



What happens next?

A guide for anyone 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 – Andrea, Anne, Audrey, Beverley, Carol, Clare, Della, Esther, Jules, Julia, Lynette, Moira, Ruth, Sarah and Sue.
- The writers and reviewers - Dr Pauline Adair, Miss Christine Ang, Lynn Buckley, Dr Alison Farmer, Professor Christina Fotopoulou, Julia Merrigan, Dr Rachel O'Donnell, Andrea Oliver, Lizzie Proos, and Mr Khalil Razvi.

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Throughout the guide we have included words from women who have been through many of the experiences you are facing. Within most sections is a feature called 'How you might feel' 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 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"

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Introduction

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

At Target Ovarian Cancer we know how isolating it can be to have a diagnosis of ovarian cancer. We run events online and around the UK to provide you with opportunities to meet others who have also had a diagnosis, learn more about the disease and get advice on how to live well with it. We also offer dedicated Facebook groups for you to keep in touch, and a specialist nurse-led support line to answer your questions. If you have any questions or concerns about any of the information you read in this guide, please call us on **020 7923 5475** or visit **targetovariancancer.org.uk/supportline**

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



*"I had never heard of ovarian cancer or the symptoms before I was diagnosed. I experienced fatigue and bloating but passed it off as overworking and putting on some weight."
Sue*

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What is ovarian cancer?

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Being diagnosed with ovarian cancer can come as a big shock, even if you have been experiencing worrying symptoms. You may not have heard of ovarian cancer before and this can make you feel like you're the only person facing this diagnosis. You may also hear people using medical terms that you've not heard before and all of this can make it hard to understand what your diagnosis means.

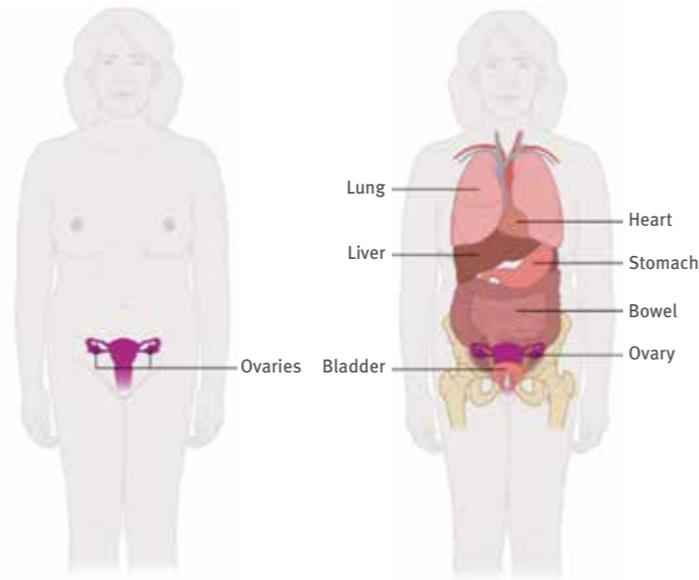
You may simply want to know: what is ovarian cancer?

What is cancer?

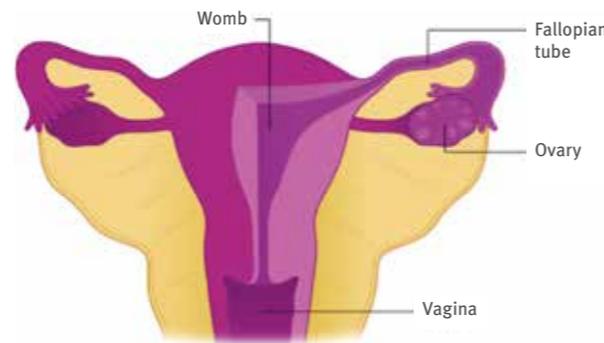
Our bodies are made up of millions of cells (building blocks). Our body is constantly replacing worn out cells with new ones, either to keep us healthy or when we injure ourselves (for example if we get a cut or a graze). This process is usually carefully controlled so that the number of new cells that our body makes is the same as the number that were worn out and destroyed. But sometimes this process can get out of control and far too many new cells are made. When this happens the collection of new cells forms a lump called a tumour. Some tumours are *benign* (where a lump is formed but the tumour can't spread) but others are *cancerous* (where the tumour grows out of control and can sometimes spread to other parts of our body). Doctors and nurses may also use the term *malignant* to describe a cancerous tumour.

What is ovarian cancer?

Ovarian cancer starts when this process occurs in cells in and around the ovaries and fallopian tubes. The ovaries are two small organs (body parts with a specific function) each about the size of an almond, located low in the area of your tummy called the pelvis (just behind your pubic area).



Ovaries are responsible for making hormones (chemical messengers) called oestrogen and progesterone. These hormones help to tell the ovaries when to release one of a woman's supply of eggs through the fallopian tubes into the womb to prepare for the chance of becoming pregnant. They also control the menstrual cycle (periods).



