**How to use this guide**

This guide is for women with recurrent ovarian cancer or whose cancer did not respond to first treatment. It focuses on your practical and emotional needs at this time. Each section has been marked with coloured tabs to help you choose the information you wish to read.

You may also find some useful information in our guide *What Happens Next?* – for women with a recent ovarian cancer diagnosis.

Throughout the guide we have included tips and experiences from both women who have been through what you are facing, and their families. We would like to thank Janet, Penelope, Eilish and her family, Mary, Emma, Yvonne and David, Carol and Joy for sharing their insights into the impact of recurrent ovarian cancer on their lives. We hope their words will help you feel you are not alone.

If there is something you wish to know about ovarian cancer that is not included, or for information about additional support provided by Target Ovarian Cancer please get in touch on 020 7923 5475 or info@targetovariancancer.org.uk and ask for our Supportive Services team.

Warmest wishes
From all of us at Target Ovarian Cancer

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Within each section of this guide is a feature called **How you might feel**. These are written by Dr Alison Farmer.

“I originally trained as a nurse and later switched to research. I completed a PhD, looking at the psychological aspects of breast cancer, in 1996. After working as a Teaching Fellow at the University of Southampton for a number of years, teaching psychosocial oncology, I recently decided to return to nursing and put some of the theory into practice. I was diagnosed with ovarian cancer in 2001 and my experience of surgery and chemotherapy has given me valuable insight into the physical and psychological consequences of the disease.”

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**Throughout this guide we refer to:**

- **Your oncologist**: The person who organises chemotherapy or other treatments. Oncologists are sometimes referred to as clinical or medical oncologists.

- **Your surgeon**: The person in charge of your operation or surgery. Surgeons are sometimes referred to as gynaecological oncologists.

- **Your clinical nurse specialist (CNS)**: A senior nurse who has had extra training to look after women with gynaecological cancers. In some areas a gynae-oncology CNS may not be available, in which case you may be cared for by a gynaecology nurse.

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We would like to thank the Chicky Alexander Van Hay and Geoffrey Van Hay Fund for generously supporting the development of the content of this guide.
Dealing with the news

Some people find the news that cancer has returned (or recurred) more upsetting than the original diagnosis. You may still be recovering from your initial treatment or you may have hoped that cancer was far behind you. Some people find that their mind freezes and others experience strong emotions such as intense fear and worry. Everyone is different but no-one wants to be back here again.

It can be very difficult to take in specific information at this time. You may find you forget a good deal of what you are told, so never feel afraid to contact your CNS, oncologist or surgeon to request information or to ask for any details to be written down.

You may be anxious to begin treatment immediately or you may want to take time out to consider different options. In some situations your medical team may choose to delay treatment. You can read more about this in the Treatment options section of this guide.

A small warning for those of you who use the internet – much of what you read about ovarian cancer can be shocking, and statistics can paint a very grim picture. It is important to remember that there are many different types of ovarian cancer and different women will respond in different ways. Sometimes this is based on stage and grade and sometimes on factors that we don’t yet understand. You are an individual, not a statistic.

Sharing the news

The way in which you receive the news of your recurrence may affect how you share this news with others. If family or friends are with you then this may happen naturally. For women who receive the news when alone, sharing the details can feel an extra burden, especially if you are unsure of quite what it means. There is no right or wrong way to share these details, or what you choose to share. You may wish to wait a few days before you tell others, or to restrict the information to close family or friends, or to ask someone close to you to let others know on your behalf.

You may have found from your initial diagnosis that people around you can react in very different ways. Some people may be wary of raising the subject with you, while others will want to talk about nothing but your condition. Don’t be afraid in either case to let people know when you do, or don’t, want to talk. You may find that people around you attribute labels such as ‘brave’ and ‘courageous’. They may tell you they could never cope as you have. The reality is we all cope in our own way with what life throws at us. Whatever you feel about this, good or bad, be kind to yourself and acknowledge that initially at least, responses from others will vary but are likely to be well intended.

Sharing the news can help you to make the necessary arrangements for support during treatment. It is the first stage to enlisting the help of those close to you. Preparing for lack of energy or other side effects can help to make this time a lot easier.

If you live alone and without family close by, you may find this time particularly challenging. Travelling to and from appointments and having low energy levels can make life difficult. Even if you value your independence, asking others for practical help such as running errands, assisting with lifts or shopping can be invaluable. You may find that many people are happy to help in this way including friends, colleagues or neighbours. You may want to seek practical assistance from your local community or faith group during this time. These groups are often used to providing support for others and often operate a rota to support those travelling to and from hospital. You may also find that your local council offers services which can be useful during this time.
“I was just beginning to think I might be one of the lucky ones and when it came back I just got such a bang down to earth because it is a hell of a shock.” Yvonne
Check with your local hospital information centre, CNS or GP to find out what services are available to you.

There is an increasing awareness today that cancer affects your mind and emotional wellbeing as well as your body. Some people may become depressed or suffer from anxiety.

When we feel this way it can seem impossible to explain these feelings to others or to ask for help. Often people think that they ‘shouldn’t bother’ their CNS or GP about their feelings. It’s important to look after yourself emotionally as well as physically so please do let people know if you need some help at this time.

If you find your feelings become difficult to manage you may need some professional help. You should be able to access counselling and other supportive services either from the hospital that treated you, or via your GP. Many areas have specialised cancer support centres that offer a range of services, so do ask to see what is available near you.

