



What happens next?

A guide for women with a recent
diagnosis of ovarian cancer



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

- The women who shared their experiences – Anne, Audrey, Beverley, Carol, Clare, Esther, Jules, Julia, Lynette, Moira, Ruth and Sarah.
- The writers and reviewers – Dr Pauline Adair, Lynn Buckley, Dr Alison Farmer, Professor Christina Fotopoulou, Julia Merrigan and Mr Khalil Razvi.

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Throughout the guide we have included advice from women who have been through many of the experiences you are facing. Within each section 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

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This guide is for women with a recent diagnosis of ovarian cancer. It focuses on your practical and emotional needs in the days and months following diagnosis and offers advice on where to find support.

We know how isolating it can be to have a diagnosis of ovarian cancer. That's why we also run events around the UK to support you living with, and beyond, ovarian cancer and provide you with opportunities to meet other women and keep in touch. If you have any questions and concerns about any of the information you read in this guide, do not hesitate to get in touch with us.

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





After your diagnosis

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After your diagnosis you may receive information from every direction. Many people feel that what they need during this time is answers to questions like: What happens next? What does all this mean? What will happen to me? How will I cope? How can I tell my family and friends?

To begin to answer these questions, it might be helpful to be clear about and to understand who is looking after you as part of your treatment team.

Who is looking after me?

You will be looked after by a multi-disciplinary team (MDT). This team will involve all of the people caring for you.



"I was completely shell-shocked by my diagnosis and much of the information I was given at first fell on deaf ears. I often wished over the next few weeks that I had recorded the conversation or taken notes, as it was all such a blur."

Anne

Who's who in the team looking after you?

The main hospital staff you will come across will be:

Oncologists

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

- A gynaecological oncologist who is in charge of your operation or surgery. In this guide we use the term 'surgeon'.
- A medical oncologist who organises chemotherapy or targeted treatments. Oncologists are sometimes referred to as clinical or medical oncologists but in this guide we refer to this person as an 'oncologist'.

Gynae-oncology Clinical Nurse Specialist (CNS)

A CNS in gynae-oncology is a senior nurse who has had extra training to look after women with gynaecological cancers such as ovarian cancer. In some areas you may be cared for by a gynaecology nurse or a Macmillan nurse. Your nurse should help you to navigate your way throughout the healthcare system, from the point of diagnosis. Your relationship with your nurse can transform your care. Most women find them a huge source of support and strength. Throughout this guide, we refer to your nurse as your CNS.

Chemotherapy nurse

Depending on your treatment plan, your chemotherapy nurse will help you through your chemotherapy treatment and any side effects that you may experience.

There are often others involved in the multi-disciplinary team (MDT) such as pathologists, radiologists, psychologists and nutritionists. The MDT will meet up regularly to discuss the care and treatment of all their patients, review test results and recommend treatment plans. It is important to remember that you should also be fully involved in decisions about your treatment plan.

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

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After your diagnosis you should be told who the main person looking after your care and treatment is. This person is known in most hospitals as your key worker. This is usually a Clinical Nurse Specialist (CNS). You should be given contact details for your key worker so that you can get in touch with them with any questions or problems. It is important that you understand what is happening to you and why. If, for any reason, you are unsure who your key worker is or how to contact them, do ask a member of your medical team to write down the details for you.

"I think my main emotion at the time was probably disbelief; they're talking about somebody, but that somebody can't be you. This sort of thing happens to somebody else – right? Wrong!"

Jules

"Prior to my diagnosis I was so ill I had to be admitted to hospital. That's where I met my amazing Clinical Nurse Specialist Rosemary, who came to explain that I had ovarian cancer. She was good enough to show me my CT scan so that I could understand what was going on, and see that the tumour was quite self-contained."

Beverley

"I found managing friends and family a very wearing experience in the immediate aftermath of diagnosis. I needed to spend time to absorb everything, so I appointed a very good friend to be a 'loudspeaker', disseminating information to others and giving me the space I needed."

Anne

"It's a truly horrible thing to have to tell those you care about the most this news.

People closest to me went away and found out what the diagnosis meant and I didn't have to spell it out to them. It helped knowing that they had found out about it and understood. I found it difficult talking to other people who hadn't grasped the implications."

Sarah

Telling people

Who you tell about your diagnosis, and when you tell them, is up to you. If you need to take a few hours, a few days, or more to think about exactly what and how you are going to tell your family and friends, that is totally reasonable.

People might react more emotionally than you are expecting, considering it is you who has been diagnosed rather than them. However, when close friends or relatives hear your news it makes cancer a reality rather than something that happens to other people. Often, family or friends may cry or go very quiet. Taking your time to prepare and telling others when you feel strong enough to cope with their reaction will help you. If you feel that you might find telling people too difficult, you might want to ask someone you trust to tell people for you. Some of your friends may drop off the radar for a while as they find your news frightening. This might seem rather selfish to you. Hopefully, many friends and family members will be supportive and help you to get through this difficult time. Your Clinical Nurse Specialist (CNS) and Target Ovarian Cancer can offer support to your family and friends too so you may want to encourage them to get in touch.


Telling children

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Talking to your children or grandchildren about a cancer diagnosis is not easy, whatever their age. It goes right to the heart of every parent or grandparent's concerns about their ability to look after and be there for their family. Young children will understand the practical side of things; you have an illness and the doctors are looking after you. You might feel a little bit tired and sad or grumpy, but everyone is doing their best to get you better. The questions they ask can give clues to what is worrying them. Teenagers may ask for more information and may need a little more time to work through their feelings and think about the questions they might want to ask.

What you have been told about your diagnosis will, of course, have an impact on your feelings about what you want to say. Take things one step at a time, with your children, your family and your friends. Your CNS may be able to put you in touch with a family worker to help support you and your children.

Macmillan Cancer Support has two useful booklets: *Talking about cancer* and *Talking to children and teenagers when an adult has cancer*. You can browse these at **be.macmillan.org.uk** or ring Macmillan on **0808 808 0000** to order.

A woman with blonde hair and glasses is shown in profile, talking on a smartphone. She is wearing a white and grey striped top and a necklace with a large circular pendant. The background is a bright, out-of-focus window.

"Friends and family were great on reflection but at the time that sentence, 'you'll be all right' really got on my nerves. Who were these people? Even the doctors couldn't tell me that at the time."

Ruth



HOW YOU MIGHT FEEL

You may have been expecting the diagnosis or it might have come completely out of the blue. Either way it is never easy. If you are asked about your diagnosis you may remember how, where and when you were told, and even what the doctor was wearing. I remember my diagnosis as if it were yesterday, even though it is now a number of years ago. Some of what the doctor said may not have sunk in and you may have to ask for the information again. The stage of your cancer may not be relevant to how you are feeling at the moment, it is the fact you have a diagnosis of cancer that is distressing.

You may be feeling a variety of emotions ranging from sadness to anxiety, or perhaps hopelessness and fear. It is also common to feel anger. The anger might be directed at your doctor, if you feel the diagnosis was delayed, or perhaps at yourself for not sensing that something was wrong. You may be desperately searching for the reason you got cancer. This is quite common, and is a way of trying to gain control over the situation. Unfortunately we don't always know why cancer occurs and this can be frustrating.

We are all individuals and cope with a diagnosis of cancer in different ways. Some people see cancer as a challenge to overcome. Others would rather not talk or think about it. All these emotions are very normal and understandable, particularly just after diagnosis. There is no right or wrong way to feel.

At the time of diagnosis it is important to feel that you have support. If you have close relationships with family and friends these can be particularly important at this time but things may not be straightforward. Your family and friends will be experiencing some of the same emotions as you. Although most relationships get stronger, some people won't know what to say and may avoid you, which can make you feel hurt and rejected. Others may tell you to "stay positive". This is meant well but can be very tiring. Remember it is also OK to feel sad and not very positive about anything. Some women do need professional help at this time or after treatment has finished. The **What might help?** section of this guide explains different ways you can find this support.







Making decisions about your treatment



Some women have detailed discussions about any treatment choices there might be, while others prefer to ask their oncologist to recommend an option and almost take the decision on their behalf. You may find yourself caught up in a medical whirlwind, talking with health professionals about what happens next. In the middle of this it is really important to take a moment to make sure you have the information you need to make any decisions or choices put to you.

Whatever your feelings it can be useful to share your thoughts about the following with your oncologist or Clinical Nurse Specialist (CNS):

- How much do you want to know?
- When do you want to know it?
- How do you want to make your decisions? Do you like time to absorb information, or need to talk it through with others first?
- Is the expectation/intention of the treatment that you will achieve a cure, control of the cancer or manage symptoms?

"I didn't even have a diagnosis until after surgery and, at first, there didn't seem to be any choice about treatment. I felt like I'd got on a moving train and didn't have much control over what was happening to me – it was all a rush and I'd had no time to research my options."

Anne

The key decisions

Key decisions about treatment options include where to have your treatment, the timing of surgery and/or types and timing of chemotherapy and other drugs.

