OVARIAN
CANCER
AUSTRALIA

Resilience Kit

For women living with ovarian cancer

ovariancancer.net.au

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Resilience (n.) — the strength and capacity to adapt well in the face of adversity; an act of springing back.

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OVARIAN
CANCER
AUSTRALIA

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You are welcome to photocopy information from this **Resilience Kit** to distribute among support and community groups. Please acknowledge **Ovarian Cancer Australia** and this **Resilience Kit** as the source.

Important note
All information has been reviewed by appropriately qualified medical professionals and, to the best of Ovarian Cancer Australia's knowledge, reflects the state of knowledge at the time of printing. However, the information is general in nature and you should not rely on this information to make decisions about your medical care or treatment. It is important to obtain independent medical advice from your own health professionals about your specific situation. As new information about ovarian cancer develops and becomes available constantly, Ovarian Cancer Australia cannot guarantee and does not assume legal responsibility for the accuracy, currency or completeness of the information in this booklet.

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The internet is always being updated with new information. and you may find that some of the links in this kit no longer work. Please contact us on **1300 660 334** if you are having difficulty finding a resource listed in this kit.

We acknowledge the Aboriginal and Torres Strait Islander peoples as the Traditional Custodians of the lands and waterways of Australia and pay respects to Elders, past, present and emerging.

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TO EVERY PERSON TOUCHED BY OVARIAN CANCER

Finding out you have ovarian cancer can come as a huge shock. It can bring up a range of intense emotions.

Everyone reacts differently and there is no right or wrong way to feel. The key is knowing there is usually plenty of support available from health professionals and those close to you to help you through this difficult time.

‘Resilience’ means finding the strength to adapt and recover during tough times. Our **Resilience Kit** aims to provide you with the tools you may need to develop and maintain this strength.

While not all the information in the kit will apply to everyone, we hope to give you and those close to you reliable information to help make this challenging time a little easier.

Ovarian Cancer Australia’s **Resilience Kit** has been supporting people living with ovarian cancer since 2008. It is regularly reviewed and updated. It has been developed in close partnership with a team of health professional experts working in cancer care and, most importantly, with people who have experienced living with ovarian cancer.

Those with a diagnosis of ovarian cancer have identified the **Resilience Kit** as one of the most valuable support resources we provide. The kit contains information to help you understand every aspect of living with ovarian cancer – including diagnosis, treatment, support services and life after an ovarian cancer diagnosis.

You can access further information through our website (ovariancancer.net.au). You may also like to subscribe to our monthly email newsletter and access support forums and webinars. We can also connect you with other people via support groups held around Australia.

We hope everyone with ovarian cancer and those close to them will feel comfortable reading our **Resilience Kit** and use it to find out as much as possible about their situation. We sincerely hope you will contact us at any stage of your illness for further help and support. Call **1300 660 334** and speak to one of our support team members.

For inclusiveness this kit often uses the term 'people impacted by/with ovarian cancer' to include people of all gender identities who are impacted by ovarian cancer, and their partners, family, friends, carers and significant others. Ovarian Cancer Australia wants you, whatever your gender identity or sexual orientation, to feel safe to openly discuss all aspects of ovarian cancer with your treating medical team or other trusted healthcare professionals, at any stage of your illness.

ABOUT OVARIAN CANCER AUSTRALIA

Ovarian Cancer Australia is the country's leading organisation for ovarian cancer awareness, support, advocacy and psychological research. We are committed to saving lives and supporting people with ovarian cancer.

We are a not-for-profit organisation founded in 2001 by people directly affected by ovarian cancer. Our mission is to support those affected by ovarian cancer, give them a voice, facilitate research, and raise awareness on a national scale.

> *"It is the most frightening thing in the world to be diagnosed with ovarian cancer, especially at the age of 32. Calling Ovarian Cancer Australia for the first time was like chatting with a lifelong friend. I felt instantly supported, comforted, understood, respected and validated. My experience mattered. I mattered."*
>
> **Pauline**

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FINDING
OUT

Julie with her Teal Support Nurse Di.

“I was diagnosed with Stage 2B ovarian cancer in 2021. I felt so many overwhelming emotions at once – numbness, shock and fear to name a few.

A close friend gave me a Resilience Kit and after reading it, I called the Ovarian Cancer Australia Helpline and was immediately connected to my amazing ovarian cancer nurse, Di. The advice and support she gave me through surgery and chemo helped so much. I am forever grateful.”

Julie

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FINDING OUT

Being diagnosed with ovarian cancer brings up many difficult emotions. It's completely normal to feel shocked, scared, angry, anxious, guilty, confused or sad. You might ask yourself, "Why me?" or feel a deep sense of loneliness or despair. Your emotions may shift from day to day or even hour to hour, and it's okay to feel unsettled as you process the news. You may also worry about how your loved ones are coping with your diagnosis.

There's no right or wrong way to feel, but after many years of supporting people with ovarian cancer, we've learned some steps that can help you feel less overwhelmed. Feeling alone is common but knowing where to find information and support can make a big difference. This resource is here to help you navigate your emotions, both during treatment and beyond, and to offer comfort for you and your loved ones through the tough times ahead.

> *"It was so nice to get the Resilience Kit. I appreciated it very much as it was comforting to see others knew what I was going through."*
>
> **Tricia**

WHAT DO I DO NEXT?

SHARE YOUR FEELINGS AND BUILD SUPPORT

Ovarian cancer is a lot to handle by yourself. Sharing your feelings with those closest to you may help lighten your load and ease anxiety. The love and support from family and friends is often invaluable. Don't be afraid to lean on them and accept any offers of help during this difficult time. Accepting support can also help others feel useful.

However, not everyone has a support network of friends or family around them to help them through this tough time. Feeling isolated and alone is extremely hard but you don't have to 'do it alone'. The **Ovarian Cancer Australia** Support and Information Helpline is available Monday to Friday during business hours (AEST). To speak with an ovarian cancer nurse please call **1300 660 334**, or email **support@ovariancancer.net.au**. They will offer ideas for support in many areas throughout your treatment and care.

No matter how tough this journey may become, you don't have to travel it alone.

Some people find it easy to talk about their feelings, while others find this harder. When you are ready, talk to someone you trust. Talk to those you feel comfortable with when you feel ready. Being honest helps others know how to best support you.

No one person can give you everything you need. Talking to someone outside your close support circle can be helpful. They may give you a different perspective and help you find practical ways to cope.

Good people to talk to might include:

- your family GP
- your specialist doctors (oncologist, surgeon)
- a specialist cancer (oncology) nurse
- other healthcare professionals (physiotherapist, dietitian, social worker, psychologist or counsellor)
- your family minister, priest or other spiritual adviser
- your partner, if you have one, and other close friends and family
- neighbours
- members of a cancer support group.

Please see **Chapter 4: Support** for details.

> *"I was blessed; people came out of the woodwork wanting to help. It was so lovely and helped me so much."*
>
> **Diane**

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GO AT YOUR OWN PACE

Everyone reacts differently to information: some may want to learn everything and read a lot; others may feel overwhelmed by too much information. Your needs will change at different times during your cancer diagnosis, and not all resources will be useful to everyone.

TELLING OTHERS

Sharing your cancer diagnosis can stir up emotions for both you and those close to you. People will want to support you, but their reactions may vary. Share only what you are comfortable with people knowing. It is okay to tell close friends more than you tell some family members or work colleagues – what you share is up to you. Not everyone needs to know everything.

How you tell people may vary, too. Some may prefer to do it in person, while others might find it easier to send a text or email. This can give others time to process the news. You may also prefer family members to share the news with others.

While others' concern and support are appreciated, constant calls and visits can be exhausting. It is important to let people know when you need a break. Most people will understand and won't feel hurt by this. Ask family and friends to help manage the communication for you.

The tips below may be helpful:

- Ask someone you trust to take on the role of 'information provider'. They can do regular updates via email, text or social media.
- Create a Facebook page or a personal blog keeping family and friends updated on your progress.
- Nominate a friend or relative to organise a 'visitor roster' during your hospital stays and at home. This can be helpful when you are feeling unwell or during treatment.
- If you are tired, let people know you can only talk for a few minutes, or that you will call them back when you have more energy.

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> *"Some friends were not comfortable talking about cancer and they could not relate to me any more. Others were really supportive, which helped me so much."*
>
> **Laura**

- Set aside daily rest times and ask friends and family not to contact you at this time.
- Help people to help you. This means trying to be specific about what you find helpful or unhelpful. It is okay to say you are not in the mood to talk about your cancer today.
- It is also a good idea to redirect offers of support to things that are helpful. For example, if someone offers to cook food for you and this is not helpful, you may reply, 'Thank you but I am okay for meals at the moment; however, would what be helpful is if you could drive me to an appointment next week'.

> *"Unbelievable! With the help of my family, I could keep going."*
>
> **Marlene**

RESOURCE

Gather My Crew, gathermycrew.org.au

LOOKING AFTER YOUR NEEDS

It may not come naturally to put your needs before others'. However, looking after yourself and saving your energy will allow you to focus on making choices that work in your favour.

As time passes, you may find it easier to cope. But for now, the tips below may help:

- **Listen to your body.** Rest when you need to, but also try to get regular, gentle physical activity.
- **Exercise.** Moderate daily exercise has been shown to reduce fatigue and increase physical, mental and emotional energy. Consult your doctor before starting any new exercise regimes. They may suggest a referral to a physiotherapist or exercise physiologist who can assess your fitness level and help plan an exercise program specific to your needs.
- **Pace yourself.** Try and spread activities out so you are not using all your energy at once. For example, rather than one 30-minute walk a day, try three 10-minute walks spread across morning, midday and afternoon.

- **Eat healthy, nutritious foods.** A varied diet helps give you strength to manage treatments and their side effects. You may also like to consult with a dietitian for more personalised advice. (Read 'Managing symptoms and side effects' in **Chapter 2: Treatment.**)
- **Maintain a sleep routine.** If possible, keep to a regular sleep pattern, aiming for 7 to 8 hours of sleep per night to lower anxiety and increase clarity.

> If you are having trouble getting to sleep or staying asleep, seek advice from your doctor, who may suggest support from a psychologist. The psychology and counselling service at **Ovarian Cancer Australia** has trained health professionals to provide you with strategies that may help you get a better night's sleep. Please call **1300 660 334** or ask your Teal Support Nurse for more information. You may also find some tips at **petermac.org/patients-and-carers/information-and-resources/can-sleep-improving-night-time-sleep-problems**.

- **Accept help.** Let others assist with tasks like cooking, cleaning, shopping or getting to appointments.
- **Set boundaries.** Say no to things you don't feel up to. You don't need to please everyone.
- **Stay social.** Keep up social connections, whether through a coffee date, a walk or a phone chat/texts.
- **Keep a journal.** Writing about your emotions can help you to process overwhelming feelings.
- **Engage in enjoyable activities.** Return to hobbies you love or try new ones, either alone or with friends, like writing, music, yoga, bushwalking, swimming, listening to podcasts, volunteering with animals or watching Netflix.

Taking some or all of these steps can help improve or maintain your health, especially during challenging times.

IF THINGS GET REALLY TOUGH …

There may be times you feel overwhelmed, which is very normal. With time and the love and support of those close to you, these intense feelings of distress usually ease.

However, if you are feeling alone and continue to feel anxious, sad or emotionally numb, or if you are having suicidal thoughts, you may be suffering from depression or anxiety. Sadness is different from depression. Please talk to your doctor or cancer nurse. Effective treatments and help are available. (See **Chapter 3: Staying well**.)

DON'T DELAY IN ASKING FOR HELP

Ask your healthcare team what support is available. Many hospitals provide access to mental health or other health professionals who can give you support.

- **Ovarian Cancer Australia's** Support and Information Helpline (**1300 660 334**) can refer you to specialised counselling services.
- **Beyond Blue** (**1300 22 4636, beyondblue.org.au**) can also provide information and support to help anyone in Australia achieve their best possible mental health.
- If you need urgent help at any time of the day or night, call the **Lifeline** 24-hour telephone counselling service (**13 11 14**).
- **13YARN** is the first national crisis support line for mob who are feeling overwhelmed or having difficulty coping. You can call 24 hours/7 days and talk with an Aboriginal or Torres Strait Islander Crisis Supporter (**13 92 76**).
- You can also gain information and support from the **Cancer Council Helpline** (**13 11 20**).

UNDERSTANDING OVARIAN CANCER

When you or someone you love has been given a cancer diagnosis, you are likely to have many questions. What is it, what caused it, why wasn't it found sooner, what does this mean for the future?

The next few pages aim to answer your most urgent questions.

WHAT IS CANCER?

Our body is constantly making new cells to grow and replace old or damaged cells. Normally cells grow in a predictable and organised way. But sometimes cells behave and grow abnormally and form a growth or lump called a 'tumour'. There are many different types of cancer, but they all begin with this uncontrolled growth of abnormal cells.

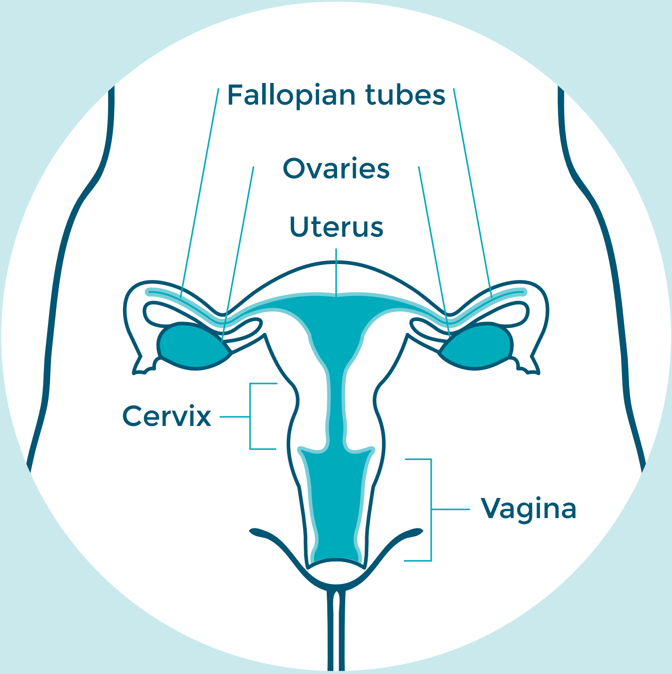
A tumour can be benign or malignant. Benign tumours are not cancerous and do not spread. Malignant tumours are cancerous and can spread from where the cancer started in the body (primary cancer) and travel through the blood or lymphatic system to other parts of the body. When this happens, the cancer that develops in another part of the body is called a 'secondary cancer' (metastasis).

> *"I just remember hearing the word 'cancer', and then I went numb. It was as though everything stopped as my mind struggled to process what I had just heard. This can't be happening."*
>
> **Laura**

WHAT ARE THE OVARIES?

The ovaries are 2 small (about 2 to 4 cm) almond-shaped organs that are part of the female reproductive system. They sit on either side of the womb (uterus). Other parts of the female reproductive system include the fallopian tubes, cervix and vagina.

Each ovary contains germ cells that eventually develop into eggs (ova). In women who are having periods, a mature egg is released by the ovary each month (ovulation). Your ovaries also produce the hormones oestrogen and progesterone, which regulate your menstrual cycle and affect the development of female body characteristics – such as breasts, body hair and body shape.



WHAT IS OVARIAN CANCER?

Ovarian cancer is a general term used to describe a cancerous (malignant) tumour starting in the ovary. The ovaries are made up of 3 main kinds of cells:

- epithelial cells
- stromal cells
- germ cells.

Each of these cells can develop into a different type of tumour. Through research, we also know that some ovarian cancers start in the fallopian tubes and 'drop' cells onto the ovary as they grow. For this reason, ovarian cancer is now sometimes referred to as tubo-ovarian cancer or even fallopian tube cancer (discussed later in this chapter).

The average age of people when they are diagnosed with ovarian cancer is 64. While many are diagnosed over the age of 50, ovarian cancer impacts people of all ages. This **Resilience Kit** contains information for everyone.

Ovarian cancer is the ninth most common cancer in Australia. It is estimated that 1,786 Australians will be diagnosed with ovarian cancer each year. You can read more about statistics and outlook for ovarian cancer in **Chapter 2: Treatment**.

TYPES OF OVARIAN CANCER

Epithelial ovarian cancer

Epithelial ovarian cancer develops from the cells lining the surface layer (epithelium) of the ovary or fallopian tube. It is the most common type of ovarian cancer, accounting for 9 out of every 10 cases. It most often affects women over the age of 50; the average age of diagnosis is the early 60s.

There are several types of epithelial ovarian cancers, including:

- high-grade serous (the most common type)
- endometrioid
- clear cell
- low-grade serous
- mucinous.

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High-grade serous ovarian cancers

This is the most common type of epithelial ovarian cancer. It is fast growing. Diagnosis is usually made when symptoms develop, which is generally when the cancer is already at an advanced stage (stage 3 or 4 – see 'Staging and grading your cancer' in **Chapter 2: Treatment**). Most high-grade serous ovarian cancers are believed to begin growing slowly in the fallopian tubes. Once the cancer reaches the ovaries, it can spread quickly to surrounding tissues, lymph nodes and organs, as well as other more distant parts of the body (e.g. lungs, lymph nodes, liver and, rarely, bone).

This cancer is usually treated with surgery and chemotherapy and sometimes targeted therapies. Sometimes high-grade serous cancer is caused by an inherited gene change (also known as a variant). Genetic testing to look for disease-causing (pathogenetic) variants in people with high-grade serous ovarian cancer is very important both to help cancer treatment selection and for assessing cancer risk in family members (discussed in 'Hereditary ovarian cancer and genetic testing').

Endometrioid ovarian cancer

This is the second most common type of epithelial ovarian cancer. It often presents in younger women and in an earlier stage of disease than high-grade serous ovarian cancer.

Surgery is the most common type of treatment, sometimes followed by chemotherapy, depending on the stage of the tumour.

Clear cell ovarian cancer

This is a type of epithelial ovarian cancer that is usually diagnosed in its early stages. It is a higher-grade tumour, meaning it grows and spreads more quickly. Clear cell ovarian cancers account for approximately 10% of epithelial ovarian cancers in Australia, with higher rates in other countries.

Endometriosis increases the risk of developing clear cell ovarian cancer. This type of ovarian cancer is also associated with inherited gene variants. Genetic testing is very important to help plan cancer treatment and for assessing cancer risk in family members.

Treatment is similar to other ovarian cancers, by surgery and chemotherapy. Clear cell ovarian cancer doesn't usually respond as well to platinum-based chemotherapy as other epithelial ovarian cancers. Resistance to chemotherapy may develop earlier.

If you have been diagnosed with this cancer, discuss treatment options with your doctors as you may have access to ongoing clinical trials.

Low-grade serous ovarian cancers

About 10% of epithelial ovarian cancers are low-grade serous cancers. They typically occur in younger women but can also start in older women.

These cancer cells are usually hormone receptor positive, which means they have proteins that attach to a specific hormone. For example, some ovarian cancer cells have receptors for the hormone oestrogen, so they are hormone receptor positive, and need oestrogen to grow.

Low-grade serous ovarian cancers are relatively chemotherapy resistant and grow slowly on the surface of cells.

Surgery is the most common type of treatment for these types of cancers. Chemotherapy, targeted therapies and hormone blockers (inhibitors) are often used after surgery to help reduce the risk of the cancer coming back.

Mucinous ovarian cancer

About 3% of ovarian cancers are this rare type. This cancer can have a similar appearance under a microscope to gastrointestinal cancers and is most common in people under 40 years. They tend to be large tumours, which means they are often found before they have spread. However, a person does not always have symptoms, so the diagnosis may be delayed.

Mucinous tumours are distinct from other types of epithelial cancers. In general, they do not respond as well to platinum-based chemotherapy as other ovarian cancers but there are new treatment options being trialled. (See **Chapter 2: Treatment**.)

Mucinous tumours can be cancerous (malignant), non-cancerous (benign) or borderline (between cancerous and non-cancerous).

OTHER CANCERS RELATED TO EPITHELIAL OVARIAN CANCER

Other cancers – primary peritoneal and fallopian tube cancer – have similar symptoms and treatment.

Primary peritoneal cancer

This is a rare cancer of the cells that line the inside of the abdomen (peritoneum), which are similar to epithelial cells. It is possible to develop primary peritoneal cancer even if you have had your ovaries and fallopian tubes removed. Primary peritoneal cancer is always diagnosed in the later stages (stage 3 or 4).

Primary peritoneal cancer is a relatively rare cancer that develops in a similar way to epithelial ovarian cancer. People diagnosed with this type of cancer should also be offered genetic testing. See 'Hereditary ovarian cancer and genetic testing' later in this chapter.

Fallopian tube cancer

The fallopian tubes link the ovaries to the uterus. As discussed above, many epithelial ovarian cancers (particularly high-grade serous cancers) start in the fallopian tubes and spread to the ovary. Cancer beginning in a fallopian tube is sometimes called 'fallopian tube cancer' or 'tubo-ovarian cancer'. These terms refer to the same disease.

IMPORTANT FACTS TO REMEMBER

- High-grade serous cancer, fallopian tube cancer and primary peritoneal cancer refer to the same type of disease.
- Treatment for all these cancers is the same or very similar.
- The information in this resource and other resources from **Ovarian Cancer Australia** applies to all of these diagnoses.

NON-EPITHELIAL OVARIAN CANCER TYPES

There are several other types of ovarian cancer including:

- germ cell ovarian cancer
- sex cord stromal tumours
- small cell ovarian cancer
- borderline ovarian tumours.

Germ cell ovarian cancer

Germ cell ovarian cancer occurs when abnormal cells form in the cells in the ovary that eventually develop into eggs. This type of ovarian cancer is rare and accounts for approximately 4% of ovarian cancers. Germ cell tumours affect mainly teenagers and people in their 20s.

Germ cell ovarian cancer usually only develops in one ovary. There are 3 main types:

- dysgerminomas
- immature teratomas
- yolk sac tumours.

Germ cell tumours also include choriocarcinoma and embryonal carcinoma.

Symptoms can include:

- abdominal/pelvic pain, discomfort
- bloating/distention of the tummy
- a lump which can be felt when touched (palpable ovarian mass)
- twisting of the ovarian tissue causing pain (ovarian torsion)
- changes to the menstrual cycle (increased or decreased bleeding)
- vaginal bleeding in post-menopausal women.

The exact causes of germ cell ovarian cancers aren't well known. Changes that happen to cells that develop in the ovary very early on in life could be responsible. Inherited gene variants are not thought to be the cause.

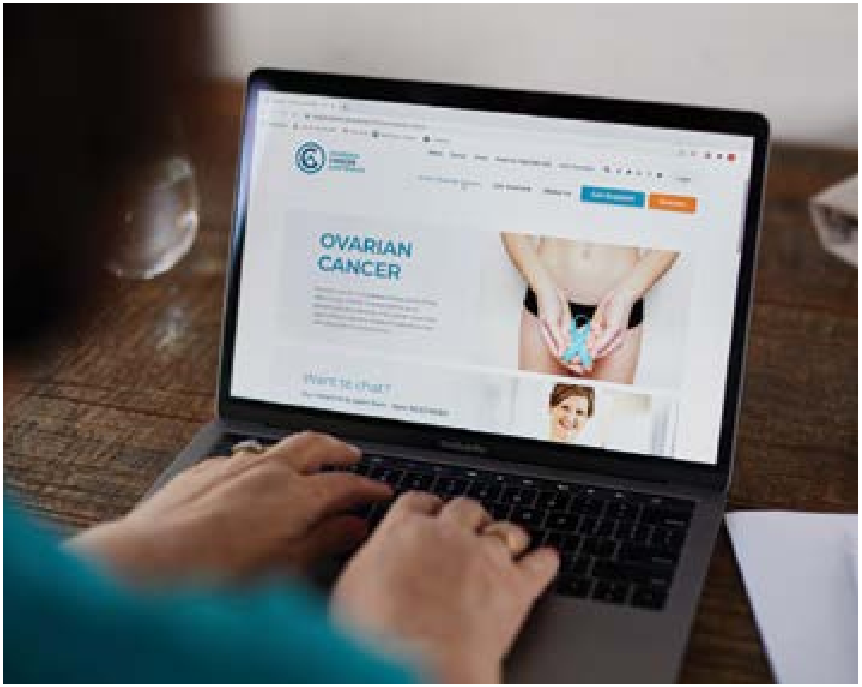
Treatment often begins with fertility-sparing surgery, aiming to conserve one ovary and its fallopian tube, and the uterus, where possible. This is followed by chemotherapy, if required. Because germ cell tumours are typically fast growing, they tend to respond well to chemotherapy. They are curable in most people.

Sex cord stromal cancers

These are rare cancers of the ovary. Granulosa cell tumours are the most common type. Other types include fibromas and Sertoli-Leydig tumours.

Only about 5% of ovarian cancers are sex cord tumours. They are often found in the early stages. Treatment depends on your age, cancer stage and type of tumour. Surgery is the main treatment. Some people also have chemotherapy.

Some hereditary conditions are associated with sex cord stromal tumours. You may be advised to seek genetic testing. See 'Hereditary ovarian cancer and genetic testing' later in this chapter.



Small cell ovarian cancer

This is a rare type of ovarian cancer. It usually occurs in younger people.

One type of small cell ovarian cancer is ‘hypercalcaemic’. It usually occurs in younger people and is strongly associated with variants in a gene called SMARCA4. You may wish to consider genetic testing if you have a hypercalcaemic tumour.

Symptoms are vague and similar to other ovarian cancers. Treatment guidelines for this type of ovarian cancer are being developed. Treatment mainly involves surgery followed by chemotherapy.

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Borderline ovarian tumours

Borderline ovarian tumours describe abnormal cells arising in the tissue covering the ovary but which are usually not considered to be cancer. They may spread through the abdominal cavity if they are on the surface of the ovary. They can turn into a cancer, but this is rare (<1%).

Borderline ovarian tumours usually affect women aged between 20 and 40, and surgery alone is usually curative.

There is a risk of recurrence if the cancer cells have already spread from the ovary at diagnosis, or if the ovary involved is not completely removed.

If you wish to have children, you can usually opt for fertility-sparing surgery. You will need to have long-term follow-up after treatment.

RISKS AND CAUSES

We don't know the exact causes of most ovarian cancers. Some factors may increase a person's risk of developing ovarian cancer.

INCREASING AGE

Getting older is the biggest risk factor for developing ovarian cancer. Ovarian cancer can happen at any age, but usually in people who have been through menopause, with the average age of diagnosis being 64.

HEREDITARY FACTORS

Hereditary cancer is cancer that happens in families due to inherited gene changes (variants). This means it 'runs' in families. Having a strong family history of ovarian, breast, endometrial or colorectal cancer may put people at an increased risk of ovarian cancer.

About 20% of all ovarian cancers are caused by inheriting from a parent a disease-causing (pathogenic) genetic variant in a gene such as BRCA1 or BRCA2. A disease-causing variant can be present in a person with ovarian cancer, even when there is no family history of cancer.

People of Ashkenazi Jewish descent are more likely to carry BRCA variants than the general population.

Read more about 'Hereditary ovarian cancer and genetic testing' later in this chapter.

Other factors that may increase the risk of some types of ovarian cancer include:

- endometriosis
- diabetes
- use of hormone replacement therapy (also known as menopause replacement therapy or MRT)
- being overweight
- smoking tobacco
- not having had children.

It is important to know that many people who develop ovarian cancer do not have these risk factors, and many people with some, or all, of these risk factors do not develop ovarian cancer.

PROTECTIVE FACTORS

There are also protective factors against ovarian cancer including:

- surgical removal of the ovaries and fallopian tubes
- having delivered a child
- having used oral contraceptives.

Although these factors reduce the risk of ovarian cancer, people can still develop ovarian cancer (including primary peritoneal cancer after removal of the ovaries and tubes).

You may read on the internet that certain other things listed below can increase your risk of developing ovarian cancer. However, there is not enough scientific evidence to suggest that any of the following affect the risk of ovarian cancer:

- diet
- alcohol
- aspirin and non-steroidal anti-inflammatory drugs
- talcum powder
- infertility treatment.

SYMPTOMS

The symptoms of ovarian cancer can be vague. They can come on very slowly or rapidly.

Possible symptoms may include:

- pain in the lower abdomen or pelvic area
- bloating and a full feeling in the tummy (abdomen)
- change in bowel habits (e.g. constipation or the feeling of needing to go more often, with loose bowels or not emptying bowels properly)
- having the feeling of needing to pass urine more urgently and more frequently
- loss of appetite
- back pain
- extreme tiredness/fatigue.

In addition, the following less-common symptoms may be present:

- abdominal swelling
- indigestion
- vaginal bleeding after menopause
- back pain
- feeling or being sick (nausea or vomiting)
- irregular periods or bleeding outside of regular menstruation before menopause
- painful sex
- breathing problems – shortness of breath
- weight loss or gain
- twisting of ovarian tissue causing pain (ovarian torsion)
- a lump which can be felt.

All the symptoms discussed in this section can be caused by other, less serious medical conditions. However, if you have any of them, we strongly advise you to see your GP, particularly if the symptoms are persistent and troublesome. They will be able to examine you and, if necessary, do further tests to find the cause. If you have any abnormal test results and/or your GP has concerns, they should refer you to a specialist gynaecological oncologist.

SCREENING FOR OVARIAN CANCER

Screening means testing healthy people to find a disease in its early stages. People being screened usually have no signs of the disease. For cancer screening to be effective there must be an accurate test that can pick up early-stage cancer when treatment is more likely to cure the cancer. It is important the test does not give a positive result in people who do not have cancer (known as a ‘false positive’).

At present there is no reliable population screening test for early ovarian cancer, even for those at a higher genetic risk. Research is ongoing to develop tests to detect ovarian cancer at earlier stages and improve patient outcomes.

> *“Population screening is also very hard because, even with an almost perfect test, there will be many more false positives than true positives, and this comes at a cost to women.”*
>
> **The Ovarian Cancer National Action Plan: 2020–2025**

The Ovarian Cancer National Action Plan sets out a roadmap to reduce the incidence, increase the survival rate and improve the quality of life of people diagnosed with ovarian cancer in Australia. It was developed over many months in partnership with people living with ovarian cancer; key organisations; and leaders in ovarian cancer including researchers, policy makers and ovarian cancer health professionals. You can download a copy of this plan from **ovariancancer.net.au**.

The following tests can help to diagnose ovarian cancer, but are not effective as population screening tests:

- CA125 blood test
- transvaginal ultrasound.

CA125 BLOOD TEST

CA125 is a protein in the blood that is present in everyone. The level of CA125 can rise due to several factors, including cancer. For this reason, CA125 is called a 'tumour marker'. A tumour marker is a chemical made by cancer cells that circulates in the blood of a person with cancer.

The level of CA125 increases in about 50% of people with early-stage ovarian cancer and 80% of people with an advanced stage of ovarian cancer. However, CA125 can also rise due to other, non-cancerous conditions, including menopause, irritable bowel syndrome, ovarian cysts, menstruation, fibroids and endometriosis.

RESOURCE

Ovarian Cancer Australia – CA125 test fact sheet, ovariancancer.net.au

TRANSVAGINAL ULTRASOUND

This examination is done by inserting an ultrasound probe into the vagina. It is not accurate in diagnosing ovarian cancer: it is not always easy to tell the difference between a harmless cyst on the ovaries and a malignant tumour.

A study found that even if ovarian cancer was detected earlier using the current available tools, it didn't change the overall outcomes or survival.

CA125 and transvaginal ultrasound tests are unreliable screening tests for ovarian cancer. They would result in too many cancers being missed and too many people being incorrectly diagnosed and having unnecessary (and often invasive) procedures.

They are useful to help with diagnosis in someone who is having symptoms such as those outlined in 'Symptoms', earlier in this chapter.

DIAGNOSING OVARIAN CANCER

Your GP is usually the first person you go to if you have symptoms. They will examine you, discuss your symptoms and order a CA125 blood test and an ultrasound. They may also suggest an internal vaginal examination to see if your uterus and ovaries feel normal. If you prefer, you can ask for a female doctor to do this. It is your choice: do not be afraid to ask.

ULTRASOUND

An ultrasound uses soundwave echoes to create images of your internal organs (ovaries and uterus). This test is done by a sonographer. It can be done in 2 ways.

1. **Abdominal ultrasound.** You lie on a table and the sonographer moves the ultrasound device (transducer) over your abdomen.
2. **Transvaginal ultrasound.** You lie on a table and the sonographer inserts the gel-covered transducer (smooth handheld device) into your vagina. It should not be painful, but it can feel uncomfortable. This method gives a clearer picture. If you have concerns about it being done this way, talk to your specialist.

If the ultrasound and other tests suggest cancer, your GP will refer you to a specialist in women's health and cancer (a gynaecological oncologist). You should be seen within 2 weeks. The specialist will do a physical examination, take a detailed health history, ask about your family history of cancer, and likely also order further tests.