There are many different types of ovarian tumours classified (organised) by the different types of cell that they come from:

- **Epithelial ovarian cancer**
Nearly all ovarian tumours (around 90 per cent) come from epithelial cells, which are the cells that line or cover the ovaries or fallopian tubes. The most common type of epithelial ovarian cancer is high-grade serous ovarian cancer. Other types include endometrioid ovarian cancer, clear cell ovarian cancer and mucinous ovarian cancer.
- **Sex cord and stromal ovarian cancer**
Around five per cent come from stromal cells, which are cells that make up the core of the ovaries (for example granulosa-cell tumours).
- **Germ cell ovarian cancer**
Around five per cent come from germ cells, which are the cells in the ovaries that develop into eggs (for example dysgerminomas).

There are also rare types of ovarian cancer (for example sarcomas), which start in the connective tissue (tissue which joins or separates organs) within the ovaries.

What about primary peritoneal cancer (PPC)?

People diagnosed with primary peritoneal cancer (PPC) that starts in the peritoneum (a large, thin, flexible sheet tissue that covers the organs inside your tummy) are treated in the same way as people with ovarian cancer. This is because

primary peritoneal cancer is thought to be the same as ovarian cancer, in that it acts the same way and responds to the same treatment.

The information in this guide will be relevant to women with all types of ovarian cancer and PPC.

You can also visit targetovariancancer.org.uk for more information and support.





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Your diagnosis

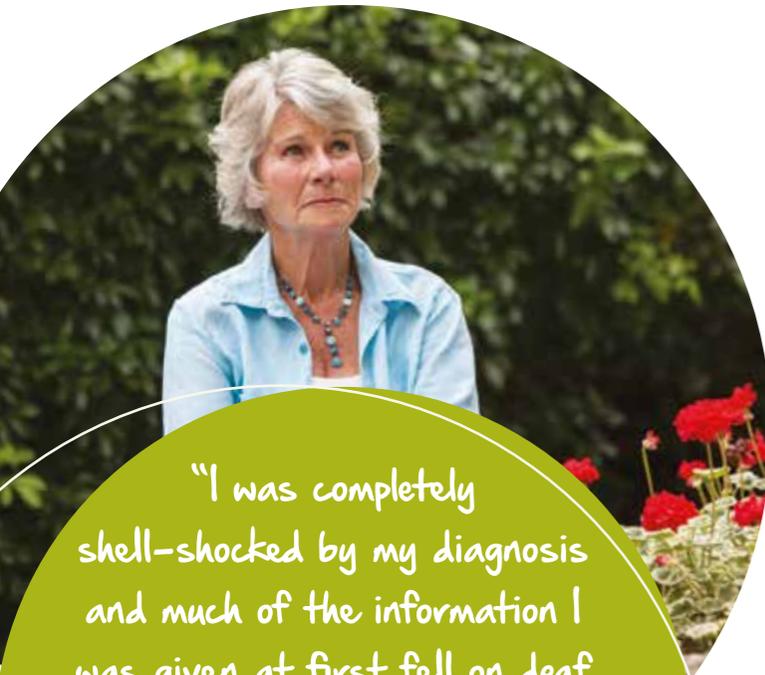
When you first learn of your diagnosis you may be given lots of information all at once. This can make it difficult to hear or understand everything you are told. You may feel shocked, frightened and upset, or you may be feeling quite numb and unable to take in everything that is going on around you.

As you start to think about your diagnosis you may feel that you need 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 is helpful to understand who is looking after you and who you might meet 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 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. Over the next few weeks I had often wished that I had recorded the conversation or taken notes, as it was all such a blur."

Anne

The main hospital staff you will come across will be:

Oncologists

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

- A gynaecological oncology surgeon who is in charge of your operation. Gynaecological oncology surgeons are surgeons who have had extra training to operate on people with ovarian cancer, womb cancer, cervical cancer, vulval cancer or vaginal cancer (gynaecological cancers). In this guide we call this person a 'surgeon'.
- A medical oncologist organises chemotherapy (drugs that aim to kill cancer cells) or targeted treatments (drugs used to identify and attack cancer cells with less harm to normal cells). In this guide we call this person an 'oncologist'.

Gynae-oncology Clinical Nurse Specialist (CNS)

A gynae-oncology CNS is a senior nurse who has had extra training to look after women with gynaecological cancers such as ovarian cancer. In some places CNSs are called specialist gynaecology nurses and in other places they are called Macmillan nurses. Throughout this guide we call this person a 'CNS'. Your CNS should be the person who is involved in every step of your care and treatment and might sometimes be called your key worker. They will help you to find your way through the healthcare system, from the

time that you are first diagnosed. Most people find them a huge source of support.

Chemotherapy nurse

If you are treated with chemotherapy, a team of chemotherapy nurses will help you through your treatment and any side effects that you experience.

Other health professionals

Other people who may be involved in the MDT are:

- Radiologists (doctors who carry out and read scans like x-rays and CT scans).
- Psychologists (specialists who help support mental health during a cancer diagnosis and beyond).
- Pathologists (doctors who diagnose the cancer by looking at cells under a microscope in the laboratory).
- Nutritionists or dietitians (specialists who give guidance on food and drink as fuel for the body).
- Physiotherapists and occupational therapists (specialists who help people with movement and to cope with or everyday tasks that are difficult due to illness).

The MDT will meet up regularly to discuss the care and treatment of 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.

"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 Rosemary, my amazing Clinical Nurse Specialist, 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', giving 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. 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

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

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 gynae-oncology 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 not sure who your key worker is, or how to contact them, ask a member of your medical team to write down the details for you.

