OVARIAN
CANCER
AUSTRALIA

Supporting someone with ovarian cancer

A guide for carers, friends and family

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Introduction

This resource has been created for everyone who is standing alongside someone with ovarian cancer, or who wants to offer support and care during this time. It discusses the wide range of emotions, responsibilities and questions that can come with being in a supportive, caring role. You might see yourself as a 'carer' or you may not use that word at all. You might just see yourself as a partner. You might be providing day-to-day care or simply want to stay connected with your friend/relative/current or ex-partner and remain helpful in meaningful ways.

About this resource

When someone you care about is diagnosed with ovarian cancer, it can be hard to know what to do, what to say and how best to help. Whether you are a partner, parent, sibling, young or adult child, aunt, uncle, cousin, close friend, or someone who plays a support role from near or far, your care and support matter a lot.

Many cancer diagnoses are now described as a 'we-disease', because they affect not only the person with cancer but also their partner, family, friends and even colleagues. All may share in the emotional, physical and psychological distress. They can also feel the shock, sadness, fear, and sometimes guilt or loneliness. It can all feel overwhelming at times. Each person copes differently, and support may be needed both individually, as a couple and/or as a family. For some, this experience may only last a few months, but for many it continues over years, bringing new challenges and changes along the way.

We understand that when you are caring or supporting someone with ovarian cancer it is not 'one size fits all', and that the support you offer and how you feel can change over time. This resource includes practical tips, emotional support, real stories from people who have been in your shoes and guidance to more help when you need it.

Importantly, this resource is here to remind you that you are not alone, and that your wellbeing, both physical and emotionally, matters too.

RESOURCE

If someone you know has been recently diagnosed or is just starting treatment, please contact us for a copy of the *Resilience Kit*. Developed by Ovarian Cancer Australia, the kit will answer many of your loved one's questions, from diagnosis through treatment and beyond, www.ovariancancer.net.au/booklet/resilience-kit

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.

How to use this resource

We have designed this resource so that it will be easy to dip in and out of, depending on your relationship with the person who has ovarian cancer and the type of support you are giving at the time. You may find that more than one section applies to you and that's okay. You can read the whole resource or skip ahead to the sections that you feel are only relevant to your individual situation.

The content is divided into three chapters:

1. **For carers:** If you are providing ongoing, regular or intensive care (practical, emotional, physical); either in-person or from afar.
2. **For family and friends:** If you are a relative (close or extended) or a friend wanting to support and stay connected, understand what your loved one or friend is going through, and how you can best help, without overstepping or overwhelming them.
3. **For everyone:** With topics like intimacy, communication, grief, tips on what to say and where to get help.

We also discuss some common misunderstandings (myths) about cancer and caring for someone with cancer. The glossary at the end explains medical terms or 'jargon' that may come up when you are caring for someone with cancer and who may be having treatment.

We have also included real voices and reflections from people who have supported someone with ovarian cancer. It can be very reassuring to hear from others who have also had this experience. We hope these quotes offer valuable insight, reassurance and sometimes even a little humour – which can be a huge relief during difficult times.

Our main hope is that this resource will help you feel informed, supported and maybe a bit more prepared for what lies ahead.

What does being a 'carer' mean?

A carer is someone who provides unpaid or paid support to a person who is living with an illness, disability or frailty. They help them manage daily life including their medical care, and emotional and physical wellbeing.

A carer can be a family member, friend or neighbour and they may or may not live with the person they are caring for. Every carer experience is different, and their role can change over time and how much or how little they are needed depends on:

- **The stage of the person's illness.** Advanced stages of ovarian cancer may require more intensive physical and emotional care.
- **The type of illness.** Ovarian cancer often involves many cycles of treatment and sometimes recurrences, which affects the amount and type of care needed over time.
- **The person's age and independence.** For example, older women or those with side effects of treatment may need more help with self-care, nutrition and transport to appointments.
- **Cultural, family or community expectations.** Some cultures expect family members to take on a full-time carer role, while others may prefer to get outside help.
- **The carer's own health and circumstances.** A carer managing their own health problems or work responsibilities may struggle with the demands of caring for someone with ovarian cancer, along with possibly also caring for their children and elderly parents.

> “*Early on, you don't realise all the roles that a carer plays and how much this can change throughout the months/years as the needs of the loved one and yourself change.*” **– A carer**

TYPES OF CARERS

Informal carers

Informal carers are usually family members or friends who provide care without being paid. They may help with everyday tasks such as:

- transport to and from hospital appointments
- cooking meals and shopping
- household chores and management
- attending medical appointments for support
- managing medications
- offering emotional support.

These carers are often not trained health professionals but are essential to the person's care and wellbeing.

Formal carers

Formal carers are trained professionals who are paid to provide care. They may include nurses, personal care workers, allied health professionals or palliative care workers. Formal carers work with informal carers and the broader healthcare team to support the person's physical and emotional needs.

This resource is for informal carers.

UNDERSTANDING THE ROLES: CARER, FAMILY AND FRIEND

Ovarian cancer is too big for one or two people to face. Coping is often made easier with a support network. For some women, this may include the love and care of family and friends. For others, neighbours, professional care, peer support groups or community services play a vital role. However it is made up, every support network is important.

But sometimes family and friends don't realise just how important their love and support are. When someone is diagnosed with ovarian cancer, the people around them (partners, family members, friends) often need to step into different support roles. Some may become dedicated carers, helping with day-to-day responsibilities of the person's medical care. Others may only feel able to provide the stability and familiarity of their love, friendship and reassurance.

Whether you are helping with cooking meals, attending medical appointments with the person or simply making time to sit beside them to chat when they are feeling low, your support is valuable and makes a meaningful difference.

WHY THESE ROLES MATTER – YOUR IMPACT

You may worry that there is nothing you can do to help and afraid you might say or do something that will upset the person with ovarian cancer. While their situation may be beyond your control, what won't have changed is how much you matter to them. If you were an important part of their life before the diagnosis, you will most likely continue to be important to them now.

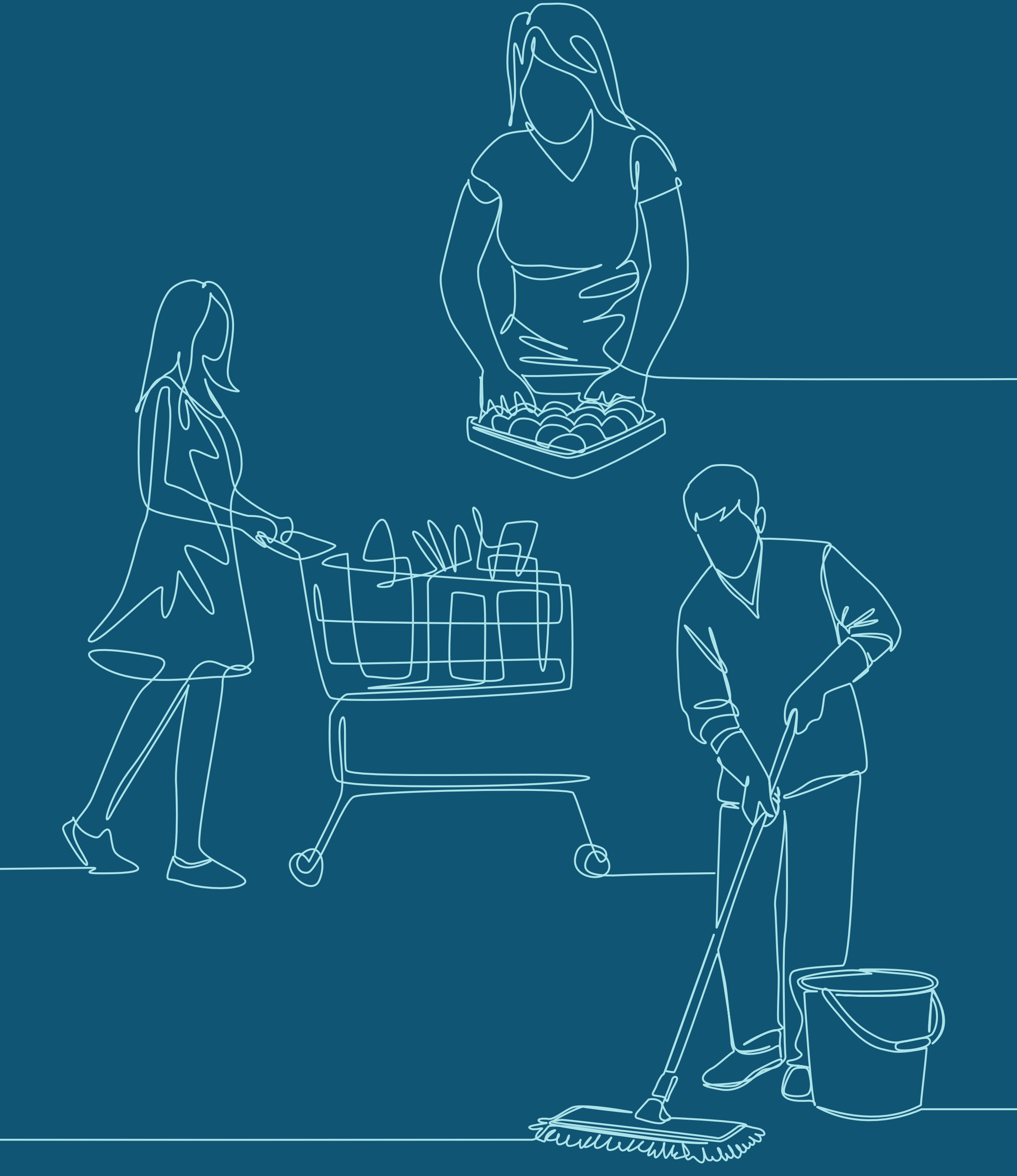
Carers, family and friends play a vital role in the wellbeing of someone with ovarian cancer. Most women with ovarian cancer will agree that their carers, family and friends are invaluable during diagnosis, treatment and beyond. Your presence can:

- ease fear and anxiety
- reduce feelings of isolation
- help the person feel more in control during a difficult time.

From attending appointments to sharing a quiet moment, your support can bring comfort, strength and hope. **You are an essential part of their care team and what you do truly matters.**

Ovarian cancer is too big for one or two people to face.

Every support network is important.



CHAPTER 1:
For primary carers

This chapter is for those providing regular or intensive care and support for someone with ovarian cancer.

The changing role of a carer

The role of the primary carer often changes depending on where the person is over the course of having cancer. At diagnosis, the carer's role may be focused on emotional support. However, this can evolve into more hands-on care and support during treatment and if someone's health declines. Being prepared for these changes, whether you are near or distant, can help carers adjust and gain the right support at each step of the way.

CARING FOR SOMEONE IN THE EARLY STAGES OF CANCER

Someone in the early stages of ovarian cancer often needs significant emotional support as they come to terms with their diagnosis, treatment and future. This can be a challenging time for many carers, who may also be providing vital practical help such as:

- transporting them to appointments
- listening in and taking notes during consultations
- managing meals and cleaning the house
- helping with the children and other family members.

Simply being a steady, reliable presence – a 'safe space' – can be incredibly reassuring for the person with cancer.

CARING FOR SOMEONE IN THE LATER STAGES OF CANCER

In later, more advanced stages of ovarian cancer, the carer's role often becomes much more involved. It may mean:

- managing medications
- assisting with hygiene care and mobility
- providing more care and support for children and other family members
- supporting the person through more complex physical or emotional needs.

It can also mean having to give up your work to become a full-time carer.

TYPES OF CARE (EMOTIONAL, PHYSICAL, PRACTICAL)

The caring role is often varied and involves being able to navigate, prioritise and start care for someone at the right time – when they are accepting of it and you feel willing and able to provide the care they need. It can be a bit of a tricky ‘dance’ at times as you try to ensure you are not overstepping or taking away someone’s independence at the wrong moment.

Emotional care

The emotional needs of someone with ovarian cancer will evolve and change throughout the time from diagnosis, through treatment and after treatment is over. At diagnosis, someone may feel shocked, angry, overwhelmed and frightened. As time goes on and they process more and start treatment, they may feel anxious, worried and sad. After treatment, they may feel very lost, lonely, fear the cancer coming back and grieve their previous life before cancer.

Having to move on in life after so much change can be isolating and difficult. Helping someone get through all these emotions can be rewarding but also exhausting at times. You have the challenge of wanting to be strong for the person you are caring for, while also dealing with your own emotional reaction.

It is normal to go through a period of adjustment where you may not be sure what to say or do. As you take in the news, you might feel a strong urge to reach out and offer support to the person who has been diagnosed. Often, what women find most valuable is not answers or explanations but simply having someone who can listen with empathy and be there alongside them. Your presence, understanding, and willingness to hear their concerns and uncertainty can make a huge difference.

Some relationships will become stronger through the challenges you both face. However, others drift apart, and it is important to allow people some independence and space if they need it. It may only be temporary but for some relationships it might be permanent.

Physical care

Physical care may include assisting them:

- with their mobility
- with their hygiene needs (e.g. standing nearby while they shower or, if they need more help, assisting them to shower)
- to get dressed
- to get in and out of bed.

It can also mean helping manage any physical side effects of the ovarian cancer and its treatment such as fatigue and pain. This may involve giving a massage or encouraging gentle exercise if appropriate. It may also mean assisting with medication and monitoring reactions and symptoms, or helping control incontinence of bowels or bladder.