Our website www.targetovariancancer.org.uk carries a directory of support groups and centres around the UK.

Although it seems like an awful lot to deal with, hopefully you will, like Janet, be able to get some perspective on your recurrence: “My oncologist was excellent and her positive outlook really made me feel then as though this was just another hurdle to be overcome, not the end of everything as I had first feared.”

“For me, the hardest part was having to tell my husband, sons and elderly parents that all was not as well as I had hoped.”

Janet
It may have been a few months since your initial diagnosis or many years; it may have come completely out of the blue or be something you have been waiting for. Whatever your situation, it does not make it any easier to deal with the shock of hearing that your ovarian cancer has returned. You may be feeling a whole range of different emotions, such as overwhelmed, shocked or angry.

If you feel well and have no physical symptoms you may be feeling particularly frustrated at not knowing where the cancer is, or to what extent it has returned. This can lead to you feeling helpless and not know how to control your recurrence which is a very common reaction.

It is normal to try to think of an explanation as to why your cancer has come back. Many people blame themselves and feel guilty that they have let family and friends down. You may feel that you didn’t try hard enough, eat the right foods or think positively enough. None of these are reasons for your cancer’s return, so please try not to feel guilty. It is not uncommon to find that your mood flits from worry about the future to feeling hopeful and positive. These fluctuations are very common as you begin to digest the information you have been given.
Getting on with life
Dealing with your own emotions and feelings, and those of your family and friends

So here you are, still dealing with the news that your ovarian cancer has come back and inevitably, although you are living with one of the most challenging and stressful times of your life, you find yourself needing to look after other people’s feelings too as they deal with your news.

It may be that those close to you find the news frightening and in some ways harder to cope with than you. You may have gone into action mode, pulling on your innermost resources and reserves of strength to face this next challenge and get through it. Maybe you are the one that wants as much information as possible, whilst your partner wants information only on a need to know basis. You may find yourself feeling ‘guilty’ that your cancer has come back. You know this is irrational, but you want to spare those around you anxieties and worries.

You may find that on bad days, difficult thoughts creep into your mind and you have to find a way of dealing with them. Your family and friends may also have difficult moments, and because they are one step removed from the cancer, they might feel even more powerless than you in the face of the ovarian cancer coming back. This can have a detrimental effect on communicating and understanding each other at this time. Digesting information can be difficult when you and those close to you are upset or stressed and can get in the way of the natural flow of your conversation.

All these stresses and strains in your relationships with others are, in their own way, additional challenges and can be as stressful as dealing with a return of your ovarian cancer.

Take a deep breath. As with all things in our lives, we cannot control other people’s reactions and emotions. You know your family and friends, you know their personalities, and you know what they were like before you got the cancer. They will probably react according to their personality and how they feel about their own lives. You may be surprised; sometimes people find an inner strength that you just were not expecting, and they may be inspired to swing into action mode to support you.

Seeking out information and support

Every woman will seek different things from her oncologist and CNS when they receive the news that the cancer is back. Some women will want as much information as possible; others will want some information but not every medical detail. It may be the other people in your life seem to have a greater hunger for information. This can feel at odds with where you are and what you want. Perhaps they are seeking more medical detail because in some way it gives them a sense of control at a difficult time.

Women we spoke to whose ovarian cancer had come back had a variety of experiences with their relatives and families. Some had children who just did not want to know any facts, they just wanted reassurance. One or two partners were very hungry for facts and sought out opportunities for conversations with the oncologist and CNS. People have so many different ways of coping with health problems and change.

It may be that actually encouraging your family members to speak to your CNS would help them support you. By understanding your condition and perhaps some of their own anxieties they may become better company and the stresses may become less between you.

Some women say that although their husbands were not the type to discuss their feelings, talking to a professional, a counsellor or a nurse helped them feel more able to cope and become a better support. Being able to talk honestly about your different requirements for information will help develop an
appreciation of each other’s needs. Target Ovarian Cancer can provide information about where family, friends and carers can find additional support.

**Worrying about your children**

You may be afraid of telling your children that your cancer has come back. It is much better to be honest with your children from the beginning. Even young children can be helped to come to terms with the return of your ovarian cancer through play or books.

Another fear may be that your daughters could develop ovarian cancer. If you are worried about this and particularly if you have others in your family affected by breast or ovarian cancer it is a good idea to speak to your GP, CNS or oncologist. Have a look at our website [www.targetovariancancer.org.uk](http://www.targetovariancancer.org.uk), or the detailed section in our *What Happens Next?* guide which you can order from us.

However your relationships unfold during this time you may find it really helpful to make some time to meet other women going through similar experiences and learn how they are coping or simply make sure you have enough ‘me time’, which will allow you to unwind. Have a look at the section **Healing at a difficult time** for more ideas, or contact Target Ovarian Cancer for other support information.

**When things feel tough**

Fear has been described as the most crushing side effect of having a diagnosis of recurrent cancer. One of the greatest fears is that the cancer will shorten your life. You may find yourself preoccupied with your past life, with regrets of what you have still not achieved. It can be difficult to deal with these thoughts and the emotions that go with them, and you may feel very drained. However, it may be possible to resolve some of these feelings by perhaps making contact with someone you have fallen out with or doing some of the things you have always wanted to. Many people report that the intense feelings of fear felt at the time of their recurrence do become more bearable with time.