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 longer to think about exactly what and how you are going to tell your family and friends, that's OK.

People might react with more emotion than you are expecting. When close friends or relatives hear about your diagnosis it makes cancer a reality rather than something that happens to other people. It is not unusual for family or friends to cry or become very quiet and this can be hard for you to cope with. It might feel as though people are avoiding you or can't seem to talk to you in the same way as before. Often

people are worried about saying the wrong thing or upsetting you so may simply need reminding that you're the same person as before your diagnosis.

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 telling people might be too difficult for you, you can ask someone you trust to tell people for you.

Hopefully, many friends and family members will be supportive and help you to get through this difficult time. Your 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.

"Even now, after treatment, I see a look of fear on people's faces when I bump into them in the street or the supermarket. My approach has always been to smile and start a conversation that we would have had before cancer – asking about their children or something. I usually find they relax and we fall into a natural chat. It can be helpful to have some conversation openers in mind to help in these situations"

Andrea



Telling children

Talking to your children or grandchildren about a cancer diagnosis is not easy, whatever their age. Young children will often understand the practical side of things and have a simple understanding that you have an illness and the doctors are looking after you. They may appreciate that you might feel a little bit tired, sad or grumpy, and that everyone is doing their best to get you better. The questions they ask can give clues as to what is worrying them.

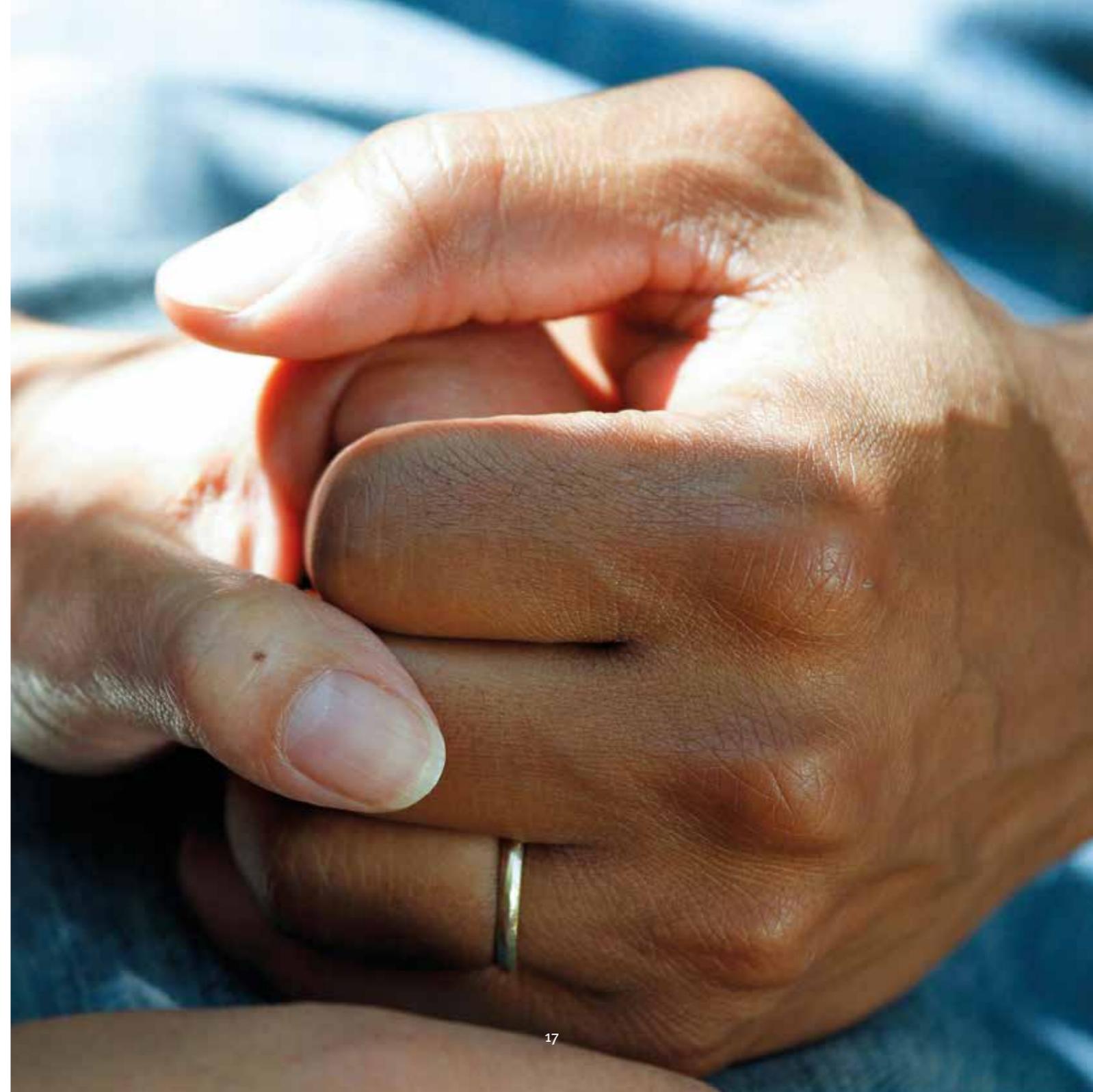
Teenagers may ask for more information and may need a little more time to work through their feelings and think about the questions they might want to ask. Even when your children are adults themselves, finding out that a parent has cancer can be difficult to cope with. It can help to be open and honest with them about your diagnosis and how you are feeling and include them in the situation.