This will be to work out:

- how far the cancer has grown
- if the cancer has spread to other parts of your body
- which treatment is best for you.

The results of these tests will help your doctor to confirm your diagnosis and the stage of your cancer. (See 'Staging and grading your cancer' in **Chapter 2: Treatment**.)

Further tests may include the following.

- **CT (computed tomography) scan.** This gives a 3-dimensional (3D) image of your organs. It will help find out if the cancer has spread. It may not identify all ovarian tumours.
- **Biopsy.** Under local anaesthetic and using imaging to help guide the sample, a radiologist will pass a needle into the tumour. A small sample of tissue (biopsy) will be taken and tested to help confirm a cancer diagnosis.
- **Chest x-ray.** This can check if a cancer has spread to the lungs.
- **Removal of fluid from your abdomen.** This is sometimes done if there is a build-up of fluid in the abdomen (ascites). The fluid is tested in the laboratory for cancer cells. See **Chapter 2: Treatment** for more information.
- **Laparoscopy.** This is a small operation done under a general anaesthetic. Several small 5 to 10 mm cuts will be made in your abdomen and a thin fibre-optic tube with a small camera on the end (laparoscope) inserted. This enables tissue samples to be removed for testing in the laboratory.
- **Laparotomy.** This operation will be offered if a laparoscopy is not suitable for you. If cancer is found during the laparotomy, the surgeon may continue with the operation to remove the cancer. This would only happen if you had consented to this possibility before the laparotomy.

If you need further tests, your doctor will discuss them in more detail with you.

Your doctor may also recommend that you have other scans such as MRI (magnetic resonance imaging) or PET (positron emission tomography).

WAITING FOR RESULTS

You and those close to you are likely to feel very anxious about waiting for results and what your results may mean for your future. It is only natural to fear the worst.

Some tests come back within a day or so, but others can take a week or more. To ease any anxiety, ask your doctors and nurses exactly how long it will take and how they will relay this information to you (e.g. phone call or clinic appointment).

Tips

While waiting for your test results, you may find the following tips helpful:

- plan some activities that you usually enjoy
- try to remain in the present moment as much as possible, rather than worrying about what the future may hold
- distract yourself with hobbies or activities you enjoy
- speak with your cancer nurse at the hospital and close friends and family. You can also call the **Ovarian Cancer Australia** Helpline on **1300 660 334** during business hours and speak with one of our support nurses.

RESOURCE

Cancer Mind Care Topics – Cancer Mind Care, cancermindcare.org.au

GETTING INFORMATION

YOUR HEALTHCARE TEAM

Many people with ovarian cancer find that learning about their diagnosis and treatment is empowering. It helps you know what to expect, reduce anxiety and make informed decisions about your care. Feeling in control can also boost your resilience.

Your healthcare team will provide key details about your cancer's type, stage and grade, as well as the most suitable treatment options for your type of ovarian cancer.

It's common to feel overwhelmed and forget some information during appointments, especially if you are nervous or struggling to understand medical terms. This is normal, as your brain is processing a lot of information and emotions.

PRACTICAL TIPS

- **Bring a companion.** Take a friend or family member to appointments, especially the first few, for support and help with taking notes.
- **Record conversations.** Ask your doctor if you can record your discussions to review later. Most are happy to allow this.
- **Use a notebook or app.** Write down questions for your medical team and note their answers during appointments.
- **Clarify unclear information.** Don't hesitate to ask your doctor to explain terms you don't understand. Refer to the Glossary for help.
- **Request a written summary.** Ask your doctor to give you a written summary of your treatment plan.

And remember, there is no such thing as a silly question – ever!

ONLINE

The internet offers a wealth of information on ovarian cancer and support services. However, online resources should not replace advice from your doctor or healthcare team. Not all information is accurate or relevant to your situation – some websites may even provide misleading or biased information. Tips to help can include:

- **Discuss information.** Share useful information you find online with your doctor for further guidance.
- **Use trusted resources.** Rely on reputable websites from major cancer organisations, hospitals and universities. You will find plenty of these sites throughout this kit and on the **Ovarian Cancer Australia** website **(ovariancancer.net.au)**. Check the author's qualifications and when the information was last updated.

- **Be cautious of unfamiliar sources.** Verify who is behind the information and their motivations (e.g. are they selling a product or service?). Ask a family member or friend to help if needed.
- **Beware of biased search results.** Online searches can be distorted toward negative outcomes based on how terms are phrased.

A WORD OF CAUTION

Be wary about asking 'Dr Google', as a lot of medical and cancer information on the internet has not been reviewed by experts. **Some of it is wrong and can be dangerous to follow, and may confuse and upset you.**

GO AT YOUR OWN PACE

Everyone needs different levels of information. Some may want to learn as much as possible, while others may find it overwhelming. The resources that help one person may not suit another. Throughout your journey, your information needs may change. If reading or learning about statistics increases anxiety, it may be helpful to take a break and revisit it later.

You may need to ask family members to avoid talking to you about information they find on the internet or 'have heard', if you find it upsetting.

Remember, this is your unique cancer journey. Talk to your doctor for information specific to your diagnosis and treatment.

YOUNGER WOMEN

Ovarian cancer is more common in older people, with most cancers affecting women over age 50. This can mean younger people with ovarian cancer feel isolated and overlooked.

If you are a younger patient, you may be concerned about:

- your ability to have children after treatment
- early menopause as a result of your treatment
- explaining your cancer to and caring for younger children
- managing work, study and finances
- missing out on key life events and achievements.

HAVING CHILDREN AFTER TREATMENT

Some cancer treatments can affect a person's ability to have a child (fertility). If you want children now or in the future, it is very important to talk to your specialists before your treatment begins. Options for preserving your fertility may include:

- surgery to protect your ovaries from treatments
- fertility-sparing surgery
- embryo banking/freezing
- egg banking/freezing
- ovarian tissue banking/freezing.

Not all options will be suitable for all people.

Factors influencing your choices for fertility preservation before and after treatment for ovarian cancer include:

- your age
- the stage of your cancer
- the type of treatment planned
- your cultural and religious beliefs.

Discuss your situation with your specialist, who may refer you to a fertility expert.

RESOURCE

Cancer Council – 'Fertility and cancer: A guide for people with cancer' booklet, 13 11 20, cancer.org.au

FERTILITY-SPARING OPTIONS

If you have germ cell ovarian cancer, early epithelial ovarian cancer or a borderline tumor, you might be able to have fertility-sparing surgery, which could help preserve your ability to have children later.

Chemotherapy can impact fertility. If you need chemotherapy after fertility-sparing surgery, your doctor may recommend a treatment to protect your remaining ovary from the chemotherapy's toxic effects.

There are also fertility options before starting treatment, such as ovarian stimulation and egg or embryo freezing. Ovarian tissue freezing is another option, though the risk of cancer cells being transferred makes it less likely to be used for future grafting. However, new methods may allow eggs to be developed outside the body.

You may also want to discuss with your doctor other options for having children, such as adoption or surrogacy, where another woman carries and gives birth to a child for you.

FRANCINE'S STORY

Being diagnosed with ovarian cancer at the age of 31 and without having kids (but planning to) was extremely upsetting. I suddenly felt my choices to have (or not to have) children had been taken away from me. This felt like a punishment for focusing on my career until that point.

Luckily the fertility clinic at the hospital where I was being treated offered to freeze my ovarian tissue. The hope is I will eventually be able to have a family through surrogacy. We know it won't be easy, but I feel I was given an option again.

If you have advanced epithelial ovarian cancer, your treatment will likely involve removing both your ovaries and uterus, which means you won't be able to get pregnant. Losing fertility can be as hard to accept as the cancer diagnosis itself, or even harder. However, options like donor eggs and surrogacy can help you have a family. It's important to speak with a fertility specialist about your choices.

Whether or not you were planning to have children, the possibility of cancer treatment affecting your fertility can bring feelings of loss or anger. Talking about these feelings and seeking emotional support can help.

Please talk to your doctor or healthcare team to get the support you need.

MENOPAUSE CAUSED BY CANCER TREATMENT

Removing your ovaries and uterus causes an 'immediate' or 'surgical' menopause. Instead of the gradual transition that usually happens with age, you may get sudden symptoms. This can be a shock and adjusting emotionally can take time. There are effective treatments and health professionals to help you cope with surgical menopause.

Chapter 2: Treatment covers early menopause, managing its effects and getting support.

TALKING TO AND CARING FOR YOUNGER CHILDREN

If you have younger children, you may worry about telling them about your cancer and how you will look after them during and after treatment. Read 'Talking to children about cancer' in **Chapter 3: Staying well** for practical tips and a list of resources to help you support children of all ages.

Chapter 4: Support offers many practical support services to help you with everything from house cleaning to childcare.

Make the most of all help offered. It will allow you to focus on healing and being with your children.

WORK, STUDY AND MONEY

A cancer diagnosis at a younger age may affect your career, study and finances causing extreme stress. **Chapter 4: Support** discusses practical issues, including services that can provide financial support and managing your return to work or study.

> *"In a matter of weeks, I went from being fully active and independent, to being bedridden in hospital, feeling like I had no control over my life anymore. My super-organised and meticulously planned-out life was suddenly plagued with uncertainty."*
>
> **Laura**

FEELING OVERWHELMED?

Speak to a support team member at **Ovarian Cancer Australia** on **1300 660 334** or email **support@ovariancancer.net.au**.

Visit **ovariancancer.net.au** for access to our webinar library, and to join an online forum to connect with women and hear their stories.

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HEREDITARY OVARIAN CANCER AND GENETIC TESTING

Hereditary ovarian cancer refers to an increased risk of ovarian cancer that is passed down in families. Most people with ovarian cancer develop it by chance and it is not inherited. Some people, however, develop a variant, usually in BRCA genes, which can be inherited by their child.

HOW DISEASE-CAUSING VARIANTS HAPPEN

Our cells normally grow and divide in a controlled way, thanks to our cancer protection genes. However, cancer can develop when, over time, multiple errors in these cancer protection genes build up within the same cell. An error that prevents a cancer protection gene from working and could therefore cause cancer is called a **pathogenic variant**.

Most pathogenic variants happen randomly over a person's life due to a mix of:

- environmental factors
- genetic factors
- the process of ageing.

Sometimes, a pathogenic variant in a cancer-protection gene can be passed from the biological parent to their child (meaning it is inherited). The variant affects all cells in the person who inherits it.

The person is not born with cancer but has an increased risk of developing certain types of cancer across their life. The specific cancers they may be at risk of developing will depend on which cancer protection gene is faulty and where in the body that gene is involved in controlling cell growth.

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BRCA VARIANTS AND OVARIAN CANCER RISK

Certain cancer protection genes help prevent ovarian, fallopian tube and peritoneal cancers. If these genes are not working properly, a woman's risk of developing these cancers can increase. The 2 main genes involved are:

- BRCA1 (BReast CAncer1)
- BRCA2 (BReast CAncer 2).

Pathogenic variants in the BRCA1 and BRCA2 genes are responsible for most hereditary ovarian cancer cases and make up about 15% of all high-grade serous ovarian cancers. It is rare for BRCA 1 and BRCA 2 to lead to other types of ovarian cancer.

The BRCA1 and BRCA2 genes also help control cell growth in the breasts, prostate and pancreas. Because of this, people who inherit a pathogenic variant in the BRCA1 or BRCA2 gene are also at a higher risk for these cancers compared to the general population.

MISMATCH REPAIR GENES AND OVARIAN CANCER RISK

RAD51C, RAD51D, BRIP1 and PALB2 are called mismatch repair genes.

Lynch syndrome is a condition that occurs when a person inherits a pathogenic variant in a mismatch repair gene. This syndrome increases the risk of ovarian cancer (mainly endometrioid or clear cell types). It also raises the risk of cancers in the bowel, endometrium (lining of the uterus) uterus, prostate and ureters (the tubes that carry urine from the kidneys to the bladder).

OTHER GENETIC LINKS TO OVARIAN CANCER

There are also other rare genetic links to ovarian cancer, and ongoing research may find more genetic links not currently known.

Inheriting a pathogenic variant in one of these genes increases a person's risk of developing ovarian cancer but doesn't mean that they will definitely develop ovarian cancer.

WHY IT'S IMPORTANT TO KNOW IF YOU HAVE A PATHOGENIC VARIANT

Knowing whether someone with ovarian cancer has a pathogenic variant in an ovarian cancer protection gene is important because it may influence:

- **Treatment choices.** For example, women found to carry a pathogenic variant in BRCA 1 or BRCA 2 may be offered PARP (poly ADP-ribose polymerase) inhibitor drugs for maintenance treatment to help prevent disease recurrence (see **Chapter 2: Treatment**, 'Biological therapies').
- **Clinical trial opportunities.**
- **Future health management.** Knowing you have a variant might prompt you to take up available screening options.
- **Family health management.** Knowing you have a variant may alert other blood relatives that they may also be at increased risk if they carry the same pathogenic variant.

The thought of having a pathogenic ovarian cancer protection gene can be overwhelming. It is important to remember that things can be done to address any increased cancer risk for you and your family.

> *"Finding out my sister and I both had the BRCA2 gene variant made sense. Finally, there was a reason why both mum and her sister had been diagnosed with and had passed with ovarian cancer. It is more important for us to know and take preventative steps than not to know at all!"*
>
> **Karen**

INVESTIGATING YOUR FAMILY HISTORY

Most people diagnosed with ovarian cancer do not have a family history of the disease. However, looking into your family history of cancer can sometimes help identify those who might have a hereditary form of ovarian cancer.

Signs that may suggest a hereditary risk/pathogenic variant in your family include:

- multiple relatives on the same side of the family with breast, ovarian, bowel or endometrial cancer
- a family member diagnosed with cancer at a younger age (e.g. breast cancer before the age of 40) or someone who has had more than one type of cancer, such as both breast and ovarian cancer
- breast cancer in a male blood relative
- Ashkenazi Jewish ancestry, as pathogenic variants in the BRCA 1 and BRCA 2 genes are more common in this population.

GENETIC TESTING FOR OVARIAN CANCER

Since a significant number of high-grade serous ovarian cancers will be due to a pathogenic variant in either the BRCA 1 and BRCA 2 gene, current guidelines recommend that all women with high-grade serous ovarian cancer should be offered genetic testing.

If you have a different type of ovarian cancer, talk to your doctor about whether genetic testing is appropriate for you.

There are 2 types of genetic testing for ovarian cancer:

1. **Somatic testing.** This tests the tumour tissue for pathogenic variants and is ordered by your specialist. If a variant is found, it can predict if certain drugs (like PARP inhibitors) will be effective. Most variants found in the tumours are not inherited.

2. **Germline testing.** This tests a blood or saliva sample for pathogenic variants and can be ordered by your specialist or a Family Cancer Service. If a variant is found, it is present in all cells, including the cancer cells. This information can indicate whether specific drugs should be tried/considered, and if the person has a higher risk of other cancers. Additionally, if a germline variant is identified, family members may have the option for predictive genetic testing to see if they carry the same variant.

RESOURCES

- The Human Genetics Society of Australasia, hgsa.org.au
- Ovarian Cancer Australia – 'Genetic testing and hereditary ovarian cancer: A guide for people with ovarian cancer' (booklet), ovariancancer.net.au

HRD (HOMOLOGOUS RECOMBINATION DEFICIENCY) TESTING

One way that cells repair damaged DNA is through a process called homologous recombination. HRD is when the cancer cells struggle to repair themselves. PARP inhibitors further block this repair, leading to more cancer cell deaths. HRD testing helps doctors predict if someone's ovarian cancer will respond to PARP inhibitors. (We explain more in **Chapter 2: Treatment**, 'PARP inhibitors'.)

HRD testing is done using tumour tissue and is now covered by funding in Australia.

Doctors used to think only pathogenic variants in the BRCA1 and BRCA2 genes caused HRD. However, research has shown that changes in other genes can also lead to HRD. In fact, up to half of high-grade serous ovarian cancers may have HRD.

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If you are unsure about your eligibility for HRD testing, or have already had this test, talk to your medical team for more information.

For information on how genetic testing can affect your treatment, see **Chapter 2: Treatment**, 'Personalised medicine and targeted treatments'.

WILL I HAVE TO PAY FOR GENETIC TESTING?

It's normal to worry about the costs of genetic counselling and testing.

Medicare covers most genetic testing for people with ovarian cancer who have a **high probability** of having a pathogenic variant that could influence the choice of treatment. Genetic testing is also funded for relevant family members of people who have been found to carry a pathogenic variant.

If you have questions about whether you qualify for publicly funded genetic testing, talk with your specialist doctor.

INSURANCE AND GENETIC TESTING

We know that people may have questions about the impacts of genetic testing on life insurance policies, as this can impact decision making. It is important to note that in Australia, a moratorium has been in place to ensure people can undertake genetic testing without impacts to life insurance, and work is being done to make this permanent. If you are unsure, we encourage you to discuss your personal situation with an insurance broker.

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TREATMENT

Hannah, woman with
ovarian cancer.

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TREATMENT

This chapter introduces the people who are part of your treatment team, the various treatments for ovarian cancer, tips on managing side effects and other aspects of treatment.

Every person with ovarian cancer will have an individual treatment plan based on their cancer type and stage and their general health. Other personal factors, like future family planning, may also be considered.

For most people, treatment for ovarian cancer (including fallopian tube or primary peritoneal cancer) involves a combination of surgery and chemotherapy. The most important factor of your treatment is that you are cared for by the right team of specialised health professionals.

> *"The doctor and patient relationship is so important. I found it the single most important thing when I was diagnosed and still do 8 years later. I still stay in touch with my surgeon and chemotherapy doctor."*
>
> **Kristen**

YOUR HEALTHCARE TEAM

We strongly recommend that your surgery is performed by a gynaecological oncologist. It is also ideal if your care is coordinated by a multidisciplinary team. This team includes various health professionals who consult together about your care. Each health professional specialises in a different area of care. Multidisciplinary teams at gynaecological cancer centres offer the best care for people with ovarian cancer. You should have a main contact person on the team, such as your specialist oncologist, surgeon or specialist nurse.

RESOURCE

Canrefer – Find the names of individual gynaecological oncologists (many of whom work in multidisciplinary treatment centres), canrefer.org.au/gynaecological-oncologists

If you cannot access a gynaecological cancer centre, especially if you live in a rural or regional area, ask your GP or specialist for referrals to other health professionals (such as dietitians, occupational therapists). This ensures that you receive a full range of care. Most people will have to travel to a metropolitan cancer centre for their surgery. However, chemotherapy can often be given at your local cancer centre.

You may need to use visiting health professionals or seek advice through linked phone and internet services. Many rural centres also have links to the centralised multidisciplinary meetings. A multidisciplinary team is made up of health professionals with different expertise who work together to reach the same goal (see the next section, 'Meet your healthcare team').

Ovarian cancer is sometimes diagnosed unexpectedly during surgery; in such cases the surgeon did not expect to find cancer or may have expected to find a different problem. If a general surgeon or gynaecologist performed the surgery, it is important that you next see a gynaecological oncologist to discuss the best options for further treatment.

MEET YOUR HEALTHCARE TEAM

Your healthcare team will include various doctors and other healthcare professionals introduced to you over time.

As your needs change, so may the members of your team and the leader of your team. These health professionals will support you from diagnosis through treatment to follow-up care and beyond (refer to **Table 1**).

Table 1: Health professionals who care for people with ovarian cancer

Health professional	What they do
Gynaecological oncologist	performs surgery and will plan and manage your overall treatment; helps you through all stages of your cancer and is a crucial part of the multidisciplinary team.
Medical oncologist	plans and manages your chemotherapy and other forms of medical treatment for your cancer; helps you through all stages of your cancer and is a crucial part of the multidisciplinary team.

Gynaecological ('gynae') oncology nurse ('cancer nurse specialist')	specialises in cancer care and will plan, monitor and provide your care from the time you are first in hospital; liaises with everyone else on your team; provides information and support. Not every hospital will have a gynae oncologist nurse, especially in regional, rural or private hospitals. But there may be a regional cancer nurse / cancer care coordinator who can support you locally.
General practitioner (GP)	liaises closely with your specialist doctors and nurses at the hospital; helps you through all stages of your cancer and is a crucial part of the multidisciplinary team.
Radiologist, interventional radiologist, nuclear medicine physician	takes images/scans, interprets them and performs procedures under imaging guidance (X-rays, ultrasounds, MRIs, CT and PET scans).
Radiation therapist	administers radiotherapy.
Physiotherapist and occupational therapist	helps you with any physical and practical issues for your immediate and ongoing recovery.
Counsellor, psychologist, psychiatrist	provides emotional support and skills to help you and those close to you manage anxiety, anger, mood changes like depression and sleep problems, and pain.
Dietitian	provides practical tailored advice about eating/drinking and can help you manage side effects of treatment – such as nausea, poor appetite, sore mouth, taste changes, constipation and diarrhoea.

Social worker	provides emotional support and helps you and those closest to you to adjust. Social workers can link you and your family to support services for financial assistance.
Palliative care team	includes doctors, nurses and others who work with you and those close to you to provide symptom relief and improve your quality of life.
Pastoral care worker	provides spiritual support.
Exercise physiologist	provides guidance for exercising during your treatment.
Genetic counsellor	offers information and support about hereditary risk and cancer genetics and explains your options for genetic testing, the results and that they mean for you and your family; explains risk reduction if a hereditary gene is found.
Pathologist	examines cells under the microscope to accurately define the type of cancer you have.

> *“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**

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YOUR OVARIAN CANCER SUPPORT NURSE

Another important healthcare professional you may like to access during your treatment and care is one of **Ovarian Cancer Australia's** Teal Support Nurses.

The Teal Support Program is a free telehealth outreach program supporting people with ovarian cancer throughout their diagnosis, treatment and beyond. The main aim of the program is providing continuity of care when you are not regularly seeing your treating team and focusing on areas of care where there are unmet needs.

Your Teal Support Nurse will liaise with your treating medical team as needed so that everyone is working together to give you the best possible care. The Teal Support Program is the embodiment of our vision that no person with ovarian cancer walks alone.

RESOURCE

Ovarian Cancer Australia – Teal Support Program, ovariancancer.net.au

PLANNING YOUR TREATMENT

Whatever the stage of your cancer, your multidisciplinary team of expert doctors and nurses will discuss which treatment is best for you.

The type of treatment you have will depend on:

- the type of ovarian cancer you have
- the size of the tumour and how far it has spread (the stage of the cancer)
- how aggressive your cancer is (how quickly cancer can grow and spread)
- your age
- your general health and fitness level
- your individual values and wishes.

The main treatments for ovarian cancer are surgery and chemotherapy. Most people will need surgery. However, the timing, type and extent of surgery depend on the stage of your cancer. Very early-stage cancers might only need surgery.

For more advanced cancer, chemotherapy is often used alongside surgery. You may have chemotherapy before surgery to shrink the tumour and then afterwards to help reduce the chance of the cancer coming back.

Not everyone will have the same treatment for their ovarian cancer. While initial treatment may be similar, maintenance therapy and access to other drugs differ for each person.

Maintenance therapy is ongoing treatment to help keep cancer under control and prevent it from coming back after the initial treatment has been completed. Your doctor and multidisciplinary team will tailor your treatment based on the stage and grade of your cancer, as well as individual needs including results from your genetic testing.

DISCUSSING TREATMENT OPTIONS

Your doctors and nurses will discuss your treatment options, including the benefits as well as the possible long and short-term side effects.

It is important that you are clear with your doctors about your treatment preferences and ask questions to make an informed decision. Here are some tips about talking to your doctor about your treatment:

- Don't be afraid to ask questions – you need to understand all your options.
- Take a list of questions to your appointment so you don't forget.
- Request copies of your test results and treatment information.
- Keep a daily record of your symptoms and emotions to share with your doctor.
- Ask your doctor or pharmacist for a list of your medications, dosages and reasons for taking them. Take someone close to you to appointments to help you remember key information.

Don't be afraid to speak up and ask questions. This will help build a strong and honest 2-way communication channel between you and your doctors / medical team. This can build trust and enable you to feel more empowered to make important decisions about your medical care and overall situation.

CAN I ASK FOR A SECOND OPINION?

You can ask for a second opinion from another gynaecological oncologist or medical oncologist at any time. 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 allow you to choose which doctor you would prefer to manage your treatment. Most cancer specialists understand the importance of being sure you are getting the best treatment possible for your situation. So do not be afraid to ask or worry that you may be hurting the doctors' feelings by seeking a second opinion. It is your right.

After receiving a second opinion, you may decide you prefer to be treated by your original doctor or the second-opinion doctor – either choice is okay.

TELEHEALTH

Telehealth (also known as e-health) is remote care when the health provider (e.g. doctor, nurse, counsellor) and the patient cannot meet face to face. This can be done using phone or face-to-face video calls (e.g. Teams, Zoom).

Telehealth has become very popular since the COVID-19 pandemic, improving access to healthcare for people with chronic illness and cancer. And it is becoming a more accepted and frequently used way for patients to communicate with their treatment team, especially if you live a long distance from your cancer centre.

Using telehealth can also save you time and money when travelling to appointments. However, surgery for your cancer may need to be done in a major cancer centre, which may require you to travel to the hospital before your surgery. Check with your gynaecology oncology team.

RESOURCE

Department of Health, search for telehealth, health.gov.au

OPTIMAL CARE PATHWAYS

The purpose of these Department of Health-supported pathways (cancer.org.au/cancercareguides) is to improve patient outcomes by providing consistent, safe, high-quality and evidence-based practices to all people undergoing treatment.

You can refer to the ovarian cancer pathway to learn about the optimum standards of care at each stage of ovarian cancer diagnosis, treatment and follow-up.

While treatment may vary, the expected standards of care should not differ whether treatment is provided in a public or private service.

RESOURCE

Cancer Australia – 'Optimal care pathway for women with ovarian cancer' and 'Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer', canceraustralia.gov.au/optimal-cancer-care-pathways

STAGING AND GRADING YOUR CANCER

The stage of your cancer describes how far the cancer has grown and how far it has spread. Doctors around the world use the same system. Stages are numbered from 1 to 4 (or sometimes Roman numerals I to IV). Within each stage there may be a substage numbered a, b or c (see Table 2).

This staging system is called the FIGO system after its authors, the International Federation of Gynecology and Obstetrics.

This staging system is used for all ovarian cancers and for primary peritoneal cancer. Primary peritoneal cancers are usually diagnosed at either stage 3 or stage 4.

Knowing the stage of your cancer helps your specialist decide on the best treatment for you. It also gives a guide to the likelihood of the cancer coming back.

The tests and scans you have done provide some information about the stage: the cancer's size and whether it has spread to nearby tissue or other parts of your body. But until you have surgery your doctor might not be able to tell you the exact stage of your cancer.

Ovarian cancer tumours are also graded as either high grade or low grade by the pathologist examining the cancer tissue under a microscope. Low-grade tumours resemble normal tissue, whereas high-grade tumours are less like normal tissue and may be more likely to spread.

Serous cancers are commonly high grade and the most common type of advanced stage ovarian cancer.

Table 2: Staging ovarian cancer

Stage	What does this mean?
1	The cancer is only in your ovary or ovaries, or just on the surface.
1a	The cancer is completely inside one ovary.
1b	The cancer is completely inside both ovaries.
1c	The cancer is in one or both ovaries and there is some cancer on the surface of an ovary, or cancer cells are found in fluid in your abdomen during surgery, or the ovary ruptures before or during surgery.
2	The cancer has spread outside your ovary or ovaries into your pelvis.
2a	The cancer has spread to your uterus or fallopian tubes, or both.
2b	The cancer has spread to nearby pelvic organs and may involve the surface of your bladder, uterus, fallopian tubes, bladder, sigmoid colon or rectum.
3	The cancer has spread from your pelvis into your abdominal cavity or to your lymph nodes.
3a	Using a microscope, cancer cells can be seen in lymph tissue in the abdomen / in biopsies from the lining of your abdomen.
3b	There are visible tumour growths measuring 2 centimetres or less across in the lining of your abdomen.
3c	There are tumour growths measuring more than 2 centimetres across in the lining of your abdomen and may also have spread to your lymph nodes.
4	The cancer has spread to the liver, lungs or other organs or is found in fluid surrounding the lung tissue.

Ovarian cancer is usually diagnosed in its advanced stages (stages 3 and 4).

YOUR OUTLOOK AND STATISTICS

Everyone's experience of ovarian cancer is different. Your response to treatment and what this means for you in the longer term will depend on:

- the type of ovarian cancer you have
- the stage at which it was diagnosed
- the grade of the tumour
- your general health and your age.

More people are living longer after a diagnosis of ovarian cancer. Even advanced stages of cancer often respond well to treatment.

Ongoing research into ovarian cancer brings hope of new and improved treatments for now and in the future.

RESOURCE

Ovarian Cancer Australia – 'Research into ovarian cancer' (fact sheet), ovariancancer.net.au

If your cancer cannot be cured, it may still respond well to treatment, meaning you will have fewer symptoms and improved quality of life.

You may read or hear about statistics on 5-year and 10-year survival rates. These terms do not mean you will only live for 5 or 10 years. It simply tells you the number of people who live 5 years or more after their diagnosis of cancer. However, many people will live well beyond 5 years.

Remember: statistics are general. You are an individual and 'general' statistics may not apply to you.

> *"Statistics can be misleading. It's important just to see where you are today and to keep walking ahead … doing your best."*
>
> **June**

No one can tell you exactly how long you'll live with ovarian cancer. It depends on your own situation and treatment. No 2 patients are exactly alike. People respond differently to treatment.

Your doctor is the best person to ask about your own outlook (prognosis).

TREATMENT: SURGERY

Surgery is the main treatment for ovarian cancer and is used to:

- confirm the diagnosis
- work out the type, grade and stage of the ovarian cancer
- remove as much of the cancer as possible.

The type of operation you have will depend on the stage of your cancer, which might only become clear during the surgery. This means many people will go into the operation not exactly sure of what is going to be done. This can be worrying. But your surgeon (gynaecological oncologist) will have explained all the possible options to you before your surgery. Ask your surgeon what the surgery will involve and the different options once they know the stage of your cancer.

Your surgeon will also explain the possible risks and side effects of surgery. This may include a discussion about infertility, which can be very difficult for people who still want to have children / more children. If this is the case, ask your doctor to refer you to a fertility specialist. There is information about infertility and ovarian cancer in **Chapter 1: Finding out**.

If your tumour is a germ cell, sex-cord stromal, borderline or early epithelial ovarian cancer, you may not need extensive surgery, and fertility can usually be preserved. To read more about fertility-sparing surgery, see 'Younger people' in **Chapter 1: Finding out**.

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BEFORE YOUR SURGERY

Before you have your operation for ovarian cancer, you will have several tests to check that your heart, lungs and kidneys are fit enough to have an anaesthetic and a major operation. You will meet the surgical team and those who will care for you after your surgery (surgeon, nurses and physiotherapist). At this appointment you will sign a consent form for your operation.

You will arrive at the hospital on the day of your operation or the night before. You can ask any remaining questions then.

An intravenous cannula will be inserted. An intravenous cannula is a small, flexible tube that is inserted into a vein to give you fluids, medications or nutrients directly into your bloodstream.

You will be advised before you arrive at the hospital when you should stop eating and drinking.

WHAT MIGHT HAPPEN DURING SURGERY?

Depending on the stage of your cancer, you may have surgery to remove:

- both ovaries, fallopian tubes and your uterus, including the cervix
- one ovary and fallopian tube
- as much of the cancer as possible (‘debulking’ or cytoreductive surgery).

During surgery, a cut is made from the top of your belly button down to the top of your pubic hair – or longer if needed. This operation is called a ‘laparotomy’. For early-stage cancers, ‘keyhole’ (laparoscopic) surgery may be used, involving much smaller cuts.

Ovaries, fallopian tubes and uterus

If the cancer has spread to these areas, your surgeon will remove your uterus (total hysterectomy), ovaries and fallopian tubes (bilateral salpingo-oophorectomy).

Omentum

The omentum is a layer of protective fatty tissue covering the abdominal organs. It is always checked for cancer and removed if necessary (omentectomy).

Debulking (or cytoreductive surgery)

For advanced ovarian cancer, debulking surgery removes as much of the tumour as possible, including the ovaries, fallopian tubes, uterus, omentum and other affected areas. This means the chemotherapy will be more effective as it has fewer cancer cells to deal with.

Lymph nodes

Lymph nodes in your pelvic area will be checked for cancer and possibly removed to help work out the cancer stage. Removing these lymph nodes can cause problems with how well your lymph fluid drains and you may develop lymphoedema. This is discussed later in this chapter in 'Managing symptoms and side effects'.

Abdomen and bowel

Ovarian cancer can also spread to the lining of your abdomen or to your bowel. Tissue and fluid samples from these areas are taken and examined by a pathologist. If cancer is found, the surgeon will remove as much as possible.

