OVARIAN CANCER AUSTRALIA

Fear of Cancer Recurrence and Cancer Progression

A guide for women with ovarian cancer and their families

OVARIAN CANCER AUSTRALIA

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Contents

‘No Woman Walks Alone’ by Tarsha Davis

Acknowledgement of Country

Ovarian Cancer Australia acknowledges the Traditional Custodians of the lands on which we live, work and provide support, including the Wurundjeri Woi Wurrung and Bunurong people of the Kulin Nation where this booklet was produced. We recognise their continuing connection to land, waters, skies and community.

We pay our respects to Elders, past and present and extend that respect to all Aboriginal and Torres Straight Islander Peoples, including those affected by cancer, their families and carers.

As an organisation committed to care, compassion, and equity, we honour the courage, resilience and enduring cultures of First Nations Peoples across Australia. We recognise the integral role of Country, culture, community, kinship, and tradition to health and wellbeing.

Created by proud Kuku Yalanji and Palawa artist Tarsha Davis, this commissioned artwork captures the strength, support and spirit at the heart of Ovarian Cancer Australia's vision that no woman walks alone. The winding teal path represents the complex journey following an ovarian cancer diagnosis, with Aboriginal symptoms of community reflecting the layers of care that surround each woman. At the centre, the U-shape represents the woman herself, encircled by her closest loved ones and the broader Ovarian Cancer Australia community. Patterns of Country and animal tracks woven throughout the artwork reflect the cultural belief that land, ancestors and spirit walk beside us, affirming that at every step of the journey, she is held, supported and never alone.

Introduction

One of the most common worries women have after finishing treatment for ovarian cancer is the fear of their cancer coming back. You may hear this called ‘fear of cancer recurrence’. For some women, particularly those living with ongoing disease, the fear may be more about the cancer progressing. This is called ‘fear of cancer progression’.

These fears are a natural and expected response and are shared by women living with any stage of ovarian cancer. While fear may sometimes help with problem-solving and taking positive action, sometimes the fear can be overwhelming and interfere with day-to-day life. This may make planning for the future difficult.

Many women say their fears change over time and may increase during periods of stress or change. While fear may not disappear completely, there are ways to lessen and manage it while living a meaningful life.

About this booklet

This resource is designed as a self-help guide and has workbook pages throughout. It offers information, strategies and reflections to help women understand and manage their fears and worry.

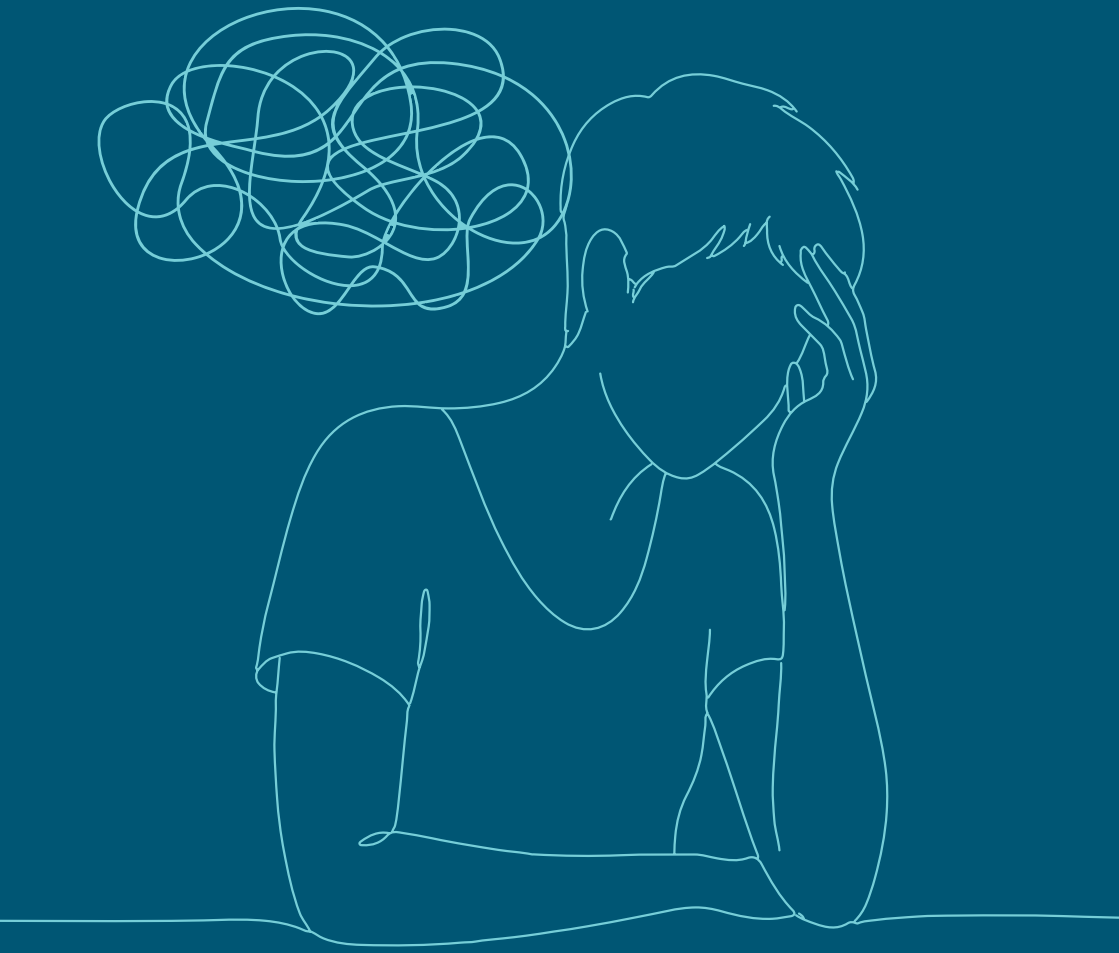
Throughout the booklet, there will be a small lightbulb icon to signal that this is a section to fill out or an exercise to try.

It includes:

- explanations of fear of recurrence and progression
- common causes of fear and worry
- psychological and practical strategies to manage fears
- ways to ask for support when fears feel overwhelming
- identifying values and what matters most for you
- space to acknowledge and manage fears relating to death and/or dying
- information for carers, family and friends
- how to find information online
- further support and resources.

If you have a cancer recurrence or progression, we encourage you to speak openly with your specialist healthcare team, including doctors and nurses. You can talk about your fears and concerns about future treatment options.

“We need to recognise how we communicate with our health professionals. Writing down and asking questions and expressing your fears so they can make you more comfortable in your appointments and help you.”
— Jennifer, woman with lived experience.



SECTION ONE:
Understanding fear of cancer recurrence and progression

What the terms mean

Fear of cancer recurrence refers to worry or concern that cancer may come back after treatment has finished. This fear may show up as:

- persistent thoughts about the cancer coming back or spreading
- being highly focused on bodily sensations or symptoms
- difficulty thinking about planning for the future
- feeling stuck in a cycle of worry.

Fear of cancer progression refers to worry or concern that cancer may:

- grow bigger
- spread to other parts of the body
- be spreading without any obvious symptoms
- become harder to treat or incurable.