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 as you come to terms with the news.

Macmillan Cancer Support has two useful booklets: *Talking about cancer* and *Talking to children and teenagers when an adult has cancer*. You can look at these at be.macmillan.org.uk or ring Macmillan on **0808 808 0000** to order one for free. There are also organisations that offer practical support for looking after children, and those that directly support children and young people to cope when an adult has cancer. You can find more details about these in the **Who might help?** chapter at the end of this guide.

"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





Della's story

“ I was diagnosed with triple-negative breast cancer in 2010. So when I began experiencing discomfort in my pelvic area a few years later, I quickly made an appointment with my GP. The doctor seemed to think that I might have some fluid in the area, but I didn't think too much of that. My stomach kept swelling and I was very uncomfortable – I couldn't wear trousers and was struggling to eat.

At this stage, I had visited the GP more than once, but he just recommended that I drink prune juice. Eventually I was given some blood tests, and when they got that result back, they told me to go to A&E. At the hospital I was told I had ascites – fluid in my abdominal area (tummy) – and given a CA125 test. They thought then that it could be cancer, but they didn't know what kind. It was only when they got the CA125 number back and

saw that it was over 600 that they told me it was ovarian cancer. I've now had chemotherapy and I've just started taking olaparib. So far I've had no adverse side effects, I just drink loads of water and move more to avoid aches and pains. To know that there is a treatment plan in place gives me hope, and my latest blood test was really encouraging – my CA125 level is down to 35.

I want to educate people about ovarian cancer, especially within my own community. Before I had breast cancer 10 years ago, I had no idea about cancer, what it was or who could get it. I want people to know that you can live a good life after a cancer diagnosis. Overall I just try to face the cancer, name and shame it, talk about it – and then when I'm done, I do things to take my mind off the situation. ”



HOW YOU MIGHT FEEL

You might have been expecting your diagnosis or it might have been a complete shock. Either way, it's never easy. If you're 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's 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 to be given to you again. The stage of your cancer may not be relevant to how you are feeling at the moment; it's the fact you have a diagnosis of cancer that's distressing.

You may be feeling a variety of emotions ranging from sadness to anxiety, or perhaps hopelessness and fear. It's also common to feel angry. The anger might be directed at your doctor, your family, or even at yourself. You may feel focussed on trying to understand why you got cancer. Unfortunately it's not always possible to know why some people get cancer and this can be frustrating.

We're 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. Some people find a diagnosis of cancer can cause low mood (depression). All these emotions are normal and understandable, particularly just after diagnosis. There's no right or wrong way to feel.

At the time of diagnosis, it's important for you to have support. Friends and family can be particularly important if you have good relationships with them as they may be experiencing the same emotions as you. But things might not be straightforward. Although some relationships get stronger, some people won't know what to say and may avoid you, which can make you feel hurt. Others may tell you to "stay positive". This is meant well but can be very tiring and frustrating. Remember it's OK and understandable to feel sad. Some people do need help from a mental health professional at this time or after treatment has finished. The **Who might help?** section of this guide explains different ways you can find this support.



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Making decisions about your treatment

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Some people like to have detailed discussions about all the treatment choices there might be, while others prefer to ask their medical team to recommend an option. Whatever your preference, it is really important for you to take some time to make sure you have the information you need, so that you can make decisions that are right for you.

Whatever your feelings it can be useful to share your thoughts about the following with your surgeon, oncologist and CNS:

- How much detail do you want to know?
- When do you want this information?
- How do you want to make your decisions?
 - Do you like to take some time to absorb information before deciding?
 - Do you need to talk it through with anyone before deciding?
- What is the goal (intention) of the treatment?
 - Will this treatment cure the cancer?
 - Will the treatment control the cancer or control the symptoms?
 - Will you need more treatment in the future?

The key decisions

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Key decisions about treatment options include whether or not to have treatment, what type of treatment to have, where to have your treatment and the timing of surgery and/or chemotherapy.

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

- What treatment options are available for me?
- What are the benefits of a particular treatment and how effective is it?

- What are the risks involved in having the treatment now and in the long term?
- What are the side effects: how might the treatment affect me physically, emotionally and sexually?
- How long are these side effects expected to last?
- What might help me 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?
- Can I continue to work?
- If I stop working, when will I be able to return?
- Where can I be treated?
- Would a different specialist centre (a hospital or clinic with experts in ovarian cancer treatment) offer me other treatment options?
- Is it possible to take part in a clinical trial (a research project about ovarian cancer treatments or drugs) at this centre or any other centre?

"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



"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

Your CNS has an important role to play in making sure that your views are represented in conversations about your treatment, 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, at home or at work.

It might help to take a family member or friend to your appointments. Talk to them before your appointment about what you would like to know from the oncologist. If you find it difficult, they can ask your questions or write down the answers to questions you ask. This might help you remember what was said.