Asking some of the following questions may help you decide what you want to do:

- Where can I be treated?
- What treatment options are available?
- Would a different specialist centre offer me other treatment options?
- What are the benefits of a particular treatment and what is the evidence that it is effective?
- What are the risks involved in having the treatment now and in the long term?
- Are there potential side effects? How long are these side effects expected to last? What might help to reduce, control or recover from these side effects?
- How is any treatment likely to affect my life and health in general?
- Will I be able to go on holiday?
- When will I be able to return to work?
- How might the treatment affect me physically and sexually?
- Am I eligible for clinical trials at this centre or any other centre?



"I found that social media, social networks and reading blogs from other women can also provide support at this time. Hearing how other women have felt and what their treatment was can make you feel less alone."

Julia

Know that you can ask for help

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Your CNS has a special role to play in making sure your views are represented so let them know how you feel, and what is affecting your decision-making. This may well include things that are going on outside the hospital, in your home or work life.

It might help to take along a friend or family member, particularly one who is calm and listens to you. Talk them through what you want to know from the oncologist. If you wish, they can ask your questions or write down the answers to questions you ask. This will help you remember what was said.

Keep asking if you don't understand

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Health professionals might slip into medical jargon – just ask them to explain it another way. Don't worry about asking again, they would prefer you understand what is going on and will be happy to make sure that you do.

"Having someone with me during my appointments was so important. I needed someone to write things down. There's so much to take in, I was sat there in a daze and always forgot the things I wanted to ask. Health professionals also do slip into jargon a lot of the time so I found it really helpful to have someone with me who was confident enough to ask them to explain things again."

Esther

Second opinions

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Having discussed the possibilities for treatment with your oncologist, you may still feel uncertain as to how to proceed. If you would like to seek a second opinion, just ask. Your CNS or your GP should be able to advise you on how to go about this, and your oncologist should be happy to refer you as this puts you back in control of your decision.

"Before and after surgery, it was important to me to understand and be part of the decision making process, and for that I needed good quality information. We are all different but for me, feeling empowered was vital and there is a lot of evidence that the 'expert patient' can improve outcomes. This certainly helped my recovery – both practically and psychologically."

Sarah

HOW YOU MIGHT FEEL

A few years ago doctors used to tell patients what treatment they were going to have without asking their opinion. However, these days doctors are likely to discuss treatment options with you and might even ask you to decide which treatment you want. You might be very keen to be involved in treatment decisions or you might find the thought of choosing a treatment very stressful. Many of us just want the doctor to show that he or she cares, and to make the decisions for us. Our feelings change over time and as we come to understand more so don't be afraid to let your team know if your feelings change.



"I built up a really good rapport with my surgeon which I think really helped. I was able to take in paper with my list of questions written down, and they really listened to me."

Lynette







Treatment



Starting your treatment may bring mixed feelings. You may feel very positive that you are being well cared for, but it is normal to experience feelings of apprehension or fear. You may be worried about what your treatment will involve, whether you will be in pain and what side effects there may be.

It is common to treat ovarian cancer with surgery to remove as much of the cancer as possible, and chemotherapy (drugs which aim to kill cancer cells).

Your treatment will depend on the type of ovarian cancer you have, as well as the stage and grade. You may have surgery before starting chemotherapy treatment or your oncologist may recommend starting chemotherapy first, then having surgery, followed by some more chemotherapy once you have recovered from surgery. Occasionally if the cancer is diagnosed at a very early stage it may be treated by surgery alone. In some cases, usually of more advanced cancer or if you are not fit enough to cope with a big operation, surgery is considered too risky. In these cases, chemotherapy will act as your initial treatment and, after three cycles of chemotherapy, surgery will be reassessed.

All of these treatment options can be very effective. Your oncologist and surgeon should discuss with you what treatments are available, based on your individual clinical needs and what is available locally, and your personal preferences should also be taken into account.

For some women there is increased anxiety surrounding treatment due to the number of blood tests that are required and insertion of drips (intravenous infusions) into the arm. You can ask your nurse to apply a topical anaesthetic cream to the arm about half an hour before the blood test as this will ease the discomfort.

You can find out more about types of ovarian cancer, stages and grades at **targetovariancancer.org.uk/types**

Surgery

Before your surgery

You will be examined and given a series of tests to check that you are fit enough to have surgery. Your surgeon will explain what will happen during the operation. It is often difficult for the surgeon to know exactly how much surgery is needed until they begin to operate, so they may discuss different possibilities and options with you. Surgery will also confirm the staging and grading of your cancer, which is not possible to do through scans alone.

For many women with ovarian cancer, surgery normally includes removing the womb and cervix, both ovaries and fallopian tubes (called a salpingo-oophorectomy), and the omentum (a sheet of fat that hangs in front of the abdomen). It may also involve removing enlarged lymph nodes and parts of other organs that may be affected. This is sometimes called debulking or extensive or ultra-radical surgery. In order to ensure that all of the cancer is removed the surgery may include the removal of a part of the bowel.

If you have any questions, concerns or fears about your surgery, don't be afraid to raise them with your surgeon or talk to the nurses about how you are feeling. There may be additional concerns about fertility and facing an early menopause if you are a younger woman. There's more information about this in the **Younger women** section of this guide and at **targetovariancancer.org.uk/youngerwomen**

If you think of questions later you can also ask your Clinical Nurse Specialist (CNS) or key worker about anything you didn't understand. Your surgeon is there not just to operate but also to support you after the operation and take care of any issues or concerns that you might have.

"I'm a very sociable person but after my surgery, I chose not to go out for three weeks. I set aside time for myself. I didn't want to feel in a rush, or to be frustrated that things were taking longer than they might have before. We achieve the goals that we set for ourselves, and I wanted to recover."

Lynette

"When I was first told about the operation, I found out that I might have to have a stoma. My surgeon even arranged for a bowel surgeon to be in theatre with her. I only consented to this on the morning of the operation because it wasn't something I wanted, but most of all I wanted them to do the best job they could."

Lynette

After your surgery

Surgery puts your body through a great deal of stress, so it is very important to allow time to heal and recover. In the first weeks following your surgery you should take things very gently, allowing yourself plenty of time to rest. Why not stock up with a few good books, box sets or films to help you relax? Make sure you also get lots of sleep. Listen to your body as you gradually increase your level of activity: it will tell you how far you can go and what you can take on, depending on how you feel.

Side effects

- Will you be in pain? You will be given medication to ensure you are as comfortable as possible.
- How tired will you be? It is usual to feel tired after your surgery as your body is working hard to recover. You may experience extreme tiredness or fatigue that can occur very suddenly. It is important to build up activity gradually to help you deal with this.
- If your surgery did include the removal of a part of the bowel, the surgeon may have created a stoma. For a more detailed explanation, please visit **targetovariancancer.org.uk/stoma**, **colostomyassociation.org.uk** and **stomawise.co.uk**.

If you are concerned about any side effects, contact your CNS.

Chemotherapy

Chemotherapy is given to kill cancer cells that may remain in your body after surgery. The drugs are given through a drip into a vein and the treatment is given over several hours.

What chemotherapy will you have?

Usually you will be offered a combination of a platinum-based chemotherapy (most commonly carboplatin, but sometimes cisplatin) and paclitaxel (a taxane, most commonly called Taxol®). Sometimes carboplatin will be recommended on its own.

It is standard practice to give chemotherapy once every three weeks for six cycles. There is ongoing research into giving smaller weekly doses over the same period, and having chemotherapy directly into the stomach (intraperitoneal chemotherapy) but these are not yet standard treatments. Your oncologist should discuss all the appropriate treatment options available to you.

"Talking to other women who have been through surgery and chemotherapy can really help at this time."

Julia



What happens when you have chemotherapy treatment?

Most women go to the chemotherapy unit at their local hospital. You will usually spend most of the day at the hospital so you could think about taking a relative or friend to keep you company. A couple of magazines and a good book can also help to pass the time.

At the hospital a number of blood samples will be taken for testing before each cycle of chemotherapy. These test different parts of the body to check you are healthy enough to receive treatment. Once your blood test results are available, your treatment can start.

You will be shown into the treatment room where you will be invited to settle yourself in a comfy chair. The nurse will place a needle into one of the veins on your hand or arm and attach a drip so that the drugs can enter your blood stream. This might feel a bit uncomfortable as the drip goes in. If you are having carboplatin and paclitaxel then the nurse will give you the paclitaxel first followed by the carboplatin.

Will you have any side effects?

Many women treated with chemotherapy will experience mild side effects that can be easily treated; it is rare for side effects to be severe. For most women the side effects do not start straight away and most people are able to drive home from hospital. When you see the list of all the possible side effects it can be quite worrying but remember most women will not experience

"My first chemo session felt as though it wasn't real. Although I had a cold cap on and an infusion prepared before the treatment started, I still thought the nurse would say, 'Sorry, you're the wrong person, you don't need chemotherapy!'"

Julia

all these side effects and hopefully those that do affect you will be mild.