These fears are often more noticeable for women living with persistent or advanced ovarian cancer, though they can happen at any stage. You may have concerns about:

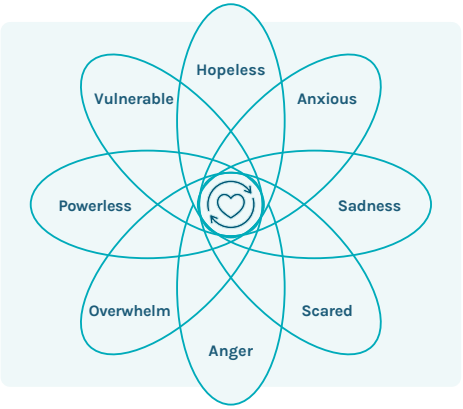
- treatment options
- the difficulty of living with symptoms ('symptom burden')
- a sense of loss of independence or control in your life
- uncertainty about the future
- being a burden to others
- fears about death or dying.

Research into **fear of cancer progression** is growing. This booklet is informed by women with lived experience of ovarian cancer and the health professionals caring for them.

How the terms are similar and different

Fear of cancer recurrence and **fear of progression** can both involve many emotions tied to grief, uncertainty and loss of control.

Commonly experienced emotions are shown on the right.



There are some differences.

- **Fear of cancer recurrence** is a fear that the cancer will return.
- **Fear of cancer progression** is fear about what lies ahead if the cancer continues to grow, changes or spreads. It may also involve fear that there may be no further treatment options.

Some women find one of these fears fits their experience more closely than the other, while many women relate to both.

Why fear makes sense

Both fears are common and understandable, given the impact of the cancer diagnosis, treatment and beyond. Fear and anxiety are part of the body's natural protection system. If we did not feel fear or anxiety, we would not recognise danger or respond to threats. After a cancer diagnosis, this fear can sometimes be helpful and prompt us to:

- ask questions
- seek support
- stay involved in our care.

Although fears may lessen over time, for some people, they can have a significant impact on day-to-day life. Even when treatment is successful, many women describe feeling uncertain and concerned about the future. Many also speak about a period after treatment when everything slows down and the reality of what has happened begins to sink in.

Considering all this, it is not surprising that many women find themselves asking questions like:

- What if my cancer comes back?
- How will I cope if it comes back?
- Is there treatment available if it returns or progresses?
- How will my children, partner, family or friends cope?
- If it comes back, will it be worse than last time?

These questions reflect the multiple worries that many women carry throughout their cancer experience. Unfortunately, not all questions about the future have clear answers. Uncertainty can leave you feeling anxious, scared, lonely, sad or helpless. You may find it difficult to manage thoughts about the cancer coming back or progressing or feel unsure about making plans in the future.

With time, support and strategies, it is possible to reduce fear and learn ways to live with, and alongside, uncertainty.

"You're living on adrenaline when diagnosed, initial treatment, surgery … after that, I noticed a postponed grief reaction. Everything slows down and that's when the fear creeps in. That's where the support is needed most." **— June, woman with lived experience**

Will your cancer come back or progress?

Thoughts about your cancer coming back or progressing can arise at many different points during treatment and follow-up care. How likely it is that cancer will return ('recur') or continue to grow ('progress') depends on several factors, including:

- the type of ovarian cancer
- its stage and grade
- the treatments you have already had
- factors specific to you (such as genetic make-up) and the treatment options available to you.

Every person's situation is different. Your cancer specialist can give you the most accurate information about your own situation and what this may mean for you.

"I am in a good spot at the moment as last month I reached the 10-year mark, and that is pretty good going for Stage III, so I am feeling most fortunate. Mind you, I still experience real fear when tests are due. One never really feels safe again." **— Jan, woman with lived experience**

How you may know if your cancer has come back

It is important to speak with your GP or cancer specialist if you develop symptoms such as:

- new or worsening pain
- unexplained weight loss
- persistent fatigue
- abdominal swelling or bloating
- changes in bowel or bladder habits
- other changes in your health.

Your medical team may investigate symptoms through:

- physical examination
- blood tests, such as CA125
- imaging tests, such as CT, PET and ultrasound.

Sometimes, women notice physical changes before any tests show a change. At other times, scans or blood tests may show changes even when you feel physically well.

Tell your doctor about any worrying symptoms. This is part of taking care of your health. It does not necessarily mean something serious is wrong.

It is important to know that for some women, the CA125 test result is not an accurate marker for confirming their cancer has come back.

Your specialist can also explain which symptoms to watch for, based on your own situation. It can help to write these down and be aware of any changes.

Responding to new or changing symptoms

Many women describe becoming very aware of physical sensations after a cancer diagnosis or treatment. A mild ache or pain can cause worry that the cancer has come back or is progressing.

Living with this anxiety can be exhausting. However, not every symptom means your cancer has returned or progressed. Many symptoms may relate to:

- treatment side effects
- other medical conditions
- everyday illnesses or infections
- normal daily activities or fatigue.

"I used to find it confronting when my specialist would say: 'I'll just send you for a scan to rule out …' But now I find it reassuring because if my doctor is vigilant and I do have a recurrence, it will be found early."
— Jenny, woman with lived experience

Managing fear of recurrence is about finding a balance – you don't have to react to everything urgently. But nor do you want to ignore important symptoms.

Types of fears and worries

When women worry about cancer coming back or progressing, they may experience many fears, including:

- coping with more treatment and possible side effects
- whether treatment will work
- needing to take time away from work, study or family life
- attending follow-up appointments or tests
- loss of independence or changes to daily life
- becoming a burden to people close to you
- fears about pain, suffering, death and/or dying.

Some fears, particularly those related to future treatment, loss of independence, or death and dying, may be more common when cancer progresses.

How strongly these fears are felt varies from person to person. Research shows that women may experience increased fear if they:

- are younger
- experienced significant treatment side effects such as pain and vomiting, and/or severe reactions to chemotherapy (anaphylaxis)
- feel isolated or have limited support
- feel they did not receive enough information about their cancer or treatment, especially about sexual changes
- had mental health problems, such as anxiety, depression and trauma, before their cancer diagnosis.

"It's different for different people. If you peel away all the fear, for me, it's really about pain, suffering, death, money, my job, my family."
— June, woman with lived experience

Common causes of fear and worry

Fear and worry can occur at any time. Many women notice that worry increases at certain times listed below.