Practical care

Practical care may include helping with daily household chores and maintaining daily routines, and managing life outside of treatment. For example, carers are often responsible for:

- driving to and from the medical appointments and treatment
- picking up prescriptions and managing medications
- cleaning, laundry and gardening
- cooking nutritious meals to cater to a changing appetite
- organising paperwork such as bills and helping facilitate access to legal help, for example, to organise Wills and powers of attorney
- coordinating family and friends' visits and communication
- diary keeping for appointments and treatments
- coordinating others helping support and the medical team.

All these tasks can greatly help ease the mental load for the person with cancer.

CARING FROM A DISTANCE

Not everyone who cares for a person with cancer can live close by. But you can still provide valuable care and support from a distance. Your role will be less hands-on but you can still provide important support by:

- regular phone or video calls
- helping coordinate medical appointments, or offering to listen in to a medical appointment via phone
- organising local support services (e.g. My Aged Care, cleaners, gardeners)
- assisting with paying bills or facilitating access to legal help.

Your role, even from a distance, can still be very meaningful and helpful.

How ovarian cancer may impact you as a carer

Caring for someone with ovarian cancer can be deeply emotional and at times overwhelming. You want to help but may not know how. If you're used to being in control, it can feel unsettling and frightening to realise you can't always 'fix things'. Even when you love the person dearly, caring can bring feelings of fatigue or burden. Recognising this doesn't mean you care less – it simply means you are human.

A diagnosis is usually followed by weeks of rapid decision-making, appointments, treatment and recovery. Both you and your loved one will be trying to take this in, and you may both feel flooded with emotions.

The main impacts for carers

Physical and emotional challenges

Identity and relationship changes

Medical issues

Work, study and money

PHYSICAL AND EMOTIONAL CHALLENGES

Caring can take a real toll on your mind and body. You may feel drained, especially if you're helping with tasks such as mobility or hygiene. Emotionally, sadness, anxiety, anger or loneliness are all common, particularly if you're sleep deprived or worried about finances and the future. You may even feel guilty for having these thoughts, but they are completely normal.

At times you may feel you have to be the strong one in the relationship, putting your own needs aside. Yet caring for yourself is just as important – it gives you the strength to better care for the person with cancer. Taking regular breaks, protecting your own wellbeing and seeking emotional support from people you trust are vital, not selfish. You can read more in 'Caring for yourself' later in this chapter.

IDENTITY AND RELATIONSHIP CHANGES

Becoming a carer to someone close to you often brings changes to your role and sense of identity. You may have to reduce your work hours or give up a job that once defined you. Even if you are still working, others may see you primarily as a 'carer', not the partner, child or parent you have always been. For intimate partners, the shift from an equal relationship to caregiver and patient can feel disorientating. For adult children caring for a parent, it can feel unnatural or even upsetting to reverse your familiar family roles.

These changes can affect your confidence and sense of self, and it is normal to feel uncertain or unsettled. You may grieve the relationship you once had, even while still wanting to stay close and help. Keeping the lines of communication open and allowing space to talk about what's changed for both of you can help maintain the necessary emotional connection and support.

“*I had to blend into the new reality, accept the situation and work within the parameters of my new world.*” **– Tom, a partner and carer**

If you are caring for your intimate partner, you may find it helpful to read 'Intimacy and sexuality', later in this chapter.

MEDICAL ISSUES

If the person you are caring for agrees or wants you to, you may also need to:

- monitor and record symptoms, treatment regimens and/or medications and their side effects for the person you are caring for, to report to medical staff
- organise medical appointments, scans and collection of medications
- attend all your loved one or partner's medical appointments with them
- navigate the healthcare system and advocate to ensure they are getting the best possible care
- develop your own medical knowledge around cancer and treatments.

> *"Getting into the habit early on with monitoring and recording information is so important and helpful right from diagnosis ... over weeks and months all the information blends in, so it's great to start this really early, having a buddy to be your extra ear."* **– A carer**

These responsibilities can occasionally feel heavy or exhausting, even when you genuinely want to help. You and the person you are caring for will need to decide what each of you feels comfortable taking responsibility for. Sometimes these tasks can feel like a full-time job and create emotional and financial stress, especially if you need to take leave or adjust your work commitments. The level of responsibility can change over time, depending on treatment and on how much the person you are caring for wants help versus maintaining independence.

WORK, STUDY AND MONEY

Having to take time off work or study during your caring role may be confronting and cause concern about your financial situation. Depending on your situation and employer, it can become difficult to maintain regular income. You may not have carers leave available, and you may wonder:

- How long will I be off work?
- How will we manage financially?
- Will my employer or study institute allow me to return when I am ready?
- What policies are in place for partners who take time off work to care for a loved one?

If the person you are caring for is your partner and isn't working, this may increase the financial impact for your family. You may have to face significant financial burdens. This is sometimes called 'financial toxicity' – the financial side effects of cancer. Some difficult choices might have to be made in your situation for the good of both partners.

For some people, continuing to work full or part time is good for financial and emotional reasons. Being at work will allow you to think about something other than your partner's health. It can help balance your emotional and mental health with that of your partner's. But this may not always be possible. All families' circumstances differ. For practical reasons you may not be able to make the choices you would otherwise hope to.

You may like to explore the following sources of help.

- The social worker at the hospital where the person is having treatment can advise if they are eligible for government financial assistance or help with transport costs. Local councils may also be helpful.
- A financial counsellor can help with managing finances. The National Debtline can help with free financial counselling (https://www.nationaldebtline.org/).
- You may be eligible for paid carers leave and/or Centrelink carer payments.
- You may be able to delay payment of some bills. Look into concessions, payment relief or rebates for people who are sick.
- Patients aged 65 and over should consider getting a My Aged Care assessment sooner rather than later, as they can take a long time to process.
- Your partner/loved one may be able to access some of their superannuation (early release of money). Or they may be eligible for disability or income protection insurance payments through their fund.

RESOURCES

- Cancer Council – 'Cancer and your finances' (booklet), cancercouncil.com.au; 'Superannuation and cancer' (booklet), cancer.org.au
- Ovarian Cancer Australia has a psychosocial team that can support and refer you to specialist financial and practical help and support. Call 1300 660 334, email support@ovariancancer.net.au or visit www.ovariancancer.net.au
- Cancer Council – 'Superannuation and cancer' (fact sheet), www.cancer.org.au/assets/pdf/superannuation-and-cancer
- Cancer Council – Legal, workplace and financial planning referral services, 13 11 20
- My Aged Care – If you need some help around the house or think it's time to look into aged care homes, My Aged Care is here to help, www.myagedcare.com.au
- Ask Izzy – connects people who are in crisis with the services they need right now and nearby, www.askizzy.org.au

Physical and emotional symptoms carers may experience

Research shows that caring for someone with cancer can be a major cause of burnout, and that carers often experience as much or even more stress, at times, than the patients themselves.

Carers' needs deserve to be recognised, validated and supported. This can happen through practical services, such as home-based support and respite services, as well as emotional support services, including psychology and counselling and support groups. Addressing your own needs can improve outcomes for the person you are caring for, including recovery from surgery and transitioning home from hospital. It can also improve your own wellbeing. See 'Further support and resources' at the end of this resource.

PHYSICAL SYMPTOMS

Caring for someone with ovarian cancer, particularly in advanced stages, can take a toll physically. You may not take any notice of these symptoms at first, as you are too busy providing care. However, it is important not to ignore your physical health during this time: if you become physically unwell, you will not be able to be the carer you want to be.

The following are some of the most common physical symptoms carers can experience, especially if you have been caring for a long time.

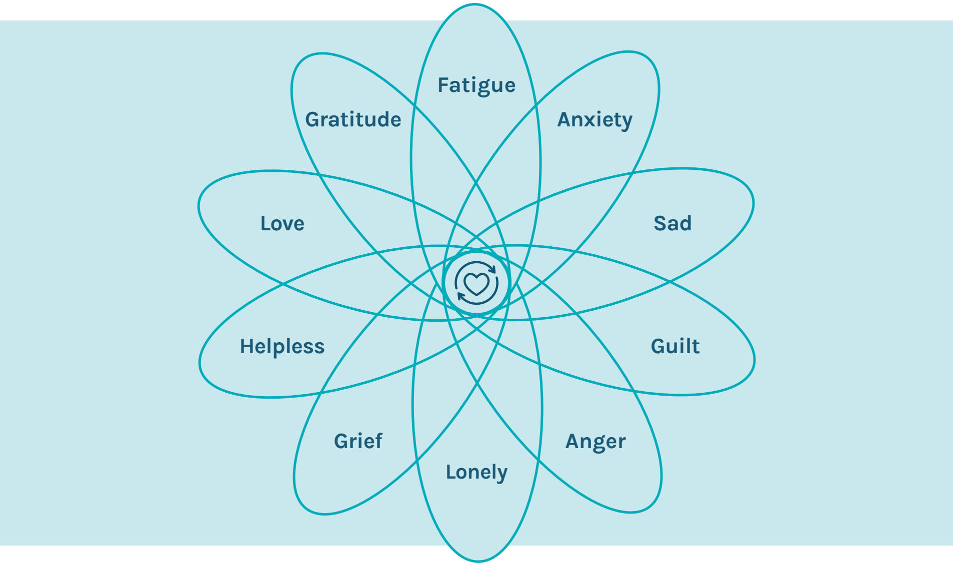
- **Fatigue or low energy**. This can be from disrupted sleep, emotional exhaustion, or simply from the physical demands of caregiving such as driving to appointments and taking a heavier workload in the house, cleaning or caring for children.
- **Sleep disturbances.** Worry, stress and night-time caregiving duties for the person who is unwell and/or children often lead to poor sleep.
- **Somatic symptoms.** These are physical symptoms that arise in your body often due to emotional and psychological factors. You may develop neck and shoulder pain, migraines, or gut issues such as diarrhoea, nausea and vomiting. Some people can have chest pain, feeling like your heart is racing, or shortness of breath, without any known heart or lung problems.
- **Lowered immunity.** Ongoing long-term stress can affect physical health, and this will increase your susceptibility to illness and infection.
- **Neglect of self-care.** Many carers skip meals, delay medical care, forget to take their own medications and/or stop their usual exercise routines. All of these things will put a strain on your physical health and wellbeing.

We explore some physical symptoms further in the next section about emotional symptoms, as they often overlap. Also see 'Caring for yourself' in this chapter.

EMOTIONAL SYMPTOMS

There's no 'right' way to feel when someone close to you has ovarian cancer. Many carers describe feeling emotionally overwhelmed. Your world may feel upside down. Your own mental health, relationships and ability to cope day to day can be deeply affected. You may be grieving the life you once had, or your plans for the future, even while doing your best to provide support. Some emotions can be distressing, while others may bring unexpected closeness, clarity or connection.

Emotional experiences carers often describe are discussed briefly in the following pages.



CARER EXHAUSTION, FATIGUE AND BURNOUT

Carer fatigue, also known as 'compassion fatigue' or 'caregiver burnout', is a state of physical, emotional and mental exhaustion that can often be experienced by those providing care for a loved one. This fatigue happens due to the ongoing demands and emotional toll of continuous caregiving. It can potentially impact the carer's wellbeing/health as well as the quality of care they are able to provide.

Carers often push their own needs aside until they reach physical or emotional exhaustion. This can be worsened by hospital visits, financial pressures, juggling family needs or constantly having to be so attentive and alert.

It may help to review your expectations of yourself and remember that you don't have to do everything perfectly or on your own. Pace yourself, ask for and accept help, and take time out to rest and relax where possible.

"How can I maintain a positive attitude when I am dealing with this illness, taking on more household duties, maintaining an income? It is hard but try to prioritise. Do the things that have to be done. And if you can't, they will have to wait until tomorrow." **– Tom, a partner and carer**

ANXIETY AND SADNESS

Many carers feel anxious and/or sad, especially when the future is uncertain or routines are constantly changing. You may feel you need to hide how you are coping, or don't want to burden others. Signs of depression can include:

- sleep or appetite changes
- mood swings, tearfulness or irritability
- withdrawing from people or activities
- loss of libido
- using alcohol or drugs to cope.

"You might find yourself with suicidal thoughts, but help is there, don't be a rock – seek help and do it early and regularly." **– Tom, a partner and carer**

GUILT

Maybe you think your own needs and feelings are not important in comparison to the person you are caring for. You might feel guilty that you don't have cancer or for needing a break, not being 'strong enough' or struggling to meet every situation or demand. Some people feel guilty for still wanting intimacy or space for themselves. Guilt is common and does not mean you are doing anything wrong. Remind yourself that you are doing a really good job!

ANGER AND RESENTMENT

You might feel resentful about how your life has changed, or angry at the situation. Perhaps your role in the relationship has shifted, or the person you are caring for doesn't acknowledge what you are going through too. Resentment can creep in, and it is natural to crave for life to be 'normal' again. In these times, take some space, even just a small break to process things and adjust.

“It can take time to understand your own moods and emotions; tiny things may make you short-tempered and snappy, particularly in work or social situations. Learn what your triggers are, acknowledge that exhaustion can make you reactive. It can be confusing for those around you, so it’s important to be self-aware and considerate, but also to forgive yourself in these moments.”
– Emma-Jane, a carer

Unresolved anger may appear as:

- less patience
- clenched jaw, fists or teeth grinding
- restlessness, agitation or obsessive thoughts
- yelling, pacing or using harsh words.

