



# TARGET OVARIAN CANCER

For every woman. For life.



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A guide for women with recurrent  
ovarian cancer

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We would like to thank everyone who has contributed to this guide:

- Andrea, Esther, Julia, Julie, Karen, Lynette and Yvonne for sharing insights into their ovarian cancer experience and helping us make this guide special.
- The writers and reviewers - Dr Pauline Adair, Lynn Buckley, Professor Richard Edmondson, Dr Alison Farmer, Professor Christina Fotopoulou, Julia Merrigan, Karen McLaughlin, Professor Iain McNeish and Mr Khalil Razvi.

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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. In 1996 I was awarded a PhD for my work on the psychological aspects of breast cancer. After working as a Teaching Fellow at the University of Southampton for a number of years, teaching psycho-oncology, I recently decided to return to nursing and now work as a Psycho-oncology Nurse Specialist, offering psychological support to people with cancer. I was diagnosed with ovarian cancer in 2001 and my experience of surgery and chemotherapy has given me valuable insight into the impact of the disease."*



# Introduction



This guide is for women with recurrent ovarian cancer or whose cancer did not respond to initial treatment. It focuses on your practical and emotional needs at this time. The information has been divided into different coloured sections so you can pick and choose which bits you'd like to read.

Throughout the guide we have included tips and experiences from women who have been through what you are facing. We hope their words will help you feel you are not alone.

If there is something you would like to know about ovarian cancer that is not included in this guide, or for information about additional support provided by Target Ovarian Cancer please get in touch.

With warmest wishes,  
**From all of us at Target Ovarian Cancer**





## Dealing with the news



Some people find the news that their 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 it is very difficult to process any information, while others experience strong emotions such as intense fear and worry. Everyone is different but no one wants to be facing a recurrence of ovarian cancer.



"I was told I had a 50/50 chance of it coming back but you live in hope that it won't. I was sad and disappointed."

Karen

"I knew from the beginning my cancer would never go away. I adjusted to treating it like a long term condition in that I focused on keeping as well as possible."

Julia

"Getting your diagnosis back can be an enormous shock. I was two years in remission and to be honest, you can get a bit complacent at your appointments after so long. I just wasn't expecting it."

Esther

"I'm very black and white. It came back, it's growing again. What can I do? Get on with it. You have to keep looking at the way ahead. You look at what you have, you look at your family and the people you love and you keep going. I'm not going to be a statistic."

Lynette

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 Clinical Nurse Specialist (CNS), key worker, oncologist or surgeon to request information or to ask for any details to be written down. You might like to think about taking a friend or family member with you to any appointments so that they can write down any questions and answers for you.

*"My CNS is a great person to know. It's easy to feel like you're mithering, asking all of these questions, but never feel like that. Ask questions, no matter how silly. I asked ridiculous questions!"*

*Esther*

### **Why has it come back?**

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After surgery and chemotherapy following the initial diagnosis, some women have a normal CT or MRI scan and a normal CA125 blood test. However, sometimes their cancer can still come back, even years after finishing initial or first line treatment. The simple answer to the 'why' question is that CT or MRI scans and CA125 blood tests cannot detect near invisible deposits of

*"Ovarian cancer is unpredictable in every sense of the word. The diagnosis, the treatment, the future. You never know what is going to happen but I just try to get on with everything to the best of my ability."*

*Lynette*

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 years after a woman has finished treatment and others just months after.

*"I suspected my cancer had come back around six months before it showed up on the CT scan. I suppose that gave me the time to get used to it and get my head around what was going to happen."*

*Karen*

## Seeking out information and support

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Every woman will seek different things from her oncologist and CNS when she receives the news that her 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 that the other people in your life seem to have a greater hunger for information than you, and 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.

You may be anxious to begin treatment immediately or you may want to take time out to consider your different options. In some situations your medical team may choose to delay treatment and this may be difficult to understand. You can read more about this in the **Your 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.

*"If I was to give advice to anyone, it would be to speak to your CNS, GP or oncologist about anything you're concerned about. If you're going to look online for answers, look at Target Ovarian Cancer's website, where you can get the facts."*

*Karen*



## Sharing the news

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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 when you find out then this may happen naturally. For women who receive the news when alone, sharing this 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, weeks or more before you tell others, or to restrict the information to close family or friends. You may want to ask someone close to you to let others know on your behalf.

Women we spoke to whose ovarian cancer had come back had a variety of experiences with their relatives and friends. Some had children who just wanted reassurance, others had partners who were very eager for information and sought out opportunities for conversations with their oncologist and CNS. People have so many different ways of coping with health problems and change; those close to you will find their own means.

Some women said that although their partners were not the type to discuss their feelings, talking to a professional, a counsellor or a nurse helped them feel more able to cope. It may be that encouraging your family members to speak to your CNS would help them to understand your

diagnosis and some of their own anxieties. This may help them to better support you. Being able to talk honestly about your different requirements for information will help develop an appreciation of each other's needs. Target Ovarian Cancer and your CNS/key worker can provide information about where family and friends can find additional support.