Tick which triggers resonate with you:

- [ ] In the lead-up to follow-up appointments, scans or blood tests
- [ ] Anniversaries, such as the date of diagnosis or finishing treatment
- [ ] Birthdays, holidays or special events
- [ ] At times when distraction is often not possible, such as nighttime when trying to sleep
- [ ] Hearing personal stories about someone you know being diagnosed with or dying from cancer
- [ ] Hearing media stories about cancer
- [ ] Developing unexplained symptoms, such as headaches, abdominal pain or fatigue
- [ ] When starting something new, such as a job
- [ ] Experiencing long-term side effects from treatment
- [ ] Stressful life events, such as relationship changes, job loss, financial stress
- [ ] Add your own:

_____

"It is not always there on a daily basis but if cancer comes into the news or I am going back for a follow-up test or if I hear about a friend having cancer – then I start to worry about my cancer coming back."
— Jan, woman with lived experience

Key takeaways: Fear of cancer recurrence and progression

- **What it means: Recurrence** means the cancer returns after a period with no detectable disease. **Progression** means the cancer grows, spreads or becomes more active in the body.
- **Signs to watch for:** New, persistent or worsening symptoms. Changes in scans or blood tests (for example, CA125 for some women). But remember, not every symptom means recurrence or progression.
- **Responding:** Report new or worrying symptoms promptly to your GP or cancer specialist.
- **Emotional impact:** Feeling fear is normal and may increase around scans, appointments or new symptoms. If it affects your daily life, extra support and strategies can help.

When you might need extra support

While fear of recurrence or progression is common, it may be helpful to seek additional support if you notice any of the following.

- Worry consumes your day-to-day.
- You are often checking your body.
- You are looking for constant reassurance.
- You avoid or are afraid of going to medical appointments.
- You feel panic or distress between appointments.
- You have difficulties with sleep.
- You have difficulty functioning in daily life or making plans for the future.

Section two explores practical and psychological strategies to help you manage these fears.

“I wasn’t sure if I would make it to my 60th birthday after diagnosis and treatment but since then I have been able to celebrate 2 more birthdays – every day is a gift – value every day you have.”
— Jennifer, woman with lived experience

SECTION TWO:
Strategies to manage the fear

It may seem difficult to manage thoughts about the cancer coming back or progressing. With time and effort, many women say their fear reduces, allowing them to move forward and regain a sense of control over their life.

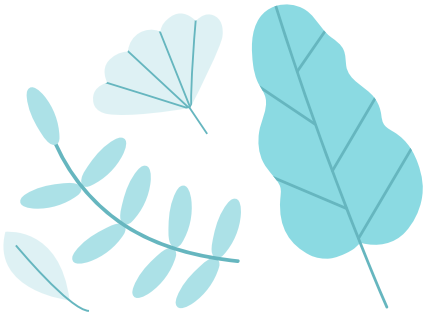
In this section, we offer practical and psychological strategies to manage your fears of recurrence and progression. If your anxiety persists and affects your day-to-day life, you may need further support. We cover this in **Section three**.

Managing unhelpful thoughts

Recent research has focused on ways to manage fears relating to recurrence and progression. Several strategies have been found to help women manage these worries, and these are covered in this section. These techniques will not get rid of your fears, but rather help you stop getting too caught up in always worrying about it.

Note: *A special thank you to researchers at the University of Sydney who helped to provide content for the sections on attention training, postponing worry and detached mindfulness.*

"I found it incredibly helpful to work out how mind and emotions are connected." **— Jenny, woman with lived experience**

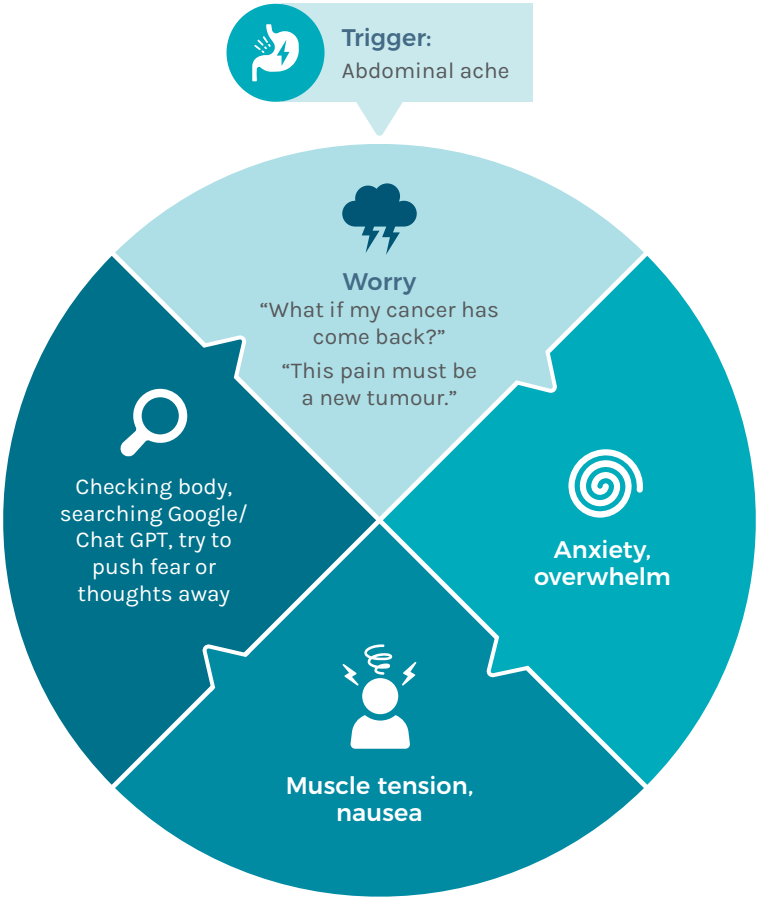


CHALLENGING UNHELPFUL THOUGHTS

The cycle of repeated worry

When fear increases, thoughts about cancer coming back or progressing may increase, leading to constant reassurance-seeking. You might find yourself:

- checking your body repeatedly for symptoms
- searching Google for answers
- asking others for confirmation that you are 'okay'
- booking extra GP or specialist appointments.



Noticing this cycle is the first step in gently stepping back from it and finding alternative, and more helpful, ways to manage.

While thoughts about cancer recurrence or progression are normal, when fear or anxiety is high, our mind can fall into predictable thinking traps that feel convincing but aren't always realistic or helpful.

Noticing and challenging these thinking traps can reduce the fear that comes along with our thoughts.

Tick off which thinking traps you resonate with:

☐ **Jumping to conclusions:**
- Am I making assumptions based on minimal information?
- What evidence do I have to support or not support this?

☐ **Catastrophising:**
- Am I assuming the worst-case scenario?
- What are some more likely explanations for what is happening?

☐ **'Should' and 'must' statements:**
- Am I putting pressure on myself by saying 'I should / have to / must …'
- Would I hold other people to the same standard?

☐ **Mental filter:**
- Am I focusing on the negative and 'threats' of a situation and ignoring the positives?
- Am I noticing only information that supports fear of recurrence?
- Am I focusing on one detail without zooming out on the whole picture?

☐ **Mind reading:**
- Am I mind reading and believing I know what others are thinking?

☐ **Emotional reasoning:**
- Am I assuming something is wrong because I feel fearful?

The following table gives examples of unhelpful thoughts, identifying the thinking trap, and suggests a more balanced thought.

When thinking of a more realistic, balanced thought, you might like to ask yourself:

- Can I identify any thinking traps from the list above?
- Is there another way to look at this situation?
- How would I comfort a friend who has similar thoughts?
- What is the evidence for and against my thought?

