

Back here again

A guide for anyone with
recurrent ovarian cancer



Welcome to our guide for anyone with recurrent ovarian cancer.

This guide is for you if your ovarian cancer has come back (recurrent ovarian cancer). It's also for you if the cancer didn't respond to the first ovarian cancer treatment you had (progressive ovarian cancer).

This guide has been written with experts in ovarian cancer and its treatment – so you can trust that it's reliable, accurate and up to date. It focuses on your practical and emotional needs as you deal with this news.

There's a lot of information in this guide. We have broken it down into sections so you can read as much as you want to and come back to it when you feel ready.

1	How recurrent ovarian cancer is diagnosed	4
2	Treatment	7
3	Dealing with the news	32
4	Managing day-to-day life	43
5	Help for you	59

Throughout the guide we have included **Notes from Alison**. These are written by Dr Alison Farmer. She is a psycho-oncology nurse specialist and was diagnosed with ovarian cancer in 2001.



Notes from Alison

“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 decided to return to nursing. I 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.”

Dr Alison Farmer

1 How recurrent ovarian cancer is diagnosed

In this section

- ▶ When you finish your first treatment, your treatment team will monitor you with regular follow-up appointments.
- ▶ If you have any concerning symptoms, your CA125 blood test result is higher than normal or there is an unusual finding when you are examined, your treatment team will arrange for more tests.
- ▶ Your treatment team will use blood tests, a CT scan and may use an MRI scan to find out if the cancer has returned.

After you finished your first treatment for ovarian cancer you will have had regular follow-up appointments with your treatment team. At your clinic appointments your doctor will have asked you how you are feeling, and they may have examined you. They may also have done a **CA125 blood test**. This is a blood test used to diagnose ovarian cancer and sometimes to check for signs of the cancer returning.

If ovarian cancer returns or has grown, you may have symptoms that are persistent and unusual for you. The symptoms may be similar to those you had the first time, or they may be different. Not everyone will develop symptoms if ovarian cancer comes back.

If you had any concerning symptoms, your CA125 blood test result was higher than normal or there was an abnormal (unusual) finding when you were examined then your team will have arranged more tests to find out if the cancer had come back.

These tests usually involve:

- ▶ blood tests, including a CA125 blood test. If you've already had one, your team will do another one. They look for an upwards 'trend' in your CA125 levels rather than acting on a one-off change
- ▶ a **CT scan** which uses x-rays and a computer to create images of the inside of the body
- ▶ sometimes other types of scans, such as an **MRI scan**. This uses strong magnetic fields and radio waves to create detailed images of the inside of the body.

Occasionally, your treatment team may also have recommended a **biopsy** as well as a scan to find out whether the cancer had returned. This is when a small sample of tissue is taken from your body so that it can be looked at under a microscope to see if it contains cancer.

Speak to your treatment team or call our nurse-led support line on **0808 802 6000** if you have any questions about these tests or their results. Our support line is free to call from UK landlines and mobile phones.



How are CA125 blood tests used for monitoring?

CA125 is a protein that's found in your blood. CA125 blood tests can be used to check for signs of ovarian cancer returning and to monitor your treatment. The level of CA125 in your blood may rise because of ovarian cancer, but it may also rise because of other causes not related to cancer. Usually, a normal level is under 35 units per millilitre (u/ml).

A raised CA125 level isn't a reliable sign of ovarian cancer returning for everyone. Some women may not have raised CA125 levels even when diagnosed with ovarian cancer. Others may have naturally high levels in their blood. If your CA125 level isn't a reliable sign for you, your team will tell you how they plan to monitor you. This may be by having CT scans and doing physical examinations.

For more information about follow-up appointments and monitoring tests visit targetovariancancer.org.uk/monitoring

If it is found that the cancer has returned or grown, your treatment team will arrange an appointment to talk to you about your treatment options. There are many different treatment options including surgery and chemotherapy. Your team will look at many factors when recommending a particular treatment plan. These include:

- ▶ where in your body the cancer has come back
- ▶ whether the cancer has come back in one part or in more than one part of your body
- ▶ how long it has been since your last treatment for ovarian cancer
- ▶ your general health and how well you would cope with the treatment options
- ▶ your own wishes for treatment.

Your team will also talk to you about the support that's available to help you through this difficult time.

2 Treatment

In this section

- ▶ Treatment for recurrent ovarian cancer will usually be recommended when your team has found clear evidence of the cancer growing on scans.
- ▶ Treatment can include surgery, chemotherapy, targeted therapies and hormone therapies. This will depend on the type of ovarian cancer you have, how you responded to your original treatment and your own wishes.
- ▶ It's likely that CA125 blood tests will be used to measure and track your response to the treatment. CT scans may also be used.

Your oncologist and clinical nurse specialist (CNS) will talk to you about the treatments that are available and suitable as well as what type of treatment you would prefer.

Your treatment team should also talk to you about taking part in a **clinical trial** if there is one available. You can then decide if you would like to find out more about joining the trial. Read more about clinical trials on page 29 of this guide.

In some cases, if the cancer detected is small and it isn't causing you symptoms, your treatment team may suggest **active surveillance**. This means they will monitor your symptoms and do regular scans but wait to start treatment when there is more significant tumour growth. There is more information on active surveillance on page 13 of this guide.

Treatment options for recurrent ovarian cancer include:

- ▶ surgery
- ▶ chemotherapy (drugs used to kill cancer cells)
- ▶ targeted therapies (drugs that attack certain types of cancer cells with less harm to normal cells)
- ▶ hormone therapies (drugs that block the action of certain hormones in the body to slow down cancer growth)
- ▶ radiotherapy (when beams of high energy are used to kill cancer cells).

Often treatment can involve a mix of these options.

Which treatment you have will depend on:

- ▶ what type of ovarian cancer you have
- ▶ how well you responded to your last treatment
- ▶ the time since your last treatment
- ▶ whether your initial tumour had gene variants or hormone sensitivity
- ▶ your own wishes.

This section is focused on treatment options for **epithelial ovarian cancer**. If you have a rarer type of ovarian cancer such as **germ cell** or **stromal cell** tumours, your team will talk to you about your treatment options. You may be referred to a specialist treatment centre or there may be clinical trials you can take part in. Ask your team about these options.



Good to know

Our video with an oncologist explains the different treatment options for ovarian cancer that has come back. View the video by scanning this QR code with your phone camera or by visiting targetovariancancer.org.uk/recurrent-treatment



Who is looking after me?

You will be looked after by your treatment team, as you were when you were first diagnosed. This is called a **multi-disciplinary team (MDT)**. Your team is made up of different healthcare professionals. They specialise in treating gynaecological cancers such as ovarian cancer. The main hospital staff you will come across will be:

Oncologists

An oncologist is a doctor who treats cancer. Depending on your treatment plan you will meet:

- ▶ A **medical** or **clinical oncologist** who organises chemotherapy, hormone treatments, radiotherapy and targeted treatments such as PARP inhibitors. In this guide we call this person an **oncologist**.
- ▶ A **gynaecological oncology surgeon** who will do your surgery if that's an option for you. They have had extra training to operate on those with ovarian cancer. In this guide we call this person a **surgeon**.

Gynae-oncology Clinical Nurse Specialists (CNS)

This is a nurse who has had extra training to look after anyone with gynaecological cancers, including ovarian cancer. In some places CNSs are called **specialist gynaecology nurses**. In other places they are called **Macmillan nurses**. You may also hear them called your **key worker**. In this guide we call them a **CNS**.

Your CNS should be the person who is involved in every step of your care and treatment from when you are first diagnosed and through any further treatment. You may have access to one CNS or a team of CNSs depending on where you live in the UK.

Chemotherapy nurse

If you are treated with chemotherapy, a team of **chemotherapy nurses** will help you through your treatment. They will also help with any side effects that you have.

Other health professionals

Other people who may be involved in the MDT are:

- ▶ **radiographers** – who do scans like x-rays and CT scans
- ▶ **psychologists** – who help your mental health during and after a cancer diagnosis
- ▶ **pathologists** – who look at the cells in a laboratory to see if they are cancerous and to find out what type of cancer it is
- ▶ **anaesthetists** – who choose the right anaesthetic for you if you have surgery. This stops you from feeling pain during the operation. They also help you to prepare and recover from surgery
- ▶ **nutritionists or dietitians** – who give advice about what to eat and drink
- ▶ **physiotherapists** – who help you with movement and exercise
- ▶ **occupational therapists** – who help you cope with daily tasks that are difficult because of illness.

When you go to your outpatient appointments you may also see:

- ▶ **pharmacists** – who prescribe medication
- ▶ **advanced clinical practitioners** – who work under the guidance of **consultants** (senior doctors).