If your bowel is affected, the surgeon may remove part of it and re-join the 2 ends. Very rarely, the surgeon will need to make an opening in your abdomen, called a 'stoma', which allows bowel waste to pass directly out of the body.

The stoma may be temporary and later reversed. There may be some situations when the stoma is permanent. If you need to have a stoma, a specially trained stomal therapy nurse can show you how to look after the stoma, answer your questions, and provide you with encouragement and support in adjusting to having a stoma.

RESOURCE

The Australian Council of Stoma Associations – access to local stoma associations and support groups, australianstoma.com.au

Diaphragm, spleen or pancreas

Some people will also require surgery to their diaphragm, spleen and pancreas if cancer has spread to these areas. This is considered additional surgery, which can mean a longer recovery and possibly more complications. Your doctor will explain this to you in detail before the surgery.

Tissue samples and results

After your surgery, samples of tissue you have had removed will be examined by a pathologist (also part of your multidisciplinary team). The results of all testing may take up to a week. The results will help your doctors decide on further treatment.

Waiting for the results can be a stressful time: see **Chapter 1: Finding out**, 'Waiting for results'.

Residual cancer

Surgery aims to remove all visible cancer cells, but sometimes this isn't possible. Any cancer remaining after surgery is called 'residual disease'. Your surgeon will talk to you about any residual disease you may have and recommend treatment, usually chemotherapy.

WAKING UP FROM SURGERY

You will most likely be in a recovery ward under close watch by nurses when you wake up from surgery. They will attend to your pain relief. Some people may wake up in the intensive care unit, particularly if they have had additional surgery.

You may have several tubes in place:

- a drip into a vein in your arm for fluids and pain relief medicine
- an oxygen mask to help you breathe
- one or 2 tubes in your abdomen to drain away fluid
- a catheter in your bladder to drain urine
- a tube into your nose going into your stomach to remove fluid
- an epidural (into the space around the spinal cord) catheter for administering pain relief
- transversus abdominis plane (TAP) catheters inserted under the skin near your incision that administer local pain relief at the wound site.

These tubes will be removed as you start eating, drinking and going to the toilet, which is usually on day one or 2 after surgery.

Pain relief

Ovarian cancer surgery is major surgery. You are likely to have some pain after your operation. Your treatment team will make sure you are getting enough pain relief, so you are as comfortable as possible during your recovery.

Pain relief medicine may be given through:

- an epidural – an anaesthetic injection that blocks pain in a particular region of the body
- PCA (patient-controlled analgesia), through an intravenous drip. A PCA allows you to control the pain relief medicine yourself.

If you are still having pain, tell your nurse, who will get your doctor to review your pain relief needs. It is important your pain is managed; this will help you recover as quickly as possible.

Read more about pain relief in 'Managing symptoms and side effects', later in this chapter.

Eating and drinking

After surgery, you may not be able to eat and drink normally for a few days. The medical team will guide you on when to start eating and what foods to have. You will have fluids through a drip for a while, then gradually begin drinking and eating again, usually on the same day as your surgery. This will encourage your gut to function normally.

If you are having difficulty resuming normal food intake, a dietitian can adjust your hospital menu or provide drinks to meet your nutrition needs. In some cases, you may need a nutrition formula given directly into a vein (this is called 'parenteral nutrition' and is different to an intravenous drip).

Moving around

You will usually be encouraged to get out of bed on day one after your operation to prevent blood clots, relieve stomach discomfort and to promote the healing process. A physiotherapist will help you start moving again. They will also encourage you to do breathing exercises to help prevent you developing any lung infections.

You will also have injections into your tummy for a few days after your surgery, which will help stop blood clots. These injections will likely continue for 2 to 3 weeks after you leave hospital. Before you leave hospital, your nurse will show you or a family member how to administer these injections.

You will be given special stockings (anti-embolic or TED stockings) to help prevent clots developing. You may also have calf compression devices (SCUDS) on your lower legs. These massage your legs to help keep the blood circulating while you are in bed.

EXERCISE AND RECOVERY

A physiotherapist will see you while in hospital to work out a plan of gentle exercise to help your recovery.

On the first day after surgery, this will involve simply sitting out of bed and walking with some assistance. Each day, you will be able to walk a little further.

Your physio will explain how to build on this program of gentle walking once you are home. As your body is healing from surgery, the aim is to have an ideal balance between exercise and rest. You can read more about the benefits of exercise in **Chapter 3: Staying well**.

Your physio will also explain how and when to start doing pelvic floor muscle exercises. These exercises are really important for strengthening the muscles that support the organs in your pelvis and will help to improve your bladder and bowel control after surgery and as a result of menopause.

RESOURCES

- Continence Foundation of Australia, continence.org.au
- National Continence Helpline, 1800 330 066

BEFORE YOUR DISCHARGE

Your healthcare team will talk to you about support services to help you manage when you get home, such as community nursing, home and domiciliary care, and respite services. Refer to **Chapter 4: Support**.

"I began attending pilates and yoga classes a few months after my surgery to help me rebuild my core strength and practise relaxation. I also enjoy going for regular walks either by myself or with friends. I find a nice walk does wonders when I'm feeling stressed or anxious, and it reminds me how lucky I am to have this beautiful life to enjoy."

Laura

RECOVERING AND GOING HOME

Your hospital stay is usually about 3 days, depending on how you are recovering.

Surgery means that your body has undergone a major change. It is important to take things slowly, listen to your body and ask for help when needed.

Before you go home, your healthcare team will explain what activities are safe as you recover, including returning to work, lifting, housework, gardening, exercise and driving. Avoid heavy lifting and housework for about 6 weeks. This means nothing heavier than a full kettle. Your gynaecological oncologist will advise when you will be ready to drive again.

Your doctor will also likely recommend avoiding sex for 5 weeks to allow your wounds to heal properly, although many people need more time. Ovarian cancer and its treatment can change the way you feel about your overall sexuality, relationships and intimacy. Partners may also be concerned about this. For more information, read 'Intimacy and sexuality' in **Chapter 3: Staying well**.

RESOURCE

International Centre for Allied Health Evidence, University of South Australia – search for 'discharge planning checklist', or unisa.edu.au

POSSIBLE SIDE EFFECTS AFTER SURGERY

After any operation there are potential risks, some of which can be serious. It is important to treat any complications as soon as possible. Your healthcare team will monitor you very closely for possible side effects including:

- infections in your wound, bladder or chest
- heavy bleeding from your vagina or tummy wound (haemorrhage)
- bladder or bowel problems (constipation, inability to pass urine)
- blood clots in your pelvis or legs and, rarely, your lungs.

These side effects can happen quite soon after your surgery. Tell your nurses or doctors immediately if you are worried about any symptoms. Remember, these side effects are caused by major surgery and not by your cancer.

Longer-term side effects you may have after surgery are:

- swelling in the legs (lymphoedema)
- early menopause
- infertility.

> *"I did laps of the corridor after my surgery, gradually going further every day. Chemotherapy really knocked me, but I still kept walking. I was very tired but got myself down to the beach and I really started to feel better. I found meditation very helpful."*
>
> **Denise**

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Lymphoedema

Lymphatic fluid usually drains from your legs via lymph nodes in your pelvis. If these nodes are removed from your pelvis during surgery, lymph fluid may not drain properly. This can cause a build-up of fluid and swelling in one or both legs, called ‘lymphoedema’.

Lymphoedema can also be a side effect of radiotherapy and sometimes may be caused by the cancer itself.

Lymphoedema usually develops gradually – sometimes months or even years after you have finished treatment. Lymphoedema can’t be prevented or cured. But recognising the early signs allows for treatment to start early to reduce swelling, improve movement and prevent infections. This treatment, called ‘manual lymphatic drainage’ is usually done by a physiotherapist or lymphoedema therapist.

Signs to be watch for

See your GP or another member of your healthcare team if you notice:

- a feeling of heaviness, tightness or tension in your leg or foot
- swelling in your leg – you may see dents in your skin when you take off tight socks or shoes
- aching in your leg or foot
- swelling or aching in your genital area.

Research has shown that ankle swelling/tightness can be a very early symptom of leg lymphoedema due to cancer treatment. You may even get ankle swelling before your feet swell up. Be sure to mention this to your GP or cancer nurse if it happens.

Coping

Lymphoedema can affect the way you feel about your body and appearance. You may feel more self-conscious or less attractive even if you cover up the swelling. Be kind to yourself and try to remind yourself it will get easier and there are things that can be done to help.

What can help?

If you develop any signs of lymphoedema, talk to your GP, cancer nurse or physiotherapist, who can provide advice and treatment. Health professionals such as physiotherapists, nurses and lymphoedema therapists specialise in treating lymphoedema.

Treatment may include gentle exercise, elevation, compression, lymphatic drainage and paying special attention to skincare. A few tips to help include:

- Try to eat a healthy diet and exercise to maintain a healthy weight, which helps manage lymphoedema.
- Avoid sport or activities with repetitive movements in the affected limb as this can make it worse. Gentle exercise is important but check with your doctor first.
- Talk to trusted friends or support people about your feelings and concerns.
- If work affects your lymphedema, discuss possible adjustments with your employer to avoid making your lymphoedema worse.

RESOURCES

- Cancer Australia – Lymphoedema booklet available in several community languages, canceraustralia.gov.au
- Australasian Lymphology Association – search for a specialist near you, lymphoedema.org.au

MENOPAUSE CAUSED BY OVARIAN CANCER TREATMENT

If you were still having periods (menstruating) before your surgery and both ovaries are removed, you will have a surgical menopause. Your body will no longer produce the same levels of oestrogen and progesterone and your periods will stop immediately.

Instead of a gradual transition that usually happens with age, you may have symptoms of menopause soon after your surgery. Many people find this a shock. It can be hard to adjust emotionally as the symptoms can be difficult to cope with.

If you still have one ovary after surgery, chemotherapy or radiotherapy can also result in menopause.

RESOURCE

Ovarian Cancer Australia – fact sheet on early menopause from cancer, ovariancancer.net.au

The drop in oestrogen that happens at menopause can result in symptoms such as hot flushes and vaginal dryness, as well as health risks such as an increased risk of osteoporosis and heart disease.

Seeking information and support as soon as possible can make a big difference to your emotional wellbeing. It will help if you can talk to a member of your healthcare team before your surgery.

> *“After surgery, I was handed a bundle of information on early menopause. I didn’t think there was any rush to read them – surely this was something I could deal with when I got home. However, within 4 or 5 days I started to get hot flushes and feel very cranky. When my surgeon asked me how I was feeling, I burst into tears!”*

Carolyn

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DEALING WITH LOSS AND MOOD CHANGES

For many people, immediate menopause results in feelings of loss and grief: loss of control over your life, loss of choices about having a family, and loss of part of your identity as a person.

As well as this sense of loss, people who go through surgical menopause are at a higher risk of anxiety, depression and mood changes than people who go through menopause naturally. This is probably due to a combination of the very sudden hormonal changes in your body as well as coping with your cancer diagnosis and its treatment.

WHAT CAN HELP?

Many self-help techniques, lifestyle changes and medicines (including hormone replacement therapy (HRT)) can help relieve the uncomfortable symptoms and reduce the health risks associated with menopause. Not every person can have HRT after treatment for ovarian cancer. Your GP or a doctor specialising in women's health can give you more information.

RESOURCES

- Ovarian Cancer Australia – fact sheet on menopause caused by ovarian cancer treatment, www.ovariancancer.net.au
- Australasian Menopause Society – for information on menopause, HRT and doctors who specialise in menopause, menopause.org.au

It can be really helpful to seek support to manage the challenging emotions that accompany the physical and psychological changes associated with menopause. Talk to your family, friends and members of your healthcare team. Try to relieve your stress in ways you know used to help you. This may involve writing in a journal, drawing, meditating, going out with friends, listening to music, walking or doing yoga. All of these can help you express your thoughts and feelings.

Always ask for professional help if your feelings of loss, depression and anxiety continue. Many different treatments can help, including counselling, dietary changes and possible medications.

Read about 'Sadness, loss and depression' in **Chapter 3: Staying well**.

RESOURCE

Jean Hailes for Women's Health, jeanhailes.org.au

WHEN YOU ARE FEELING WELL ENOUGH

Gentle physical activity may help to ease hot flushes, help you sleep better and increase your overall feelings of wellbeing. Being active also helps to protect against osteoporosis and reduce your risk of heart disease.

INFERTILITY AFTER TREATMENT

Ovarian cancer treatment in people of childbearing age can affect their ability to have children. Talk to your gynaecological oncologist about options for preserving your fertility before your treatment begins.

There is detailed information about possible infertility in younger people in **Chapter 1: Finding out**.

> *"It's been difficult to deal with multiple issues simultaneously: the cancer diagnosis, the treatment and its side effects, my fertility options and menopause. When undergoing treatment, learn to say yes to any assistance offered!"*
>
> **Ilka**

TREATMENT: CHEMOTHERAPY

Most people with ovarian cancer will need chemotherapy. Chemotherapy is anti-cancer drugs (cytotoxics). The aim of the treatment is to either destroy the cancer cells or slow down or stop the growth of the cells.

WHY AND WHEN IS CHEMOTHERAPY USED FOR OVARIAN CANCER?

If your ovarian cancer has started to grow outside the ovary, research shows that having chemotherapy after surgery can improve your survival and reduce the risk of the cancer coming back. Some people may have chemotherapy before surgery to help shrink the cancer. Your medical oncologist will talk to you about how chemotherapy may benefit your own situation.

If your cancer comes back (recurs) after your initial treatment, your oncologist may suggest using chemotherapy again, possibly with the same or different drugs.

CHEMOTHERAPY DRUGS USED FOR INITIAL TREATMENT

The standard chemotherapy is usually a 'platinum-based' drug – carboplatin or cisplatin. The platinum-based treatment is usually combined with paclitaxel (Taxol). Using 2 different drugs together is called 'combination chemotherapy'.

SIDE EFFECTS OF CHEMOTHERAPY

As well as destroying cancer cells, chemotherapy can also damage healthy cells in your body. This can cause a range of side effects. Side effects depend on the drugs used, but also vary from person to person and from one chemotherapy cycle to the next. Side effects can include nausea, vomiting, fatigue, hair loss, skin changes, diarrhoea, peripheral neuropathy, constipation, and changes to memory and concentration ('chemo brain'). Chemotherapy drugs can also cause your blood counts to drop, which can cause anaemia, and increase risk of bleeding or getting an infection.

Thankfully, side effects are usually temporary and there are many things you can do to prevent or reduce them. For more information read ‘Managing symptoms and side effects’ at the end of this chapter.

RECURRENT OVARIAN CANCER

Other chemotherapy agents that may be used to treat recurrent ovarian cancer (cancer that has come back) include:

- gemcitabine (Gemzar)
- liposomal doxorubicin (Caelyx)
- topotecan (Hycamtin, Potactasol)
- cyclophosphamide (Cyclonex)
- etoposide (Vepesid).

Like all treatments, chemotherapy depends on your individual situation. Sometimes only one drug is used. Your oncologist may recommend using a new, more targeted type of chemotherapy if it is suitable for your type and stage of ovarian cancer. Your oncologist may talk to you about a clinical trial using a different type of chemotherapy or targeted treatment. Always ask your doctor which chemotherapy drugs they recommend for you and why.

Please note: The drugs listed in this document are correct at the time of publication. There are sometimes changes in the types of drugs and combinations of drugs used to treat cancer.

HOW WILL MY CHEMOTHERAPY BE GIVEN?

Chemotherapy for ovarian cancer is usually given intravenously (IV). This means injecting drugs into a vein. IV chemotherapy may be given directly into a vein with a thin needle and a drip or using a central line.

A central line is a type of IV (tube) and is much longer than a regular cannula. It is inserted into a large vein, usually in the neck, groin or chest, to give fluids or drugs or withdraw blood.

To insert it, a doctor or nurse will clean the skin, numb the area with some local anaesthetic and then insert the tube using a needle. The central line usually has just one entry point in the skin, where the needle is first inserted. The tube is then threaded through the vein towards the heart where there are larger veins that can handle larger amounts of fluid and drugs. It can stay in for a few months and can be used for taking blood as well as for receiving your chemotherapy drugs. This means your nurse does not have to find a new vein each time you come for treatment.

There are different types of central lines (port-a-caths, PICC lines and Hickman lines).

IV chemotherapy is usually given in an outpatient or day patient clinic at your treatment hospital. You will be able to sit in a comfortable chair, and, if you choose to, can usually have a family or a friend with you for company and support. Occasionally, some people may need to stay in hospital for a short time. Some types of chemotherapy are in a tablet form (oral chemotherapy) taken by mouth. Oral chemotherapy can usually be taken at home.

Sometimes, chemotherapy is delivered directly into the tummy (abdomen) – called ‘intraperitoneal (IP) delivery’. IP chemotherapy is not suitable for everyone. Your specialist will discuss this option with you if they feel it is going to be helpful.

If you are having IP chemotherapy, your surgeon will insert a catheter or a port into your tummy, and the chemotherapy will be given through this port.

The port is removed as a surgical day procedure when chemotherapy is finished. Those who receive IP chemotherapy also receive IV chemotherapy. IP chemotherapy can have more severe side effects than other types.

Your oncologist or oncology nurse will explain your specific treatment.

CHEMOTHERAPY CYCLES

Each treatment period of chemotherapy is called a 'cycle', which includes the actual treatment and a rest period where your body can rebuild healthy cells and regain its strength. You will usually have a blood test before each treatment to make sure your body's healthy cells have had time to recover.

For ovarian cancer, a treatment cycle varies but is usually every 3 weeks. Your doctor will discuss with you the number of cycles you will have.

> *"I think the first chemotherapy session is the hardest; it's the unknown and I was really very afraid. But it wasn't too terrible, it's a bit like giving blood only rather than donating, you receive fluids."*
>
> **Michelle**

WILL MY CA125 BE MEASURED DURING TREATMENT?

CA125 is a protein in blood that is also found on most ovarian cancer cells. For many people with ovarian cancer, the CA125 test can indicate the effectiveness of their treatment. If their CA125 level is falling during treatment, it usually means the treatment is working. If the level is rising, it may be a sign the treatment is not effective.

For some people, the CA125 level is a sign of what is happening with their ovarian cancer. In these cases, doctors

Andrea, woman with ovarian cancer.

tend to use the CA125 level at the time of diagnosis as a baseline comparison for what is happening with the cancer during treatment.

For these reasons, the CA125 test can be useful during treatment. But this is not the case for every person with ovarian cancer.

RESOURCE

Ovarian Cancer Australia – CA125 fact sheet, ovariancancer.net.au

Chapter 3: Staying well includes more information about how the CA125 test may be used as part of your follow-up care.

KEEPING A TREATMENT RECORD

You may like to keep a record of your treatment schedule and what you experience – including side effects and what helped you to cope with them. This will be useful for your next cycle of chemotherapy to remind you what you want to discuss with your oncologist or other members of your treatment team.

RESOURCES

- North-eastern Melbourne Integrated Cancer Service – My Cancer Care Record, vics.org.au
- CalvaryCare – an app that allows you to manage your healthcare and wellbeing, search your app store
- Cancer Council – free and comprehensive booklets and fact sheets about chemotherapy, 13 11 20, cancer.org.au

> *"My son documented all of my doctor visits and chemo sessions, so I was able to refer to it during my treatment (as I forgot a lot). I am able to go back now and refer to what has happened, and which doctors said what."*
>
> **Beatrice**

TREATMENT: RADIOTHERAPY

Most people with ovarian cancer have surgery followed by chemotherapy. Although less common, some people also have radiotherapy.

Radiotherapy uses radiation to destroy cancer cells or injure them so they cannot multiply. The radiation used is similar to that used for a general x-ray. This destroys cancer cells in the treated area. Normal cells are also affected by radiation, but are better at repairing themselves than cancer cells.

Radiotherapy is not routinely used in first-line treatment of ovarian cancer. In advanced ovarian cancer it can shrink tumours and help to relieve symptoms such as pain. If cancer comes back, it may be in an area that is suitable for radiotherapy – such as a lymph node.

If radiotherapy is suggested, the treatment will be carefully planned with your healthcare team. During one of your first appointments, you will have a CT scan. Your radiation oncologist will use a machine called a 'simulator' to work out where your treatment should be directed, so that it destroys the most cancer cells and avoids as much healthy body tissue as possible.

The actual radiotherapy only takes a few minutes. Radiation therapists will help position you on the bed and make sure you are comfortable. While the machine is switched on, you will be left alone for a few minutes, but the staff will see and hear you through an intercom should you need help.

There may be short-term or long-term side effects from radiotherapy, which your healthcare team will discuss with you.

Short-term side effects depend on what part of your body is treated. But they can include fatigue, diarrhoea, feeling sick and an irritable bladder – most of these go away a few weeks after treatment finishes.

Some people continue to have side effects for a while after treatment ends; these can include changes in bowel and/or bladder function.

Talk to your healthcare team about ways to reduce or manage any side effects. 'Managing symptoms and side effects', at the end of this chapter, includes many practical ideas.

RESOURCE

Cancer Council – 'Radiotherapy' (booklet),
13 11 20, cancer.org.au

QUESTIONS TO ASK YOUR HEALTHCARE TEAM

You may find the following list of questions helpful when thinking about what to ask your doctor about your treatment for ovarian cancer.

GENERAL TREATMENT QUESTIONS

- What type of cancer do I have?
- What stage of disease do I have?
- What grade is my cancer?
- Has my cancer spread to other parts of my body? If so, how far?
- How fast is it growing?
- What type of treatment is available? What do you recommend and why?
- Who will be part of my multidisciplinary care team?
- How long will these treatments take? What written information can you give me about these treatments?
- How much will these treatments cost? Are there any ways to reduce the cost?
- Are there any clinical trials suitable for me?
- Are the latest tests and treatments for my type of cancer available in this hospital?
- Am I eligible to have genetic testing? Will you test my tumour as well as do a blood test?
- Will my treatment be given by a doctor who specialises in ovarian cancer?
- Can you arrange for me to have a second opinion?

SURGERY QUESTIONS

- Is my surgery being performed by a gynaecological oncologist?
- How soon will my surgery be done?
- What can I expect after the operation?
- How will you control my pain after my operation?
- Will the treatment affect my sexual feelings or relationship?
- Will surgery affect my ability to have children? If so, can I preserve my fertility or eggs?
- How long will I need to take off work?
- When will I be able to drive?

CHEMOTHERAPY QUESTIONS

- How soon after surgery will I start chemotherapy?
- Will I have to stay in hospital for chemotherapy or will I be an outpatient?
- Which drugs will I have?
- How will the chemotherapy be given?
- What are the short-term and long-term side effects of this chemotherapy?
- Will it affect what I can eat? Are there specific foods I should or shouldn't be eating?
- Are there any complementary therapies that might help me deal with side effects?
- Will I have pain due to the treatment? If so, what can be done about this?
- Is it safe to have sex during my period of treatment?
- Will I be able to work during my period of treatment?
- Can I talk to a gynaecology oncology nurse?

TREATMENT: BIOLOGICAL THERAPIES

Biological therapies are a newer type of cancer treatment.

They work by changing the way the cells in our body work. They can interfere with the signals or blood supply that make cancers grow or block the DNA repair in cancer cells. They are often used as 'maintenance' treatment to try and prevent the cancer from regrowing. They may need to be given through a drip or may sometimes be in tablet form.

Biological therapies used to treat ovarian cancer include:

- bevacizumab (MVASI, Avastin)
- olaparib (Lynparza) and niraparib (Zejula) to treat patients with HRD or BRCA-positive advanced ovarian cancer (stages 3 and 4). (For more information on BRCA and HRD, refer to **Chapter 1: Finding out**, 'Hereditary ovarian cancer and genetic testing'.)

BEVACIZUMAB (MVASI, AVASTIN)

Bevacizumab is used to treat people with ovarian cancer. It is sold under the brand name MVASI (also known as Avastin).

Bevacizumab is a targeted therapy that blocks the protein vascular endothelial growth factor (VEGF). VEGF plays a key role in the development of new blood vessels. By blocking VEGF, bevacizumab may block the blood supply that feeds the ovarian cancer cells / tumour. This may prevent new blood vessels forming, which can stop the cancer from growing and spreading. Drugs that work in this way are called 'angiogenesis inhibitors'.

Bevacizumab is currently being used for people with ovarian epithelial, fallopian tube or peritoneal cancer. But it is not suitable for everyone with these types of cancer. It is used for some people with a stage 3 or 4 cancer as a first-line treatment, or for people whose ovarian cancer has returned.

Bevacizumab is used in combination with other drugs (such as chemotherapy). It is given with chemotherapy into the vein.

Like all drugs, angiogenesis inhibitors can have side effects. The most common side effects include high blood pressure, bleeding, kidney problems and wound healing problems. Your specialist will discuss these with you in detail.

PARP INHIBITORS

This section discusses homologous recombination deficiency (HRD) and BRCA gene variants. For more information, refer to **Chapter 1: Finding out**, 'Hereditary ovarian cancer and genetic testing'.

PARP (poly ADP-ribose polymerase) is a protein in our body that helps damaged cells to mend themselves. Cancer cells with HRD (including BRCA) depend on PARP to repair their DNA. PARP-1 inhibitors are a targeted treatment that stops PARP from mending the DNA, which means cancer cells don't survive. Healthy cells without cancer have other ways of mending their DNA damage, so they are able to survive.

Strong evidence supports using PARP inhibitors to significantly lengthen the time for the cancer to come back in people with HRD ovarian cancer. Their use has moved from treating people with relapsed ovarian cancer to being a first-line maintenance therapy. Early use of PARP in people who are newly diagnosed with stage 3 or 4 HRD epithelial ovarian cancer seems to offer the most benefit.

PARP inhibitors are most effective in people with pathogenic variants in the BRCA 1 and BRCA 2 genes or who test positive for HRD, making biomarker testing essential. They have also been shown to work when a similar variant (called a 'somatic variant') is found in the cancer.

Genetic testing is therefore very useful, to help doctors work out the most effective treatment for you.

PARP drugs that are being used in current treatments include:

- niraparib (Zejula)
- olaparib (Lynparza).

Several of the other genes identified as being associated with a higher risk for ovarian cancer are linked to the same pathways as the BRCA 1 and BRCA 2 genes. Therefore, it is possible that the ovarian cancers that have occurred because of a pathogenic variant in those genes might respond to PARP inhibitors in a similar way as the BRCA 1 and BRCA 2 related tumours.

What does 'first-line' and 'second-line' mean?

- **'First-line maintenance therapy'** means using PARP inhibitors soon after initial chemotherapy is complete, to try to stop the cancer from coming back.
- **'Second-line therapy'** is the treatment given after the disease has come back (recurrence), or if initial treatment isn't working.

As evidence continues to build, we are hopeful that further treatment options will become more readily available for those impacted by ovarian cancer. In the meantime, we recommend speaking with your cancer specialist if you think you or someone close to you may benefit from having a PARP inhibitor.

We understand this information can be confusing and encourage you to discuss your eligibility with your treating medical team. While we are unable to advise on individual eligibility, we can provide additional support and information. Call our Ovarian Cancer Support Nurses to discuss further via our helpline on **1300 660 334** (9 am to 5 pm).

RESOURCE

Ovarian Cancer Australia – 'Latest developments in ovarian cancer' (webinar), ovariancancer.net.au

Side effects of PARP inhibitors

If your specialist advises that PARP inhibitors will help your type of ovarian cancer, you will begin to take them about 2 to 3 months after finishing chemotherapy. PARP inhibitors are in tablet form, and you take them by mouth (orally). Your doctor will advise how often you need to take these at home.

You may have no side effects from PARP inhibitors, but side effects may include:

- changes to your blood counts (red and white blood cells and platelets) meaning you may be more at risk of getting an infection, bleeding or anaemia
- stomach (abdominal) pain, diarrhoea, nausea, vomiting, poor appetite and taste changes
- stomach pain
- joint and muscle pain
- fatigue
- shortness of breath
- changes to your usual sleep pattern (insomnia)
- skin changes including rashes, itchiness, redness or soreness to hands and feet
- dizziness or headaches
- changes to your memory or concentration (like 'chemo brain').

Your medical team will monitor your blood pressure and heart and take regular blood tests to make sure you are not having any unwanted side effects.

Let your medical team know if you feel any different or think you are having any side effects from the drugs. They may be able to adjust the dose to lessen these side effects.

For more information see 'Managing symptoms and side effects' later in this chapter.

IMMUNOTHERAPY

Immunotherapy is a cancer treatment that boosts the immune system to target and kill cancer cells. Unlike chemotherapy, which uses drugs that can harm both cancerous and healthy fast-growing cells like hair and skin, immunotherapy helps the body's immune system recognise and destroy only cancer cells.

Clinical trials are assessing the effectiveness of immunotherapy in ovarian cancer, although to date no benefit has been shown.

Ask your cancer specialist if immunotherapy might be an option for your type and stage of ovarian cancer.

PERSONALISED MEDICINE AND TARGETED TREATMENT

Historically, cancer treatment has had a 'one size fits all' approach. Treatment for ovarian cancer has generally involved debulking surgery with chemotherapy before and/or afterwards.

We now know that individual cancers can have differences in their genetic make-up. This means that people can benefit from treatments that target their cancer specifically. This is called 'personalised medicine'.

Personalised medicine is a growing area of ovarian cancer research and treatment. It involves gathering information on someone's individual genetics, or the genetics of their cancer, to better guide treatment decisions.

Targeted therapies are designed to target cancer cells specifically, to try to reduce side effects and improve results. Some of these treatments target genetic variants in cancer cells.

RESOURCE

Ovarian Cancer Australia – information about personalised medicine programs, ovariancancer.net.au

IS PERSONALISED MEDICINE AVAILABLE TO ME?

Various programs in Australia are trying to identify elements of individuals' cancer that can guide doctors' decision-making around treatment choices and clinical trials.

We recommend discussing these with your treatment team, asking questions such as:

- Have I had any genetic testing done (tumour testing, blood testing) and what were the results?
- Are there any clinical trials that might suit my type and stage of disease?
- Am I eligible for any personalised medicine programs, and if so, could you help me with linking in with them?

LIFE AFTER TREATMENT

After completing treatment and not having such regular contact with your healthcare team, some people feel alone. Remember, your treatment team will still support you if needed. Be sure to ask them for contact numbers in case you want to call for advice.

You may also begin to worry about the cancer coming back, which we discuss in the next section. This is when joining a support group can be really helpful.

RESOURCE

Ovarian Cancer Australia – information about support groups in your area, 1300 660 334, ovariancancer.net.au

When treatment finishes, it can help to plan a special event with those close to you, or even a holiday to mark the end of your treatment. This can help give your body and mind a rest from all you have been through since your diagnosis.

RESOURCE

Ovarian Cancer Australia – 'Life following ovarian cancer treatment. A booklet for people who have been treated for ovarian cancer, and their families, partners and friends', 1300 660 334, ovariancancer.net.au

> *"Those chemo nurses are angels in disguise; I was so blessed. When mine were not around I felt insecure. They were so supportive."*
>
> **Diane**

TREATING OVARIAN CANCER THAT COMES BACK (RECURS)

Cancer that comes back is called a 'recurrence'. A recurrence of ovarian cancer usually means the cancer has started to grow again near where the original cancer began or in another part of your body.

It can be difficult to learn that your cancer has come back. However, there is still treatment available. While a cure may not be possible, many women can live for an extended time with a good quality of life. Everyone is different, so it is important you speak with your oncologist about your individual situation and outcomes.

The approach to treatment and the prognosis depends on many factors including how long it took for the cancer to come back after completing chemotherapy. The longer the interval before it comes back, the better. If the interval is greater than 6 months, this is called 'platinum-sensitive ovarian cancer'. If the interval is shorter and less than 6 months, it is called 'platinum-resistant ovarian cancer'.

The most common type of treatment for ovarian cancer that has come back is chemotherapy. This is called 'second-line' chemotherapy. The aim of treatment is to shrink the cancer and control it for as long as possible. You and your healthcare team will work together to treat and manage the cancer.

RESOURCE

US National Ovarian Cancer Coalition – 'Recurrent ovarian cancer' (booklet), ovarian.org

WHICH TREATMENT WILL I HAVE?

The best type of treatment for advanced or recurrent cancer will depend on several factors including:

- where in the body the cancer is and how big it is
- previous treatment (if any) and how well you responded
- any side effects you had from your first treatments
- how long it has been since your last chemotherapy finished
- your overall health and wellbeing
- which treatment you prefer.

All of these are important to consider because they can all influence how well the chemotherapy will work and how well you will cope with side effects. Several different chemotherapy drugs may help you. Your oncologist or specialist nurse can talk to you about their benefits and possible side effects.

Depending on your response to previous chemotherapy and whether the cancer had hormone proteins on its surface, your oncologist may also talk to you about using hormonal therapies such as anastrozole, tamoxifen or medroxyprogesterone. Hormonal therapies help block or lower the amount of hormones in the body to slow down or stop the growth of cancer. They are sometimes used for people with epithelial ovarian cancers, and more commonly used for people with stromal tumours.

