

Deciding whether or not to have immediate treatment

A decision aid for women who have had treatment for ovarian cancer and have rising CA-125 without any symptoms.



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This booklet and you

Why we developed this booklet

If you are reading this booklet you will have already been diagnosed and treated for ovarian cancer. At present, you will currently not have any symptoms related to the cancer or treatment, but you will have rising CA-125 levels, which may raise concerns about whether or not the ovarian cancer is returning. This booklet is designed to help explain the treatment options available to you and their benefits and risks. It also offers some advice on how to make the decision that will best suit your preferences, values and current situation.

This booklet is designed to add to, but not replace, any discussions that you may have with your oncologist, surgeon, GP, other members of your health care team and family, about the options available to you.

What's happening now...?

So far you will probably have had surgery with additional chemotherapy to treat ovarian cancer. You are now in what is called "regular follow-up". Generally, follow-up consultations are scheduled for every three months in the two years after initial treatment and then at six monthly intervals after that. Your medical team will have advised you of your follow-up schedule and will want you to contact them if you develop any unusual or worrying symptoms between appointments.

At follow-up consultations, the health care team monitors your progress and will be looking for signs of the cancer returning. For some women, the cancer will never come back. However, for a large portion of women it is likely to return. Whether or not the cancer returns will depend on a number of factors such as the stage of the cancer when you were diagnosed and your response to the initial treatment.



During follow-up consultations it is important that you discuss with your doctor any current symptoms or on-going side effects from previous treatment. You will also usually have both a physical examination and a blood test to measure a tumour marker called CA-125. This helps your medical team to assess whether the cancer has returned or is likely to return at some point in the future.

cancer cells and is released into the blood stream.

As part of your follow-up, you will have a blood test to assess your current levels of CA-125. It is normal to feel somewhat anxious before follow-up appointments and about the results of the CA-125 test. However, it is important to talk with your medical team if your anxiety is becoming overwhelming.

CA-125

What is CA-125?

Tumour markers are substances that are often detected in higher-than-normal amounts in the blood, urine or body tissues of some patients with certain types of cancer. CA-125 (cancer-antigen 125) is a tumour marker that can be used to monitor ovarian cancer. It is found on the surface of ovarian

What does a change in CA-125 mean?

There is no common agreement about how much increase in CA-125 levels is needed in order to indicate that the ovarian cancer has returned. Instead, for women who have been treated previously for ovarian cancer, the doctor will be looking for a **progressively (continually) rising or a significantly elevated CA-125 level.**



Your doctor will often 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:

- the CA-125 level when you were first diagnosed
- the CA-125 level at which you first experienced symptoms
- the rate that CA-125 levels decreased during treatment
- if the CA-125 level is now rising quickly or slowly and
- how large the recent rise in CA-125 level is
- whether the CA-125 continues to rise or remains the same when next tested

The results can often be difficult for patients to interpret and understand. It is best to discuss any questions you may have about CA-125 with your doctor.

The CA-125 test is NOT the whole picture

Although increasing CA-125 levels may mean that something is happening, it doesn't necessarily mean that there is a need to start treatment immediately.

CA-125 **cannot** give you answers about:

- When symptoms may come back
- The severity or spread of the cancer
- When to start treatment

The CA-125 level is just a "number", although an important one. It provides some information, but is not the whole picture.

When symptoms may come back.

The time between increasing CA-125 levels and the return of symptoms can vary greatly between women. On average, symptoms will return within five (5) months. Some women, however, can experience gradually increasing CA-125 levels over a long time (over two years) before there are any signs or symptoms.

The severity or spread of the cancer if it is confirmed to have returned.

While there may be a relationship between the size of the increase in CA-125 levels and the severity and spread of the cancer, often this is not the case. Sometimes those with high CA-125 levels may only have small tumours. Other women with larger tumours may show no increases, as they have tumours that produce little or no CA-125. In general, what clinicians will be looking for is the **rate** that the CA-125 levels are rising, rather than the numbers.

When to start treatment

A large European study compared starting chemotherapy in response to rising CA-125 levels alone with waiting until there were symptoms or other signs of recurrence. The results suggest that treating on the basis of CA-125 levels alone is unlikely to provide any long-term benefits.

“ The CA 125 is like being on a roller-coaster ride waiting for the ups and downs. ”

“ Because you know that it is an indication but it's not definite, I try and limit myself and how much I think about it. ”

Coping with rising CA-125

In your situation, you have been told that your CA-125 levels are rising but there are no other signs or symptoms that you have recurrent ovarian cancer. This can be a very challenging period because it may not be clear whether or not the cancer has returned, nor whether or not to start treatment.

This uncertainty can be very difficult for both you and your family to deal with. However, your doctor can provide you with guidance and recommendations about which of the available treatment options may suit your values and life situation.

You may have some of the same emotions that you felt when you received your initial diagnosis. Women commonly feel shocked by the news of rising CA-125 and fearful. Some women say they have other feelings as well, such as helplessness, denial, panic, anger, or guilt. Some women may find these emotions and treatment decisions overwhelming and difficult to manage. If you are finding it difficult to cope, it is important that you seek support from your family, friends, GP, surgeon, oncologist or other members of your health care team (nurse, psychologist or counsellor).

“ The second time round is a lot more realistic for you. I've been through a whole lot of emotions. I started reading a lot more things and talking with others, and this has helped me cope. ”

There are many ways to cope (with this situation) at this time.

Some women strive to maintain an optimistic attitude, some find acceptance of the situation helps and others find strength in their faith. Many women speak of trying to appreciate this symptom-free time and continuing to live each day as normally as possible.

