

Making a decision that's right for you.

A decision aid for women considering further chemotherapy for refractory or resistant ovarian cancer.



A
Decision
Aid

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This booklet and you.

This booklet has been written for women who have had a diagnosis of recurrent ovarian cancer, which is refractory or resistant to chemotherapy. This diagnosis can bring new challenges, concerns and questions. It involves making further decisions about treatment and working out the best steps to take.

The purpose of this booklet is to help you make an informed decision about your treatment options. The booklet provides:

- information about the options available;
- the benefits and risks involved with each option;
- advice on how to make a decision that will best suit your values and goals;
- questions you may like to ask your doctor; and
- examples of how other women in similar situations have approached treatment decisions.

It also recognises that emotional support is just as important as physical care, and this is discussed in the section "Coping with resistant and refractory ovarian cancer" on page 6.

This booklet is designed to add to, but not replace, discussions that you will have with your oncologist, nurse, other members of your multidisciplinary team and your family about the options available to you. It is another resource you can use to ensure that you are making a decision that is right for you.

 *The following sections discuss recurrent, resistant and refractory ovarian cancer and treatment options. They contain a lot of medical information and new terms. If you are finding it difficult to read all at once, it may be helpful to come back and re-read it again at another time. There is also a glossary of terms on page 62.*

Coping with resistant and refractory ovarian cancer.

“*How do you cope with it? First of all, I went into denial and wouldn't accept it and then you just sort of get on with your life. And I suppose the only way you can do that is to keep on doing the every day normal things that you would have normally done.*”

Coping with resistant and refractory ovarian cancer can be very challenging. You may experience the same emotions that you felt when you received

your initial diagnosis. Women commonly feel shocked and fearful at the thought that chemotherapy has been less effective than in the past. Some women also have other feelings, such as uncertainty, frustration, helplessness, denial, panic, anger, or guilt.

Sharing your feelings and thoughts with your healthcare team can help you to cope. Some women find that talking with family and friends is very comforting, while others may need to spend time alone to understand and process their feelings before they confide in others.

There are many ways to cope at this time. Some women strive to maintain an optimistic attitude; some find that acceptance of the situation helps; and others find strength in their faith. Many women speak of trying to appreciate any symptom-free time and continuing to live each day as normally as possible.

Some women may find the emotions and treatment decisions associated with recurrent ovarian cancer overwhelming and difficult to manage. If you have any concerns or are feeling distressed, it is important that you seek support and talk with your healthcare team.

One constructive way to cope is to empower yourself with information. The more informed you are, the easier it is to decide what is best for you.

 *Emotional support is as important as physical care. Members of your health care team can tell you what types of support are available and how to access them.*

Understanding resistant and refractory ovarian cancer.

WHAT DOES 'RESISTANT' OR 'REFRACTORY' MEAN?

When cancer returns this typically means that the cancer cells are no longer responding to the latest platinum-based chemotherapy drug. This may be because cancer cells that had previously responded to chemotherapy are now resisting the effects of the drug and growing again (**resistant**). Alternatively, the cancer cells may have never responded to the drug in the first place (**refractory**) and have continued to grow or change during chemotherapy.

Medical professionals also use the terms “resistant” or “refractory” to distinguish between different types of recurrent ovarian cancer based on the time when the cancer returned. **Time to recurrence** is the time between when your last chemotherapy cycle finished and the diagnosis of recurrent ovarian cancer.

TYPES OF RECURRENT OVARIAN CANCER

Refractory: When cancer continues to grow *during* chemotherapy.

Resistant: When cancer returns *in less than 6 months* from the end of the chemotherapy.

Sensitive: When cancer returns *after more than 6 months* from the end of the chemotherapy.

When the tumour size has not reduced or changed by the end of chemotherapy, it is referred to as **stable**.

When cancer cells become resistant to one drug (e.g., platinum), it does not necessarily mean that they will be resistant to ALL available drugs. For example, if a woman is well, the doctor may recommend treating her with another type of chemotherapy drug to see if the cancer will respond to that one instead. On the other hand, there may be a time when after trying several different drugs, the cancer becomes resistant/refractory to many chemotherapy drugs (**multiple drug resistance**).

MORE ABOUT CA-125

During follow-up consultations, you may be told you have rising CA-125 levels. This news can often cause anxiety and confusion. Even though rising CA-125 levels may be used as an indicator for diagnosing recurrent ovarian cancer, many other factors are also considered.

The tumour marker CA-125 (cancer-antigen 125) is found on the surface of ovarian cancer cells and is released into the blood stream.

What does a change in CA-125 mean?

There is no common consensus about how much CA-125 levels need to increase to indicate that ovarian cancer has returned. The doctor will be looking for a **progressively rising or markedly elevated CA-125 level**.

Your doctors will want to monitor the changes over time, as a single, small rise may be due to other factors such as an infection. They will take into account a number of factors when considering the significance of any change, including your past CA-125 levels and how rapidly it is now rising.

Although it is used as an indicator, the CA-125 level is just a 'number'. It provides some information, but is not the whole picture.

CA-125 levels **CANNOT** tell you:

- when symptoms may return or get worse;
- how severe the cancer is; or
- whether to start chemotherapy

Goals of treatment for resistant and refractory ovarian cancer.

“*You look for inspiring stories and say to yourself ‘maybe that can happen to me’. I guess that is one of the ways you cope.*”

When recurrence of ovarian cancer is confirmed, your healthcare team will discuss with you what you can expect from your treatment, what realistic goals you can set at this stage and the best approach to take.

There are currently no known treatments that can cure resistant or refractory ovarian cancer. However, **although there is no cure, there are still treatment options available.**

AIMS OF TREATMENT for resistant and refractory ovarian cancer:

- slow the spread or stabilise the progression of the disease in order to prolong life;
- maintain and optimise quality of life; in other words, allow you to lead as normal a life as possible, for as long as possible;
- slow down the development of symptoms of cancer; and/or
- remove or reduce cancer-related symptoms when these return.

When planning any further treatment, your healthcare team will carefully consider the likelihood that you will benefit from the treatment. The likelihood of benefit will then be weighed against the likelihood of side effects and reduced quality of life.

WHAT IS CONSIDERED WHEN CHOOSING A COURSE OF TREATMENT?

There is no standard (generalised) treatment plan for women with resistant or refractory ovarian cancer. Instead, **your healthcare team will 'tailor' your treatment** based on a number of factors specific to your personal situation, including:

1 How well you are at the moment (also known as performance status) and whether you have other medical complications or other current diseases (also known as co-morbidities)

If you are not well, it can be difficult to cope with the side effects of chemotherapy and you may need to stop treatment early. Your doctor will be particularly cautious about recommending chemotherapy if you have other serious medical conditions and complications such as bowel obstructions or liver disease.