You may be afraid that the cancer treatment will not be able to control the disease and that you may experience severe pain. If this is one of your fears be sure to talk to your CNS or oncologist as soon as possible. Most people do not experience severe pain and most pain can be controlled with regular painkillers. People who experience pain can suffer from more stress and lower mood so it is important not to suffer in silence. You may already know a lot about your ovarian cancer, but the doctors and nurses may not be able to give you concrete information about what course your cancer will take. This might add to your fears. They are not avoiding your questions; they may genuinely not know the answer.

Some people describe coping with recurrent cancer as like ‘living in limbo’ or with the ‘Sword of Damocles’ hanging over them. If you find you are feeling constantly agitated and irritable you may benefit from some psychological support from a professional. They will be able to help you with strategies for dealing with negative thoughts. Fear is a very understandable emotion but some fears may be unfounded and are often due to misconceptions. Your CNS can help you understand which fears are real and which are not, or can refer you for further support. Please remember there is no right or wrong way to feel.
You may feel that life will never be the same again and at this stage you can’t imagine ever getting back to normal. You may find it hard to believe, but many women come to accept that their ovarian cancer has become a long term condition and they continue their usual activities, despite ongoing treatment. Having a sense of normality is very important and can help you feel a little more in control.

It can be difficult balancing family and friends with the demands of your ovarian cancer and personal time, a bit like trying to keep ‘all the balls in the air’. Women tend to put personal time at the bottom of their list of priorities so try to remember to factor in some time to do things you enjoy. Many women find that it is the simple things in life that give them most pleasure such as going for a walk somewhere green and relaxing, enjoying a stroll with the dog or spending time with the people they are closest to. Some women find they have a greater appreciation of the little things in life.

One feeling consistently reported by women with ovarian cancer is that they feel isolated.

Ovarian cancer is seen as a less common cancer in comparison with breast cancer, for example. Sharing your experience with other women in a similar situation can be helpful. The Target Ovarian Cancer website has details of gynae cancer support groups all over the UK or if you can’t find one in your area, your CNS may be able to put you in touch with other women locally. If support groups do not appeal to you there are plenty of activities you can get involved with through Target Ovarian Cancer. Have a look at the website for more details www.targetovariancancer.org.uk
Treatment options

There are a number of treatment options for women with recurrent ovarian cancer. Chemotherapy is the treatment most commonly offered and on occasion, surgery may be considered. There are a number of chemotherapy treatments available on the NHS for recurrent ovarian cancer. Your oncologist or CNS should discuss with you available treatments and how they might be suitable for you. Increasingly new types of drugs (targeted agents) are being used or trialled.

For some women, the news that their cancer has come back can be the start of a new phase. You may feel that you would like to be more involved in making decisions about your treatment and care than you were before, and you may have opinions about whether a treatment option is right for you based on how you responded to it previously. You might consider the pros and cons of participating in a clinical trial, or explore the possibility of accessing drugs other than those approved for recurrent ovarian cancer in the NHS.

When does treatment for recurrent ovarian cancer start?

Until recently CA125 blood tests have been done every three months for the first three years then six-monthly, as part of the ongoing follow up and monitoring of women with ovarian cancer. However, some doctors have now opted not to measure CA125 levels at follow up appointments, unless the woman develops symptoms. This is because research has now shown that beginning chemotherapy when the CA125 levels start rising (but before there are any symptoms) does not have an effect on survival rates. Waiting until symptoms occur can be worrying for some women who want to start treatment as soon as possible, however there are benefits to waiting. It lengthens the time period between platinum-based chemotherapy treatments, which is thought may help the response to the drug, and reduce the chances of developing resistance to it. Overall it may improve your quality of life, because over the course of time if there are a number of recurrences, there would be less time spent having treatment and dealing with the side effects. It is important for you discuss your preferences with your CNS or oncologist, as you may have a particular reason for wanting to start treatment as soon as possible, for instance to attend and be well for an important event.

Once you begin treatment it is most likely that a CA125 test will be used to assess your response to treatment, unless you are amongst the small proportion of women whose CA125 level has never registered as abnormal. CT scans and ultrasounds may also be used to assess your response to treatment.

Different types of chemotherapy

Oncologists divide recurrent ovarian cancer into two groups, called ‘platinum sensitive’ and ‘platinum resistant’, depending on how long it has been since you finished your last platinum based chemotherapy containing either carboplatin or cisplatin.

If it has been six months or more since your last treatment with carboplatin or cisplatin, your cancer is ‘platinum sensitive’ – this means that there is a greater chance it will respond to more platinum. In these circumstances, your oncologist will suggest giving you more carboplatin, usually in combination with another drug, such as paclitaxel (Taxol®), liposomal doxorubicin (Caelyx®), or gemcitabine. Sometimes the term ‘partially platinum sensitive’ is used, and refers to when recurrence occurs between six and twelve months after the last treatment.

Women who live in England and have platinum sensitive ovarian cancer, may be offered the drug bevacizumab (Avastin®) alongside chemotherapy and after chemotherapy has finished. This drug is not routinely available on the NHS in the
“Recurrence in its own way was less scary than initial diagnosis, when for me my greatest fear was all the unknowns.” Mary
UK, because of its cost, but it is licensed to treat recurrent ovarian cancer. (See the later section on Accessing funds for non-standard drugs for more information).