Keep asking if you don't understand

Health professionals might use medical jargon (special medical words that are difficult to understand) and words or terms that you've not heard before – if you don't understand what they mean, just ask them to explain it another way. Don't worry about asking again, they would prefer that 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

Having discussed treatment options with your oncologist and/or surgeon, you may still feel uncertain about what to do. If you would like to get a second opinion, just ask. A second opinion is when you speak to another oncologist and/or surgeon about your diagnosis and treatment options. Your CNS, hospital doctor or GP should be able to let you know how to go about this, and your hospital doctor should be happy to refer you (pass your notes onto another surgeon or oncologist in a different hospital).

"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

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 that you share the decision by telling them which treatment you would like. You might be very keen to be involved in treatment decisions or you might find this stressful. It's important to tell the doctors and nurses how you would like to make decisions. Your feelings might change over time so don't be afraid to let your team know if you would like more or less involvement.



"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



There are different types of ovarian cancer. To be able to fully understand what your treatment options are it is helpful to have specific information from your medical team about your diagnosis including the type of ovarian cancer, the stage and grade. You can find out more about the different types of ovarian cancer, stages and grades at targetovariancancer.org.uk/types

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Treatment



Starting cancer treatment can cause mixed feelings. You may feel very positive that you are being well cared for, but it's also normal to feel anxious or scared. You may be worried about what your treatment will involve, whether you will be in pain and what side effects there may be.

It's common to treat ovarian cancer with surgery to remove as much of the cancer as possible, and chemotherapy. Your specific treatment will depend on the type of ovarian cancer you have as well as the stage (how much cancer there is and how far it has spread) and grade (how fast it is likely to grow).

You may have surgery before starting chemotherapy, or your oncologist may recommend starting chemotherapy first (called neoadjuvant chemotherapy) and then having surgery, followed by some more chemotherapy once you have recovered from surgery. The order in which you have your surgery and chemotherapy has not been shown to make any overall long-term difference to the effectiveness of your treatment.

On rare occasions, if the cancer is diagnosed at a very early stage it may be treated by surgery alone.

For some women surgery is not considered the best option for treating their cancer. This may be due to pre-existing medical conditions that mean your body will not cope with a big operation. Or it may be that having surgery to remove the cancer would cause too much damage to surrounding organs and structures. In these cases chemotherapy alone is the recommended choice of treatment. If after three cycles of chemotherapy your scan shows that the cancer is more operable, then surgery will be considered at this stage.

Your oncologist and/or surgeon will discuss with you what treatments are available, based on your individual needs. Your case will have been discussed at an MDT meeting but your personal preferences will also be taken into account. It's important that you feel comfortable and confident to tell your medical team how you feel before and during your treatment, and to ask them any questions you have. They will be able to

reassure you if you are anxious and make sure that you understand everything that is happening to you.

If you choose not to have treatment, or if these treatments are not suitable for you, you may be offered treatment to manage some of the symptoms caused by your cancer. This is known as 'supportive care'. Target Ovarian Cancer has a guide called *My care, my future* which has been written specifically for women living with incurable ovarian cancer. Download or order your free copy at targetovariancancer.org.uk/guides or by calling **020 7923 5475**.

"I think it's important to let your team know how you feel, to ask any questions and to remember that there's no such thing as a stupid question. In a hospital setting where staff are dealing with cancer every day it can sometimes be forgotten that this is alien to someone newly diagnosed."

Andrea

Surgery

Preparing at home

It's important to make sure that you are well rested before your operation and to plan ahead. For example, you might consider making sure that there is plenty of food in the house so that you don't need to worry about going to the shops. You also want to consider making sure that everything you might need in the house is within easy reach of your bedroom – or even whether you might choose to sleep in a different place to be closer to the bathroom while you recover. Making some small changes can make your recovery easier.

Before your surgery

At the hospital you will be examined and given some tests to check that you are physically fit enough to have surgery. Your surgeon will explain what will happen during the operation. It is often difficult for the surgeon to know or predict exactly how much surgery you will need until they begin to operate, so they may discuss different possibilities and options with you. Surgery will also confirm the stage and grade of your cancer, which is not possible to do through scans alone.

"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

What does surgery involve?

Surgery normally includes a hysterectomy, where the womb (uterus) and neck of the womb (cervix) is removed, along with both ovaries and fallopian tubes (called a salpingo-oophorectomy). The omentum (a sheet of fat that hangs within the tummy) will also be removed. Your surgery may also involve removing enlarged lymph nodes (small structures that are part of your immune system containing white blood cells, which help your body fight infection and disease) and parts of other organs that may be affected by the cancer.

Some women need more extensive surgery, sometimes called cytoreductive, debulking or

ultra-radical surgery, to make sure as much of the cancer as possible is removed. This is when, in addition to removing the ovaries, fallopian tubes, womb and omentum, more tissue is removed from other organs compared to standard surgery. This may include parts of the bowel, diaphragm, liver and peritoneum (a large, thin, flexible sheet of tissue that covers the organs inside your tummy) if they are found to contain cancer. Occasionally it may be necessary to remove your spleen (an organ in the upper left side of your tummy that forms part of your immune system).

Creation of a stoma

If surgery extends to the bowel, in most instances the affected part of the bowel can be removed and the two ends put back together again (this is called an anastomosis). But sometimes this is not possible or safe and your body will need a new way for your faeces (poo) to be passed. In this situation your surgeon will make an opening through your abdominal wall and bring the end of the bowel through it. This is called the creation of a stoma or ostomy (an artificial opening). You can read more about the different types of stomas and how to manage them at targetovariancancer.org.uk/stoma or download or order our free mini guide, *Ovarian cancer and stomas*, at targetovariancancer.org.uk/guides or by calling 020 7923 5475.