One of the effects of chemotherapy is that it reduces the number of white cells in your blood and that means your ability to fight infections may be affected. This is why the hospital will want you to contact them immediately if you get a temperature or feel ill in the days or weeks following treatment. There is no need to avoid family, friends and other members of the public, but you should avoid people with serious infections. Your hospital should give you a 24-hour helpline number to ring if you are feeling ill at any time during your chemotherapy and in the weeks after treatment.

"One of the worst parts of treatment was losing my hair – especially as I'd always taken great pride in my appearance. It helped that I arranged to have a wig that was very similar to my own hair. I ended up naming my wig 'Sarah' and every time I was out of the house I'd ask whether Sarah was OK. It was a great way of checking that my wig wasn't crooked in public!"
Clare

Other common side effects of chemotherapy can include:

- Tiredness and fatigue – most women feel very tired during chemotherapy so it is important to plan time to recover your energy.
- Hair loss – it is rare for carboplatin to cause hair loss, however nearly all women treated with paclitaxel will experience temporary hair loss. This will usually start two to four weeks after treatment begins. You may be offered a cold cap to help minimise hair loss. Cold caps can be uncomfortable and treatment does

take longer when they are used, however some women find they work really well, and you can ask for support to make it work for you. You may also wish to find out about a free wig service your hospital may offer. Ask your CNS for more details about cold caps and wig services that are available in your hospital.

- Feeling or being sick – you will be given anti-sickness medication to take home. If you do vomit you need to contact your chemotherapy team and they will change your prescription.
- Tingling or numbness in hands and/or feet – chemotherapy can affect your nerves which may cause your feet or hands to tingle or feel numb. This is known as neuropathy.
- Some women have reported symptoms which they refer to as 'chemo brain' or 'chemo fog'. This is the inability to think as clearly following chemotherapy as you did before treatment. It is not fully understood what causes this but Cancer Research UK offers a little more explanation on their website. To find out more, search 'chemo brain' at [cancerresearchuk.org](https://www.cancerresearchuk.org)

Many people find that as treatment continues they become used to the side effects and can plan around them. If you are badly affected do not hesitate to get in touch with your hospital as they will be able to help you. There are some tips for dealing with side effects in the **Back to everyday life** section of this guide.

"I had carboplatin and paclitaxel. I wasn't sick. I did lose my taste and hair but I wouldn't wear a wig or hat! If people stared or had a problem with it, then it was their problem."

Ruth

"I wore a cold cap to try to prevent hair loss which I struggled with at first but lots of hair did fall out. It was thin and wispy but just enough for me to feel OK without a wig."

Anne

"When I was having chemotherapy I experienced something called peripheral neuropathy which gave me the oddest sensations in my toes! But I knew that the chemotherapy was helping me, and I focused on feeling lucky that my hands weren't affected so I could still sew."

Lynette

"I was lucky and felt pretty well throughout my chemo, but I did find it helpful to keep busy to take my mind off myself, my illness and the side effects. I managed to complete several half-finished projects during my sick leave."

Anne

Radiotherapy

Radiotherapy is not generally used to treat ovarian cancer but is sometimes recommended for stage Ic and stage II cancer after surgery to help kill off any cancer cells left behind. Your doctor will only suggest this if there are very small areas of cancer left in your pelvis and there is no sign of cancer in your abdomen.



Other drugs

Depending on individual circumstances such as the type of tumour, whether surgery is possible and where you live in the UK, you may be able to access other drugs. The way drugs are approved for use in the NHS differs across the UK which means that there can be some differences in what drugs are available depending on where you live.

In England and Scotland, a targeted therapy called bevacizumab (also known by the brand name Avastin®) is currently available to some women with advanced ovarian cancer. Bevacizumab targets a protein called vascular endothelial growth factor (VEGF) that helps cancer cells develop a new blood supply. It is given through a drip into the vein in combination with the first line of chemotherapy drugs and after chemotherapy has finished as a maintenance drug. Ask your oncologist whether you are eligible.

Drugs are sometimes reassessed to decide whether they should be available on the NHS. The information above is up to date as of October 2016. Contact Target Ovarian Cancer for the most up to date information.

Clinical trials

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 who has recently been diagnosed with ovarian cancer, you may be eligible to take part in a trial. Each trial will have strict criteria for joining 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 about them specifically.

You might want to ask about:

- 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** – 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.



HOW YOU MIGHT FEEL

For many of us a variety of treatments lie ahead and sometimes in differing orders; some have surgery first, some chemotherapy. If surgery is recommended you may want it done quickly so that the cancer can be removed, or you may be dreading it as it may mean the end of your fertility. Chemotherapy can be another hurdle. Facing the first dose of chemotherapy can be particularly hard as we all have an image in our heads of what it will be like. A lot of myths surround chemotherapy. The image we have of it from television or films can be quite false. There are different chemotherapy drugs and we don't all react to them in the same way. The doctors and nurses will tell you what side effects to expect, but each person will react slightly differently so be sure to let them know how you feel throughout your treatment.

If you are told you are going to lose your hair you may feel very upset. Having no hair constantly reminds us of our cancer and makes us feel different. You may want to prepare for losing your hair by getting a short haircut and perhaps buying scarves, hats or a wig. This can be an emotional experience and you may feel particularly vulnerable at this time. You may wake up one morning to find much of your hair on the pillow or in

the shower tray. At this point many people shave their hair off. My husband shaved my head, burst out laughing and said, "You look like Alf Garnett but I still fancy you!" Laughter can sometimes come at the most unexpected times. Wigs can be hot and itchy but the good news is that they are now such excellent quality that they look like natural hair. It is entirely your choice whether you wear one or not. Going out for the first time when your hair is gone takes courage. As time goes by, and you see that people react with kindness, it becomes easier. Remember – your hair will grow back.

At each clinic appointment the doctors and nurses will ask you how you are. One of the things you may be feeling is extreme tiredness. Sometimes doctors forget to ask us about tiredness and some of us think that it is not worth mentioning the fact that we are exhausted because we think it is understandable. It may also be tempting to play down side effects and keep them to yourself so that it looks like you are coping better than you are. Looking back I am not sure why I felt I had to give the impression of coping really well and I regret not putting my feet up more. If you are unusually tired, or have other side effects, do speak to the doctors and nurses about it as there may well be something they can do to help.

"I used to keep a diary and every day recorded any symptoms that I had. This was a great help."

Julia

"I can't walk up the stairs like I used to. I get a bit breathless and tired. But I can walk up stairs, and I'm grateful for that."

Lynette

"I have to take lots of different tablets at specific times of the day so I've made myself a chart to tick them off! It helps me to remember what I've had and when, and gives me the reassurance that I'm doing things properly."

Lynette







Family history, genetic testing and hereditary ovarian cancer



Now you have had a diagnosis of ovarian cancer, it is a common reaction to worry that your daughter, granddaughter or sister may also be at risk.

In most cases, ovarian cancer is a sporadic or one-off illness that is not related to family history. However, about 15 to 20 per cent of cases of ovarian cancer occur because of a genetic cause - a mutation in one or more genes known to increase the risk of ovarian cancer that has been passed on from your mother or father. Some types of ovarian cancer are more likely to be caused by a mutation in a gene than others.

Hereditary ovarian cancer is most commonly caused by a mutation in either the BRCA1 or BRCA2 gene. Some mutations in other genes are also known to be associated with an increased risk of ovarian cancer however scientists have not yet found all of the genes associated with an increased risk.

The mutated BRCA1 or BRCA2 gene can be passed through the generations from parent to child, and can be inherited through the mother or father's side of the family. Mutations in genes, including the BCRA1 and BRCA2 genes, can occur in any family. Some communities, such as Ashkenazi Jews, are up to ten times more likely to carry a mutation in one of their BRCA genes than the general population. If you are from an Ashkenazi Jewish family you should let your oncologist know.

Should I be tested?

Women diagnosed with non-mucinous ovarian cancer in the UK, irrespective of family history, should be offered genetic testing for mutations in their BRCA1 and BRCA2 genes. Over 90 per cent of ovarian cancers diagnosed are non-mucinous. Some women may not be eligible, due to the specific type of cancer they have or the age at which they first developed ovarian cancer, but it is important all women discuss genetic testing with their GP or clinician to find out if testing is appropriate.

As guidance on genetic testing is relatively new, in some areas of the UK testing may not be automatically offered. If you haven't been offered a test, arrange to talk with your oncologist and discuss whether you may be eligible. You can also contact your local genetics centre for advice – **bsgm.org.uk/information-education/genetics-centres**

All women need to be adequately supported by a genetic counsellor through the testing process. This process is getting quicker, but can still take a number of weeks. It may identify mutations on either the BRCA1 or BRCA2 gene, but the test may well be inconclusive, even when several family members are affected. This is why it is important to have expert support to understand the results and their implications for you and your family.

"Discovering I had a BRCA1 mutation actually settled me on one level – I knew then that nothing I could have done would have prevented me getting cancer and that I hadn't contributed to it through eating bacon or whatever the latest myth is."