Practice log

Have a go at filling out the table with some of your own thoughts:

Date	Situation/trigger
16 / 6 / 26	Reading a social media post about recurrence

Unhelpful thought	Balanced thought
The cancer will come back, or progress, and I will never be able to cope with more treatment or pain.	I'm noticing my mind is catastrophising and jumping to the future. My doctor said the cancer might come back or progress. I got through it last time with support, and I can again.

Date	Situation/trigger
19 / 6 / 26	Headache

Unhelpful thought	Balanced thought
This headache must mean the cancer has come back and spread to my brain.	This is a "must" statement. I've had tension headaches before I had cancer. If it persists for a few days, I'll see my GP.

Date	Situation/trigger
/ /	

Unhelpful thought	Balanced thought

Date	Situation/trigger
/ /	

Unhelpful thought	Balanced thought

Date	Situation/trigger
/ /	

ATTENTION TRAINING TECHNIQUE

When someone feels anxious or stressed, they tend to direct their attention in particular ways. For example, they may repeatedly think about how awful or unfair their situation is. This sets up a cycle of self-focused attention, which increases worry, maintains low mood and promotes unhelpful behaviour, such as unnecessary GP visits. This may provide short-term relief, but in the long term, it keeps someone feeling under threat.

The attention training technique (ATT) helps to put your attention where you want to, rather than where it goes automatically. Practising ATT regularly can reduce a tendency to think repeated thoughts (rumination). It can shift your attention flexibly when unwanted thoughts about recurrence or progression arise.

It is recommended that you practise for 10–15 minutes, each day, for a month. It is like going to a 'gym' for your attention: the more you exercise your attentional muscles, the stronger they become.

"At first, I thought ATT was a bit weird, but the more I did it, the more I enjoyed feeling like I was in control over what I thought about, not my brain!" **— Susan, woman with lived experience.**

How to practise ATT

You can practise ATT by focusing your attention on different sounds around you. For example – Sit comfortably in a quiet space you like being in, then:

1. Focus on one sound (for example, a clock, traffic, birds) and keep your attention on it. After 30 seconds, switch your attention to a different sound.

2. Next, practise moving your attention quickly between sounds.

3. Finally, try to broaden your attention to notice and listen to several sounds all at once.

The aim is to practice controlling where your attention goes. Your mind may wander; simply acknowledge this and bring back focus to the target sound.

You may also find these guided audios at **Afternoon Break** helpful: https://www.youtube.com/@AfternoonBreak

Practice log

'Self-focus' is how much of your attention is focused inwards on your body, thoughts, and feelings.

How self-focused are you?
0 = no self-focus
10 = very self-focused

Date and duration of training (minutes)	Self-focus before training (0–10)	Self-focus after training (0–10)	Reflections
16 / 7 / 26 10 minutes	9/10	6/10	Easier to focus on one sound, need practice moving between sounds.
/ /			
/ /			

POSTPONING WORRY

It is common for people to try to avoid worrying about cancer coming back or progressing. However, these thoughts often return at times when we may have less distractions (such as night-time) or when hearing about other people's stories.

One way of dealing with this is to only allow yourself to focus on these worries at a particular time each day – create a 'worry time'. By learning to postpone your worry, it will:

- mean your worries are less intrusive
- help you to manage your worry effectively
- increase feelings of self-control.

For example, imagine you are at work and your mobile rings. You have the choice to answer it and disrupt your work or to let the caller leave a message and return the call later. It is about choosing *when* to think about things rather than responding to every thought as it appears.

Practise postponing your worry using the steps below.

My worry time

1. Create a worry period

Choose a time, place and duration (max 20 minutes, not within 2 hours of bedtime).

Time: _____ Place: _____ Duration: _____

2. Postpone your worry

When worries arise during the day, write them down and remind yourself you will focus on them later.

3. Return to worries during your worry time

Reflect on your worries in the planned time. Any remaining worries can be noted for the next session. Ask these 2 questions during your worry time:

Which worries are solvable?

If solvable, write down all the things you could do to address each worry.

Example: how long after treatment ends is my scan? → action plan: call nurse/doctor to confirm scan date and write into diary.

Which worries are unsolvable? Write them down here. If unsolvable, engage in mindfulness and relaxation exercises – refer to sections 'Detached mindfulness' and 'Finding calm in your body'.

Example: what will my scan results be?

At first, worry postponement may feel strange, but with time and practice, it can work. People are often surprised by how 'worry time' can contain their worries.

DETACHED MINDFULNESS

Detached mindfulness means being aware of your thoughts or feelings without judging, reacting to or suppressing them. It does not mean suppressing your thoughts, as this uses up a lot of energy and can make them return even more strongly. Try this thought suppression experiment to better understand how this might work:

For three minutes, try to avoid thinking about a blue giraffe. Don't allow yourself to have any thoughts about it, push it away. What did you notice? Did you think of a blue giraffe?

Now, let your mind roam freely for three minutes. If you have thoughts of a blue giraffe, watch them in a passive way as part of a landscape of thoughts, like watching clouds passing in the sky or waves at the beach. What do you notice?

As you might notice, actively trying not to think about these things only serves to increase thoughts about them. Detached mindfulness helps you to:

- become an observer and more mindful of your thoughts
- understand that the self is much greater than just the content of your thoughts
- see thoughts and feelings as passing internal events
- accept your thoughts and feelings without judgement or reaction.

The aim of detached mindfulness is not to get rid of worries about cancer recurrence or progression, which is likely to be impossible, but to help you become less caught up in them.

‘LEAVES ON A STREAM’ PRACTICE

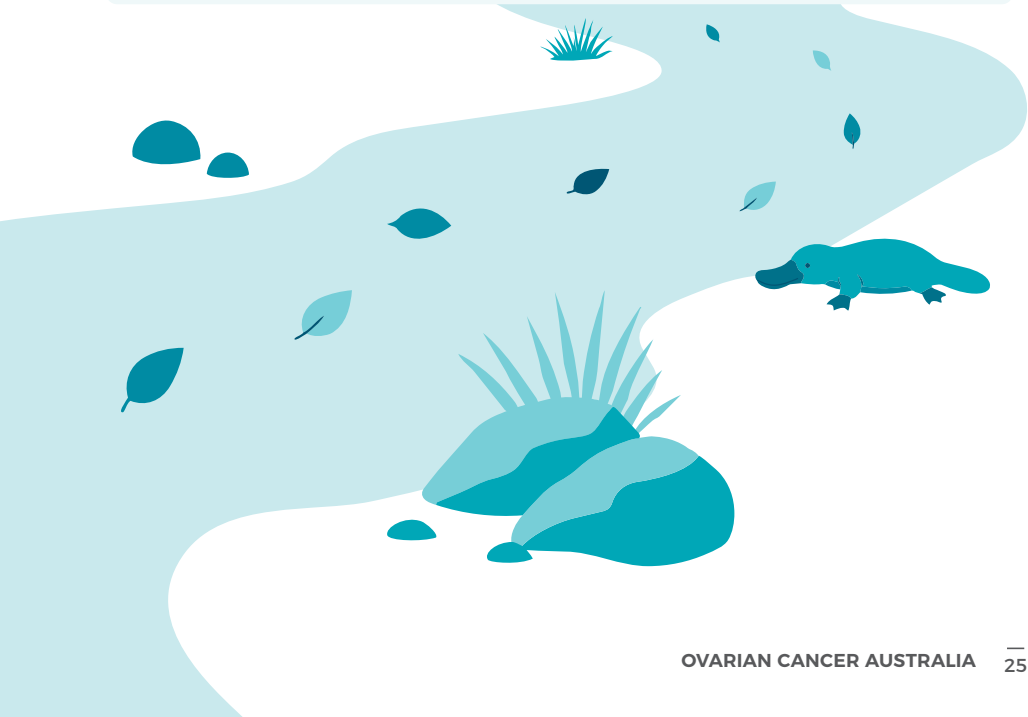
This exercise helps you notice your worries as thoughts, not facts. Instead of getting caught up in them, you imagine each worry as a leaf floating down a stream. You don’t need to push the leaves away or hold onto them – you just watch them come and go. Over time, this can help you feel less overwhelmed by your thoughts.