However your relationships evolve during this time, you may find it helpful to make some time to meet other women going through similar experiences to share how you are coping and talk to people who have been there too. Simply making sure you have enough time for yourself will also allow you to unwind and may help you to process the news. Have a look at the **Sources of support** section for more ideas.

## Reaction of others

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Although you are still dealing with the news that your ovarian cancer has come back, and this may well be one of the most challenging and stressful times of your life, you may also find yourself feeling as though you need to look after other people's emotions as they deal with your news.



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 diagnosis. 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 attribute labels such as 'brave' and 'courageous' to you. 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, try to be kind to yourself and remember that responses from others will vary but are likely to be well intended.



It may be that those close to you find the news frightening and it may appear that they are finding it 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, while your partner wants information only on a need-to-know basis. You may even find yourself feeling guilty, and wanting to spare those around you anxieties and worries. Remember that you are important too.

It's also not unusual to find that difficult thoughts creep into your mind and you have to find a way of dealing with them. Your family and friends may also have challenging moments, and because they are one step removed from the cancer, they might feel even more powerless than you in the

face of your ovarian cancer coming back. This can sometimes make it hard to communicate with and understand each other, and digesting information can be difficult when you and those close to you are upset or stressed.

Any of these 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. If you are finding this particularly hard, take a deep breath. 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 your cancer diagnosis. 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.

*"I have found that people are different the second time around. It's like they think that as you've got through it the first time, you'll cope just fine again – and it's just not always the case."*

*Karen*

## HOW YOU MIGHT FEEL

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 you may 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 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.



*"I speak to my husband about it a lot and he's really supportive. We talk a lot about the future but we've not decided anything. I'm not even sure what it is we're supposed to be deciding, but as long as we just keep talking I'm sure we'll work it out!"*

*Andrea*







## Managing day to day life

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### **Asking for practical support**

Going through cancer treatment once is tough enough. Being faced with the prospect of having to do this all again may feel like an impossible challenge to cope with. Having low energy levels can make life difficult, so asking others for practical help such as running errands, assisting with shopping, or travel to/ from appointments can be invaluable.

Many people are happy to help in this way including friends, colleagues or neighbours, and you may be surprised at where offers of support come from. If you are part of a strong local community or faith group, you may want to seek practical assistance from them during this time. You may also find that your local council offers services which can be useful, including support for those travelling to and from hospital. Check with your local hospital information centre, Clinical Nurse Specialist (CNS) or GP to find out what services are available to you.

*"Since my treatment ended I've had a couple of times when I've broken down emotionally. It helped to get it out of my system as since then it's been the odd few tears."*

*Andrea*

## Your emotions

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You may already have made some changes to your life after your first diagnosis. But a recurrence of ovarian cancer can affect your mental health and emotional wellbeing as well as your body. It's understandable if you have the odd 'duvet day' when you feel upset. But if this is becoming more common or your emotions are feeling out of control, you may need some extra help.

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. But it's important to look after yourself emotionally as well as physically so do let people know if you are struggling at this time.

*"I think positive vibes are very important. Once you've slipped down that ladder it is very hard to climb back up again. But when you're down, there's always a positive light at the end of the tunnel. I was holding myself together before, I can hold myself together afterwards."*

*Lynette*



*“Talking to other women who have been through what you are going through can be very helpful.”*

*Julia*

## **Dealing with fear**

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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.

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.

Whether or not you already know a lot about your ovarian cancer, it's also important to keep in mind that your 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. Try to remember that they are not avoiding your questions, they may genuinely not know the answer.

*“I've always tried to turn a negative into a positive, as hard as that may be. Sometimes I've just needed a bit of help finding that positive.”*

*Karen*

Some people describe coping with recurrent cancer as living in limbo. If you find you are feeling constantly agitated and anxious you may benefit from some psychological support from a professional. They will be able to help you with strategies for dealing with difficult thoughts. Fear is a very understandable emotion but it may be possible to resolve some of these feelings by perhaps making contact with someone you have not spoken to in some time, or doing some of the things you have always wanted to do. Your CNS can help you understand which fears are real and which are not, or can refer you for further support. Many people report that the intense feelings of fear felt at the time of their recurrence do become more bearable with time, but there is no right or wrong way to feel.

If you feel that you would like to have some more professional help dealing with your feelings, there are plenty of choices available. The best first step would be to ask your CNS, key worker or GP about the services available within your NHS Trust. Many women have found that talking problems through with their CNS or GP can be very helpful. They can give a lot of insight into your situation and will be able to refer you to more specialist services. If you want to find a therapist yourself and feel you can afford to use these services privately, there is a list of websites in the **Sources of support** section that can help you find a registered professional.