If you are noticing any of the above signs, feel free to reach out for support listed in ‘Further support and resources’ at the end of this resource.

“Take time out – even 10 minutes outdoors, recognise triggers and patterns – with emotional or physical feelings that occur at the time, then learn to pause for one minute before responding or reacting to a situation.”
– Emma-Jane, a carer

LONELINESS AND ISOLATION

Changes to your social, work or family life can leave you feeling cut off from others. Even when surrounded by people, you may feel that few truly understand what you are going through.

“Be proactive in getting out with friends for an hour or two to have a coffee or a drink, to play golf or simply walk, or do lunch somewhere. Being out with a couple of friends is very revitalising for your wellbeing.” **– Tom**

“Although I initially retired upon my partner’s diagnosis, I did eventually return to a part-time job. This has kept me in touch with my industry colleagues and helped me stay connected.” **– A carer**

ANTICIPATORY GRIEF – FEAR OF YOUR LOVED ONE DYING

Anticipatory grief is mourning that begins before a loved one has died, often when their condition worsens or prognosis is uncertain. You may feel sadness, guilt, fear or anger for imagining life without them, but these emotions reflect your love and the strain of preparing for possible loss.

Carers often try to 'be strong', but many find that sharing their fears, whether with a counsellor, support group, trusted friend or even their loved one, lessens feelings of isolation and brings closeness. Some carers also find it helpful to gently plan for the future, such as discussing wishes for care or making legal or financial plans. This does not mean giving up hope, but it can provide relief and free you to focus on the time you have now.

FEAR OF THE CANCER COMING BACK OR PROGRESSING

Many carers describe intense fear and uncertainty about their loved one's cancer coming back. This fear may surface around follow-up scans or anniversaries, or when your partner seems unwell. It can bring a deep sense of grief, helplessness or dread about the future, especially if the last round of treatment was long or difficult.

You might find yourself constantly on alert, watching your loved one closely for any changes that could indicate cancer recurrence or progression. It is a heightened watchfulness that is exhausting and stressful for anyone caring for someone with cancer. It is normal to also feel a sense of loss or lack of control, as so much about the future is uncertain.

You might find yourself questioning how you will cope if cancer returns, what treatment options exist or how your family will be affected. These questions are normal, but not all of them have answers and that uncertainty can feel overwhelming. Talking to a trusted person, GP or counsellor may help you manage this fear and keep it from taking over your daily life.

“*As my wife is on a two-year immunotherapy drug trial, I find that having the regular three-weekly oncologist's appointments and following drug treatments diarised gives me a target to aim for. The fear of recurrence is very real, but we will deal with it at the time if needed.*” **– A carer**

HELPLESSNESS WHEN THE CANCER CANNOT BE CURED

Finding out that the person you love has incurable cancer can be devastating, even if you suspected it might happen. You may feel completely helpless, overwhelmed by sadness, fear or uncertainty about what lies ahead. These feelings are completely normal and shared by many carers.

You might worry about how to support your loved one, what to say, or how to prepare for what is to come. There may be a sense of grief for the life you had envisioned together and anxiety about how you will manage emotionally and practically. These feelings can be incredibly intense, but you are not alone in them. Reaching out for support can make a big difference in how you cope and care.

Note: Your doctor can give you a general guide on how the cancer will progress. Try not to rely on survival statistics. And try to remain present and in the moment. Things may turn out differently than you expected.

LOVE, CONNECTION, GRATITUDE AND GROWTH

Despite the difficulties, many carers also describe many moments of unexpected joy, emotional closeness and deep connection. These don't get rid of the hard days but can help you get through them.

> *"It is important to touch on the beauty of caring: what caring does for you and your mindset, the honour of sharing something so uniquely personal, the conversations, the exchange of love, and the beautiful opportunity you have to recognise the preciousness of time."* **– Emma-Jane, a carer**

Carers speak of:

- stronger relationships and emotional intimacy
- an increase in mutual trust and loyalty
- moments of humour, relief or shared understanding
- a deeper sense of meaning, gratitude or purpose
- personal growth, patience and empathy.

Table 1: Resources to help carers with emotional and physical symptoms

Service	**Description and contact**
Ovarian Cancer Australia	Speak with an ovarian cancer nurse. Call 1300 660 334, Monday to Friday, 9 am to 5 pm. www.ovariancancer.net.au Resilience Kit – see section titled 'If your cancer won't go away' for palliative and end-of-life care support. www.ovariancancer.net.au 'Fear of recurrence' (booklet). Downloadable booklet for managing fear of cancer returning. www.ovariancancer.net.au/store/products/13/fear-of-recurrence-booklet Male Partners Program. Peer connection and tailored support for male carers and partners. www.ovariancancer.net.au National service offering free counselling, practical advice and support for carers. Call 1800 422 737, Monday to Friday, 8 am to 6 pm. www.carergateway.gov.au
Carer Advisory and Counselling Service	Refers carers to services and provides practical support. Call 1800 242 636.
Beyond Blue	Mental health support for anxiety and depression. Call 1300 22 4636 or visit www.beyondblue.org.au
Lifeline Australia	Crisis support and suicide prevention. Call 13 11 14. www.lifeline.org.au
Headspace	'Meditation for Anger'. Guided 10-day mindfulness program for managing anger (not specific to cancer). www.headspace.com/meditation/anger
Cancer Council	'Finding calm during cancer' (podcast). Search on www.cancercouncil.com.au
Cancer Council	'Caring for someone in their last months' (podcast). Information and support for carers during end-of-life care. Advanced cancer podcasts

Caring for yourself

WHY IT'S IMPORTANT

Caring for someone with ovarian cancer can be incredibly rewarding but can also sometimes be physically, emotionally and mentally draining. It is easy to focus all your energy on your loved one and put your own needs on hold. But remember that caring for yourself isn't selfish – it is necessary.

When you take care of your own wellbeing, you are much better able to support the person you care about. Looking after your own health, emotions and identity helps you stay balanced, especially through those really tough days.

QUESTIONS TO ASK YOURSELF

Often carers don't notice how much they have stopped caring for themselves. But you must keep 'you' on your radar. Some gentle daily check-ins with yourself might help such as asking yourself:

- Am I eating regularly?
- Am I eating nourishing food and drinking enough water?
- When was the last time I moved my body, did some exercise or went outside?
- Have I had time alone today, even for a few minutes?
- What parts of my life have I neglected and allowed to take a backseat lately?
- When did I last chat with a good friend?
- When did I last feel able to let someone know exactly how I was feeling?

- When did I last do something solely for me, like read a book, take a long bath, play sport, have a massage or watch a movie?
- How am I really feeling, both physically and emotionally?
- Do I feel energetic or flat?
- Am I feeling more worried or low in mood than usual?
- Am I sleeping more or less than usual?

Many of us find it difficult to understand our own needs, especially when caught up in caring for someone else. You don't need to be able to answer all these questions but simply asking them regularly can help you notice what is missing for you or what you might need right now.

On the next page we have pulled out some questions which you can use as a self check in. Please take the opportunity to reflect and write down any thoughts that come to mind. You can replicate this for the other prompting questions we have provided.

Questions to ask yourself

Am I eating nourishing food and drinking enough water?

When was the last time I moved my body, did some exercise or went outside?

What parts of my life have I neglected and allowed to take a backseat lately?

When did I last feel able to let someone know exactly how I was feeling?

How am I really feeling, both physically and emotionally?

TIPS: NUTRITION, EXERCISE, SLEEP

These areas are often overlooked, especially if you are stressed or juggling extra work and home tasks. Try not to place unnecessary pressure on yourself: no one manages to eat well or exercise perfectly all the time. But remind yourself that even small actions can make a difference. For example:

- Choose foods that nourish and comfort you – and remember, not every meal needs to be perfectly healthy or planned.
- Allow others to help by cooking meals for you.
- Keep lots of healthy snacks close by to grab when you feel unable to stop and cook (e.g. nuts, crackers, fruit, protein bars).
- Preparing meals in advance and freezing them when you have time is a great way to ensure you eat well. **Lotsa Helping Hands** (lotsahelpinghands.com).
- Stretch, walk around the block or just do some gardening for half an hour. Moving your body does not have to mean going to the gym or doing a full workout.
- Try to take time to wind down before you sleep. Sleep can be very difficult when you are stressed. Reading a book, having a bath or turning off all devices before you go to bed may give your body time to rest.

MAKING TIME FOR FUN AND REST

Remind yourself that is okay for you to still have some fun and downtime in your life. The person you are caring for will most likely also benefit from you feeling joyful or more rested. It can just be 10 minutes calling a friend for a laugh or meeting a friend for a coffee to lift your spirits. Watching a funny movie, doing something fun and spontaneous that will bring joy is also important when you can make time.

Doing these things with the person you are caring for helps to continue the relationship outside of the caring role.

COUNSELLING AND THERAPY

Many people worry that seeking professional help means they are weak or not coping well enough, but it is not a sign of failure. Reaching out to a counsellor or psychologist is a positive step, especially if you are having trouble coping or adjusting to change.

There are several types of therapy which carers have found helpful. For example, Cognitive Behaviour Therapy and Acceptance and Commitment Therapy are two therapy approaches which can help people manage feelings of overwhelm, stress and carer burnout.

Psychologists and counsellors use a mix of different approaches, so the most important thing is to find someone you feel you can trust and speak openly with. Your GP can be a good starting point for a referral. For further information read ‘Seeking further support’, later in this chapter.

YOUR SUPPORT CREWS

You may have a few close friends who act as your informal support crew – those who check in, provide meals, help with transport or do other tasks. It’s important this support works for both of you, including people you both trust. While you focus on caring, they can quietly watch out for your wellbeing, noticing changes you might miss. A simple *How are you going?* can remind you you’re not alone. They can step in when things get tough, help you notice small ‘wins’ and give you time to recharge.

If you don’t have a large support crew, look for help through support groups such as Ovarian Cancer Australia, Cancer Council carer groups or local palliative care services. Many councils offer carers’ morning teas or gatherings (search ‘carers morning tea’ online).

Let people help when they offer. If they don’t know how, suggest simple things: making a meal, taking your loved one to an appointment or sitting with them while you rest or go out. Accepting help isn’t a weakness – it means you’re human and loved. Those who help want to make life easier for you and your loved one.

GETTING A HELPING ROSTER IN PLACE

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 easy for some people to accept or ask for help.

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 carers 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 online tool that allows friends, family and colleagues to help others in need when and how they need help.

RECONNECTING WITH YOUR IDENTITY

Carers often say that it is easy to lose touch with the parts of themselves that are not the 'carer', for example, being a partner, friend, parent and colleague. You may also forget about your needs, passions and ideas.

Try to hold onto some things that matter to you, like a hobby, talking about something other than cancer or planning for the future. They can help give you strength and balance among the challenges you are facing.

HAVING YOUR OWN HEALTH ISSUES

Many carers may already have their own acute or chronic health concerns such as asthma, heart issues or diabetes. If you need daily medications, it is important to stick to this routine.

Having health concerns may put you more at risk of developing other issues or feeling more tired and unable to do certain things. Be kind to yourself and be sure to keep up your own medical appointments when they are needed. Try not to put off going to the doctor if you develop any abnormal symptoms or feelings.

Don’t forget to take care of yourself while you are taking care of others.

FINDING CALM WITHIN YOUR BODY

Being on high alert for the person with cancer often means we forget to find a moment of calm within ourselves. Strategies like meditation, mindfulness, yoga and breathing exercises can help relieve stress and reduce stimulation in the body.

RESOURCE

- Cancer Council Australia – Finding calm during cancer (podcast), search at www.cancercouncil.com.au

HOBBIES

Try to keep doing the things that you enjoy. If you don't have any hobbies, now could be a good time to think about finding one. Research shows that people who have hobbies are less likely to suffer low mood, anxiety and depression. Hobbies such as joining reputable online communities, woodwork, music, sport, cooking, gardening, painting, drawing, or watching movies can bring joy, freedom and achievement into your life. Many online platforms can facilitate digital hobbies, like Pinterest and design tools.

While caring for your partner, you may need to pause some hobbies, but it is important to have interests and conversations beyond their cancer. This can be a welcome break for both of you. Even if you can't be as involved as before, you can still stay connected by adjusting your role. For example:

- If you can't play sport or go to the gym at the moment, you might still enjoy watching sport with friends or following your team online.
- If you enjoyed volunteering, you could still stay connected by helping with occasional admin tasks from home.
- If you were part of a book club, you could still share what you are reading in a group chat and keep in touch with the reading group.

- If you no longer have the time and energy to cook and host dinner parties, you might still share recipes or do some meal swaps with friends.
- If you can no longer manage the garden, you could plant a few pots near windows and the back door or grow some cuttings to give to friends.
- If you can't perform with your music group/choir, you might still enjoy listening, sharing playlists, or supporting others in the group with song choices.

While these alternatives may not satisfy you as much as doing everything you love, they can help you stay connected.