Occasionally (in approximately 10 per cent of cases), women can become allergic to carboplatin – this most commonly appears during the second or third cycle of chemotherapy for recurrent disease. If this happens, it is sometimes possible to continue with carboplatin at a later date, using so-called ‘desensitisation regimes’, where the carboplatin is restarted at a very low dose and gradually increased. It is also sometimes possible to switch to cisplatin, which is very similar to carboplatin. However, if the allergy is severe, it sometimes is necessary to stop platinum chemotherapy altogether.

If your cancer has returned within six months of your last treatment with platinum (either carboplatin or cisplatin), your cancer is called ‘platinum resistant’. In these circumstances, it is unlikely that it will respond to platinum chemotherapy again, and different drugs are used. These include paclitaxel (often given once per week rather than every three weeks), liposomal doxorubicin (Caelyx®), topotecan and gemcitabine.

In platinum resistant ovarian cancer, these drugs are usually given alone (as so-called ‘single agents’). Remember both you and your cancer are unique and your oncologist will propose using the drugs that he or she thinks will have the best impact on your ovarian cancer.

**Surgery**

Most women diagnosed with recurrent disease will be offered chemotherapy to treat their symptoms. Surgery is not routinely used in terms of treating recurrence. You might be offered surgery if it has been three years or more since you finished your first treatment, and during this time you have not experienced symptoms, your clinical team has not detected any signs of cancer until this point, and they are confident that all tumours could be removed, usually
when it is confined to one place. There is a trial called DESKTOP III currently underway in the UK designed to see if surgery for recurrent ovarian cancer, in addition to chemotherapy, is better than chemotherapy alone. You can find out if this trial is running at a centre near you by visiting our Clinical Trials Information Centre, just enter your postcode and keyword ‘DESKTOP’: clinicaltrials.targetovariancancer.org.uk/find-trials or by calling Target Ovarian Cancer or speaking to your surgeon.

Surgery may also be recommended in certain circumstances to deal directly with certain symptoms such as a blocked bowel, or bowel obstruction.

Any possible surgery for recurrent ovarian cancer should be assessed and then if appropriate, carried out by a surgeon with expertise in this area, so that all risks and benefits can be considered. You can always ask for a second opinion as to whether surgery is or is not an option.

**Radiotherapy**

Radiotherapy is not often used because ovarian cancer frequently grows back at several sites within the abdomen, and radiotherapy is best suited to disease that is confined to a limited area. However it can be used to control symptoms in certain circumstances.

**Hormone therapy**

Hormone therapy, using drugs such as tamoxifen and letrozole, is best known as a treatment for breast cancer. However, it appears it can also be useful in recurrent ovarian cancer, especially in women whose disease is growing very slowly and in women who do not wish to receive more chemotherapy. However there have not been any large scale clinical trials to see how hormone therapy might compare to standard treatments, and who might benefit most from such an approach.

**Other drugs for recurrent ovarian cancer**

Most women with recurrent ovarian cancer will be offered standard treatments by their oncologists. In general this means drugs that are licensed for treating women with ovarian cancer in Europe/UK and approved for use within the NHS on the grounds of clinical and cost effectiveness. Alternatively they may be asked to take part in a clinical trial of a new drug, or a new combination of existing drugs. However some women may wish to ask about accessing other drugs.

**Non-standard drugs**

Sometimes oncologists prescribe drugs to women with ovarian cancer outside the clinical trial setting that are not yet licensed for ovarian cancer. This is referred to as prescribing ‘off license’. An oncologist may, but is not obliged to, prescribe a drug ‘off license’ if they believe the patient may benefit, and they have confidence that the drug is safe because it is licensed for treating other types of cancer. This happens more commonly in Europe than the UK at present.

An oncologist may also choose to prescribe a drug which is licensed but not approved, or not yet approved, for use in the NHS. In either case the oncologist may well have to make a special application for funding for the drug which may or may not be accepted.

**Accessing funds for non-standard drugs**

Within England, certain cancer drugs that are not approved for routine use on the NHS can be accessed via a special fund called the Cancer Drugs Fund [CDF], designed to improve access to cancer drugs. Currently only Avastin® is included on the CDF listings for women with recurrent ovarian cancer who meet the criteria. The fund runs until 2016.

In the other UK countries, and for other drugs, Individual Patient Treatment Requests [IPTRs] or Exceptional Funding Requests [EFRs] have to be
The rates of successful applications vary widely across the UK and within individual nations.

Occasionally manufacturers of the drugs in question will run a compassionate access scheme for patients who meet certain criteria, meaning the drug company meet the cost; however approaches to the drug company must be made by your oncologist.

If you are interested in accessing new drugs, talk first to your oncologist about any drugs beyond the standard ones that might be accessible. It is important you find out about the suitability and potential risks and benefits of any of the drugs in question. Not all drugs will benefit all women. As funding often needs to be sought, it is important to note it can be quite stressful going through this process at a time when you are unwell. If your oncologist is reluctant or unsure about discussing other drugs, but you are still interested, you can always ask for a second opinion. You will always need the support of an oncologist, as they have to make the applications for funding on your behalf.

**How drugs get approved for use on the NHS**

A drug is given a license by the European Medicines Agency [EMA] or the Medicines and Healthcare Products Regulatory Agency [MHRA] in the UK once it is deemed safe to use in a certain group of patients, and has shown to be of some benefit. Manufacturers of drugs generally submit applications for licenses once the results of clinical trials are published. This process can take up to a year.