*“I’ve started making plans for the future. I’ve decided that cancer isn’t going to take over my life – it’s going to fit in with what I want to do.”*

*Andrea*

*“You’ve got to live your life. Just go forwards. Otherwise it’s wasted time. Enjoy what you have got rather than worrying about what you might not have.”*

*Gvonne*



## Concern for family members – genetic testing and hereditary ovarian cancer

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It is a common reaction to worry that your daughter, granddaughter or sister could be at risk of developing ovarian cancer. About 15-20 per cent of cases of ovarian cancer occur because of a genetic cause. Most women with ovarian cancer are now eligible for a genetic test to see if there's a mutation in your BRCA1 or BRCA2 genes which may have caused your ovarian cancer. Speak to your oncologist or CNS/key worker about this if you haven't been offered a test.

If you do have a mutation, your family members will also be able to get tested and get information about what measures they can take to reduce their increased risk of ovarian or breast cancer.

If you have a mutation in your BRCA1 or BRCA2 gene it may have implications for your treatment. A new maintenance treatment called a PARP inhibitor which can target cancer cells is available for some women with relapsed, platinum sensitive ovarian cancer, and other drugs may be available through clinical trials. Access and funding to drugs differs across the UK. There is more information about this in the **Your treatment options** section of this guide. You can also ask your oncologist for more information.

We have a lot more information in our guide *Genetic testing and hereditary ovarian cancer* available to order or download at **targetovariancancer.org.uk/guides** or by calling **020 7923 5475**.

*"I think it's important to keep busy. I can tell when I start thinking about it too much because I get this feeling of sadness come over me. If I want to have a little cry, I have a little cry. I try to remain as positive as I can and I find it helps to have a strong mental attitude."*

*Andrea*



## HOW YOU MIGHT 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 part of their lives 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 often 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 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. Have a look at [targetovariancancer.org.uk](http://targetovariancancer.org.uk) for more details.



*"I have a 'new normal' now – and it's a normal I enjoy as much as possible."*

*Julia*





## Your treatment options

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Chemotherapy and targeted therapy are the most common treatments offered for women with recurrent ovarian cancer. Surgery and hormone therapies are sometimes offered too.

Your oncologist and Clinical Nurse Specialist (CNS) should discuss with you available and suitable treatments and your personal preference.

The possibility of taking part in a clinical trial – where available – should also be discussed with you so you can decide if this is something that you would like to explore.

## When does treatment for recurrent ovarian cancer start?

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Treatment for recurrent ovarian cancer usually begins when there is some evidence that the cancer has returned – most commonly when a woman begins experiencing symptoms (such as bloating, abdominal pain, difficulty eating or feeling full quickly and needing to wee more often or more urgently than usual), alongside confirmation usually from a CT scan that the tumour is growing.

Although CA125 levels may be measured regularly as part of the ongoing follow up and monitoring of women who have had a diagnosis of ovarian cancer, this is not universal in the UK. This is because research has shown that beginning chemotherapy when a woman's CA125 levels start rising (but before there are any symptoms) does not have an effect on the success of the treatment, and an elevated level of CA125 is not in itself enough to define a recurrence.

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 may help the response to the drug, and reduces the chances of developing resistance to it. Overall it may even 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. However, it is also perfectly acceptable to start treatment as soon as recurrence is detected.

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, or just because that is what is psychologically right for you.

Once you begin treatment, it is most likely that a CA125 test will be used to assess your response, unless you are among 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. Your CNS or oncologist will be able to explain your treatment plan in more detail.



## 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.

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.

### Platinum sensitive

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®) or pegylated liposomal doxorubicin hydrochloride (PLDH or Caelyx®).

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.

Sometimes the term 'partially platinum sensitive' is used, and refers to when recurrence occurs between six and twelve months after the last treatment.

Some women will have very platinum sensitive disease when they are diagnosed with recurrent ovarian cancer and have multiple courses of this treatment over many years. However the majority will develop resistance to platinum based chemotherapy over time.





## Platinum resistant

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 (Taxol®) - often given once per week rather than every three weeks or pegylated liposomal doxorubicin hydrochloride (PLDH or Caelyx®). In platinum resistant ovarian cancer, these drugs are usually given alone (as so-called 'single agents').

For some women in some areas of the UK, oncologists may also consider the use of other agents including topotecan, etoposide, gemcitabine and cyclophosphamide. Specific guidance for the use of these drugs is not clear. In Scotland, Taxol® is sometimes given with bevacizumab (Avastin®). See 'other treatments' for more information about this therapy.

The term 'resistant' is only really true for the first two relapses and new descriptions are likely to emerge. Always ask your oncologist if you are unclear about any terminology he/she is using.

## Surgery

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Surgery may be an option if your cancer has returned. We are waiting for the results of large clinical trials to see if this surgery is effective, but surgery is often considered if certain criteria are met. These include that all visible disease was removed at the first operation, there has been at least a year since previous treatment and that your surgeon believes that he or she will be able to operate successfully. This means that it should not matter whether your cancer is confined to one place or has spread, as long as the surgeon feels confident that all tumours could be removed.