The MDT meet up often to talk about the care and treatment of their patients. They review test results and talk about plans for treatment. Remember that you should always be fully involved in decisions about your treatment.

“When I spoke to my oncologist and was initially told it was a recurrence, I was upset. Then he said to me, ‘The drugs we have now, like maintenance drugs, have come on so far even in the last few years that they were being trialled when you were first diagnosed.’ He was massively reassuring.

In my head I thought, ‘it’s a recurrence, there’ll be nothing’. But when he spoke about what’s available now, he seemed so positive about the hope for a good life after a recurrence. I went away thinking, I can do this because there’s something on the other side.”

Emma



Who should I speak to if I have questions or problems?

You should be told who the main person looking after your care and treatment is. This is usually a CNS. You should be given their contact details so that you can get in touch with them with any questions or problems.

It's important that you understand what is happening to you and why. You may have different key contacts for different parts of your treatment. If you are not sure who they are, or how to contact them, ask someone in your treatment team to write down the details for you. There is space at the end of this guide to keep any useful contacts.

“There were a couple of CNSs who were brilliant, and I would talk to them if I had any queries. I didn't really understand what the surgeon had actually taken out after my surgery. So I sat down with my CNS and she drew it out for me.

I also talked to her about intimacy with my husband because that is massively affected. And she was really good; very understanding but very practical. The CNSs were a lifeline for me.”

Sarah

When does treatment for recurrent ovarian cancer start?

Your team will usually recommend starting treatment when they have found clear signs of the cancer growing on scans. Sometimes your CA125 level may be rising over time without any other sign of cancer activity. This is when there are no symptoms and no sign of cancer growth on your scans.



It is unlikely that your team would recommend starting treatment based only on a raised CA125 level. This is because research has shown that starting chemotherapy when your CA125 levels start rising but before you have any symptoms does not have an effect on how successful the treatment is.

A raised CA125 level is also not enough on its own to prove that the ovarian cancer has come back. Your team will monitor you closely with regular reviews and scans to make sure treatment is started quickly when it is needed. They will also monitor your wellbeing. You may hear this called **active surveillance** or **watchful waiting**.

It is also possible that there are early signs of cancer found on your CT scan but they are too small to cause any symptoms. In this situation your team may still recommend active surveillance rather than starting treatment straight away.

Waiting until you have symptoms or until there are signs of more significant tumour growth on scans can be worrying if you want to start treatment as soon as possible. But there are benefits to waiting. It means you have a longer period between **platinum-based chemotherapy** treatments such as **carboplatin** and **cisplatin**. This may mean you respond better to those drugs. It reduces the chance of your body developing resistance to the treatment. It may also improve your quality of life as you avoid the side effects of treatment for longer.

It is also OK to start treatment as soon as it has been confirmed that the cancer has come back. It is important to talk to your CNS or oncologist about what you want to do. You may have a particular reason for wanting to start treatment as soon as possible. For example, you may want to attend and be well for an important event. Or it may simply be because that's what is right for you and your emotional and mental wellbeing.



How it felt for me

“When I was first diagnosed and had treatment, I remember thinking that if I ever had a recurrence I could never watch and wait. But when it happened, my oncologist explained that there actually wasn't enough disease for them to be concerned that it needed to be treated then and there. Putting my body through chemotherapy it didn't need at that point could be detrimental rather than helpful.

My oncologist was very clear that if I couldn't cope psychologically, he would jump in and treat it. But I felt a calmness around it because the team made it seem very normal to watch and wait and just see what happened.

I'm so pleased now that I did because I had 16 months of no treatment, without any kind of panic. I just went back to three monthly scans and blood tests. During that time my CA125 was going up steadily. But nothing showed on the scans for quite a few months. Then it started to show itself on CT scans, but it was doing exactly what my oncologist expected it to do, which was to show itself slowly.

Watch and wait for me was a bit of a no brainer. Every experience is different, and I think if I'd not been feeling well, my decision and my team's decision would have been different. But for me, the decision was made to treat it when the time was right. I'm really pleased that I did it that way.”

Emma

How will my response to treatment be monitored?

Once you begin treatment, it's most likely that a CA125 blood test will be used to measure and track your response to the treatment. This is unless you are someone whose CA125 level has never risen outside the normal range. There is more information about this on page 6.

CT scans may also be used to find out how well you are responding to treatment. Your CNS or oncologist will be able to explain your treatment plan in more detail. They can answer your questions if there's anything you don't understand.

Your treatment options

Secondary debulking surgery

More surgery may be a treatment option for recurrent ovarian cancer. This is called **secondary debulking surgery**.

Two clinical trials (called DESKTOP III and SOC1) showed that, for those whose ovarian cancer had come back once, surgery to remove all visible cancer followed by chemotherapy was more effective in treating the cancer than chemotherapy on its own. But to benefit from a second operation there are certain criteria (rules) that need to be met. These include:

- ▶ all cancer that was visible on scans and during surgery was removed during your first surgery
- ▶ the cancer has returned more than six months after your first-line chemotherapy
- ▶ you don't have **ascites**. This is a build-up of fluid in the tummy area
- ▶ your surgeon feels an operation is possible and that they can remove all visible signs of cancer again.

Specialist surgeons will be part of your MDT meeting. They will consider whether more surgery is possible for you. You will be able to discuss the potential risks and benefits of this with them.

They may recommend more tests such as a **PET-CT scan** to help them decide if surgery might be an option for you. This is a scan that combines a PET scan and a CT scan. A CT scan uses x-rays while a PET scan uses an injection of liquid to show the activity of cells in your body.

Surgery may be offered if the ovarian cancer comes back once. If it comes back for a second time or more and you meet the criteria again then surgery may be an option again. But there currently isn't enough evidence to show that the benefits of having surgery more than twice outweigh the risks.

If your MDT doesn't feel that surgery is an option, you can ask for a second opinion from a different surgeon in a different MDT. Your CNS will be able to help you do this if it's something you want to explore.

Chemotherapy

It's likely that you will be offered more chemotherapy. It can be given as treatment on its own or with other treatments such as surgery.

The type of chemotherapy that your team recommend will depend on:

- ▶ what treatment you have already had
- ▶ when you last had treatment
- ▶ how well you are.

If you have a rarer type of epithelial ovarian cancer, such as **low-grade serous**, you may be offered different treatment options instead of chemotherapy. Your treatment team will talk to you about these.

“Try to keep an open mind that whenever a recurrence comes your body is different than it was when you last had treatment. What you expect from treatment might be different to what actually happens.”

I got myself organised with what I would need during chemotherapy. I presumed it would be the same as last time when I had really painful joints so I couldn't move around as much as I wanted to. But my body has responded differently this time, and I haven't felt as badly in myself.”

Emma

It's common to get some side effects from chemotherapy. These can usually be easily treated. You can use the **chemotherapy side effects tracker** at the end of this guide to keep track of any side effects.

Read about the common side effects of chemotherapy at targetovariancancer.org.uk/chemotherapy



Your treatment team may use one of these terms to describe the ovarian cancer if it comes back:

The term your team use depends on how long it's been since you last had treatment with a platinum-based chemotherapy drug, such as carboplatin or cisplatin.

Both you and the cancer are unique. Your oncologist will recommend using drugs that they think will have the best impact for you.

Platinum refractory

If the cancer continues to grow during chemotherapy or it comes back within four weeks of completing your previous chemotherapy.

Platinum resistant

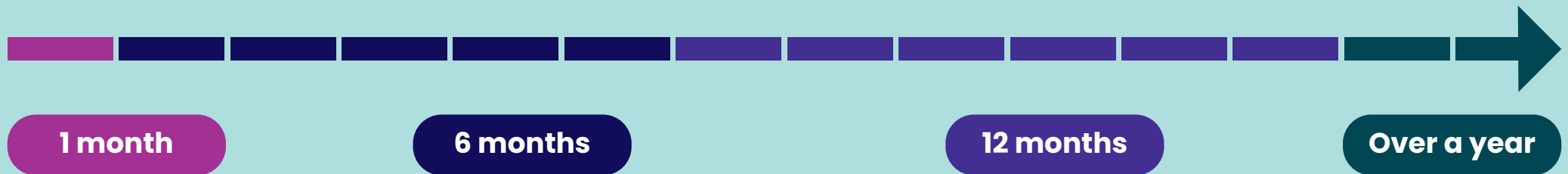
If the cancer comes back less than six months after you completed your previous chemotherapy.

Partially platinum sensitive

If the cancer comes back between 6 and 12 months after you completed your previous chemotherapy.

Platinum sensitive

If the cancer comes back more than 12 months after you completed your previous chemotherapy.