Tips for daily life

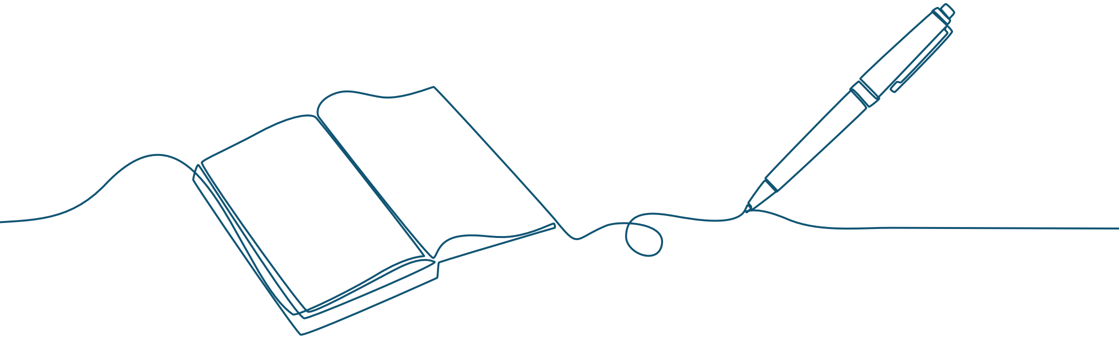
ORGANISING APPOINTMENTS AND TRANSPORT

As a carer, going to medical appointments can take over daily life, so staying organised can help lessen stress. Use a shared calendar or diary (digital or paper) to track appointments, treatments, test results, medications and symptoms. Plan transport in advance, whether driving, organising hospital transport or accepting help from others. If you attend appointments, help prepare questions, take notes and offer quiet support. Just being there can mean a lot.

MANAGING MEDICATIONS AND SIDE EFFECTS

Keeping track of medications can be overwhelming, especially if there are multiple prescriptions and changing dosages. Tools like pill boxes or Webster packs can make this much easier. Help monitor for side effects and encourage the person to talk about any symptoms they have with the medical team.

Carers often find it helpful to keep a logbook of any side effects and when they happen, to discuss with the medical team at appointments. Staying informed about what each medication does, and possible side effects, can also help you feel more confident and reassured in your role.



ACCEPTING HELP IN THE HOME

Accepting practical help at home with cooking, cleaning or shopping can make a big difference, especially on tough days and if fatigue is a major issue.

KEEPING NOTES AND COMMUNICATING WITH THE MEDICAL TEAM

Carers often play a major role in communicating with doctors, nurses and other healthcare professionals. Use a notebook or an app such as CancerAid (developed in Australia), Medisafe or CaringBridge to track symptoms, side effects, medication changes and test results.

Listening carefully and writing things down during appointments can also mean you and your loved one can review what was said later, especially when you are emotional and overwhelmed and it is easy to forget things. Add dates next to your notes so you can recall the timeline of events.

RELAYING INFORMATION TO OTHERS WITHOUT EXHAUSTING YOURSELF

It can be tiring to repeat medical updates over and over to family and friends. But it is understandable people want to be kept in the loop as they care.

Choose a method that works for you, whether it's a group text/WhatsApp group, a shared email update, or a private online journal or app, like **CaringBridge** (www.caringbridge.org) or **Gather My Crew** (www.gathermycrew.org).

It may also help if you and the person with cancer decide together who will take the lead in communicating, and how, so that it works for both of you. This way, you can keep close friends and family informed without completely wearing yourself out emotionally. And remember, it's okay to set some boundaries around when and how you update others. You need your energy, and you matter too.

> *"Initially, I started to keep family and close friends informed of my partner's progress/condition. However, I have found that I need to 'filter' the information to certain family members and friends. I find it easier to not give a detailed update unless it is absolutely necessary. This has relieved me of any unnecessary stress."* **– A carer**

Intimacy and sexuality if you are caring for your partner

Most couples experience changes in their relationship and roles when one partner is diagnosed with ovarian cancer. As a carer who is also a romantic or sexual partner, the impact can feel deeply personal and sometimes confusing. Whether you are in a heterosexual or same-sex relationship, you may notice changes in your partner's body image, feelings about sexuality, desire for sex, and how you communicate and experience intimacy.

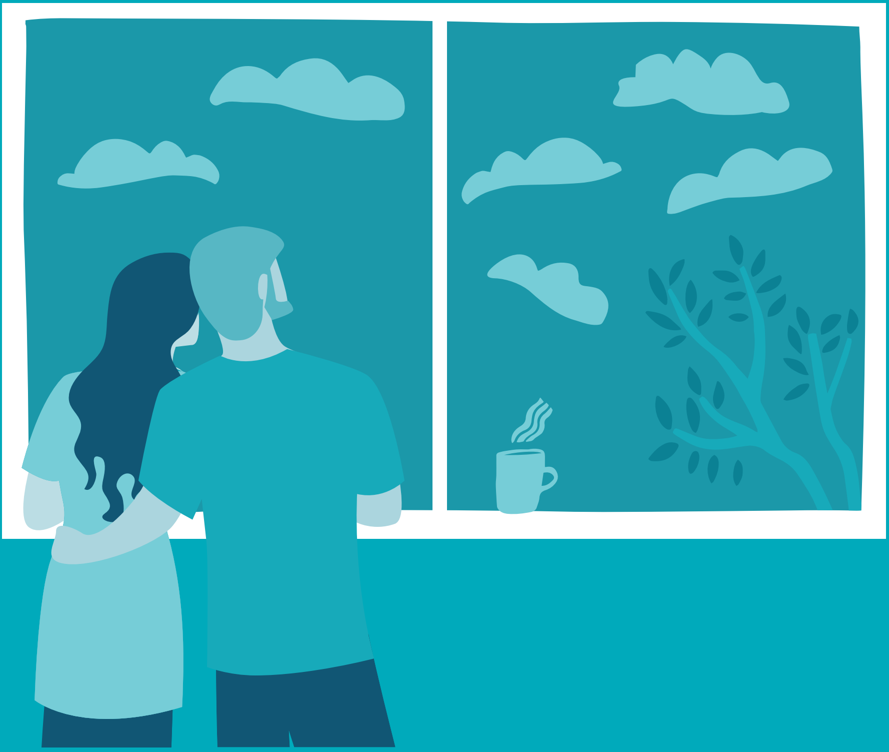
> “*The fear of my ‘new body’ and my relationship and the changes that happened in my body were the catalyst that kick-started me getting help. It is the sexual and bodily recovery, and I needed to unpack the emotional side of things as well as the physical.*” **– A woman with ovarian cancer**

Caring can be exhausting, and the pressures of home, work and shifting roles may leave little space for intimacy. You may feel your own needs are less important while your partner is undergoing treatment. Many partners worry that sex could cause pain or harm, but for both of you to feel supported, it's important to talk and renegotiate your relationship, including intimacy. There are ways to gently reshape and rekindle connection that respect your partner's changing body and your evolving relationship.

RESOURCE

- Ovarian Cancer Australia – ‘Sexuality, body image, relationships and ovarian cancer’. This resource explores these topics in depth and offers insight into how ovarian cancer can affect sexuality and intimacy, search at www.ovariancancer.net.au

Real intimacy isn't built in bedrooms, but in conversations where your raw thoughts, fears and truths are met with love, patience and a desire to understand.



WHAT SEX MEANS TO YOU BOTH MAY CHANGE, AND THAT'S OKAY

When most people think of sex, they often think of penetrative intercourse. But sex is much more than that. It's whatever brings you or your partner physical pleasure and emotional closeness. This might include touching, hugging, kissing, massage, snuggling, masturbating or using sex toys together or alone, or simply lying beside each other and talking (pillow talk). It's about connection.

UNDERSTANDING YOUR PARTNER'S CHALLENGES

Most people with ovarian cancer are not routinely asked about how treatment affects their sexuality, but many have said they would like to talk about it. They may want to rethink what sexuality means to them, and how they can still feel sensual, attractive or capable of enjoying intimacy, if and when they are ready. Cancer treatment can affect body image, self-esteem, sexual function and mood. Your partner might be experiencing:

- changes to their desire or interest in sex
- physical pain or discomfort during sex
- hormonal changes like vaginal dryness or menopause
- emotional effects such as anxiety or sadness about their body and what they have lost.

“*Every time I hop in the shower, get dressed or put on a dress, have to put on my hormone replacement patch – I am reminded of my surgery – which is every day.*” **– A woman with ovarian cancer**

“*My partner has been through it all with me and she has a really high sex drive, so we have had to work hard with this, but I am so lucky she is very patient.*” **– A woman with ovarian cancer**

Even after treatment, some of these effects can continue, especially if surgery or early menopause has happened.

“*We had to think more about being intimate and working out when it might be alright to be intimate. So, if I told Larry I am alright, he had to jump.*” **– Sue, a woman with ovarian cancer**

“*Visual stimulation is naturally a part of our sex life, and my partner and I can still use that, which is good as it's something her and I are both familiar with from before my diagnosis. So, we can bring this in without it being something forced or abnormal.*” **– A woman with ovarian cancer**

FAQS

Will I cause my partner pain?

It's normal to feel anxious about hurting your partner during sex. Painful sex (dyspareunia) can occur after surgery, menopause or with certain treatments. It's not your fault, and your partner may not always be able to predict how their body will respond. Try to talk openly, go slowly, and explore new ways of being close. Consider:

- using lubricants for dryness
- taking a warm bath beforehand
- planning a 'plan B' if pain arises (like cuddling or doing something relaxing together)
- seeking medical advice about pain relief or hormonal support.

Will we ever enjoy sex again?

Yes, many couples find a new way of enjoying intimacy. It might be different, but it can still be satisfying. Be patient with yourself and each other. It may take time and trial and error.

What if I feel less attracted to my partner now?

This can be confronting but try to reflect on where those feelings come from. Sometimes it's grief or fear. Sometimes it's seeing your partner in a medicalised or vulnerable way. Give yourself time. And don't hesitate to seek help if these feelings are persistent or distressing.

What if I feel guilty or too demanding?

Wanting physical closeness is not something to feel ashamed of. But always make sure your partner knows there's no pressure. Intimacy can be playful, gentle and pressure-free. Touch, flirtation, massage and pillow talk can be enough for now

What if I have my own sexual health issues?

Caring for someone else can mean putting your own health last. But stress, anxiety and exhaustion can also affect your own sexual function. If you are dealing with issues like low libido, erection or ejaculation problems, or simply confusion about how to navigate your own needs, consider speaking with a GP, sexologist or counsellor. Help is available for both of you.

COMMUNICATION AND SUPPORT

Being both a partner and a carer can make it hard to talk about your own needs. You might feel pressure to stay strong. You may or worry that raising intimacy or sexual concerns is selfish, yet your closeness and connection remain important.

Open, gentle communication with your partner, and when needed with health professionals, can help you share needs, support each other, and explore new ways to connect both physically and emotionally. You don't need to have all the answers. Just starting the conversation is what matters most.

If a face-to-face direct discussion feels difficult, maybe reading a resource together can guide you both and open up these conversations in a safe, supportive way.

RESOURCE

- Ovarian Cancer Australia – Sexuality, body image and relationships after ovarian cancer booklet has a section, 'Let's talk about erotica, sex toys and more', which you and your partner may find helpful to read together, search at www.ovariancancer.net.au.

EXPLORING PLEASURE

Intimacy doesn't have to mean penetrative sex. You and your partner can discover what feels good through touch, self-pleasure or sex toys. For more ideas and guidance, read Ovarian Cancer Australia's sexuality booklet.

CONNECTION BEYOND SEX

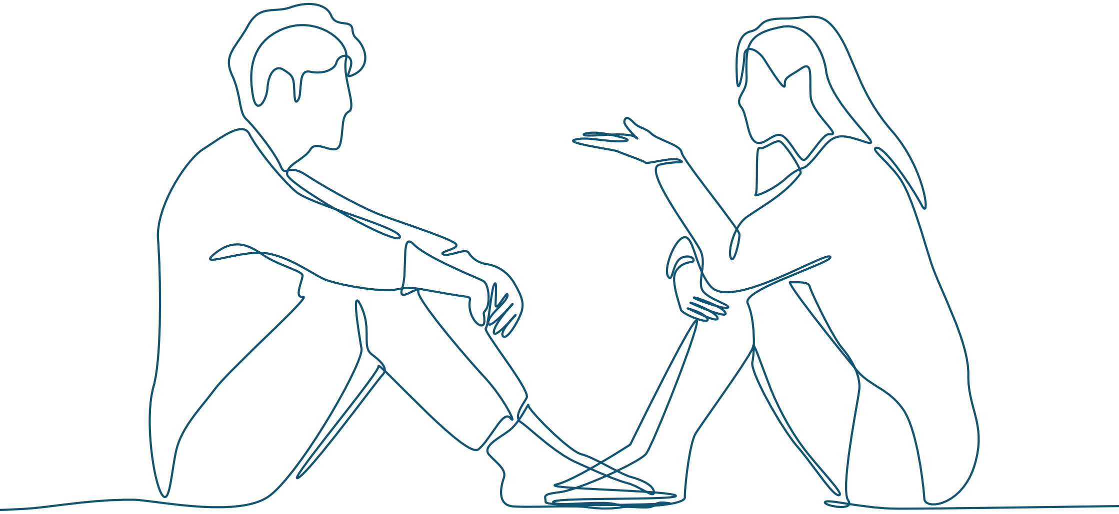
Remember: sex isn't the only form of intimacy. Emotional closeness through shared memories, touch, laughter or meaningful conversation can be just as powerful.