One constructive way to cope is to empower yourself with information. The more informed you are, the easier it will be to decide what is best for you. The next pages will provide information about recurrent ovarian cancer, treatment options and decision making to help you with this process.

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 recurrent ovarian cancer

What is recurrent ovarian cancer and how is it diagnosed?

While recurrent cancer may not be confirmed in your case, it is helpful to know more about it so that you can make a more informed treatment decision.

Recurrent ovarian cancer refers to the reappearance or relapse of ovarian cancer after initial treatment. A diagnosis of recurrence is normally confirmed by a rising level of CA-125 **together with** other clinical evidence that the cancer has returned. This other clinical evidence can include



- (1) the return of symptoms such as abdominal swelling, bowel changes, pain or lack of appetite;
- (2) a change observed in a physical examination; or
- (3) changes on a CT, PET or ultrasound

Sometimes a woman may show some changes on a scan or symptoms without a rising CA-125. This may also indicate recurrence.

Recurrent ovarian cancer and second-line treatment plan and goals

When ovarian cancer is confirmed to have returned, a new series of chemotherapy treatment cycles (also known as “second-line” treatment) will normally be suggested and discussed. Second-line treatment plans can vary greatly from woman to woman depending on their medical history and other personal factors and may include the same or different drugs (see page 16 for more information). Your medical team will discuss your options in detail.

Recurrent ovarian cancer is unlikely to ever be “cured” by chemotherapy, as there are no known treatments that permanently eliminate recurrent ovarian cancer. However, women are now living many years with recurrent ovarian cancer, which is managed as a chronic disease.

Possible second-line treatment goals are to:

- achieve further remission(s);
- slow the progression of the disease (stabilise it) to prolong life;
- maintain and optimise quality of life, in other words, allow you to lead a normal life for as long as possible;
- slow the development or reappearance of symptoms of cancer; and /or
- remove or reduce symptoms related to the cancer when they do return.

The effectiveness of second-line treatment

The longer it has been between the completion of first-line chemotherapy and the start of second-line chemotherapy, the more likely it is that second-line chemotherapy will be effective.

The period between first and second-line treatment is known as the “treatment-free” interval. Previous studies have shown that women with a treatment-free interval of greater than 12 months generally have longer times between relapses and may, ultimately, live longer.

This is because their tumour is more likely to respond to treatment. These women will also have had a longer rest between



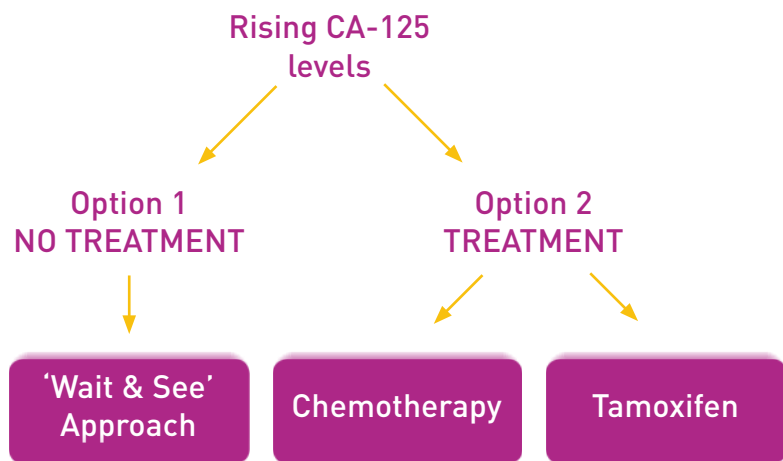
treatments, so may be more able to tolerate any potential side effects of chemotherapy and continue with the treatment for the duration of the recommended course.

Your options with rising CA-125 levels and with no symptoms

The information in this booklet can be helpful when you have rising CA-125 levels but the suspicion of recurrent ovarian cancer has not been confirmed by the presence of any symptoms or clinical signs.

The decision that you and your doctor now face is whether to:

- (1) start second-line treatment; or
- (2) postpone having second-line treatment until you have other signs or symptoms indicating the return of cancer



Note: Surgery is not an option now but might be at a later time if there are other signs of the return of cancer, e.g. evidence on a CT scan

Regardless of which option you choose, your medical team will ensure you get the best medical care



Which of these options are best for me?

At present, there is some evidence from a large European trial to suggest that starting treatment based on CA-125 levels alone is unlikely to provide any long-term benefits. **Your medical team will help you decide when it is a good time for you to start treatment**, based on their skills, experience and clinical "intuition". They will aim to balance the goals of treating the cancer and maintaining your quality of life for as long as possible. However, if your CA-125 levels are rising quickly or there are other signs or symptoms indicating that

the cancer has returned, initiating chemotherapy sooner rather than later may increase the chance that the cancer will respond to treatment and not grow too large. The ideal time to start is just before or just as symptoms reappear.

Once you have read through the next pages about the benefits, risks and side effects of the options it is important that you discuss your treatment plan with your health care team and ask how suitable each of these options might be for you.

Based on their clinical experience, your medical team will advise you about whether or not they believe a particular option should be considered.

Option 1:

'Wait and See' approach

A 'Wait and See' approach means that you will continue follow-up care without any treatment at this time. You will continue with follow-up visits and your health and CA-125 levels will be more frequently monitored by your medical team. You will be asked to contact your doctor or medical team at the first sign of any symptoms appearing or any changes to your well-being.