Time passed since last platinum-based chemotherapy

Chemotherapy for platinum-sensitive recurrent ovarian cancer

If it has been 12 months or more since your last treatment with carboplatin or cisplatin chemotherapy, the cancer is called **platinum sensitive**. This means that there is a higher chance the cancer will respond to more platinum-based treatments. In this case, your oncologist will suggest giving you more carboplatin. This is usually given with another chemotherapy drug, such as:

- ▶ paclitaxel (Taxol®)
- ▶ pegylated liposomal doxorubicin hydrochloride (PLDH, or Caelyx®)
- ▶ gemcitabine.

If it has been between 6 and 12 months since your last treatment with platinum-based chemotherapy, the cancer is sometimes called **partially platinum sensitive**. In this situation you're likely to be offered the same platinum-based treatments as those who are platinum-sensitive.

You may continue to have platinum-sensitive cancer and be offered multiple courses of platinum-based chemotherapy over time. Chemotherapy drugs can be reused as long as they're effective and the side effects are manageable. Unfortunately, it's common to develop resistance to platinum-based chemotherapy over time. This type of cancer is then called **platinum resistant**.

Allergic reactions to carboplatin

Occasionally you can become allergic to carboplatin. Different studies have shown different rates of allergic reactions to it. The risk of having an allergic reaction to carboplatin gets higher the more treatments you have.

If you do have an allergic reaction, it is sometimes possible to continue with carboplatin later, using something called a **desensitisation regime**. This means that all future doses of carboplatin are given very slowly. To begin with, it is given at a very low dose. The dose is then gradually increased. The treatment takes longer than normal but there is less chance of having another reaction to it. It can take most of a day for each chemotherapy session.

It is also sometimes possible to switch to a drug called cisplatin. This is a very similar drug to carboplatin. If you have a very bad allergy, you may need to stop platinum chemotherapy altogether. If this happens to you, your oncologist will talk to you about other treatment options.

“I had a small reaction to carboplatin on cycle three which meant I had to have the rest of the cycle slower. That was fine, and it's not been an issue since.”

Emma

Chemotherapy for platinum-resistant ovarian cancer

If the cancer needs treating again within six months of your last treatment with platinum chemotherapy it is called **platinum resistant**. In this case, it is less likely that the cancer will respond well to platinum chemotherapy again, so different drugs are often used. These include:

- ▶ paclitaxel (Taxol®), which is usually given once a week rather than every three weeks
- ▶ pegylated liposomal doxorubicin hydrochloride (PLDH or Caelyx®).

In platinum-resistant ovarian cancer, these drugs are usually given on their own.

In some areas of the UK, your oncologist may also consider the use of other drugs including **topotecan**, **etoposide**, **gemcitabine** and **cyclophosphamide**. Your team will be able to talk to you about the risks and benefits of these options in more detail.

Chemotherapy for platinum-refractory ovarian cancer

If the cancer continues to grow during chemotherapy, or it comes back within four weeks of completing your previous chemotherapy, it is called **platinum refractory**. In this situation you're likely to be offered the same treatments as those who are platinum-resistant.

Bevacizumab is a type of drug called a **targeted therapy**. You may also hear it called Avastin®. Targeted therapies specifically target the things about a cancer cell that make it different from a normal cell. Research suggests that for those with platinum-resistant ovarian cancer, having bevacizumab with chemotherapy can:

- ▶ increase the chance of the treatment shrinking the cancer
- ▶ keep the cancer under control for longer than chemotherapy alone.

At the time of this guide's publication (January 2025) bevacizumab is available in some parts of the UK for those with advanced (stage 3 or 4) recurrent ovarian cancer. Talk to your team about whether this is an option for you.

To find out about up-to-date drug availability where you live in the UK, ask your oncologist, visit **targetovariancancer.org.uk/drugs** or call our nurse-led support line on **0808 802 6000**



Good to know

In recent years cancer specialists have started to find that grouping those with ovarian cancer into platinum sensitive and platinum resistant may be too simple. This means that those who have platinum-resistant disease may still benefit from more chemotherapy with platinum-based drugs. Your team will talk to you about this if they think it could be a treatment option for you.

Maintenance therapy (PARP inhibitor drugs)

Chemotherapy for recurrent ovarian cancer can be very effective. But for most people, the cancer will return again at some point in the future, and they will need more treatment.

In some situations, a **maintenance treatment** can be given after chemotherapy. A maintenance treatment is a drug that aims to increase the amount of time that the cancer remains inactive. This is when the cancer stops growing. It means that you might be able to have a longer gap before needing more chemotherapy.

The main group of drugs used as a maintenance treatment for recurrent ovarian cancer are **poly ADP-ribose polymerase (PARP) inhibitors**. These are a type of targeted therapy that stop cancer cells from repairing damage in their DNA. This means that the cancer cells will die.

If there is a good response to platinum chemotherapy for recurrent ovarian cancer, research shows that taking a PARP inhibitor afterwards can keep the cancer under control for longer than chemotherapy alone. You can currently only have a PARP inhibitor once. So if you had a PARP inhibitor after your first course of chemotherapy, you won't be offered another one.

PARP inhibitors have been shown to work particularly well in those who have a **BRCA gene variant**. This is an inherited change in the BRCA1 or BRCA2 genes. The gene variant can increase the risk of some cancers, including ovarian cancer, breast cancer and prostate cancer. For more information about gene variants visit targetovariancancer.org.uk/genetics



Good to know

There are two ways a BRCA gene variant can happen:

- ▶ It can be an alteration in the cells of your body, which is inherited (passed down) through families. This is called a **germline variant**.
- ▶ It can develop in the cells of the tumour, which is called a **somatic variant**. These aren't passed down to family members.

There are three PARP inhibitors currently in use in the UK. They are called **olaparib** (Lynparza®), **niraparib** (Zejula®) and **rucaparib** (Rubraca®).

In the UK, if you have stage 3 or 4 high-grade epithelial ovarian cancer, fallopian tube cancer or primary peritoneal cancer and you have responded well to platinum chemotherapy you may be able to access a PARP inhibitor. This is as long as you haven't already had one before. Exactly which drug you are offered will depend on:

- ▶ where you're being treated in the UK
- ▶ whether you have a BRCA gene variant
- ▶ which drug your team think will suit you best.

PARP inhibitors are given as tablets and can be taken at home for as long as needed. They are only stopped if the side effects are too bad or there are signs that the ovarian cancer has become active again.

If you have been diagnosed with stage 3 or 4 high-grade epithelial ovarian cancer, you may be able to access PARP inhibitors after you've finished chemotherapy.

Find out which PARP inhibitor you may be able to have by scanning this QR code with your phone camera or by visiting targetovariancancer.org.uk/drugs



You may have more chemotherapy if the cancer comes back after a PARP inhibitor. But it is unlikely that you will then be given PARP inhibitors again after this chemotherapy. This is because it is not yet clear whether giving a PARP inhibitor a second time as maintenance treatment is effective. This is being investigated in clinical trials.

For more information about the latest clinical trials visit targetovariancancer.org.uk/clinical-trials or call our nurse-led support line on **0808 802 6000**



Good to know

Access to different targeted drugs through the NHS can change. The information in this guide is up to date as of January 2025. For the most up-to-date information on ovarian cancer treatments visit targetovariancancer.org.uk/drugs or call our nurse-led support line on **0808 802 6000**

Other treatments

Hormone therapy

Hormone therapy, using drugs such as **tamoxifen**, **letrozole** and **anastrozole**, can also be useful in treating some types of recurrent ovarian cancer.

It may be used in those:

- ▶ with a hormone sensitive tumour
- ▶ with a small amount of disease (low volume)
- ▶ whose cancer is growing very slowly
- ▶ whose cancer doesn't respond well to chemotherapy
- ▶ who do not wish to have more chemotherapy.

Hormone sensitive ovarian cancer means that the cancer cells can grow in response to hormones in your blood called **oestrogen** and **progesterone**. In these cases, hormones can cause tumour cells to grow. Hormone therapies work by reducing the amount of oestrogen and progesterone in your body or by blocking oestrogen and/or progesterone and stopping them from reaching the cancer cells.

Low-grade serous ovarian cancer is often hormone sensitive. Your oncologist will talk to you about whether hormone therapy might be a treatment option for you.

Mitogen-activated protein kinase (MEK) inhibitors

MEK inhibitors work by targeting proteins (called MEK proteins) that help cancer cells to grow. By blocking these proteins, MEK inhibitors slow or stop the growth of the cancer cells.

Trametinib is a MEK inhibitor drug used to treat certain types of ovarian cancer. It can be given if you have low-grade serous ovarian cancer that has come back. It can also be used if you have low-grade serous ovarian cancer that has continued to grow after platinum-based chemotherapy. This is called **progressive ovarian cancer**. It is given instead of chemotherapy as a tablet that you can take at home. Like PARP

inhibitors, you can only have trametinib if you haven't been treated with it before.