Answering your questions about surgery

If you have any questions, concerns or fears about your surgery, don't be afraid to talk about them with your surgeon or talk to the nurses about how you are feeling.

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

"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

If you are a younger woman you may have additional concerns about your fertility and facing early menopause.

There's more information about this in the **Younger women** section of this guide and at targetovariancancer.org.uk/youngerwomen

After your surgery

Surgery puts your body through a lot of stress, so it is very important to give yourself time to heal and recover. In the first weeks after 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? 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.

You will be given blood thinning injections for 28 days after surgery as well as compression stockings to wear. These gently squeeze the legs and will help reduce the risk of blood clots developing in your legs and lungs. You can reduce this risk further by making sure you drink enough water (avoiding a lot of caffeinated drinks such as coffee, tea and cola), going for short walks inside the house or outdoors and wiggling your toes when you are sitting or lying down.

Side effects

Many people are worried they will be in pain after an operation. You will be given medication to ensure you are as comfortable as possible.

It is common to feel tired after your surgery as your body is working hard to recover. You may experience severe tiredness or fatigue that can come on very suddenly. It is important to build up activities gradually to help you through this.

If you are worried about any side effects, talk to your CNS or key worker about how you feel.



Chemotherapy

Chemotherapy means drugs given to kill cancer cells in your body. You may have chemotherapy treatment before or after surgery.

Some people feel more anxious about chemotherapy because of the number of blood tests that are needed and/or having drips (intravenous infusions) put into veins in their arm. If this is something that worries you, you can ask your nurse to put some anaesthetic cream (numbing cream) on your arm about half an hour before the blood test, as this will make it less uncomfortable.

What chemotherapy will you have?

Your oncologist will decide with you which chemotherapy drugs you'll have. Many people get a combination of a platinum-based chemotherapy (most commonly carboplatin but sometimes cisplatin) and paclitaxel (most commonly called Taxol®). Sometimes carboplatin will be recommended on its own.

Chemotherapy is usually given once every three weeks for six cycles. This means you will have six sessions of chemotherapy in total, each one three weeks apart. This gap is to let your body recover from each session of chemotherapy treatment before the next one starts. Sometimes,

if you are not very well or if you have a lot of side effects from the chemotherapy, your oncologist may decide to give you your chemotherapy in a smaller dose every week.



What happens when you have chemotherapy treatment?

Most people go to the chemotherapy unit at their local hospital. At the hospital a number of blood samples will be taken for testing before each cycle of chemotherapy. These are checks to make sure that it is safe to go ahead with the treatment.

When you have your treatment, 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 cannula (a small tube like a needle) into one of the veins on your hand or arm and attach a drip so the drugs can enter your bloodstream. These drugs are given over several hours. 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.

You may also have treatment through a tube (PICC line, portacath or central line) in your chest. These are semi-permanent and stay in place for the course of your treatment.

You will usually spend most of the day at the hospital so you might want to ask a relative or friend to keep you company, if allowed by your hospital. A couple of magazines or a good book, or watching something on your phone or tablet can also help to pass the time.

"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

Will you have any side effects?

Many people treated with chemotherapy will experience mild side effects that can be easily treated. It is rare for side effects to be severe. For most people, side effects do not start straight away and they are able to make their own way home from hospital. When you see the list of all the possible side effects it can be quite worrying but remember most people will not experience all these side effects and hopefully if you are affected, they will be mild. Your oncologist and the chemotherapy nurses will monitor you very closely throughout your treatment to pick up any side effects and help you cope with them. This may involve giving you medications like steroids, anti-sickness medications or laxatives (medication that helps to empty your bowels).

“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

One of the effects of chemotherapy is that it reduces the number of white blood cells in your blood and that means you might not be able to fight infections as well as before. 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. This can happen at any time, but your blood count is likely to be at its lowest seven to 14 days after your chemotherapy. You should avoid people who have infections (viral infection or infections treated with antibiotics). Your hospital should tell you whether you need to limit your contact with other people, but if you have any questions at all about this, don’t hesitate to ask them. Your hospital should also give you a 24-hour helpline telephone number to ring if you are feeling ill at any time during your chemotherapy and in the weeks after treatment. Many hospitals will also give you a list of specific things to look out for (for example a rash or raised temperature).

Common side effects of chemotherapy can include:

Tiredness and fatigue

Most people feel very tired during chemotherapy, so it is important to plan time to recover. Chemotherapy fatigue is not like normal tiredness and is not made better by sleep. If you are finding it hard to sleep because of steroids or other medication try doing some restful activities such as reading or watching television instead. As research has shown that one of the best things for fatigue is to keep active, it’s important to get a good balance between resting and doing some physical activity. Even a gentle walk around the block, when you’re able, can help to give you an energy boost.