Potential BENEFITS of the 'Wait and See' approach

No differences to longer-term outcomes

There is some evidence to suggest that waiting until there are other signs and symptoms of recurrence before starting treatment will make no difference to your longer-term outcomes.

No side effects, so you can maintain your current quality of life

As you are not receiving treatment, you will not experience any of the side effects, risks or inconveniences associated with any of the treatments. You will be able to maintain your current quality of life.

By delaying chemotherapy, you will be increasing the treatment-free interval, on average for an additional 5 months until symptoms appear. This may lead to:

- **more effective treatment later on**

You will have more time to lose any resistance to the chemotherapy (where the cancer no longer responds to the drugs) that was built up from when you had your last treatment. This can mean any additional chemotherapy later on may be more effective as the tumour may be more likely to respond.

- **more time to recover from the effects of chemotherapy**

Your body's ability to cope with the side effects of chemotherapy will

increase, and you may be less likely to experience side effects if you need chemotherapy later.

- **fewer treatments**

As you are delaying the start of treatment until there are other signs or symptoms of ovarian cancer, it is likely that you will have fewer rounds of treatment over the course of the disease than if you started treatment now.

Potential SIDE EFFECTS and RISKS of the 'Wait and See' approach

- **If you delay treatment, there may be a risk that the cancer will continue to develop (if it has returned)**

There is a risk that cancer cells may continue to multiply during the time that you are waiting for symptoms or signs to confirm the return of cancer. If the cancer is left too long and grows too big, it may not respond as well to treatment and there may be additional cancer-related complications. However, your doctor is aware of these risks and will be closely monitoring you to determine if there are any changes that would indicate the cancer is growing and the need to start treatment soon.

- **There may be some anxiety if you do nothing**

Some women find it difficult to wait for treatment and prefer to be more actively doing something when they have rising CA-125 levels. They may feel they want to start treatment immediately.



Option 2: Chemotherapy

Chemotherapy is the use of drugs to destroy cancer cells.

There are a number of different chemotherapy drugs that can be used either by themselves or in combination as part of second-line treatment. Your oncologist will make recommendations about which chemotherapy drugs are best to be used in your situation. **This will depend on:**

- the severity of your initial cancer;
- whether there was any remaining disease when the initial treatment ended;
- how long it has been since your last treatment (different drugs will be recommended if it has been less than 6 months from your last treatment);
- side-effects of previous treatment;
- if the cancer is present in other parts of your body;
- other personal factors like your age and general health;
- your treatment preferences, values and life situation; and
- whether you are taking part in a clinical trial.

Chemotherapy schedule: How and when the chemotherapy will be given will depend on which treatment drugs your doctor recommends. This will be determined during the planning process.

Potential BENEFITS of chemotherapy

- **There is less chance that the cancer will be left too long, grow too big, and therefore not respond as well to treatment later on.**
- **There is no evidence that chemotherapy will slow the return of cancer-related symptoms but it may reduce the risk of developing symptoms or complications that require hospitalisation.**

It is possible that even though cancer cells may respond to chemotherapy (e.g., slowing their growth), you may still experience some symptoms such as pain, bowel changes, bloating and loss of appetite. You may then require further cycles of treatment to alleviate these symptoms. There is evidence, however, that early chemotherapy may reduce the risk of developing more severe cancer-related problems and the need for hospitalisation.

What we know about Chemotherapy when recurrence has been confirmed:

Even though recurrent cancer may not have been confirmed in your case yet, it may be helpful for you to have some information about the effects of chemotherapy for women where recurrent ovarian cancer has been **confirmed**. This may help you make a decision about whether chemotherapy is right for you at this moment in time.

Benefits:

Where recurrence has been **confirmed**, chemotherapy may:

- reduce or stabilise the cancer. This means that the cancer stops developing for a period of time. You may have a break in treatment and return to being regularly monitored;
- be used to manage the symptoms associated with the return of cancer.

Chemotherapy **will not** be able to “cure” or completely remove the cancer. Instead it may be able to help slow the spread of disease, achieve further remissions, prolong life, manage symptoms and optimise quality of life.

Response:

A **good response** to chemotherapy means that the tumour either disappears, shrinks or gets smaller, or remains stable (doesn't grow bigger). The number of women who may respond to chemotherapy will vary greatly depending on the “treatment-free” interval (time between first and second treatments). When the treatment free time has been longer than 24 months, up to 70% of women (70/100) can be expected to show a good response. When the treatment-free period is short (less than 6 months), about 10-20% of women (10-20/100) show a good response.

Potential SIDE EFFECTS and RISKS of chemotherapy

Chemotherapy may cause unwanted side effects. Each woman will respond differently to this treatment; some have few side effects, whereas others may experience many. While you are having chemotherapy, it is important that you let your doctor know if you are experiencing any side effects, so that they can discuss ways to alleviate or minimise them.

There are a number of chemotherapy drugs that can be used as part of second-line treatment, each with highly variable side effects. For this reason, we can only provide a general indication of the side effects you could experience. Your oncologist will tell you in detail about how likely you are to experience side effects with each of the chemotherapy options available, and how long they may last.

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 and bleeding, and anaemia
- Rashes
- Sad or unhappy moods due to the experience of having chemotherapy
- Redness and soreness of hands

and feet (hand foot syndrome)

- Tingling and numbness of the hands and/or feet caused by nerve damage (peripheral neuropathy)
- Joint and muscle pain

Rare but potentially serious side effects

(These will require immediate medical care)

- Infections requiring hospitalisation
- Heart attack or stroke
- Blood clots (thrombosis)
- Severe diarrhoea

Ongoing (chronic) side effects

- Alterations in kidney function or kidney damage
- Alterations in hearing

The specific risk of individual side effects will depend on the chemotherapy drugs used for second-line treatment. Your doctor will be able to discuss the potential side effects of your chemotherapy regime with you.