Surgery may also be recommended in certain circumstances to deal directly with certain symptoms such as a blocked bowel, or bowel obstruction. This may involve the creation of a stoma. For a more detailed explanation and more information, please visit **[targetovariancancer.org.uk/stoma](http://targetovariancancer.org.uk/stoma)**, **[colostomyassociation.org.uk](http://colostomyassociation.org.uk)** or **[stomawise.co.uk](http://stomawise.co.uk)**

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.

*“When the new tumour developed, my surgeon said she didn’t know whether she’d be able to do anything for me: I’d been told five years ago that they’d never operate again. She said she’d take a look but make no promises. After the operation, she told me she’d removed more than she ever thought possible.”*

*Lynette*



## Other treatments

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### Radiotherapy

Radiotherapy is not routinely used to treat a recurrence of ovarian cancer. However it can be used to control symptoms in certain circumstances. Your oncologist will be able to speak to you about whether radiotherapy is suitable for you.

### 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 treating some types of 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 in ovarian cancer, and who might benefit most from such an approach.

### Targeted (biological) therapies

Targeted therapies, sometimes known as biological therapies, are drugs that encourage the body to attack the cancer itself through strengthening the immune system or interfering with the cancer cells' growth.

Bevacizumab (also known by brand name Avastin®) is a targeted therapy. It targets a protein called vascular endothelial growth factor (VEGF) that helps cancer cells develop a new blood supply. It is given through a drip in combination with chemotherapy and as a maintenance drug after the chemotherapy course is completed. Maintenance drugs seek to ensure that the benefits received from the chemotherapy are continued after the chemotherapy course is completed.

Olaparib (also known as Lynparza®) is a biological therapy known as a PARP inhibitor that has been shown to be effective in some women with ovarian cancer who have a mutation in their BRCA1 or BRCA2 gene. It targets the DNA of the tumour, so it can't repair itself. It is given as a maintenance drug following platinum-containing chemotherapy.

Funding and access to bevacizumab and olaparib differs across the UK.

## Funding and access to drugs across the UK

### Standard drugs and treatments

Most women with recurrent ovarian cancer will be offered standard treatments by their oncologist. This means drugs that are licensed for treating women with ovarian cancer in the UK and approved for use within the NHS on the grounds of clinical and cost effectiveness. This includes the chemotherapy drugs discussed earlier. However, for some drugs, access differs across the UK because of the way they are approved.

Funding for individual drugs is regularly reviewed so the information provided below is correct as of January 2017. For the most up to date information, call Target Ovarian Cancer or check our website: **[targetovariancancer.org.uk](http://targetovariancancer.org.uk)**

In England and Wales, drugs are approved by the National Institute of Health and Care Excellence (NICE). NICE has approved the use of olaparib (Lynparza®) as a maintenance therapy for relapsed, platinum sensitive ovarian cancer for women with a mutation in their BRCA1 or BRCA2 gene, if they have had three or more courses of platinum-based chemotherapy. NICE does not fund the use of bevacizumab (Avastin®) in women with platinum sensitive recurrent ovarian cancer.

Northern Ireland tends to follow NICE guidance.

In Scotland, drugs are approved by the Scottish Medicines Consortium (SMC). The SMC has approved the use of bevacizumab (Avastin®) in combination with paclitaxel for the treatment of advanced platinum resistant recurrent ovarian cancer in eligible women. Speak to your oncologist about whether you are eligible for this. The SMC has also approved the use of olaparib (Lynparza®) as a maintenance treatment for relapsed, platinum-sensitive ovarian cancer for women with a mutation in their BRCA1 or BRCA2 gene, if they have responded to platinum-based chemotherapy.

In addition, within England only, certain cancer drugs that are not approved for routine use on the NHS by NICE can be accessed via a special fund called the Cancer Drugs Fund (CDF), designed to improve access to cancer drugs. However, there are currently no drugs for women with recurrent ovarian cancer available through the CDF.



## Non-standard drugs and treatment

Some women may wish to ask about other ways to access different drugs, not yet licensed or approved. Sometimes oncologists prescribe drugs to treat women with ovarian cancer outside the clinical trial setting that are not yet licensed for ovarian cancer if they believe she may benefit. This is referred to as prescribing 'off license' or 'off label'.

An oncologist may also choose to prescribe a drug which is licensed but not yet approved for NHS funding. 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.

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

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, 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.

## Clinical trials

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Clinical trials are research studies that investigate potential new drugs, new ways of giving treatment or different types of treatments and compare them to the current standard treatments. Often studies are randomised, so you will not know whether you are receiving the new or the standard treatment. However research has shown that taking part in a trial improves long-term survival, even if you do not have the drug/procedure being tested, and that those hospitals which undertake medical research provide better treatment.