1. Imagine sitting in a comfortable position, next to a stream with leaves floating on the surface.

2. As worries come up, imagine putting them on each leaf.

3. Watch the leaves float further downstream, representing your thoughts coming and going.

Follow along with a leaves on a stream audio from **Cancer Council NSW**: https://podcasts.apple.com/au/podcast/meditation-03-leaves-on-a-stream/id1558621064?i=1000513186862



Practice log

Date and time	Strategy Used	Reflections
16 / 7 / 26	Detached mindfulness using imagery of thoughts as passing clouds	I resonated with imagery of clouds, easy to visualise. Felt less caught up in my thoughts afterwards.
/ /		
/ /		
/ /		
/ /		

Finding calm in your body

When living with fear of cancer recurrence or progression, your body may feel constantly on high alert and looking out for signs that something is wrong. This can lead to ongoing worry, muscle tension and feeling on edge.

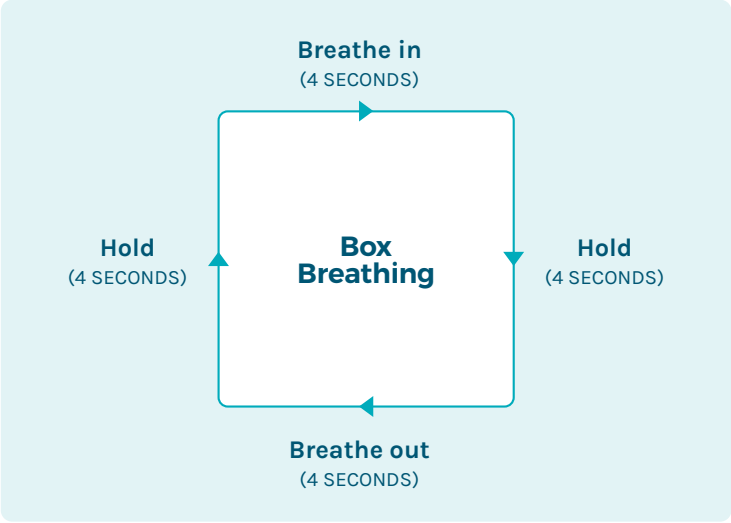
Relaxation strategies can help calm your body when stress or worry builds up. They won't take the fear away completely, but they can help you feel calmer and a little more in control when the fear and uncertainty show up.

BOX BREATHING

Box breathing helps to slow your breathing steadily, signaling to your body that you are safe.

1. Inhale through your nose for 4 seconds.
2. Holding your breath in for 4 seconds.
3. Exhale through your mouth for 4 seconds.
4. Hold for 4 seconds.
5. Repeat.

Tip: *Practice box breathing for approximately 2–5 minutes when you are not feeling fearful and/or anxious to help build up the skill. It will then be easier to implement when you need it.*



Grounding yourself

When fear or anxiety shows up, it often pulls attention into worry thoughts and catastrophic thinking. 'Dropping anchor' (or ACE) is a technique that helps to anchor or ground yourself in the present moment, creating space for fear, and reconnecting with what you can control right now.

A ACKNOWLEDGE THOUGHTS AND FEELINGS

Gently notice and name what is showing up, without trying to push it away.

- I'm noticing worry about my cancer coming back.
- I'm noticing my mind is going to the worst-case scenario again.
- I'm noticing anxiety in my chest.

C COME BACK INTO YOUR BODY

Anchor your attention into your physical sensations to ground yourself in the present moment.

- Press your feet into the floor – what does it feel like? Notice the contact.
- Feel your back against the chair.
- Gently stretch your hands and roll your shoulders.

E ENGAGE IN WHAT YOU ARE DOING

Refocus your attention on the activity you are doing. To re-orient yourself:

- Engage in your senses: What are 5 things you can see? 4 things you can hear? 3 things you can feel/touch? 2 things you can smell? 1 thing you can taste?
- Engage fully with your next activity or task at hand.

Tip: *For feelings of overwhelm, you may need to run through this exercise a few times. That is very normal.*

"Find 'dropping anchor' audios here: https://www.actmindfully.com.au/free-stuff/free-audio/

Practice log for relaxation

How relaxed are you? 0 = not relaxed 10 = completely relaxed

Date and activity	Feeling of relaxation before (out of 10)	Feeling of relaxation after (out of 10)
18 / 9 / 26 Box breathing for 3 minutes	2/10	6/10
/ /		
/ /		
/ /		
/ /		
/ /		

Communication is key to support

When you are living with the fear that cancer might come back or progress, talking with others can help you feel less alone. Sharing your concerns can also help the people around you – friends, family and health professionals – understand what you are going through and how they can support you.

It may not always feel easy or come naturally. But honest and open communication can make it easier to manage uncertainty and find the support you need during difficult times.

TALK ABOUT YOUR FEARS

Some people say they don't talk about their fears as they don't want to burden those close to them. But the people around you often want to help, even if they don't know how. Simply being heard can make a big difference – research has shown that not expressing your concerns about cancer coming back is associated with increased worry.

You may gain support from talking to:

- friends and family
- your doctors and nurses
- other women who have had ovarian cancer, such as a support group (online or face to face)
- psychologists and counsellors.

"You have to be an advocate for yourself – asking doctors what else is out there so you can link into your GP for a Mental Health Care Plan and pain management plans, or exercise program at the hospital."
— Jennifer, woman with lived experience

COMMUNICATING WITH YOUR HEALTHCARE TEAM

- Talk openly with your healthcare team about your fears, symptoms or concerns. There are no silly questions.
- If you are worried your treatment is not working, or notice any changes, let your team know so they can discuss next steps or treatment options with you.
- Consider bringing a family member or close friend to appointments to listen, take notes and support you.
- Your medical team or GP can also connect you with additional supports, such as psychologists or counsellors.