> "*Partners need strategies to support themselves and their own health.*"
> **– Sue, a woman with ovarian cancer**

Revisit what brought you together. Go on a date. Look at old photos. Give yourselves time and permission to rediscover each other in a new way.

RESOURCES

- Relationships Australia – for relationship and sexual counselling, www.relationships.org.au
- Society of Australian Sexologists – to find a sex therapist in your area, https://societyaustraliansexologists.org.au/



Practical issues

When you are supporting someone with ovarian cancer, you may face practical issues that you are unsure how to cope with. Managing your work or finances, or questions about Wills and advance care plans/directives are all common concerns. The following information will hopefully help guide you to navigate these issues more smoothly.

CARER'S ALLOWANCE

If you are providing daily care and support to someone with ovarian cancer, you may be eligible for a Carer Allowance or Carer Payment through Centrelink. 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.

A hospital social worker or GP can help guide you through the application process. You may also be entitled to a Health Care Card, which provides discounts on medicines, transport and other services.

To find out more and to apply for either allowance call Centrelink on 13 2717
or visit centrelink.gov.au.

Navigating Centrelink while caring for someone with ovarian cancer can feel overwhelming, stressful and confusing. Many carers have said they give up simply because they do not have the energy, time or understanding of the system to pursue it further. But we gently encourage you to keep trying, because these payments exist to support people like you and you are entitled to them. Explain to Centrelink your situation as best you can. You can go into a Centrelink office to seek help with the application process, which can be challenging. You can also ask the social worker at your loved one's cancer treatment centre or their GP for further help and guidance. You deserve the support, and it's okay to ask for it. If your application is refused, you are entitled to appeal it.

OUT-OF-POCKET COSTS

Even with Medicare or private health insurance, costs can quickly add up. Carers often cover expenses like petrol, parking, accommodation for medical appointments, home help or over-the-counter pharmacy supplements or other supplies. You may be able to claim certain costs or access concessions through your state or territory government. Services like Medicare and PBS Safety Nets can reduce long-term health expenses, and programs such as Angel Flight offer travel assistance if you live remotely.

RESOURCES

- Angel Flight – 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 angelflight.org.au
- Telstra Priority Assistance – 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 provider), 13 22 00
- National Debt Helpline – a not-for-profit service that helps people tackle their debt problems. They are not a lender and don't 'sell' anything or make money from you. Their professional financial counsellors offer a free, independent and confidential service, 1800 007 007
- Medicare and PBS Safety Nets, www.servicesaustralia.gov.au

ACCESSING SUPERANNUATION OR INSURANCE EARLY

If the person you are caring for has a serious or terminal illness, they may be able to access superannuation early or make a claim through income protection, trauma or life insurance. This may also apply to carers if their ability to work is affected.

Contact the relevant super fund or insurer to find out what's available. Super can often be accessed tax-free in cases of terminal illness, but specific paperwork is required. A financial counsellor or social worker can help you navigate the process.

RESOURCE

- Cancer Council – 'Cancer and your finances' (booklet), cancercouncil.com.au; 'Superannuation and cancer' (booklet), cancer.org.au; Legal, workplace and financial planning referral services , 13 11 20

NAVIGATING POWERS OF ATTORNEY OR GUARDIANSHIP

If your loved one is too unwell to manage financial or legal matters, they may choose to appoint someone they trust as a power of attorney or guardian. This ensures important decisions about their care, finances or living arrangements are made according to their wishes. It's best to have these conversations early and ensure legal documents are in place, in case your loved one later becomes unable make informed decisions.

ASSISTING WITH WILLS OR MEDICAL DECISION-MAKING

Although difficult, it's important to talk about your loved one's wishes for the future. This might include helping them write or update a will, prepare an advance care plan/directive, or appoint a medical decision-maker.

These legal processes can provide peace of mind for both the person with cancer and those close to them.

If you are unsure where to start, these people may be able to help:

- hospital social workers
- GPs
- palliative care teams.

See **Chapter 3: For everyone**, 'Advance care planning'.

Seeking further support

Life will be different following a diagnosis of ovarian cancer: the effects of the disease and its treatment present unique challenges. Caring for someone with ovarian cancer can be emotionally and physically demanding, and it's completely normal to need support.

FINDING SUPPORT

Many people and organisations can help make the journey a little easier. This might include talking with family or friends, joining a carers' group, or seeking professional help such as counselling or peer support. Support groups and online forums can provide friendship, inspiration and laughter, and other services can assist with finances, meals, childcare or household tasks.

Finding the right support can take time. You may only need it for a short period or may need it for longer. Don't give up if a particular counsellor or service doesn't feel right at first; try another one. What matters most is reaching out for the support you need.

Table 2: Professional support services for carers

General support services	
Ovarian Cancer Australia Helpline 1300 660 334 support@ovariancancer.net.au	Provides supports including being able to speak with a psychologist and a specialist ovarian cancer nurse.
Relationships Australia 1300 364 277 relationships.org.au	Offers relationship support services for individuals, families and communities. Local offices available across Australia.
Cancer Council 13 11 20	Provides free, confidential telephone information and support; can refer you to subsidised counselling with experienced cancer psychologists or social workers, either face-to-face or via phone.
Australian Psychological Society 1800 333 497 psychology.org.au	Offers a 'Find a psychologist' service to help locate someone with experience in the area you need, including grief, carer stress or cancer-related concerns.
Carer Gateway 1800 422 737 carergateway.gov.au	A national support service for carers, offering free counselling, coaching, peer support groups, and practical assistance like respite care and financial advice.
Palliative Care Australia palliativecare.org.au	Offers resources and support for carers involved in providing end-of-life care, including emotional and grief support.
For men	
Male Partners Program www.ovariancancer.net.au/page/219/male-partners-program	A program to support male partners of women with ovarian cancer.
MensLine Australia mensline.org.au	A free 24/7 national service offering phone and online counselling, support and referral for men facing relationship, mental health or carer-related challenges.
Australian Men's Shed Association 1300 550 009 mensshed.org	A safe, welcoming environment where men can connect, build things, learn skills and support each other. Over 500 sheds nationwide.

For same-sex couples	
The C Word 13 11 20	A telephone support group offered via the Cancer Council for same-sex-attracted women affected by cancer.
Q life www.qlife.org	Access free, anonymous LGBTIQ+ peer support via phone and webchat across Australia.
For Aboriginal and Torres Strait Islander people	
Yarn Safe 1800 650 890 headspace.org.au/yarn-safe/mental-health-and-wellbeing	Focuses on mental health and wellbeing and is part of the headspace network.
Yarn for Life yarnforlife.com.au	Offers useful resources for Aboriginal and Torres Strait Islander people.
Our Mob and Cancer 1800 022 222 www.ourmobandcancer.gov.au/	Developed for Aboriginal and Torres Strait Islander people by Aboriginal and Torres Strait Islander people. Find information about cancer and how to get support.
Other helpful options	
Lifeline 13 11 14 lifeline.org.au	24-hour crisis support and suicide prevention service. Offers support for anyone feeling overwhelmed, including carers.
GriefLine 1300 845 745 griefline.org.au	Offers support for grief, loss and loneliness, which many carers experience during and after a loved one's cancer journey.
Head to Health headtohealth.gov.au	A government-supported hub for digital mental health support, including resources tailored for carers and people under emotional stress.

CHAPTER 2:
For friends and family

This chapter is for those providing regular or intensive care and support for someone with ovarian cancer.

Being diagnosed with ovarian cancer is a difficult time for women and for their families and friends. Ovarian cancer is too big for one or two people to face. The best way for people to cope is within a support network. A crucial part of most women's support networks is the love and care provided by family and friends. But sometimes family and friends don't realise just how important their love and support are.

You may find yourself worried that there is nothing you can do to help and afraid you might say or do something that will upset your friend or loved one with cancer.

> *"A lot of my friends just didn't know what to say and didn't keep in touch in the hard times. This was an added stress for me."*
> **– Sandra, a woman with ovarian cancer**

> *"The support I received made me realise how lucky I was to have such a beautiful family and friends who made me feel so much stronger."*
> **– Caroline, a woman with ovarian cancer**

Understanding their needs

HOW CANCER CHANGES RELATIONSHIPS

When someone is diagnosed with ovarian cancer, it impacts everyone around them. It can feel like the rug has been pulled out from under everyone's feet. Quite a few things often have to change and shift.

Relationships may become closer, more fragile or simply different. Some people withdraw, unsure of what to say or do; others may find it helpful to be more open and chat. But remember, you don't have to have all or even any of the answers. Often the most meaningful support is simply being present. Many women say that being acknowledged, included and simply remembered made the biggest difference.

> “*Because you look well, people do not realise the pain inside – both physical and emotional – and sometimes they do not realise that you still need their support and love and help.*” **– Doreen, a woman with ovarian cancer**

ASKING HOW TO HELP, NOT ASSUMING

Everyone with ovarian cancer will have their own unique needs, both physically and emotionally. These needs will change over time and during the different stages of the illness – from diagnosis, through treatment and beyond. The most supportive people are those who take the time to ask, listen, and remain patient and flexible.

> “*It was best when people offered help and support that acknowledged my actual needs rather than assumed needs.*”
> **– Kristin, a woman with ovarian cancer**

> “*When friends asked: ‘What can we do?’ I felt overwhelmed; I already had so much to think about, and the question is so broad that I couldn't name what I needed.*” **– Emma-Jane, a carer**

Specific, practical offers such as dropping off a meal or offering transport to appointments/chemotherapy sessions can be much easier to respond to. Even just checking in with text messages not requiring an answer, like *I'm thinking of you* can be so reassuring and helpful.

It just removes the pressure for your friend/loved one to feel they need to answer you, especially if they feel physically and/or emotionally low in energy. A return emoji is often all they can manage but be reassured this will be a powerful acknowledgment of your care. There is nothing wrong with asking how someone is doing – it shows that you care.

RESPECTING BOUNDARIES AND TIMING

There will be times when the person with cancer does not want to talk about their cancer or may not even want company. This is very normal behaviour for someone going through cancer and its treatment and it is usually not rejection. It is just their way of coping. Respect their emotional space and let them guide when and how they want company or to talk.

“If your loved one does not want to talk about cancer today, it does not mean they won’t want to in the future. Listen to their cues and respect that they may want to come back to this in another conversation.” **– Rebecca, a carer**

FLEXIBILITY AND SUPPORT

Support can look different from day to day. One day you might have a deep and meaningful conversation with your friend/loved one and the next day all they want is some distraction.

“Going for a walk with me, taking me out of the house, just distracting me from my problems were good – and talking about things not cancer-related.”
– Vivian, a woman with ovarian cancer

Being flexible also means recognising that your friend/loved one is likely to still want to care about you, too.

“Just because someone has cancer doesn’t mean they don’t want to care back for you. They still want to provide their love and support and may feel guilty about the sacrifices you’re making. You have to let them care too – you’re still her daughter; she’s still your mum.” **– Emma-Jane, a carer**

It is important to respect their wish to give back to you when they can.

Practical ways to help

THOUGHTFUL GESTURES AND PRACTICAL SUPPORTS

Daily tasks can become overwhelming when someone is feeling unwell or exhausted from treatment. Help with cooking, cleaning, shopping or transport can lift a huge burden. It is often the small, thoughtful things, like changing sheets, vacuuming or taking the bin out, that make the biggest difference.

Being specific in your offer can help:

- *I'm going past the shops. Can I grab anything for you?*
- *I've got a free afternoon. Want me to do the school pickup?*

> “*What is helpful is when people make batches of food and drop it off, no questions asked. Nourished with intent.*” – **A carer**

Small acts of kindness, like a meal drop, foot massage or freshly painted nails, can make a difficult day much easier.

> “*A lovely friend brought up pedicure gear and gave me a foot massage and painted my toenails when I was having chemo.*”
> **– Sandra, a woman with ovarian cancer**

Even if you are not nearby, staying in touch matters. The key is to let them know you are there, while also giving them space if needed.

You may find it helpful to read the information on communication and what not to say and what might help – see **Chapter 3: For everyone**, ‘What not to say’.

HELPING OUT SO THE PRIMARY PARTNER/CARER GETS A BREAK

Partners are often the full-time carer, but not always. Whoever is in this role can carry a huge emotional and physical load. Giving them some of your time will allow them a little space to breathe and do something for them. Offer to sit with your friend or relative so their partner can take a walk, see a friend or just rest.

> “*While all the caring and support is given to my wife, sometimes my feelings and emotions are forgotten, but I am hurting too.*” **– Jim, a partner and carer**

“Spend time with them so that their partner can have time to themselves – to clear their mind, tinker in the shed, go in the yard.”
– A woman with ovarian cancer

“It is important to have time for self and maintaining identity outside of carer role. This also provides a release and something to look forward to. It also provides a sense of ‘anonymity’, a break from being seen only through the lens of cancer.”
– Peter, a partner and carer

SUPPORTING CHILDREN IN THE FAMILY

When a parent is diagnosed with cancer, it can have a big impact on the children in the family. They may feel confused, anxious or left out, especially if routines change or family members are very emotional. Family and friends can play an important role in helping children feel safe, supported and included during this time.

“I wanted to keep my children’s lives as normal as possible – everyone does. People I didn’t know well turned out to be a great help by regularly taking them to sports matches.” **– Sandra, a woman with ovarian cancer**

USING THE SAME LANGUAGE AS THE PARENTS

When supporting a family where a parent has cancer, follow the lead of the parent in how the situation is explained to children. Children are highly sensitive and pick up on emotional cues. Be consistent and clear. Use the same language and tone the parent is using to describe the situation to avoid confusion or distress.