CHEMOTHERAPY SCHEDULE AND DELIVERY METHOD

Talk to your oncologist about the most suitable schedule and delivery method for second-line chemo. Considerations may include whether intravenous (IV) access is a problem for you or whether nausea and vomiting may make oral chemotherapy less suitable.

> *"I take every day one at a time, and I look forward to travel and more grandchildren."*
>
> **Marlene**

IS SURGERY AN OPTION?

Surgery is an important part of the initial treatment for ovarian cancer, but its role in treating recurrent ovarian cancer is not so clear. When ovarian cancer recurs, it is not usually a single tumour that can be easily removed.

Your gynaecological oncologist may consider further surgery if it has been some time since your original surgery, and there is good evidence the new cancer, or a significant part of it, can be removed. Usually, surgery is not an option if it is less than 12 months since your first completed treatment.

RESOURCE

Ovarian Cancer Australia – 'Fear of recurrence' (booklet), 1300 660 334, ovariancancer.net.au

CLINICAL TRIALS

Ask your medical oncologist if there is a current clinical trial that may be suitable for you. Most of the improvements we have in the treatment of ovarian cancer today are based on the results of previous clinical trials. These trials are used to assess new treatments and quality of life for both initial and recurrent ovarian cancer.

See the 'Clinical trials' section that follows.

RESOURCE

For helpline advice on recurrent ovarian cancer, call Ovarian Cancer Australia on 1300 660 334 or Cancer Council 13 11 20

> *"Being healthy, eating well and enjoying some exercise helps you to cope with a recurrence."*
>
> **Debbie**

CLINICAL TRIALS

Treatment for ovarian cancer is constantly being improved.

The main way improvement happens is through clinical trials. In clinical trials, new treatments can be developed, evaluated and compared with current treatments.

Participating in a clinical trial may provide individuals with a better outcome from ovarian cancer, as well as benefiting others who may eventually receive the treatment being trialled.

WHAT IS A CLINICAL TRIAL?

A clinical trial is a carefully designed research study involving people. Each study has a specific aim, which may include finding better ways to:

- prevent, diagnose or treat ovarian cancer
- control symptoms and side effects of the cancer and its treatment
- improve quality of life during and after treatment.

The main aim of clinical trials is to find out if a new treatment or procedure:

- is safe and has side effects
- works better than the current standard treatment.

WHILE THERE IS MUCH PROMISING RESEARCH ...

It is important to remember that many ovarian cancer clinical trials are in the very early stages. Not all trials will result in the discovery of a new and effective treatment for ovarian cancer. Some trials may not be available to you in your state or territory, at your treatment hospital or even here in Australia. However, it is important and reassuring to know that the current treatment for ovarian cancer is based on previous clinical trials.

SHOULD I JOIN A CLINICAL TRIAL?

Your doctor may suggest you take part in a clinical trial, or you may ask if there is a trial you can be part of. Not everyone will be eligible for all trials. You will need to meet the guidelines for any proposed trial.

If there is a trial suitable for you, speak with your healthcare team and the people close to you. Advantages of participating in a clinical trial include:

- receiving new treatments before they are widely available
- having your treatment very closely monitored and followed up
- knowing your participation could improve future ovarian cancer treatments for other people.

Participating in a clinical trial may also mean additional tests, paperwork and possibly side effects. Your doctor or trials nurse will discuss this with you before you make a decision.

You can withdraw from a clinical trial and return to regular treatment at any time if you choose.

RESOURCE

Cancer Council Victoria – 'Clinical trials for cancer' (booklet), 13 11 20, cancervic.org.au

PHASES OF TRIALS

Clinical trials go through a number of phases (phases 1 to 4) to answer specific questions. Each of these phases tests the effectiveness and safety of the new treatment in the hope the new treatment will be better than the current standard treatment. As a new treatment progresses through each phase of the clinical trial, greater knowledge is gained about its safety and effectiveness.

RESOURCES

To find current and new trials in Australia, visit:

- Australia New Zealand Gynaecological Oncology Group (anzgog.org.au)
- Australian New Zealand Clinical Trials Registry (anzctr.org.au)
- Cancer Australia (australiancancertrials.gov.au)

PALLIATIVE TREATMENT

Palliative treatment helps to relieve symptoms of a cancer that has come back or cannot be cured. It can control or slow down the growth of a cancer. This might be for many months or sometimes years. Palliative treatment will also help control symptoms of cancer, such as pain, shortness of breath and constipation.

Palliative treatment does not aim to cure cancer, but to slow growth and improve people's quality of life. See **Chapter 5: If your cancer won't go away** for more information and questions for your medical team.

With ovarian cancer, palliative treatment can include:

- chemotherapy
- radiotherapy
- biological therapies (targeted therapies)
- procedures to help remove build-up of excess fluid (ascites) in the abdomen (abdominal paracentesis) or the chest (thoracentesis)
- surgery is usually only used to help relieve symptoms that cannot be treated in other ways.

WORKING WITH YOUR TEAM

Working in partnership with your healthcare team and playing an active role in making treatment decisions can help to give you a greater sense of control over your illness and your life.

MANAGING SYMPTOMS AND SIDE EFFECTS

Ovarian cancer and its treatment can cause symptoms and side effects. These vary from person to person, at different times of the cancer and treatment. Coping with these symptoms and side effects can be very difficult. Most people say the side effects of treatment can be the hardest part of having cancer.

This section includes practical tips to help you deal with symptoms and side effects that may affect you. We also explain where you can go to get further information and support.

We suggest you try to deal with any side effects early. Don't try to 'stick it out' and hope they will stop or let them build up until they are unbearable. The earlier you get help or take prescribed medications for side effects, the more likely they can be controlled and allow you a better quality of life.

FATIGUE

Fatigue is one of the most common problems people face during and after their cancer treatment. Some people say that it is the most difficult side effect of their cancer and its treatment.

Fatigue means feeling very tired and having no energy. It is a weary and completely 'worn-out' feeling. It refers to physical and mental (cognitive) fatigue. People with cancer often describe their fatigue as overwhelming and debilitating. They say it is not relieved by sleep and can negatively affect your ability to do day-to-day activities, your self-esteem and your relationships. Your fatigue may be mild, moderate or severe. It can depend on the stage of your cancer and how long you have been having treatment.

Fatigue may be caused by chemotherapy, radiotherapy or other medicines. The cancer itself may also cause fatigue.

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> *"I was so tired, very fatigued and I slept a lot and forgot so much. This was the most frustrating part of my treatment."*

Beatrice

Low red blood cells (anaemia) can also leave you feeling very tired and short of breath. Realising that fatigue is common for people with cancer, and asking for help, are important first steps in coping with it.

People experiencing cancer-related fatigue may report some or all of the following symptoms:

- low or no energy
- overall body weakness
- mental or emotional exhaustion
- difficulty thinking clearly or concentrating
- muscle aches and pains
- challenges with daily tasks such as dressing, showering, cleaning or cooking
- sleep issues, including insomnia or excessive sleeping
- loss of enjoyment in usual activities
- feelings of sadness or irritability.

Living with cancer-related fatigue can have a huge impact on various aspects of daily life, including work, relationships and your sex life. You may look okay but still have extreme fatigue. Your family and friends might not fully grasp how cancer-related fatigue is affecting you. They may not realise that this type of fatigue can be long term and think you can continue to do the things you did before you had cancer and its treatment. This can be frustrating and upsetting but it is important to explain it to them so they can support you in the best way possible.

If ongoing fatigue is a problem, talk to your doctor. They may suggest things to help you. See our suggestions to help with fatigue on the following pages.

Research shows that regular exercise during your cancer treatment reduces cancer-related fatigue. It is now recommended as part of cancer treatment plans, with patients who exercise regularly experiencing less fatigue both during and after their treatment.

If doing your usual amount of physical activity and exercise is too much, try setting smaller goals or 'chunk' your activity across the day to manage fatigue (e.g. a 10-minute walk in the morning and afternoon rather than a 20-minute walk in one session).

RESOURCE

Australian Cancer Survivorship Centre – 'Coping with cancer-related fatigue' (fact sheet), petermac.org

Ask your treatment team for a referral to an exercise physiologist. They will help you manage your fatigue with an effective exercise program to suit how you feel each day. For example, on days you feel the most tired, you may have exercises that can be done lying down.

General exercise tips:

- Plan your day so you have enough energy to do some exercise. Many people have the most energy mid-morning.
- On days you feel the most fatigued, lie down and do gentle stretches. Doing something is better than nothing.
- Break up your exercise into a few short sessions throughout the day.
- Always rest when you feel you need to. Rest and recovery are very important.
- Always seek medical advice about any exercise regime you plan to do before you begin.

Exercise must be appropriate to what you can cope with during each stage of your illness.

If you've taken time off work or studies for treatment, discuss returning to work/study with your employer/teachers. Under Australian law, employers must reasonably accommodate an employee to return to work after illness. This may mean a phased return or flexible work hours.

RESOURCES

- Cancer Council Australia – 'Cancer, work and you', www.cancercouncil.com.au
- Livework Cancer, www.liveworkcancer.com

NUTRITIONAL AND DIETARY PROBLEMS

People with ovarian cancer can have eating and digestive problems. These problems may be worse if you have advanced cancer. They can include:

- loss of appetite
- weight loss
- feeling and being sick (nausea and vomiting)
- feeling full after only a small amount of food
- changes in bowel habits such as constipation
- loss of or changes in taste (metallic taste)
- sore mouth (dry mouth and ulcers).

These problems can be a result of your cancer, treatment, tiredness, pain and depression. These symptoms may affect your ability to consume sufficient nutrition. Many people with ovarian cancer have periods of time where they are malnourished. Getting support from an accredited practising dietitian with experience in cancer is ideal. In addition to working with a dietitian, ask your doctor about the best medical management of these symptoms.

Anti-sickness medications (anti-emetics) and natural therapies (such as acupuncture and/or ginger) can help prevent and treat these side effects.

LOSS OF APPETITE AND WEIGHT LOSS

The aim is to maintain your weight during treatment, even if you feel you're carrying extra weight. If you notice you're losing weight, ask to speak with a dietitian.

- Eat small meals/snacks every 2 to 3 hours to avoid getting too hungry, which can make you feel sicker.
- Have plenty of nutritious snacks on hand (nuts, crackers with cheese, yoghurt, fruit, dried fruit, muesli bars, boiled egg).
- Try to make eating times relaxing and enjoy eating with others if possible.
- Accept help from family or friends. Ask for nutritious meals that can be frozen and reheated.
- If you're losing weight, add olive oil, butter, cheese or cream to meals. This adds calories without adding extra bulk.
- Include protein (red meat, chicken, fish, eggs, tofu, legumes, nuts and dairy foods) regularly across the day to maintain muscle.
- Homemade smoothies made from milk, yoghurt and fruit can boost your nutritional intake when you're not feeling well.
- Ready-to-drink supplements can help if you're struggling to eat well. Your dietitian can recommend one that is appropriate for your needs.

FEELING AND BEING SICK

Feeling sick (nausea) and being sick (vomiting) affects your ability to eat and drink. Nausea can be caused by pain-relieving drugs, constipation, cancer growth, a blockage of the bowel or slow digestion. It is important to try to control nausea and vomiting so you don't become dehydrated. Refer to the tips in **Table 3**.

MOUTH CARE AND TASTE CHANGES

Changes to taste due to side effects from cancer treatment (chemotherapy) can be distressing. The changes happen in the lining of the mouth and the salivary glands, which make saliva. The healthy balance of bacteria in the mouth can become disrupted, which may lead to mouth sores/ulcers, infections and tooth decay. Your mouth may feel very dry and sore, making eating and drinking more difficult. Keep your mouth clean and as healthy as possible during your treatment.

These tips may help:

- Keep your lips moist with lip balm and sip on water or suck on ice blocks to keep your mouth moist.
- For mouth ulcers, keep your mouth clean and moist by using regular alcohol-free mouthwashes and salt gargles.
- Avoid rough, crunchy or dry foods (crisps, nuts, dry biscuits) and choose foods that are moist (casseroles, stews, soups, pasta sauces).
- Try chewing on sugar-free gum or sucking on mints.
- If food tastes bland, add fresh herbs, lemon juice or other sauces (e.g. soy sauce) to add flavour.
- If you notice a metallic taste in your food, have a small piece of fresh fruit or juice just before eating, or suck mints and boiled sweets in between meals. Some people find using plastic cutlery rather than metallic cutlery helps.
- See your dentist if you develop any tooth ache or gum problems.

Refer to **Table 3** for more tips.

Table 3: Tips for dealing with fatigue, nausea and vomiting

Fatigue	Nausea and vomiting
Plan your day and set goals you can manage.	Ask your doctor about medications to help with nausea and vomiting.
Don't use all your energy in one hit (e.g. the morning) but rather pace your activity across the day.	Acupuncture can help with nausea.
Ask for help from those close to you: they will want to help.	Eat small amounts often and try to eat before you get too hungry (an empty stomach can make nausea worse).
Take regular rests before you get too tired.	Keep your lips moist with lip balm. Suck on ice blocks / sip water regularly to keep your mouth moist.
Avoid rushing – allow plenty of time to get places, like appointments.	If you have mouth ulcers, keep your mouth clean and moist by using regular mouthwashes.
Sit or lie down to do things where possible, such as preparing meals, talking on the phone and playing with children.	Sip ginger in drinks or suck on ginger sweets; ginger can combat nausea.
Eat a well-balanced and healthy diet.	Salty foods can help with nausea but not if you have mouth ulcers. Some people find fatty foods worsen nausea.
Say 'yes please' when others offer to do things for you like cooking or shopping.	Have plenty of nutritious snacks at hand (nuts, crackers, dried fruit, chocolate, fruit and yogurt).
Take time to do things you enjoy and that you know will help you relax: massage, listening to music, being with those you love.	Some people find cold foods easier to tolerate than hot foods when feeling sick.
Drink plenty of fluids to keep up your energy and hydration levels.	

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PAIN

People with cancer have pain for many reasons. It may be caused by the cancer, the treatment or something else. The main causes include:

- side effects of surgery, chemotherapy or radiotherapy
- infections
- spread of cancer to other organs in the body
- blockages in organs such as the bowel
- the tumour pressing on nerves, organs or bone
- bone fractures if the tumours spread to the bones
- muscle stiffness due to less movement than usual or tension.

It can be very frightening to be in pain. You may worry about having a lot of pain due to your cancer or its treatment. It may help you to know there is always something that can be done to help cancer pain.

There are different types of pain, such as nerve pain, bone pain, chronic pain, referred pain and muscle pain. Each one may be relieved using different treatments or pain-relieving drugs.

Talk to your doctor to work out the cause of your pain and how to best manage it. Refer to **Table 4** for tips on managing pain.

RESOURCE

Cancer Council – 'Overcoming cancer pain' (booklet), 13 11 20, cancer.org.au

HAIR LOSS

Chemotherapy may cause hair thinning or loss. This is because it affects the healthy cells involved in hair growth.

Hair loss is usually temporary. If it happens, it will start about 2 weeks after your first treatment. Hair generally starts to return after your final treatment ends.

Hair loss is common and usually very rapid with paclitaxel. You may lose hair all over your body, including eyebrows, eyelashes, arms, legs, nasal hairs and pubic hair. Your hair will grow back once you finish chemotherapy, usually within weeks or months. While your hair is falling out, your scalp can feel itchy, tender and hot.

Many people struggle with hair loss because hair and its appearance are closely related to our identity and self-esteem. Losing your hair makes cancer obvious to others and this can be difficult to cope with. Many say losing their hair is one of the hardest parts of having cancer.

It is only natural to feel frightened, angry and upset about losing your hair. But it helps to remember it is almost always temporary.

Some people who have very long hair may be able to cut their hair before treatment and donate it to make wigs. Those who have done this say it brought something positive out of a traumatic situation. Contact **Cancer Council 13 11 20** to find out about donating your hair.

When it comes to hair loss, it's a great help to be prepared and think about ways to lessen the shock before you start chemo.

Read our tips on coping with hair loss in **Table 4**.

> *“Sometimes I’d have no hair, sometimes I’d have a turban, and sometimes I’d have a wig and my grandson Thomas would try and recognise which grandma it was today!”*
>
> **Diane**

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Can I prevent losing my hair (cold caps)?

Preventing hair loss from chemotherapy is not always possible. However, you may be able to reduce the amount of hair you lose by using cold caps. Cold caps decrease the scalp temperature, and this reduces the blood flow to the scalp and lowers the amount of chemotherapy that gets to your hair follicles, meaning the risk of hair loss may be reduced.

There is no guarantee that cold caps will work, and you will not know until you try it. Some people still have hair thinning or lose their hair completely. Not all treatment centres offer cold caps.

Cold caps are not suitable for everyone having chemotherapy and many people are not able to tolerate them as it is quite unpleasant to have your scalp cooled for several hours. You would need to discuss this option with your specialist doctor.

RESOURCE

Look Good … Feel Better – free 2-hour workshops are run in hospitals and cancer centres by beauty professionals who volunteer their time; offers useful tips on using cosmetics to deal with changes in your skin, hair and general appearance, 1800 650 960, lgfb.org.au

> *"If you are going to lose your hair, make sure you attend a Look Good … Feel Better session beforehand, so you are prepared and have some sassy hats and wigs on standby."*
>
> **Jan**

Table 4: Tips for managing pain and hair loss

Pain	Hair loss
Let your healthcare team know if you are in pain.	Cutting your hair very short before treatment may help some people.
Take your pain medication at the recommended times. Don't wait until the pain becomes severe, as pain relievers won't work as well.	Find a wig you love. You can borrow a wig for a small fee from some hospitals and cancer care units. Private health insurance may cover part of the cost of buying your own wig.
Using heat packs, having a warm bath and massage can help to ease some pain.	Contact your state/territory Cancer Council; some organisations offer free wigs.
See if either resting or gentle movement helps your pain.	Express your personal style by buying or borrowing colourful scarves, turbans or hats.
Distract yourself with music, watching Netflix, TV, or chatting with friends and family.	Treat your existing hair and scalp gently and protect bald heads (they are very sensitive to the sun and cold!).
Acupuncture, meditation and relaxation techniques can help to relieve pain. See 'Complementary therapies' in **Chapter 3: Staying well**.	Use hair and skin products without added chemicals or perfumes to avoid irritation.
	Ask your doctor about cold caps to prevent full loss of hair.

CONSTIPATION

Constipation may be caused by your cancer treatment, anti-sickness (nausea) or pain-relieving drugs. It can also be a result of the cancer affecting the bowel, or being less active when you are unwell. It is important to let your doctor know if you are constipated, as leaving it too long can lead to more serious problems. The symptoms you may have if you are constipated include:

- fewer bowel actions
- hard or lumpy bowel actions
- pain, straining or discomfort when having a bowel action
- abdominal pain or discomfort.

For tips on preventing and/or controlling constipation see **Table 5**.

BOWEL OBSTRUCTION

The bowel can sometimes become blocked because of surgery or due to the cancer growing. This blockage is called a 'bowel obstruction'. Symptoms include nausea, vomiting, abdominal pain, difficulty passing gas, abdominal swelling and cramps that come and go. You may also leak liquid faeces from your rectum.

> *"The worst side effect of chemotherapy for me was constipation. I ended up taking laxatives a couple of days prior to the chemotherapy sessions and this helped. It really is one of those subjects no one wants to mention, but looking back, I wish I had known this: it took me 3 sessions before I got it sorted out."*
>
> **Michelle**

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Contact your doctor as soon as possible if you have any new or different symptoms. A bowel obstruction can often be relieved with treatment in hospital. Sometimes a further operation may be necessary.

DIARRHOEA

Some chemotherapy drugs, radiotherapy and antibiotics can cause diarrhoea. Stress, anxiety and infections can also cause diarrhoea. Talk to your doctor if you have diarrhoea, stomach pain or cramps. For tips, refer to **Table 5**.

Table 5: Tips for managing diarrhoea and constipation

Diarrhoea	Constipation
• Drink plenty of fluids to prevent dehydration.	• Drink plenty of liquids – aim for 2 litres of clear fluids daily.
• Reduce insoluble fibre: avoid grainy breads and cereals, nuts and seeds, and raw fruit and vegies.	• Do something active every day, even if it is just a gentle walk around the house or block. When you move your body, the muscles in the intestine are more active.
• Increase soluble fibre found in oatmeal, potatoes, bananas and rice.	• Increase the fibre in your diet by eating wholegrain breads, cereals, vegetables and fruit.
• Reduce dairy products or try low or no lactose alternatives.	• Talk to your doctor as they may suggest medication (laxatives) if simple measures are not working.
• Avoid caffeine and alcohol.	• Don't ignore the urge to have your bowels open.
• Ask your doctor about anti-diarrhoea medication suitable for you.	• If you have not had your bowels open for 3 days or more consult your doctor.

HEARING CHANGES

Some chemotherapy drugs, especially platinum-based chemotherapy, can damage your inner ear (ototoxicity). It can cause loss of hearing, high-pitched sounds, ringing in your ears (tinnitus) or dizziness. This can be very distressing.

Let your doctor know if you notice any change in your hearing or if you have ringing in your ears or dizziness. For tips, refer to **Table 6**.

Table 6: Tips for managing skin problems and hearing changes

Skin problems	Hearing changes
• Use gentle skin care: soap-free cleansers and low-irritant moisturisers.	• Avoid exposure to loud noises to help prevent further damage.
• Protect your skin using hats, sunglasses and at least SPF 30+ sunscreen for sensitive skin.	• Drink plenty of fluids as dehydration can worsen dizziness.
• Do not rub or massage the treated area. Wear loose, cotton clothing to reduce irritation.	• Have quiet background music playing when you are trying to rest/sleep. This may help you to pay less attention to ringing in your ears, making it easier to rest and sleep.

SKIN PROBLEMS

Chemotherapy may cause skin problems including redness, itching, dryness and breakouts, while radiotherapy can cause dry or red skin in the area being treated. For tips, refer to **Table 6**.

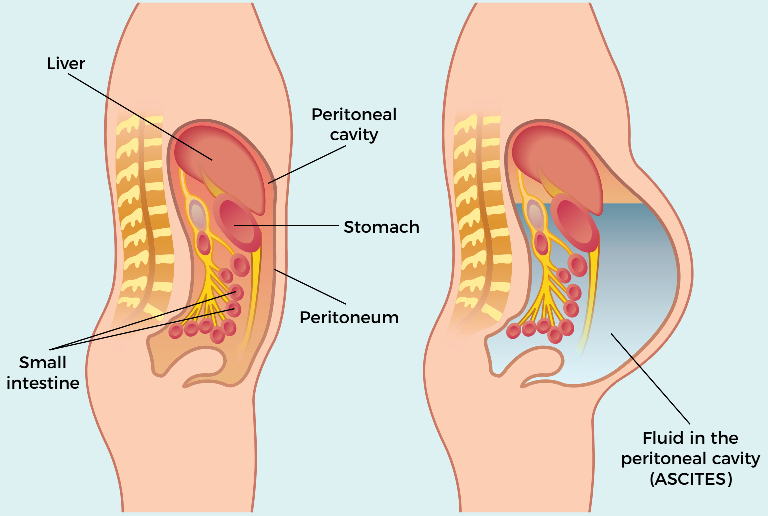
FLUID BUILD-UP (ASCITES)

Ovarian cancer can cause a build-up of fluid in the abdomen known as ‘ascites’ (pronounced a-site-eez). It is sometimes called ‘malignant ascites’.

Ascites is often associated with advanced ovarian cancer. About 90% of people with stage 3 and 4 ovarian cancers have ascites at some stage in their illness.

The abdomen contains the bowel, liver, spleen, bladder, pancreas and stomach. Covering these organs is a layer of tissue (peritoneum). It is made up of 2 layers: one lines the wall of the abdomen and the other covers the organs. A small amount of fluid is produced within these layers to allow the organs in the abdomen to move smoothly. With ascites, fluid builds up between the 2 layers and causes the tummy to swell up **(Figure 1)**. This can be very uncomfortable.

Figure 1: Comparison of a normal abdomen and an abdomen with ascites



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The main symptom is abdominal swelling, which can happen over a few days or months and is very uncomfortable. The build-up of fluid puts pressure on all the abdominal organs, which can lead to further symptoms such as:

- bloating
- abdominal pain
- back pain
- loss of appetite
- indigestion
- constipation
- needing to pass urine often
- breathlessness as the swelling spreads and puts pressure on the lungs
- tiredness and weakness (fatigue)
- feeling or being sick.

As well as a physical examination and blood tests, your doctor may also do some tests to diagnose ascites, including an ultrasound and/or CT scan. A sample of the fluid is taken to check for cancer cells or infection.

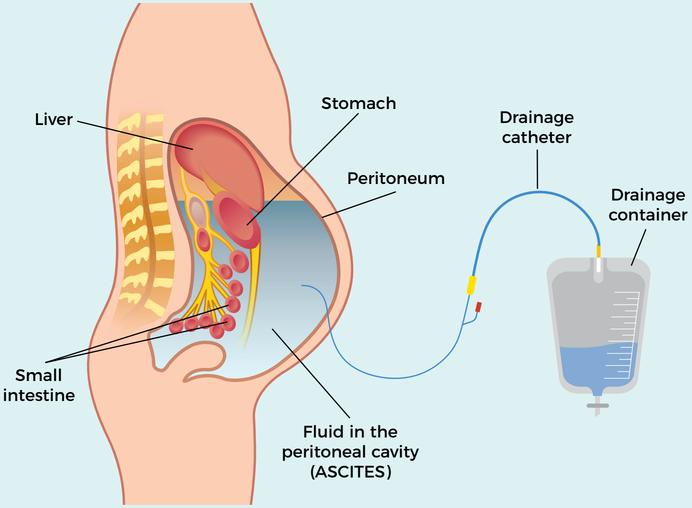
To treat the fluid or prevent it from building up in your abdomen your doctor may suggest one or more of the following treatments:

- having a tube inserted to drain the fluid (paracentesis – see **Figure 2**)
- chemotherapy.

In most people, draining the fluid usually relieves symptoms. The fluid can build up again over time so your doctor may suggest a course of chemotherapy to help prevent this happening. You may also need it to be drained again.

Although uncommon, possible complications following any of these procedures include infection, pain, blockages and leaking of fluid after the tubes are removed. Your doctor will discuss the risks involved in any procedures prior to it happening.

Figure 2: Fluid (ascites) being drained from the abdomen



Talk to your doctor if you have any symptoms that suggest fluid is building up in your abdomen or lungs.

‘CHEMO BRAIN’

After having chemotherapy, many people have problems with their short-term memory, concentration and processing information. This is often called ‘chemo brain’.

This problem can be frustrating and debilitating, especially if you have previously had a good memory or if you need to concentrate carefully for work or study. It’s not clear if chemo brain is caused by chemotherapy alone or a combination of factors – including chemotherapy, the stress of living with cancer, hormonal changes and the natural ageing process.

Regardless of its exact cause, it is a real and distressing problem. It can help to know that many other people have the same problem! You can do practical things to help, and the problem usually improves with time.

Don’t be hard on yourself when you forget things or feel a bit confused. Just take a break and acknowledge it is a side effect from your treatment.

Talk to your doctor or another member of your healthcare team if you have ongoing concerns about your memory or concentration. Refer to **Table 7** for tips on managing chemo brain.

> *“I had to keep reading things over and over with the studies I was doing because my chemo brain made concentrating very hard. I had to do it bit by bit but it was still possible.”*
>
> **Vicki**

Table 7: Tips for managing chemo brain and infection risk

Memory and concentration changes: 'chemo brain'	Managing infection risk
• Use a calendar on your phone or diary to keep track of appointments, birthdays and important tasks.	• Watch out for warning signs such as fever, feeling unwell, fatigue, cough or diarrhoea. Seek medical advice immediately if you notice any symptoms.
• Write lists: phone calls to make, emails to return, items to buy.	• Avoid people with colds, coughs and other infections.
• Schedule tasks that require a lot of concentration for times of the day when you feel most alert.	• Always wash your hands well with warm water and soap.
• Keep your brain active with crosswords, Wordle, puzzles, reading, interesting conversation and hobbies. Don't push yourself too much.	• Avoid large, crowded places like public transport and shopping centres where you may be more likely to catch an infection.
• Rest where possible to prevent tiredness that can affect concentration.	• Seek your doctor's advice before getting any vaccinations (such as flu and COVID-19).
• Gently exercise at a level that is suited to your recovery. Exercise is great for your brain. Always check with your doctor before starting any new exercise program.	• Eat well and stay hydrated. Avoid raw or uncooked food.
• Have a look at Brain Gym Australia (**braingym.org.au**) for some ideas.	• Wear a mask out in public places and practise social distancing where possible.

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INFECTION AND CHANGES IN YOUR BLOOD COUNTS

Chemotherapy can reduce the number of white blood cells in your body (neutropenia), and this can increase your risk of developing infections.

Febrile neutropenia is a condition where a person has a fever and a low level of neutrophils, which are a type of white blood cell that helps you fight infections. If they are low, it will mean that you are more vulnerable to picking up infections and illness.

Your white blood cell count will be checked regularly during treatment. If a blood test shows your count is low, your medical oncologist may delay the next round of chemotherapy.

If you feel like you have a fever, seek help immediately. It is important to have a thermometer at home in case you feel you have a fever. Febrile neutropenia is serious and needs urgent medical intervention.

IMPORTANT NOTE

If your temperature reaches 38 degrees or over, you should attend the emergency department immediately.

Seek urgent help if you have any unusual symptoms that may indicate you have an infection such as a fever, sore throat, shaking (chills), diarrhoea, vomiting, burning when you pass urine, redness or swelling around a wound or your chemotherapy device (central line, PICC line, Hickman line).

If you are unable to get to the emergency department, call 000.

Treatments can also affect your level of red blood cells and platelets. If your red blood cells become too low (anaemia), you may need to have a blood transfusion. Decreased platelets can lead to serious problems such as bleeding that won't stop. Seek immediate help if you have a nosebleed or notice you are bruising easily.

Bleeding or bruising is a rare side effect of chemotherapy caused by a drop in blood platelets. Your doctor will keep a close eye on your platelet count during treatment, but always let them know if you are bruising more easily than usual, are bleeding from your gums or nose, or have blood in your bowel motions.

Refer to **Table 7** for tips on managing infection risk.

URINARY PROBLEMS

Surgery for ovarian cancer can involve cutting the tissue around the bladder and ureter. Most people will have difficulty emptying their bladder in the days after surgery, and so a catheter is used to drain away urine. Sometimes, it may take a little longer for bladder function to return to normal, but ongoing problems are very rare.

Radiotherapy may cause an irritable bladder. It can sometimes cause longer-term problems with urinary function. Menopause can also cause urinary tract changes including frequency, burning and incontinence.

Tell your doctor or nurse about any urinary symptoms.

RESOURCE

Continence Foundation 1800 33 00 66,
continence.org.au

SLEEP PROBLEMS

Many people suffer insomnia (difficulty getting to sleep and/or staying asleep) and/or disrupted sleep after cancer, leading to fatigue. Disturbed sleep is often described as trouble sleeping, poor-quality sleep and daytime tiredness. Difficulty falling or staying asleep can be frustrating and cause anxiety and low mood. Worrying about sleep can worsen the problem.

Tips for better sleep:

- Maintain a regular sleep schedule. Short naps (under an hour) during the day are fine but avoid long naps.
- Avoid strenuous exercise before bed.
- Go to bed only when you feel sleepy.
- If you can't sleep, get up and do something relaxing until you feel sleepy.
- Try deep, slow abdominal breathing exercises or yoga before bed.
- Avoid caffeine, alcohol and stimulants like cigarettes before bed.
- Herbal teas such as chamomile help some people relax before bed.
- Make your bedroom as calm and as comfortable as possible and try not to work or use screens before bedtime.

Talk to your doctor if your sleep issues are persistent and your mood is being affected by lack of sleep. They may suggest a 'sleep hygiene plan'. This can involve changes to lifestyle, medication changes and an exercise plan, along with other techniques and therapies that help with relaxation. You may find it helpful to read the information on the Peter MacCallum Cancer Centre website (**www.petermac.org**) about their Can Sleep service. This service helps people with cancer improve night-time sleep problems.

NERVE PROBLEMS: PERIPHERAL NEUROPATHY

Peripheral neuropathy is the result of damage to the nerves outside the brain and spinal cord (peripheral nerves). It can be a side effect of certain chemotherapy drugs (such as carboplatin and paclitaxel). These drugs can damage nerves that affect the feeling and movement in your hands and feet. The most common symptoms of peripheral neuropathy include:

- tingling, burning, numbness or pain in the hands or feet
- loss of feeling, especially in the hands and feet
- muscle weakness
- problems with balance or walking, and clumsiness
- constipation
- feeling lightheaded or dizzy.