2 The likely side effects of recommended chemotherapy drugs

Your doctor will talk to you about the expected side effects of different chemotherapy drugs. If there is more than one option available, then you may be able to discuss the side effects you would most like to avoid.

3 Impact on your quality of life

Chemotherapy can have a huge impact on all aspects of your quality of life. Quality of life refers to the effect of treatment on your overall sense of well-being, including physical, emotional, social, sexual and financial well-being. Changes to your quality of life as a result of treatment can depend on many factors, including: how well you are coping and the support available to you; your current symptoms and whether chemotherapy can alleviate these symptoms; the chemotherapy side effects; and whether you have had a break in treatment.

4 What are your goals and desires

Your healthcare team will consider your values and goals when recommending the next step. For example, some women have a strong desire to continue chemotherapy throughout the entire course of the disease, whereas for other women, there comes a time when they would prefer to stop chemotherapy and focus on their quality of life. The worksheets on pages 39-55 give some examples of how other women have made their treatment decision, and provides a guide to help you identify and clarify your values.

Palliative care.

WHAT IS PALLIATIVE CARE?

Palliative care refers to the multi-disciplinary and holistic care of someone being treated for any advanced illness that is not likely to be cured. It focuses on optimising quality of life and comfort, by relieving pain and symptoms of the illness, as well as providing emotional, spiritual, social, sexual and financial assistance. It aims to provide support to you as well as others involved in your care, such as family and friends.

Many women fear that they will be overwhelmed by the effects of advancing cancer. A palliative care team can work closely with you to:

- manage the side effects of treatment;
- manage the symptoms associated with ovarian cancer;
- manage the social and emotional effects of what is happening, for you and your family.

Some of the physical issues palliative care specialists are experienced in managing include problems with pain, sleep, bowels, eating, fatigue and breathing, as well as sadness, depression and fear. If these issues are troubling you, mentioning them to your doctor may help guide you to the appropriate support services.

Some options that may be available include, but are not limited to, medications, radiotherapy, blood transfusions, oxygen provision, adequate hydration and surgery.

NOTE: chemotherapy may also be offered as part of palliative care, and this is covered in more detail on page 21.

Other options that may be available include nursing care, massage, relaxation techniques, meditation, counselling, dietary and nutritional advice, practical help with daily living and emotional or spiritual support.

Whichever strategies are recommended, your healthcare team will discuss the options available to you.



ISN'T PALLIATIVE CARE JUST FOR PEOPLE WHO ARE ABOUT TO DIE?

This is a common myth. Palliative care is actually for anyone who has an advanced illness. The aim is to improve your quality of life so that you can live as well as possible for as long as possible.

You can choose to stop using the services if the disease stabilises or your needs reduce again. It is a good idea to contact palliative services early so that any needs you have can be addressed quickly and you can prevent unnecessary difficulties.



**YOUR HEALTHCARE
TEAM CAN EASILY
MAKE A REFERRAL TO
PALLIATIVE CARE
FOR YOU**

WHO PROVIDES IT?

Palliative care can be offered by those who are involved in your day-to-day care, such as oncologists, aged care staff, nurses and social workers. You may also be referred to a specialist palliative care team with medical, nursing, allied health and voluntary staff. Palliative care can be provided in many places: your home, an aged care facility, a hospice or in hospital. Your oncologist will be able to provide more information and refer you to palliative specialist services in your hospital or community, and you can also speak to your GP about local services.

WHEN MIGHT THIS BE RECOMMENDED?

Palliative care is likely to be introduced early in your treatment plan. It can be helpful for coping with the side effects of chemotherapy, to assist with symptom management or even to help with the emotional adjustment during various stages of the illness. The goal of palliative care is to minimise the ongoing, negative consequences of the cancer such as pain, anxiety and symptoms.

 *Some useful websites with information about palliative care:*

Palliative Care Australia

Website: www.palliativecare.org.au

Palliative Care Information Service (PCIS)

Phone: 1800 772 273

Website: www.pcis.org.au

Care Search - Palliative care knowledge network

Website: www.caresearch.com.au

Cancer Council - Website about palliative care

www.cancercouncil.com.au/editorial.asp?pageid=1957

Asking Questions Can Help: An aid for people seeing the palliative care team

by Dr Josephine Clayton, Prof. Phyllis Butow & Prof. Martin Tattersall, Medical Psychology Research Unit, University of Sydney, 2002 at:

<http://www.palliativecare.org.au/portals/46/resources/AskingQuestionsCanHelp.pdf>

Summary of the different options available.

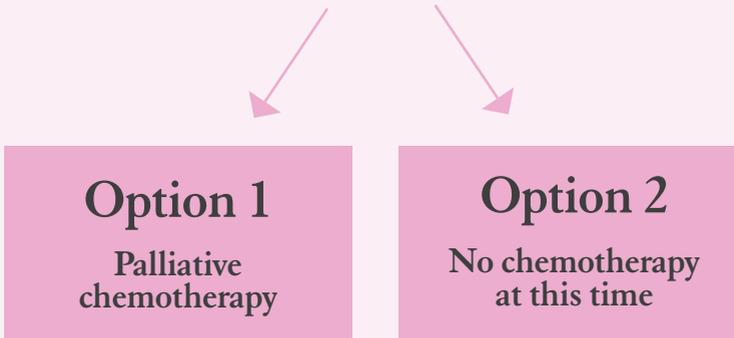
“*Do I actually pursue the chemo and go through all that pain, go through everything that has to happen to get to the end? Or do I just lay back and try not to worry about it?*”

As discussed in the previous section about the goals of treatment, your healthcare team will take into account a number of factors when recommending a treatment plan. Typically, the key options are:

- *Palliative chemotherapy*, with the aim of slowing tumour growth and/or relieving symptoms; or
- *No chemotherapy* at this time, with management of symptoms as they arise.

One of these approaches may be more highly recommended to you, depending on your individual situation. The following sections provide more information about each of these options and when they may be appropriate choices for you.

Treatment options for resistant and refractory ovarian cancer



Palliative Care

Palliative care is available to you at any time during your care, regardless of whether you choose to have chemotherapy or not at this point. Palliative care aims to help anyone who has an advanced illness to improve their quality of life, so that they can live as well as possible for as long as possible.

** Regardless of which option you choose, your healthcare team will help you get the best supportive care.*

Option 1: Palliative Chemotherapy

“*When the doctors offered me more chemo a surge of joy went through me. I thought, ‘Great, let’s get on with it!’ I think something is being done for it, there’s something happening.*”

“*When you have your chemotherapy, it is no picnic, as you know. It makes you feel pretty drowsy, lousy, any other words you can add. But, you still have to say, ‘Well, tomorrow I’ll feel better. The day after that I’m going to feel better again.’*”

WHAT IS INVOLVED?