If you are unsure how much the children know, gently ask the parent before discussing anything. Respecting their wishes helps maintain trust and supports the child’s sense of security.

OFFERING AGE-APPROPRIATE SUPPORT

If your friend has children, think about what you can do to help preserve the children's usual routine. Children and teens often struggle to understand what's happening, especially when their routines are disrupted. Offering practical help such as driving them to school, sporting or social occasions, helping them with their homework, or simply spending time with them playing or chatting can ease some of the strain on parents and the kids.

It can be helpful for children of all ages to speak with adults other than their parents about their mother's situation. Children might worry that expressing their fears will upset their parents and they may feel more comfortable sharing their concerns and questions with you. Teenagers may respond well to a special lunch out with you to allow them the freedom to express how they are feeling. What each child needs will vary by age, but a sense of security and normality is what is most important.

RESOURCES

- Cancer Council – 'Talking to kids about cancer' (booklet), 13 11 20, cancer.org.au
- Cancer Hub, 1800 431 312, https://cancerhub.org.au/
- CanTeen – an online service for young people whose lives have been affected by cancer, canteen.org.au

Staying connected

VIDEO CHATS, TEXTS, LETTERS, GROUP MESSAGES

Staying in touch with your friend or loved one with cancer, through a phone call, text message or video chat, can make a real difference to someone going through cancer and its treatment. Even if you feel unsure about what to say, simply letting the person know you are thinking of them can bring a whole lot of comfort. Short messages like *I'm thinking of you* or *No need to reply, just sending love* are quick, easy but meaningful ways to stay connected, especially when someone's energy or emotions are low.

Some people also find it helpful to have one trusted friend take on the job of passing on updates to everyone else in their friend and family circle. This means they don't have to keep repeating news.

> *"Disseminating and relaying medical information to other family members and close friends can take its toll ... do this in a brief way, and in a way which protects the carer ... from needing to answer further questions, from depleting their own energy levels."* ***– A carer***

SENDING CARE PACKAGES OR SMALL REMINDERS

Sending 'care packages', small cards or something handmade can be so uplifting to someone going through cancer and its treatment.

> *"My friend would give me a small brown paper bag which I wasn't allowed to open until I was in Chemo chair. The bag would have two things inside (a snack, a joke, lip balm, hand cream, word search, crystal for good luck, colouring book) – I loved getting those little bags."*
>
> **– A woman with ovarian cancer**

BEING HONEST ABOUT YOUR OWN AVAILABILITY

While you may want to help your friend or loved one, it is okay if you can't always be there. They will understand life is busy. If you are caring from a distance or have limited time, it does not make your support less meaningful.

Be upfront and honest about what you can and can't do to avoid disappointment or misunderstandings. For example, you could say, *I'm tied up this week, but I'd love to drop something off next Monday.*

Set clear expectations but still show how much you care. When friends and family are genuine and realistic about how much time they can give, it builds trust and gives carers and the person with cancer permission to be honest too.

LONG-DISTANCE SUPPORT STILL MATTERS

If you live far away, your role still matters. Video chats, scheduled calls, letters or surprise gifts are simple ways to stay involved. And you can still help to give the main carer/partner a break.

Schedule video chats or phone calls when appropriate. If the person with cancer is quite unwell or very tired, offer to do most of the talking or suggest you don't talk but that you both watch your favourite movie or TV show together on face time. Reassure the person that if they want to sleep while you watch, that is okay, too. This will just allow the carer to have some downtime knowing someone else is keeping an eye on things.

> “*Having a friend or relative contact me always left me feeling very loved.*”
> **– A woman with ovarian cancer**

SUPPORT IN HOSPITAL AND DURING CHEMO

- Stay in touch, especially when your friend is unwell or in hospital – a short text or quick call shows you care.
- If your friend has received lots of flowers, consider a book, fruit basket or something comforting.
- Before visiting, check if she needs anything brought from home.
- If your friend is up for company in hospital, offer quiet support – help with small tasks or just sit with a book while she rests.
- Bring light entertainment like music, books or magazines for days she's stuck at home.
- Note her chemo schedule and send a quick good-luck message before each session. This can mean a lot.
- If she's open to it, ask specific questions like *Any fevers this week?* or *How's the pain?* – but don't push if she's not in the mood.
- Offer to celebrate the end of treatment with cake, champagne and close friends.

Supporting a friend with cancer

Check in regularly, but let your friend set the pace and timing for contact.

Listen more than you talk as sometimes a quiet presence says the most.

Offer practical help, like meals or errands, instead of asking what they need.

Always ask before visiting, offering help, or sharing advice as consent matters.

Don't shy away from sadness or difficult emotions but take time to acknowledge them gently.

Keep including your friend in everyday life and conversations, even when plans need adjusting.

Your own emotions

It is natural to feel many emotions when someone you care about is diagnosed with ovarian cancer. Like them, you may feel grief, confusion, fear, anger or sadness.

Friends and extended family often describe feeling unsure where they fit in. You may care deeply but not always be included in day-to-day decisions, which can feel isolating and frustrating.

Sometimes you might also worry that your feelings don't matter as much as those of immediate family. But having someone close to you diagnosed with cancer touches everyone who loves the person. It is only natural to acknowledge your emotions and seek support if you need it. Talking to a trusted friend, your GP or a counsellor can help you work through feelings without adding to your loved one's concerns.

FEELING HELPLESS OR UNSURE

Many friends and family say that one of the hardest things is the sense of helplessness. Not knowing what to say, how to support in the best way, or whether your presence is even wanted or welcome. You may find yourself wondering if you are 'doing enough' or worrying you will say the 'wrong thing'. These thoughts are very common, especially when the person is in pain, has side effects from cancer treatment or is so tired they are not communicating as they normally would.

While you cannot take the cancer away, showing up with kindness, patience and a willingness to listen matters more than you might think. You don't need to have the right words or 'fix' things. Just being there or letting them know that you are thinking of them will make the world of difference. It's okay to say: *I don't know what to say, but I care*, or *I'm here and can be with you or leave you alone, just whatever you need.*

You may find it helpful to read the information on communication and what not to say in **Chapter 3: For everyone.**

FINDING YOUR ROLE

Many friends and family say it can be hard to know what their role is at first, and you may even think you need to stay away. You might not be in daily contact, or part of every hospital visit or medical decision, but your support still really matters. You may be the one who brings some laughter and lightness into an otherwise challenging situation. You might check in briefly each day, or quietly help behind the scenes with any chores, updates or just saying *Hi, I am still here if you need me.*

Your role will likely change as the person's treatment and emotional and physical needs change. Staying flexible and gently asking *Would it help if I did …?* can go a long way. Even small offers like this play a huge part in creating the strong support network your loved one needs to keep going.

LOOKING AFTER YOUR OWN WELLBEING

Supporting someone with cancer can be emotionally exhausting, even if you are not the main carer. It's easy to focus more on the person who's unwell than yourself. If you find you are always anxious, hypersensitive, having trouble sleeping or withdrawing from others, these could be signs that you need to pause and look after yourself too.

Make time for doing things that you know restore your energy, such as time in nature, connecting with friends, reading and moving your body. If you are overwhelmed by updates or questions from others, it's okay to step back or ask someone else to take over communications for a while. Taking care of your own mental health is not selfish and it is just part of ensuring you can continue to support someone else.

For further information about managing your emotions go to **Chapter 3: For everyone**, 'Processing your emotions'.

Navigating family dynamics

WHEN RELATIONSHIPS ARE STRAINED

It's not unusual for tensions to happen within families or friendship circles when someone close is diagnosed with cancer. Everyone is worried, trying to help, and coping in their own way and this can sometimes lead to misunderstandings or conflict. Being aware of these changes and recognising when things are becoming strained can help prevent unnecessary 'blow-ups'.

Try to give each other space, especially when emotions are running high. Respect that others may be feeling tired, upset or overwhelmed, even if they show it differently. Sometimes, stepping back and letting someone else take the lead for a while can ease pressure. In moments of tension, it's often better to take the attitude 'pause and say less'. Giving each other the benefit of the doubt and focusing on the common goals of caring for your loved one can help keep maintain and sometimes strengthen relationships through this challenging time.

Remember:

- We all cope with stress differently – some people get very practical, others emotional, angry, upset or withdrawn.
- Longstanding family issues might resurface under stress and may either worsen or soften.
- Encourage open, kind and appropriately timed communication when everyone is calm. Don't try to 'fix' things during the heat of the moment.
- If anyone in the family or friendship group is becoming aggressive, abusive or difficult to manage, seek professional help immediately.

OFFERING HELP WITHOUT PRESSURE

Ovarian cancer treatment can bring a whirlwind of appointments, medications and side effects, making it hard to ask for or accept help. Gently offering support without pressure or expectation can make a big difference. Try specific kind gestures like, *I'm free Monday afternoon if you need anything, or I'm taking my kids for ice cream so shall I collect your kids too? Mine would love that.* Even a quick text to say you can drop off groceries can mean a lot.

Some days your loved one may not want visitors, while others may just want quiet company or a simple reminder you are still there. Be patient if offers of help are not taken up straight away. Needs shift from day to day so just knowing you are a steady presence is often the best comfort. Continuing to show up with patience, flexibility and without expectations is one of the most powerful things you can do.

WHEN SOMEONE ELSE IS THE MAIN CARER

When someone else – such as a partner, adult child or close friend – is the main carer, it is important to respect their role, routines and the decisions they are making day to day. Even if your closest bond is with the person who has cancer, try to work alongside the main carer and think about how you can support them too. With permission, it may help to check in directly with the carer to ask what is needed or how best to help, without being pushy.

Offering gentle, practical support like helping with shopping, school runs providing meals, or simply checking in can be a big help to both the person with cancer and their carer. If you sense resistance or tension, it may be best to step back for a while and focus on staying connected with your loved one through regular messages or calls. Even from the sidelines, your care and presence can still make a difference.

Communicating as a family

Sharing medical updates respectfully

Sharing private medical information is sensitive so it is very important that the person with cancer is clear about who within the family they want to know what about their illness. Ask them what they feel comfortable sharing and with whom. Respect their decisions and try not to feel hurt if you have not been included in certain information.

A group family chat can be helpful if the person is comfortable with this. However, be sure to stick to the facts and avoid any 'drama' or 'speculation' about the person's illness and treatment. Respecting privacy helps maintain trust and prevents added stress.

Different coping styles

We all cope in different ways, and it is important to recognise and respect this with each other within the family, especially during challenging times. Some people cope by getting busy and being practical, others may want to talk things through, yet others may withdraw and become more emotional. It is important to let each other cope in their way without judgement. There is no one 'right way' to respond to someone you love being sick. Just allow people time to manage their own feelings. But if you feel you need further support you may benefit from seeing a professional counsellor. See 'Further support and resources' at the end of this resource.

Managing external noise: Social media and acquaintances

External friends and family may be well meaning but it can take its toll to constantly have everyone asking you questions, calling, texting or visiting. Some people may think they have all the answers and want to solve all your problems. This can become overwhelming and frustrating. Consider nominating one person to take control of communication, whether through group texts, emails or a private social media group, to protect the person with cancer (and the main carer) from unnecessary stress.

CHAPTER 3:
For everyone

This chapter includes information that will be helpful everyone: primary carers, as well as family and friends.

Communication

WHAT NOT TO SAY

We all know what it is like when we have something difficult going on in our lives and we hope others will understand, but then they say the wrong thing. People often struggle to find the right words when talking to someone with cancer. While intentions are usually kind, some comments can feel upsetting, minimising, dismissive or sometimes even patronising. It is okay not to know what to say and let others know this. Here are some things that women with ovarian cancer and their carers have said were unhelpful.

For the person with cancer:

- “Don’t worry, it’ll all be fine.”
- “You look great – are you sure you’re sick?”
- “At least it’s not [insert other cancer or scenario].”
- “My friend had cancer, and they were fine.”
- “It must have happened for a reason.”
- “Everything happens for a reason.”
- “You’re so strong – you’ve got this.”
- “Stay positive!”
- “Have you checked out ‘google’?”
- “You’re lucky it was caught early.”
- “You must be done now that chemo’s over.”
- “My aunty died of that.”
- “Have you tried this ‘miracle cure’ or ‘special diet’?”
- “I read something online that says ...”
- “You don’t look like you have cancer.”

For carers:

- “You must be exhausted; how do you cope?”
- “Don’t worry, I am sure she will be fine.”
- “You need to take better care of yourself.”
- “Let me know if you need anything [without follow-through].”
- “Are you sure you are doing the right thing?”
- “You don’t look like you are coping very well.”
- “When I was caring for my mother, I wouldn’t have done it that way.”
- “It may seem hard now, but I am sure things will get back to normal soon.”

WHAT MIGHT HELP – CONVERSATION STARTERS

Simple, short, open-ended questions that give the person control over what they share are often best. Some of these suggestions might work better in a text message than in person. But the idea is that short meaningful messages that can offer gentle connections without the pressure to respond are often the most helpful. For example:

“Would you like to talk about how things are going or is it not the right time?”

“That sounds really hard.”

“What you are going through is so tough so just know you have got so many people around who care about you and want to help.”