At the time of this guide's publication (January 2025) trametinib is available in some parts of the UK. To find out about up-to-date drug availability where you live in the UK, ask your oncologist, visit **targetovariancancer.org.uk/drugs** or call our nurse-led support line on **0808 802 6000**

Surgery for control of symptoms

Surgery may also be recommended in some cases to deal with symptoms such as **bowel obstruction**. This is when your bowel becomes partly or completely blocked.

This surgery may involve creating a **stoma** or an **ostomy**. This is where the end of the bowel is brought through an opening in the wall of the tummy. Sometimes a **stent** may be used instead of a stoma. A stent is a tube that is put into the bowel to keep it open.



You can read more about the different types of stomas and how to manage them at **targetovariancancer.org.uk/stoma**. You can also order or download our guide, *Ovarian cancer and stomas*, at **targetovariancancer.org.uk/guides** or by calling **0808 802 6000**

Radiotherapy

Radiotherapy is where radiation, or high-energy rays, is used to kill cancer cells. It isn't often used to treat recurrent ovarian cancer but sometimes it can be used to control symptoms. It may also be used to treat ovarian cancer that has come back in one part of the body. Your oncologist will be able to talk with you about whether radiotherapy is an option for you.

Funding and access to standard drugs and treatment

Most women with recurrent ovarian cancer will be offered standard treatments by their oncologist. These are drugs that are **licensed** for treating those with ovarian cancer in the UK. Licensed drugs have been researched and then tested in clinical trials before they are available for wider use. They are approved for use within the NHS because they work well for treating ovarian cancer and they are cost effective. This includes the chemotherapy drugs mentioned earlier in this section.

Access to other treatments can be different depending on where you live. In England, drugs are assessed by the National Institute for Health and Care Excellence (NICE). NICE decisions are also followed in Wales and Northern Ireland. In Scotland the decision is made by the Scottish Medicines Consortium (SMC).

Some drugs have promising trial results but there is not enough clinical evidence for NICE to approve them for routine use. This is when they are routinely given and funded by the NHS. If this is the case, they can be made available on the Cancer Drugs Fund (CDF), which is a way of funding cancer medicines in England. This allows more time for evidence to be gathered about the drug. After this evidence has been gathered, NICE will then reconsider if the drug should be routinely given or not. While the CDF only applies in England, Wales and Northern Ireland usually make treatments available on the same basis.

Funding and access to non-standard drugs and treatment

You may wish to ask about other ways to access different drugs that are not yet licensed or approved to regularly treat ovarian cancer. Sometimes oncologists prescribe drugs to treat ovarian cancer outside of clinical trials if they believe you may benefit. This means they are not yet licensed for ovarian cancer. It is called 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 have to make a special application for funding for the drug. This application may or may not be accepted.

Occasionally a drugs company will run a **compassionate access scheme**. This means you can access a drug if you meet certain criteria, and the drugs company will meet the cost. Applications to the drugs company must be made by your oncologist.

If your oncologist is reluctant or unsure about talking to you about other drugs, you can always ask for a second opinion. You will always need the support of an oncologist, as they have to apply for funding for you.

Clinical trials

Clinical trials are research studies that explore potential new drugs, new ways of giving treatment or different types of treatments. Often studies are **randomised**. This means that, like tossing a coin, you will be put into a group by chance. These groups are sometimes called the **treatment group(s)** and the **control group**. Depending on the type of trial, groups may be split in different ways:

- ▶ One group may be given the new drug being tested and the control group would be given standard treatment, so that they can be compared.
- ▶ The treatment group might be given the new treatment and the control group might be given a placebo as well as standard treatment. A **placebo** is a treatment that has no effect.
- ▶ Both groups may be given the new treatment but in different ways.
- ▶ Some trials may be comparing more than one new treatment at once so there may be a few different treatment groups.

You might not always know which group you are in, but you will be closely monitored no matter which treatment you have. This may include having more regular tests and checkups during or after treatment than if you were not part of a clinical trial.

Each clinical trial has strict criteria (rules) for who is able to join the trial. This is to make sure that the treatment is tested on similar groups of people and that we know who the results of the trial apply to.

Not all cancer centres are involved in clinical trials. You should ask your oncologist what trials you might be suitable for and in which hospitals the trials are happening. You might want to ask:

- ▶ What trials are suitable for me at my local treatment centre?
- ▶ If I'm willing and able to travel, what trials are available at other centres?
- ▶ 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 would taking part involve?

You may also be asked to take part in research studies, for example into your wellbeing. This may involve completing surveys or being interviewed. You can decide if you join a clinical trial or a research study or not.

You can search live UK ovarian cancer trials on our website at targetovariancancer.org.uk/clinical-trials

Notes from Alison

“Facing a future that has lots of cancer treatments is not something that anyone looks forward to. With experience you will find ways to cope. Set small, achievable goals, plan pleasant activities in between treatment and accept offers of help. Facing treatment again can be particularly difficult when you have experienced it before. You may dread the physical changes brought about by the treatment, particularly the hair loss and fatigue. The amount that you dread the treatment can depend on your experience the first time round. If you found your primary (first) chemotherapy treatment very distressing, or hated a particular side effect, then make sure you talk to your doctors and nurses about this.

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 the cancer has come back. It is understandable that you will want to explore every option and 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 to feel that you would like to find out more about complementary therapies (therapies that complement your medical treatment) at this time. This can give you a greater sense of control. But it is always important to talk to your medical team about any complementary therapies you want to use first.”



3 Dealing with the news

In this section

- ▶ Dealing with the news that the cancer has come back or grown can be really challenging.
- ▶ You may find it helpful to talk to or meet other people going through similar experiences to share how you are coping.
- ▶ Target Ovarian Cancer's support line, private Facebook groups and support events are here for you.

Being told that the ovarian cancer has come back or grown can be more upsetting than when you were first diagnosed. You may still be recovering from your treatment or you may have hoped that cancer was far behind you. Your mind may 'freeze' and it can be very difficult to take in any information.

Some people experience strong emotions such as intense fear and worry. It is very normal to feel upset that the cancer has come back or grown. It is important to look after yourself during this time.



Top tips to help you get the information you need

It can be hard to take information in when you find out that the cancer has come back or grown. Here are some things you can do to help:

- 1 Write down any questions you want to ask your treatment team before your appointment. During the appointment, write down the answers so you can read them back later. You can also ask to record the appointment on your phone so that you can listen back to it.
- 2 It is always OK to ask your treatment team to explain things again or to explain them in another way. They may use medical terms which are difficult to understand.
- 3 Ask for a copy of the letter that goes to your GP if you haven't been sent a copy directly and you feel it would help you.
- 4 Take a friend or family member with you to any appointments if you find it difficult to take information in. Talk to them about the questions that you have and ask them to write down the answers that you are given.
- 5 Your CNS is there to make sure that your views are known in decisions about your treatment. Talk to them about how you feel and what is affecting your decisions about treatment. This might be things that are going on outside the hospital, like at home or at work.

Good to know

Asking some of the following questions may help you feel more in control and decide what you would like to do:

- ▶ What treatment options do I have?
- ▶ What can impact which treatment I can have? (For example, how long it's been since your last treatment can affect your treatment options)
- ▶ Will I have a different treatment if I've had more than one recurrence?
- ▶ How will certain treatments help me and how effective are they?
- ▶ Does the treatment have any risks now and in the long term?
- ▶ What treatment will I have if I had an allergic reaction to chemotherapy last time?
- ▶ What are the side effects of treatment? How might the treatment affect me physically, emotionally and sexually?
- ▶ How long do these side effects last and what might help me to reduce, control or recover from them?
- ▶ How will treatment affect my life and health in general?
- ▶ Will I be able to go on holiday?
- ▶ Can I continue to work?
- ▶ If I stop working, when will I be able to return?
- ▶ Where can I be treated?
- ▶ Would a different cancer centre offer me other treatment options?
- ▶ Is it possible to take part in a clinical trial at this cancer centre or any other centre?

Why has the cancer come back?

There is no simple answer to the question of why the cancer has come back. We still don't fully understand why some cancers return. We also don't yet understand why some cancers come back a long time after finishing treatment and others come back much sooner.

After surgery and/or chemotherapy treatment for ovarian cancer some women have 'normal' CT or MRI scan results. They may also have 'normal' CA125 blood test results. Despite this, sometimes cancer can still come back, even years after finishing your initial (first-line) treatment. This is because CT or MRI scans and CA125 blood tests can't detect near-invisible areas of ovarian cancer that may still be in the body after treatment. These areas of cells can, at some point, grow again.