As someone whose ovarian cancer has come back, you may be eligible to take part in a trial. They have strict criteria for joining them to make sure that the results can be relied upon by comparing like with like, and not all treatment centres are involved in trials. Your oncologist should know what is possible, but sometimes you may need to ask specifically about clinical trials.

You might want to ask:

- What trials are you eligible for at your treatment centre?
- If you're willing and able to travel, what is available at another centre?
- What is the aim of the trial?
- What is the evidence that this new treatment might be effective?
- What are the possible risks and benefits of taking part?
- What taking part would involve compared to not taking part?

You may also be asked to take part in research studies, for example into your wellbeing, which may involve taking part in interviews and surveys.

Remember, if you are suitable, it is your decision whether or not to join a clinical trial. The Target Ovarian Cancer Clinical Trials Information Centre - [targetovariancancer.org.uk](http://targetovariancancer.org.uk) - gives lots of information for women considering taking part in a trial, and a search facility to find out about trials taking place in your hospital or other centres you may wish to consider.

*"I've been on a clinical trial for three years now, and I was the first person in the world on this particular one. I didn't know - nobody knows - what the side effects would be, but I was willing to try it. It might help others in the future and it's also helping me now. If I were royalty, I wouldn't have received better treatment and care."*

*Lynette*

*"I was first diagnosed in 2012 and I didn't go in for the clinical trial I was offered. I was shell-shocked and didn't understand what was happening. Since then I've become more knowledgeable and learnt so much more about the disease, and I have opted to take part in a trial. My advice to anyone considering it would be, 'Don't be afraid - it could be the best thing for you'."*

*Esther*



## Keep active and eating well

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Keeping active and eating well can be beneficial in helping you to cope with the demands of treatment. If you are experiencing side effects of chemotherapy (eg nausea, vomiting, loss of appetite) you may want to try eating small, frequent meals and snacks rather than three large meals each day. You may also find cold foods help to reduce cooking smells and therefore help to limit nausea. Eating slowly and sitting in an upright position may also help, and nourishing drinks such as fruit smoothies and milkshakes can help you maintain your weight.

Being more active can help you cope with side effects such as fatigue and can help improve your emotional wellbeing too. You may have worries about increasing your level of activity but it has been proven that doing exercise has fewer risks than being inactive. Start doing some form of exercise little and often, perhaps 10 minutes every day, and gradually build up the amount you do. Maybe you could start walking to your local shops instead of taking the car, or walk up and down your stairs more often? Perhaps you could raise your legs and move your arms when watching TV or you could put on some music and dance?

You can ask your CNS or oncologist if you have any concerns or want to know more about what diet and exercise are right for you, or there is lots of information online:

- Maggie's Online Centre has a nutritional advisor who you can contact: **[community.maggiescentres.org](https://community.maggiescentres.org)**
- Penny Brohn UK has very good information on healthy eating: **[pennybrohn.org.uk/nutrition](https://pennybrohn.org.uk/nutrition)**
- The World Cancer Research Fund (WRCF) has excellent guides – *Eat Well, Move More and Healthy Living After Cancer*: **[wcrf-uk.org](https://wcrf-uk.org)**
- Macmillan has lots information about maintaining a healthy lifestyle including a selection of simple recipes: search healthy eating at **[macmillan.org.uk](https://macmillan.org.uk)**

## HOW YOU MIGHT FEEL

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, 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.







## Sources of support

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Perhaps you have already visited a cancer support centre or have used complementary therapies. Maybe 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 some more support, from talking to a professional to simply chatting to someone online or visiting a cancer support centre.



## Target Ovarian Cancer

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If you're worried about anything you've read in this guide or want any more information you can contact the Target Ovarian Cancer Support Line. This is a nurse-led advice, information and signposting service for anyone concerned about any aspect of ovarian cancer, from symptoms, diagnosis and treatment to clinical trials, practical and emotional concerns. Call **020 7923 5475** or email **support@targetovariancancer.org.uk**

If you have any questions about your diagnosis, treatment or how you're feeling, you can also search through our directory of frequently asked questions or ask one of your own at **targetovariancancer.org.uk/experts**

### Online support

Many charities have forums you can join to read about other people's experiences and share your feelings. Target Ovarian Cancer has a private Facebook group for women with ovarian cancer to talk about their concerns. Find out more at **targetovariancancer.org.uk/intouch**

HealthUnlocked is an online forum with hundreds of health communities. There is an ovarian cancer specific chat forum run by Ovacom: **healthunlocked.com/ovacom**

Macmillan Cancer Support and Maggie's Cancer Centre also have excellent online forums which can give invaluable support: **community.macmillan.org.uk** or **community.maggiescentres.org**

### Support centres and hospices

Many hospitals offering cancer treatment will have either their own or a charity-run cancer support centre (such as Macmillan or Maggie's) onsite, or there may be a local cancer support centre, or hospice, nearer to your home. A lot of people are worried about the idea of a hospice and think that they are only for people at the end of life, but in fact, these centres can be a great source of comfort for many people and offer a range of specialist services for all stages of cancer. These teams are also experts in supporting you with any symptoms that you might experience.