Chemotherapy is the use of drugs to destroy cancer cells. It is intended to reduce the cancer or stabilise the growth of cancer cells, with the aim of either: (1) achieving another remission, or (2) alleviating symptoms.

There are a number of different chemotherapy drugs that can be used, either alone or in combination, as part of treatment for refractory or resistant ovarian cancer. The chemotherapy drugs used for resistant and refractory cancer may differ from the drugs used when you first had chemotherapy. Your oncologist will make recommendations about which drugs are best to use in your situation.

WHEN MIGHT THIS BE RECOMMENDED?

Doctors will recommend chemotherapy when there is sufficient reason to believe that the tumour will respond to the treatment. While not able to cure the cancer at this stage, the chemotherapy could shrink the tumour or stabilise the growth of further cancer cells to either:

- 1 Alleviate cancer symptoms, or slow down the development or reappearance of cancer symptoms**
Often pain and other symptoms associated with cancer are related to the size, position and growth of the tumour. By reducing the size or stabilising the tumour, chemotherapy can provide relief from symptoms.
- 2 Prolong life expectancy or achieve further remissions**
Some indicators that the tumour's growth may slow down are that: you are relatively well; you have few remaining side effects from previous chemotherapy; and/or the previous chemotherapy was well tolerated (please refer to the section on goals of treatment on page 11 for the factors doctors look for in order to recommend chemotherapy).

POSSIBLE OUTCOMES AFTER CHEMOTHERAPY

- **Complete response:** No evidence of tumour based on scans and blood tests
- **Partial response:** Reduction in size of tumour
- **Stable disease:** No change in the size of the tumour
- **Progressive disease:** Increase in the tumour size, which means the cancer has not responded to treatment

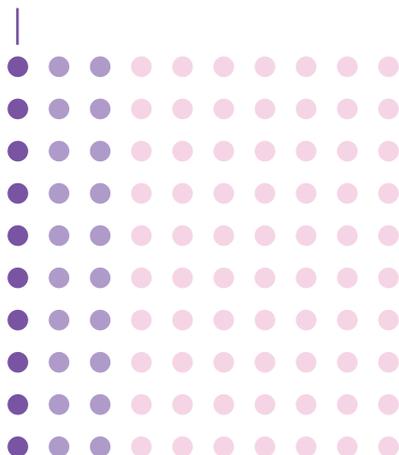
WHAT ARE MY CHANCES OF RESPONDING TO CHEMOTHERAPY?

Chemotherapy used for resistant or refractory patients typically results in a relatively low response rate. A response to chemotherapy means that the cancer shrinks or stabilises after treatment, potentially achieving further remissions.

Resistant ovarian cancer: response rates

Women with **resistant ovarian cancer** generally have a 10-30% likelihood of responding to chemotherapy. This means that out of 100 women having chemotherapy for resistant ovarian cancer, anywhere from 10 to 30 of them will have their cancer reduced or stabilised as a result of the chemotherapy. The other 70 to 90 women will not respond to the chemotherapy (their cancer will continue to grow).

10/100 women are likely to respond to treatment.

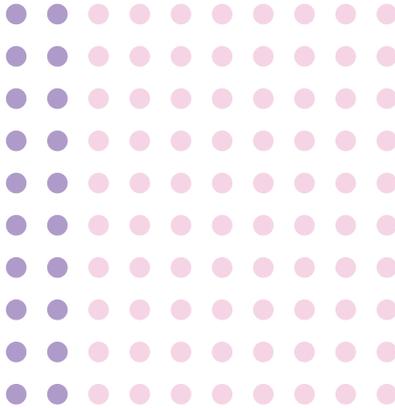


|
an additional
20/100 women
may to respond
to treatment.

About 10-30 out of 100 women with resistant ovarian cancer will respond to treatment

Refractory ovarian cancer: response rates

Women with **refractory ovarian cancer** will have up to a 20% chance of responding to chemotherapy. This means that out of 100 women having chemotherapy for refractory ovarian cancer, anywhere from 0 to 20 women will have their cancer reduced or stabilised as a result of the chemotherapy. The other 80 to 100 women will not respond to the chemotherapy (their cancer will continue to grow).



About 0-20 out of 100 women with refractory ovarian cancer will respond to treatment

up to 20 out of 100 women may respond to the treatment

** Your doctor will discuss this further with you, including the likelihood that you will respond to a particular drug, depending on your circumstances.*

POSSIBLE **BENEFITS** OF CHEMOTHERAPY

1

Can reduce or stabilise disease

There are a number of chemotherapy drugs that can be used to treat resistant and refractory ovarian cancer. Your chance of responding to chemotherapy was outlined in the previous section.

2

There is less chance that the cancer will be left too long and, therefore, not respond as well to chemotherapy later on

If it looks promising that the cancer will respond to another line of chemotherapy, initiating chemotherapy sooner rather than later increases the chance that the cancer will respond to treatment. Doctors will closely monitor each person to determine the optimal time to start chemotherapy.

3

Can be used to manage the symptoms associated with the return of cancer

By reducing the volume (size) of the tumour, chemotherapy may provide substantial relief from distressing cancer-related symptoms.

4

Gives many women purpose and hope

Some women may find it difficult to stop having chemotherapy and prefer to continue with chemotherapy as a way of coping with the disease.

POSSIBLE SIDE EFFECTS OF CHEMOTHERAPY

Chemotherapy may cause unwanted side-effects

Each woman responds differently to treatment; some have few side effects, whereas others experience many. While you are having chemotherapy, it is important that you let your healthcare team know if you are experiencing any side effects, so that they can discuss ways of stopping or minimising them.

There are a number of chemotherapy drugs that can be used in this setting, each with different side effects. For this reason, we can only provide a general picture of the side effects you might experience. Your oncologist can discuss with you in detail how likely you are to experience side effects with each of the chemotherapy drugs available, and how long they may last.

 *Your doctor will discuss your risk of experiencing the different side effects associated with the recommended chemotherapy drugs.*

Common side effects

Usually these side effects are not severe enough to require you to reduce the strength of chemotherapy or discontinue it.

- Lack of energy or tiredness
- Diarrhoea/constipation
- Thinning or loss of hair
- Nausea and vomiting
- Mouth sores/tenderness
- Temporary damage to the bone marrow, making you more susceptible to infection, bruising, bleeding and anaemia
- Rashes and redness
- Sadness or low mood due to experiencing chemotherapy
- Tingling of the hands and/or feet caused by nerve damage (peripheral neuropathy)
- Joint and muscle pain
- Abnormal kidney and liver blood tests

Rare, but potentially serious side effects

These will require immediate medical care.