Research is still happening to develop highly sensitive and more reliable ways of finding those tiny groups of cancer cells so we can know for sure whether there is any cancer left.



Notes from Alison

“It may have been a few months since your first 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 the 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 frustrated at not knowing where the cancer is, or to what level it has returned. This can lead to you feeling helpless and out of control, which is a very common reaction.

It is normal to try to think of a way to explain why the cancer has come back. You might find yourself blaming yourself. Or you might feel guilty or that you have let friends and family 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 the cancer's return. It is common to find that your mood changes regularly from worry about the future to feeling hopeful and positive as you begin to take in the information you have been given.”

Finding information and support

Everyone will want different things from their oncologist and CNS when they find out that the cancer has come back. Some will want as much information as possible. Others will want some information but not every detail. It may be that your family or friends seem to want to know more than you. This can feel strange compared to what you want. For some people, knowing medical details gives them a sense of control at a difficult time.

You may want to start treatment straight away. Or you may want to take some time to consider different options. In some situations, your treatment team may advise you to delay treatment and you may find it hard to understand why. You can read more about watchful waiting on page 13 of this guide.



Good to know

A lot of what you read about ovarian cancer online can be shocking. Statistics can make everything seem much worse. It is important to remember that there are lots of different types of ovarian cancer. Everyone will respond in different ways to their diagnosis and treatment. Sometimes this is based on the stage and grade of the cancer (how much cancer there is and how it acts). Sometimes it is based on factors that we don't understand.

You are an individual, not a statistic so be careful when looking for information online. Keep to trusted websites for information such as Target Ovarian Cancer, the NHS, Macmillan and Cancer Research UK.

Call our nurse-led support line if you have any questions about where to find reliable information on **0808 802 6000**

↕ How it felt for me

“When I was first diagnosed, I went on every forum that I could find and really frightened myself. Then I realised, that largely you were going to hear the negative stories on a forum because the people that are out there living their lives are not going to be on a forum.

Online forums are quite useful when you ask something specific. I asked about clinical trials and got people’s experience of different trials. But if you aren’t sure what you’re looking for, the internet is a potentially dangerous place to be because it’s so easy to go down other rabbit holes of information that aren’t necessarily helpful.”

Emma

“It’s easy to say, ‘don’t google’, but everybody does. Try not to, but if you do, take everything you see online with a massive pinch of salt because it’s old news, especially with how new treatments for ovarian cancer are progressing. Many treatments we have now weren’t available 10 years ago so the stats that you see online are no longer representative of what you can expect.”

Sarah



Sharing the news

The way you find out about the cancer coming back may affect how you share this news with others. If you find out the news alone, telling other people can feel like an extra burden or challenge. It may be especially hard if you are not sure how you feel or what a recurrence means for you right now. You may wish to wait a few days, weeks or longer before you tell others. You may wish to keep the information within close family or friends. Or you may want to ask someone close to you to let others know for you.

You may have children who just want reassurance. You may have partners who are very keen to find out more and to talk in detail with your oncologist and CNS. People have so many different ways of coping, those close to you will find what works for them.

Some family members may not be ready to talk at the same time as you. This can make it hard to talk to each other. Even if your family aren’t the type to talk about their feelings, talking to a health professional, a counsellor or a nurse may help them feel more able to cope. It may be that encouraging them to speak to someone about their feelings will help them to understand your diagnosis and some of their own worries. In turn, this may help them to better support you. Being able to talk honestly about your different needs for information and support will help you to understand each other at this time.

“I was a very independent person before all this, and I still remain independent. But I also know that I sometimes need a bit of help. I find being open and transparent with my family is the best way to go for me because I need people to know that I might need help. Sometimes accepting that help from someone else can make that little bit of difference to you and just make everything a little bit better.”

Wendy

Your CNS and Target Ovarian Cancer can help your family and friends to find more support. You may want to encourage them to get in touch with our support line, which is for everyone affected by ovarian cancer, including friends and family.



Good to know

Target Ovarian Cancer's specialist nurses are here to listen. Call the support line on **0808 802 6000** or email **support@targetovariancancer.org.uk**

We have information about support for family and friends: **targetovariancancer.org.uk/family-and-friends**

Macmillan has more information about emotional support for family and friends. Search **supporting someone** at **macmillan.org.uk**

Maggie's also offer support to families: **maggies.org/supporting-families**

Coping with the reactions of others

Dealing with the news that the cancer has come back may 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 feelings as they come to terms with the news.

You may have found from your first treatment that people around you can react in very different ways. Some people may be wary of talking about cancer with you. Others will want to talk about nothing but your diagnosis. Let people know when you do, or don't, want to talk.

“Some people don't want to talk about my recurrence at all, and I think it's for fear that they will upset me. I'm constantly saying to them, 'you're not bothering me, I'm happy to talk about it.' And if I don't want to talk about it on a particular day, I'll just say.”

Wendy

You may find that people give you labels such as 'brave' and 'strong'. They may tell you they could never cope in the way that you are. The reality is we all cope in our own way with what

life throws at us. Whatever you think and feel about this, try to be kind to yourself and remember that people will respond in different ways but are likely to mean well.

It may be that those close to you find the news frightening. It may sometimes seem that they are finding it harder to cope with than you. You may be finding extra reserves of strength to face this next challenge and get through it. Maybe you are the one who wants as much information as possible, while the people supporting you want information only on a need-to-know basis. You may even find yourself feeling guilty and wanting to protect those around you from worries.

Watch or share our support event on how to support a loved one with an ovarian cancer diagnosis: **targetovariancancer.org.uk/supporting-loved-one**

It's 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. As they don't have your diagnosis, they might feel especially powerless. This can sometimes make it hard to talk to and understand each other. Talking about anything can be difficult when you and those close to you are upset or stressed.

Any strains in your relationships with others can be extra challenges. They may feel as stressful as dealing with the cancer returning. But we can't control other people's reactions and emotions. You know your family and friends and their personalities, and you know what they were like before your cancer diagnosis. They will probably react based on their personality and how they feel about their own lives in relation to your diagnosis. You may be surprised, sometimes people find an inner strength that you just weren't expecting. They may be inspired to swing into problem-solving mode to support you.

Macmillan has more information to help you talk about cancer with your loved ones. Search **talking about cancer** at **macmillan.org.uk**

How it felt for me

“When I first was diagnosed, a few people that I thought were friends told me the worst stories and it was really unhelpful. With my recurrence I was more mindful of who was around me rather than taking on everybody else's emotions if they weren't helping me. This time I've been careful who I've kept close. I've told the people who I absolutely know and trust to be close to me.”

Emma

“I've been much better after my recurrence in terms of connecting with people who are supportive and hopeful rather than people who drain you and tell you negative stories. Everyone has good days and bad days, especially through treatment. You need those positive, encouraging people around you to build you up even when you're having a really bad day.

If there are people that are negative, just be selfish, and don't go near them. They may not mean it, but you don't need it. It's so important to be reminded that there is always hope and that people live with cancer now for a long time.”

Sarah

“I've had great support from my family and friends, everybody has been mindful of making everything as easy as possible for me. But I have lost a few friends along the way. I think they just don't know how to deal with it. And that's absolutely fine, it's just one of those things that happens.

I have made new friends in my village from being out walking the dog more. I've also made friends with people from Maggie's. Sometimes the most important thing is being able to say to somebody, 'I'm having a really bad day, fancy meeting for a coffee?' And that person will make you feel better.”

Wendy

4 Managing day-to-day life

In this section

- ▶ Asking for practical support from friends, family, colleagues and neighbours can really help at this time. Your local council may be able to help you too.
- ▶ Speak to your oncologist or CNS about your worries as they can support you. Target Ovarian Cancer's specialist nurses are also here to listen to any worries you may have.
- ▶ You may find it helpful to have some professional support. This can help you to understand and manage your feelings.

Asking for practical support

Starting cancer treatment again can be a tough challenge to your wellbeing. If you have low energy levels, other symptoms or side effects, think about asking others for practical help. This could be:

- ▶ helping you to go shopping or with other tasks
- ▶ travelling to/from appointments with you
- ▶ talking to other people on your behalf, like your treatment team.

Many people will be happy to help in this way including friends, colleagues or neighbours. 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 ask for practical help from them. Your local council may also offer services which can be useful. Some offer specific support for travelling to and from hospital.

“I am lucky to belong to quite an active church and during treatment, on chemo days, people provided meals so my husband and I didn't need to cook. Our kids were in their early teens at the time and still needed feeding! Having that kind of practical support during those couple of chemo days was really helpful.”

Sarah

Check with your local hospital information centre, local cancer support centre or CNS to find out what services are available to you.