Hair loss

It is rare for platinum chemotherapy to cause hair loss, however nearly everyone 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 wear in hospital while you are given chemotherapy to help minimise hair loss. A cold cap is a thin hat that is frozen. Having this tight against your scalp reduces the blood flow to the skin on your scalp and hair which means that less of the chemotherapy drugs reach your scalp and hair. Cold caps can be uncomfortable and treatment does take longer when they are used, but some people 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 the 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. Some people prefer to wear head scarves or hats at this time and your CNS will be able to help you find information about this as well.

Feeling or being sick (vomiting)

You will be given anti-sickness medication to take home after your chemotherapy treatment. If you do vomit (are sick) or feel nauseous, always let your chemotherapy team know as they may be able to adapt your medication.

“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

Changes in taste

Some people find that food and drink taste different from normal during chemotherapy treatment. This is usually temporary but can be difficult if you are also feeling sick because of your treatment. Speak to your CNS if this is causing you concern as there are simple tips that can help. You might also find it helpful to read Target Ovarian Cancer’s mini guide, *Ovarian cancer, diet and nutrition*, available from targetovariancancer.org.uk/guides or by calling 020 7923 5475.

“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

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 peripheral neuropathy. This can be frustrating but there are some medications and complementary therapies (treatments that can be used alongside conventional medical treatments such as surgery and chemotherapy) that may help to ease the symptoms.

Concentration

Some people 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 were able to before treatment. This is usually temporary but may last as long as two years after chemotherapy. It is not fully understood what causes this but Cancer Research UK offers more explanation on their website. To find out more, search 'chemo brain' at cancerresearchuk.org.

Many people find that as treatment continues they become more used to the side effects and can plan their normal activities around them. For example, some people can feel very tired a specific number of days after chemotherapy and so don't plan any trips or activities on those days. But if you are badly affected please get in touch with your hospital as they will be able to help you. There are also some tips for dealing with side effects in the **Back to everyday life** section of this guide.



"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

"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



Radiotherapy

Radiotherapy involves using radiation such as x-rays to treat cancer. It is not usually used to treat ovarian cancer. In special circumstances your oncologist may suggest radiotherapy, but they will discuss this with you if this is the case. For more information about radiotherapy visit macmillan.org.uk

Other drugs

Depending on your individual circumstances, such as the type of tumour and whether surgery is possible, you may be able to have other anti-cancer 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.

Bevacizumab

Bevacizumab is a type of drug called a targeted therapy. These drugs specifically target the things about a cancer cell that makes it different from a normal cell. You might also hear it called Avastin®. At the time of this guide's publication, January 2021, it's currently available to some women with advanced ovarian cancer in England and Scotland.

Bevacizumab (Avastin®) targets and attacks 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 at the same time as the chemotherapy drugs

(platinum and paclitaxel) and also continues after chemotherapy has finished as a maintenance drug (a drug that aims to keep your ovarian cancer under control for as long as possible). After chemotherapy has finished your oncologist will give you 12 more doses of bevacizumab with one dose (cycle) each week. Ask your oncologist whether bevacizumab may be an option for you.

PARP inhibitors

PARP inhibitors are a type of targeted therapy. They work by stopping the cancer cells repairing themselves, so the cells die. At the time of this guide's publication (January 2021), there are three PARP inhibitors available on the NHS in the UK: niraparib, olaparib, and rucaparib.

Which of these you can access and at what stage of your treatment depends on your personal situation, whether you have a BRCA mutation (an inherited alteration in the BRCA1 or BRCA2 gene, which is known to increase the risk of ovarian cancer) or whether you test positive for homologous recombination deficiency (HRD, which means your cancer's DNA finds it harder to repair itself).

PARP inhibitors only work in some people with ovarian cancer, but as more is being learnt about them, more people are able to access them. Your oncologist will talk to you about all the treatment options available for you.

What is a BRCA mutation and why does it affect when I can have a PARP inhibitor?

Genes are instructions made from DNA, which tell the cells in our bodies how to work. Every cell in our body contains genes that decide and control our body's functions, growth and appearance. Each person has two copies of most genes, one inherited from their mother and one from their father.

In general, our genes enable our cells (the building blocks that make up our body) to function normally. However, sometimes the genes that were inherited have small changes, known as alterations or mutations. These mutations can stop a cell from repairing itself properly if it becomes damaged. This can sometimes result in an increased risk of developing cancer compared to people who don't have the genetic change.

Cancer cells in those who carry the BRCA1 or BRCA2 gene mutations are less likely to be able to repair themselves. Using PARP inhibitors can block this further so that cancer cells are less likely to repair themselves and grow.

As part of your treatment plan you may be offered genetic testing (using a blood test) to find out if you have a BRCA mutation and are suitable for specific

types of PARP inhibitor therapy. There are two ways that you may be able to access genetic testing in your area.

- You may be given the option to be referred to a specialist NHS genetic service. This is run by clinicians who are specially trained in ensuring that you are fully supported throughout the whole process, from preparing to make a decision about doing the test, to coping with the results of the test.
- You may be offered genetic testing that is done by the same team and in the same place as your ovarian cancer treatment (the oncology clinic). This is called mainstreaming and means that genetic testing can happen faster than if you had to go elsewhere, because the blood test is often taken at the same time as your normal appointment. You will be counselled about the implications of having the test by an oncologist or nurse who may have had some additional training in this area. If your test result shows that you have a genetic mutation you will often then be referred to a genetics service to discuss the implications of that result for you and your family.