Other potential RISKS of chemotherapy

By starting treatment when CA-125 levels are rising and with no accompanying symptoms, it is likely that you will start treatment around **five months** earlier than if you had waited.

There is also a risk that you will increase the number of times that you will have chemotherapy for recurrent ovarian cancer than if you were treated on the basis of symptoms alone. The number of times a person has had previous treatments may affect how well future chemotherapy cycles will work.

Some reasons for this are:

- Every time you have additional chemotherapy, you are at increased risk of experiencing side effects.

Your doctor will help assess how likely this will be based on your age, general health, chemotherapy drugs chosen, reactions to previous chemotherapy and length of time from last treatment.

- There is a risk with each course of chemotherapy that your body may become less able to cope with the side effects and toxicities associated with treatment.

There will be a limit to the amount of chemotherapy that your body will be able to handle. There is a risk that if you have chemotherapy too soon with rising CA-125 levels, your chemotherapy options may be limited later when they may be of more benefit, such as when symptoms or a visible tumour returns.

- There is a risk with each course of chemotherapy that your body may develop resistance to the chemotherapy drugs.

This may limit your chemotherapy options later when they would be of more benefit, such as when symptoms appear or there is a tumour visible on scans.

Option 3: Tamoxifen

Tamoxifen is a drug that can be given to women to prevent the hormone oestrogen entering into cancer cells. There is evidence that in some cases oestrogen may be responsible for encouraging ovarian cancer cells to divide and grow.

Tamoxifen is routinely used to treat and prevent breast cancer by stabilising the tumour, so it doesn't increase or decrease in size. Tamoxifen has been shown to have a similar effect on ovarian cancer cells. Tamoxifen is given to potentially stop further cancer growth by preventing the action of oestrogen on the cancer cells.

Increasingly other hormonal drugs are now being offered to women with ovarian cancer, for example, Letrozole.

If you decide to take Tamoxifen:

- You will be asked to take one tablet of Tamoxifen a day.
- You will continue to attend a follow-up consultation with a gynaecological oncologist every 1 to 3 months.
- The frequency of follow-up consultations would alter if there were significant changes to your CA-125 levels.

Potential BENEFITS of Tamoxifen

- **Easy to take**
Tamoxifen is taken as a tablet at home, so there is no need to visit a hospital or cancer centre for treatment.
- **In post-menopausal women Tamoxifen may prevent bone thinning (Osteoporosis).**



- **Tamoxifen may help prevent heart disease and lower cholesterol levels, but there is no sufficient evidence to support this yet.**

What we know about Tamoxifen when recurrence has been confirmed:

Even though recurrent cancer has not yet been confirmed in your case, it may be helpful for you to have some information about the effects of Tamoxifen for women where recurrent ovarian cancer has been **confirmed**. This may help you make a decision about Tamoxifen which is right for you at this moment in time.

Benefits:

Where recurrence is **confirmed**, Tamoxifen has been shown to shrink or stabilise ovarian cancer in some women. This may mean a period of time until the cancer develops further and more aggressive treatment is necessary. Tamoxifen **will not** be able to "cure" or completely remove the cancer.

Response:

A **good response** to tamoxifen means that the tumour either disappears, shrinks or gets smaller, or remains stable (doesn't grow bigger). For **confirmed** recurrent ovarian cancer, 10-20% of women may respond to Tamoxifen (i.e., 10-20 women out of 100).

Potential SIDE EFFECTS and RISKS of Tamoxifen

Tamoxifen can cause unwanted side effects. Each woman responds differently to this treatment. Many women have very few or no side effects, others may experience more. While taking medication, you are carefully monitored for any side effects and your doctor can discuss ways of lessening their impact.

Common side effects

(about 1 in 3 women experience these)

- **Menopausal-like symptoms (hot flushes, vaginal dryness, vaginal discharge and vaginal itchiness)**

Menopausal-like symptoms are fairly common but are usually mild and disappear when tamoxifen is no longer taken. Hot flushes can also occur in women who have already gone through menopause. Usually these side effects are not severe enough to require a reduction in the dose given or discontinuation of treatment.

- **Nausea and vomiting**

Some women feel nausea and vomiting when they first start taking the medication but this will normally end after the first three weeks. Speak to your doctor if the nausea is severe or if it continues.

Rare but potentially serious side effects

(about 1-2 in 1000 women experience these)

- **Blood clots**

Tamoxifen may double the risk of blood clots, particularly in the veins of the legs. If these clots break loose, they can block smaller vessels in the heart, lungs and brain. This can be prevented to some extent by exercise and treatments prescribed by your doctor. Clots are most common at times when you are immobilised, such as for an operation or a leg fracture. Talk to your doctor about stopping tamoxifen temporarily in these circumstances.

- **Changes in vision**

Women taking tamoxifen may be at a very slight increased risk of developing cataracts or retinopathy (a condition affecting the retina of the eye).

Your doctor will discuss side effects of tamoxifen with you.