“I’m here if you ever feel like talking.”

“Happy just to sit with you or chat about whatever comes to mind.”

“I don’t know what to say, but I want you to know I’m here.”

“Can I take over updates to the rest of the family for you?”

“Thinking of you <3 no need to reply.”

“Is there anything you are finding especially hard right now?”

“I would love to drop off a meal but no need for me to come inside, what day would work best?”

“Want me to come by and sit with you, or maybe you prefer just being alone right now?”

“Is there something you have had to stop doing that I could make time for you to do again?”

“I know it is hard to accept help sometimes, but if I offer help, it means I have got time and really want to.”

WHEN IS SILENCE OKAY?

You don't always need to say something or fill the space. Just being present, whether that is in person or through a message, can be reassuring and powerful. Sometimes, sitting quietly beside someone, or simply saying, *I don't know what to say, but I'm here* is more meaningful than trying to fix things. Silence combined with empathy, at the right time, can be very comforting. And often just being present matters more than the perfect words.

AVOIDING OUTCOME COMPARISONS WITH OTHER CANCER STORIES

Everyone's experience with cancer is different. Sharing stories about others, especially those who 'beat it' or didn't, can create fear or pressure on the person with cancer. It is usually unintentional, but it is important to respect each person's individual situation. Don't offer comparisons, even if it is about others close to you and you think it might be reassuring.

DON'T HIJACK CONVERSATIONS

It is only natural to want to connect by sharing your own experiences but try not to shift the focus onto yourself. You might not even realise you are doing it. But be sure to let the person with cancer, or their carer, feel able to direct where the conversation will go. Try to actively listen and allow space for their emotions, even if it feels uncomfortable.

Avoid saying things like: "My aunt had cancer but sadly she died last year, and it was so sad, but you seem to be much better than she was."

Don't say things like: "Gosh, that is awful you are so sick, I know what you mean, I had really bad gastro last week and yes vomiting nonstop is a nightmare."

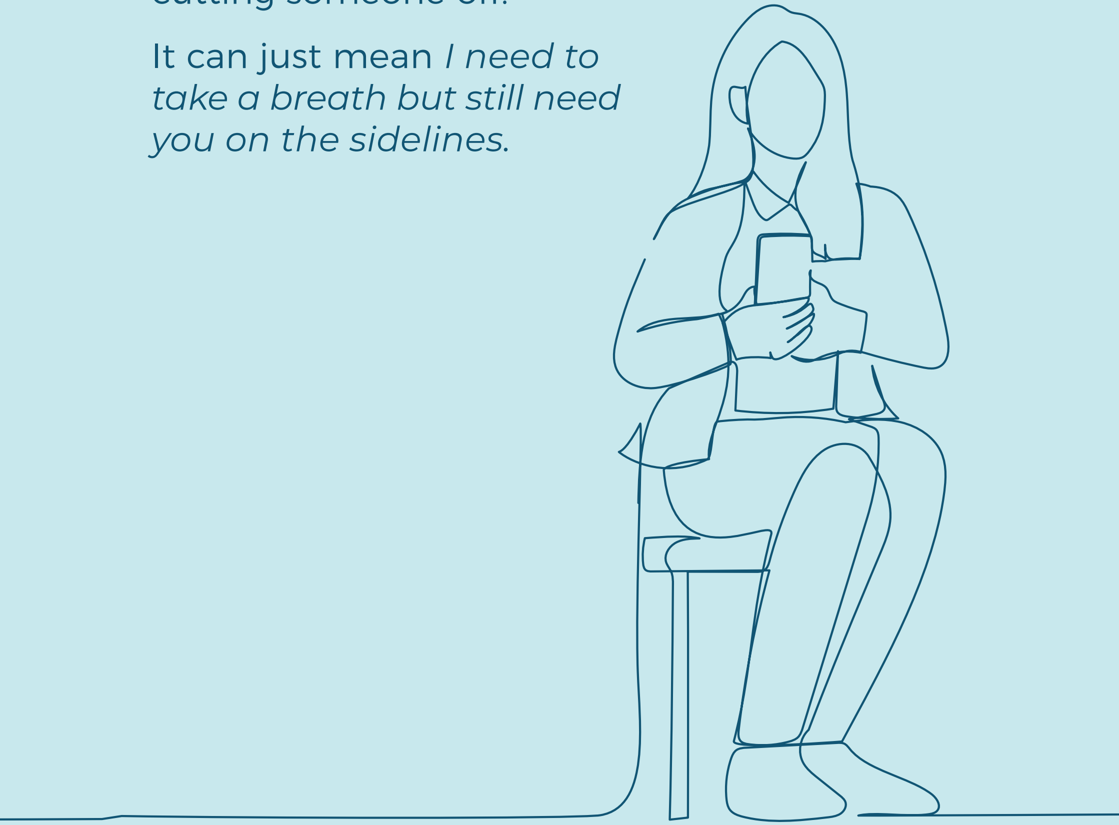
While you might feel you are truly letting the person know that you understand because you have firsthand knowledge, sometimes such comments can make them feel unheard or dismissed.

BEING AWARE OF EMOTIONAL FATIGUE

Be mindful of how and when you contact someone and what help you are offering. Sometimes the kindest and most supportive thing you can do is simply ask, *Would it help if I passed on updates to others?* or *Would you like some space today?* Space does not always mean cutting someone off and it can just mean *I need to take a breath but still need you on the sidelines please.*

Space does not always mean cutting someone off.

It can just mean *I need to take a breath but still need you on the sidelines.*



PROCESSING YOUR EMOTIONS

Whether you are caring for someone with ovarian cancer every day or supporting from the sidelines or afar, it's normal to have a wide range of emotions and sometimes they can come all at once.

Shock, fear, anger, sadness, guilt, loss and grief, hope, numbness and gratitude are all common feelings. Your feelings may shift from day to day or even hour to hour. The key is not to judge your reactions; be kind to yourself and give yourself permission to feel them.

Trying to stay strong and positive all the time is impossible for most people. Letting yourself sit with difficult feelings will also help you stay grounded during this challenging and uncertain time.

Carers have said that naming a strong emotion and being honest about how they feel can ease the stress. For example, *I feel overwhelmed today or I feel so helpless and sad*. Try gently asking yourself: What might help me right now? It could be something simple, like:

- a few minutes of rest or even taking a longer nap
- reaching out to a friend for support without judgement
- having some quiet time alone
- eating or drinking something nourishing
- sharing a moment of connection, or just a hug
- moving your body, even briefly, by taking a quiet walk
- distracting yourself by doing something you enjoy – watching TV, reading, journaling, listening to some music
- stepping away to take a few slow, deep breaths.

And remember: Everyone processes emotions differently. You might:

- cry
- feel empty
- feel differently to how you thought you might feel
- go silent
- get angry
- talk too much
- become clingy
- isolate yourself or become less social
- laugh inappropriately
- feel detached.

These are all valid ways of coping. However, signs to seek further help include:

- if things start to feel too heavy
- your emotions are interfering with daily life
- you are feeling angry all the time
- you think you might have depression and/or anxiety.

A GP, counsellor, psychologist or trusted friend can safely help you begin to process what is happening. Supporting and caring for someone with cancer is a lot to cope with, and nobody expects you to do it alone. Give yourself the same kindness and compassion you are offering the person you are supporting.

When you are going through a tough time you may look for ways to 'numb' the pain. You may be tempted to use drugs and alcohol as a way of doing this. However, they are addictive substances and often change your ability to think clearly and behave rationally. Avoid recreational drugs and consuming large quantities of alcohol as a way of coping as they will make you feel more anxious and can cause severe mental health issues.

RESOURCE

- Beyond Blue Alcohol and Mental health – 'The facts about drugs, alcohol and mental health issues', https://www.beyondblue.org.au/the-facts/drugs-alcohol-and-mental-health

Loss and grief

By Dr Oliver Holmes, Clinical Psychologist, Peter MacCallum Cancer Centre

Caring for someone with cancer presents complex emotional challenges, and this is especially the case when we talk about grief. Many people think of grief only in relation to death, but grief is a response we can have when we lose the things in life that are especially significant to us.

Not only can we grieve the loss of someone we love, but we can also grieve loss of home, time with others, future events or goals, financial security, parts of our identity and many other things. We can even grieve things that we haven't lost yet, in anticipation of a loss that we sense is coming.

There is no one process of grief that everyone goes through in the same way. Grief can bring sadness, frustration, anger, guilt, numbness and many other emotions. It can motivate us to act and move forward, or it can leave us feeling sapped of our energy. We can grieve before, during or after the loss, sometimes triggered by reminders of the loss, and sometimes seemingly out of nowhere. In short, the day-to-day experiences of grief can be unpredictable.

There tend to be two sides of grief: one where we feel and process the pain of our loss, and the other where we attend to the changes in life and do new things to move forward. Often people notice that they will swap back and forth between these two states as they live with their grief.

Allow yourself to experience both sides of grief as they arise. Here are some things that can help when you notice grief in yourself or others:

- Talk about the loss (e.g. couples impacted by cancer can share their grief together, speaking to friends or other people in a similar situation).
- Don't criticise yourself for how you feel (or what you don't feel).
- Allow yourself to cry and express your emotions.
- If helpful, organise breaks from work or usual duties.
- Talk with supportive people and ask for help if needed.
- Take care of your own health and basic needs.
- Try to stay connected with people you like and activities you enjoy.
- If your grief continues to disrupt your life or is difficult to cope with, seek support from a mental health professional or grief counsellor.

Many people find that their grief never completely goes away. However, people can grow around their grief and live meaningful and satisfying lives even with the loss they carry. If we learn to recognise, accept and respond to grief, we put ourselves in a better position to support ourselves and the ones we love as we face the challenge of loss in our lives.

Backwards and forwards with grief

Managing work and caregiving

Finding the right balance between your working and caring responsibilities can be quite tricky and exhausting. Many carers use personal leave, carers leave, or ask their employer to let them have flexible work hours or ask to work from home if appropriate, so that they can better manage their time and still work and care for their loved one.

Some workplaces may also offer additional support, such as **Employee Assistance Programs** (www.vic.gov.au/where-find-support-yourself-or-your-colleagues). If you are not sure of your rights, talk to your HR department or contact **Fair Work** (www.fairwork.gov.au/) or a **trade union** (https://www.actu.org.au/).

If the person you are caring for is unwell for a long time, it may impact your long-term work and career plans, so it might be worth considering getting advice from a financial adviser or **Centrelink** (www.servicesaustralia.gov.au/centrelink?context=1) sooner rather than later.

> “*Getting ovarian cancer is an expensive exercise – I found money just flew out the door like nobody’s business.*” **– Chris**

Advance care planning, palliative care and end-of-life care

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 future wishes for treatment, should you no longer be able to make your own decisions.

You may find it helpful to do an advance care plan together. Many couples / parents / children say it allows them to talk about difficult topics such as each other’s wishes during the palliative stage of an illness and end-of-life care.

> *“It can be very confronting to work through advance care planning and medical treatment decision-making. We used this fantastic website [https://www.myvalues.org.au/] to create a record of mum’s values: highly recommend.*” **Emma-Jane, a carer**

Palliative treatment is any treatment focusing on treating symptoms of the disease, rather than aiming to cure it. While palliative care is often involved near the end of a person’s life, it is of benefit for many people well before this and can be an important part of their treatment plan.

End-of-life care is care given to those who are near the end of life and who are no longer having treatment to cure or control their disease. End-of-life care includes physical, emotional, social and spiritual support for both the person with cancer and those close to them.

Guidelines and law around advance care planning differ for each state and territory. You can find more information about advance care planning in your state/territory online.

RESOURCE

- Advance Care Planning Australia, https://www.advancecareplanning.org.au/

Table 3: Resources for Wills, advance care planning and decision-making

Service	What they offer
Advance Care Planning Australia advancecareplanning.org.au	Info and forms for advance care directives and substitute decision-makers in every state/territory.
Palliative Care Australia palliativecare.org.au	Resources on advance care planning, end-of-life care and support services.
Cancer Council Australia cancer.org.au 13 11 20	Legal and financial support, including help with Wills, power of attorney and planning ahead.
ACT: ptg.act.gov.au NSW: tag.nsw.gov.au NT: justice.nt.gov.au (search 'advance care planning') QLD: pt.qld.gov.au SA: publictrustee.sa.gov.au TAS: publictrustee.tas.gov.au Vic: publicadvocate.vic.gov.au WA: publictrustee.wa.gov.au	Low-cost or free will-making, enduring powers of attorney and advance care planning support (state-based).
Office of the Public Advocate search 'Office of the Public Advocate' for your state/territory	Help with guardianship, medical treatment decisions and substitute decision-making. Varies by state.
My Aged Care myagedcare.gov.au 1800 200 422	Referral service for older Australians needing help with legal and advance care planning.

Relationships

A diagnosis of ovarian cancer can affect the way someone feels about themselves and their relationships with others. Intimacy may change both physically and emotionally, and it can take time to adapt. As a partner, family member or friend, your support, understanding and open communication can make a real difference.

INTIMACY

A diagnosis of ovarian cancer and the changes that follow can deeply affect a person's sense of self, their relationships and the way they connect with others.