Cancer centres and hospices will have nurses or counsellors you can speak to and provide complementary therapy and exercise sessions. Some sessions may be facilitated by a health professional so that treatment uncertainties or small concerns can easily be addressed and hopefully eradicated.

Some of these centres may also be able to offer an opportunity to meet other women in a similar situation, providing a safe environment to share experiences and gain support and understanding from each other, helping you to deal with the mixed emotions you may be feeling.

*“When I found out my cancer had come back, I joined my local cancer support centre. I have met a lovely group of ladies there and it is so nice to talk to others who understand what I am going through.”*

*Karen*

*“I’ve been a member of a support group at my local cancer centre for about eight years now. Women keep coming back for the social aspect of meeting as much as the support.”*

*Lynette*



## Complementary therapies at cancer support centres and hospices

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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. While none of these treatments are scientifically proven to ease the symptoms of medical treatment they can bring about a sense of wellbeing and relaxation. One-to-one or group therapies you may be offered include:

- Massage, which can be used for relaxation or to ease tired and strained muscles. Some 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, which can be given prior to chemotherapy to ease symptoms of nausea and vomiting and also for pain.
- 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 or anxious. 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.

Check out what your local support centre and hospice offers and try different therapies to find out which one is best for you. A professional qualified therapist from your local cancer support centre can help you to discuss therapy options and 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 Clinical Nurse Specialist (CNS) or contact Target Ovarian Cancer to find out details of your nearest cancer centre.

## Other professional support

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You may find it helpful to seek professional support to help you deal with your feelings and emotions. There are plenty of options available, including counselling, psychological support, cognitive behavioural therapy and mindfulness.

Target Ovarian Cancer has more information about all these options, which you can access at [targetovariancancer.org.uk/sourcesofsupport](https://targetovariancancer.org.uk/sourcesofsupport) or by contacting us.

### HOW YOU MIGHT FEEL

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.

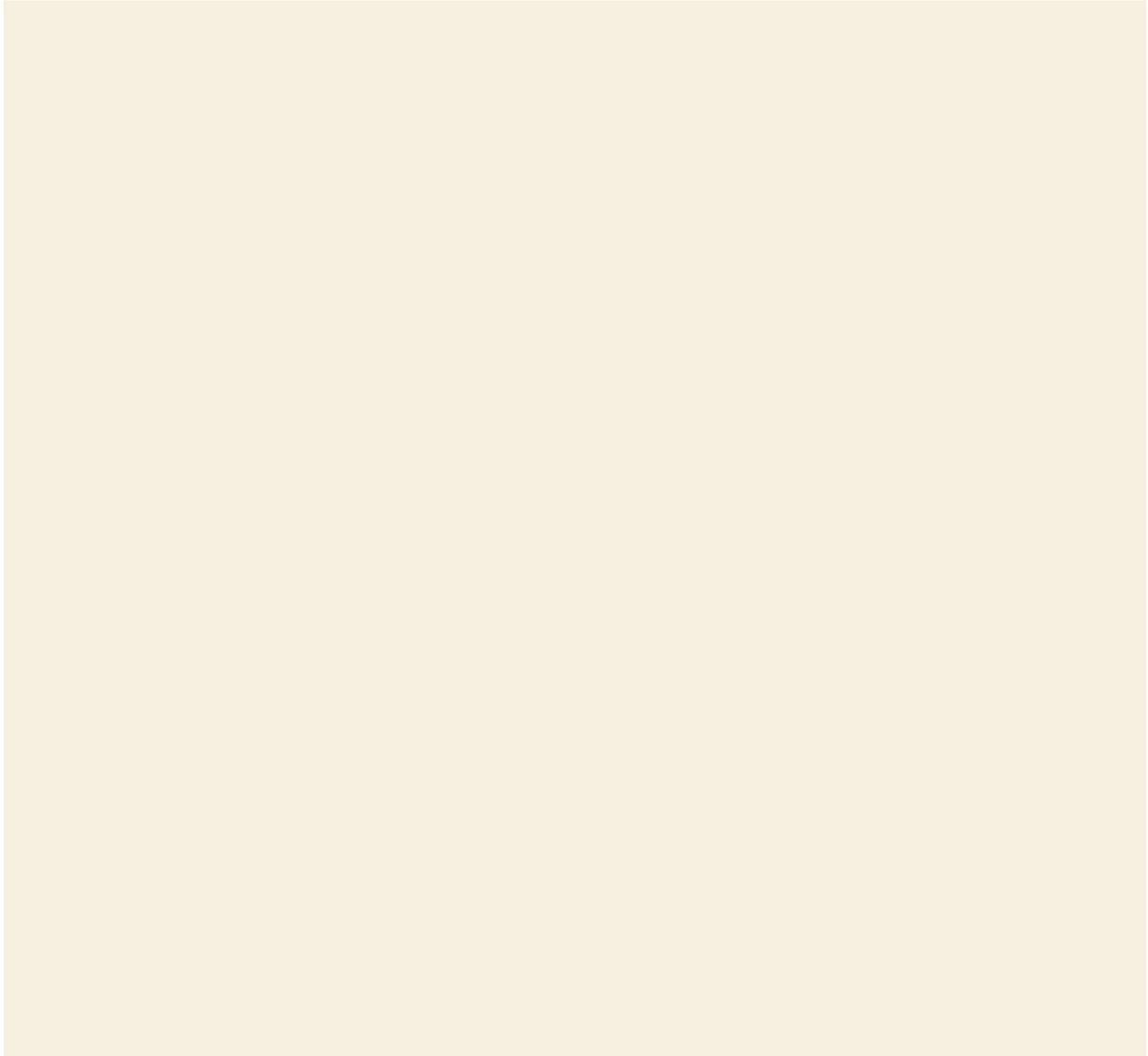
For some people there is a desire to put their 'house in order' which can mean writing a will if you did not do so before you had ovarian cancer, and thinking about what you want from medical treatment today and in the future. Although it can feel painful to think about doing these sorts of things, it 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.