- Infections requiring hospitalisation, which can be life-threatening

POSSIBLE **DISADVANTAGES** OF CHEMOTHERAPY

- 1 Every time you have additional chemotherapy, you are at an increased risk of experiencing side effects**
Your doctor will help assess how likely this is to occur based on your age, general health, chemotherapy drugs chosen, reactions to previous chemotherapy and length of time since last chemotherapy.
- 2 There is a risk with each course of chemotherapy that your body may become less able to cope with the side effects associated with chemotherapy**
There will be a limit to the amount of chemotherapy that your body will be able to handle.
- 3 Chemotherapy will involve frequent trips to the hospital**
Attending hospital or your treatment centre for chemotherapy may be time-consuming, giving you less time to focus on other things in life.
- 4 There's no guarantee the chemotherapy will work, which may lead to disappointment if it does not work the way you expected**
You may get your hopes up that chemotherapy will help, but there is no way of knowing how the cancer will respond this time.

Option 2: No Chemotherapy

“*You think ‘well, what’s important in life?’ I guess it’s really about clearing the decks and getting organised. I think it has made me go out and live every day to the fullest. I have to start enjoying what’s here now and not be so worried about what is going to happen in five years time or even tomorrow.*”

WHAT IS INVOLVED?

You may reach a point where you no longer want to continue with chemotherapy. At this time, it is okay to tell your healthcare team that you wish to stop chemotherapy. This may be a short-term break, or a more permanent decision, depending on what is important to you at the time. Most importantly though, *it is okay to change your mind and reassess your options with your doctor at any time.*

WHEN MIGHT THIS BE RECOMMENDED?

Your healthcare team might suggest a break from chemotherapy if your cancer is progressing and not responding to treatment. However, it may also be appropriate if you are struggling with the side effects of chemotherapy, or if you simply need some time away from the hospital for a while. The break from chemotherapy may be temporary or permanent. Either way, your doctor can help you reassess your options at any time.

POSSIBLE BENEFITS OF NO CHEMOTHERAPY

1 You can focus on quality of life

As you will not be receiving any chemotherapy, you will not experience any of the side effects, risks and inconveniences associated with the chemotherapy drugs. Your treatment will be aimed at optimising your current quality of life. Spending less time in hospital and being less restricted by the physical side effects of chemotherapy may give you more freedom to enjoy life. You may be able to spend more quality time with friends or family, travel and experience things you had always hoped to do, or simply get on with living life.

2 Less hospital trips and medical interventions, giving you more freedom

Not having chemotherapy will mean less inconvenience and time spent travelling to and from hospital, with more medical issues being dealt with locally, by your GP or community nurse. You will have more time to yourself to focus on what you want to be doing. Having a break from chemotherapy may also mean a break from invasive blood tests and other medical interventions, such as receiving intravenous fluid.

3 No side effects from chemotherapy

Chemotherapy side effects can significantly interfere with a woman's life, being both physically and mentally exhausting. A break from chemotherapy might also mean a break from these physical and mental struggles.

4 Opportunity to redefine hopes and goals

There may come a time when chemotherapy is deemed unlikely to be of further benefit to you, or you are physically unable to cope with additional chemotherapy. In this situation, you may decide to decline further chemotherapy. Making this decision may lead to increased acceptance or coming to terms with the next phase of the disease. You may feel that you have achieved a sense of control through making a decision and can redefine your hopes and goals.

POSSIBLE DISADVANTAGES OF NO CHEMOTHERAPY

1 Cancer-related symptoms may become worse if the cancer progresses

If your cancer continues to grow, you may experience more cancer-related symptoms, such as pain, nausea, loss of appetite, weight loss, depression, anxiety, constipation, difficulty urinating, difficulty breathing and fatigue. However, your healthcare team can help you to manage these symptoms in other ways.

2 Feeling anxious or as though you have 'lost control' if you are not having chemotherapy

Some women may feel anxious or as though they have lost control of their treatment plan. However, the medical and palliative care provided at this point can help you plan how to maximise your quality of life. While you might not be able to make the cancer go away, there are things you can do to help live as normally and comfortably as possible, for as long as possible, and manage symptoms, pain and any emotional difficulties as they arise.

3 You may feel pressured by others to continue chemotherapy

Family members and/or friends may have difficulty understanding why you may not want chemotherapy, especially if their values are different to yours. You may experience social pressure or feelings of guilt if choosing to stop chemotherapy is the opposite of what your family and/or friends want.

4 You may feel regret, wondering whether chemotherapy may have worked

It is difficult to anticipate how you may feel if you choose not to have chemotherapy. Some people may wonder what might have been or what could have happened if they had chosen to continue with chemotherapy.

Summary of the pros and cons of each option.

	What is involved?	Benefits
Palliative chemotherapy	<ul style="list-style-type: none"> ● Chemotherapy aimed at reducing or stabilising cancer, or alleviating symptoms ● Continuing regular visits to doctor ● Need to attend hospital for chemotherapy 	<ul style="list-style-type: none"> ● It reduces or stabilises the disease in 10-30% of cases in resistant ovarian cancer, or in up to 20% of cases in refractory ovarian cancer ● There is less chance that the cancer will be left too long and not respond to chemotherapy later ● Can be used to manage symptoms of the tumour ● Can give you hope and purpose
No chemotherapy	<ul style="list-style-type: none"> ● Taking a break from chemotherapy ● Option to resume chemotherapy in the future, if still appropriate for your situation 	<ul style="list-style-type: none"> ● You can focus on quality of life ● Less hospital trips and medical interventions, giving you more freedom ● No side effects from chemotherapy ● Opportunity to redefine hopes and goals

Side effects	Other risks
<ul style="list-style-type: none"> ● Common <ul style="list-style-type: none"> - Loss of energy or tiredness - Diarrhoea/constipation - Thinning or loss of hair - Nausea and vomiting - Mouth sores/tenderness - Infections requiring antibiotics - Bleeding or bruising - Rashes and redness - Sad or unhappy moods - Peripheral neuropathy - tingling of the hands and/or feet caused by nerve damage - Joint and muscle pain - Abnormal kidney and liver blood tests ● Rare, but potentially serious <ul style="list-style-type: none"> - Infections requiring hospitalisation, which can be life-threatening 	<ul style="list-style-type: none"> ● Increased risk of experiencing side effects with each line of chemotherapy ● Your body may become unable to cope with the side effects associated with chemotherapy ● Frequent trips to the hospital, blood tests and medical interventions, giving you less freedom ● There's no guarantee the chemotherapy will work, which may lead to disappointment later
<ul style="list-style-type: none"> ● Not applicable 	<ul style="list-style-type: none"> ● Increased risk of experiencing cancer-related symptoms ● You may feel anxious or feel that you have "lost control" if you are not having any chemotherapy ● Pressure from family/friends if you are not having any chemotherapy ● Possible regret, wondering if more chemotherapy could have helped

Making the right decision for me.