Sexuality is not only about sex. It's also about how we feel in our bodies, our self-worth, our confidence and our emotional connection with others. Treatments like surgery, chemotherapy or menopause-related changes may lead to pain, fatigue, low self-esteem, changed levels of libido or body image concerns. These can sometimes strongly affect how someone feels about being close both physically and emotionally.

People may begin to avoid intimacy not because they have stopped caring, but because they are trying to navigate several emotions, physical discomfort, or simply they don't feel like themselves any more. One woman reflected:

> *“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! Maybe hugs and cuddles, but nothing more.”*
> **– May, a woman with ovarian cancer**

Caring relationships often grow on understanding and patience. Emotional and physical closeness may now be more about comfort, vulnerability, or even just sitting near each other quietly, but this can still be deeply meaningful.

INDEPENDENCE

A partner or family member may intuitively want to protect their loved one after a cancer diagnosis. But it's also important to respect their independence and support them in reconnecting with who they are as a person, not just a patient. Body image, confidence and identity are all deeply tied to intimacy and emotional wellbeing.

Encourage space for self-expression. Small things, like getting dressed up, going out socially or attending a Look Good Feel Better session, can help rebuild a sense of normalcy.

> *“I feel Look Good Feel Better is such an uplifting experience … it makes you feel attractive again. The effect it had on me after losing my hair was mind-blowing.”* **– Jan, a woman with ovarian cancer**

Supporting someone's sense of self rather than focusing solely on what they need help with can deepen your emotional bond. Ask how they'd like to be supported. Respect their pace, their preferences, and let them take the lead in when and how they want to talk, connect or be intimate. Relationships built on mutual respect, trust and empathy tend to thrive, even through the toughest times.

RESOURCES

- Ovarian Cancer Australia – ‘Sexuality, body image and relationships after ovarian cancer’ (booklet), ovariancancer.net.au
- Look Good Feel Better – free 2-hour workshops run in hospitals, cancer centres and online 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

Talking about death and dying

Facing the possibility that treatment may no longer be working is incredibly hard for the person with cancer and for the people who love them. There may come a time when ovarian cancer is no longer curable, but this doesn't mean that care and support stop. Palliative care focuses on improving comfort, quality of life and helping people live as fully as possible, often for many months or even years.

Having conversations about dying are deeply personal, and they can be naturally very difficult to start. But when someone wants to talk about what's ahead and the possibility of dying, being willing to listen, even when it's hard, can be one of the most meaningful ways that you can show your love and support.

> *"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, a woman with ovarian cancer**

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.

Also, not everyone is ready to talk about death and dying, including carers, friends and family. Many people struggle with these conversations and that is okay. Talking about these possibilities is deeply personal. Many people say that navigating these topics has meant they need to seek help from a psychologist or specialist grief counsellor.

NAVIGATING DIFFICULT CONVERSATIONS

When someone close to you brings up death and dying, it's normal to feel overwhelmed, scared, or unsure of what to say. You might be afraid of upsetting them, saying the wrong thing, or not having the answers. But remember these conversations are unlikely to ever feel good but being open and honest can help both people feel less scared or overwhelmed.

Let them set the pace. They might want to talk about fears, unfinished plans, or what matters most in the time ahead. Even if you don't have all the answers, simply being there, listening without judgement and acknowledging their feelings can be a huge comfort.

You might hear terms like ‘palliative care’ or ‘supportive care’. This kind of care is not about ‘giving up’ but it is more about comfort, symptom control and emotional support for the person with cancer and those caring for them. The palliative care team also supports family and carers, helping you prepare for what’s to come and enable you to care well for the person you love.

> “*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.*” **– Theresa, Palliative Care Health Professional**

SUPPORTING SOMEONE WHO WANTS TO TALK, AND YOU DON’T

Sometimes the person with cancer is ready to talk, but you are not. You might feel that talking about death is too painful, or that it means accepting something you are not ready for. These are natural feelings, and it is important you do not feel pressured to talk in this situation.

If this happens, try to be honest and gentle. You might say, *I’m finding it hard to talk about this, but I want to be here for you. Can we take it slowly?* Or suggest they might find it easier to speak with someone else like a professional counsellor, nurse, spiritual care worker or friend.

It’s also okay to take breaks during difficult conversations. But arrange to come back to finish the conversation, especially if the other person wants to continue. Supporting someone through the end stages of cancer and life is emotionally exhausting. Be sure to seek support for yourself too. You don’t have to carry it alone and most people can’t.

WHY PROFESSIONAL SUPPORT CAN HELP

Palliative care teams include doctors, nurses, counsellors, social workers and other specialists who can help both the person who is unwell and those close to them. They can help with symptom relief, emotional support, practical needs and even bereavement care after a loved one dies.

Professional support people can also guide you through difficult conversations, advance care planning (see earlier in this chapter) and understanding what to expect. Knowing there is a team trained specifically to support you can be very reassuring during a time that often feels uncertain, scary and deeply personal and emotional.

Myths and truths and social media

We thought it might be helpful to gently clear up a few common misunderstandings, so you can feel more confident and informed in your role as a carer, friend or family member. Knowing the facts and the difference between myths and truths can make a real difference, both to you and to the person you are supporting.

It is only natural to want to search online or join forums and social media groups for more information. These spaces can sometimes provide valuable information, comfort and connection, but they can also increase worry if the information is:

- inaccurate
- overwhelming
- irrelevant to your loved one's situation.

When you are supporting someone with cancer, false information can only add confusion, stress and guilt. Try to take notice of how much time you are spending online and how it makes you feel. If it leaves you more anxious or confused, it may help to step back, limit your scrolling and stick to trusted sources recommended by your loved one's health team.

Some reliable sources include:

- **Ovarian Cancer Australia** (www.ovariancancer.net.au)
- **Cancer Council** (www.cancer.org.au)
- **Cancer Institute NSW** (www.cancer.nsw.gov.au).

Table 4: Myths and truths about cancer

Myth	**Truth**
Treatment ends when chemotherapy or radiatiotherapy ends.	Recovery is often a lengthy process both emotionally and physically. Even when active treatment finishes, the side effects and fears about recurrence can persist long after.
Once treatment is over, life goes back to normal.	Life after cancer is often completely changed. People may face ongoing side effects, emotional trauma and a 'new normal' that can take time to adjust to.
The carer knows exactly what they are doing.	Most carers are learning as they go and may feel overwhelmed, unsure or isolated but may be scared to ask for help.
Friends and family should avoid talking about cancer, so they don't upset the person with cancer.	Most people appreciate you being open and having gentle conversations, especially if they can talk about how they are feeling. Avoidance can make people feel more alone and frightened.
There is nothing I can do to help.	Small, thoughtful actions such as texts, food drops or even listening can make a huge difference. Being present matters more than perfection and your friend, partner or relative will know when you are just trying to make things easier for them. They know everyone cannot get everything right all the time.
If they don't talk about it, they must be fine.	Many people with cancer choose not to share their full experience to protect others or because it's simply too exhausting. Silence doesn't always mean they are coping well.
Staying positive will cure cancer.	A hopeful outlook can help emotionally, but it won't cure your cancer. Suggesting otherwise can cause feelings of guilt and blame.
The best way to help is to take charge and make decisions.	Support is most helpful when it respects the person's choices and pace. It's better to offer gently and listen closely than to assume what they need.
If someone has family or a partner, they don't need outside help.	Even with loved ones nearby, support networks can become stretched. Friends and community can still play a very important role.
They should avoid talking about death or fears as it's too negative.	Talking openly about fears, including death, can be incredibly important for people with cancer. It can help them feel seen, heard and supported.

Further support and resources

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.

YOUR GP

Your GP is a great resource. You may have a long-term relationship with your GP that means their reassurance and input are extremely important to you.

It is a great idea to check in regularly with your GP, who can:

- manage any health issues you are experiencing
- advise on wellbeing and how you can manage your own health, including anxiety and depression
- advise on screening for health conditions, including cancer.

RESOURCES

- Ovarian Cancer Australia – 'Sexuality, body image and relationships after ovarian cancer' (booklet), ovariancancer.net.au
- Cancer Council – 'Talking to kids about cancer' (booklet), 13 11 20, cancer.org.au
- Cancer Council – 'Cancer care and your rights' (booklet), 13 11 20, cancer.org.au
- Cancer Council Helpline – for information about support services, 13 11 20
- Cancer Council – 'Cancer and your finances' (booklet), cancercouncil.com.au; 'Superannuation and cancer' (booklet), cancer.org.au; Legal, workplace and financial planning referral services, 13 11 20
- Ovarian Cancer Australia – Support Group for Carers, ovariancancer.net.au
- Cancer Council – 'Caring for someone with cancer' (booklet), cancer.org.au, 13 11 20
- Ovarian Cancer Australia – 'Family and friends' (Facebook group), facebook.com/groups/739541970853000

OTHER USEFUL CONTACTS

Table 5: Useful contacts for carers, friends and family

Group/organisation	Support provided
Carer Advisory and Counselling Service 1800 242 636	Offers referral to services and practical information to support carers in their role.
My Aged Care www.myagedcare.gov.au	The central access point for all aged care services in Australia.
Commonwealth Carer Respite Centres 1800 052 222	Provide information, advice and access to respite care across Australia.
Carer Card Search 'carer card program' in your state/territory	A discount and benefits card recognising carers.
Carer Gateway www.carergateway.gov.au 1800 422 737	A national support service for carers, offering free counselling, coaching, peer support groups and practical assistance like respite care and financial advice.
Carers Australia https://www.carersaustralia.com.au/	Works to improve the health, wellbeing, resilience and financial security of carers and to ensure that caring is a responsibility that's shared by family, community and government.
Working Carers www.cancer.org.au/assets/pdf/supporting-working-carers	Offers support for working carers: stories, factsheets, newsletters, chat room.
Healthshare www.healthshare.com.au	An online health network with forums and support for carers.
Cancer Hub https://cancerhub.org.au/ 1800 431 312	Helps families impacted by cancer (with children aged 0–25) more easily access the practical and emotional support they need.
Ovarian Cancer Australia – Male Partner Support Group & Booklet. Search 'male partner' at ovariancancer.net.au	Resources specifically for male partners of people with ovarian cancer.
Ovarian Cancer Australia Helpline Call 1300 660 334 or email support@ovariancancer.net.au	Speak with an Ovarian Cancer Support Nurse.
Ovarian Cancer Australia – Teal Support Program www.ovariancancer.net.au	A free telehealth service that supports women with ovarian cancer through diagnosis, treatment and beyond, focusing on continuity of care and unmet needs between medical appointments.
National Cancer Institute (US) www.cancer.gov	Information for carers, families and children/teens of people with cancer.
Cancer Council NSW – Carers Telephone Support Group 1300 755 632	Regular phone support groups for carers.

Glossary

Advance care directive	A written legal document that records a person's preferences for future healthcare, including treatments they would or would not want and who they appoint as their medical decision-maker. It comes into effect if the person becomes unable to communicate or make decisions for themselves.
Advance care planning	A process of thinking about and documenting a person's preferences for future health care, in case they are unable to make decisions for themselves. It often includes choosing a medical decision-maker and writing down wishes in an advance care directive.
Cancer	A disease where cells in the body grow in an uncontrolled way. Cancer can form tumours and sometimes spread to other parts of the body.
Carer	Someone who provides support to a person with an illness or disability. This might include physical care, emotional support or help with daily tasks.
Chemotherapy	A type of cancer treatment that uses drugs to destroy cancer cells or stop them from growing.
Counselling	A supportive, confidential conversation with a trained professional to help someone explore and manage emotional challenges. Counselling can help people cope with stress, grief, anxiety, relationship issues or the impact of illness.
Counsellor	A trained professional who provides counselling. Counsellors listen without judgement and help people explore their thoughts, feelings and concerns. They may offer tools and strategies to support emotional wellbeing but do not diagnose mental health conditions.
Diagnosis	The process of identifying a disease based on symptoms, tests and examinations.
Fatigue	Extreme tiredness or lack of energy that doesn't go away with rest. A common side effect of cancer and its treatment.
Hormone therapy	A treatment that blocks or lowers certain hormones that some cancers need to grow.

Intimacy	A sense of closeness and connection with another person. Intimacy can be emotional, physical or sexual, and may involve trust, affection, touch or shared experiences. It doesn't always involve sex.
Medical decision-maker	A person legally chosen to make healthcare decisions on someone's behalf if they become too unwell to speak for themselves. This person is often named in an advance care directive and should understand the person's values and wishes.
Metastasis (or metastatic cancer)	When cancer spreads from the original site to other parts of the body.
Ovarian cancer	Cancer that starts in the ovaries, which are part of the female reproductive system.
Palliative care	Specialised care that focuses on improving quality of life for people with serious illness, including managing symptoms and emotional support.
Prognosis	The expected outcome of a disease. It can include the chance of recovery or how the illness might progress.
Progression	When cancer grows, spreads or gets worse over time. Doctors may say the disease has progressed if it has increased in size, spread to new areas or become more advanced.
Sexuality	A person's feelings, desires and identity related to sex, attraction and relationships. It includes how someone sees themselves and how they express love and connection.
Side effects	Unwanted effects of treatment, such as fatigue, hair loss or nausea.
Stage	A way of describing how far cancer has spread in the body.
Supportive care	Services that help with the emotional, physical and practical challenges of living with cancer.
Surgery	An operation to remove cancer or part of the body affected by it. In ovarian cancer care this may be called a 'debulking procedure'.

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