The symptoms of peripheral neuropathy can be mild and will usually go away once treatment has stopped. But for some people they can be severe and last longer. For example, it can be difficult to do simple tasks like doing up buttons or tying shoelaces. You may also be very sensitive to hot and cold and need to take great care when handling hot things as you may not feel it if something is burning.

Peripheral neuropathy can be challenging to cope with. Unfortunately, there is no treatment to improve the nerve damage. However, there are ways to help reduce the impact of the problem. Talk to your doctor about adjusting your treatment to avoid further nerve damage.

What can help peripheral neuropathy?

Sometimes drugs used to treat other medical conditions have been found to help with treating nerve pain. One example of this is the antidepressant duloxetine (Cymbalta). Anti-inflammatory drugs and other painkillers such as gabapentin and pregabalin (Lyrica) can also help with nerve pain.

International research suggests the following treatments may also help in preventing or controlling neuropathy related to chemotherapy:

- vitamin B6
- calcium and magnesium
- glutathione, a vitamin rich in antioxidants.

Please talk to your doctor if you want to explore any of these options. The most important tip is to tell your doctor as soon as you have any symptoms.

Other ways known to help reduce peripheral neuropathy are:

- exercise – which can help strengthen muscles, reduce pain and cramps, and improve balance and circulation
- mindfulness and meditation – may assist in drawing attention away from painful symptoms
- wearing comfortable and supportive shoes that do not cramp/confine your toes
- keeping hands and feet warm
- using roll-on deodorants instead of spray as pushing the spray can be difficult.

RESOURCE

Cancer Council – ‘Peripheral neuropathy’ (online information), cancer.org.au

EMOTIONAL EFFECTS

Cancer symptoms and side effects of treatment can dramatically affect the emotional, intimate and spiritual parts of your life. You may experience sadness, depression or anxiety and your sexual desire may be affected. See **Chapter 3: Staying well** for more information.

FOLLOW-UP CARE

After you finish your treatment, you will have regular check-ups.

Your doctor will decide how often you will need check-ups – everyone is different. Your check-ups will gradually become less frequent if you have no further problems.

If your ovarian cancer was diagnosed in the advanced stages, it is likely you will continue to have regular check-ups as often as you need them. And these will be with different members of the healthcare team (e.g. specialist nurses and doctors, social worker, physiotherapist). If your cancer comes back, you may need further treatment, and it may be different from your first treatment.

It is important you tell your specialist doctor or GP if you notice any new symptoms. In the days or weeks leading up to your appointments, you may become anxious and worry more about your cancer coming back. This is only natural, so be kind to yourself during this time.

There is more information about follow-up care and how to cope with your concerns in **Chapter 3: Staying well**. If you have any concerns in between follow-up appointments, see your GP for advice.

> *“Finishing treatment is rather frightening; you are suddenly on your own. It is terrifying, you are out there without the safety net around you, it is very hard to get used to. It was an adjustment. It didn’t last long – it was a change in circumstances that you had to get used to.”*
>
> **Jan**

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STAYING WELL

Sabrina and Julie, women with ovarian cancer.

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STAYING WELL

Having cancer and its treatment can be tough on your body, mind and soul. This chapter shares simple tips that have helped others to feel better, including coping with your emotions, talking to those close to you, and changes to your sexuality, body image and relationships. It also explores complementary therapies, diet and exercise to help calm your mind and support your physical and emotional wellbeing.

Allow yourself to explore what can help you to feel stronger and calmer. Many people with ovarian cancer have discovered lasting benefits from even small lifestyle changes, such as a new hobby or a relaxing ritual.

> *"Often lack of time, low energy and even guilt can get in the way of taking time out for ourselves. Giving yourself permission to take one moment each day, small or large, that is just for you, can help give your mind a break from the constant flow of all things cancer-related and helps put you in a better position to manage your own stressors and also those of others."*
>
> **Lauren, Clinical Psychologist and Psychosocial Team Leader at Ovarian Cancer Australia**

COMPLEMENTARY THERAPIES

Many women with ovarian cancer are interested in trying complementary therapies. These are natural therapies used alongside mainstream or conventional cancer treatments (such as chemotherapy, radiotherapy), which aim to treat both mind and body. Examples of commonly used complementary therapies include massage, mindfulness meditation, yoga and acupuncture.

RESOURCE

Cancer Council – 'Understanding complementary therapies' (booklet), 13 11 20, cancer.org.au

These will not treat or cure cancer. However, a few have been shown to help some people feel and cope better with their cancer and its treatments. They work on helping your mind and body feel better.

> *"Even 18 months post-treatment I find it difficult to switch off the cancer thoughts. When I go to yoga and Pilates classes, the atmosphere and activity draws my focus away from these thoughts and helps to give me a break from it all."*
>
> **Laura**

Other terms you may hear used to describe complementary therapies include:

- ‘integrative medicine’, which 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
- ‘holistic medicine’, which is a form of healing caring for the whole person – body, mind, spirit and emotions. Its aim is to give a feeling of optimal health and wellbeing.

RESOURCE

Cancer Council – ‘Massage and cancer: an introduction to the benefits of touch’ (booklet), 13 11 20, cancer.org.au

Carefully chosen complementary therapies can help to:

- manage symptoms and side effects – including nausea, hot flushes, dry mouth, pain and fatigue
- relieve stress, anxiety and sleeplessness
- encourage an overall feeling of wellbeing.

Research shows that those with ovarian cancer can benefit in many ways from using complementary therapies. Please seek expert advice from a qualified health professional when you are making choices about using any complementary therapy.

RESOURCE

For a list of cancer massage therapists, oncologymassagetraining.com.au

ARE ALL COMPLEMENTARY THERAPIES SAFE TO USE?

Most complementary therapies are safe to use alongside your conventional treatments. You can discuss complementary therapy with your doctor if you are unsure. Your doctor may even recommend certain therapies such as massage, acupuncture or meditation to help with reducing pain, nausea and anxiety.

Some complementary therapies are called ‘natural therapies’. However, ‘natural’ does not always mean ‘safe’. Many ‘natural’ herbal, vitamins and other supplements you can buy over the counter at the chemist have serious side effects. These supplements may interfere with other drugs you are taking. For example, some herbs can make your skin more sensitive to sunlight, so you should not take them if you are having radiotherapy treatment. Taking high doses of vitamin C while you are having chemotherapy treatment may reduce the effectiveness of treatment, and in some studies is reported to increase chemotherapy side effects.

RESOURCE

Cancer Council NSW – ‘Finding calm during cancer’ (podcast), cancercouncil.com.au

BEFORE YOU START …

Most cancer doctors support complementary therapies used alongside your conventional treatment. However, some therapies are known to interact with and cause side effects when used with conventional treatments.

We recommend you **discuss any therapy you may be using, or you are thinking about using, with your cancer specialist and GP**. They may suggest you discuss any natural products (such as herbal medicines or vitamin therapies) with your pharmacist. You need to make sure they will not interact in a negative way with medicines you are already taking or your chemotherapy.

RESOURCE

Memorial Sloane Kettering Cancer Center – for a comprehensive searchable database of herbs, vitamins and plants and information about mind and body therapies used in cancer care, mskcc.org

WHAT ABOUT ALTERNATIVE THERAPIES?

Alternative therapies are quite different to complementary therapies. They are promoted as an alternative to conventional treatments such as chemotherapy, radiation and surgery.

Alternative treatments are often unproven, expensive and may be harmful. Well-meaning friends and relatives may also suggest a certain food, diet or therapy to cure your cancer. Be very cautious of any expensive therapy that requires stopping conventional treatment or keeping it a secret from your doctor.

Examples of alternative therapies include megadoses of vitamins such as high-dose vitamin C, shark cartilage, restrictive special diets and juice fasting. There are many websites promoting so-called 'cures for cancer'. They **have not** been scientifically proven to work.

Always check with your medical team first.

RESOURCE

Quackwatch – a US non-profit organisation aiming to 'combat health-related frauds, myths, fads, fallacies and misconduct', quackwatch.com

WHICH THERAPIES MIGHT HELP?

Different therapies may help at various stages of your illness and treatment. For example:

- Massage can reduce muscle tension and pain, improve sleep and fatigue, and provide deep relaxation.
- Acupuncture has been well researched and can relieve pain, nausea, vomiting and other side effects of chemotherapy and radiotherapy for some people.
- Meditation and relaxation techniques like yoga, tai chi, music and art therapy can help with pain management, anxiety and depression.

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RESOURCE

Complementary and Alternative Medicine for Cancer – evidence-based information about complementary and alternative medicine for cancer, cam-cancer.org

Each person's condition is unique and the responses from these therapies may vary from person to person. Always check with your medical team before starting any new therapy.

> *"I went along to an art group (never having painted before) – I found it a great way to relax. Trying to mix a paint colour just right banishes all thoughts from your mind!"*
>
> **Wanda**

WELLNESS RETREATS AND PROGRAMS FOR PEOPLE WITH CANCER

Wellness retreats and programs offer an integrative, holistic approach to health and healing, focusing on complementary therapies, including meditation and visualisation, as well as information on healthy eating and physical activity.

There are several centres in Australia and overseas that run cancer programs; you may find them on the internet. However, it is important before you pay for one of these retreats that you discuss the benefits of the program with your health professionals. Ask yourself what you are hoping to get out of attending.

If you find a program claiming to cure your cancer, be suspicious. See the information above about 'What about alternative therapies?'

Always check with your medical team before committing to any program or retreat.

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A NOTE ON MEDICINAL CANNABIS

Medicinal cannabis (cannabinoids) is sometimes used by cancer patients to help manage symptoms. It may provide some relief when traditional medications are not controlling all symptoms.

Some evidence suggests that cannabinoids can provide relief for patients who have not had success with standard medications, especially for issues like nausea and vomiting caused by chemotherapy.

Medicinal cannabis will not cure cancer.

If you are considering trying cannabis or any other complementary therapy, be sure to talk to your medical team first to ensure it is safe for you.

For more information about medicinal cannabis, and the laws around obtaining it in different states of Australia, go to **tga.gov.au/medicinal-cannabis**.

FINDING A COMPLEMENTARY THERAPIST

Most reputable therapists will be members of a professional body (such as a college or association). This means they will follow a strict code of conduct. However, there will be those who are not so careful or caring, and there may not be a professional body for all types of therapies.

You need to feel confident about your therapist and know what you hope to gain from the therapy, so choose carefully. The following people and organisations can help you do this.

- GPs, specialists or oncology nurses often know about the therapists who work together with mainstream medicine.
- Some cancer treatment centres at hospitals offer complementary therapies, including meditation, relaxation and stress management.
- The Australian Traditional Natural Medicine Society is the main professional organisation for natural therapists in Australia and has a list of practitioners (**www.atms.com.au**).

- The Australasian Integrative Medicine Association is the peak body for medical practitioners who practise integrative medicine and has a list of practitioners (**www.aima.net.au**).

> *"It's the little things that can help you get through the rough times – the foot and hand massages, the company of good friends when you are feeling well, a great book and lots of rest."*
>
> **Debbie**

PHYSICAL WELLBEING: EATING WELL AND STAYING ACTIVE

Eating a variety of healthy foods and staying active can help improve your physical and overall wellbeing during and after your cancer treatment.

Eating well and being active can help:

- lift your energy levels and mood
- you to cope better with the side effects of treatment
- wounds and tissue to heal after surgery, chemotherapy and radiotherapy
- improve your body's ability to fight infection
- keep your weight at a healthy level.

For eating tips to help overcome nausea, vomiting, constipation and diarrhoea, see 'Managing symptoms and side effects' in **Chapter 2: Treatment**. It includes simple ideas to help reduce fatigue, which is another important part of your overall wellbeing.

RESOURCE

Ovarian Cancer Australia – for information on the benefits of support from an exercise physiologist and dietitian, 1300 660 334

HEALTHY EATING

Healthy eating during cancer treatment and beyond is all about eating a wide range of nourishing foods that can help you recover quickly, boost your energy levels and feel good in your body. There are generally no special foods you need to eat or avoid. A well-balanced diet means eating a variety of foods from each of the core food groups:

- fruit
- vegetables
- grains and cereal-based foods such as bread, breakfast cereal, rice, pasta, noodles
- protein-rich foods such as legumes, tofu, chicken, fish, eggs, red meat
- dairy or calcium-fortified dairy alternatives
- foods rich in healthy fats such as olive oil, olives, avocado, nuts and seeds.

RESOURCE

Cancer Council – 'Nutrition and cancer' (booklet), 13 11 20, cancer.org.au

Cancer and its treatment can often make healthy eating a challenge – especially when you are feeling sick, are constipated, are in pain, have lost your appetite or are simply too tired to eat. In these situations, don't become too worried about only eating the healthiest foods. There will be times when it is better to just eat what you feel like eating. For example, you may only feel like eating chocolate or hot chips. In the short term, it is better to take in some calories than none, especially if you are already losing weight. In time, you will want to get back to eating a well-balanced diet.

It is also very important to stay hydrated during your treatment, especially if you are having chemotherapy. Water and herbal teas are good. If you have a sore mouth due to side effects of your treatment, it may be best to avoid crunchy, spicy and citrus foods.

Some people find speaking to a dietitian helpful. Ask your GP or specialist for a referral. If you are struggling with a poor appetite and/or finding eating difficult, speak with an accredited practising dietitian for tailored advice on how you can maintain a healthy diet. This often means having flexibility with your meals and snacks to include foods high in calories and protein. Supplementary high-calorie, tasteless, nutritional powders can be added to most meals and drinks to help boost calorie intake without increasing how much you have to eat.

RESOURCE

Dietitians Australia – lists accredited practising dietitians around Australia 1800 812 942, dietitiansaustralia.org.au

Supplementary nutritional drinks can help boost your calorie intake as well. Your dietitian can arrange for these to be delivered to your home at a discounted cost.

RESOURCE

Australian Cancer Survivorship Centre – fact sheets about life after treatment, petermac.org

BEWARE OF 'ANTI-CANCER' DIETS

Beware of any special diets, foods or supplements that are promoted as being especially beneficial for people with cancer or that claim to 'cure' cancer.

None of these claims have been scientifically proven, and some can cause harm. Excluding food groups you need for health, energy and good immune function may interfere with the success of your treatment or cause you to lose too much weight.

RESOURCE

National Cancer Institute (United States) – lists healthy eating tips, cancer.gov

BEING ACTIVE

Being active can boost your energy, reduce fatigue, relieve stress, help digestion, and may improve mood and overall wellbeing during cancer treatment and recovery.

Always talk to your doctor, exercise physiologist or physiotherapist if you are unsure about which activities are safe for you, or what level of activity you can start or continue with.

If you have mobility issues after treatment, your doctor may refer you to an exercise physiologist or physiotherapist who can help you resume exercise safely. They will assess your energy and fitness and create a fitness program to help you reach your goals while considering your limitations after treatment.

> *"I am totally convinced exercise helps me. But you have to make it a priority and not be put off by the fatigue. You also have to accept it's not always sensible or possible to do as much as you used to, especially if you are working as well."*
>
> **Kristen**

Over time, you may improve endurance through gentle activities such as swimming, cycling, walking, yoga, tai chi or Pilates. Be cautious, as some exercises might not be suitable immediately after ovarian cancer surgery. This surgery may also result in early menopause, leading to a possible increase in fat and decrease in muscle. However, after recovery, a proper exercise program can:

- reduce fat
- improve muscle strength
- enhance mood
- improve sleep
- control your weight
- improve and maintain heart and bone health.

RESOURCE

Exercise and Sport Science Australia
– lists accredited exercise physiologists, essa.org.au

> *“Exercise can improve your tolerance to chemotherapy and prevent loss of physical strength due to treatment. Exercise can also help make you feel more in control of your situation and has been proven as the most effective way to help treat cancer-related fatigue.”*

Dale, exercise physiologist

Other exercise tips:

- Ask your medical team for a referral to an exercise physiologist early in your treatment for long-term benefits.
- Exercising throughout your treatment, including chemotherapy and post-surgery, is safe. But you will need to make adjustments to ensure you don’t overdo it.

> *“There is growing evidence to suggest that regular exercise after a cancer diagnosis can reduce the chance of some cancers coming back.”*

Cancer Council Australia

EMOTIONAL WELLBEING

Being diagnosed with ovarian cancer is the beginning of an emotional journey, often with no certainty about what is going to happen.

Chapter 1: Finding out discusses the range of emotions you may have when you are first diagnosed and how you might share your feelings, build support and nurture yourself. For some people, the early days of shock, anger, panic and numbness are the most frightening. Over time, these intense feelings of distress usually begin to ease.

As your journey continues, different emotions are likely to surface at different times. The phase of your treatment, your physical health and the way you have previously coped in difficult times will affect the way you feel. Your family, intimate relationships, close friends, financial and work/study situations will also influence how you feel. The intensity and persistence of emotions varies greatly from one person to another and there is no 'right' or 'wrong' way to feel.

RESOURCE

Cancer Council – runs free programs that focus on wellness after cancer, 13 11 20

WORKING THROUGH YOUR FEELINGS

Try to acknowledge any strong emotions and allow yourself the opportunity to experience them. Don't shut them out or put on a brave face – they might keep simmering away.

You may find sharing your concerns with a family member, a friend or a member of your healthcare team helpful. Saying something like 'I am feeling really alone and afraid because ...' can help begin supportive conversations, whereas withdrawing from friends and family can leave them feeling unable to help and you feeling more alone.

People sometimes say that the friends they thought would be the most supportive were not. This does not necessarily mean they do not care. Certain friends and family may be better able to cope with what is happening with you and support you better than others. Support sometimes comes from unexpected places.

Let your healthcare team know how you feel. They will want to help and if they know you are struggling, they can guide you towards support.

Chapter 4: Support includes information about support groups and networks that can help you connect with others in similar circumstances.

> *"Expect to have down times – serious bad times! We all do. Fear creeps into your room sometimes in the middle of the night. Don't fight it, just let it pass over. It will go."*
>
> **Jan**

RESOURCE

Cancer Council – 'Living well after cancer' (booklet), 13 11 20, cancer.org.au

SADNESS, LOSS AND DEPRESSION

Many people with ovarian cancer experience sadness, loss and some level of depression. These feelings are a natural response to a cancer diagnosis, treatment and recovery.

Ovarian cancer can lead to many losses such as:

- financial security
- relationships
- work security
- hopes and dreams you had for the future.

You may also feel like you have lost your sense of identity, which can be distressing. If you've had your ovaries and

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uterus removed and can no longer have children, this can bring a deep sense of loss.

The physical effects of cancer and side effects of treatment can also leave you feeling tired and low in mood.

There is an important difference between feeling low or sad for a while and being depressed. If you notice a change in how you function, feel intense sadness, lack motivation, lose interest in daily activities, have trouble sleeping or struggle with low self-esteem, you may be suffering from depression.

Thoughts of self-harm or suicide are signs you need urgent medical help.

See **Chapter 4: Support**.

ANXIETY AND FEAR

Anxiety and fear are common reactions to new and distressing situations. Not knowing what will happen next can make you feel worried and anxious. For example, before chemotherapy, you might feel unsure how your body will respond. Treatment side effects like hair loss, pain and appetite changes can also cause anxiety.

After the treatment finishes, you may become anxious about the cancer coming back. Follow-up visits can also trigger fear and worry. Feeling anxious for long periods of time can be exhausting and overwhelming. If you are feeling anxious and unsure, talk to your medical team and get the support you need.

> *"I go for a walk first thing every morning and if I don't do it I feel bad – it is my sanity. Sometimes it is not easy as I feel so tired but I psych myself into it and I am always pleased I did."*
>
> **Vicki**

PRACTICAL WAYS TO HELP YOURSELF

Here are some ways to care for yourself.

- It is normal to feel fear, uncertainty, grief and loss – allow yourself to experience these emotions.
- Try to get out regularly and spend time with people who inspire and uplift you, not those who drain you.
- Do small things that make you happy, like spending time with friends and pets, gardening, reading or listening to music.
- Try relaxation exercises, meditation or deep breathing.
- Ask for help when you need to.

MINDFULNESS MEDITATION

Some people use mindfulness meditation to help manage their anxiety. This ancient practice helps calm a racing mind by noticing thoughts as they come and go, rather than trying to clear your mind. Focus on your breath as an 'anchor' – breathe in and out, and if your mind wanders, gently bring your focus back to your breath.

Research shows that mindfulness meditation can help calm the mind and improve:

- pain
- anxiety and depression
- nausea
- immune system function
- overall quality of life.

Not everyone finds it easy to meditate. And sitting still for a while is not comfortable for everyone. But even just a few minutes of simply sitting and noticing your thoughts each day may be helpful.

RESOURCES

- Memorial Sloan-Kettering Cancer Center – Mindfulness and stress reduction resources for people with cancer, mskcc.org
- Cancer Research UK – Meditation, cancerresearchuk.org

WHERE TO GET HELP WITH DEPRESSION AND ANXIETY

For some people, feelings of sadness, anxiety and fear can be overwhelming and may not get better on their own. If you have these feelings a lot, it is important to speak with a health professional. There are effective treatments for depression and anxiety that can help you cope and improve your mood.

You can talk to your GP or cancer specialist about seeing a counsellor or psychologist. Sometimes, taking medication like antidepressants or anti-anxiety tablets can help. If you are concerned about becoming dependent or because of side effects, discuss it with your doctor. In most cases, the benefits of treatment outweigh the risks.

Your hospital might offer counselling services, or you may be eligible for rebates for sessions with a psychologist through Medicare or private health insurance. If you would like to discuss accessing support from the psychosocial support team at **Ovarian Cancer Australia**, please contact the helpline on **1300 660 334** (Monday to Friday during business hours AEST) or email **support@ovariancancer.net.au**.

Cancer Council 13 11 20 may also offer you counselling, either face to face or on the phone.

COUNSELLING AND THERAPY

Several types of therapy can help if you're struggling to adjust to life after cancer. It may take time to find the right one for you.

Psychological therapy (or 'talking therapy') helps you explore your thoughts and feelings, providing strategies to cope with distress.

Acceptance and commitment therapy (ACT) teaches you to manage unhelpful thoughts, stay present and live in line with your values despite difficult emotions.

Counsellors and psychologists who specialise in cancer care can support you in adjusting to your diagnosis and managing emotional challenges. It is important to find someone you feel comfortable with, ideally someone experienced with cancer patients. Your GP or medical team at your cancer treatment center can help refer you to the right therapist.

RESOURCE

Better Health – information on cognitive behavioural therapy (CBT) and ACT, betterhealth.vic.gov.au

STIGMA AND DISCRIMINATION

Depression and anxiety are still often very misunderstood, and many people feel ashamed or afraid to talk about their struggles. This stigma can make it harder to seek help or get a diagnosis, leaving people feeling isolated or uncertain.

It is important to challenge the stigma around mental health. Depression and anxiety are real illnesses, just like diabetes or heart disease, and they often require treatment and support.

Remember, everyone experiences depression and anxiety differently. You might look fine on the outside, but you still feel deeply affected inside.

If you are dealing with depression or anxiety, whether related to cancer or for other reasons, keep these points in mind:

- You can still function at a high level and be successful while struggling with depression.
- You can have a supportive family and still feel depressed.
- Depression can affect anyone, at any age.
- Successful cancer treatment doesn't prevent depression.
- It is okay to seek help when you need it.

> *"There are no silly questions. This is a new experience which many people describe as a whirlwind. If you're not sure where to turn, it can be helpful to give the Support Team at Ovarian Cancer Australia a call. We can provide you with reliable, easy-to-understand written resources, ways to connect with other people with a diagnosis, or just an 'ear' to talk to about your experience."*

Hayley, Senior Research Manager, Ovarian Cancer Australia

MORE INFORMATION

Beyond Blue (**beyondblue.com.au**) has information about coping with depression and anxiety, including a depression symptom checklist and information about finding a counsellor. Call **1300 224 636** for non-urgent advice or to have information sent to you.

If you are having suicidal thoughts, call **Lifeline Australia** on **13 11 14**. You may also want to call the suicide call back service on **1300 659 467**. They can provide counselling sessions via phone or online (**suicidecallbackservice.org.au**).

13YARN is a free and confidential service run by Aboriginal and Torres Strait Islander people and is available 24/7 on **13 92 76**.

RESOURCES

- 'Reducing stigma and discrimination', www.beyondblue.org.au
- 'Stigma, discrimination and mental illness', betterhealth.vic.gov.au
- 'Depression: stigma and mental health', healthtalk.org

SPIRITUALITY

Spirituality is about your personal sense of purpose and peace, and your beliefs about the meaning of life.

There are different ways to express your spirituality. For many, it is through their connection with other people, with nature, and possibly with a higher power. For some people, organised religion provides a way to express spirituality.

It is normal for a diagnosis of cancer to both intensify and cause upheaval in your spiritual life.

- You may feel angry and betrayed by life, fate or a higher power – and you may doubt or question your previous beliefs.
- Your faith may be a great source of comfort and give you strength.
- You may become aware of spiritual matters and feel the need to explore these more deeply or perhaps for the first time.

You may want to talk to a chaplain, minister, priest, rabbi, imam or other religious leader. Or you may want to explore your own ways of connecting more deeply with others and the world. This may include spending more time in nature, appreciating art and music, reading more widely about spiritual ideas, meditating or writing in a journal.

> *"Mental, physical and spiritual health is an integral part of staying well. I may not have the discipline to stick to it daily but I am conscious of it."*
>
> **May**

INTIMACY AND SEXUALITY

Sexuality is not just about having sex with others or about how often you have sex. You are a sexual being in your own right and your sexuality is not based on being in a relationship.

Sexuality is largely about the way people express and feel about themselves sexually. It relates to the emotional, spiritual and physical sexual feelings, thoughts, attractions and behaviours you may have towards other people and within yourself. Body image and self-esteem also play a key role.

You can express your sexuality in many ways:

- hugging
- kissing
- holding hands
- body language and eye contact
- listening to and sharing views with someone
- the intimate expression of sex (hugging, kissing, holding hands, massage)
- physical sex (masturbation, foreplay, penetrative or oral sex)
- thinking about sex and sensuality
- massage
- clothing you wear
- how you style your hair and makeup
- the ways you walk, speak and move.

> *"With so many things happening to your body – scars, hair loss, night sweats, aches and pains – I think they can usually sense that sex is not high on the agenda! Hopefully they understand that it is a physical condition, not a personal situation. Maybe hugs and cuddles, but nothing more; that was how it was for me anyway!"*
>
> **May**

Sexuality is about your overall sexual health and wellbeing. Caring for your sexual self as much as you do your physical, emotional, mental and spiritual health is important. Your sexuality can also be influenced by your culture and society.

HOW OVARIAN CANCER MAY AFFECT YOUR SEXUALITY

Treatment for ovarian cancer includes:

- surgery
- chemotherapy
- radiotherapy
- biological therapies.

These treatments and their side effects may affect your sexuality, sexual desire, body image and relationships with others, whether you have a partner or not. It is difficult to predict the exact changes for each person. During and after cancer treatment, you may have a mix of emotions about sexuality, body image and relationships. Some common concerns include:

- **Lowered libido (sex drive).** Treatment may cause menopause, which can lower your libido and lead to vaginal dryness.
- **Reproductive loss.** If you've lost reproductive organs or become infertile, it can feel like a big loss.
- **Fatigue, depression and pain.** These symptoms can affect your interest in intimacy, whether it is sex, talking or cuddling.
- **Body image.** Scarring, hair loss and other changes may make you feel less attractive. You may not want to be touched or have your appearance discussed. If you are not in a relationship, you might worry about how a future partner will react to your illness, your feelings or your body.

These feelings are normal, and it's okay to talk about them and ask for support.

WHAT CAN HELP?

Understanding these changes, communicating about them openly and finding ways to ease anxiety can help you feel better.

Talking openly about sexuality can be difficult for some people, but it can be important. Share your feelings with your partner, including any worries you have about having sex again causing pain, or not feeling attractive. Honest communication helps avoid misunderstandings, like your partner avoiding intimacy because they think they are being considerate. This can make you feel like they no longer find you attractive.

Ask your partner how they are feeling. They may also be worried about intimacy, afraid of upsetting you or causing you pain. They might feel guilty thinking about intimacy while you're unwell or worry about 'catching' cancer or being affected by your treatment. Talking about these concerns together can help.

Here are some tips:

- Plan intimacy for times when you have the most energy. Making a 'date' with your partner can be a fun way to build emotional closeness and spark desire.
- Explore other ways of being intimate, like touching, cuddling, kissing or massaging. These can be just as satisfying as sex.
- Take things slowly and be creative to find what feels good. Problems usually get better with time and practice.
- Learning how your body responds to touch can boost confidence. Masturbation, using sex toys and other aids can be helpful for exploring your own body.
- Vaginal moisturisers and water-based lubricants can relieve dryness and help to make sexual activity more comfortable.

- Ask your doctor whether hormone therapy might help improve your libido, vaginal dryness and other symptoms of surgical menopause.
- Consider talking to a counsellor, sex therapist, sexologist or a doctor with specialist training in sexuality and cancer. **Ovarian Cancer Australia** also has a sexual health counselling clinic you may find helpful. See 'More information' for details.

> *"After my operation I approached my next sexual relationship with extreme embarrassment – but more importantly, real fear about sexual ability. I had not dared discuss the implications with my doctors at the time of my operation. Better communication skills on the part of both doctor and patient would perhaps have allayed my fears in the first place."*
>
> **Maggie**

RESOURCE

Ovarian Cancer Australia – 'Sexuality, body image and relationships after ovarian cancer' (booklet), ovariancancer.net.au

MORE INFORMATION

Some public hospitals have sexual health clinics, and it may be helpful to explore what is available through public hospitals in your area.

Some psychologists specialise in sexual health. Ask your GP about writing you a mental health plan, which will enable you to see a psychologist and be eligible for a Medicare rebate for up to 10 sessions per year.

You can also find your own counsellor, psychologist or sex therapist from the following organisations. But you will have to pay for the sessions. If you have private health cover, you may be able to claim some of it back.

- **Australian Psychological Society** (**psychology.org.au** or **1800 333 497**)
- **ASSERT NSW** (**assertnsw.org.au**) can provide details of sex therapists in all states
- **Society of Australian Sexologists** (**societyaustraliansexologists.org.au**)
- **Relationships Australia** (**relationships.org.au**) can also provide sexual counselling.

Many sex therapists provide services via phone or Skype.

> *“Have date nights! It was great for us to go out like a normal couple and enjoy a different environment out of the home. Great for me because it took my mind off things and it was a time for my husband to unwind as well.”*
>
> **May**

Rebuilding your body image is an important part of your emotional and sexual healing. How you feel about your body and yourself affects your confidence, your sense of attractiveness and your sexual desire. 'Look Good … Feel Better' can help put you back in touch with your body, raise your self-esteem and improve your overall sense of wellbeing.

RESOURCE

Look Good … Feel Better – free 2-hour workshops are run in hospitals and cancer centres by beauty professionals who volunteer their time; offers useful tips on using cosmetics to deal with changes in your skin, hair and general appearance, 1800 650 960, lgfb.org.au

> *"Look Good Feel Better is such an uplifting experience, in that it makes you feel attractive again: I would give this a much bigger profile. The effect it had on me after losing my hair was mind blowing and I would like to see every patient being encouraged to attend a session."*
>
> **Jan**

DOMESTIC VIOLENCE WHEN YOU HAVE CANCER

WARNING: This section may be distressing for some readers, especially those who have experienced abuse or trauma. If you feel uncomfortable, feel free to skip it. Support is available, and details are provided at the end of the section.

Domestic violence can deeply impact health, treatment decisions and care during and after ovarian cancer. Women with cancer are at risk of domestic violence, which may come from a partner, family member or someone else they live with.

Abuse can take many forms, and survivors may experience one or more of the following:

- **Physical.** Hitting, biting, slapping, kicking, choking or using objects or weapons to harm you, with or without visible injuries (bruising, cuts or scarring).
- **Sexual.** Any unwanted sexual activity, including forced actions or taking advantage of someone unable or unwilling to consent.
- **Emotional/psychological.** Verbal abuse, constant criticism, manipulation, intimidation, humiliation or behaviours meant to make you feel worthless or controlled.
- **Financial.** Controlling your access to money or financial resources.
- **Coercive control.** Tactics like gaslighting (where a person or group of people makes someone question their sanity, perception of reality or memories), controlling your appearance or diet, isolating you from loved ones, monitoring your activities, or extreme jealousy or possessiveness.

Although statistics on domestic violence are hard to establish due to underreporting, it is known that women, children and trans people are at increased risk.

RESOURCE

Family and domestic violence – Information, referrals and support for people affected by family and domestic violence, servicesaustralia.gov.au/family-and-domestic-violence

When someone is being abused and has cancer, they may suffer even more complications. For example, the person with cancer may be relying on the abuser for help with activities of daily living (showering, eating), medications, financial needs and transport to appointments. This allows the abuser to feel more in control and powerful, leaving the person with cancer feeling more frightened or unable to change their situation.