Macmillan has lots of information about practical support on their website. Search **preparing for treatment** at macmillan.org.uk

Your emotions

A recurrence of ovarian cancer can affect your mental health and emotional wellbeing as well as your body. It may take some time to accept the news that the cancer has come back. It is understandable if you have the odd day when you feel upset and overwhelmed. But if this is becoming more common, or your emotions are feeling out of control, you may need some extra support.

“Before I started treatment again, I did prepare and say to my husband, children and closest friends that I would need time. I had to be really clear what I could cope with and to remind everybody how rubbish I was going to feel.

I'm lucky that they all get it and they're not rushing me to do anything but also not expecting me to be the really ill person because I don't want that either. Being kind to yourself and managing those people around you that are trying to be helpful is really important.”

Emma

When we feel upset, frightened or hopeless it can seem impossible to explain these feelings to others or to ask for help. You might feel that you shouldn't bother your CNS or GP with your feelings. But it is important to look after yourself emotionally as well as physically. Let someone know if you are struggling. There is help available. Take a look at the **Top tips for finding professional support** later in this section and the **Help for you** section at the end of this guide for more information on where to access emotional support.

Speaking to a specialist nurse

Target Ovarian Cancer's specialist nurses are here to listen to any worries you may have. You can contact our nurse-led support line Monday to Friday, 9am–5pm by calling **0800 802 6000** or by emailing support@targetovariancancer.org.uk

Speaking to our specialist nurses can be a real comfort. No question or concern is too small or big. They have supported thousands of people with ovarian cancer, as well as friends and family members affected by a loved one's diagnosis. They can give you confidential advice and support on practical or emotional concerns that you or your loved ones might have. They can also help you to find more support near you.

If you don't feel like speaking on the phone you can get in touch with our specialist nurses through our contact form on targetovariancancer.org.uk/contact-our-support-line

If you're unsure about using the support line, try our online tool to see how our nurses can help on targetovariancancer.org.uk/support-line-tool



↕ How it felt for me

"I found the support line really useful because often I wouldn't have a specific question in mind that I could pose to my CNS, I would just want a chat but I wasn't really sure what about.

I'd give the support line a call and say, 'Look this is my situation and this is where I'm up to...' and as you start talking, questions naturally come out and get addressed. The conversation would just flow and by the end I would feel reassured."

Rose

"I'm not usually the sort of person who would ring a support line, but I rang because I didn't know what else to do. I connected with the nurse Val straight away and now if I've got questions and I can't reach my CNS, I'll ring Val. Now all my family say, 'just give Val a ring'. It's like she's become a kind of member of our family.

My husband and daughter have also spoken to Val which really helped them. I feel really lucky I've got this person outside of my team, who knows the whole situation and has the time to chat."

Emma

Meeting others

You may also find it helpful to talk to or meet other people going through similar experiences to share how you are coping. There are many ways to meet others who are in a similar situation to you.

- ▶ The Ovarian Cancer Community group is a private Facebook group for everyone affected by ovarian cancer, including friends and family. In Touch is a group only for those with an ovarian cancer diagnosis where you can find comfort from others who understand. Join today: **targetovariancancer.org.uk/community**
- ▶ Our free online support events offer you the chance to meet leading experts as well as others affected by ovarian cancer. Find out more and sign up on our website: **targetovariancancer.org.uk/supportevents**
- ▶ Attending a support group can help you feel less isolated by sharing experiences, stories or tips with people who understand. Support groups are often held in cancer centres which may also offer other services that can help your emotional wellbeing. You can search for a local support group or cancer centre at **targetovariancancer.org.uk/supportgroups** or call **0808 802 6000**



Notes from Alison

“ 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 people come to accept that the cancer has become part of their lives. 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 ovarian cancer treatment and personal time. It may feel a bit like trying to keep 'all the balls in the air'. It can be very easy to put personal time at the bottom of your list so remember to spend time doing things you enjoy. Many people find that it is the simple things in life that give them most pleasure. This could be going for a walk somewhere green and relaxing, enjoying a stroll with the dog or spending time with the people you are closest to. Some people find they have a greater appreciation of the little things in life.

Often those with ovarian cancer say that they feel isolated. Ovarian cancer is a less common cancer compared to breast cancer, for example. Sharing your experience with others in a similar situation can be helpful.”

Dealing with fear

Some women with recurrent ovarian cancer have said that fear is their most difficult side effect. You may be frightened about where or why the cancer has come back. You may be worried about going through treatment again. Some people are scared that the cancer will shorten their life. You may find yourself thinking over your past or having regrets about things you haven't managed to do yet. It can be difficult to deal with these thoughts and the emotions that go with them. They can make you feel very drained.



Good to know

Emotional fatigue is the exhaustion you may feel when you use lots of emotional energy. Emotional fatigue is different to tiredness, which is easier to recover from by resting. You may feel exhausted or flat and it may impact your mood. If you feel this way, it may help to arrange for extra practical or emotional support.

You may be afraid that the treatment will not be able to control the cancer or that you may be in a lot of pain. If these are some of your fears talk to your CNS or oncologist as soon as possible so they can help you. It is unlikely that you will experience very bad pain. Most pain can be controlled with regular painkillers.

Your treatment team may not be able to give you firm information about how the cancer will behave this time. They may not be able to tell you what the outcome of your treatment will be, even if you already know a lot about the type of ovarian cancer you have. This might add to your fears. Try to remember that they are not avoiding your questions – they may genuinely not know the answer.



Some people describe coping with recurrent cancer as living in limbo because it can feel like an uncertain situation you can't control. If you find you are feeling constantly restless, tense and anxious you may find it helpful to have some professional support. This can help you to understand and manage your feelings.

Your CNS can help you understand your fears. They can also put you in touch with other health professionals for more support.

A psychologist will be able to help you with different ways to deal with difficult thoughts. Psychologists are experts in supporting your mental health and can do so during a cancer diagnosis and beyond. There is more information on different psychological therapies and how to access them in the **Help for you** section at the end of this guide.



Good to know

Scanxiety (scan anxiety), is a term used to describe feelings of distress and anxiety around upcoming medical tests and their results. This includes tests like the CA125 blood test and scans like CT scans. It is a very common experience for those with a diagnosis of ovarian cancer.

Scanxiety impacts people in different ways and at different times, but if you have these feelings, you're not alone. There are things you can do to help.

Read about scanxiety and watch our information videos at targetovariancancer.org.uk/scanxiety



How it felt for me

"A recurrence is hard mentally. I got some counselling privately and that helped. It taught me mindfulness, how to go to my safe happy place, visualisation and gratitude, which did help when I was going through a tough spot.

I like to research, and to find stories of hope. People recommended books, some of which I found helpful. Finding what helps you cope is very personal. I took what worked and made sense to me and forgot the rest."

Sarah

"The hardest thing with a recurrence is to do with your mind, it can be harder to keep being positive. I never did any meditation or anything like that when I was first diagnosed, but since my recurrence I went to a meditation class at Maggie's and now I do random YouTube mindfulness and meditation videos at home. I also recently joined a local mediation group, which has been really great."

Wendy

Making time for flow state activities

Fear is a very understandable emotion. Activities that hold your attention and help you to be present in the moment have been shown to help reduce fear and anxiety. These are known as **flow state activities**. Different people have different activities which help them enter a state of flow or deep focus. Making extra time for these activities may help you to manage and process distressing news, thoughts and emotions. Some examples of flow state activities are:

- ▶ gardening
- ▶ painting or drawing
- ▶ solving puzzles
- ▶ reading or writing
- ▶ playing an instrument
- ▶ practicing yoga.



“To take care of myself emotionally after my recurrence I went back to basics, to my coping mechanisms from my diagnosis four years ago which throughout my life I’ve always done. Life takes over and you’re busy, but I know that I need to ground myself again at certain times– it’s almost like a box of tricks I can turn to. I started to walk regularly. When I go for a walk, I don’t bring my phone with me. There are health benefits from walking, but it’s also a kind of meditation. I come back and I feel my thoughts are different. I can come back into a positive place. Things like doing yoga myself at home and breathing properly also help.”

Emma

Top tips for finding professional support

You may feel that you would like to have professional help dealing with your feelings. There are many ways to get support:

- 1 Talking to your CNS can be very helpful. They can help you to understand your situation better. Your CNS will also be able to tell you about the services available in your local area like a local cancer centre.
- 2 Your GP will be able to refer you to specialist mental wellbeing support to help you manage fear. Support is available across the UK but the type of support available may be different depending on where you live.
- 3 Target Ovarian Cancer’s support line can help you find support in your area. You can contact our support line Monday to Friday, 9am – 5pm by calling **0808 802 6000** or by emailing **support@targetovariancancer.org.uk**
- 4 You can access a psychologist for free through your local Maggie’s Centre. To find your nearest centre visit **maggies.org/our-centres** or call **0300 123 1801**
- 5 You can access emotional support and counselling services through your local Macmillan Cancer Support Centre. Macmillan also offer four free remote counselling sessions through Bupa. To find your local centre visit **macmillan.org.uk/in-your-area** or call **0808 808 00 00**
- 6 If you want to find a therapist yourself and you can afford to use services privately, the sites listed in the **Help for you** section can help you find a registered professional.