**Approval for use in the NHS**

Once a drug is licensed, the National Institute for Health and Care Excellence [NICE] and the Scottish Medicine Consortium [SMC] will, if asked, assess a drug for its use within the NHS in their respective areas. They will consider the clinical and cost effectiveness of the drug. In other words, does the drug in question work better than standard treatments offered (either for all patients, or for a particular group of patients) and is the price to the NHS of using the drug acceptable for the amount of benefit seen. Again this process can take some considerable time, and the different UK countries may reach different conclusions. This means it can take up to two years, or more, from results of trials being announced to the drugs being approved for use.

**Clinical trials**

Clinical trials are research studies that thoroughly test all new medical treatments and procedures. Drugs and treatments are generally assessed in three clinical trial phases before they can be considered as a standard treatment option.

**Phase I**: This is the first time the treatment has been tested outside of the laboratory. Around 30 patients or less usually participate. They are people for whom there are no standard treatment options available. The aim of a Phase I trial is to find a safe treatment dose and look at possible side effects. If the treatment is safe and appears to have a positive effect, it will go into Phase II.

**Phase II**: Builds on the findings from Phase I, improving knowledge of potential side effects and on the best dose to give. A Phase II trial will also start to look at which type of cancer the treatment might work best for and usually involves a hundred people or less. If the new treatment shows potential benefit it may progress to Phase III.

**Phase III**: This phase recruits the largest number of patients with hundreds or even thousands of patients taking part throughout the UK and often across the world. Phase III compares the new treatment with a standard treatment and will look to see if the new treatment extends life (overall survival [OS]) or extends the time before the cancer gets worse (progression free survival [PFS]).
Because each clinical trial is designed to answer a very specific set of questions about a new drug or treatment, there are very strict guidelines about who can participate in a particular trial.

**What are the benefits of participating in a clinical trial?**

Many women view taking part in a clinical trial as a very positive experience. Some of the benefits they identified include:

- Getting a new treatment before it is widely available
- Being one of the first to benefit if the drug or treatment works
- Receiving additional monitoring and care – you will need to attend regular tests and check-ups
- Helping advance medical knowledge for the benefit of women both now and in the future

Studies have also shown a clinical benefit for those taking part in trials, whether or not they actually receive the trial drug. This could be because trial design will mean additional care and monitoring at the hospital.

However, it is also worth considering that new treatments are not always better than standard treatments and that the new drug or treatment might not work for you. Sometimes there are unexpected side effects. As trials compare new treatments with standard treatments, you may be selected to receive either the new treatment or the standard treatment. So by agreeing to be in a trial, it does not necessarily mean you will receive the new drug being tested.

**How do I find out about clinical trials?**

Speak to your oncologist; they will be able to tell you about trials in your local hospital that are suitable for you. If there is no appropriate trial in your local hospital they may be able to give you
information about trials in other hospitals.

Having discussed the possibilities for treatment with your oncologist, you may still feel uncertain as to how to proceed. You are entitled to seek a second opinion either at your current hospital or at a different hospital which is perhaps more involved in clinical trials. Your CNS and/or oncologist should be able to advise you on how to go about this.

You can find more information about all aspects of clinical trials and search for trials across the UK on our award-winning Clinical Trials Information Centre: clinicaltrials.targetovariancancer.org.uk

Questions to ask your oncologist

Learning that your disease has come back is often very difficult and it is sometimes more distressing than learning of the original diagnosis. Knowing what questions to ask and ensuring that you get clear answers is extremely important.

Why has it come back?

After surgery and chemotherapy following the initial diagnosis, some women have a normal CT scan and a normal CA125. However, sometimes the cancer can still come back, even years after finishing their initial or first-line treatment. The simple answer to the ‘why’ question is that CT scans and CA125 cannot detect invisible deposits of ovarian cancer that may remain. We need to develop highly sensitive and reliable methods to detect those tiny groups of cancer cells. However, we still don’t fully understand why some cancers return, and why some return five years after finishing chemotherapy and others just months after.

What can be done and can it be cured?

It is really important to emphasise that there are lots of options for women with recurrent ovarian cancer. The outlook for women with recurrent ovarian cancer has improved in the past few years and there are new and potentially promising treatments becoming available. However, unfortunately, it is rare that treatments for recurrent ovarian cancer make the disease disappear forever – it almost always comes back again at some point. The aim of treatment is to keep the disease under control and keep you feeling well for as long as possible in between treatments.

I need to start treatment now, don’t I?

Many women who are told that their cancer has come back may reasonably want to start treatment straight away – this would be a natural reaction. Many women first discover that their cancer has returned when their CA125 blood test starts to rise – yet they often feel completely well. If your cancer has returned but you feel well, most oncologists will suggest that you can delay starting treatment. However, if you feel that you want to start treatment sooner you will need to discuss this with your oncologist. Your CNS will also be able to help you at this time.
Now that your cancer has recurred it has changed from an acute to a long term condition. This means that you will experience periods, between treatment, of feeling well and leading an ordinary life.

Facing a future involving lots of cancer treatments is not something that anyone looks forward to but with experience you will develop coping strategies that help you get through it. Set small, achievable goals and plan pleasant activities in between treatment and accept offers of help.