If you (or someone else) are in danger, or if you have been threatened, physically hurt or sexually assaulted, call triple zero (000).

RESOURCE

1800 RESPECT – National Sexual Assault, Domestic Family Violence Counselling Service, 1800 737 732, 1800respect.org.au

PARTNERS, FAMILY AND CLOSE FRIENDS

Ovarian cancer affects not just you, but your family and close friends as well, and they may react in different ways. They might feel anger, sadness, fear, anxiety, guilt, or just be overwhelmed, as you probably are.

Those closest to you may struggle with wanting to stay strong for you while also processing their own shock. Some relationships may grow stronger through this shared challenge, so value these connections. However, not everyone may cope in the same way, and some friendships may change.

It's normal for people to need time to adjust and figure out how to support you. They may not always know what to say or do, but they may want to help.

Be as open and honest as you can about how you're feeling and what you need. This helps your loved ones understand and gives them the space and permission to share their feelings too.

RESOURCE

Ovarian Cancer Australia – booklet for family, friends and carers of women with ovarian cancer, 1300 660 334, ovariancancer.net.au

Also see **Chapter 4: Support**.

TALKING TO CHILDREN ABOUT CANCER

When a parent or grandparent has cancer, children often guess something is wrong, even if they're not quite sure what it is. It is a natural instinct to want to protect children of any age from upsetting news. But by talking to children as soon as possible, you will help to reduce many of their fears and help them to cope better.

If you don't feel able to tell your children by yourself, you may like to ask your partner, a grandparent or another loving relative or friend to help.

RESOURCE

Cancer Council – 'Talking to kids about cancer' (booklet), 13 11 20, cancer.org.au

How much you tell your children will depend on their age, but all children need to know the following.

- They did not cause your cancer and they can't make it go away.
- Cancer is not contagious: they cannot catch it by touching you or being close to you.
- You are going to have treatment and your doctors are going to do everything they can to help you get well.
- It is 'normal' to have side effects from treatment – like feeling tired and losing your hair.
- Life at home will be different, but they will always be cared for and you will always love them.

Encourage your children to ask questions and then do your best to answer them simply and honestly. Tell your children how you are feeling and encourage them to express their own feelings and concerns.

As time goes on, new questions, situations and feelings will arise. Keep your children updated on what's happening, even if they don't ask.

If you are worried about your children and how they are coping, talk to your doctor or a social worker in your treatment team. There are many different types of trained counsellors who can help.

CanTeen is an online service for young people whose lives have been affected by cancer. CanTeen has produced a helpful booklet 'Now what? Dealing with your parent's cancer' and have a counselling service for young people aged 12 to 24 who have a mum or dad with cancer. The service allows young people to talk to a professional face to face, online or over the phone.

RESOURCE

CANCER HUB – 1800 431 312, https://cancerhub.org.au/

For more information about children and teenagers see **Chapter 4: Support**.

LIFE AFTER CANCER

Many people go through a mixture of good and bad feelings after their treatment is over. You may feel relief and happiness. But it isn't unusual to also feel frightened and lost, especially during the first few months.

You no longer have the regular attention and support from your nurses and doctors. Your family and friends may not visit as much. You may get the feeling those around you think you are feeling okay. Many cancer survivors say they feel lonely and angry about this. Yet they also feel they should be able to cope now treatment is over. It can be a confusing time and it is very natural to have concerns about your future and how you will cope.

RESOURCE

Ovarian Cancer Australia – 'Life following ovarian cancer treatment: A booklet for people who have been treated for ovarian cancer, and their families, partners and friends', ovariancancer.net.au

Like many cancer survivors, you may feel:

- isolated, alone and abandoned
- unsure about how to get your life back on track
- unsure about your relationships and people who do not understand how you feel
- fearful your cancer will come back
- anxious about follow-up appointments
- worried about long-term side effects and how these may affect your work, social life, relationships and hobbies
- angry, frustrated and lacking in confidence about your body, sexuality and general health
- 'survivor's guilt' – feeling guilty you are still here while others are not.

RETURNING TO A ‘NORMAL’ LIFE

Many cancer survivors find it difficult to get back to normal day-to-day life after their treatment finishes. Some say it never happens and life can’t return to how it was before their diagnosis. However, people say they adjust and create for themselves a ‘new normal’. Sometimes people say their cancer changed their life for the better. It is a process of evolution – evolving as a different person.

> *“One of the hardest parts about coping with ovarian cancer has been trying to live a normal life at the same time as living with the unknown. I’ve got through the treatment by researching and applying strategies to help me rebuild my energy levels.”*
>
> **Kristen**

While not everyone will have difficulty after treatment finishes, many say their fears won’t go away. You are likely to still need a lot of support during this time. Whether you are returning to work or study, or your full-time parent duties again, it is likely to take time to adapt. Be kind to yourself and don’t expect to feel good about everything straight away. Give yourself time to adjust and accept the ‘new normal’.

RESOURCE

Australian Cancer Survivorship Centre – for fact sheets about coping with fear of cancer recurrence and the emotional impact of cancer and its treatment, petermac.org; ‘Just take it day to day’ (video), youtube.com/@petermaccancercentre/videos

MORE INFORMATION

- **The Cancer Council's** 'Cancer, work and you' (**13 11 20**, **cancer.org.au**).
- **Work after Cancer** (**workaftercancer.com.au**) has advice for people diagnosed with cancer, their loved ones, clinicians and employers about their options, rights and responsibilities.
- **Live Work Cancer** (**www.liveworkcancer.com**) supports people navigating cancer alongside work and career.
- **Cancer and Careers** (US) (**cancerandcareers.org**) is for working women with cancer and includes supportive information and interactive tools.
- How do I manage difficult conversations at work? is a webinar on the **Cancer Council NSW** website, **cancercouncil.com.au**

> *"I had difficulty concentrating and retaining information when I went back to study. I used to be very organised and not have to write things down but now I have to write everything down. Everything is different now. I have to arrange my follow-up appointments around my uni classes. It can be frustrating."*
>
> **Laura**

FOLLOW-UP

Follow-up refers to the checks and tests that you will have regularly once your treatment has finished.

When treatment ends, you may receive a treatment summary and follow-up plan from your specialist, GP or other members of your healthcare team. This may be called a ‘treatment plan’ or ‘survivorship care plan’.

WHAT IS INCLUDED IN YOUR TREATMENT PLAN / SURVIVORSHIP CARE PLAN

- Your diagnosis and the tests used to form the diagnosis
- Information about the tumour
- A treatment summary
- Current toxicities
- Treatment plans from healthcare team members
- Potential longer-term / late effects and how these will be prevented or treated
- Information about supportive care based on a needs assessment
- A wellness plan with wellbeing and rehabilitation recommendations (such as goals for maintaining a healthy weight, the barriers you might encounter and strategies to address them)
- Preventive health recommendations relevant to your situation
- Contact information for key members of your healthcare team
- Things that will trigger a review of the plan (such as recurrence)
- How you will quickly access care if needed (including rapid re-entry into hospital system)

You may want to contribute to the plan, and you can ask about developing a survivorship care plan with your specialist, your GP, a specialist nurse or another member of your healthcare team.

A survivorship care plan includes your treatment plan and follow-up schedule (tests required and when they should be done) and other information you may find helpful.

The plan may be updated if your health needs change. Things that will trigger a change in the plan include longer-term / late effects requiring treatment, cancer recurrence or a change in your wellbeing goals and rehabilitation plans.

RESOURCE

Australian Cancer Survivorship Centre – Survivorship care plans, petermac.org

COORDINATION OF FOLLOW-UP

Some people have most of their follow-up care with their GP, while others see their specialist. Often, it's a combination of both. Talk with your GP, surgeon, oncologist and specialist nurses to make a plan. Your treatment plan will be agreed upon by you, your GP and your specialist.

If you live in a remote area, a local GP, general gynaecologist or cancer nurse may handle your reviews. They will update your specialist and refer you for more specialised care if needed.

RESOURCE

Ovarian Cancer Australia – To speak with an Ovarian Cancer Support Nurse call 1300 660 334 or email support@ovariancancer.net.au

If you have been treated for ovarian cancer, it is important to know who to contact if you have new symptoms. It's natural to worry about signs that the cancer might have returned. A good follow-up plan will provide clear guidance. A survivorship care plan, created with your specialist, GP, or nurse, will explain which symptoms can be checked by your GP and which need hospital care.

See **Chapter 4: Support** for more information.

A good rule of thumb is to report any new, unusual, worrying or persistent symptoms to your doctor.

RESOURCE

Cancer Council – 'Optimal care pathway for women with ovarian cancer', cancer.org.au

Follow-up schedule

The follow-up schedule outlines what tests and appointments you will need in the future. These will depend on your own cancer – its stage and the treatments you have received. The follow-up schedule may look something like the example in **Table 8**.

Table 8: An example follow-up schedule

When (after finishing treatment)	Review every	What the appointment will entail
Until year 2	3 months	Review and examination carried out by one of your treating specialist doctors – includes pelvic examination, physical examination and CA125 marker if warranted. Further tests (CT scan, PET scan, CA125, MRI) if recurrence suspected.
Years 3 to 4	4 to 6 months	
Year 5	6 months	
Ongoing	12 months	

NOTE: This is an example. Your follow-up plan may be different.

Your follow-up appointments may make you anxious. They can also be reassuring. It is also an opportunity to ask questions of your specialist.

TIPS ON COPING WITH CHECK-UPS

Many cancer survivors feel anxious before routine check-ups, and it's normal to have trouble sleeping, eating or coping in the days leading up to the appointment. You might worry about returning to the hospital, reliving treatment memories, or fear the cancer may come back. Finding ways to manage these feelings is important, and these tips may help:

- Take someone you trust to check-ups for support.
- Plan something enjoyable after your appointment, like lunch or a movie.
- Try to see the check-up as a way of caring for yourself and increasing your chance of getting treatment early if problems arise.
- Try making your appointments in the morning to avoid a full day of worry. This cannot be guaranteed to happen, but it is always worth asking.
- Prepare for your follow-up appointment. Get the most out of the appointment – make a list of questions to ask.
- Relaxation techniques, like meditation, may help calm your nerves before an appointment. Avoid other stressful events or tasks where possible before your check-up.

RESOURCE

Australian Cancer Survivorship Centre – 'Questions you may wish to ask about the time after treatment' (fact sheet), petermac.org

> *"Tests are only tools and living by test results can be difficult. You may feel fantastic but the tests tell you differently and it is very hard to live with. It is hard to keep their influence in proportion. They are only one indicator of your health and need the interpretation of a health professional."*
>
> **Carmel**

FEAR OF YOUR CANCER PROGRESSING OR COMING BACK

Most people who have been treated for ovarian cancer feel anxious and frightened about the cancer spreading further through their body (progressing) or coming back (recurring).

You may worry about what will happen if your treatment needs to change or whether there will be treatment options if your cancer comes back or spreads.

These anxieties or fears are known as:

- fear of cancer progression
- fear of recurrence.

FEAR OF CANCER PROGRESSION

If you have ovarian cancer you may think about what will happen if your cancer spreads or keeps spreading (metastasis). While metastatic ovarian cancer may not go away completely, there are treatments that can control it for a long time. We discuss these in **Chapter 2: Treatment**. If one treatment stops working, there is likely to be another option to try. New treatments are being developed and tested all the time for ovarian cancer patients. So you can always hold some hope as there are ways to help manage cancer that has spread, even if the fear of cancer progression does not seem to go away.

FEAR OF YOUR CANCER COMING BACK (RECURRENCE)

Following treatment, you may worry about your cancer coming back (recurring). Even for those who have early-stage ovarian cancer, these worries can be common. Fear of a recurrence is one of the most common things people who have had cancer worry about. It is especially worrying in the first few months after treatment finishes. For some people, the fear is so strong that day-to-day life becomes a struggle. With time, the fear does lessen, but many say it never completely goes.

Knowing how likely it is the cancer will come back depends on several factors, such as the type of cancer, the stage and grade of the original cancer, which treatments you had and how you responded to them. Your doctor is the best person to talk with as they know your individual situation. They will let you know what symptoms to watch out for and report.

HOW TO COPE WITH FEAR OF RECURRENCE

- Be aware of any new symptoms and seek medical help.
- Take steps to minimise anxiety.
- Do your best to accept uncertainty.
- Focus on wellness and ways to stay positive.
- Take control of what you can and leave what you can't.
- Write down your worries and only allow yourself to think about them at a specific designated time (known as 'a worry time').
- Be cautious about constantly looking up things on Google. It is always best to check with your doctor if you have concerns or notice new symptoms or changes to your body.
- Don't be afraid to ask for help and get support.

RESOURCE

Ovarian Cancer Australia – 'Fear of cancer recurrence' (booklet), 1300 660 334, ovariancancer.net.au. Further resources at our website can assist in addressing fear and worry about cancer progression and recurrence.

> *"It is hard not to worry before follow-up appointments – they remind you of everything that happened in the past and you always think: 'What if …?"*
>
> **Laura**

> *"Instead of fighting the possibility that cancer may return, I have accepted the notion. I hope that I am better equipped to deal with it should it return. I feel more in control over a situation in which I have little control."*
>
> **May**

WHEN CANCER COMES BACK

If your cancer comes back, you'll need to make new decisions about your treatment and care. Lean on the people, practices and beliefs that helped you during your first diagnosis, and look for small ways to find strength and comfort each day.

When ovarian cancer recurs, it is often treated as a chronic illness. The cancer may come back several times, but it can often be treated and stabilised, with long periods where no treatment is needed. While a cure may not be possible, it means you can live for a longer time with a good quality of life.

HOW WILL I KNOW IF THE CANCER HAS COME BACK?

You and your doctor may suspect your cancer has come back if you begin to have symptoms similar to those when you were first diagnosed. Or you may notice other changes in your health. Always tell your doctor about any new symptoms or symptoms that have returned.

Your doctor may also suspect your cancer has come back based on changes found in your follow-up physical examination, or if your CA125 level has been rising. (See **Chapter 2: Treatment**, section titled 'Follow-up care' for more about rising CA125 levels.) Some people may have signs the cancer has come back even though their CA125 isn't rising.

If tests or symptoms suggest your cancer has recurred, it may then be confirmed by an ultrasound or CT scan. Always report any changes or symptoms you have to your doctor. They may not mean your cancer has come back but it is best to check. See **Chapter 2: Treatment** for information about treatment for recurrent cancer.

Many people say finding out their cancer has come back is more stressful than their initial diagnosis. Ask for all the support you need. You may want a family member or close friend to come to appointments with you, and this may be a time when you need to talk to someone such as a counsellor or psychologist who can provide you with extra emotional support.

> *"After the initial shock of being told I had a recurrence, it was important for my family and I to know what my options for treatment were and the consequences of these treatments. Understanding your options gives you a sense of some control of your disease, which can alleviate some of the uncertainties and fears."*
>
> **Debbie**

PRACTICAL MATTERS

PSYCHOSOCIAL CONSIDERATIONS

After any serious illness, people may be faced with practical problems. Many people with cancer decide they want to organise their financial matters, such as insurance and superannuation. Others are keen to organise their Will, enduring power of attorney and enduring guardian, and state their wishes about future medical care if they become unable to make decisions for themselves (an advance care plan). This section briefly discusses these issues and suggests where you can get further help and support along the way.

Taking care of practical matters such as organising an advance care plan and preparing your Will ensures others know about and can act on your wishes. This can also relieve your partner or other family members from making difficult decisions on your behalf, knowing that they are acting in accordance with your stated wishes.

It is best if you can organise these documents while you are relatively well. They may not be used for some time but having them prepared can avoid future anxiety and remove any legal questions arising about your wishes. Think of these documents as a form of ongoing communication with the people you love and with your healthcare team. You can make changes to these documents at any time to reflect what is happening in your life.

INSURANCE, SUPERANNUATION AND LOANS

Getting life or travel insurance after you have a cancer diagnosis can be more difficult than usual. You will need to provide your medical history for many insurance policies. But there are people who can help guide you through this process to give you the best chance of getting the insurance you need. The Superannuation and Insurance Advice Service is a free service providing legal advice to people with disabilities.

RESOURCE

Chronic Illness Alliance, chronicillness.org.au. You can get free advice by telephone or by appointment if you live in Victoria.

Cancer Council Australia (**13 11 20**) has a Pro Bono Program for people who meet their eligibility criteria and means test. They help people affected by cancer gain access to free legal, financial, small business accounting and workplace assistance.

ADVANCE CARE PLANNING

Many people, whether they are ill or not, find it reassuring to have an advance care plan. An advance care plan allows you to write down your wishes for treatment if you cannot make your own decisions.

Guidelines and rules around advance care planning differ for each state and territory. You can find more information about advance care planning in your state/territory online.

Give a copy of your advance care plan to your healthcare team and any family members you think need it and keep a copy in your medical file. Your medical file should also be marked to say it contains this document.

RESOURCE

Advance Care Planning Australia,
advancecareplanning.org.au

> *“I have done an advance care plan and my daughter has a copy of it, as does my son. It was important for me to do this now whilst I am still well so my family know what I want.”*
>
> **Beatrice**

ENDURING POWER OF ATTORNEY

An enduring power of attorney is a legal document that allows you to choose a trusted relative or friend to make decisions for you if you become unable to make decisions for yourself.

There are different types of enduring power of attorney. Depending on the state or territory in which you live, there may be separate enduring powers of attorney that you choose to take care of financial and legal decisions, or for medical treatment decisions. This may be called an ‘enduring guardianship’.

You can obtain information and advice about enduring powers of attorney from your solicitor, the Office of the Public Advocate, community legal centres and services in your state or territory (search online) or through a social worker at your treatment centre.

Keep a copy of your Will, enduring power of attorney, advance care plan and other essential papers – such as your mortgage, bank accounts, investments, insurance and credit card details – in one place where they are easy for family members to access.

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YOUR WILL

Your Will states who you would like to receive your possessions, money and property when you die.

If you have any special concerns about the custody or guardianship of children, talk to your family solicitor or ask a social worker at your treatment centre for help in accessing legal advice.

Your Will may also say who you wish to care for your pets and name any special items you want given to certain people. You may wish to include instructions for your funeral and burial in your Will.

If you do not write a Will, your estate will be divided according to law, which may not necessarily reflect your wishes.

Although you can buy Will kits from newsagencies and other outlets, a solicitor can better advise and assist you with preparing your Will or updating an existing Will.

RESOURCE

Cancer Council – 'Cancer care and your rights' (booklet), 13 11 20, cancer.org.au

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SUPPORT

Life will be different following a diagnosis of ovarian cancer: the effects of the disease and its treatment can present all kinds of unique challenges.

Many people and organisations can provide you and your family with information and support to make the journey a little easier: support groups and online forums provide friendship, inspiration and laughter, and other services can help with finances, meals, childcare and cleaning.

This chapter provides useful ideas and sources of information for people with ovarian cancer and those close to them. Make the most of everything these support systems can offer.

> *"Twelve years on and the women in my support group remain amongst my dearest friends. You'll recognise us if you see us out and about – we're the women laughing and hugging each other, on the dance floor, or raising a glass while the rest of the world sits politely to the side wondering what our secret is!"*
>
> **Julie**

KEY SUPPORTS FOR THE PERSON WITH CANCER

OVARIAN CANCER AUSTRALIA NURSE HELPLINE

The **Support and Information Helpline** is available from 9 am to 5 pm for the cost of a local call. It is staffed by our ovarian cancer nurses. Call **1300 660 334** to speak with an ovarian cancer nurse. It is a direct telephone and email connection for people impacted by ovarian cancer, their partners, family and friends to the support team at **Ovarian Cancer Australia**. It is a source of support, onward referral, information and connection.

It is also a means for the general public who have concerns about symptoms or testing to have these explained.

You can also get in touch by emailing us at **support@ovariancancer.net.au** and we will get back to you as soon as possible.

YOUR OVARIAN CANCER SUPPORT NURSE

The Teal Support Program is a free telehealth outreach program with specialised ovarian cancer nurses supporting those with ovarian cancer and those close to them throughout their diagnosis, treatment and beyond.

The main aim of the program is to provide continuity of care when you are not regularly seeing your treating team and focus on areas of care where there are unmet needs.

The Teal Support Program is the embodiment of **Ovarian Cancer Australia's** vision that no one with ovarian cancer walks alone.

To find out more about accessing your own ovarian cancer nurse, phone the helpline on **1300 660 334** or visit our website and fill in a form (**www.ovariancancer.net.au**).

OVARIAN CANCER AUSTRALIA PSYCHOLOGY AND COUNSELLING SERVICE

This service provides one-on-one counselling via telephone or video telehealth. If you would like to discuss accessing support from the psychosocial support team, please contact the helpline on **1300 660 334** (Monday to Friday during business hours AEST) or email **support@ovariancancer.net.au**.

SUPPORT GROUPS AND NETWORKS

Support groups provide people with ovarian cancer the opportunity to share their experiences, receive emotional support and be informed.

Many people feel they need to talk to someone who really understands their situation and 'speaks the same language'. The right support group can give you this.

RESOURCE

Ovarian Cancer Australia, Teal Support Program, ovariancancer.net.au

> *"Support groups are important as I could not find anyone else who had ovarian cancer. At support groups you can speak to someone in the same situation as you."*
>
> **Vivian**

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WHAT IS A SUPPORT GROUP AND WHO CAN JOIN?

Support groups come in many forms:

- in-person meetings
- online forum
- social media pages
- telephone / video chat groups.

Some groups are for all types of cancer, while others focus specifically on ovarian, gynecological or women's cancers. These groups may be led by health professionals or people who have lived through cancer themselves.

Some groups welcome family and friends, and there are also groups for those caring for someone with ovarian cancer. If you're unsure, contact the group facilitator before attending to learn more about what they offer and see if it's a good fit for you.

HOW CAN A SUPPORT GROUP HELP ME?

Support groups can help you feel less alone and connect with others going through similar experiences. Whether in-person, online or by phone, talking with others in the same situation can help you realise your feelings are normal. Many find that support groups are a place where they can relax, laugh and share practical tips.

Evidence shows you are less likely to suffer anxiety if you join a support group. It may help you feel less isolated and better able to cope with cancer and its side effects. Many people say that it is not just about what they receive from those in the support group, but how good it can make you feel to give back, too.

In addition to support groups, one-on-one counseling with a health professional can help with the emotional impact of ovarian cancer. **Chapter 3: Staying well** includes information about accessing counselling services.

“Being a part of the support group helps me feel less alone. I am able to give and get support from other women that are living with ovarian cancer and what that means for our physical and mental health. It really helps to share our experiences with others whether in person or online.”

Robyn

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LIVING IN A RURAL OR REGIONAL COMMUNITY

If you live in a rural or regional community and have ovarian cancer, your physical distance from treatment centres and support services can become another hurdle to overcome. Many people need to travel to a metropolitan area for treatment or ongoing care, and this can place an added burden on them and their family: physically, emotionally and financially. Services can help in different ways, such as with transport or counselling. Always let your GP or social worker know if you are having difficulty accessing the services you need.

TELE-SUPPORT GROUP

Ovarian Cancer Australia (**1300 660 334**) holds monthly tele-support groups. These are online groups that you can join via video or phone. The groups are like a teleconference. Many people say that they help to reduce feelings of isolation and distress if they are not able to access face-to-face support groups.

Facilitated by health professionals, tele-support groups provide an opportunity for people to connect with others in a similar situation, gain information about diagnosis and treatment, and learn about other support options. The service is accessible anywhere in Australia; all you need is access to a telephone.

> *"The best thing I did was to join a support group. They understood what I was going through, acted as a network for further information, gave me a new way to think about issues, cheered my successes and held my hand when I was down."*
>
> **Julie**

"If I didn't have the tele-support group, I would feel very isolated. The facilitators always get back to us with answers to our questions."

Maree

ONLINE SUPPORT

Online support groups, forums and social media pages provide a convenient way for those with ovarian cancer, their family, friends and carers to connect with others who are going through similar experiences. There is usually someone you can chat to online at any time of the day or night. Online support can be especially helpful if you live in a rural or regional area, or you find it hard to travel to a face-to-face group.

Remember, not all the information you get from online groups may be accurate or suitable for you. Be sure to talk to your healthcare team about new information you come across such as treatment suggestions. Refer to **Table 9**.

Some people find that online forums, support groups or social media can be overwhelming when dealing with ovarian cancer. If you feel that these options aren't helpful for you, it's perfectly okay to take a break or not participate. Focus on what feels right for you.

"Just knowing there is hope and women who understand, truly understand, is just what I need."

Clara

Table 9: Online support

Group/organisation	Contact for further information
Ovarian Cancer Australia – for support groups around Australia.	Search at **ovariancancer.net.au** or call **1300 660 334**
Ovarian Cancer Australia Facebook Support Group.	**facebook.com/groups/359547902456355**
Ovarian Cancer Australia monthly online support group for women under 50 years.	**ovariancancer.net.au/page/127/younger-women**
Cancer Council forums, Cancer Connect and Cancer Council support groups.	Search at **cancer.org.au** or call **13 11 20**
Cancer Council NSW hosts an Advanced Cancer Patients Telephone Support Group, open to people with any advanced cancer living anywhere in Australia.	Call **13 11 20**
Healthshare is a free social health network connecting people and providing a place to get support and information.	Search for ovarian cancer at **healthshare.com.au**
Cancer Hub is for young people aged 12 to 25 with cancer.	**cancerhub.org.au** or call **1800 431 132**
QLife is a national, free, confidential LGBTI phone and webchat service, open 3 pm to midnight every day. Talk to a peer counsellor and get information and referrals, including for people with cancer.	**qlife.org.au** or call **1800 184 527**

THE PRACTICAL SIDE OF LIFE

Ovarian cancer has a huge impact on the practical day-to-day parts of your life. The need to prepare meals, pay bills, have clean clothes or care for children doesn't go away when you have cancer.

Fortunately, many people and organisations can help. The next few pages will help you and your family access the practical support you need so that you can put more of your energy into your recovery and spending time with family and friends.

ACCEPTING HELP FROM FRIENDS AND FAMILY

When you accept offers of practical support, it helps your family and friends to feel useful and valuable, and it allows you to conserve your energy and focus on your recovery – usually everyone wins! However, it does not come easily to some people to accept or ask for help.

GETTING A HELPING ROSTER IN PLACE

Lotsa Helping Hands (**lotsahelpinghands.com**) lets you or a friend create a free, private group calendar to organise helpers who can pitch in with cooking meals, providing rides and other tasks during times of medical need, end-of-life caring, or when family caregivers need a break. Everyone who is invited into the private group can be informed with status updates, photo galleries and message boards.

Gather My Crew (**gathermycrew.org**) is an easy-to-use free app / online tool that allows friends, family and colleagues to help others in need when and how they need help.

> *"Even if a support service doesn't sound useful, give it a try, you might be surprised. These support services are developed for a reason!"*
>
> **Julie**

SUPPORT SERVICES

Many support services are available. It is often a matter of finding the right person or organisation to steer you towards the support services that will be helpful to you.

Your GP can help with many things such as creating a primary care plan for physiotherapy, podiatry, occupational therapy and exercise physiology. You can also ask for a mental health care plan through your GP for counselling and psychological help.

RESOURCE

Contact ovarian cancer nurses via the Ovarian Cancer Australia Support and Information Helpline on 1300 660 334 or ovariancancer.net.au

The types of support services available include:

- community or district nurses
- private nursing agencies
- home care nursing services
- volunteer respite care services.

Each service will provide different kinds of help. Some may have costs involved, while others will be free. If you have private health insurance, your policy may cover all or part of the fee. Your healthcare team can help you access these services, or you can search the internet for a specific service that suits your needs.

RESOURCE

Cancer Council Helpline 13 11 20 – for information about support services

Help with meals, shopping and cleaning

Meals on Wheels (**mealsonwheels.org.au**) delivers meals during the week for a small charge for people who have difficulty preparing their own.

Other organisations sell frozen meals in bulk, which can be helpful when you're too tired to cook. Check online for services in your area or ask your healthcare team for recommendations. Many supermarkets can deliver, so you can keep your freezer stocked with ready-made meals.

Some local councils offer support to help people of all ages with shopping, light cleaning and meals.

My Aged Care (**myagedcare.gov.au**), for people over 65 years, may provide an assessment for a home care package, which includes advice and help with shopping, meals, home cleaning, maintenance and other specialised services.

Help with children

Australian Government **Child Care Access Hotline** (**1800 670 305**) is a free telephone service to help you find a childcare service and can provide information on assistance in paying childcare fees. The hotline is available from 8 am to 9 pm Monday to Friday. **Startingblocks.gov.au** is an Australian Government website providing more information on childcare options and assistance.

> *"Getting ovarian cancer is an expensive exercise – I found money just flew out the door like nobody's business … I still reflect on how much I have to be grateful for given I live in a part of the country where I don't need to leave my town to get treatment, and although I have family caring responsibilities, I don't have financial worries on top of the medical issues I'm facing."*
>
> **Chris**

Finances

Cancer can create a heavy financial burden on you and your family. You may lose income if you need to stop working for treatment, and there can be extra costs for medical appointments, tests (if not done in the public system), transport, accommodation and childcare. If you have a partner, they may need to take time off work to care for you, adding to the financial strain. This is sometimes called 'financial toxicity' – the financial toll of cancer.

There are some avenues of support available for financial concerns when you have cancer.

- You may be able to access some of your superannuation. Your fund can tell you about early release of money. You may also be eligible for disability or income protection insurance payments through your fund.
- A hospital social worker can guide you on financial assistance and transport costs.
- A financial counsellor can help with managing your money.
- Your partner or carer may be eligible for paid carers leave.
- You may be eligible for a Centrelink benefit or allowance yourself, which may help if you are unable to work.
- Your carer may qualify for Centrelink carer payments.
- Some bills may be delayed or eligible for concessions or rebates.
- **The National Debt Helpline** (**1800 007 007**) can help with free financial counselling.

RESOURCES

- Cancer Council – 'Cancer and your finances' (booklet), cancercouncil.com.au
- 'Superannuation and cancer' (booklet), cancer.org.au
- Legal, Financial Planning, Small Business and Workplace Referral Services, 13 11 20

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Help with medical expenses

Members of your healthcare team, Centrelink or a community social worker can help with information about the financial benefits available to you and your carers, as well as eligibility and assistance with claims. They can also give you information about any out-of-pocket expenses for tests, surgery, your hospital stays and medicines. These costs will vary depending on whether you are a public or private patient.

Several government programs can assist with medical expenses.

- The **Medicare Safety Net** is designed to help people who have a lot of medical expenses. Once you have spent a certain amount for non-hospital medical costs in a calendar year (the safety net threshold), you may then be eligible to receive a higher rebate from Medicare for future medical costs. This means you pay less for medical visits and tests for the rest of the year. Individuals do not need to register for the Medicare Safety Net but couples and families do. Visit **medicare.gov.au** or call **13 20 11** to find out more.
- The **PBS Safety Net** helps with the cost of prescription medicines if you or your family need a lot of medicines in a year. Once you or your family reach the safety net threshold, you can apply for a PBS Safety Net card – then your PBS medicine will be less expensive or free for the rest of the calendar year. Ask your pharmacist for the PBS Safety Net Prescription Record Form or contact the PBS information line on **1800 020 613**. You can also find out more at **medicare.gov.au**

Centrelink and other financial benefits

- **Centrelink** (**centrelink.gov.au** or **13 2717**) can provide information about your financial entitlements, as well as allowances (financial support) for people who are unable to work or need extra help due to illness. You may be entitled to a Health Care Card if you are a low-income earner. A Health Care Card entitles you to cheaper prescription medicines under the PBS and concessions on services such as ambulance, dental and eye care.
- If you are a carer, you may be eligible for a carer's allowance payment. See the information for carers at the end of this chapter to learn more.
- Ask your manager, supervisor or human resources person what benefits may be available to help you, such as sick leave or other entitlements. You may like to verify your employer's advice through your trade union, a professional association or a solicitor. Income protection, trauma, disability or life insurance, and superannuation can often be accessed during times of serious illness. Superannuation legislation enables people with a terminal illness to access superannuation funds without incurring tax penalties. You will need to talk to your fund provider about accessing these funds.
- **Australian Prudential Regulation Authority** (**apra.gov.au** or **1300 558 849**) is a useful source of information about superannuation entitlements.
- **Cancer Council 13 11 20** can offer information about financial assistance available to you.
- You may wish to organise an enduring power of attorney or guardianship – a legal document that allows you to choose a trusted relative or friend to make legal and financial decisions for you if you become unable to do this yourself. Please see 'Practical matters' in **Chapter 3: Staying well**.

If you don't feel up to dealing with medical bills and claim forms, ask a family member or friend to help you. You can also contact Medicare and your private health insurer for a summary of benefits they have paid you during the financial year.