Concern for family members – genetic testing and hereditary ovarian cancer

When you have a diagnosis of ovarian cancer, it is common to worry that your family members may be at risk. In most cases, ovarian cancer is a one-off (sporadic) illness that is not related to family history. But up to 2 in 10 cases of ovarian cancer are hereditary and happen because of a genetic cause. A genetic cause means there is a variation (or a change) in one or more of your genes that increases the risk of ovarian cancer. This variation will have been inherited (passed on) from your mother or father before you were born and could be passed on to your children if you have them.

If you have been diagnosed with epithelial ovarian cancer you should be offered access to genetic testing for variants in your BRCA1 and BRCA2 genes, even if you have no family history of ovarian cancer. It is likely genetic testing was done at the time of your first treatment. If this wasn't the case for you, talk to your oncologist or CNS.

If you have a gene variant in your BRCA1 or BRCA2 gene, your family members will be able to have genetic testing too. They will be able to find out if they also have the gene variant. If they have one, they will get information about what they can do to manage their increased risk of ovarian cancer and some other cancers, such as breast cancer and prostate cancer.



Good to know

Depending on where you live in the UK, if you have been diagnosed with epithelial ovarian cancer, you may be tested for variations in other genes as well as BRCA1 and BRCA2. These include the BRIP1, PALB2, RAD51C, RAD51D, MLH1, MSH2 and MSH6 genes.

If you have a gene variant in any of these genes then your local genetics team will be able to advise on whether your family members would benefit from testing and will explain how to arrange this.

For more information about genetic variations, the impact of the test results on your family and how it might affect your treatment:

- ▶ Visit targetovariancancer.org.uk/genetics
- ▶ Order or download our guide, *Genetic testing and ovarian cancer*, at targetovariancancer.org.uk/guides or by calling 0808 802 6000

Eating well

Eating well can help your body cope with the demands of treatment. This means eating foods that are made up of things that help your body to repair and look after itself. You will want to eat foods that give you the energy you need during treatment. In general, there is no right or wrong thing to eat as long as you continue to be a healthy weight and eat a balanced diet.



The World Cancer Research Fund studies how diet and physical activity affect cancer risk and survival. They have a report called *Diet, Nutrition, Physical Activity and Cancer: A Global Perspective*. You can also download the booklet *Eat Well During Cancer* for recipe ideas and tips to manage side effects of treatment from wcrf-uk.org

Read more about diet and nutrition at targetovariancancer.org.uk/diet

Download our information sheet, *Ovarian cancer, diet and nutrition*, at targetovariancancer.org.uk/guides or by calling 0808 802 6000

Top tips if you are feeling sick or being sick

The side effects of treatment can cause you to feel nauseous (feel sick) or vomit (be sick). You may lose your appetite. If you have any of these side effects, you may want to try:

1 having more small meals and snacks throughout the day rather than three large meals each day

2 eating cold foods as this helps you to avoid cooking smells which can sometimes cause people to feel sick

3 eating slowly and sitting in an upright position

4 eating at certain times of day (for example, not late at night)

5 drinking nourishing drinks such as fruit smoothies and milkshakes as these can help you build up your weight and keep weight on if you're finding it hard to eat.



Keeping active

Staying active is also an important part of being as healthy as possible. Physical activity can help with side effects such as tiredness. It can also help improve your emotional wellbeing. You may worry about becoming active but it has been proven that doing exercise has fewer risks than being inactive.

Start by doing some form of gentle exercise little and often, perhaps 10 minutes every day. You can gradually build up the amount that you do. There are many ways that you can become more active that don't involve going to the gym. Gentle exercise includes:

- ▶ walking up and down your stairs more often
- ▶ walking to your local shops instead of taking the car
- ▶ raising your legs and moving your arms when watching TV
- ▶ dancing to some music
- ▶ doing slow, low impact exercise such as yoga.

Speak to your CNS or oncologist if you want to know more about what diet and types of exercise are right for you.

Target Ovarian Cancer runs weekly online yoga and relaxation sessions for anyone with an ovarian cancer diagnosis. Sign up to take part: targetovariancancer.org.uk/digital-events

Top tips to start exercising from our community

“I think the best place to begin being more active is to go out for a walk. Going out for a walk, getting the fresh air in your face even if it's just 15 minutes a day around the block, makes such a difference.

You can do YouTube videos at your own pace and they're free. I find Qigong and Tai Chi videos on YouTube. They help you to learn how to breathe and do very slight movements.

Also, Maggie's or local cancer centres usually have gentle exercise classes you can join. I recently joined a cancer rehabilitation class at my local sports trust which I learnt about through Maggie's. I love it because the programme has been made up for me. The trainer takes onboard your diagnosis and stage and plans a programme for you to build muscles up slowly again after treatment. I've also met lovely people who are now friends. It's given me the confidence to go to the gym and know I'm not going to hurt myself. Everybody in the class is in the same position as you, everybody's had a cancer diagnosis and are either through their treatment or still on treatment, so people know what you're going through.”

Wendy



5 Help for you

You may have already visited a cancer support centre or used complementary therapies along with your usual medical treatment. Maybe you have not yet needed more support, but you feel now that you would like some extra help. There are lots of ways to get some more support, from talking to a professional to talking to someone in a similar situation online.

Target Ovarian Cancer

Support line

Need someone to talk to about ovarian cancer?

Call our free, nurse-led support line and you'll speak directly to a specialist nurse. Our specialist nurse team have supported thousands of people just like you. Whether you need practical information, advice or just a listening ear, we're here for you.

Call us today: **0808 802 6000**

Our support line is open Monday to Friday 9am–5pm, excluding bank holidays. Calls are free from UK landline and mobile phones.

If you don't feel like talking, please use our contact form or email support@targetovariancancer.org.uk



Facebook groups

Our Ovarian Cancer Community group is a kind, supportive, private group for everyone affected by ovarian cancer, including friends and family. You will find support to help you every step of the way.

Our In Touch group is a safe and supportive space only for those with an ovarian cancer diagnosis. This is a private community where you can talk honestly and openly about how you are feeling – and find comfort and understanding from others living with and beyond ovarian cancer.

Join us today: targetovariancancer.org.uk/community

Support events

Our programme of digital events is shaped by you and the support that you have told us you need. From diet and nutrition tips to updates on new treatments, yoga and relaxation classes to having a virtual cup of tea and a chat, there is lots to explore. Our support events also offer you the chance to meet leading experts as well as others affected by ovarian cancer.



You can find out more and sign up to our upcoming support events on our website: targetovariancancer.org.uk/supportevents

To watch our previous events back at a time that suits you, visit our YouTube playlist: youtube.com/@TargetOvarianCancer/playlists

Website

Our website targetovariancancer.org.uk has more information about ovarian cancer as well as stories from women who have had a diagnosis of ovarian cancer.

You can also download or order more of our guides for free at targetovariancancer.org.uk/order-guides

Register to receive our latest news, information and events by email at targetovariancancer.org.uk/signup, and follow us on Facebook, X and Instagram.

Online and telephone support

- ▶ The Macmillan Support Line is available everyday, 8am–8pm. You can contact them for free on **0808 808 00 00**. This service also offers an interpretation facility in over 200 languages.
- ▶ Maggie's provides online cancer support where you can access specialist advisers and meet others through online support groups. Contact your local Maggie's centre for more information: maggies.org
- ▶ Samaritans are also available 24 hours per day, 365 days per year and you can talk to them about anything that is troubling you. They are available on **116 123**, free of charge, or email jo@samaritans.org

Support groups

Simply being around people who know what you're going through can help. Often groups have members who have had different types of cancers but there may be a group just for those with gynaecological cancers.

Support groups are for sharing experiences and for helping each other with emotional and practical support. If you have any questions about your treatment, speak to your treatment team.

Your CNS may run a support group locally or you can visit targetovariancancer.org.uk/supportgroups or call **0808 802 6000** to find a group near you.

↕ How it felt for me

“Going into a local support group for the first time is really daunting. I didn’t want to walk in there by myself so I took a friend with me. Take someone with you, and it doesn’t feel so scary. These places are so welcoming. When I walk into Maggie’s now, everybody knows my name and it’s almost like the place gives you a hug.