“ It’s a bit of a dilemma. The doctor said ‘you know you’re really well, and if we started chemo now all we’d be doing is making you feel sick again.’ ”



“ When the doctors offered me more treatment, 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. ”

	What is involved?	Benefits	Side effects	Other risks
Wait and See approach	<ul style="list-style-type: none"> Continuing regular visits to the doctor No treatment for cancer at this time 	<ul style="list-style-type: none"> No differences to longer-term outcomes It will extend the treatment free interval so chemotherapy is potentially more effective later on. The body has more time to recover and it is likely that you will receive fewer treatments over time No treatment side effects, so current quality of life is maintained 	None	<ul style="list-style-type: none"> If present, cancer may continue to develop since it is untreated, which may cause complications There may be some anxiety for you while waiting to start treatment
Chemotherapy	<ul style="list-style-type: none"> Continuing regular visits to the doctor Need to undergo chemotherapy 	<ul style="list-style-type: none"> Effectiveness is not confirmed for a diagnosis based on rising CA-125 levels alone. Where recurrence is confirmed chemotherapy may reduce the size or slow the growth of (stabilise) cancer in recurrent ovarian tumours May help you to avoid developing cancer-related problems that would require hospitalisation 	<p>Common side effects</p> <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 Sad or unhappy moods Redness and soreness of hands and feet (hand foot syndrome) Tingling and numbness of the hands and/or feet caused by nerve damage (peripheral neuropathy) Joint and muscle pain <p>Rare but potentially serious</p> <ul style="list-style-type: none"> Infections requiring hospitalisation Heart attack or stroke Blood clots (thrombosis) <p>Ongoing (chronic) side effects</p> <ul style="list-style-type: none"> Alterations in kidney function or kidney damage Alterations in hearing 	<ul style="list-style-type: none"> Treatment will start around five months earlier than if you had waited Increased risk of experiencing side effects with each treatment May develop resistance to future chemotherapy, or your body may become unable to cope with the side effects associated with treatment May have more courses of chemotherapy over time
Summary of the available options				
Tamoxifen	<ul style="list-style-type: none"> Continuing regular visits to the doctor A tablet taken once a day 	<ul style="list-style-type: none"> Effectiveness is not confirmed for a diagnosis based on rising CA-125 levels alone. When recurrence is confirmed, tamoxifen may slow the growth of recurrent ovarian cancer in about 10-20% of women Easy to take (at home) May prevent bone thinning (osteoporosis) 	<p>Common</p> <ul style="list-style-type: none"> Menopausal-like symptoms Nausea and vomiting <p>Rare but potentially serious</p> <ul style="list-style-type: none"> Blood clots (thrombosis) Changes in vision 	None

Decision making

Making the right decision for you

The previous pages have outlined the main options available to you: the 'Wait and See' approach, chemotherapy and tamoxifen, and their potential benefits, risks and side effects. Not everyone will feel the same about what to do next. Some may be willing to put up with the side effects of treatment in exchange for the peace of mind that they have started chemotherapy. Others may feel the trade-off isn't worth it in terms of the impact of treatment on their quality of life.

The following steps may help when you are deciding which option suits you best:

- (1) Understand what it means to have increasing CA-125 levels without any other signs of recurrence of ovarian cancer
- (2) Understand your current options and the benefits, side effects and risks of each option
- (3) Review the pros and cons of each option
- (4) Assess the importance to you of the pros and cons of each option
- (5) Get more information and clarify any uncertain areas
- (6) Work out which option appeals to you most
- (7) Decide on the level of involvement that you want from your doctor and tell them your preferences

Who should make the decision about whether or not to start chemotherapy?

Some people prefer to leave decisions about their medical care up to their doctor. Others prefer to decide for themselves. 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 then discuss this with your doctor so that they can advise you in the most appropriate manner.

“ You think well, what's important in life? Is it really important that I do this, or are there other things? ”

“ I guess it's clearing the decks and getting organised, but I try and live each day and be as positive as I can. ”

This worksheet starts with examples of how some women view the pros and cons of the options available (next six pages). This is followed by your own worksheet where we invite you to list the pros and cons of the statements and rate how important these are to you.

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 statement has three options beneath it describing how important each statement is to you. By circling one of the options you can indicate (and see at a glance) how important each issue is to you:

Circling **Very important** → the issue is **a very big concern** to you

Circling **Somewhat important** → the issue is **a small concern**

Circling **Not important** → the issue is **no 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 to her), she circles somewhat important.

.....

I will have to cope with the short-term side effects
"I think I'll be able to handle that"

Not Important **Somewhat Important** Very Important

.....

At the bottom of the worksheet you can indicate (by circling one of the 7 diamonds) which way you are leaning in your decision.

Where am I leaning: Taking the 'Wait and See' approach ◆◆◆◆◆◆◆ Taking a treatment option

By circling the 4th diamond, this person is indicating she is still unsure about the 'Wait and See' approach.