The previous pages have outlined the potential benefits, risks and side effects of the options available to you: palliative chemotherapy or no chemotherapy at this time.

Not everyone will feel the same about what to do next. Some women wish to continue with treatment when there is a chance that they will benefit from this. Some women prefer to stop chemotherapy when it is not likely that they will benefit any more, and instead, focus on maintaining a high quality of life.

The following steps may help you to decide which option best suits you:

1. Decide on the level of involvement that you want from your doctor and tell them your preferences (the exercise on the next page may help you with this)
2. Understand what it means to have resistant or refractory ovarian cancer
3. Understand your current options and the benefits, side effects and risks of each option
4. Review the pros and cons of each option
5. Assess the importance to you of the pros and cons of each option
6. Get more information and clarify any uncertain areas
7. Work out which way you are leaning

Who should make the decision about treatment options?

Some people prefer to leave decisions about their medical care up to their doctor, some prefer to decide for themselves, and others prefer joint decision-making with their healthcare team. Consider the following statements about making treatment decisions, and tick the one that best describes how you feel:

- The doctor should decide for you
- The doctor should decide but seriously consider your opinion
- You and the doctor should decide together on an equal basis
- You should decide but seriously consider the doctor's opinion
- You should decide using all that you learn about the health matter



You can discuss your preferences with your doctor so that they can work with you in the most appropriate and beneficial manner

Worksheets.

“*Everything happened so quickly when I was told about the cancer returning. I needed to make it all slow down so I could go over the options. I wanted to have the pros and cons listed. This is the way I work and how I’ve always done things when I’ve had to make a tough decision. Then you can see it in front of you in black and white.*”

Any treatment decision involves weighing up the likely benefits of the treatment (pros) with the side effects, risks and other impacts of the treatment (cons).

The following pages include some example worksheets to read through, which show how other women viewed the pros and cons of the options available. These example worksheets are to demonstrate how to use the worksheets only, and are not intended to suggest which specific treatment option is the right one for you. To help you make your own decision, we have provided you with blank worksheets where you can go through the pros and cons of the options and rate how important these are to you (pages 52 - 55).

* *There are no right or wrong answers. Your personal values and preferences should guide you when rating the importance of the pros and cons.*

Each pro or con statement has three options describing how important you consider the issue to be. By circling one of the options you can indicate how important each issue is to you:

Circling 1 indicates that the issue is not important, which means it is not a concern to you.

Circling 2 indicates that the issue is somewhat important, which means it is a small concern to you.

Circling 3 indicates that the issue is very important, which means it is a big concern to you.

For example:

One of the cons of chemotherapy is the side effects. If a woman feels that she will be able to handle these (i.e. this issue is only a small concern), she circles that it is 'somewhat important' for her.

There is a higher chance that I will experience side effects of chemotherapy this time.

“I think I’ll be able to handle that”

1

2

3

Indicates that the issue is not a concern to you

Indicates that the issue is a small concern to you

Indicates that the issue is a big concern to you

After rating how important you consider each statement, at the bottom of the worksheet you can indicate (by circling one of the 5 dots) which way you are leaning in your decision.

Overall, are the pros or cons more important to me? (please circle)

Pros more important



Cons more important

By circling the 3rd dot, this person is indicating she is still unsure (50/50) about having further chemotherapy. In this situation, she may need to discuss the options more with her healthcare team.

Example 1: Susan's decision.

Susan is 55 years old, and lives with her husband and two daughters aged 19 and 22. She was diagnosed with ovarian cancer four years ago.

When first diagnosed, she underwent surgery and first-line chemotherapy, and remained in remission for almost two years. She then relapsed and had second-line chemotherapy. She responded well to this and was in remission for just over a year. Her CA-125 levels then started to rise again, but since she had no other symptoms, Susan decided to wait and see what happened. When she started to experience symptoms five months later, she had third-line chemotherapy. She had another recurrence four months later, and underwent fourth-line chemotherapy.

With each recurrence, Susan has been feeling more tired, and her nausea and vomiting seem to get worse with each cycle of chemotherapy. She is currently experiencing a constant dull ache in her abdomen with occasional episodes of sharp, cramping pains. Her CA-125 levels continue to rise, and Susan has to decide whether to have more chemotherapy.

She has been really looking forward to an overseas holiday with her husband next month, and doesn't want to miss out on going.

Example 1 worksheet: Palliative Chemotherapy

Susan's decision-making

Points to consider

PROS of palliative chemotherapy (Advantages)

There is a chance that I may have another remission or that the cancer will stabilise, meaning I may live longer

The cancer is more likely to respond to treatment now than if I leave chemotherapy until later

My cancer symptoms may improve

I need to continue with chemotherapy, to feel like I'm fighting the cancer

Other pros:

CONS of palliative chemotherapy (Disadvantages)

There's a higher chance I will experience side effects from chemotherapy this time

My body may not be able to cope with the side effects of chemotherapy this time

Chemotherapy will involve frequent trips to the hospital and everything that this involves

I may get my hopes up, even when there's no guarantee the chemotherapy will make any difference

Other cons:

Overall, are the pros or cons more important to me? (please circle)

Pros more important



Cons more important

For Susan, the disadvantages are more important, so she is leaning away from choosing this option.

Some pros and cons are listed in the table below, with Susan's thoughts about each one in purple. There is space for any additional pros or cons to be added at the bottom of each section. *These are example worksheets to demonstrate how to use the worksheets only.*

Personal response Susan's thoughts on each point	Level of importance Susan circled how important each point is		
<i>"I have two wonderful children and a husband – I have too much to live for to give it all away."</i>	1	2	3
<i>"The breaks between recurrences and chemo are getting shorter – I'm not sure how much the cancer would respond to chemo anyway."</i>	1	2	3
<i>"If the tumour grows the pain and discomfort could get worse. Chemo might prevent this, but there are also other ways to manage it."</i>	1	2	3
<i>"Although fighting the cancer has always felt important, a break from chemotherapy may help me feel re-energised."</i>	1	2	3
	1	2	3
<i>"This is not new. I've been getting nausea and vomiting from chemo for a while now – so I'd be expecting side effects this time too."</i>	1	2	3
<i>"The side effects of chemotherapy keep getting worse, but so do the cancer symptoms – I'm not sure one is better or worse than the other."</i>	1	2	3
<i>"Chemotherapy and the hospital visits would mean I couldn't go on our holiday overseas – I have been really looking forward to this trip."</i>	1	2	3
<i>"The doctor explained that I might only have a 10% chance of it working, but even a small chance is important."</i>	1	2	3
	1	2	3