Anne

What are the implications if I do have a mutation in my BRCA1 or BRCA2 gene?

Some women find it helpful to have an explanation for why they developed ovarian cancer. However, there will be other implications for you. In the case of the BRCA1 or BRCA2 genes you will have a higher risk of developing breast cancer (in comparison to the general population). You will be offered information and support to decide about the best risk managing option for you. These options include screening, drugs or surgery.

The results of genetic testing may also have implications for the treatment you are offered for ovarian cancer. New types of targeted treatments for cancers linked to a mutation in the BRCA1 or BRCA2 genes, called PARP inhibitors are being developed. Ask your oncologist about your eligibility for this treatment or to new clinical trials.

Target Ovarian Cancer has further information to help you and family members understand about hereditary ovarian cancer. You can download our guide *Genetic testing and hereditary ovarian cancer* at **targetovariancancer.org.uk/guides** or contact us to order a copy.

What are the implications for other family members?

Other members of your family may also have the gene mutation if you do, including your mother or father, siblings and your aunts, uncles and cousins, depending on the side of the family the mutation is passed down through. The children – sons and daughters – of someone with a BRCA1 or BRCA2 gene mutation have a 50 per cent (one in two) chance of having inherited it and therefore being at increased risk. They also have a 50 per cent (one in two) chance of having inherited a normal copy of the gene from the parent with the gene mutation. If you carry a mutation in one of your BRCA genes, it is much easier for your relatives to be tested, as it will be clear where the mutation in the BRCA gene occurs.

Women with a BRCA1 or BRCA2 gene mutation have a high risk of developing breast and ovarian cancer and men may have an increased risk of developing prostate cancer and male breast cancer. There may also be a small increased risk of pancreatic cancer for men and women who carry BRCA2 gene mutations.

Family members will make their own decisions about genetic testing, and if they are found to be at increased risk, they will also need help and support to make decisions about what to do with that knowledge.





Back to everyday life after treatment

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Going through surgery and/or chemotherapy is tough enough, but you are at least looked after and guided through the experience. When you go back to everyday life after treatment, many women feel there is no one to guide them through what happens next. For many it will be three months before a follow up appointment or contact with a professional. After such an intense experience that may seem an eternity.

"When you're first diagnosed and undergoing treatment it's all so full on. Then everything finishes: your treatment is over for now, or your next check-up is three or six months away and you can feel a bit abandoned. This is when you need friends around you, or people in the same position as you, to build a feeling of solidarity. Target Ovarian Cancer really helped to make me feel less alone, and put me in touch with others in similar positions. It really helps with that feeling of abandonment that is so common."

Esther

Finding a new routine

Let's face it, an ovarian cancer diagnosis changes things. Going home and trying to get back to a routine, whether that's looking after children, caring for parents or your partner, or just looking after yourself will be demanding in a different way. Getting back your energy might be tough. Some people will experience fatigue which is not just a question of feeling a bit tired but actually feeling pretty exhausted most of the time. This is the effect of treatment, as well as the draining emotions you have been through. It will get better but it takes time. Be good to yourself and find a pace you can cope with. You need a plan to get through this time and slowly get back to everyday life. Creating a new routine to help frame the day might help to give you a sense of normality again, though this can be daunting and everyone will have different expectations about what they want their life to be like now. Some women may want to use a diary or day planner to help focus, while others may just want to take each day as it comes.

If there was ever a time when you deserve a bit of help with the housework, cooking and practical stuff, this is it. Try to think about people in your life that may be all too happy to cook you the odd meal, run errands and help with the everyday. Perhaps your local community is great at supporting each other, or your family and friends are close by? For those of us in a different situation, getting help may be more difficult.

You might have to ask, which can feel hard, but many friends will be delighted to be asked to do something practical. It will give them a feeling of being needed; they'll feel good about helping you out.

If you have a day when you feel weepy and miserable try not to be hard on yourself. The new picture of your life may be similar to your old life, or it may be very different. Learning to accept that and carry on your everyday life can be hard and sometimes you may need help from friends, family and professionals – and perhaps from friendships formed through cancer experiences. You should be able to contact your Clinical Nurse Specialist (CNS) if you feel like you need their support during this time, or have a look at the section of this guide called **What might help?**

"I think if you are the kind of person that gets up at six in the morning to do your cleaning and you don't feel like it anymore, then don't do it."

Ruth

"I was always happy to ask for help. You need to let the people who care for you 'do' for you. It makes them feel better. Let them be involved – and give yourself a rest. Make the most of being fussed over. As a woman, we spend so much of our lives looking after other people – be selfish for once."

Moira



Identity and body image

Dealing with an altered body image can be particularly difficult after an ovarian cancer diagnosis. You may have surgical scars, or now have a stoma, you may have experienced a surgical menopause, have gained or lost weight during your chemotherapy or may be facing the temporary loss of your hair. Meeting other women who have experienced this can be helpful and supportive, and your Clinical Nurse Specialist (CNS) will continue to support you to help you get used to this new way of life. Some oncology units have volunteers who can give advice about putting on makeup and scarves. Look Good Feel Better is a charity that offers makeup workshops and resources to women after cancer treatment. Visit lookgoodfeelbetter.co.uk or ask your CNS about the support that is available in your area.

"One of the greatest challenges to my body happened during chemotherapy when I put on three stone in four months. I hadn't considered that side effect or how deeply I might feel its effects. I know people talk about body image, but I think it's more significantly self image. It felt like such a shallow thing to be worried about how you look, but actually it's not about how you look, it's about your perception of yourself."

Sarah

Relationships with those close to you

A diagnosis of cancer can change how you feel about yourself and it can have an impact on your relationships. Some people might find that it brings them closer to the people around them, while others might find that their relationships are more strained. Your friends and family may find life after your diagnosis particularly hard to deal with. This might be especially true of your parents and children. Friends may be very busy with their own families and careers. They may feel they are being supportive but it is whether you feel supported that is important.



Some people appear to be surrounded by family and friends but still feel lonely, while others have one close friend and feel well supported and cared for.

Your family and friends may benefit from getting support to cope with your diagnosis, and you may feel better to know they are supported. Target Ovarian Cancer and your CNS can provide support for family, friends and carers, so ask them to get in touch.

"When so much happens, it changes you. I became suddenly someone who was sick and needed to be looked after, whose whole identity was shaken and I think that's quite complex – it's a mixture of the physical issues and also confidence. But that continues to change too, though now the changes are for the better and it's an amazing feeling to reconnect with part of who I am and to feel that there is still more good to come."

Sarah

Resuming your social life

For some women ringing friends to make arrangements to socialise may seem like a burden. Others look forward to picking up 'normal life' again and seeing friends can be the best way of doing this.

You may find some friends are nervous and don't know what to say. Others will want to talk about nothing else. Don't be afraid to let people know when you do or don't want to talk about how things are going. Everyone's attitude to cancer is different. Some people find being close to someone with a serious condition like cancer is frightening as it is a reminder that any of us can develop a serious illness at any time in our lives. It's something that a lot of people don't like to think about. If your friends or family have not known anyone to have had cancer they may be cautious about seeing you.

If this is your experience, you could try attending a local support centre, group or course. You may not have thought this would be for you, but it may be worth giving it a go. Many people living with cancer find support centres a place to meet other people who understand what they are going through. Ask your CNS about whether there is a survivorship/living beyond cancer course that you could attend at the local hospital, or contact Target Ovarian Cancer to find out where your nearest support group is. You can also search for local support groups at **targetovariancancer.org.uk/supportgroups**

Relationships with your partner

Sex might be the last thing on your mind if you've just received your diagnosis. It may take a while before you are ready to resume your sex life, particularly if you have had major surgery. For some women though, having sex during this time can actually help them feel cared for, loved and secure. Your response will be very personal. Rather than full sex you may just want a cuddle at this time. Physical contact with a partner will release certain chemicals in your brain and make you feel better, so whether it's a cuddle, a kiss or more it might help you to combat the stress you are trying to cope with.

For many women, having sex again after treatment is a sign that life is getting back to normal. But it may require a bit more time and effort than it did before your cancer treatment. You may have to reassure your partner that you want to try sex or touch each other intimately. Sex can help us feel connected to our partner and give us a boost of pleasure so, if it's something you feel you want, it is worth having a go.

On your own

Enjoying our bodies is not just for women with a partner. We can make ourselves feel good by touching our bodies and loving ourselves. There is nothing wrong with this at any time of our life and when you are living with cancer, this may help you cope. It may also help you feel that you 'own' your body. After having had doctors examining you, touching yourself may be comforting and help you reconnect with your body.

If there is a problem

Sometimes women have difficulties having sex again. This is not unusual and your CNS will be happy to speak to you about any concerns that you might have. It may be that you can solve the problem by talking to a sex therapist (this is usually a psychologist who is specially trained). There should be a sex therapist available to you in your area through your local NHS. You can ask your CNS or GP to refer you if you think this would be helpful. You may feel shy but sex is an important area of our lives. It will help both you and your partner move past what you have been through and give you both a sense of being a team again.