Other useful contacts

- **Angel Flight** (**angelflight.org.au**) is for people in financial need who need to travel to medical facilities. All flights are free and must be booked by a health professional. Ask your doctor or visit the Angel Flight site for more information.
- **Telstra Priority Assistance 13 22 00** provides people living with cancer in a remote area with priority service to repair any faults on their telephone line (whether or not Telstra is their telephone provider).

TRAVELLING FOR TREATMENT

When you need to travel to receive treatment or care, there are some simple, practical things you can do that can help.

- If possible, travel with a friend or family member and ask them to come with you to your appointments.
- Be prepared. Make sure you have all the documents you need, as well as appointment details and directions (use Google Maps for maps and directions).
- Take a notebook/electronic calendar/smartphone to jot down questions for your healthcare team (refer to **Chapter 2: Treatment**, 'Questions to ask your healthcare team').
- Keep in mind you may need to unexpectedly spend a night away from home if you are not well enough to travel home.
- Book your appointments to suit you and your family and to maximise the time you have at home.
- Talk to your family using free programs such as Skype, Viber, WhatsApp or Telegram Messenger.
- Many hospitals offer free wi-fi access.

TRAVEL AND ACCOMMODATION ASSISTANCE

Each state and territory has a scheme that can help towards the costs of your travel and accommodation when you need to travel to a metropolitan or regional centre for treatment. The eligibility requirements for financial assistance can vary, so please contact your local scheme, listed on the next page, for more information. **Cancer Council 13 11 20** can tell you more about the scheme in your area.

Where there is a central number for these schemes we have included them below, but in some states and territories, there are separate phone numbers for different regions. You will find these phone numbers on the following websites:

- **New South Wales Isolated Patient Travel and Accommodation Assistance Scheme** (**health.nsw.gov.au**, search for 'IPTAAS')
- **Victorian Patient Transport Assistance Scheme** (**health.vic.gov.au**, search for 'VPTAS')
- **Queensland Patient Travel Subsidy Scheme** (**health.qld.gov.au**, search for 'PTSS'). The Integrated Patient Transport Unit can also provide information on **13 43 25 84**
- **SA Patient Assistance Transport Scheme** (**countryhealthsa.sa.gov.au**, search for 'PATS' or call the PATS Central Office on 1**800 188 115**)
- **Tasmanian Patient Travel Assistance Scheme** (**health.tas.gov.au**, search for 'PTAS')
- **WA Patients' Assisted Travel Scheme** (**wacountry.health.wa.gov.au**, search for 'PATS')
- **ACT Interstate Patient Travel Assistance Scheme** (**health.act.gov.au**, search for 'IPTAS' or call **02 6205 3299**)
- **Northern Territory Patient Assistance Travel Scheme** (**health.nt.gov.au**, search for 'PATS').

Some health insurance companies cover some travel and accommodation expenses, depending on your plan. If you have private health insurance, check with your provider to see if you are covered for any travel and accommodation expenses.

HELP WITH LANGUAGE OR CULTURAL BARRIERS

If you or your carers do not speak English as their first language, several services can help you to access information and support in a range of languages. This can be a big help in understanding information from your doctor and in feeling less alone.

- **Translating and Interpreting Service** (TIS) **National** (**13 14 50**) offers free telephone interpreting services all day, every day. You can call this number to contact many government, non-profit, community and medical services free of charge through an interpreter. (Services that you can contact include **Ovarian Cancer Australia's** Support and Information Helpline **1300 660 334** and **Cancer Council 13 11 20**.) When you call TIS National, you tell the operator which language you speak and give them the name and phone number of the service you wish to contact. The interpreter and staff from **Ovarian Cancer Australia** (or another service you have called) will then talk to you together on the same line.

  If you need an interpreter to attend a doctor's appointment or need medical information translated, a member of your healthcare team can organise this for you. Interpreters need to be booked in advance. There usually isn't any cost for this service (but always check to be sure).
- **Cancer Council 13 11 20** (**cancer.org.au**) may suggest other information and support in your language – including support groups, talking to someone else with cancer, telephone counselling and cancer education programs. The Cancer Council also has information translated into a range of community languages.
- **Palliative Care Victoria** (**pallcarevic.asn.au**) has bilingual brochures about palliative care in a range of community languages. The translated section of each brochure is also available online as an audio file.

PEOPLE WHO ARE DEAF, HARD OF HEARING OR HAVE DIFFICULTY SPEAKING

Phone relay service

If you are deaf, hard of hearing or have difficulty speaking, you can call any phone number including organisations and services listed in this kit through the **National Relay Service**. You can use the internet, a telephone typewriter (TTY) or a regular phone (for people with speech impairment) to call the service.

- TTY users should call **13 36 77** for regular phone numbers or **1800 555 677** to call 1800 numbers.
- Speak and Listen users should call **1300 555 727** or **1800 555 727** to call 1800 numbers.

Interpreting service

National Interpreting and Communications Services (**nicss.org.au**) provides sign language interpreting services to professional and government service providers and people who use sign language to communicate. You may wish to book an interpreter for appointments with your doctor or other health professionals. Ask your treating doctor or nurse about how to do this. Visit the website to book an interpreter and request prices.

ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE

Ovarian Cancer Australia recognises the health challenges faced by Aboriginal and Torres Strait Islander women and aims to provide culturally appropriate information and support to those diagnosed with ovarian cancer.

By including this dedicated section in our **Resilience Kit**, we strive to ensure that Aboriginal and Torres Strait Islander women have access to resources and guidance which are culturally informed and sensitive to their unique needs.

The information in this section has been adapted from the **Our Mob and Cancer** website (**ourmobandcancer.gov.au**). **Ovarian Cancer Australia** extends our heartfelt thanks to the Our Mob and Cancer team for their invaluable resources and dedication to supporting Aboriginal and Torres Strait Islander communities affected by cancer. Your commitment to raising awareness and providing culturally appropriate information is truly inspiring. We are grateful to be able to use it in our resources as we hope it will make a significant difference to many. Thank you for your important work.

In this section we include information on:

- being diagnosed with ovarian cancer
- Women's Business
- yarning with someone
- deciding about care when passing into The Dreaming
- Sorry Business
- where to get help and support.

BEING DIAGNOSED WITH OVARIAN CANCER

Everyone's experience with cancer is different. You might hear many different stories from people who have survived cancer. It can be overwhelming to remember everything you've learnt and some information may be difficult to understand or accept. It is important to keep in mind that everyone's symptoms and treatment will be different; what one person goes through might not be the same for you, and that's okay. It does not mean they are wrong, it's just different.

When facing a cancer diagnosis, spiritual and cultural beliefs about what causes serious illness may be on your mind. The things you believe and understand may differ from the doctors, nurses or Aboriginal and/or Torres Strait Islander health workers. It is probably a good idea to yarn about these things with your medical and healthcare team and family.

We would like you to know that cancer is **not**:

- your fault
- a breach of cultural protocols
- taboo
- a disease you can catch from someone else.

RESOURCE

'Why cancer is no shame job', ourmobandcancer.gov.au/why-cancer-is-no-shame-job

For information about ovarian cancer, prevention, diagnosis, treatment, living with cancer, finding support and clinical trials please go to the '**Our Mob and Cancer**' website at **www.ourmobandcancer.gov.au**.

You may also find it helpful to read other parts of this **Resilience Kit** to get more information about ovarian cancer.

WOMEN'S BUSINESS

Women play such a big role in family and community, helping to maintain balance in Aboriginal and Torres Strait Islander culture. Women have many different responsibilities and tasks that benefit those they care about and Country.

This is why it is so important for you to take care of yourself during your cancer journey. Your family and your mob need you around for a long time to pass down knowledge systems and traditions to future generations.

Engaging in Women's Business is really important while dealing with cancer. Participating in these important practices supports to strengthen not only your wellbeing but also that of others.

Women's Business may look different in each family and community, but it often includes:

- the health and wellbeing of our women and children
- ceremony and protocol
- making decisions about family and community business
- caring for sacred sites
- keeping culture alive through language, song, dance, art and storytelling.

You can ask for cultural protocols to be followed especially where you are dealing with a gender-specific cancer or symptoms that affect your reproductive organs, or any other part of your body.

If you notice any changes in your body, it's important to get them checked early. The sooner cancer is detected, the better for you and your family. Talk with your doctor, nurse or health worker about any changes in your body you are having. Cancers that can affect only women include gynaecological cancers, which are cancers of the female reproductive organs. These include cancers of the:

- ovaries
- womb, including endometrium (lining of the womb)
- cervix
- vagina
- vulva.

Most changes are not cancer, but it's really important to get checked to be sure. If you are facing cancer, there are many ways to seek help and support. Here are some options:

- Ask for female health practitioners (doctors and nurses) throughout your cancer journey.

- Bring another woman (mother, grandmother, aunty, sister, partner, friend) with you to medical appointments and procedures for support.
- Call on the women in your family and community to conduct Women's Business and ceremony to help you through your cancer journey.
- Ask for a female advocate to assist you in navigating your medical treatment.
- Ask that health practitioners (doctors and nurses) and healthcare providers respect and follow Aboriginal and Torres Strait Islander and Women's Business protocols.

Remember, your family and mob are our best teachers. Leaning on your Elders and family to help you uphold cultural protocol during your cancer journey is an important part of your treatment plan. If you need help with Women's Business, talk to your Aboriginal and Torres Strait Islander Health Worker.

YARNING WITH SOMEONE

Having cancer can feel overwhelming and it is common to feel alone – like you are the only one. Luckily one of the strengths of mob is that they rally around each other during tough times. Sharing worries by yarning with those you trust can remove feelings of loneliness and can bring you strength and hope. Mob who have had cancer say that yarning with others about what's happening for them is helpful.

"We need to be able to talk openly," **one Aunty says. And** *"Talk – and listen – not only to your health care team but also to your family and friends,"* **an Uncle advises.**

If you are feeling overwhelmed or worried, you might want to yarn with people you trust about:

- your feelings
- your thoughts
- what you want to do
- what you need to feel better.

RESOURCE

'Cancer in our mob',
www.ourmobandcancer.gov.au/cancer-in-our-mob

Who can I yarn with?

- Your doctor is someone you can always ask questions and yarn to about cancer or anything else that worries you, even if it is not related to your health.
- Have a yarn with other people in your mob who have gone through cancer. Many mob say this can really help. They might share feelings and ideas that are similar to yours, as well as different ones too, and offer a new perspective.
- Elders have experience dealing with health problems and the worries that come with being sick. They are a valuable source of wisdom and strength in community and are often willing to share their stories and what they know to help their mob.
- Cancer support groups for Aboriginal and Torres Strait Islander people are a great place to yarn and hear other people's stories and information about dealing with cancer. Ask your doctor, nurse or Aboriginal and/or Torres Strait Islander health worker about local groups or online groups.
- You can always yarn with your doctors, and hospital staff about your concerns. If you prefer to yarn with mob, ask for the Aboriginal and/or Torres Strait Islander liaison officer or health worker. They can help you find local counsellors too.
- You can contact your local Aboriginal and Torres Strait Islander Health Service to find someone to yarn with. To find a service near you, visit **NACCHO** (**www.naccho.org.au/naccho-map/**) or go to this map of Aboriginal and Torres Strait Islander health and medical services (**https://healthinfonet.ecu.edu.au/key-resources/health-professionals/health-workers/map-of-aboriginal-and-islander-healthmedical-services/**) and search 'Aboriginal Community Controlled Health Organisation'.

You can find a social and emotional wellbeing (SEWB) service for Aboriginal and Torres Strait Islander people (**healthinfonet.ecu.edu.au**). Either 'search by location' or 'show full list' and look through by state and territory.

- **Yarn Safe** focuses on mental health and wellbeing (**1800 650 890**, **headspace.org.au/yarn-safe/mental-health-and-wellbeing**) and is part of the headspace network.
- **Yarn for Life** (**yarnforlife.com.au**) includes a lot of useful resources.
- **Head to Health** (**headtohealth.gov.au/living-well/support-aboriginal-torres-strait-islander-people**) is another place you can find people to yarn with and other support for Aboriginal and Torres Strait Islander people.
- You can call **Our Mob and Cancer** (**1800 022 222**) any time of the day or night, to yarn with a nurse.
- **Health Direct** (**healthdirect.gov.au/australian-health-services**). Enter your area to search for services including places to stay if you have to travel for tests or treatment.
- **Cancer Council** (**13 11 20**, **cancer.org.au**) has support and information.
- **Lifeline Australia** (**13 11 14**, **lifeline.org.au**) has a free 24-hour counselling service.
- **Beyond Blue** (**1300 224 636**, **beyondblue.org.au**) can connect you with someone to talk to.

DECIDING ABOUT CARE WHEN PASSING INTO THE DREAMING

If your cancer progresses to a point where you need to prepare for passing into The Dreaming, take time to think about what you want. Consider where you want to be in the final days, how you want to be cared for, who you want with you and where you would like the resting place for your body to be.

Being on Country during your final days can be a source of strength and comfort. If getting home to Country is not possible, yarn with family, Elders and community about any traditional ceremonies or cultural protocols you want to fulfil. Mob might help find ways to bring your Country to you, too.

Yarn with Elders of the Country you're on, and ask them about what others have done, what protocols to remember, and who might be willing to spend some time sharing about Country and culture with you. They will be honoured to help you to make the arrangements.

Deciding where to be cared for can take time, and that's okay. It is a personal choice so have yarns with family, your doctor, nurses and Aboriginal and/or Torres Strait Islander health worker about the best options to allow you to be together with those you love and care about.

SORRY BUSINESS

Sorry Business is very important to Aboriginal and Torres Strait Islander peoples. Sorry Business is any process relating to palliative care, passing into The Dreaming, preparing for such circumstances and the ceremonies that follow when someone enters The Dreaming. It is Aboriginal and Torres Strait Islander people's way to continue their values of honour and respect during times of sickness, grief and loss.

A cancer diagnosis might start you thinking about Sorry Business and the possibility of passing into The Dreaming. This response is normal, and it is important to acknowledge your feelings as part of your cancer journey. Yarn with someone you trust, like a family member, friend, Elder or your healthcare team.

Palliative care helps people with metastatic cancer (incurable cancer) live as comfortably as possible by managing pain and other symptoms.

We know that Aboriginal and Torres Strait Islander people care deeply about family and community and what happens to them after they are gone. Planning ahead and yarning about your wishes with family and loved ones is a helpful part of preparing for Sorry Business.

Remember, you don't have to do this alone. If you can no longer care for yourself, sharing your wishes with family and those you care about can help them to make decisions about your treatment, and manage your affairs, such as:

- your finances
- your home and belongings
- dependants or people in your care
- family and community responsibilities
- work and career matters
- your spiritual, emotional and physical healthcare.

Planning ahead allows you to honour who and what is important to you. If you are unsure how to approach Sorry Business, reach out to your Elders, family and mob. Each family and community has its own ways of conducting Sorry Business and they can guide you through the protocols and traditions around bereavement and funerals.

Some things to consider include:

- specific people you want caring for you
- who will look after your dependants
- wearing traditional clothes during your cancer journey
- listening to music that is special to you
- conducting ceremony during your cancer treatment plan
- returning to Country or visiting sacred sites
- spending time with family and loved ones you have not seen for a long time
- recording memories and stories for future generations
- deciding who will manage your business
- preparing a Will which can outline your wishes for when you pass into The Dreaming.

RESOURCE

Palliative care – www.ourmobandcancer.gov.au/if-cancer-comes-back-or-won%27t-go-away/Palliative-care

SUPPORT FOR PARTNERS, CHILDREN, FAMILY MEMBERS, CARERS AND FRIENDS OF THOSE WITH OVARIAN CANCER

This section has been written for family, friends and carers of people with ovarian cancer. People with ovarian cancer may want to read this section to get a better feeling for the issues facing family and friends and then pass it on to the people who are closest to them and helping to care for them.

When a family member or close friend has been diagnosed with ovarian cancer, it is the beginning of an intense journey that has no rules. It is a difficult and emotional time for the person who is diagnosed – and for those close to them.

Finding out your mother, sister, daughter, partner, friend, aunt or loved one or family member has cancer can be overwhelming. You may be surprised by your own feelings and reactions. You may feel helpless or be worried you will say or do the wrong things.

How you cope with your family member's or friend's experience of ovarian cancer will depend partly on the type of relationship you had before they were sick and how you communicated in the past.

If you are the partner, parent, sibling or a child of someone with ovarian cancer, you may feel intense levels of distress when they are first diagnosed. Although these feelings tend to settle over time, you are likely to have periods where you are very worried, anxious, upset and frightened about the future. Roles within your family can often change, and this may often involve a great deal of adjustment for everyone.

If you are a friend of someone with ovarian cancer, it can be difficult to know where you fit in. You may also have strong emotions, but other people may be less aware of this. You may have concerns about how involved you should be and what the right or wrong thing to say is – you may be worried you will 'overstep your mark', especially if your friend has close family members.

A partner, child (adult and younger), other family member, friend or neighbour may also be a person's carer. This can be a very special and sometimes challenging role.

In this section, you will find information to help you support your family member or friend with ovarian cancer. There are also details of services to help to support your needs and concerns in this important role.

There are 4 main parts to this section – some, or all, of the information in each part may apply to you. Read through each to see what practical tips and sources of support you can find about:

- family relationships
- helping a family member or friend with ovarian cancer
- carers
- counselling and support services for family, friends and carers.

FAMILY RELATIONSHIPS

PARTNERS

As the partner of someone with ovarian cancer, you can have deep concerns about the person you love, and, at the same time, may need to take on new roles and extra responsibilities. You may feel you need to be the stronger person in the relationship and don't want to burden your partner with your own worries and fears. You may not believe your needs are as important as those of the person with cancer and may not seek out the support you need for yourself.

While your partner is having treatment and receiving support from members of the healthcare team, support group and wider support network, you may feel like a bystander. You may feel you can't do as much as you would like to help your partner. This can be very difficult if you are often used to being supportive by 'doing' and find it harder to simply be there, to talk and to listen.

There are a few really important things to remember at this time.

The love, care and support you provide for your partner will be a vital part of their support network – don't underestimate how much it means to them. If you were important to them before ovarian cancer, you are still important to them now – sometimes more so.

> *"Your partner is on the journey with you. They are the ones who know most closely how lonely and difficult the road is. They lie beside you night after night when you only sleep an hour at a time. You need them and somehow you have to look after each other."*
>
> **Carmel**

- **Talk together.** Open and honest communication goes a long way to help ease the stress cancer will have on your relationship. Tell each other how you are feeling. Try not to assume your partner knows how you feel or that you may offend or hurt your partner by being honest.
- **Go to medical appointments together.** This may help you feel more involved and help you to better understand the diagnosis and treatment. This will help you to know when and how to offer support. Going to support group meetings together is another way of providing support. Check if the group welcomes partners (some do).
- **Talk about your changed roles within the family.** While you are taking on new responsibilities, your partner is adjusting to being more dependent on you. Wherever possible, still involve them in household decision-making.
- **Get support for yourself.** Some couples find it helpful to see a counsellor, social worker or psychologist individually or together. Caring for yourself when you are a carer is extremely important. You may want to make an appointment to talk to someone by yourself. Start by asking about counselling services available through your hospital or treatment centre or ask your GP for a referral. You can also call the **Ovarian Cancer Australia** Support and Information Helpline on **1300 660 334** or **Cancer Council 13 11 20**.

SAME-SEX COUPLES

If you are a same-sex couple, you may feel support services are not sensitive towards your relationship. A social worker at your treatment centre, the Cancer Council's Cancer Connect program or specialised gay and lesbian support services may be able to give you the more specific support you need. You will find details of counselling and support services at the end of this section.

INTIMACY WITH YOUR PARTNER

Having ovarian cancer can change how someone feels about sex and being intimate. It can affect a person's libido as well as changing how a woman's body functions sexually.

As the partner of someone with ovarian cancer, you are most likely going to be affected as well. If your partner does not feel like being intimate or having sex, you may feel rejected. This can put a lot of stress on a relationship. Your partner may feel they are no longer attractive, or you are no longer attracted to them. Their body may not work in the same way as it used to.

They may be frightened of sharing their feelings with you. They may not want to hurt you by saying they are not yet ready to be intimate again. A person may worry that even a kiss or a cuddle will lead to having sex before they feel ready. Because of this, they may avoid contact altogether.

It is important to be as open as possible with your partner. Let them know they are still attractive to you and there is no pressure to become physically intimate. Reassure them you are happy to just sit, hold hands and chat if that is all they want to do. If you both communicate your feelings, it will help build more trust and a deeper relationship.

See **Chapter 3: Staying well** for the section on 'Intimacy and sexuality' during cancer and its treatment.

RESOURCE

Ovarian Cancer Australia – 'Sexuality, body image and relationships after ovarian cancer' (booklet), ovariancancer.net.au

> *"I had to reframe things in my mind. This has been so important and helpful. I had to get out of the clinical/medical/ cancer treatment space and back into the sexual space."*

Woman with ovarian cancer

MALE PARTNERS PROGRAM

This **Ovarian Cancer Australia** program supports men caring for partners with ovarian cancer. The emotional impact of caregiving can reduce overall wellbeing and quality of life. Intimacy and sexuality are also significant challenges and rank highly among unmet needs of male partners. View our webinar 'Emotional impact of caring for your partner with ovarian cancer and issues of intimacy and sexuality' (**ovariancancer.net.au/find-support/support-groups-and-networks/male-partners-program**).

See the end of this section for more resources for male partners. You will find helpful information about looking after yourself under 'Carers', later in this chapter.

CHILDREN AND TEENAGERS

Children and teenagers feel and show the distress of their mother's or grandmother's ovarian cancer in different ways. How they react will depend on their age and gender, and the way family members communicated before mum/grandmother was sick.

After a diagnosis of ovarian cancer, roles within a family will usually change and children, especially older children, often need to take on extra responsibilities.

Children may feel their needs are no longer as important and no-one understands how much they are hurting.

Just like adults, children have many different coping strategies. It is important to recognise this. Denial is one type of coping mechanism, although it may be mistaken for not coping.

Talking openly is really important, so each family member understands the others. Professional support is available. Family counsellors are at most hospitals. It can be very helpful to start the process of talking together as a family with a counsellor's guidance.

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Acknowledgement

Speak to the child's schoolteacher as well. They can provide extra support and monitor for signs of distress that the child may not express at home. Referral to the school counsellor may be helpful, especially if there are behavioural issues or if educational attainment is affected.

RESOURCE

Cancer Council – 'Talking to kids about cancer' (booklet), 13 11 20, cancer.org.au

See the end of this section for more resources for children and teenagers.

FAMILY MEETINGS

Family meetings can be helpful if you are feeling unsure or confused about treatment options and plans. They allow you, your family, friends and carers to communicate directly with the healthcare team. This way, everyone can hear and discuss important information together, reducing misunderstandings. It can be very helpful to include all members of the healthcare team in these meetings.

> *"By far the most support I have received has been from my family (my 2 sisters and my father) and my dog, who, I am convinced, knows that I am unwell and consequently has become much cuddlier and more loving."*
>
> **Anne**

PARENTS AND SIBLINGS

When a young person is diagnosed with ovarian cancer, parents can worry or feel guilty that they are somehow responsible. Parents often play a huge role in their care, sometimes being their major support. Being a primary care giver can be challenging for young adults who seek independence.

Parents naturally want to protect their child, attend appointments and be involved in decisions. While some young adults may be happy and relieved for this to happen, others may prefer more privacy and independence in their own care. It's important for the person with cancer to have control and be able to decide how much their family is involved.

Parents may also have other children to care for, causing siblings to feel isolated. Siblings can be a source of support but may also struggle to know how to help. Open communication within the family is so important, and seeking support when needed is crucial.

For more information, call the **Ovarian Cancer Australia** Support and Information Helpline at **1300 660 334**.

> *"Finding out mum had ovarian cancer was gut-wrenching. I felt completely helpless and instantly went into denial."*
>
> **Clare, daughter of woman with ovarian cancer**

EXTENDED FAMILY AND FRIENDS

A diagnosis of ovarian cancer will also have a significant impact on extended family, such as aunts, uncles, nieces and nephews, on close friends and on colleagues.

As a close friend or a member of the person's extended family, the following things are important.

- Get support for yourself if you are feeling upset, angry or unsure how to cope.
- Realise how important you are to your friend with ovarian cancer – as a friend you can provide wonderful support, both emotional and practical. See the next section for ideas of the types of support you can offer.
- Talk openly with your friend. Don't let ovarian cancer become the big subject you never talk about.

HELPING A FAMILY MEMBER OR FRIEND WITH OVARIAN CANCER

People who have lived with ovarian cancer have these suggestions for the types of practical and emotional support family and friends can offer:

- **Stay in touch**. Call, email or visit. It is helpful to check how your loved one is feeling before visiting.
- **Go with them to treatment**. Offer to attend chemotherapy, or create a 'chemo coping pack' with treats (like hand cream, chocolate, lip balm) and fun things (crosswords, magazines, cards).
- **Offer specific help**. Instead of a general 'Let me know if I can help,' suggest something specific like cooking, transport, listening, taking their kids out or gardening. Keep offering support during and after treatment.
- **Be mindful during treatment**. Your friend may be more vulnerable to infections, so don't visit if you are sick or have sick children with you. Always wash your hands well before visiting.

"It pays to spend time learning about ovarian cancer and its effects. Just remain open to information, have patience with what you, your family and mother will be about to experience."

Sonja, daughter of woman with ovarian cancer

- **Help your friend enjoy life**. Cancer can make everything feel heavy. Your friend may appreciate a break from it – whether it's going for a walk, having a meal, or just sharing a coffee or glass of wine.
- **Be there when they need to cry**. Don't try to stop them. Just sit with them so they know they're not alone.
- **Bring some fun**. When they don't want to talk about cancer, plan something lighthearted like lunch, music or a weekend getaway.
- **Caregiver support**. If you're also a caregiver, see the 'Carers' section later in this chapter for help.

RESOURCES

- Ovarian Cancer Australia – 'Family and friends' (booklet), 1300 660 334, ovariancancer.net.au; our online forum has a section for family and friends to share their personal stories and useful information with one another in a secure online environment
- Ovarian Cancer Australia Support Group for Carers, Family and Friends, facebook.com/groups/739541970853000

CARERS

Carers of people with ovarian cancer play a very special and often challenging role. Each care situation is different, and a carer may be a partner, child, other family member, friend or neighbour.

In many cases, the carer is the person with cancer's partner, and this can mean you are emotionally, physically, practically and financially involved and affected by what is happening in your partner's life.

ACCESSING INFORMATION AND SUPPORT

Carers often don't recognise their own role, seeing it as a natural part of loving someone with cancer. This can lead to not acknowledging the stress of caregiving or asking for help. But it's just as important to take care of yourself.

To be an effective carer, you need good information and support. Many carers find support groups helpful, and some welcome family and friends as well. There are also groups just for carers, offering inspiration, information and comfort. See the beginning of this chapter for more on finding support.

- **Carers Australia** (**carersaustralia.com.au**, **1800 242 636**) works with carers' associations in each state and territory to help improve the lives of carers. These associations provide counselling, advice, education and advocacy, and represent carers.
- Some carers may be eligible for government benefits to help with finances. The Carer Payment provides income support if you can't work full-time due to the demands of caring for someone with a serious condition like ovarian cancer. This payment is means-tested.

- The Carer Allowance is a smaller, supplementary payment that isn't means-tested and can be received alongside wages or other Centrelink payments. It's also tax-free and includes an annual supplement. To learn more or apply, call **Centrelink** on **13 2717** or visit **centrelink.gov.au**.

LOOKING AFTER YOURSELF

You will be much better able to care for someone else when you look after your own emotional and physical needs. Make sure you:

- talk to someone about your feelings
- get plenty of sleep
- eat a wide variety of fresh, healthy foods
- make time to be active
- take regular time out for yourself and do things you know you enjoy or enjoyed in the past – for example, gardening, going to the movies, spending time with friends
- are aware of signs of anxiety, depression and sleeping problems in yourself, and ask for help when you need it. Your GP, cancer nurse, social worker or a counsellor at your cancer treatment centre are good places to start. Or call **Ovarian Cancer Australia** on **1300 660 334** for further information and support.

Table 10: Useful contacts for carers

Group/organisation and contact details
Carer Advisory and Counselling Service offers referral to services and practical information to support carers in their caring role. • **1800 242 636**
All aged care services can be found through **My Aged Care**. • **myagedcare.gov.au**
Commonwealth Carer Respite Centres are located around Australia and provide information and advice on aged care and caring as well as access to respite care. • **1800 052 222**
The Carer Card is a discount and benefits card providing recognition, understanding and support for carers. • Search for Carer Card Program in your state/territory
Working Carers helps people who are working and caring, providing stories, fact sheets, newsletters and a chat room. • **cancer.org.au/assets/pdf/supporting-working-carers**
Healthshare is a free social health network that connects people and provides a place to get support and information. Healthshare has several online forums for carers. It's free to register. • **healthshare.com.au**
Read **Ovarian Cancer Australia's** family and friends booklet • **ovariancancer.net.au** or call **1300 660 334**
Ovarian Cancer Australia's Male Partner Support Group and Male Partner booklet. • Search at **ovariancancer.net.au**
Read **Cancer Council** booklet 'Caring for someone with cancer' • Search at **cancer.org.au** or call **13 11 20**
National Cancer Institute (US) has helpful information for carers, family and friends, including information for children and teenagers who have a family member with cancer. • **cancer.gov**
Cancer Council NSW hosts a Carers Telephone Support Group, which is open to people providing primary care for a family member, friend or loved one with cancer. The groups are held for one hour twice a month. • **1300 755 632**

TIPS FOR CARERS

Here are some ways of listening and supporting that carers of people with ovarian cancer have found helpful:

- **Listen.** Don't feel you have to offer solutions or 'fix things'. Being there to listen and care is one of the most helpful things you can do.
- **Be informed.** Use this kit to find reliable and up-to-date information sources.
- If you go along to doctor's appointments, **help the person you care for to think about the questions they want to ask, and ask questions yourself.** Listen carefully to what the doctor says and take notes.
- **Involve the person** you are caring for in shared activities you know you both have always enjoyed doing together such as going shopping, going to the movies, going for a walk, playing cards, talking and laughing. Also recognise there will be times when they want to be alone.
- Allow the person you are caring for to **make their own decisions**, accepting that they may be different from your own.

> *"It is very difficult for your partner because they are grieving and shocked like you. You can't expect them to respond in the exact way you would like. Often they just seem shell-shocked when you want them to say that you will survive, and you will be well again."*
>
> **Carmel**

COUNSELLING AND SUPPORT SERVICES FOR FAMILY, FRIENDS AND CARERS

FOR ALL FAMILY MEMBERS AND FRIENDS

- **Ovarian Cancer Australia** psychology and counselling service: contact the Support and Information Helpline on **1300 660 334** (Monday to Friday during business hours AEST) or email **support@ovariancancer.net.au**
- **Relationships Australia** (**relationships.org.au**, **1300 364 277**) is a network of community-based, not-for-profit organisations providing relationship support services for individuals, families and communities.
- **Cancer Council 13 11 20** Cancer Councils in each state and territory offer free, confidential telephone information and support, and can also organise specialised cancer counselling with a counsellor or psychologist at a subsidised cost. Counselling is available face to face and over the phone.
- Contact the **Australian Psychological Society** (**psychology.org.au**, **1800 333 497**) to find a psychologist in your local area who has experience and skills in the particular area you need.
- **Cancer Council NSW** (**cancercouncil.com.au**) has information about genetic testing and family history of cancer.
- **Cancer Council Queensland** (**cancerqld.org.au**) has a webinar on coping with the emotional impacts of breast and gynaecological cancer.
- **Cancer Council WA** (**cancerwa.asn.au**) has information about familial aspects of ovarian cancer, as well as a presentation on ovarian cancer genetics and risk-reducing surgery.
- **Cancer Council Victoria's** (**cancervic.org.au**) 'Challenging choices' webinar discusses issues arising from being a carrier of the BRCA1 and/or BRCA2 gene variant.

- **Centre for Genetics Education** (**genetics.edu.au**) has many excellent fact sheets relating to cancer in the family, gene mutations, genetic counselling, breast and ovarian cancer, and inherited predisposition.
- **Inherited Cancers Australi**a (formerly Pink Hope) (**inheritedcancers.org.au**) is a patient-focused organisation committed to supporting, educating and advocating for families with inherited cancers.

You may also find the following international websites helpful:

- **American Cancer Society** (**cancer.org**)
- **Cancer Research UK** (**cancerresearchuk.org**).

If you would like information about dealing with the practical and emotional needs of having ovarian cancer, call **Ovarian Cancer Australia** on **1300 660 334**. We can provide information about support groups and networks that can help you connect with other people in similar circumstances. We can also suggest how you can connect with counsellors and psychologists who specialise in helping people with cancer.

If you have continuous feelings of sadness, anxiety and fears relating to your cancer or your cancer coming back, we strongly advise you to seek medical help. Asking your specialist or GP for a referral to a counsellor or psychologist can help with managing your fears. You can also talk to your GP about a mental health care plan to receive Medicare-subsidised support from a psychologist.