1 Not Important

2 Somewhat Important

3 Very Important

Example 1 worksheet : No Chemotherapy

Susan's decision-making

Points to consider	
PROS of no chemotherapy (Advantages)	I can concentrate on improving my current quality of life, instead of coping with the chemotherapy
	There will be less hospital trips, blood tests and medical interventions, giving me more freedom to do what I want
	I won't have to put up with the side effects of chemotherapy
	I can accept my situation and focus on enjoying the time I have
	Other pros:
CONS of no chemotherapy (Disadvantages)	My cancer symptoms may get worse, and I'll have to cope with this
	I might feel like I've lost control of the treatment of my cancer
	I may experience pressure from people I know who believe I should be taking a more active approach
	I may regret not having chemotherapy at this time, wondering whether it could have helped
	Other cons:

Overall, are the pros or cons more important to me? (please circle)

Pros more important Cons more important

For Susan, the advantages are more important, so she is leaning towards choosing this option

Some pros and cons are listed in the table below, with Susan's thoughts about each one in purple. There is space for any additional pros or cons to be added at the bottom of each section. *These are example worksheets to demonstrate how to use the worksheets only.*

Personal response Susan's thoughts on each point	Level of importance Susan circled how important each point is		
<i>"It would be a big relief if I could focus on experiencing life again, such as spending time with my family and doing things I want to do."</i>	1	2	3
<i>"A break from chemo would mean I can go overseas with my husband, rather than being stuck going in and out of hospital."</i>	1	2	3
<i>"I could really do with a break from the nausea, vomiting and tiredness of chemo."</i>	1	2	3
<i>"I have accepted the cancer, and would like to spend more time with my family doing things I've always wanted to do."</i>	1	2	3
	1	2	3
<i>"If the symptoms get worse while I'm overseas, I don't know how I'll access medical services – I'm not sure how I would cope."</i>	1	2	3
<i>"I would feel more in control of my life again by choosing to do what I want – which is go on a holiday and take a break."</i>	1	2	3
<i>"My family would understand, and know it's important for me to make this decision for myself."</i>	1	2	3
<i>"Since there's only a 10% chance of it helping, I feel confident that I would not regret going overseas and enjoying life to the fullest."</i>	1	2	3
	1	2	3

1 Not Important

2 Somewhat Important

3 Very Important

Example 2: Annie's decision.

Annie is a 62-year-old woman who lives alone, although she has a very supportive network of family and friends. She was diagnosed with ovarian cancer two years ago.

When first diagnosed, she underwent first-line chemotherapy and surgery. The chemotherapy caused significant peripheral neuropathy (nerve damage), making it difficult to button her clothes and causing her to frequently drop things. Six months after completing her treatment she was diagnosed with recurrent disease, and had fluid retention around her abdomen (ascites). Annie started second-line chemotherapy and had a short period of remission lasting three months. With her next recurrence, she again had ascites, as well as abdominal pain. She underwent third-line chemotherapy, and was referred to palliative care for help in managing her symptoms.

When she has chemotherapy, Annie becomes very nauseated and fatigued, and finds it hard to leave the house except for hospital appointments. She currently requires regular fluid drainage for her ascites, is feeling weak, and has abdominal pain and a constant feeling of pressure on her bowel. Her CA-125 levels continue to rise, and Annie has to decide whether to have more chemotherapy.

Annie's niece, to whom she is very close, is getting married in six months, and would very much like her to attend the wedding.

Example 2 worksheet: Palliative Chemotherapy Annie's decision-making

Points to consider

PROS of palliative chemotherapy (Advantages)

There is a chance that I may have another remission or that the cancer will stabilise, meaning I may live longer

The cancer is more likely to respond to treatment now than if I leave chemotherapy until later

My cancer symptoms may improve

I need to continue with chemotherapy, to feel like I'm fighting the cancer

Other pros:

CONS of palliative chemotherapy (Disadvantages)

There's a higher chance I will experience side effects from chemotherapy this time

My body may not be able to cope with the side effects of chemotherapy this time

Chemotherapy will involve frequent trips to the hospital and everything that this involves

I may get my hopes up, even when there's no guarantee the chemotherapy will make any difference

Other cons:

Overall, are the pros or cons more important to me? (please circle)

Pros more important



Cons more important

For Annie, the advantages are more important, so she is leaning towards choosing this option.

Some pros and cons are listed in the table below, with Annie's thoughts about each one in purple. There is space for any additional pros or cons to be added at the bottom of each section. *These are example worksheets to demonstrate how to use the worksheets only.*

Personal response Annie's thoughts on each point	Level of importance Annie circled how important each point is		
<i>"If there's a chance I may be able to make it to my niece's wedding, then it's a chance worth taking."</i>	1	2	3
<i>"If the cancer responds to treatment now, my abdominal pain and ascites may improve."</i>	1	2	3
<i>"Chemo might provide more relief from the abdominal pain and ascites."</i>	1	2	3
<i>"This is really important for me in my life. I have to give it another go."</i>	1	2	3
	1	2	3
<i>"I have experienced side effects with every round of chemo, so this would be expected again."</i>	1	2	3
<i>"I have been through the side effects of chemotherapy before, and there's no reason why I can't do it again."</i>	1	2	3
<i>"I have a good support network, so I can cope with this."</i>	1	2	3
<i>"I won't know if the chemotherapy will help until I give it another go."</i>	1	2	3

1 Not Important

2 Somewhat Important

3 Very Important

Example 2 worksheet: No Chemotherapy

Annie's decision-making

Points to consider	
PROS of no chemotherapy (Advantages)	I can concentrate on improving my current quality of life, instead of coping with the chemotherapy
	There will be less hospital trips, blood tests and medical interventions, giving me more freedom to do what I want
	I won't have to put up with the side effects of chemotherapy
	I can accept my situation and focus on enjoying the time I have
	Other pros:
CONS of no chemotherapy (Disadvantages)	My cancer symptoms may get worse, and I'll have to cope with this
	I might feel like I've lost control of the treatment of my cancer
	I may experience pressure from people I know who believe I should be taking a more active approach
	I may regret not having chemotherapy at this time, wondering whether it could have helped
	Other cons:

Overall, are the pros or cons more important to me? (please circle)

Pros more important



Cons more important

For Annie, the disadvantages are more important, so she is leaning away from choosing this option

Some pros and cons are listed in the table below, with Annie's thoughts about each one in purple. There is space for any additional pros or cons to be added at the bottom of each section. *These are example worksheets to demonstrate how to use the worksheets only.*