## Notes

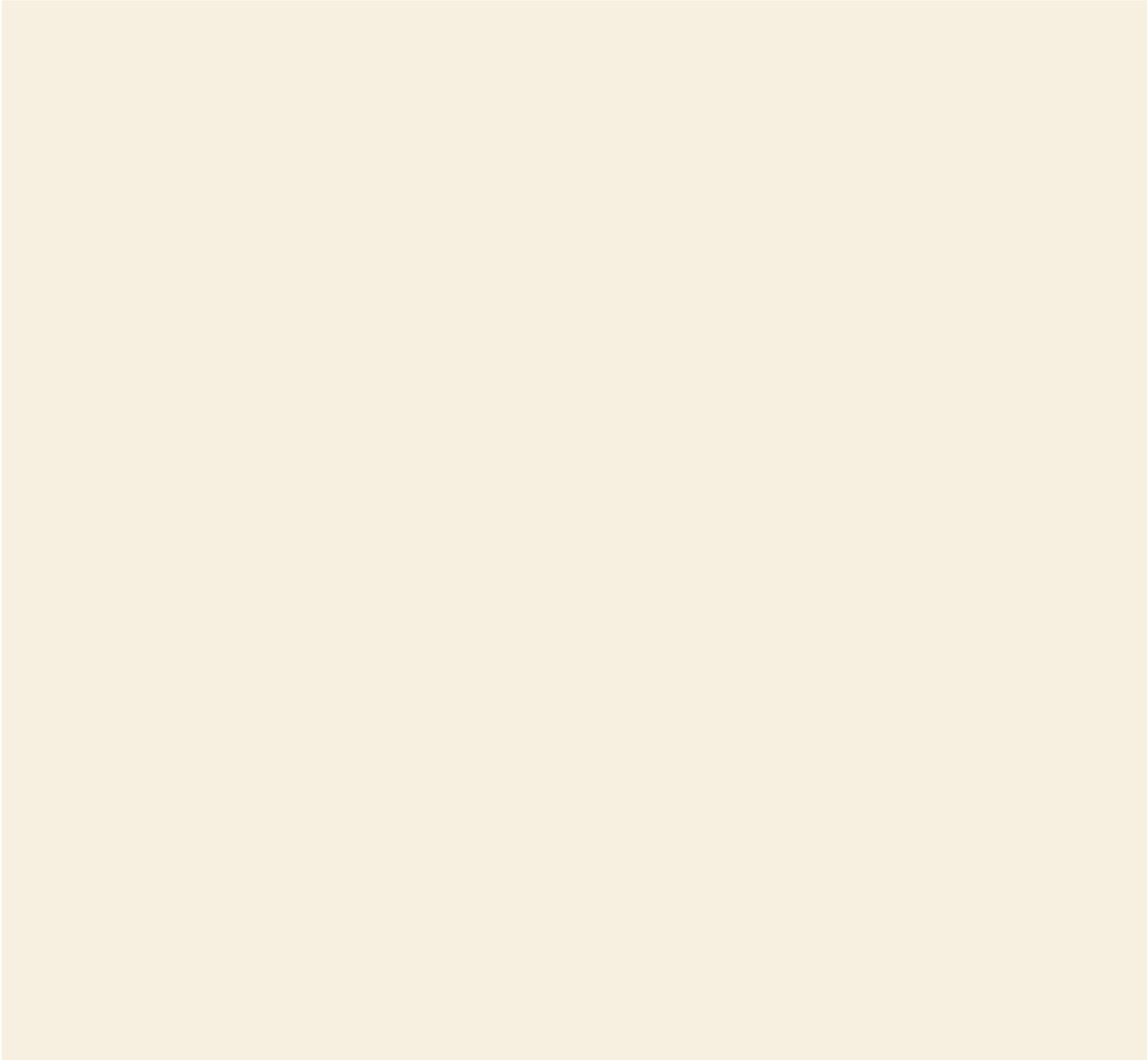
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**Useful contacts** You can use this space to record useful contacts such as your CNS etc.