If you are experiencing vaginal dryness or painful sex following treatment, you may benefit from using a lubricant to improve moistness. Your CNS will be able to give you more advice and information about this, and you should be able to find a large variety of lubricants quite easily on the shelves of the larger chemists.

Whatever your problem – talk about it; it's worth it.



HOW YOU MIGHT FEEL

Finishing treatment can be frightening and you may feel vulnerable. Although you have finished treatment the emotional and physical side effects don't go away overnight. It is normal to still feel many of those emotions that you felt when you were given the diagnosis so don't be hard on yourself. Family and friends might be expecting you to be 'getting over it' or may want to wrap you in cotton wool and stop you doing anything. Either reaction can be frustrating. If people are treating you differently let them know you are the same person that you were before you had cancer, try to tell them how you feel and what you want from them.



"I am a teacher and my school has been brilliant at managing my return to work. They have offered me every support imaginable and 15 months on I am still 'phasing' back into full time work. I'm so grateful to them as I've often felt ready to take on more before I have been, but they have slowed me down."

Anne

Getting back to work

Working through cancer treatment or returning to work after treatment is a very personal decision. You might feel that working is a financial necessity for you. Perhaps it marks a return to normal life and brings a sense of control at an otherwise uncertain time. You might feel you need to focus your energy on treatment and recovery. There are no right or wrong answers, so you must do what is right for you.

Working through cancer treatment or returning to work

You're going to need to take some time off work, for surgery and for chemotherapy. You don't have to tell your employer that you are being treated for ovarian cancer but with lots of appointments and the impact on your energy, it could make it easier for them to understand your situation and support you if they know.

Ask your Clinical Nurse Specialist (CNS) or oncologist about how your treatment might affect your working life. You can ask questions such as:

- How often will I need to have treatment?
- How long will each treatment take?
- How will this affect my ability to work?

This is important information that can be used by you and your employer to come up with a sensible work plan. Talking things through with someone at work and coming up with a clear work plan to support you through this time can help you feel more in control.

It's useful to add some extra recovery time into your work plan, as it is difficult to know in advance how treatment might affect your ability to work. You can always build up your working hours or workload if you are feeling well.

If you decide not to work through your cancer treatment, you can still keep in touch with your colleagues. Why not ask for regular updates on relevant work or projects? You could even ask if there are small projects that you could work on from home. You may also decide that you prefer not to hear from work when you are trying to recover. Do what feels right for you.

It is important that your employer is flexible in their approach as your needs will change from initial treatment to returning to work and managing possible side effects. Your experience will also have an emotional impact and you may find yourself reacting to things differently or feeling less sociable. If you feel that this is happening and affecting your work try to be open with your employer so that they can adjust things to help. Many people prefer to discuss issues with someone independent from their actual team or management. If your workplace has an Occupational Health or Human Resources department then these are the ideal people to discuss your situation with. They can then represent your needs to the relevant members of staff.

"Going back to work after seven months away was when the tiredness really hit me. The doctors warned me about it but it was worse than I thought. My husband helped out a lot with the cleaning and looking after our son, so that I could get back to work and concentrate on getting a routine. It took a further eight months for the fatigue to wear off."

Ruth

Your rights

Everyone living with or beyond cancer is protected under the Equalities Act 2010 (in England, Scotland and Wales) or the Disability Discrimination Act 1995 (in Northern Ireland) against unfair treatment in the workplace, both now and in the future. It doesn't matter if you have symptoms/side effects or not and the law still applies when you have finished treatment and have been discharged from hospital. It also protects you from discrimination by future employers. Your employer is required by law to make reasonable adjustments to help you work through your treatment or return to work after treatment. This might include reallocating some of your duties, altering your work hours, and allowing time off for appointments.

What is or isn't reasonable will depend on the nature of your work but the essential thing is that

your employer makes considerate alterations to your work role where needed and that you feel supported and respected by them throughout a difficult time.

If you are self-employed or work for a small organisation

If you are self-employed or work for a small business or organisation, it may well be up to you to handle the communications and set up a return that is realistic for you. Approaching organisations such as Citizens Advice (citizensadvice.org.uk) can help ensure that you are aware of any rights or support available to you.

What if there is a problem?

If you feel that your employer or colleague is making unreasonable demands you can get advice from a number of organisations:

- Citizens Advice
- Advisory, Conciliation and Arbitration Service (ACAS) for free employment advice
- If you are a member of a trade union, you can speak to your local representative
- If your employer runs an employee assistance programme you can use this service to speak with a trained professional about a range of issues including health and legal matters
- For comprehensive advice on work issues you can visit the *Work and cancer* pages at macmillan.org.uk

Financial help

There are different types of benefit entitlements available to you depending on the impact your cancer has had and your financial circumstances. These include benefits that replace your earnings, help with housing costs or extra costs resulting from your illness.

Many people are unaware of the financial help and support that is available to them during this time. This means that large sums of money go unclaimed each year. Macmillan have a benefits helpline staffed by trained advisers and can be reached on **0808 808 0000** or through macmillan.org.uk



HOW YOU MIGHT FEEL

If you are going back to work, the first few weeks can be quite tough. Colleagues will be curious and may treat you differently at first, but work can be a welcome distraction. Your hair may not have grown back fully and you are likely to be very tired. You may also have lost a bit of confidence and feel unusually forgetful or as if your brain isn't working properly. This is known as 'cognitive impairment' or 'chemo brain' and is quite common after cancer treatment. When I went back to work I found that I had to read from notes when giving a lecture, but this only lasted a few months. It can be very frustrating if your work is affected or you can't remember people's names. Writing lists as reminders can help and it will improve with time.





Taking care of yourself



Complementary therapies

There are lots of different complementary therapies available and you might want to use some of these alongside your hospital treatments, to help you relax or to ease symptoms and side effects. Some complementary therapies are common, like massage and acupuncture, and some you may not have heard of before. All of these therapies can help improve your mood and many people find they can help with different problems like sickness or pain.

None of these therapies should replace your actual treatment, but they may give you an extra boost. As cancer is a complex condition, it is important that you use a registered therapist and always keep your Clinical Nurse Specialist (CNS) and oncologist aware. Most hospitals have links with a local cancer support centre which might offer a range of therapies on site for free, so it's good to find out about these and check there first.

"When I started having chemotherapy, my local cancer support centre offered me acupuncture which helped with nausea and vomiting. I also had a course of reiki which was really helpful. It made me feel calmer and less anxious. I still have reiki three and a half years on and have done level 1 training myself. This has also supported me to meditate and use mindfulness. I feel I have helped my heart and soul while the medics take care of my body."

Julia

How do I find out more?

Cancer Research UK has very thorough information about each therapy on its website: **cancerhelp.org.uk/about-cancer/treatment/complementary-alternative**

Physical activity

Being more active can help you with some of the side effects that you may experience such as fatigue and can improve your emotional wellbeing too. You may have worries about becoming active 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.

There are many ways that you can start to become active and it does not mean that you have to go to the gym. Walking is free and you can start walking to your local shops instead of taking the car, or walk up and down your stairs more often. You can raise your legs and move your arms when watching TV or you can put some music on and dance.

Many cancer centres offer gentle exercises such as yoga, thai chi and qi gong and their trainers will have skills in working with people who have had surgery and/or chemotherapy.

Give it a go and find out what exercise you enjoy and that feels right for you right now. Get advice from your CNS or oncologist if you are not sure how much and what exercise you are OK to do.

"It's three years since my chemotherapy. It took me a long, long time – and I suspect I still might have a little way to go – to get over the fatigue. The big thing for me was that I knew in order to get better, get fitter, lose some weight and deal with the fatigue, I had to get out and walk. And getting a dog was the best way to do that! We have a two-year old wirehaired vizsla called Jarvis. He's a special dog and a fabulous handful and distraction at times."

Sarah



There is very little evidence that supports a diet specifically for those with ovarian cancer, but a balanced diet and maintaining a healthy weight can help you sustain your energy levels and improve your response to treatment.

For a healthy diet, ensure you eat lots of fruits and vegetables and try to limit the amount of red meat, replacing it with lean white meat, fish, beans and pulses.

When you suffer from chemotherapy side effects

How do I find out more?

Macmillan has more information on physical activity. Visit [macmillan.org.uk](https://www.macmillan.org.uk) and search for 'physical activity' or call **0808 808 0000**.

Diet and nutrition

Many women with ovarian cancer find themselves wondering whether their diet is linked to their diagnosis and they may feel that they must make considerable changes in their eating habits. This is a perfectly normal reaction.

If you are experiencing side effects of chemotherapy (ie nausea, vomiting and 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. Ask your CNS or a dietician if you have any concerns or want to know more about whether nutritional supplements may be right for you.

How do I find out more?

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

"The more we talk about 'living with cancer' the more we can help other women who are afraid or anxious about the future. We're living proof that it's possible to live life virtually to the full, despite having cancer."

Audrey

Will the cancer come back?

