital visits and check-ups are mostly over.

It can also be a challenging time, where follow-up appointments create anxiety.

If your cancer does come back, there are new decisions for you to make about your treatment and ongoing care. Draw on the people, practices and beliefs that gave you strength in the earlier part of your journey — and use every day to look for new sources of strength and joy.

“ I have learnt to enjoy being myself and appreciate the life around me. I can endure: step-by-step, day-by-day. ”  
— May





“While we have the gift of life, it seems to me the only tragedy is to allow part of us to die — whether it is our spirit, our creativity or our glorious uniqueness.”  
 — Gilda Radner