Facing treatment again can be particularly difficult having experienced it before. You may dread the physical changes brought about by the treatment, particularly the hair loss and fatigue. The extent that you dread the treatment can depend on your experience the first time round. If you found your primary chemotherapy treatment very distressing, or hated a particular side effect, then be sure to discuss this with the doctors and nurses.

If you are the type of person who wanted information after your initial diagnosis then it is likely that you will want even more information now that your cancer has come back. It is understandable that you will want to explore every avenue and most people look for any new treatments that might be available. This can be time consuming and exhausting. Always remember that you can discuss your treatment with the medical and nursing staff. It is ok to ask questions or share your opinion and experience of your treatment. It is also very common for people to feel that they would like to explore complementary therapies at this time. This can give you a greater sense of control, but it is always wise to discuss any complementary treatments with the medical staff, have a look at the next chapter for more ideas.
“Attending the gynae-cancer group at my local support centre helps more than I had anticipated. I meet others who ‘have been there’ and understand.” Mary
Healing at a difficult time

Perhaps you have already visited a cancer support centre or have used complementary therapies. Maybe until now you have not felt the need to access additional support but you feel now that you would benefit from some extra help. There are lots of ways to get support from talking to a professional to simply chatting to someone online or visiting a cancer support centre. You may also find some useful information in our guide What Happens Next? for women with a recent ovarian cancer diagnosis. It covers support groups and centres, online communities and blogs, telephone support and professional support including psychological therapies.

Support centres

Some hospitals may have either their own or a charity-run cancer support centre (such as Macmillan or Maggie’s) on site, or there may be a local cancer support centre nearer to your home. They will have nurses or counsellors you can speak to and provide complementary therapy and exercise sessions. Women with recurrent cancer should be able to access the services of their local hospice. A lot of people are worried about the idea of a hospice and think they are only for people at the end of life. In fact they are centres that offer a range of specialist services for all stages of cancer.

Some of these centres may be able to offer an opportunity to meet other women in a similar situation, providing a safe environment to share experiences, gain support and understanding from each other, helping you to deal with the mixed emotions you may be feeling. The friendship and camaraderie within a group can enable you to explore ways of coming to terms with the recurrence and provide tools to cope with the uncertainties of the future.

Some groups may be facilitated by a health professional so that treatment uncertainties or small concerns that sometimes feel ‘silly’ can easily be addressed and hopefully eradicated. Of course there may be occasional sadness for the group if someone dies but it is important to acknowledge how that makes everyone feel and know that there is the support of the group around you. Many groups forge long and meaningful relationships, and the deep understanding that can exist allows you to feel more confident and in control, enabling you to seize the challenge of the changes you are going through.

Complementary therapies

Support centres and hospices may offer complementary therapies which some people find can be extremely beneficial at this time. Just to make it clear, complementary therapies ‘complement’ the treatments received in hospital; they are not alternative treatment. Therapies you may be offered include massage, which can be used for relaxation or to ease tired and strained muscles. Women who receive reflexology (massage of the feet) have reported that this helps with peripheral neuropathy (damage to the nerve endings) of the feet, which causes numbness and tingling. Acupuncture can be given prior to chemotherapy to ease symptoms of nausea and vomiting and also for pain. Whilst none of these treatments are scientifically proven to ease the symptoms of medical treatment they can bring about a sense of wellbeing and relaxation.

Group relaxation is a popular complementary therapy that is frequently offered by cancer support centres and can be very beneficial when you are feeling stressed. It may focus on the body allowing you to relax and may use ‘guided imagery’ where the group leader guides you through imaginary locations such as a beach or relaxing place, helping you build the skills to achieve deeper relaxation.
When we are anxious our brain finds it difficult to process information. We find we just can’t focus or think straight and may not sleep well. Relaxation can be an effective self-help activity to help you to deal with the variety of emotions you may experience and gives the body time to recuperate.

Although it can be daunting to first visit a support centre or a hospice, many women find this service a great comfort both during and after treatment. One-to-one complementary therapy sessions, or participating in a group activity, are two options that people often use to help with relaxation. One-to-one complementary therapy sessions are ideal for when you feel less sociable.

Check out what your local support centre and hospice offers and try different therapies to find out which one is best for you. You may find that you really enjoy Pilates or that you enjoy receiving a Reiki massage where a practitioner passes their hands over the body, without touching, whilst you are lying down. Or you may prefer the Bowen Technique massage where pressure is applied to your muscles along the back with breaks in between to allow you to relax more deeply.

A professional qualified therapist from your local cancer support centre can help you to discuss therapy options, provide reassurance and advice based on your specific situation. The rapport you have with your therapist is a key element to maximising your relaxation experience. Ask your CNS or contact Target Ovarian Cancer to find out details of your nearest cancer centre.
It is possible that you may be feeling a sense of loss since your diagnosis. The loss you feel may include the loss of independence. Sometimes families can be a little overprotective and feel they are doing the right thing when they take over your household tasks or start running your day to day life. If this has happened and you would prefer to carry on with your routine as normally as possible then try to discuss your feelings with your family. You can always ask your CNS to meet with you and your partner or carer to help explain what you need now and what you don’t want now.

You may also be feeling a loss of physical, sexual or emotional closeness. There can be many misunderstandings following a diagnosis of recurrent cancer. Your partner may feel nervous about physical contact in case it hurts you and at the same time you may feel rejected. Again, try to talk to your partner about this.