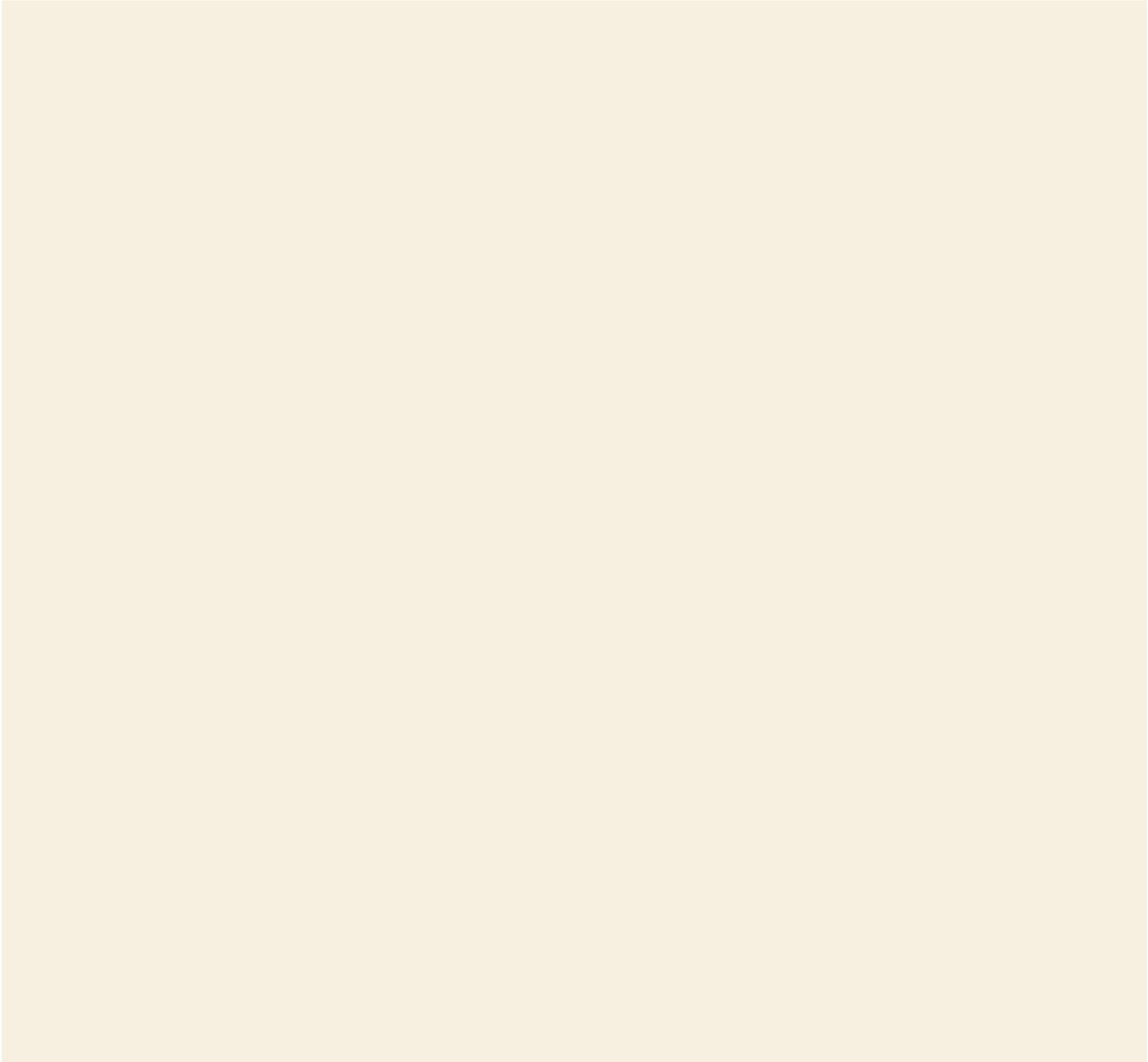


## Questions I want to ask





**My next steps**



## About Target Ovarian Cancer

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Target Ovarian Cancer is the UK's leading ovarian cancer charity. We work to:

- improve early diagnosis
- fund life-saving research
- provide much-needed support to women with ovarian cancer.

We're the only charity fighting ovarian cancer on all three of these fronts, across all four nations of the UK. Ovarian cancer can be devastating. But there is hope – Target Ovarian Cancer. We work with women, family members and health professionals to ensure we target the areas that matter most for those living with ovarian cancer.

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 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.



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