Personal response Annie's thoughts on each point	Level of importance Annie circled how important each point is
<i>“Chemotherapy is what would improve my quality of life, especially if I can feel stronger and have less abdominal pain.”</i>	1 2 3
<i>“Although chemotherapy is debilitating, I think I will feel more free once I have gone through it.”</i>	1 2 3
<i>“I’m currently putting up with cancer symptoms, and the side effects of chemo can’t be worse than that.”</i>	1 2 3
<i>“Although I have accepted the cancer, I’m not quite ready to let it determine how much time I have left.”</i>	1 2 3
	1 2 3
<i>“I know the side effects of chemo can be hard to deal with, but I’d rather prevent the cancer symptoms from getting worse.”</i>	1 2 3
<i>“If I ended all treatment, I am sure I would feel like the cancer had won.”</i>	1 2 3
<i>“Although she’d never say anything, I know my niece really wants me to attend her wedding.”</i>	1 2 3
<i>“I’m sure I would regret not having chemotherapy, especially if it resulted in me missing my niece’s wedding.”</i>	1 2 3
	1 2 3

1 Not Important

2 Somewhat Important

3 Very Important

Palliative Chemotherapy: Your decision-making

Points to consider

PROS of palliative chemotherapy (Advantages)

There is a chance that I may have another remission or that the cancer will stabilise, meaning I may live longer

The cancer is more likely to respond to treatment now than if I leave chemotherapy until later

My cancer symptoms may improve

I need to continue with chemotherapy, to feel like I'm fighting the cancer

Other pros:

CONS of palliative chemotherapy (Disadvantages)

There's a higher chance I will experience side effects from chemotherapy this time

My body may not be able to cope with the side effects of chemotherapy this time

Chemotherapy will involve frequent trips to the hospital and everything that this involves

I may get my hopes up, even when there's no guarantee the chemotherapy will make any difference

Other cons:

Overall, are the pros or cons more important to me? (please circle)

Pros more important



Cons more important

Personal response

Your thoughts
on each point

Level of importance

How important each
point is to you

1 2 3

1 2 3

1 2 3

1 2 3

1 2 3

1 2 3

1 2 3

1 2 3

1 2 3

1 2 3

1 Not
Important

2 Somewhat
Important

3 Very
Important

No Chemotherapy: Your decision-making

Points to consider

PROS of no chemotherapy (Advantages)

I can concentrate on improving my current quality of life, instead of coping with the chemotherapy

There will be less hospital trips, blood tests and medical interventions, giving me more freedom to do what I want

I won't have to put up with the side effects of chemotherapy

I can accept my situation and focus on enjoying the time I have

Other pros:

CONS of no chemotherapy (Disadvantages)

My cancer symptoms may get worse, and I'll have to cope with this

I might feel like I've lost control of the treatment of my cancer

I may experience pressure from people I know who believe I should be taking a more active approach

I may regret not having chemotherapy at this time, wondering whether it could have helped

Other cons:

Overall, are the pros or cons more important to me? (please circle)

Pros more important



Cons more important

Personal response

Your thoughts
on each point

Level of importance

How important each
point is to you

1 2 3

1 2 3

1 2 3

1 2 3

1 2 3

1 2 3

1 2 3

1 2 3

1 2 3

1 2 3

1 Not
Important

2 Somewhat
Important

3 Very
Important

Further resources.

“In some ways, I feel strengthened by what I’ve had, all that I’ve been through. I can see a lot of kindness in people that I couldn’t see before. I can see sort of a companionship, particularly in people who have the same condition or any type of cancer. I think somehow I just feel stronger mentally than I did before.”

Many people seek information on the internet and over the phone about ovarian cancer treatments, research and support services. Not all information is accurate or reliable, so make sure you discuss any questions, ideas or concerns with your healthcare team and ask them which sites they might recommend for you.

Listed below are contact numbers and websites of leading cancer organisations. As the information they provide can only be general and not specific to your situation, it is important to discuss any questions you have with your healthcare team.

INFORMATION & SUPPORT

Cancer Council Helpline

Phone: 13 11 20

Gynaecological Cancer Support

Website: www.gynaecancersupport.org.au

The National Ovarian Cancer Network Australia

Phone: 1300 660 334

Website: www.ovca.org.au

Cancer Institute NSW

Website: www.cancerinstitute.org.au/cancer_inst/patients/

Clinical trials.

“I wanted to know if there were any other treatments, and there was a new one being tested in a clinical trial.”

Your oncologist may sometimes suggest that you consider a clinical trial, perhaps for a new drug or combination of drugs and/or treatments. Clinical trials are used to evaluate the effectiveness and safety of new medical treatments and are a vital part of research. Many surgical techniques and drugs used today for ovarian cancer (i.e. current standard procedures) have been tested in clinical trials in the past.

Participating in clinical trials means you volunteer, along with a large group of people, to test out the new treatment. For some people clinical trials raise fears of “experimentation” or “being a guinea pig”. However, strict standards and protocols exist to govern how clinical trials are conducted. An ethics committee approves each clinical trial, and this committee makes sure that the rights and safety of the study participants are protected.

 *Some useful websites with information about clinical trials:*

Australian New Zealand Gynaecological Oncology Group (ANZGOG)
<http://www.anzgog.org.au/content.aspx?page=trialwhatis>

Australian Clinical Trials Registry
<http://www.anzctr.org.au/trialsearch.aspx>

Complementary and alternative medicine.

“*I consulted a dietitian and became a lot more careful about what I eat. I have always had a good diet, but I've changed some things, and now I feel better than I ever felt before in my life.*”

Most women reading this booklet will be very familiar with conventional medicine, which includes all medicine practiced by persons with a medical degree (e.g. your oncologist, surgeon or GP). It is also increasingly common for women to seek out complementary and alternative medicines to cope with the effects of recurrent ovarian cancer. Complementary and alternative medicines cover many therapies that are not part of conventional medicine, and are often used to manage the side effects of chemotherapy, psychological distress and symptoms of the disease.

Even though the terms 'complementary' and 'alternative' medicine are typically used together, there are differences between them.

Complementary therapies are used together with conventional medicine. Common types of complementary therapies include acupuncture, herbal medicines, homeopathy, naturopathy, nutritional therapy, counselling and psychological support, chiropractic manipulation, massage, yoga, music therapy, reflexology and relaxation techniques, such as meditation and visualization.

There is increasing evidence to support the benefits of some of these therapies. For example, relaxation techniques and counselling may assist with managing stress, anxiety and depression caused by treatment, and acupuncture may help chemotherapy side effects.

Alternative therapies are used in place of (as an alternative to) conventional medicine. These therapies may be harmful if the practitioner promotes extreme practices or encourages you to stop using conventional treatments while using these alternative therapies. Examples of alternative therapies include ozone therapy, high dose vitamins, melatonin, strict diets, and shark extract.

It is important that you speak with your doctors about your use of complementary and alternative therapies, because some may interfere with your current treatment or chemotherapy. It may also be helpful to put your healthcare team in contact with any providers of complementary or alternative therapies you use, so they can communicate with each other about your ongoing care.