For some people there is a desire to put their ‘house in order’ which can mean writing a will if you did not do so before you had ovarian cancer, and thinking about what you want from medical treatment today and in the future. Although it can feel painful to think about doing these sorts of things, it is something we should all do whether we have cancer or not. It may feel more poignant for you doing this now, but you will hopefully feel relieved when you have made these decisions and you can get on with living your life to the full.
Tips, thoughts and insights

In this part of our guide we hear from women who have been through what you are facing and from professionals who care for women like you.

Janet

When my cancer was diagnosed as having returned only six months after completing chemotherapy the first time, I was absolutely devastated as I was convinced that I had ‘seen it off’.

One of my most difficult times was at my first repeat session of chemotherapy when the nurse was completing the questionnaire and asked how I had felt when I was re-diagnosed – I just burst into tears and that told her everything! It was the first time I had cried as up to that point I had convinced myself that the treatment worked well the first time and would hopefully do so again.

I drew strength from meeting another lady at chemo who was in the same situation as myself and we got through it together. It really helped me to have someone to chat to, moan to, cry to, who knew exactly where I was coming from. For all other people want to help, it isn’t the same as having someone there who has first-hand experience of the situation.

I had assumed that the side effects would be the same the second time around as I was repeating the same treatment (paclitaxel and carboplatin) but actually I found that I didn’t have all of the same ones as I had previously, but I also had some which I hadn’t had before – very odd!

This time around I have also become involved with a support group at the hospital for ladies with gynaecological cancers, which I didn’t use previously and I have found it a great help.

Penelope

When I was told that my cancer had returned it just felt like my world had come to an end and there was no hope for the future. It felt much worse the second time around – as if this really was the end of the line. I felt as if I spent weeks crying.

I can’t emphasise enough how good it is to have wonderful friends, mine have been a godsend. My best friend came straight away to the hospital when I rang and said I was not well again, she stayed with me through all my tests and the devastating results. I don’t know what I would have done without her – she is my ‘guardian angel’.

Make sure you always take someone with you to appointments as your mind does not focus well and it is easy to forget and not take in what is being said to you.

The diagnosis makes us reassess what’s important. My motto is ‘live for today’ – when you are feeling well enough enjoy every moment, go out, have a nice meal, enjoy a trip to the theatre.

Mary

I view my ovarian cancer as a ‘chronic health condition’ which needs management; frequent tests, reviews, periods of treatment and back again to ‘watch and see’. This makes many of the above aspects less worrisome and has taught me to live in the ‘now’. I enjoy and plan for what is achievable and leave the more distant future to look after itself. Whenever scary thoughts try to take hold in my head I tell myself: “I have done this before, I was ok then and I am doing ok again now”.

Alison Keen, Head of Cancer Nursing

My experience comes from sitting alongside women at diagnosis, through various treatments and in the anxiety-ridden times between follow up appointments. Women have shared their thoughts and insights with me on what has helped them cope with the uncertainty:
The need to explore all options, and clearly understand what treatments may be available in the future, including those in clinical trials.

Occasionally living for a while in ‘denial’ as if nothing has changed can be a relief.

Setting the ground rules out for those you love. Tell them clearly what you want and don’t want – if you prefer not to talk about cancer unless you bring up the subject, let them know; if you don’t want your family to be over-protective, or more helpful, let them know.

Getting practical issues that need to be ‘got out of the way’ done. This may mean taking early retirement and finding out if your employer is willing to release your pension now if this appropriate for you, collecting important items together for family and friends, writing important letters.

Treat yourself to regular complementary therapies (for example aromatherapy, Reiki, reflexology), or do the things you really enjoy. You can access these sorts of therapies free through your local cancer support centre.

Recording thoughts and feelings in a diary.

Many women just try to ‘get on with life’ and enjoy the time when not having treatment to the full.

**Professor Iain McNeish, Oncologist**

Telling women that their cancer has come back is what oncologists dread most. However, there is much that we can do for women with relapsed cancer now; our understanding of what ovarian cancer is and why it comes back means that we are developing new treatments. The outlook for women is improving all the time and we hope that we can help you to fight this disease for a long time to come.

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**Mr Robin Crawford, Gynaecological Oncologist (Specialist Surgeon)**

We are making advances in the care for women with ovarian cancer. Guidance on the symptoms of ovarian cancer from the National Institute for Health and Care Excellence [NICE], support for early recognition and diagnosis are being implemented. Centralisation of care has led to improvements in survival and we are seeing new drugs coming through which may help specific groups of women with ovarian cancer. It is a blow to receive the news that the cancer has returned and we want to help you to reduce your symptoms. Discussion with your oncology team and involvement in trials may help you and others.

We hope you have found this guide helpful and that we have given you some food for thought. We also have a guide for women with a recent diagnosis of ovarian cancer called **What Happens Next?**, including special sections about treatment, back to everyday life and work, and a section for younger women. If you would like to order this publication, take part in our events or get involved in our work please complete and return the reply slip in this guide.

For further information and support contact us at on **020 7923 5475, info@targetovariancancer.org.uk** or visit **www.targetovariancancer.org.uk**
Target Ovarian Cancer is the national ovarian cancer charity working to save lives and help women diagnosed live their lives to the full, wherever they are in the UK.