FOR MEN

- For more info about our **Male Partners Program**, please see information about partners earlier in this chapter
- **MensLine Australia** (**mensline.org.au**) offers a free 24-hour, 7-day phone and online counselling, information and referral service for men with family and relationship concerns.
- **Australian Men's Shed Association** (**mensshed.org**, **1300 550 009**) is a not-for-profit organisation that creates a safe and busy environment where men of any age can get together, work in the shed, learn new skills and receive support when dealing with difficult situations, including their wife's, partner's, family member's or friend's ovarian cancer diagnosis. There are over 500 sheds registered throughout Australia so look on their website to find a shed near you.

FOR SAME-SEX COUPLES

- **C Word** is a telephone support group for same sex attracted women affected by cancer. Contact **Cancer Council 13 11 20** for more information.

> *"Be honest with your children. Don't hide the truth to protect them; protect them by telling the truth. With older children, talk openly and honestly about the treatment and maybe take them along to an appointment."*
>
> **Clare, daughter of woman with ovarian cancer**

FOR CHILDREN AND TEENAGERS

- **Kids Helpline** (**kidshelp.com.au**, **1800 55 1800**) is a phone, web and counselling service available for young people aged 5 to 25. The service is free, private and confidential and available 24 hours a day, 7 days a week. Young people can choose to talk with a female or male counsellor and can chat about anything at all that is worrying them – big or small. The website also lists Parentline phone numbers in each state and territory that concerned parents can call.
- **CancerHub** (**cancerhub.org.au**) offers support for families with children aged 0 to 25.
- **Australian Child & Adolescent Trauma, Loss & Grief Network** (**tgn.anu.edu.au**) offers support for positive and hopeful outcomes for young people and their families experiencing trauma, loss and grief.
- **Reach Out** (**reachout.com**) is an Australian website inspiring young people to help themselves through tough times by building skills and providing information, support and referrals.

You'll find more resources for children and teenagers in **Chapter 3: Staying well**.

GOOD BOOKS

Cancer Council NSW compiles a list of recommended reading divided into helpful categories. Each title on the list meets the Cancer Council NSW's criteria (**cancercouncil.com.au**).

Rosetta, Teal Support Nurse.

IF YOUR CANCER WON’T GO AWAY

> *“It is a privilege to walk alongside women as they navigate this challenging pathway.”*

Wendy
Gynaecology Clinical Nurse Consultant

CONTENTS

This section is written for people who have been told their cancer is not curable. This means your cancer may no longer be responding to treatment.

You may not want to, or ever need to, read this chapter. However, we include it for people who would like further information about coping with a cancer that won't go away. Hopefully the information will reassure you there are several treatments and a lot of support available for those in the advanced stages of ovarian cancer.

IF YOUR CANCER WON'T GO AWAY

For some people with cancer, there may come a time when their cancer advances and it is no longer responding to treatment. Others may receive an initial diagnosis of advanced cancer, meaning the cancer is incurable. This can be very difficult to come to terms with. However, it doesn't mean there won't be treatment to help control your cancer or its symptoms.

The aim of treatment for incurable cancer is to provide care and support so people can live as fully and comfortably as possible. Your medical team calls this type of care 'palliative' or 'best supportive care'. While palliative care itself is not aimed at curing your cancer, it can be offered together with active treatment to help reduce your symptoms, give you a better quality of life, and provide you and your family or carers with emotional, spiritual and practical support.

Palliative care provides a nurturing support system of medical and allied health professionals to help people with advanced cancer and those close to them cope during a chronic or life-limiting illness. The main aim of palliative care is to improve quality of life and provide symptom management for the person who is unwell and support those closest to them.

> *"Life is truly precious and very unpredictable. It is important to be with those you love and to respect and embrace them and life."*
>
> **Debbie**

It is important to be aware that women with advanced/incurable ovarian cancer can survive for many years, even after having several courses of palliative chemotherapy. It may not cure your cancer, but it may help you live for many months or years longer.

PALLIATIVE CARE

Palliative care can be given at any stage during advanced cancer. It is important to remember people can live with advanced or incurable ovarian cancer for quite some time. Support can be provided in your home, in hospital or in a hospice setting. The services offered through palliative care differ depending on your individual needs.

Palliative care doctors and nurses are specialists in managing the troubling symptoms of cancer and side effects of treatment. Seeing a palliative care doctor or nurse is like seeing any other medical doctor.

There are many benefits in thinking about palliative care when you are still well. It is important you receive the opportunity to be actively involved in and plan for your ongoing care. It can provide practical psychological and medical comfort and support for people faced with an illness in its advanced stages.

> *"Palliative care doesn't mean that it is time to 'give up', but it is a way you can seek support and resources from people who know how to and want to improve your quality of life by caring for your physical, social and emotional needs."*

Theresa, Manager Palliative Care, Department of Health and Human Services Victoria

HOW PALLIATIVE CARE CAN HELP ME AND THOSE CLOSE TO ME

A specialist palliative care service uses a team of health professionals to provide you and your family with care tailored for your needs. The team may include:

- specialist palliative care consultant
- community specialist palliative care nurse
- family support worker (social worker, psychologist or counsellor)
- physiotherapist
- occupational therapist
- dietitian
- pastoral care worker
- massage therapist
- volunteers.

Your palliative care team works together with members of your healthcare team, including your GP and cancer specialist.

Referral to a palliative care team can be made by medical staff while you are in hospital. Or you, your GP or a family member can make the referral. Depending on your needs, which will change over time, a palliative care service can provide you and those close to you with:

- management of pain and other difficult symptoms
- specialist nursing in the home, hospital or hospice setting
- nutritional care and support
- assessment of and practical help with daily living including equipment to help you manage at home
- emotional and spiritual support
- an understanding of the physical changes and symptoms you are experiencing and how to manage these, so you are more comfortable
- assistance with advance care planning
- grief and bereavement counselling.

> *"Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual."*
>
> **World Health Organization**

PAIN RELIEF

Many people worry about the pain they may have if their cancer advances. Palliative care teams are experts in pain relief, and, in almost all cases, pain can be controlled. Not everyone with advanced cancer will have pain, but if you do, it is important to seek help from experts. There are many different pain management medicines available. Finding the right dose and combination often depends on the individual and the type of pain.

In addition to prescribing medication, your palliative care team may be able to suggest where you can access massage, acupuncture and relaxation techniques that can help with pain relief. Read about coping with cancer pain in **Chapter 2: Treatment**.

Some people with advanced cancer think that they must put up with pain and discomfort or put off having their symptoms reviewed until they 'really need it'. What we find is that relief from physical symptoms can reduce other stressors too, so don't hesitate to ask for symptom relief. If your pain is well controlled you will feel better able to manage eating and drinking, mobilising, anxiety, depression and communication/intimacy with those you love. It also relieves those close to you from having to see you in pain, which can be very distressing.

PALLIATIVE CARE SERVICES

Palliative care services are provided in a range of places. Most are provided at home by a community-based palliative care service or a community nurse. Services are also provided in hospitals, outpatient clinics and specialist inpatient palliative care units/hospices.

Inpatient palliative care units

A palliative care unit in a hospital is a place where specialist palliative care staff care for you in a home-like environment, but with all the benefits of hospital equipment and 24-hour nursing care.

These palliative care units can allow you to bring difficult symptoms under control and have 24-hour care. In some instances, people who do not want to die at home, or are not able to, will remain in a hospital or hospice for end-of-life care. Other people return home if they can manage their symptoms there. You may also go into a palliative care inpatient unit for a short time to give your carers a rest.

Community palliative care

Once you are referred to the community palliative care team, a nurse will visit you and your family at home. They'll get to know you, assess your needs and explain how palliative care can help. Together, you, the nurse and the palliative care doctor will create a follow-up plan, which might include regular check-ups, phone calls or daily visits for symptom control if you are unwell.

It is not unusual for some people to enter community palliative care for a period of time, and then come off the program again as symptoms are managed, returning if needed later.

Community palliative care can also provide bereavement support to loved ones.

Palliative care in aged care

Sometimes, palliative care may be provided in an aged care setting. If this is the case, community palliative care teams will provide consultation and support to the aged care team.

Access and referral

Palliative care services are available and respectful to everyone with advanced cancer, regardless of their culture, background, religion or belief system.

You can be referred to a palliative care service by any member of your healthcare team or by your carers, or you can make direct contact with your local service yourself. You will need a doctor's referral to be admitted to an inpatient palliative care unit, and there are often criteria around admission times to these units.

The cost of palliative care services varies according to the type of service provided, but those provided in the public health system are generally free. Ask a member of your healthcare team about any costs involved and any rebates available from Medicare or your private health fund.

FINDING PALLIATIVE CARE SERVICES IN YOUR AREA

For a list of all palliative care facilities available in your area, visit **Palliative Care Australia** (**palliativecare.org.au**) or your state or territory palliative care organisation:

- New South Wales **palliativecarensw.org.au**
- Victoria **pallcarevic.asn.au**
- Queensland **palliativecareqld.org.au**
- Western Australia **palliativecarewa.asn.au**
- South Australia **palliativecaresa.org.au**
- Tasmania **pallcaretas.org.au**
- Australian Capital Territory **pallcareact.org.au**
- Northern Territory **pallcarent.org.au**

Or call the **National Palliative Care** Information Line on **1800 660 055** for information about services in your state or territory. Available Monday to Friday 9 am to 5 pm.

Rural and regional palliative care services

CareSearch (**caresearch.com.au**) is Australia's palliative care knowledge network, where you can find links to helpful resources and services for patients and families in rural areas.

RESOURCE

Cancer Council – 'Understanding palliative care', and 'Living with advanced cancer' (booklets), 13 11 20, cancer.org.au

HOPE IS IMPORTANT

Hope is what gets you through each day, and there is always the possibility of finding a glimmer of hope on the darkest days.

Hope means different things to different people, and what you hope for may change over time.

Make plans to do the things that are important to you and keep setting goals – large and small, short term and long term. You may hope to go to a grandchild's concert, to pick your first summer tomatoes, to be free of pain, or to simply share more experiences that bring you joy with the people you love.

Sharing your hopes, goals and dreams with your healthcare team will enable them to provide you with care centred on your needs.

WHERE TO FROM HERE?

Finding out your cancer can no longer be treated is likely to bring up many confronting emotions for you and those close to you. Confusion, sadness and intense grief are common feelings. Depending on your age and situation, you may be grieving the loss of what you expected and wanted life to be, or simply grieving about leaving loved ones behind; not wanting them to feel sad or suffer because you are gone.

Maybe you are feeling 'it is time' and although it is sad to be leaving your loved ones and life behind, you may no longer have the energy or desire to talk much any more. You have been through enough and want to be able to say your goodbyes. But you might be worried about expressing that to those you care about.

You and those close to you may have many questions at this time about:

- palliative care services and how to access them
- which health professionals are involved in palliative care
- what to expect in the end-of-life phase
- medications to help with pain and other symptoms
- getting your affairs in order
- lifestyle and quality of life when cancer can't be treated
- and much more.

RESOURCE

Refer to Palliative Care Australia's 'Asking questions' page to help you think about what questions to ask your healthcare team to ensure you and those close to you get the best possible care at this stage in your illness: https://palliativecare.org.au/resource/asking-questions/

END-OF-LIFE CARE

Although we have touched on end-of-life care in the previous pages, we have not covered this in detail in this kit. We understand it is a difficult topic for many people to face, even if it is not relevant for you at this time. Many people with ovarian cancer will live for years after their diagnosis, but for others this may not be the case. If you or someone you know is dying and would like information and support, please contact Ovarian Cancer Australia on 1300 660 334.

- **Cancer Australia's** booklet 'Finding the words: Starting a conversation when your cancer has progressed' is designed to help you start conversations about your needs and care with the people who can provide support. You can find it online or order a print copy at **canceraustralia.gov.au**
- You may also find the **Cancer Council** booklet 'Facing end of life' helpful, **13 11 20**, **cancer.org.au**
- For information regarding Wills, getting insurance when you have cancer and advance care plans, see 'Practical matters' in **Chapter 3: Staying well**.

GLOSSARY

WE ARE HERE TO SUPPORT YOU

Our support team are always here for you so please don't hesitate to reach out.

GLOSSARY

After a diagnosis of ovarian cancer, it may feel like you have a whole new language to learn.

Medical professionals often use terms you may not be familiar with and can be confusing. Don't be afraid to ask health professionals to explain any words or phrases you do not understand. It is important you feel sure about everything to do with your treatment and care.

The pages that follow include definitions of some of the most common terms you may hear and read.

HELPFUL TERMS

ABDOMEN

The area between the ribs and hips containing the stomach, intestines, liver, gall bladder, bladder, kidneys and spleen. In women, the abdomen also includes the uterus, fallopian tubes and ovaries. The abdominal cavity is lined with the peritoneum.

ADVANCED CANCER

Cancer is called 'advanced' when it has spread from its original site to another area or organs. In ovarian cancer, advanced cancer is stages 3 and 4.

ANAEMIA

A deficiency of red cells or of haemoglobin in the blood, which can result in weakness and tiredness.

ANALGESIA

Medications that help to control and relieve pain.

ANTI-EMETICS

Medicine prescribed to help stop you feeling sick (nausea) and being sick (vomiting).

ASCITES

A build-up of fluid in the abdomen that causes bloating, swelling and discomfort. The fluid can be drained to relieve the discomfort.

BENIGN TUMOUR

A growth that is not cancer (non-malignant) and cannot spread to other parts of the body.

BILATERAL SALPINGO-OOPHORECTOMY

Surgical removal of both fallopian tubes and both ovaries.

BIOLOGICAL THERAPY

Treatments that help to slow down or stop the growth of cancer cells. They work by boosting the immune system to kill the cancer cells, changing how cancer cells signal to each other to grow, or stopping the growth of the cancer's blood supply. Examples include immunotherapy, vaccines, monoclonal antibodies and gene therapy.

BIOPSY

Removing a sample of tissue so it can be examined under a microscope to help diagnose cancer or another disease.

BORDERLINE TUMOURS

Tumours closely associated with ovarian cancer, although they are not strictly classified as ovarian cancer. Commonly referred to as 'low malignant potential' tumours, they are not considered to be malignant and have a very good prognosis.

BOWEL OBSTRUCTION

A blockage in the bowel that may be caused by a tumour or as a result of surgery.

BRCA1 AND BRCA2

A gene change (variant) that may be inherited from your mother or father. These variants are associated with a higher risk of breast, ovarian and other cancers.

CA125

A protein in the blood that can be raised due to factors including cancer. For this reason, the CA125 protein can be referred to as a 'tumour marker'.

CANCER

A disease where cells in the body behave and grow abnormally and form a malignant growth called a tumour. Malignant tumours can spread into other parts (tissues) of the body.

CHEMOTHERAPY

Medicines to slow the growth of or destroy cancer cells.

CT (COMPUTED TOMOGRAPHY) SCAN

A series of x-rays that are computerised to provide a cross-section picture of internal parts of the body. May be used to diagnose ovarian cancer, plan treatment and for follow-up.

CYST

A fluid-filled sac. When it develops in an ovary, it is called an 'ovarian cyst'. Most ovarian cysts are harmless and will go away by themselves. Cysts are monitored very closely because some can grow very large and cause uncomfortable symptoms and some can become malignant.

CYTOREDUCTIVE SURGERY

This surgery for ovarian cancer typically includes the surgical removal of the uterus, both fallopian tubes, both ovaries and omentum, and resection of metastatic lesions from the peritoneal surfaces or from the bowel. This is also known as 'primary cytoreductive surgery' or 'debulking'.

DEBULKING

See 'Cytoreductive surgery'.

EPITHELIAL OVARIAN CANCER

This is the most common type of ovarian cancer, accounting for 9 out of 10 cases.

EPITHELIUM

The cells that line internal and external surfaces of the body, including the skin and the outer surface of the ovaries.

FAMILY OR FAMILIAL CANCER CENTRE/SERVICE

A centre where genetic counsellors can talk to you about genetic testing if you have a family history of cancer and wish to consider testing for yourself, children or other family members.

GENES

Small pieces of DNA: the material that acts as a 'master blueprint' for all the cells in your body. Your genes determine such things as what colour hair and eyes you have and how tall you are. If you inherit specific faulty genes, it may mean you have an increased risk of certain types of cancer.

GENETIC

Relating to genes. A genetic condition is one caused by a fault in one or more genes and may have been inherited.

GENE VARIANT

A change in a gene that may be inherited.

GERM CELL OVARIAN CANCER

Ovarian cancer that begins in the immature cells in the ovary that eventually develop into ova. Only 4% of ovarian cancers are germ cell and they mainly occur in younger women.

GRADE

A number that describes how similar cancer cells are to normal cells. Grade 1 is the lowest grade, where there is the highest chance of successful treatment. Grade 3 is the highest grade. Also see ‘stage’, which is a measure of how far cancer has spread.

GYNAECOLOGICAL ONCOLOGIST

A gynaecologist who has done a further 3 years of specialist training in treating people with cancer of the female reproductive organs, including ovarian cancer.

GYNAECOLOGICAL ONCOLOGY NURSE

A nurse who specialises in cancer care and may administer chemotherapy, assist with radiotherapy, and provide care, counselling, information and support.

HIGH-GRADE SEROUS CARCINOMA

A more aggressive type of ovarian cancer that grows and spreads quickly. It usually starts in the cells lining the ovaries and often looks very different from normal cells under a microscope. This type of cancer may require more intensive treatment due to its rapid growth.

HRD (HOMOLOGOUS RECOMBINATION DEFICIENCY)

A characteristic of some cancer cells that makes it harder for them to fix or repair damaged DNA. This means that these cancer cells can die when treated with PARP inhibitor medicines.

HYSTERECTOMY

Surgical removal of the uterus (womb).

IMMUNOTHERAPY

Treatment that stimulates the body’s immune system to fight cancer.

INTRAPERITONEAL

The lining of the abdominal space is called the ‘peritoneum’. Intraperitoneal means within the peritoneum. Intraperitoneal chemotherapy is chemo delivered directly into this space. Any fluid that accumulates in this space is called ‘ascites’.

LAPAROSCOPY

A minor operation using a small telescope (laparoscope) to look into the abdomen.

LAPAROTOMY

An operation to open the abdomen and examine the internal organs.

LOW-GRADE SEROUS CARCINOMA

A type of ovarian cancer that grows slowly. It starts in the cells that produce a fluid similar to what normal ovaries make. This cancer tends to be less aggressive than other types, which can make treatment more manageable.

LYMPHADENECTOMY

Surgical removal of one or more lymph nodes.

LYMPH NODES

Small bean-shaped structures in the neck, armpit, groin and abdomen that filter lymph fluid to prevent harmful agents from entering the bloodstream. Ovarian cancer may spread to the lymph nodes.

LYMPHOEDEMA

A build-up of fluid that causes swelling. After lymph nodes have been removed, lymph fluid sometimes stops flowing freely through the lymphatic system, causing it to build up in one area of the body.

MRT (MENOPAUSE REPLACEMENT THERAPY) OR MHT (MENOPAUSE HORMONE THERAPY)

Prescription medicines that supply the body with hormones that are no longer produced in the body after menopause. Used to help relieve menopausal symptoms.

MRI (MAGNETIC RESONANCE IMAGING)

A computer scan using magnetic fields and radio waves to build up a detailed picture inside the body. May be used to help diagnose ovarian cancer.

MALIGNANT TUMOUR

Tumours can be benign (not cancerous) or malignant (cancerous). Malignant tumours can spread to other tissues or parts of the body.

MASS

A tumour that may or may not be malignant.

MEDICAL ONCOLOGIST

A doctor who specialises in medicines used to manage and treat cancer, including chemotherapy, immunotherapy and pain medicine.

METASTASIS

A cancer that has spread from another part of the body – also known as a 'secondary cancer'. For example, a cancer that originates in the ovaries but has spread to the lungs is not called 'lung cancer' but instead is called 'metastasised ovarian cancer'.

OMENTECTOMY

Surgical removal of the omentum, which is necessary if ovarian cancer has spread to this tissue.

OMENTUM

A layer of protective fatty tissue covering the abdominal organs.

ONCOLOGIST

A doctor who specialises in the study and treatment of cancer.

OOPHORECTOMY

Surgical removal of one or both ovaries.

OVA

The 'eggs' that form from immature cells (germ cells) in the ovary. In a menstruating woman, one ova is released each month by an ovary – this is called 'ovulation'.

PALLIATIVE CARE OR TREATMENT

Care or treatment aimed at relieving symptoms and improving quality of life when an illness is no longer curable. Palliative care can be used alongside active treatment to manage symptoms.

PARP (POLY ADP-RIBOSE POLYMERASE) INHIBITORS

PARP is a protein in our body that helps damaged cells repair themselves. Cancer cells with altered BRCA genes depend on PARP to keep their DNA repair mechanisms working. PARP inhibitors stop PARP from working, meaning the cancer cells cannot mend themselves.

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PATHOGENIC

Disease-causing. A variant in a BRCA gene that makes a person more likely to develop ovarian cancer is called a 'pathogenic variant'.

PCA (PATIENT-CONTROLLED ANALGESIA)

A device that allows the patient to control their own pain-relief medicine.

PERIPHERAL NEUROPATHY

Numbness or tingling in your hands and feet caused by some chemotherapy drugs.

PERITONEUM

A membrane covering organs in the abdomen.

PET (POSITRON EMISSION TOMOGRAPHY)

An imaging test that can help reveal the metabolic or biochemical function of your tissues and organs. It may be used to detect spread of disease or evidence of recurrence.

PLEURAL EFFUSION

A build-up of fluid around the lungs.

PROGNOSIS

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

RAD51C AND RAD51D

Inheriting faulty RAD51C or RAD51D genes has been found to increase the risk of developing ovarian cancer. These mutations are very rare, and together may contribute to less than 2% of ovarian cancers diagnosed.

RADICAL HYSTERECTOMY

An operation to remove the uterus and all the tissues holding the uterus in place (including the ovaries and fallopian tubes), and the lymph nodes around the uterus.

RADIOTHERAPY

Treatment using high energy waves similar to x-rays to destroy cancer cells.

RECURRENT OVARIAN CANCER

Cancer that reappears after it was removed or had gone into remission.

REMISSION

When cancer is not detectable or progressing after treatment. Complete remission means there is no evidence of active disease after treatment and the cancer may not come back for some time or at all. Partial remission means that there is cancer remaining after treatment, but it is less active than before. This cancer will grow again at some time in the future.

RESIDUAL DISEASE

Cancer that remains after surgery. Surgery aims to remove all visible cancer, but this is often not possible in advanced ovarian cancer. Residual disease is usually treated with chemotherapy.

SECONDARY CANCER

A metastasis – a tumour that has spread from its original site to another part of the body.

SEX-CORD STROMAL TUMOURS

Ovarian cancer that begins in the ovary cells that release female hormones. These tumours are very rare, accounting for about 5% of ovarian cancers.

STABLE DISEASE

Cancer that is neither growing nor shrinking.

STAGE

The stage of your cancer describes how advanced it is and how far it has spread.

STAGING

The process of working out the stage of a cancer. This is done during the initial surgery for ovarian cancer or it may be done with imaging for those having chemotherapy before surgery. Or via biopsy for those receiving NACT (neoadjuvant chemotherapy) in combination with CT/PET imaging.

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TRANSVAGINAL ULTRASOUND

An ultrasound examination where a small instrument is inserted into the vagina to give a clear picture of the inside of the uterus and the ovaries.

TUMOUR

See ‘Benign tumour’ and ‘Malignant tumour’.

TUMOUR MARKER

A chemical given off by cancer cells which circulates in the blood of the person with cancer.

RESOURCES

CA125

Ovarian Cancer Australia – Fact sheet on CA125, ovariancancer.net.au

CARERS

Carer Advisory and Counselling Service, 1800 242 636

Commonwealth Carer Respite Centres, 1800 052 222

Healthshare, healthshare.com.au

My Aged Care, myagedcare.gov.au

CHEMOTHERAPY

Cancer Council – Free booklets and fact sheets about chemotherapy, 13 11 20, cancer.org.au

Look Good … Feel Better 1800 650 960, lgfb.org.au

CHILDREN – TALKING TO KIDS ABOUT CANCER

Australian Child & Adolescent Trauma, Loss & Grief Network, tgn.anu.edu.au

Cancer Council – 'Talking to kids about cancer' (booklet), 13 11 20, cancer.org.au

Cancer Hub – Helps families impacted by cancer (with children aged 0 to 25) cancerhub.org.au

Kids Helpline, 1800 55 1800, kidshelp.com.au

Mummy's Wish – Practical support for mums with cancer, (mummyswish.org.au)

Reach Out, reachout.com

CLINICAL TRIALS

Australian New Zealand Clinical Trials Registry, anzctr.org.au

Australia New Zealand Gynaecological Oncology Group, anzgog.org.au

Cancer Australia, australiancancertrials.gov.au

Cancer Council Victoria – 'Clinical trials for cancer' (booklet), 13 11 20, cancervic.org.au

Clin Trial Refer, clintrialrefer.org.au

COMPLEMENTARY AND ALTERNATIVE THERAPIES

Cancer Council – 'Massage and cancer: an introduction to the benefits of touch' (booklet), 13 11 20, cancer.org.au

Cancer Council – 'Understanding complementary therapies' (booklet), 13 11 20, cancer.org.au

Cancer Council NSW – 'Finding calm during cancer' (podcast), cancercouncil.com.au

Complementary and Alternative Medicine for Cancer, cam-cancer.org

Memorial Sloane Kettering Cancer Center, mskcc.org

Oncology Massage Training, oncologymassagetraining.com.au

Quackwatch, quackwatch.com

CONTINENCE

Continence Foundation 1800 33 00 66, continence.org.au

National Continence Helpline, 1800 33 00 66

FAMILY AND FRIENDS

Ovarian Cancer Australia – Family and friends booklet, 1300 660 334, ovariancancer.net.au

FATIGUE

Australian Cancer Survivorship Centre – 'Coping with cancer-related fatigue' (fact sheet), petermac.org

FERTILITY

Access Australia, 1800 888 896, access.org.au

Cancer Council – 'Fertility and cancer: A guide for people with cancer' (booklet), 13 11 20, cancer.org.au

FINANCES

Cancer Council – 'Cancer and your finances' (booklet), cancercouncil.com.au

Legal, Financial Planning, Small Business and Workplace Referral Services, 13 11 20

Superannuation and cancer booklet, cancer.org.au

GENETICS

Ovarian Cancer Australia – 'Genetic testing and hereditary ovarian cancer: A guide for people with ovarian cancer' (booklet), ovariancancer.net.au

Ovarian Cancer Australia – Webinar on family history and genetic testing, ovariancancer.net.au/webinars

Cancer Australia – Information about family history, genetic testing for breast and ovarian cancer and family cancer clinics, canceraustralia.gov.au

Cancer Council Australia – Search for family cancers, cancer.org.au

EviQ – Information on cancer genetics and treatment, eviq.org.au

Human Genetics Society of Australasia, hgsa.org.au

Life insurance products and genetic testing in Australia, genetics.edu.au

NSW Health Centre for Genetic Education, genetics.edu.au

HELPFUL FORMS AND CHECKLISTS

North-eastern Melbourne Integrated Cancer Service – My Cancer Care Record, vics.org.au

International Centre for Allied Health Evidence, University of South Australia – Discharge planning checklist for patient and carer, https://www.unisa.edu.au/contentassets/f2ba8c38044f484b934508d39bba422e/dcpchecklist_new-version.pdf

HELPLINES

Ovarian Cancer Australia – Ovarian Cancer Support Nurses and Support and Information Helpline, 1300 660 334, ovariancancer.net.au

Cancer Council Helpline, 13 11 20

Kids Helpline, kidshelp.com.au or 1800 55 1800

LIFE AFTER TREATMENT

Ovarian Cancer Australia: 'Life following ovarian cancer treatment. A booklet for people who have been treated for ovarian cancer, and their families, partners and friends', ovariancancer.net.au

Cancer Council – Free programs that focus on wellness after cancer, 13 11 20

LYMPHOEDEMA

Australasian Lymphology Association – For resources, education, support and to find a therapist near you, lymphoedema.org.au

Cancer Australia – Lymphoedema booklet available in several community languages, canceraustralia.gov.au

MENOPAUSE

Ovarian Cancer Australia – Fact sheet on early menopause from cancer, ovariancancer.net.au

Australasian Menopause Society – For information on menopause, MRT and doctors who specialise in menopause, menopause.org.au

Jean Hailes for Women's Health, jeanhailes.org.au

MENTAL HEALTH AND RELAXATION

Better Health Channel – Stigma, discrimination and mental illness, betterhealth.vic.gov.au

Better Health information on cognitive behavioural therapy, betterhealth.vic.gov.au

Beyond Blue – Reducing stigma and discrimination, beyondblue.org.au

Cancer Research UK – Meditation, cancerresearchuk.org

Healthtalk.org – Depression: stigma and mental health, healthtalk.org

Memorial Sloan-Kettering Cancer Center – Mindfulness and stress reduction resources for people with cancer, mskcc.org

NURSES

Ovarian Cancer Australia – Teal Support Program, ovariancancer.net.au/teal-support-program

NUTRITION AND EXERCISE

Australian Cancer Survivorship Centre – Fact sheets about life after treatment, via petermac.org

Cancer Council – 'Nutrition and cancer' and 'Living well after cancer' (booklets), 13 11 20, cancer.org.au

Dietitians Australia – Lists accredited practising dietitians around Australia 1800 812 942, dietitiansaustralia.org.au

Exercise and Sport Science Australia – Lists accredited exercise physiologists, essa.org.au

National Cancer Institute (United States) – Lists healthy eating tips, cancer.gov

OPTIMAL CARE

'Optimal care pathway for women with ovarian cancer' and **'Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer'**, canceraustralia.gov.au/optimal-cancer-care-pathways

PAIN

Cancer Council – 'Overcoming cancer pain' (booklet), 13 11 20, cancer.org.au

PALLIATIVE CARE

Australian Capital Territory, pallcareact.org.au

Cancer Council – 'Understanding palliative care', and 'Living with advanced cancer' (booklets), 13 11 20, cancer.org.au

CareSearch, caresearch.com.au

National Palliative Care Information Line, 1800 660 055

New South Wales palliativecarensw.org.au

Northern Territory nt.gov.au

Palliative Care Australia, palliativecare.org.au

Queensland palliativecareqld.org.au

South Australia palliativecaresa.org.au

Tasmania pallcaretas.org.au

Victoria pallcarevic.asn.au

Western Australia palliativecarewa.asn.au

PERSONALISED MEDICINE

Ovarian Cancer Australia – Information about personalised medicine programs, ovariancancer.net.au

RADIOTHERAPY

Cancer Council – 'Radiotherapy' (booklet), 13 11 20, cancer.org.au

RECURRENT CANCER

Ovarian Cancer Australia, 1300 660 334

Ovarian Cancer Australia – Fear of recurrence booklet, 1300 660 334, ovariancancer.net.au

Cancer Council 13 11 20

US National Ovarian Cancer Coalition – Comprehensive booklet on recurrent ovarian cancer, ovarian.org

REFERRAL

Canrefer – For names of individual gynaecological oncologists, canrefer.org.au/gynaecological-oncologists

RESEARCH

Ovarian Cancer Australia – 'Research into ovarian cancer' (fact sheet), ovariancancer.net.au

SELF-CARE

Look Good Feel Better, lgfb.org.au

SEXUALITY

Ovarian Cancer Australia – 'Sexuality, body image and relationships after ovarian cancer' (booklet), ovariancancer.net.au

ASSERT NSW – For details of sex therapists in all states, assertnsw.org.au

Australian Psychological Society 1800 333 497, psychology.org.au

Relationships Australia, relationships.org.au

Society of Australian Sexologists, societyaustraliansexologists.org.au

STOMA

Australian Council of Stoma Associations, australianstoma.com.au

SUPPORT GROUPS

Ovarian Cancer Australia – Information about support groups in your area, 1300 660 334, ovariancancer.net.au/online-support-groups

Ovarian Cancer Australia – Monthly online support group for younger women (under 50), ovariancancer.net.au/online-support-groups

Ovarian Cancer Australia – Facebook Support Group for people diagnosed with ovarian cancer, facebook.com/groups/359547902456355

Ovarian Cancer Australia – Facebook Support Group for Carers, Family and Friends, facebook.com/groups/739541970853000

Cancer Council forums – Cancer Connect and Cancer Council support groups, 13 11 20, cancer.org.au

Cancer Council NSW – Advanced Cancer Patients Telephone Support Group, 13 11 20

CanTeen 1800 835 932, canteen.org.au

Healthshare, healthshare.com.au

QLife, 1800 184 527, qlife.org.au

TELEHEALTH

Department of Health – Search for telehealth, health.gov.au

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