"A big issue for me is the uncertainty … but good communication with health professionals and seeing if they can help link you into other supports, like oncology psychologists, is really helpful." **— Victoria, woman with lived experience**

Questions that may be helpful to ask your doctor about cancer recurrence and progression:

- How likely is it that my cancer will come back or progress?
- Are there ways I can reduce the chance of my cancer returning or progressing? For example, will changes to my diet and exercise help?
- What symptoms should I look out for?
- What warning signs are urgent and need immediate attention?
- How do I know if new symptoms are related to my cancer or something else?
- Who do I contact if I have worries about recurrence or progression?
- Are there follow-up tests or scans I should have regularly? How often?
- What should I do if I feel anxious or panicked about my health between appointments?
- Are there support groups or counselling services for people worried about cancer returning or getting worse?
- Are there clinical trials I might be eligible for?

Add your questions

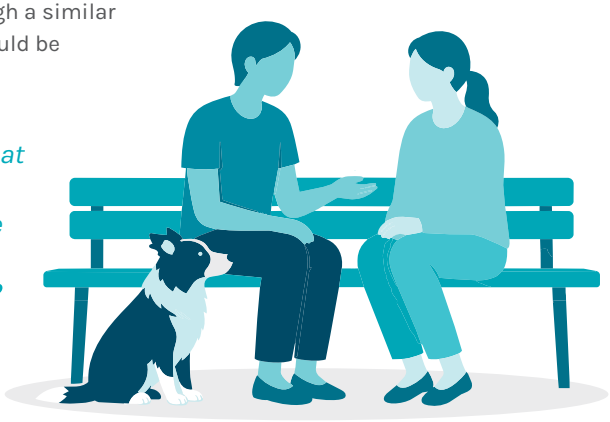
- _____
- _____
- _____
- _____
- _____
- _____
- _____

"Physical exercise helped my mental health. My chemo group exercise class really helped me to reduce overthinking, my fears and my worries." **— June, woman with lived experience**

COMMUNICATING WITH FAMILY AND FRIENDS

- Sharing with trusted family members or friends how you are feeling can help them better understand what you are going through.
- You may find it helpful to tell them what kind of support you need, such as someone to listen, practical help, or simply spending time together without talking about cancer.
- Everyone communicates differently, so finding what feels right for you is what matters most.
- Connect with people going through a similar experience if you feel like this would be helpful, such as support groups.

"Don't be isolated in this – chat to other women who have had a similar experience as no-one else quite understands it like they will. This is such a relief."
— Jan, woman with lived experience



What matters most for you

When faced with a serious health challenge like ovarian cancer, it can make you pause and think about what matters to you and how you want to spend your time. Living with the fear that your cancer might come back or progress can make life feel uncertain, making it harder to focus on what is important to you.

Your values are the things that matter most to you: how you want to care for yourself, your loved ones and the life you live. Everyone's values are different, and there are no right or wrong ones. When you understand your values, you can make choices and take actions that bring more meaning to your life.

PRACTICE: IDENTIFYING YOUR VALUES AND SETTING GOALS

Step 1 Choose one area of your life:

- Relationships
- Leisure/hobbies
- Personal growth
- Work (paid or unpaid)

Step 2 Choose your top 3 values from the list on **page 35** for this area of your life.
Tip: *First narrow down to 10, then 5, and then 3.*

Step 3. How much are you currently living by these values, out of 10?

Circle: 0 1 2 3 4 5 6 7 8 9 10

Step 4. Set a goal: Choose one value above. What is one small, specific action you can do to help you move towards living by this value?
Prompts: "I will [insert goal] because I value [insert value]" or "I will [insert goal] in order to live by/honour/act on my value for [insert value]."

EXAMPLE

Area of life: Leisure

Values:

1. Creativity
2. Mindfulness
3. Courage

How much am I living by these values?

Circle: 0 1 2 3 4 5 (6) 7 8 9 10

Goal: I will practice crocheting for 15 minutes each afternoon to honour my value of creativity.

Your values and goals

Area of life: _____

Values:

1. _____

2. _____

3. _____

How much am I living by these values?

Circle: 0 1 2 3 4 5 6 7 8 9 10

Goal: _____

_____

Area of life: _____

Values:

1. _____

2. _____

3. _____

How much am I living by these values?

Circle: 0 1 2 3 4 5 6 7 8 9 10

Goal: _____

_____

List of Values

Acceptance
Adventure
Assertiveness
Authenticity
Caring/Self-care
Commitment
Compassion
Cooperation
Connection
Courage
Creativity
Curiosity
Encouragement
Engagement
Fairness
Flexibility
Friendliness
Forgiveness
Generosity
Gratitude
Honesty
Hopefulness
Humility
Humour
Independence
Kindness
Love
Mindfulness
Open-mindedness
Persistence
Pleasure
Respect
Responsibility
Supportiveness
Trust

Add your own

Treatment options and clinical trials

It is common to worry about what might happen if ovarian cancer comes back or progresses. You may wonder whether there are further treatments available or if you are eligible for clinical trials.

For many people, there are still several treatment options available that may help to slow the cancer's growth, manage symptoms and maintain comfort and quality of life.

For some people, ovarian cancer may be managed over time in a way that is similar to a chronic illness.

Many people have several treatments over time, depending on how the cancer responds and what treatments they had before.

If cancer returns or progresses, treatment options may include:

- different chemotherapy drugs
- targeted therapies
- surgery in some situations
- treatments to relieve symptoms, such as radiotherapy
- supportive care that focuses on maintaining comfort and quality of life (palliative care).

Clinical trials are research studies that test new treatments or new ways of using existing treatments. For some people, taking part in a clinical trial may provide access to new therapies and help improve care for others in the future.

Your cancer specialist can explain whether there may be a trial suitable for you and what taking part might involve. Research and treatment for ovarian cancer continues to evolve, so new therapies are being tested all the time.

RESOURCES

- Ovarian Cancer Australia – Clinical Trials Resource Hub, www.ovariancancer.net.au/clinical-trials-resource-hub
- Ovarian Cancer Australia – Demystifying clinical trials (webinar), https://ovariancancer.net.au/find-support/webinars
- Australia New Zealand Gynaecological Oncology Group, www.anzgog.org.au
- Cancer Australia, www.canceraustralia.gov.au

Fears about death and dying

Fear of cancer coming back or progressing can be overwhelming, and it is natural to worry about death and/or dying. Thinking about the possibility that treatments may no longer be effective is very difficult, both for the person with ovarian cancer and for the people who care about them.

Noticing and acknowledging these fears can be an important first step. Common worries include:

- how pain or other symptoms will be managed
- being a 'burden' on family or loved ones
- the uncertainty of the dying process itself
- changes to identity, dignity or sense of self
- how breathing or daily functions will be affected
- losing independence and autonomy.

It is also common for women to experience anticipatory grief, which is the sadness and loss before death has happened. It can include loss of your imagined future, such as:

- seeing children or grandchildren grow up
- missing future special events, or holidays.

These fears are a normal response. Talking about them with a trusted family member, friend or health professional (psychologist, counsellor or palliative care team member) can help take some of the power away from them.

DUAL AWARENESS

Some people worry that talking about death or the end of life means 'giving up hope'. This is not the case. It is possible to focus on living your life now while also acknowledging fears about the future. This is called 'dual awareness'. It means holding two realities at the same time: continuing to engage in life and what matters to you in the present, while also allowing space for worries or fears about dying.