I know it’s scary but just do it. You just need somebody to go in with you the first time. Get yourself out of your comfort zone because it might just make that better difference to yourself.”

Wendy



Cancer support centres and hospices

Many hospitals will have a cancer support centre. This may be either their own or a charity-run centre, such as a Macmillan or Maggie’s centre. There may be a local cancer support centre or hospice nearer to your home.

You might be 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 and offer a range of specialist services for all stages of cancer.

Cancer support centres and hospice teams are experts in supporting you with any symptoms that you might experience. They will have nurses or counsellors you can speak to, and complementary therapy and exercise sessions. You may be able to go to sessions run by a healthcare professionals who can answer your treatment questions or concerns.

Some centres may also be able to help you meet others in a similar situation. They can be a safe environment to share experiences and gain support and understanding from each other. Speaking to others may help you to deal with the mixed emotions you may be feeling.

Your CNS can give you details of your nearest cancer support centres and hospices or ask our specialist nurses by calling **0808 802 6000**

Use Target Ovarian Cancer’s directory to find cancer support centres near you:
targetovariancancer.org.uk/supportgroups

Find your local Macmillan support centre:
macmillan.org.uk/in-your-area

Find your local Maggie’s support centre:
maggies.org/our-centres

Find a hospice near to where you live:
hospiceuk.org/hospice-care-finder



Complementary therapies at cancer support centres and hospices

Cancer support centres and hospices may offer complementary therapies which some people find very helpful. Complementary therapies 'complement' the treatments you receive in hospital. They are not alternative treatments for cancer. They can bring about a sense of wellbeing and relaxation. One-to-one or group therapies you may be able to have include:

- ▶ Reflexology, a type of therapy that applies gentle pressure to the feet or hands and that can be used for relaxation or to ease tired and strained muscles. Some people who receive reflexology on their feet have reported that this helps with peripheral neuropathy of the feet. This is damage to nerve endings, which causes numbness and tingling.
- ▶ Acupuncture, which can be given before chemotherapy to ease symptoms of nausea (feeling sick) and vomiting (being sick) and also for pain.
- ▶ Group relaxation, which can be very helpful when you are feeling stressed or anxious. When we are anxious our brain finds it difficult to take in information. Often we just can't focus or think straight and may not sleep well. Relaxation can help you to deal with the range of emotions you may experience and gives the body time to recover.

It can be daunting to visit a cancer support centre or a hospice for the first time. But many people find these services a great comfort both during and after treatment.

“I find Reiki really useful in terms of relaxing me. It certainly makes me stop. The thoughts will stop. I have a lovely therapist. I find it just gives myself an hour to completely relax, it makes you feel nurtured and helps with your mind.”

Wendy

Find out what your local cancer support centre and hospice offer and try different therapies to decide which one is best for

you. A professionally qualified therapist can talk to you about therapy options and what might suit your needs best.

Ask your CNS for details of your nearest cancer support centre or hospice or contact our specialist nurses on **0808 802 6000**

For more information about complementary therapies:

- ▶ Visit **targetovariancancer.org.uk/complementary-therapies**
- ▶ Download Target Ovarian Cancer's information sheet on *Ovarian cancer and complementary therapies* at **targetovariancancer.org.uk/guides** or by calling **0808 802 6000**

Psychological therapies

You may find it useful to find professional support to help you deal with your feelings and emotions. There is more information about all these options on our website. Visit **targetovariancancer.org.uk/support** or call **0808 802 6000**

- ▶ Counselling is where you speak to someone about your worries and fears. A counsellor's job is to listen and allow you to talk. Many hospitals can refer to counselling services. Cancer support centres may also offer free counselling. Ask your CNS, GP or local support centre for more information. If you would like private counselling, you can find a registered counsellor through the British Association of Counselling and Psychotherapy (BACP). You can call directly on **01455 883 300** or visit their website: **[bacp.co.uk](https://www.bacp.co.uk)**
- ▶ Psychological support will look at how cancer has affected your life and wellbeing. A psychologist will talk to you about the problems you are having. They will look at how the problems are affecting you. They can then decide what type of psychological treatment may help you. The British Psychological Society (BPS) can help you find a psychologist in your area. They offer the service in different languages if English is not your first language. You can visit their website **[bps.org.uk](https://www.bps.org.uk)** or call **0116 254 9568**

- ▶ Cognitive behavioural therapy (CBT) looks less at the causes of your feelings and more at what to do about them. It looks at how the way you think can make you feel and act. It then helps to improve your reactions to difficult situations by finding new ways to think about and deal with problems. The more specific a problem the more likely CBT will be able to help. Most clinical psychologists in the UK are trained in CBT and you can also access one through your GP. The CBT Register UK allows you to search for therapists in your local area: **cbtregisteruk.com**
- ▶ Psychotherapy is like counselling but the therapist will try to find out where emotions or problems might be coming from. A therapist will help you to think about what is happening in your life now. They will also look at what has happened to you in the past that might affect how you are feeling and acting. Psychotherapy can help you to understand why you behave in certain ways and how you might change this behaviour. The UK Council for Psychotherapy has a **Find a therapist** service available on their website: **psychotherapy.org.uk**
- ▶ Mindfulness helps you focus on the present moment and can be done at home. It is a type of meditation that can help with your wellbeing, stress and anxiety and low mood. Mindfulness and mindfulness-based cognitive therapy is taught by applied psychologists and other registered health professionals. To find out more about mindfulness, search **mindfulness** at **mentalhealth.org.uk**. You can also search **mindfulness** at **nhs.uk** or visit **pennybrohn.org.uk/resources** for mindfulness and relaxation resources.

For more information about free professional support you may be able to access take a look at **Top tips for finding professional support** on page 53.

You can also search **mental wellbeing** at **nhs.uk** for more information and advice on mental health.

Other sources of support

- ▶ Carers Trust works to improve support, services and recognition for anyone living with the challenges of caring for a family member or friend. They give information, advice and practical support to carers and can also offer practical support to families when a parent or carer has cancer: **carers.org**
- ▶ Carers UK gives expert advice, information and support to carers: **carersuk.org**
- ▶ COSRT is the College of Sexual and Relationship Therapists. They train therapists specialising in sexual and relationship issues and have a directory of members to help you find professional support in your area: **cosrt.org.uk**
- ▶ Daisy Network offers support to people who have experienced a premature menopause due to a medical condition or treatment. They offer information and share people's experiences of premature menopause: **daisynetwork.org**
- ▶ Home Start helps families with young children deal with whatever life throws at them. They can help to look after children or just be someone to talk to: **home-start.org.uk**
- ▶ Hope Support Services offers support to anybody age 11–25 when a close family member is diagnosed with cancer: **hopesupport.org.uk**
- ▶ Penny Brohn UK provides wellbeing information and support for anyone with a diagnosis of cancer: **pennybrohn.org.uk**
- ▶ Relate offers counselling, support and information for all relationships: **relate.org.uk**

Notes from Alison

“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 and friends 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 them. You can always ask your CNS to meet with you and your loved ones to help explain what you need now and what you don't want now. You can also call Target Ovarian Cancer's nurse-led support line on **0808 802 6000** to talk things through together.

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. At the same time you may feel rejected. Again, try to talk to your partner about this.

Some people may feel they want to 'put their house in order'. This can mean writing a will if you didn't do so before you had ovarian cancer. It could also mean thinking about what you want from medical treatment today and in the future. It can feel painful to think about doing these sorts of things. But it is something we should all do whether we have cancer or not. It may feel more poignant for you doing this now. You will hopefully feel relieved when you have made these decisions and you can get on with living your life to the full."



Notes

Useful contacts

Use this space to record useful contacts such as your CNS etc.

[illegible]

Questions I want to ask

Use this space to write down any questions you want to ask your treatment team.

[illegible][illegible]

Chemotherapy side effects tracker

Use this space to write down any side effects you have in the three weeks following each chemotherapy session.

Date of chemotherapy session	Week 1 side effects
1.	
2.	
3.	
4.	
5.	
6.	

Week 2 side effects	Week 3 side effects

When you need information, friendly support or someone to talk to that understands, our specialist nurses are here.

**We're open 9am–5pm, Monday–Friday.
Call us for free on: 0808 802 6000**



Get in touch for more information, support and signposting for anyone affected by ovarian cancer:



Support line: 0808 802 6000



TargetOvarianCancer



info@targetovariancancer.org.uk



@TargetOvarian



targetovariancancer.org.uk



@TargetOvarian

To access our list of references please contact us. Target Ovarian Cancer is a company limited by guarantee, registered in England and Wales (No. 6619981). Registered office: 30 Angel Gate, London EC1V 2PT. Registered charity numbers 1125038 (England and Wales) and SC042920 (Scotland).

Disclaimer: 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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