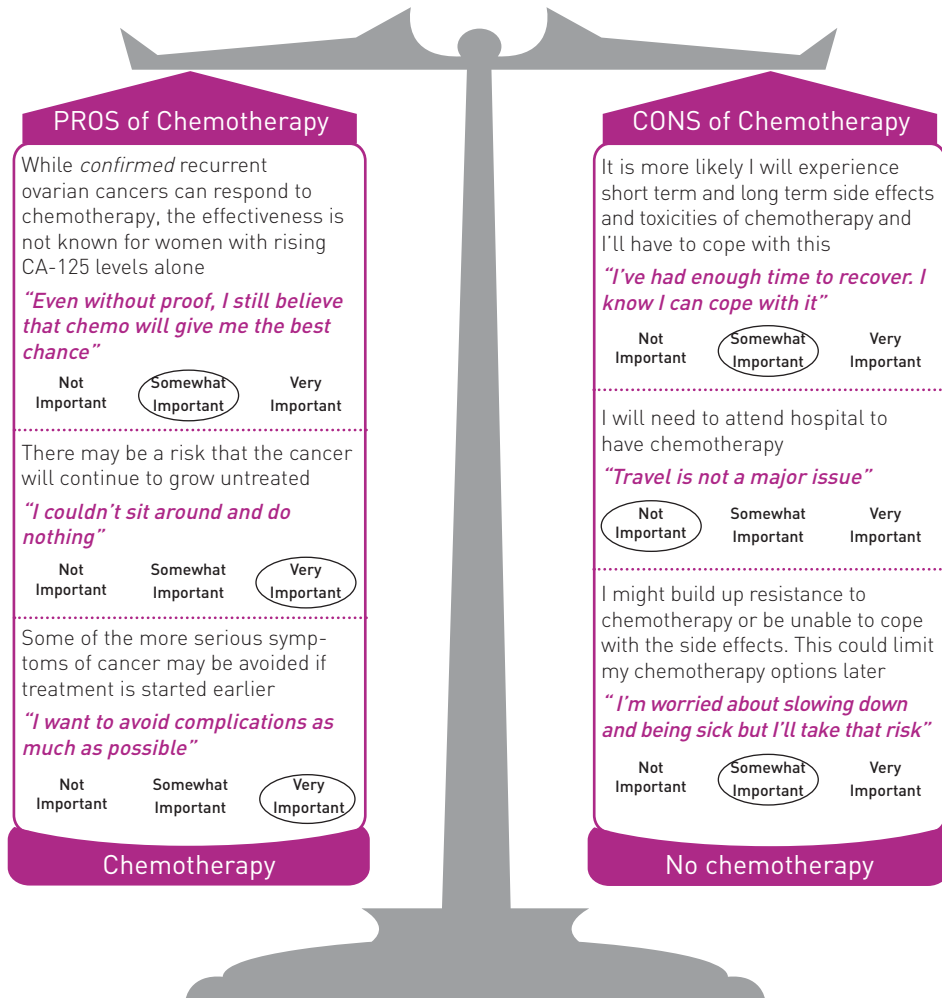
Angela's thoughts: "Will the 'Wait and See' approach suit me?"

PROS of 'Wait & See'	CONS of 'Wait & See'
It will extend the treatment-free interval, so if I need chemotherapy later it may be more effective <i>"I want cancer to be actually confirmed so I know it's the appropriate time to start treatment"</i> Not Important Somewhat Important Very Important	There may be a risk that the cancer continues to grow untreated <i>"I want cancer to be confirmed, so I know it's time to start treatment"</i> Not Important Somewhat Important Very Important
By extending the treatment-free interval my body will have more time to recover and I may have less treatments <i>"I'm still recovering from the last chemo, so I want to avoid treatment for now"</i> Not Important Somewhat Important Very Important	I will experience anxiety if I know that I have rising CA-125 levels and am not doing anything about it <i>"I might worry sometimes but think I can handle this"</i> Not Important Somewhat Important Very Important
No side effects, risks or inconveniences of treatment, so I can maintain my current quality of life <i>"I really want to enjoy this healthy time without treatment and symptoms for as long as possible"</i> Not Important Somewhat Important Very Important	
'Wait & See' Approach	Treatment

Any further questions? *Will I see the doctor more frequently?*

Where is Angela leaning? 'Wait and See' Approach ◆◆◆◆◆◆◆ Treatment

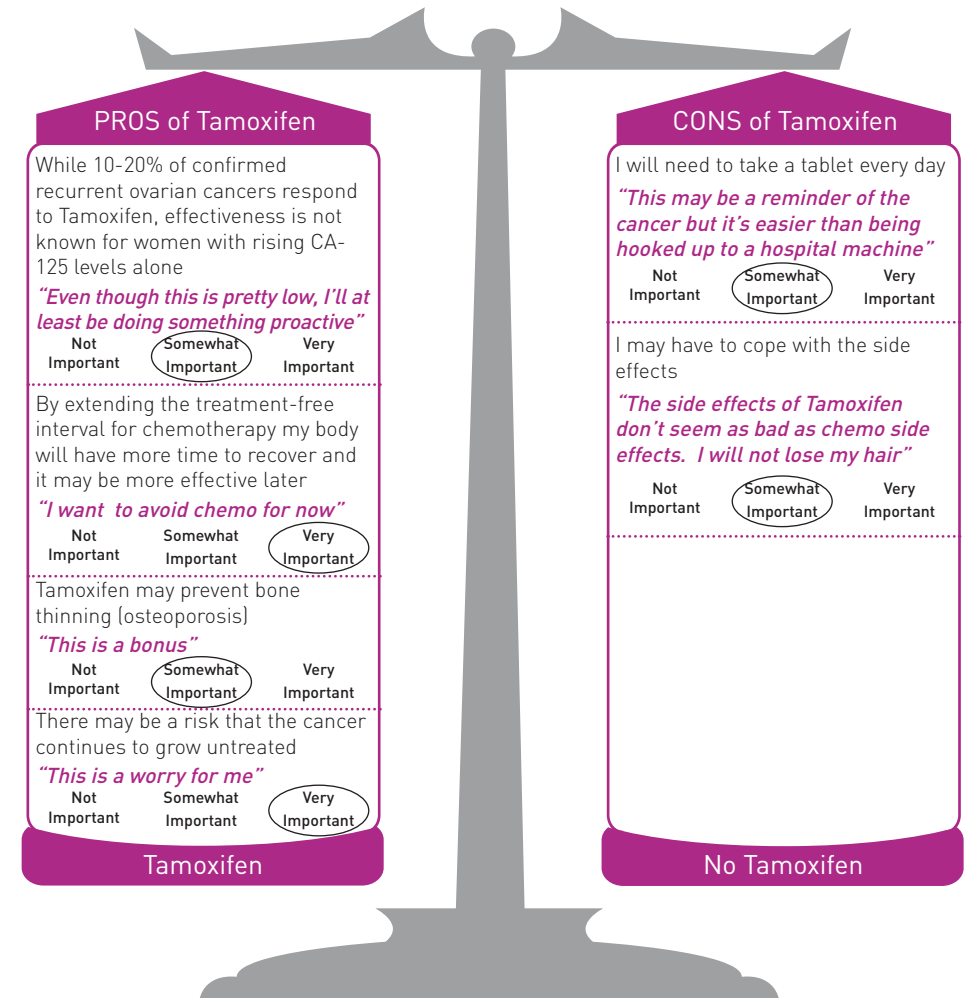
Judith's thoughts: "Will chemotherapy suit me?"