Rather than avoiding thoughts about death, dual awareness allows you to move flexibly between these two perspectives. Developing this skill can help people feel more grounded, make meaningful decisions, and experience purpose and connection, even while facing uncertainty.

PALLIATIVE CARE AND ADVANCE CARE PLANNING

'Palliative care' focuses on comfort, symptom relief, emotional support and helping people live as fully as possible.

> Palliative care is not only for the final stage of life. It can be provided from the time of diagnosis, alongside other treatments, and focuses on improving quality of life at any stage of a serious illness.

Palliative care teams include doctors, nurses, social workers, counsellors and other specialists who support both the person with cancer and those close to them. They can help with:

- **managing symptoms and side effects of treatment and cancer** – helping manage pain, fatigue, nausea and other symptoms
- **practical needs** – supporting daily life, such as transport, home help or accessing services
- **emotional support** – listening, talking through fears or connecting with a counsellor
- advance care planning – helping document your wishes and have important conversations with your loved ones
- **bereavement care** – supporting the person with cancer and loved ones, including grief counselling after loss.

"Life is precious and unpredictable. Being with those you love, sharing time, and focusing on what matters most can be deeply meaningful, even in the face of fear." **— Debbie, living with ovarian cancer**

Planning for the end of life, such as completing Advance Care Planning or thinking about preferences for care, may help reduce anxiety and give you more control over your choices. Some people also find comfort in creating memories with loved ones or doing meaningful activities together while they are feeling well.

For family, friends and loved ones

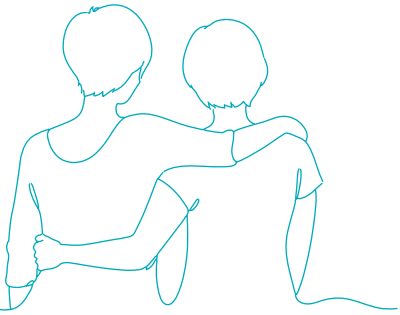
Having conversations about death and dying is deeply personal and can be very difficult to start. Simply being willing to listen, even when it feels hard, can be one of the most meaningful ways to show your love and support.

Not everyone is ready to talk about death and dying, including carers, friends and family. This is normal. If you are not ready, it's okay to be honest about your feelings while still showing support. You might say something like:

> "I am finding this hard to talk about, but I want to be here for you. Can we take it slowly?"

You could also:

- Suggest speaking with a psychologist, counsellor or spiritual care worker experienced in supporting people with cancer.
- Ask your healthcare team about palliative care services and what support is available for both patients and families.



RESOURCES

- Cancer Australia booklet 'Finding the words: Starting a conversation when your cancer has progressed', www.canceraustralia.gov.au
- Palliative Care Australia 'Asking questions' page to help you think about what questions to ask your healthcare team, https://palliativecare.org.au/resource/asking-questions/
- Ovarian Cancer Australia Resilience Kit section 'When cancer won't go away', www.ovariancancer.net.au

PLANNING AHEAD: THINKING ABOUT YOUR WISHES

Planning for the future doesn't mean you are giving up hope. But it can help reduce overwhelm, give you a sense of control and make sure your wishes are known.

Here are some ideas you might consider.

Your care preferences

- **Where would you like to receive care if you are very unwell?** For example, at home with support from family and nurses, hospital palliative care ward or in a hospice.
- **What treatments are most important to you, and which might you not want to have?** For example, you may want chemotherapy to slow the cancer growth but prefer not to have aggressive interventions if side effects would outweigh benefits; you may want to participate in a trial.
- **How do you want pain, nausea, or other symptoms to be managed?** For example, medications to control pain, anti-nausea tablets before meals, alongside complementary therapies like massage or relaxation exercises.

Daily life and support from loved ones

- **Who do you want to make decisions for you if you cannot?** For example, a partner, adult child, close friend or someone legally appointed as a medical power of attorney/ medical decision-maker.
- **What practical help would make your daily life easier?** For example, help with shopping, meals, paying bills, picking up children from school, transport to and from medical appointments.
- **Are there certain things that make you feel comforted or cared for?** For example, having a favourite blanket or pillow, listening to music you love, spending time with pets, or having regular phone calls with a supportive friend or family member.

Meaning, purpose, and values

Also see section 'What matters most for you' to help.

- **What matters most to you in the time ahead?** For example, spending more time with family and/or pets, going on a special trip or celebrating milestones with loved ones.
- **Are there people you want to spend more time with or things you want to do?** For example, catching up with close friends, sharing meals with grandchildren or taking part in a hobby that brings joy.
- **Are there personal, spiritual or cultural preferences you want to be respected?** For example, keeping the customs or practices that are important to you, prayer or meditation, or dietary/cultural practices during care.

Communication

- **Who should be involved in conversations about your care?** For example, your partner, adult children, close friends or a trusted healthcare professional.
- **Would you like professional guidance from your palliative care team, nurse, or counsellor?** For example, scheduled appointments to discuss symptom management, emotional support or guidance on advance care planning.

Tip: *You don't have to do this all at once. Small steps can still make a big difference in feeling more in control and reducing worry. You might find it helpful to complete sections with someone you trust or a health professional.*

RESOURCES

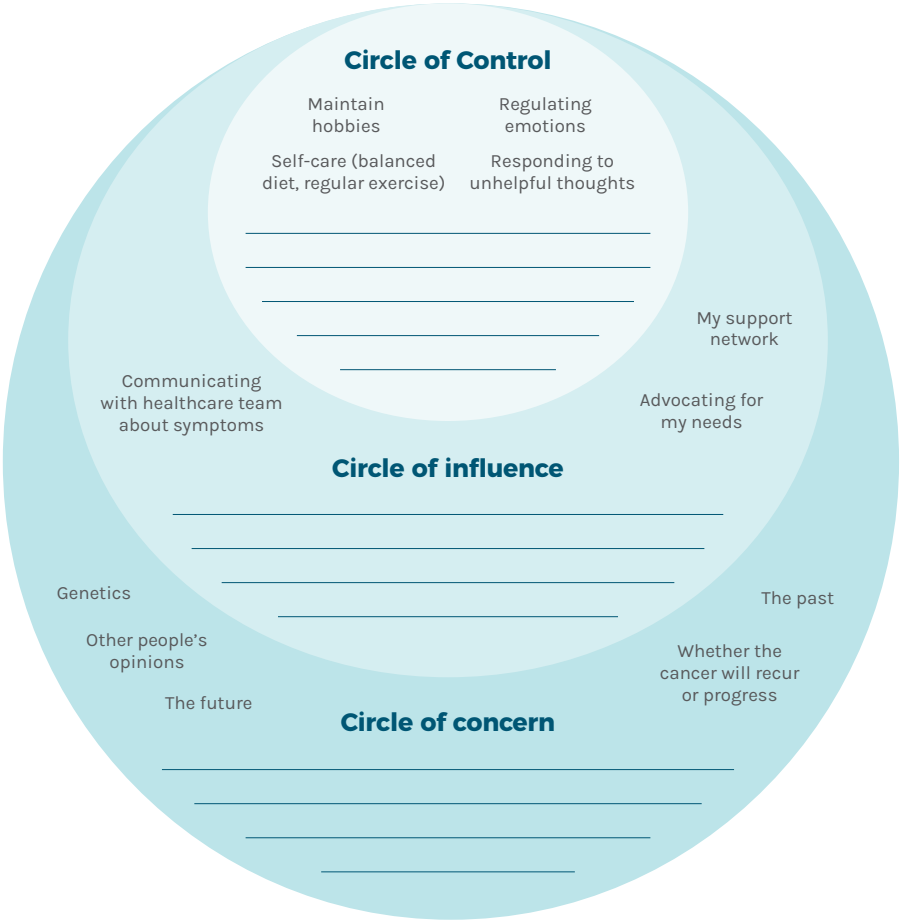
- Resilience Kit – 'Chapter 3: Staying well' for information about Wills, getting insurance and advance care plans, https://www.ovariancancer.net.au/booklet/resilience-kit