We do this by:

• improving early diagnosis
• finding new treatments
• providing support for women

We provide support for women with ovarian cancer via our website, our publications, and our programme of events and courses. We work with women, their families and friends, to campaign for improving early diagnosis and finding new treatments.

As an Information Standard accredited organisation all our publications and information are subject to an information production system that ensures quality and impartiality. All our publications are peer reviewed by experts in their field, health professionals and those affected by ovarian cancer.

We hope that you have found this publication useful, if you have any comments or suggestions please do let us know.

To access our list of references we used for this publication please contact us directly.

We make every effort to ensure that the information we provide is accurate. If you are concerned about your health, you should consult your doctor. Target Ovarian Cancer cannot accept liability for any loss or damage resulting from any inaccuracy in this information or third party information on websites to which we link.
Family and friends

Welcome to our ‘Family and friends’ pull out section of our guide Back Here Again. We have created this part of the guide because women we spoke to whose ovarian cancer had come back told us that their partners, children and friends needed special information written just for them to help support what they go through when a mother, wife, partner, sister, daughter or friend’s ovarian cancer comes back.

We know from talking to people going through similar experiences that each of you will react in your own way when you receive the news your loved one’s cancer has come back. Human beings are so unique and our life experiences all vary and these factors have an impact on how each one of us copes with life’s challenges, particularly when someone close to us is managing a long term condition.

Are you a partner?

You may be surprised how strong your feelings are, after all it is not you who has ovarian cancer, but try not to be hard on yourself, there is an explanation for this. When we are in a very close relationship with another person it is as if they become a part of our very being, we cannot imagine life without them even though at times we might fall out, have a row or disagree, we still are ‘bonded’ together.

In some ways it is just as bad for you as for your wife or partner, as alongside the news that the cancer is back you have to accept you are not in control. She can perhaps do some little things to help give her a greater sense of control such as

“It was well, do we go through the same procedure all over again? Is it going to affect the family?” David, husband of Yvonne
take the doctor’s advice, change her lifestyle, but you are looking on desperate to sort this out. So you too have a need for support at this time and you too have a need to look after yourself.

By acknowledging your feelings you may actually feel better in yourself and more able to support your partner. Sometimes people may need the support of a professional such as a clinical nurse specialist or a counsellor to feel better.

Do you want to know absolutely everything about your partner’s cancer, perhaps more than she does herself? Again don’t be surprised if this is your experience. It is a way of trying to get some control back but also a natural desire as knowledge may make you feel more able to understand the ovarian cancer and help you deal with it back in your lives again.

**Are you a daughter or a son?**

Perhaps you have your own children now and your relationship has changed over the years with your mother but the return of her ovarian cancer is concerning as you worry about her and perhaps your father too. Perhaps support her to talk about what she is going through with other women in a similar situation or her clinical nurse specialist.

**Tips from Alison Craven, Clinical Nurse Specialist**

The doctors will talk to your loved one about their treatment choices; this may involve offering to discuss success rates and prognosis. Some people may not wish to have this level of information. It is a good idea to chat about the type of questions you both have and how much information you would like.
It is ok for one of you to have further discussions with the team without the other one present. If you choose not to have sensitive information at this time it does not mean you cannot be fully involved and totally supportive of your loved one. The doctors and nurses will be sensitive to your needs and are there to give you support, information and advice at any time at the level you need.

Knowing what to say to your loved one at this stage can be difficult. They do not expect you to have all the answers nor to be a constant tower of strength. Sharing with them your sadness is a way of giving them permission to share with you their sad feelings.

You may still feel physically and emotionally tired from the initial journey and worry that you do not have the energy to support your loved one. As before there will be practical issues to consider; this time you will need to think longer term. Life will now be a mixture of remissions and treatment which may mean some permanent changes for you which were not necessary initially. It is important to think about how you will manage these. Just making a little time for yourself will give you added strength and vitality, to continue supporting your loved one. Cancer centres offer complementary treatments. It is ok for you to have complementary therapies too. I know from experience that many of the men I have supported have had their arm twisted to have a body or Indian head massage and have come back and told me how much they enjoyed it.
How you might feel

One of the most important things for a woman with recurrent ovarian cancer is having the support of her family and friends. Having a good social support network can lessen a women’s emotional distress. However, providing that support is not always easy. Having someone you love diagnosed with recurrent cancer can be devastating and family and friends can feel many of the emotions that the patient is feeling, including helplessness, anger, fear and loss of control.

The wellbeing of family and friends is very important to your loved one. She is likely to be worried about how you will cope with her illness and may be fearful of becoming a burden. This may lead to her playing down how she feels and trying to protect you from her distress. At the same time you may not know what to say and so avoid the subject of cancer. You may be tempted to try to protect her by not talking about it or even avoid her altogether. All these factors can make her feel very isolated. Lack of communication can lead to misunderstandings. If you feel that you are having difficulty communicating, talk to the clinical nurse specialist who may be able to help.

If you are the husband or partner you may find that you are taking on new roles. You may need a break from work, which can have financial implications, and you may find you get very tired or even suffer ill health yourself. Remember, help and support can come from a number of sources such as religious groups, charities, social workers and counsellors as well as friends. You have not failed if you need to bring in additional help.

Most relationships are strengthened at this time and the illness can be seen as an opportunity for you to spend some quality time together and even plan a trip that you had been putting off.

Target Ovarian Cancer can provide you with further sources of information and support.