 *Some useful websites with information about complementary and alternative medicine:*

Cancer Council - Website about complementary therapies

www.cancerCouncil.com.au/editorial.asp?pageid=1801

Memorial Sloan-Kettering Cancer Centre - Integrative Medicine Service

www.mskcc.org/mskcc/html/1979.cfm

National Center for Complementary and Alternative Medicine

<http://nccam.nih.gov/health>

National Cancer Institute (2006): Fact sheet: Complementary and Alternative Medicine in Cancer Treatment: Questions and Answers.

<http://www.cancer.gov/cancertopics/factsheet/Therapy/CAM>

Making the most of your time with your healthcare team.

“*I needed to get it all straight in my head before I could make any decision. The more questions I asked the more I understood, and the more confident I felt with the decision I made.*”

Making sure you are informed and have the answers you want will help you feel more in control of your treatment. Don't be afraid to ask your doctors the same questions again and again if you need to. The doctors will not know if you are confused about something or need more information unless you ask about it. Find out how you can get information outside of the consultations, as it is likely you will have more questions after you have had a chance to think things over. You can also ask your doctor about taping your consultation so you can listen to it again at a later stage.

QUESTIONS TO ASK YOUR HEALTHCARE TEAM

Below are some questions you may find helpful to go over with your healthcare team. You may like to use the checkboxes to mark the questions you would like to ask, and bring the list to your consultation.

- What is going on with my illness?
- What is the best way to manage it now?
- Do you recommend continuing with treatment?
- What treatment options do you recommend?
- What would be the “aim” of these treatment options?

- How likely is it that I'll benefit from each treatment option?
- How likely is it that the cancer will respond?
- How likely is it that I'll go into remission with this treatment and for how long?
- What side effects could I expect from treatment?
- Is there anything that can be done to treat these side effects?
- What has been the experience of other patients when receiving this treatment?
- How often will I need to come into the hospital for treatment?
- How long will the treatment last? When would we stop if it doesn't seem to be working?
- How do my existing health conditions affect my treatment?
- Will there be any costs associated with the treatment?
- How might my lifestyle be affected (e.g. daily activities, sexual life)?
- Can you recommend any other sources of information about the treatment options?
- Am I eligible for participation in clinical trials?
- What happens if I choose not to have treatment at this time?
- How will I be monitored? What would trigger starting treatment again?
- Can you help control my symptoms?
- How will my care be coordinated?
- What else can I do at this time?
- Could you recommend any complementary therapies that might assist?
- Who else will be available to support me?
- Can you give me any advice on how to cope better?
- Is there someone I can talk to who has been through this treatment?
- When will my next follow-up appointment be?
- Can I have a referral to the palliative care team?
- Is there any support available to help my partner/family?

Glossary of terms.

Alternative therapies: *These are used in place of (as an alternative to) conventional medicine.*

CA-125 (cancer-antigen 125): *A tumour marker that can be used to monitor the presence of ovarian cancer.*

Cancer: *A group of diseases characterised by the growth and spread of abnormal cells.*

Cells: *The basic structural and functional unit in people and all living things.*

Chemotherapy: *The use of drugs to destroy cancer cells.*

Chemotherapy cycle: *A session where a patient receives chemotherapy. A number of cycles normally make up a chemotherapy treatment course.*

Clinical trial: *A systematic research program conducted with patients to evaluate a medical treatment, drug, or device.*

Complementary therapies: *These are used together with conventional medicine.*

Cure: *To heal or eradicate disease.*

Diagnosis: *The identification of a disease from signs, symptoms, laboratory tests, radiological results and physical findings.*

Line: *A term used to describe an entire course of chemotherapy. Other commonly used terms include first-line, which is the first course of chemotherapy and second-line for the second course of chemotherapy, and so on.*

Palliative care: *Treatment that continues after a cure is no longer possible. Procedures are administered to relieve pain, manage symptoms and optimise quality of life.*

Peripheral neuropathy: *Damage to the nerve pathways that causes numbness, tingling, burning or weakness, usually beginning in the hands or feet. Peripheral neuropathy is a side effect of some types of cancer therapy.*

Platinum-based drugs: *Two platinum-based compounds that are marketed and clinically used worldwide as anti-tumour drugs: cisplatin and carboplatin. Platinum-based compounds are one of the more active chemotherapeutic agents available and are used for a variety of cancer types including ovarian cancer.*

Quality of life: *An individual's overall sense of well-being. This can often be related to a person's health perceptions and their ability to function.*

Recurrent ovarian cancer: *The reappearance or return of ovarian cancer.*

Refractory ovarian cancer: *Ovarian cancer that does not respond and continues to grow during chemotherapy.*

Remission: *Disappearance of signs and symptoms of cancer.*

Resistant cancer: *Failure of a cancer tumour to respond to a particular drug (also known as drug-resistance). It is often defined as cancer that returns less than 6 months from the end of the last line of chemotherapy.*

Response rate: *The percentage of patients whose cancer shrinks or disappears after a treatment.*

Risk: *A potential injury or harm to something that is of value, which, in this context, would be caused by the treatment choice.*

Sensitive cancer: *Cancer that is likely to respond to further chemotherapy drugs. It is often defined as cancer that returns more than 6 months from the end of the last line of treatment.*

Side effect: *Any effect caused by a drug that is different from the drug's intended effect, e.g. nausea.*

Stable disease: *When cancer remains stable (i.e. doesn't shrink in size, but also doesn't grow) during chemotherapy.*

Symptoms: *Any sensation or change in the body or its functions that is experienced by a patient and which tells them that something is wrong e.g. pain, bowel changes, bloating and loss of appetite.*

Tolerance: *The body's capacity to become less responsive to a drug, especially through repeated use or exposure.*

Treatment-free interval: *The period from the end of the last chemotherapy cycle until the start of the next chemotherapy cycle.*

Time to recurrence: *The time between your last completed chemotherapy cycle and a diagnosis of recurrent ovarian cancer.*

Tumour marker: *Substances that can often be detected in higher-than-normal amounts in the blood, urine or body tissues of some patients with certain types of cancers.*

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If you are interested in these papers, please ask a member of your healthcare team to help you access them.

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Note: It is against the law to photocopy or otherwise reproduce this booklet without the publisher's written permission. Authorisation may be sought by contacting Dr Ilona Jurásková at the below address:

Ilona Jurásková PhD, MPsych(Clin), BA(Hon)
Centre for Medical Psychology & Evidence-based Decision-making (CeMPED)
School of Psychology
Rm 341, Brennan MacCallum A18
The University of Sydney NSW 2006
AUSTRALIA

P +61 2 9036 5275
F +61 2 9036 5292
E ilona.juraskova@sydney.edu.au
W www.psych.usyd.edu.au/cemped

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