No one will be able to give you a yes or no answer to this question. There is always a possibility of the cancer returning but we don't know which women will relapse and which will not. The chance of recurrence will depend on a combination of a number of things, including the tumour stage and your response to surgery and chemotherapy.

It's normal to feel worried about your cancer coming back. No one can take these feelings away. You might worry every ache and twinge is a sign that the cancer is back. Many women go through this experience and gradually begin to live with this worry in the background rather than thinking about it all the time. It takes time to get things into perspective and live life without actively worrying about the cancer returning.

If your anxiety about your cancer returning is getting in the way of everyday life, you may benefit from speaking to a professional about your feelings. Look at the **What might help?** section for further support.

If your cancer does come back, the symptoms you might experience may not be the same as the first time. So it is important to get to know all the common symptoms of ovarian cancer so that if you do have any concerns, you can tell your Clinical Nurse Specialist (CNS) or GP and get checked out quickly.

"Dealing with this fear of never knowing what would happen was difficult for me and my family. I work hard to get the best out of every day."

Julia

Symptoms you should always report:

- persistent pelvic or abdominal pain (that's your tummy and below)
- increased abdominal size/persistent bloating – not bloating that comes and goes
- difficulty eating or feeling full quickly
- urinary symptoms (needing to wee more urgently or more often than usual)

Occasionally there are other symptoms: changes in bowel habit, extreme fatigue (feeling very tired), unexplained weight loss. If you experience these symptoms or are worried about other symptoms tell your CNS or GP straight away. You do not need to wait for your next appointment.



"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



HOW YOU MIGHT FEEL

The emotions you experienced when you were told you had cancer will not go away overnight. You may need some help to come to terms with your diagnosis and reduce some of those feelings. If you look for help this is not because you are 'weak', 'mad' or a 'failure'; it just makes sense to go to people, organisations or groups who have lots of experience of what it means to be told you have cancer. No one except you can truly know how you feel, but there are people out there who will have a good idea.

It may take you a while to find out what works for you. Some people find support groups helpful; however not everyone wants, or feels the need, to attend a support group.

Some people want to try counselling. It can help to talk to a non-judgmental person who is not a member of your family or a friend. Just talking to someone who is a good listener can be a great relief. You may be offered Cognitive Behavioural Therapy (CBT). This involves finding ways of coping with your feelings and problems and can feel more practical than other talking therapies. Counselling or therapy can help you understand how cancer fits in with other major life events and help you understand why you are feeling the way you do.

If you feel that counselling is not necessary at this point, simply writing about how you feel for 10–20 minutes a day has been shown to reduce psychological distress. Exercise can also be helpful; you may not feel like exercising if you are extremely tired but even walking around the block can be useful.

It is common for people with cancer, particularly if the prognosis is challenging, to search for new treatments and 'miracle cures' and there are plenty available for a price. If you are tempted to try a treatment you find on the internet please discuss this with your doctor first. Unfortunately, not everyone has our best interests at heart; some people just want to make money out of us at a time when we are particularly vulnerable.

Feeling low following the diagnosis of cancer is common and normal. However, if you find that your feelings start to have a big impact on your life, perhaps affecting your sleep and weight, please talk to your CNS or GP.







Younger women

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There are a number of issues relevant to younger women who are diagnosed with ovarian cancer. You have a demanding job, young children or perhaps care for an elderly relative and feel that you just don't have time to be ill. You may feel that there are lots of goals you have not yet achieved.

One of these might be having children.

Target Ovarian Cancer has co-produced an information guide for younger women with ovarian cancer that you can order at

targetovariancancer.org.uk/youngerwomen

or by contacting us.



"In between diagnosis and the oncologist appointment was the worst for me. I didn't sleep, I couldn't stop crying and I held onto my son for dear life because that is what you fear the most as a young woman with a small child – that impossible, unimaginable thought that you might have to leave them behind."

Ruth

Having children

If you were hoping to have children at some point there may be an opportunity to see a fertility doctor for advice and information before starting any treatment. However, this may not be possible if treatment has to start right away. Ovarian cancer treatment may result in the removal of both ovaries and the uterus (womb) meaning you won't be able to become pregnant naturally.

There may be options for you to consider, depending on the extent of your surgery. If the cancer has been caught early, with only one ovary involved, it may be possible for you to keep your uterus, and possibly, the unaffected ovary. If so, there is a chance that you may be able to become pregnant in the future, but you will probably be advised not to try until two years after the end of your treatment. However, there is a chance that the one remaining ovary is sometimes affected by chemotherapy and may stop working.

If you have kept your womb and are still well two years after treatment has finished, you can consider a pregnancy with a donor egg through IVF. Speak to your Clinical Nurse Specialist (CNS) about getting a referral from your GP, and find out more at The Human Fertilisation and Embryology Authority (HFEA) who regulate and license fertility clinics – [hfea.gov.uk](https://www.hfea.gov.uk)

If you have had a complete hysterectomy with your ovaries and uterus removed, you may want to consider other options for having a child,

such as surrogacy or adoption. There is more information about these options in our guide for younger women or you can visit Surrogacy UK at **surrogacyuk.org** and CoramBAAF Adoption and Fostering Academy at **corambaaf.org.uk** for more information.

Early menopause

If you have had or are having surgery to remove both your ovaries you will lose your fertility and you will also experience an early menopause. The menopause is a natural reduction of female hormones which generally occurs when a woman is in her late 40s or early 50s. In a natural menopause the hormone levels slowly reduce. Surgical removal of the ovaries results in a sudden and dramatic loss of hormones and it can be quite a shock to the system, and some women experience intense symptoms. You may experience hot flushes, vaginal dryness, mood swings, tearfulness and loss of interest in sex. Your oncologist or CNS will be able to talk to you about how these symptoms can be managed.

For some women Hormone Replacement Therapy (HRT) may be an option. There is evidence linking HRT with a small increased risk of ovarian cancer, however, current evidence suggests that HRT use after treatment for ovarian cancer is safe and does not increase the risk of the cancer coming back.

Some women prefer alternative products and therapies to help them with their menopausal symptoms. There are also a number of creams and gels that can help with vaginal dryness if this is the main problem. Cognitive Behavioural Therapy (CBT) has also been proven to treat some symptoms. There are a lot of herbal and dietary supplements marketed at helping symptoms. The evidence for the effectiveness of these is inconsistent and you should ask your pharmacist for advice as they can interfere with other medications.

You should discuss your situation with your oncologist or CNS and weigh up the benefits and risks involved. For women choosing HRT you may need to try different doses to find out what works best for you.





HOW YOU MIGHT FEEL

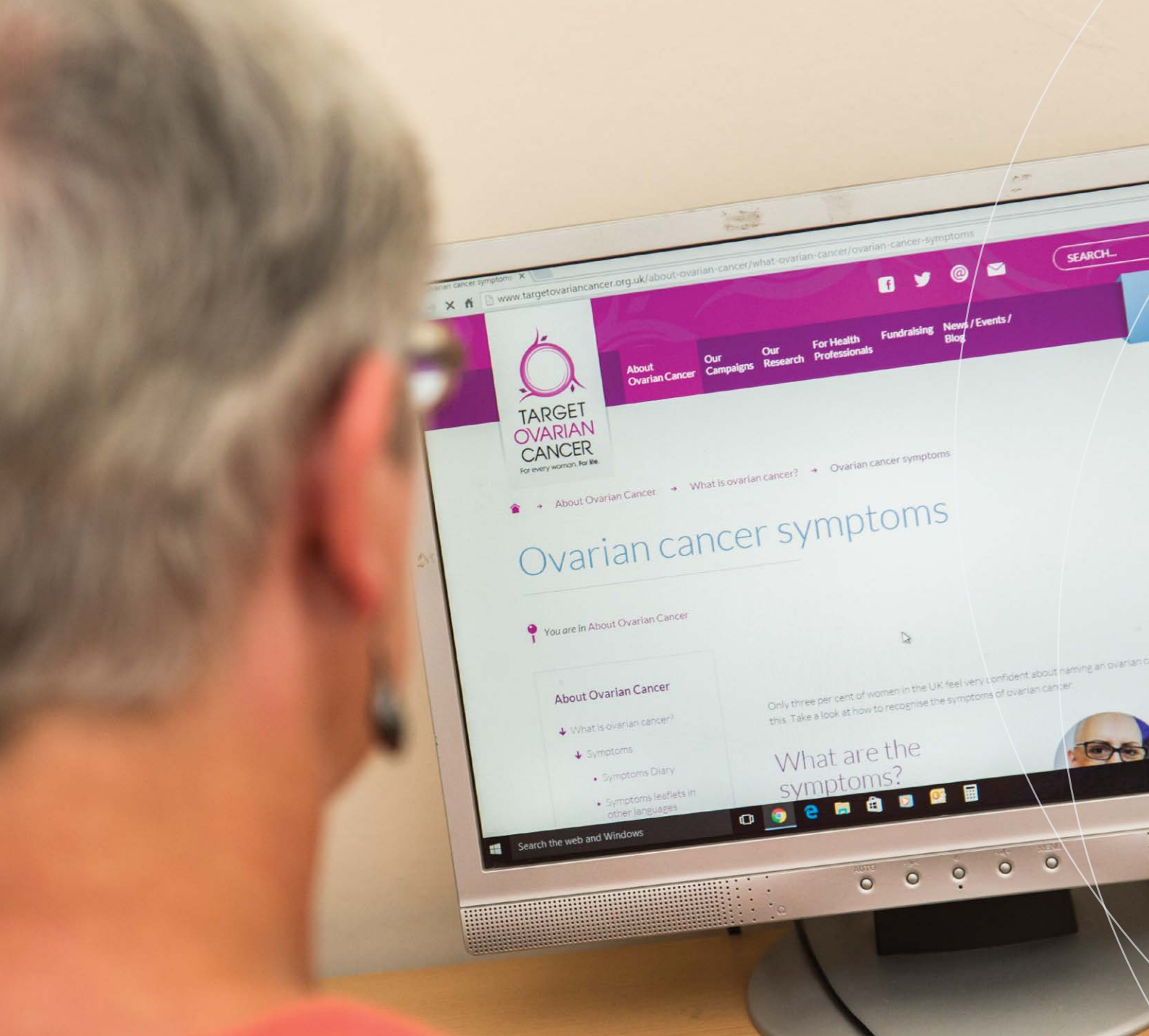
You may feel angry and upset and that life just isn't fair. You may not be sleeping well, be anxious about the future and resent the change in your lifestyle and energy levels. All these feelings are normal and understandable.