Any further questions? *Which drugs would the doctor recommend for me?*

Where is Judith leaning? Chemotherapy No chemotherapy

Anna's thoughts: "Will Tamoxifen suit me?"



Any further questions? *Will it react with my blood pressure medication?*

Where is Anna leaning? Tamoxifen No Tamoxifen

“Will the ‘Wait and See’ approach suit me?”

PROS of ‘Wait & See’

It will extend the treatment-free interval, so if I need chemotherapy later it may be more effective

Not Important Somewhat Important Very Important

By extending the treatment-free interval my body will have more time to recover and I may have less treatments

Not Important Somewhat Important Very Important

No side effects, risks or inconveniences of treatment, so I can maintain my current quality of life

Not Important Somewhat Important Very Important

‘Wait & See’ Approach

CONS of ‘Wait & See’

There may be a risk that the cancer continues to grow untreated

Not Important Somewhat Important Very Important

I will experience anxiety if I know that I have rising CA-125 levels and am not doing anything about it

Not Important Somewhat Important Very Important

Treatment

Any further questions?

Where are you leaning?

‘Wait and See’ Approach ◆◆◆◆◆◆ Treatment

“Will chemotherapy suit me?”

PROS of Chemotherapy

While *confirmed* recurrent ovarian cancers can respond to chemotherapy, the effectiveness is not known for women with rising CA-125 levels alone

Not Important Somewhat Important Very Important

There may be a risk that the cancer will continue to grow untreated

Not Important Somewhat Important Very Important

Some of the more serious symptoms of cancer may be avoided if treatment is started earlier

Not Important Somewhat Important Very Important

Chemotherapy

CONS of Chemotherapy

It is more likely that I will experience short term and long term side effects and toxicities of chemotherapy and I’ll have to cope with this

Not Important Somewhat Important Very Important

I will need to attend hospital to have chemotherapy

Not Important Somewhat Important Very Important

I might build up resistance to chemotherapy or be unable to cope with the side effects. This could limit my chemotherapy options later

Not Important Somewhat Important Very Important

No chemotherapy

Any further questions?

Where are you leaning?

Chemotherapy ◆◆◆◆◆◆ No chemotherapy

YOUR WORKSHEET

“Will Tamoxifen suit me?”

PROS of Tamoxifen			CONS of Tamoxifen		
While 10-20% of confirmed recurrent ovarian cancers respond to Tamoxifen, effectiveness is not known for women with rising CA-125 levels alone			I will need to take a tablet every day		
Not Important	Somewhat Important	Very Important	Not Important	Somewhat Important	Very Important
By extending the treatment-free interval for chemotherapy my body will have more time to recover and it may be more effective later			I may have to cope with the side effects		
Not Important	Somewhat Important	Very Important	Not Important	Somewhat Important	Very Important
Tamoxifen may prevent bone thinning (osteoporosis)					
Not Important	Somewhat Important	Very Important			
There may be a risk that the cancer continues to grow untreated					
Not Important	Somewhat Important	Very Important			
Tamoxifen			No Tamoxifen		

Any further questions?

Where are you leaning?

Tamoxifen No Tamoxifen



“ This booklet has been just the tool I needed to help me make my decision. My doctor is really good but this just explained it all in more detail.

I'm now aware of what I may have to face in the future, what my options are and what's important to me. ”

Further contacts/ Information

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.

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

Research/Information

Cancer Institute NSW

Website: www.cancerinstitute.org.au

Go Fund (Gynaecological Oncology)

Phone: 02 9382 6283 Website: www.gofund.org.au

Gynaecological Cancer Society

Website: www.gcsau.org

Ovarian Cancer Research Foundation

Phone: 1300 OVARIAN (1300 682 742) Website: www.ocrf.com.au

Ovarian Cancer Program - National Breast & Ovarian Cancer Centre (NBOCC)

Phone 02 9036 3030 Website: www.ovariancancerprogram.org.au

Sydney Cancer Centre Foundation

Phone: 02 9515 6018 Website: www.sydneycancer.com.au



Support/Information

Cancer Council Helpline

Phone: 13 11 20

Gynaecological Cancer Psychological Support Services

Website: www.gynaecancersupport.org.au

OvCa Australia - The National Ovarian Cancer Network Australia

Phone: 1300 660 334 Website: www.ovca.org.au

“ 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 that I didn't see before. I think somehow I just feel stronger mentally than I did before. ”

The development and evaluation of this Decision Aid has been funded by the Sydney Cancer Centre Foundation and the Cancer Institute NSW. It has been reviewed and endorsed by OvCa Australia. We appreciate the generous support of all these organisations.