Focus on what is within your control

Coming back to what you can control, rather than focusing on the things we can't control, can help lessen anxiety and overwhelm. The circle of control is a way to outline:

- Things we can control (circle of control)
- Things we can influence (circle of influence)
- Things we can't control (circle of concern)

Reflect on these three circles and circle any examples relevant for your fear or write down your own:



Practical tips

ATTEND FOLLOW-UP APPOINTMENTS

The lead-up to follow-up appointments can generate fear, but most women say they feel reassured after their follow-up appointment. It is often the build-up to the appointment that is most challenging time.

They also provide an opportunity to discuss your fears and link you with other professionals such as psychologists/counsellors, dietitians, exercise physiologists and social workers, who can all help with wrap-around support for your recovery.

"I used to always get anxious before a follow-up appointment, but with each positive result, my fears have diminished. At my five-year visit, I felt like I didn't need to worry any more." **— Jenny, woman with lived experience**

MAKE PLANS AND LOOK AHEAD

It is completely normal to feel unsure about the future after cancer treatment. Many women feel like they are living in a separate world from others, which can make planning ahead feel overwhelming.

Things that may seem challenging include:

- booking a holiday
- planning future changes in your work/business
- planning your retirement
- thinking about special occasions with your children or grandchildren (births, weddings and special birthdays)
- entering new intimate relationships
- taking up a new hobby
- looking for a job or doing volunteer work.

"I've gone back to casual work, which has given me a sense of control in my life." **— Victoria, woman with lived experience.**

"I've started swimming again … it's helped me regain a sense of control and freedom in my body. I haven't let the fear [of recurrence or progression stop me." **— Jennifer, woman with lived experience**

Even small steps, like planning a special event or returning to a hobby you used to enjoy, can give you a new lease on life after a very difficult time.

Focusing on what is important to you outside the 'world of cancer' and actively taking part in events helps build energy and hope, and rebuild a sense of self/identity.'

Create your own 'fear management plan'

We hope that creating your own summary 'fear management plan', using the information and strategies in this booklet, will be helpful as a resource to come back to during times of anxiety.

My triggers

Reflect on what situations increase your fear. You may find it helpful to look back to **Section one**: 'Common causes of fear and worry'.

- _____
- _____
- _____

Ways to reduce my fear and worry

Examples: *challenging thoughts, mindfulness, focusing on what is within my control, communicating with healthcare team*

Calming my body

Examples: *box breathing, grounding*

How will I know when to seek medical and/or psychological support:

Examples: *persistent new symptoms, worry is consuming, timeframe (e.g., if the symptom is still present after 5 days)*

My supports

Examples: *nurse, GP, family, friends.*

-
-
-

SECTION THREE:
Further support and information

Carers' feelings

Caring for someone going through ovarian cancer can be very rewarding – and also challenging. Carers may also feel fear about the cancer coming back and may find it hard to express their concerns, for fear of upsetting or worrying the person they are caring for.

"My biggest fear was I would not see my daughter live her life. Every other fear paled into insignificance." **— Michelle, carer of someone with ovarian cancer.**

Some people also think about what life might be like without their loved one and may feel guilty for having these thoughts. These feelings are a normal response to facing a very uncertain future and caring deeply about someone close to you who may pass away.

If you can share your fears with someone you trust, it may help ease the burden. For further information about caring for someone with cancer:

- **Ovarian Cancer Australia** 'Supporting someone with ovarian cancer: a guide for carers, family and friends', https://www.ovariancancer.net.au/booklet/supporting-someone-with-ovarian-cancer
- Carers Australia works to help improve the lives of carers through counselling, advice, education and advocacy, www.carersaustralia.com.au or 1800 242 636

Finding information online

The internet offers a wealth of information on ovarian cancer. While sometimes helpful, online resources should not replace advice from your healthcare team. Not all information is accurate or relevant to your situation. Tips to help can include the following.

- **Talk it over:** Share useful online information with your specialist or GP so they can guide you.
- **Stick to trusted sources:** Use reputable cancer organisations, hospitals and universities (look for weblinks that include '.org' and '.edu).
- **Be cautious:** Question who is behind the information and their motives. Ask someone you trust, like your specialist nurse or doctor, if unsure.
- **Limit online 'information overload':** It's okay to take breaks from online information and groups.
- **Watch for bias:** Search results can make things seem worse than they are.

"I remember spending a lot of time searching the internet for information and scaring myself to death. I would advise anyone with cancer, especially when you first find out, not to look on the internet." **— Jenny, woman with lived experience**

Be wary about 'Dr Google' or 'ChatGPT' as your source of health information, as a lot of medical and cancer information online has not been reviewed by experts. **If unsure, ask your healthcare team.**

RESOURCES

- Australian Commission on Safety and Quality in Healthcare: 'Finding good health information online', www.safetyandquality.gov.au/consumers/finding-good-health-information-online
- The American Cancer Society: 'Finding cancer information on the internet, https://cancer.org/cancer/understanding-cancer/cancer-information-on-the-internet.html

Further information and support

If you have persistent feelings of sadness, anxiety and fear about the cancer coming back, we strongly encourage you to seek support:

- **Psychosocial support services** Access to specialist oncology psychologists, counsellors and social workers who can support issues such as anxiety, fear of recurrence, sleep problems, and adjusting to life after treatment.
- Call **Ovarian Cancer Australia** on **1300 660 334** or **visit our website** at www.ovariancancer.net.au for further information about support groups and networks that can help you connect with other women in similar circumstances.

RESOURCES

- Ovarian Cancer Australia 'Managing fear of recurrence' (webinar), https://www.youtube.com/watch?v=cvbWohmtoBg
- Cancer Council 'Managing fear' (podcast), https://www.cancercouncil.com.au/podcasts/episode-11-managing-fear/
- Ovarian Cancer Australia 'Resilience Kit', https://www.ovariancancer.net.au/booklet/resilience-kit

FIRST NATIONS PEOPLES

- Yarn for Life, www.ourmobandcancer.gov.au/yarn-for-life
- Our Mob and Cancer, www.ourmobandcancer.gov.au/ or call 1800 022 222

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