Many young women find the prospect of losing their fertility extremely difficult to cope with and much worse than actually having ovarian cancer. We all have dreams and hopes about the future, and if these dreams and hopes involve having children, this will be a particularly hard time for you. Suddenly everyone I knew seemed to be pregnant and a simple thing, like seeing a pregnant woman or walking past a school would upset me. It is hard to feel joy for friends and family members who appear to have babies easily, and this might make you feel guilty. It may put

a strain on some relationships, but it is important to share those feelings rather than bottle them up. Research has shown that younger women may find that any feelings of anxiety and depression last longer than older women. Many women need a great deal of support and may benefit from professional counselling (see our **What might help?** section).

It can take a long time to start feeling better emotionally, and you may still have bad days even after your treatment has ended. As you adjust to your diagnosis and treatment any feelings of anxiety and depression will lessen and you may experience more good days than bad, but don't feel pressured to be 'back to normal' as soon as your treatment is over. Don't be too proud to accept all the help you can get, and make time to look after yourself.







What might help?



After everything that you have been through, it will take time to adapt your life. It's fine 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. The best person to speak to if you are worried is your key worker. They are qualified to provide reassurance and advice based on your specific situation. The following services also help people who are experiencing difficult times. Sometimes you might feel that you should be able to cope or that your feelings are so overwhelming you don't know how anyone could help, but try to be kind to yourself.

There are lots of ways to get support from talking to a professional to simply chatting to someone on the phone or an internet forum.





Target Ovarian Cancer

Worried about anything you've read in this guide? Or want more information? 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**

Our website **targetovariancancer.org.uk** brings you insights from women who have had a diagnosis of ovarian cancer and how they feel. You might want to become a guest blogger too and write about your experience, to help others.

You can also register with us to be the first to receive the latest news, information and events in our monthly enewsletter at **targetovariancancer.org.uk/news** and follow our Facebook and Twitter pages.

"Target Ovarian Cancer stands out for me as it has got a well-structured social media presence with dedicated members, clear focus and goals. Plus it really reaches out to connect with us women diagnosed with this disease to offer guidance, support, friendship and – most importantly – hope."

Carol

In Touch

We want to help you meet others and share similar experiences. We have a private Facebook group - In Touch - where women can connect with others, or you can find out about other ways to hear from women living with or beyond ovarian cancer. For more details, visit **targetovariancancer.org.uk/intouch**

Support events

Target Ovarian Cancer also runs a programme of free events across the UK to support women living with and beyond ovarian cancer, including our Being Together and Supporting You days. They offer an opportunity to meet other women in a friendly, relaxed environment and provide support and information. All of our events are listed on **targetovariancancer.org.uk/beingtogether**

"Target Ovarian Cancer are an amazing charity providing professional and incredibly supportive services for all women; whatever age, background, circumstance and wherever in the UK they live. They are innovative, responsive and incredibly diligent in all they do. Most of all though, I trust them."

Sarah

Support groups

Simply being around people who understand what cancer involves can help. Some groups like to share fears and worries or arrange talks about cancer from different professionals. Some groups arrange lunches or outings to boost people's spirits. Often groups are general, with members who have had different types of cancers, but there may be a group specifically for women with gynaecological cancers. Your CNS may run a support group locally or you can visit **targetovariancancer.org.uk/support** to find a group near you.

How do I find out more?

Visit **targetovariancancer.org.uk/support** or ring **020 7923 5475**

Support centres

Many hospitals offering cancer treatment will have either their own or a charity-run centre, such as a Macmillan or Maggie's cancer support centre, either on site or close to the hospital. These centres can be a great source of comfort for many people and may offer other support services. Many centres around the country run a range of activities such as massage, reflexology, even gardening. You don't have to talk about your experience, it's just a place you can relax knowing that the people around you will support you and understand what you are going through. Your CNS should be able to give you details of the support centres in your area.

"Don't give up on yourself or wish you were someone else. Don't compare yourself to anyone else. You are an individual who can not only learn from others, but be a source of inspiration and light to them as well."

Lynette

"This experience stripped me right down to basics. It made me come down to earth with a big bang."

Ruth

Online communities and telephone support

- The Macmillan Cancer Support free support line is available Monday to Friday 9am-8pm. You can contact them on **0808 808 00 00**. This service also offers an interpretation facility in over 200 languages. Their Online Community can also give invaluable support at **community.macmillan.org.uk**
- Maggie's Cancer Caring Centres have an online centre where you can meet others and access online support groups: **maggiescentres.org**
- The Eve Appeal offers a nurse-led specialised gynaecological cancer information service on all five gynaecological cancers to women who are concerned about symptoms. You can contact them on **0808 802 0019** or **nurse@eveappeal.com**

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

Other professional support

If you feel 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, the sites listed in this section can help you find a registered professional.

"Life after a cancer diagnosis is never the same, but my local support centre was invaluable in helping me to adjust to the 'new normal'."

Julia

"I believe that talking therapy can work well and I recognised that I might need some support to deal with the impact of the diagnosis. I asked my CNS and she referred me after surgery to see a fantastic oncology psychologist (there is this type of support available but you often have to ask for it). It meant that all these difficult feelings could start to come out; during surgery you just have to get through it so I had suppressed them in order to cope. For me, this support was a lifeline."

Sarah



Psychological therapies

What are they?

Psychological therapies are a common form of emotional support, with many people turning to these types of support at difficult times in their lives. They allow a person to talk about their thoughts and feelings and to manage them, especially if they are causing you problems such as feeling low in mood or more nervous than is usual for you.

How can they help?

Health professionals who work with cancer patients in the NHS have been trained to understand how cancer may cause difficulties for you emotionally, practically and in relationships. Just getting things off your chest can help. You can discuss the problems you are having and explore difficult feelings in a safe and confidential space. Being able to talk through frustrations and difficult feelings with a trained professional can allow you to feel more in control and patient with yourself and those around you.

How do I find out more?

- **Counselling** gives you the opportunity to speak to someone about fears or difficulties. A counsellor's job is to listen and allow you to talk. Many NHS Trusts offer referrals to counselling services and many cancer support centres offer free counselling services on-site. For further information contact your

CNS, GP or local support centre. Alternatively if you choose 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: **itsgoodtotalk.org.uk**

- **Psychological support** will look at how cancer has affected your life and wellbeing. A psychologist will be able to discuss the problems you are having and look at how they 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 and offer the service in different languages if English is not your first language. You can either visit their website: **bps.org.uk** or telephone **0116 254 9568**.
- **Cognitive Behaviour Therapy (CBT)** is a very practical way of looking at emotional distress. It focuses less on the causes of your distress and more on what to do about it – how to improve your reactions to difficult situations. CBT examines how our ways of thinking can trigger difficult emotions and behaviours. The therapy then works to change behaviour by finding new ways to think about and approach problems. This is a practical therapeutic approach. The more specific a problem the more likely CBT will be able to help. The CBT Register UK allows you to search for therapists in your local area: **cbtregisteruk.com**. Most clinical psychologists in the UK are trained in CBT and you can be referred to one through your GP.

- **Psychotherapy** is similar to counselling but this time the therapist will try to find out where emotions or difficulties might be coming from. A therapist will help you to think about what is happening in your life now and what has happened to you in the past that might affect how you are feeling and behaving. 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-based therapies** help you focus on the present moment. It is recognised by the National Institute for Health and Clinical Excellence (NICE) to avoid repeated bouts of depression. Mindfulness is a form of non-religious meditation that can have benefits for your sense of wellbeing, help with stress and anxiety and can be practised at home. Mindfulness meditation and Mindfulness-Based Cognitive Therapy is taught and practised in the UK by applied psychologists and other registered health professionals.