References

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

Armstrong, D. K. (2002). Relapsed ovarian cancer: Challenges and management strategies for a chronic disease. **The Oncologist**, 7 (Suppl 5), 20-28.

Fleming, L. W. (2001). Playing the waiting game: The asymptomatic patient with recurrent ovarian cancer detected only by rising CA-125 levels. **Scottish Medical Journal**, 46, 81-83.

Goonewardene, T. I., Hall, M. R., Rustin G. J. S. (2007). Management of asymptomatic patients on follow-up for ovarian cancer with rising CA-125 concentrations. **The Lancet Oncology**. 8(9), 813-21.

Gore, M. E., Fryatt, I., Wiltshaw, E., & Dawson, T. (1990). Treatment of relapsed carcinoma of the ovary with cisplatin or carboplatin following initial treatment with these compounds. **Gynecologic Oncology**, 36(2), 207-211.

Harries, M., & Gore, M. E. (2002). Part II: Chemotherapy for epithelial ovarian cancer-treatment of recurrent disease. **Lancet Oncology**, 3(9), 537-545.

Markman, M., & Bookman, M. A. (2000). Second-line treatment of ovarian cancer. **The Oncologist**, 5(1), 26-35.

Markman, M., Rothman, R., Hakes, T., Reichman, B., Hoskins, W., Rubin, S., et al. (1991). 2nd-line platinum therapy in patients with ovarian cancer previously treated with cisplatin. **Journal of Clinical Oncology**, 9(3), 389-393.

Markman, M., Webster, K., Zanotti, K., Rohl, J., & Belinson, J. (2004). Use of tamoxifen in asymptomatic patients with recurrent small-volume ovarian cancer. **Gynecologic Oncology**, 93(2), 390-393.

O'Connor AM, Roston H, Fiset V. et al. (1999). Decision aids for patients facing health treatment or screening decisions: Systematic review. **British Medical Journal**, 319, 731-34.

Peters-Engl C, Obermair A, Heinzl H, Buxbaum P, Sevelde P, Medi M. (1999). CA 125 regression after two completed cycles of chemotherapy: Lack of prediction for long-term survival in patients with advanced ovarian cancer. **British Journal of Cancer**, 81, 662-6.

Rustin, G. J., & van der Burg, M. E. (2009) A randomized trial in ovarian cancer (OC) of early treatment of relapse based on CA125 level alone versus delayed treatment based on conventional clinical indicators (MRC OV05/ EORTC 55955 trials). **Journal of Clinical Oncology**, 27:18s (suppl; abstr 1).

Vasey, P. A. (2005). Management of recurrent epithelial ovarian carcinoma, **Australian and New Zealand Journal of Obstetrics and Gynaecology**, 45, 269-277.

Glossary of terms

Anaemia: A condition in which the number of red blood cells are lower than normal. Symptoms of anaemia include feeling tired, weak, and short of breath. Anaemia is a side effect of some types of cancer therapy.

Bone marrow: The soft tissue found in the hollow interior of bones. In adults, marrow in large bones produces new blood cells.

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.

Cure: To heal or restore health and to remove disease.

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

Diarrhoea: Frequent and watery bowel movements. Diarrhoea can be a side effect of some types of cancer therapy.

Follow-up: Monitoring a person's health over time after treatment.

Gynaecological oncologist: A doctor who specialises in obstetrics and gynaecology and who provides comprehensive management for women with a gynaecologic cancer.

Hormone: An active chemical substance formed in one part of the body and carried in the blood to other parts of the body where it affects the function of cells.

Intravenous infusion: Intravenous (IV) chemotherapy is injected into a vein. A small needle is inserted into a vein on the hand or lower arm. The needle is usually attached to a small tube called an IV line, which delivers the drug to the needle from an IV bag or bottle.

Monitoring: Within a medical context this means carefully observing, measuring and recording information to determine if there are any changes.

Medical oncologist: A doctor who specialises in diagnosing and treating cancer using chemotherapy and hormonal therapy.

Nausea: The feeling of sickness or discomfort in the stomach that may come with an urge to vomit. Nausea is a side effect of some types of cancer therapy.

Oestrogen: Female sex hormone produced primarily by the ovaries.

Ovarian cancer: Cancer that occurs in a woman's ovary.

Peripheral neuropathy: Damage to the nervous system 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.

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

Recurrent ovarian cancer: The reappearance or relapse of ovarian cancer.

Remission: Disappearance of signs and symptoms of cancer.

Resistance: Failure of a cancer tumour to respond to a particular treatment.

Response rate: The percentage of patients whose cancer stabilises, shrinks or disappears after treatment.

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

Second-line treatment: A treatment program undertaken after the completion of the initial treatment regime for any relapses.

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

Stabilise: To keep from changing for a period of time.

Surgeon: A doctor specialised in performing surgery.

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.

Tamoxifen: A drug treatment that can be given to prevent the hormone oestrogen from entering cancer cells. It is most commonly used for breast cancer but has been shown to have an effect on ovarian cancer in some women.

Thrombosis: The development of a blood clot. Thrombosis is a side effect of some types of cancer therapy.

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

Toxicity: A negative (adverse) effect produced by a drug that is harmful to the patient's health.

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

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 cancer.

'Wait and See' approach: An approach to care that involves continuing with follow-up and monitoring without any treatment at this time. Also known as 'watchful waiting'.