Other sources of support

Sometimes you may feel you need some specific support in particular areas. There is plenty of help available. Here are some sources you might find helpful:

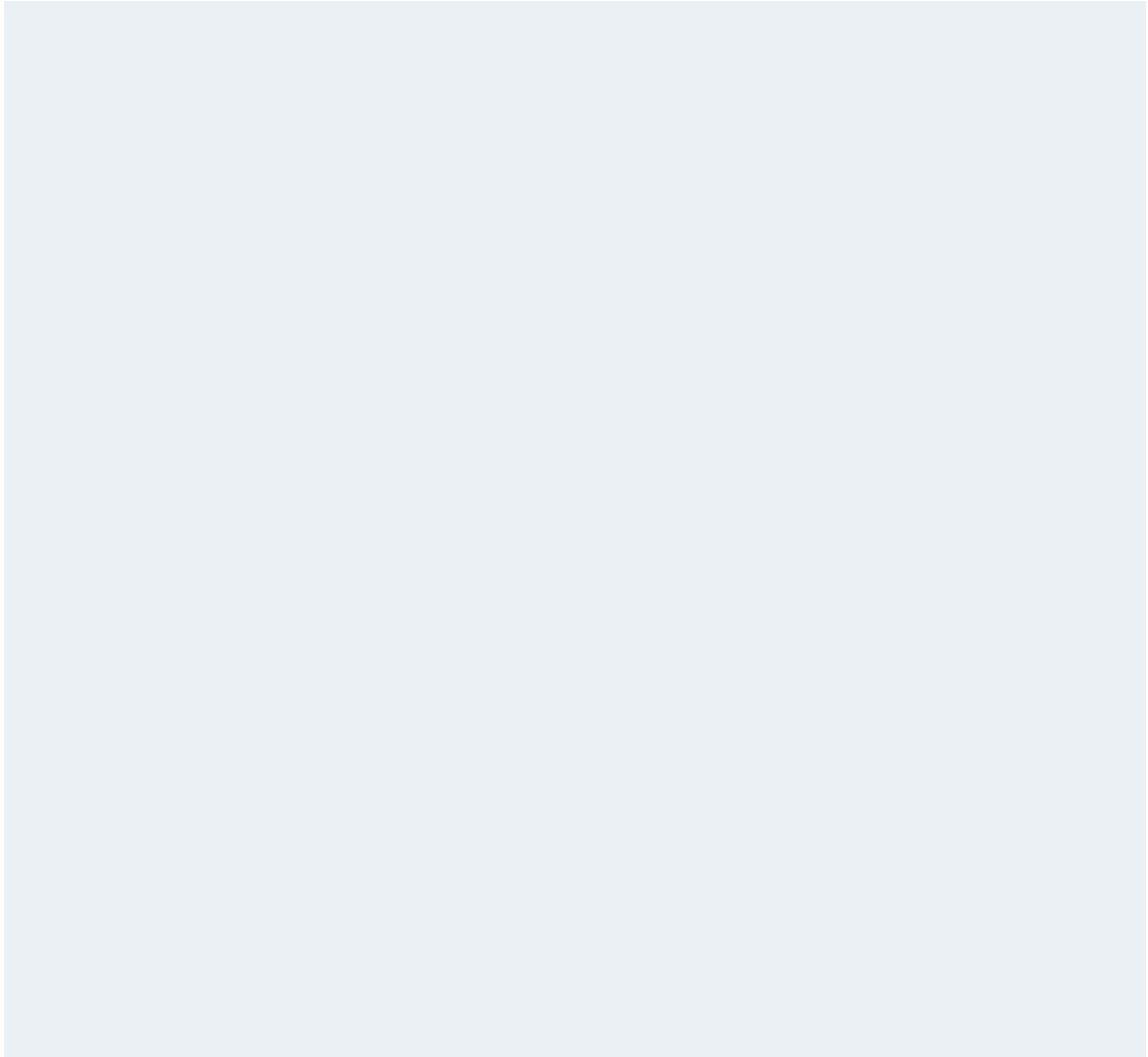
- **COSRT** is the College of Sexual and Relationship Therapists and holds a directory of members to help you find professional support in your area: **cosrt.org.uk**
- **Relate** offers counselling, support and information for all relationships: **relate.org.uk**
- **British Infertility Counselling Association** is the professional association for infertility counsellors and counselling in the UK and can help you to find a counsellor near you: **bica.net**
- **The Daisy Network** offers support to women who have experienced a premature menopause due to a medical condition or treatment. They offer information and a network of women who are willing to share their personal experiences of premature menopause: **daisynetwork.org.uk**
- **The Carers Trust** works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend. They give information, advice and practical support to carers: **carers.org**
- **Carers UK** gives expert advice, information and support to carers: **carersuk.org**



Notes

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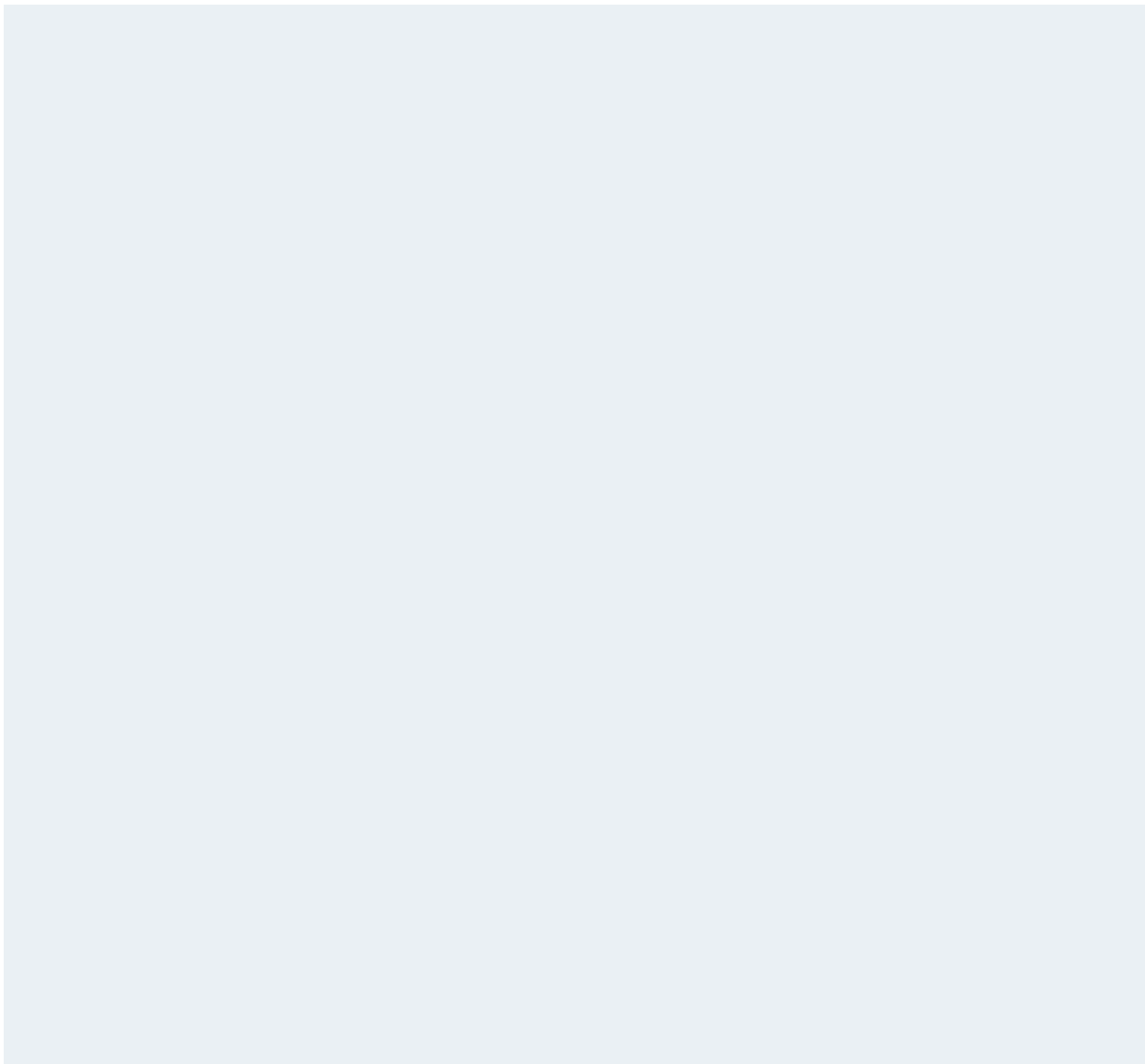
Useful contacts You can use this space to record useful contacts such as your CNS etc.



Questions I want to ask



My next steps



About Target Ovarian Cancer

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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