It's important that you think about the impact of the testing on yourself and on those who are close to you before you decide whether or not to have the test. If you have a BRCA mutation, that may mean you are at risk of developing other cancers. It may also mean members of your family also have the gene mutation. If this is the case, you

and your family members may need to think about taking action to reduce their risk of developing cancer in future.

Remember that, whichever route you go down, you have the right to access counselling before deciding whether to be tested. Your oncologist or surgeon will discuss this with you so it's important to let them know if you have any questions. There is more information about genetic testing in chapter six of this guide. Target Ovarian Cancer also has a guide called *Genetic testing and hereditary ovarian cancer* which you can order or download from targetovariancancer.org.uk/guides or by calling **020 7923 5475**.

Tamoxifen

Tamoxifen is a type of hormone therapy, which you may more often associate with breast cancer treatment. It is also used in women with ovarian cancer who either cannot have chemotherapy or have very small deposits of cancer.

Access to different drugs through the NHS changes. The information above is up to date as of January 2021. Go to targetovariancancer.org.uk/drugs or call **020 7923 5475** for the most up to date information on ovarian cancer drugs.



Clinical trials

Clinical trials are research studies that investigate 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'll be put into a group by chance. These groups are sometimes called the treatment group(s) and the control group.

- In some trials one group will be given the new drug being tested and the control group will be given standard treatment, so that they can be compared.
- In other types of studies, the treatment group might be given the new treatment and the control group might be given a placebo (a treatment that has no effect).
- In other studies both groups are given the new treatment but in different ways.

You might not always know which group you are in, but 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 the hospitals that undertake medical research provide some of the best treatment.

Each clinical trial has very strict criteria (rules) for who is able to join the trial to make sure that the treatment is tested thoroughly and the results are reliable. Not all cancer centres are involved in

clinical trials. You should ask your oncologist what trials you might be suitable for and where (in which hospitals) the trials are happening.

You might want to ask:

- What trials are you suitable for at your treatment centre?
- If you're 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, which may involve completing surveys or being interviewed.

Remember, it is your decision whether to join a clinical trial or a research study. You can search all live UK trials on our website targetovariancancer.org.uk/clinicaltrials

HOW YOU MIGHT FEEL

For many of us a variety of treatments lie ahead and sometimes in different orders; some people 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 (your ability to become pregnant and have children). 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 TV 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're 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 it's not worth mentioning the fact that we're exhausted because we think it's understandable. It may also be tempting to downplay side effects and keep them to yourself so that it looks like you are coping better than you are. Looking back, I'm 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're 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





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Family history, genetic testing and hereditary ovarian cancer



When you have had a diagnosis of ovarian cancer, it is common to worry that other family members may also be at risk. In most cases, ovarian cancer is a one-off (sporadic) illness that is not related to family history. However, up to 20 per cent of cases of ovarian cancer happen because of a genetic mutation (alteration or change) in one or more of your genes that is known to increase the risk of ovarian cancer. This mutation will have been inherited (passed on) from your mother or father before you were born. Some types of ovarian cancer are more likely to be caused by a mutation in a gene than others. Mutations are more common in high grade serous types of ovarian cancer and uncommon in mucinous or germ cells ovarian cancer.

What is a cell?
Cells are the building blocks that our bodies are made of. We have lots of different types of cells that do different things.

What is DNA?
DNA stands for deoxyribonucleic acid. It is a chemical in our cells that tells the cells how to work and behave.

What is a gene?
Genes are made up of short sections of DNA. Our genes carry information about us like the colour of our eyes. Each person has two copies of most genes, one inherited (passed on) from their mother and one from their father.

Hereditary ovarian cancer is ovarian cancer that has developed because of a gene mutation that has been passed on through one generation of a family to the next. It is most commonly caused by a mutation in either the BRCA1 or BRCA2 genes. These genes normally protect against cancer because they help repair breaks in DNA that can lead to cancer. If a BRCA gene is not working because it is mutated then this increases the chance of cancer developing. Some mutations in other genes are also known to be associated with an increased risk of ovarian cancer and scientists are learning more about these other genes.

Mutations in genes such as BRCA1 or BRCA2 can occur in both men and women in any family so a gene mutation can be passed on from either your mother or your father. They are more common in some communities than others. For example, members of the Ashkenazi Jewish population

are up to 10 times more likely to have a mutated BRCA1 or BRCA2 gene and so are more at risk of developing hereditary ovarian cancer than the general population.

Should I be tested?

In the UK, people diagnosed with non-mucinous epithelial ovarian cancers including high-grade serous ovarian cancer (the most common type) are often offered access to genetic testing for mutations in their BRCA1 and BRCA2 genes, even if they have no family history of ovarian cancer. Over 90 per cent of ovarian cancers diagnosed are non-mucinous, which means that most women diagnosed with ovarian cancer fit the criteria for genetic testing. This means that genetic testing could be available even if you don't know your family history.

Some women may not be able to have genetic testing due to the type of cancer they have (for example germ cell or sex cord-stromal tumours) but it is important to discuss genetic testing with your oncologist or a genetic counsellor (a professional who is trained to talk to you about the risks and benefits of genetic testing) to find out if it is right for you. The test may identify mutations in either the BRCA1 or BRCA2 genes or be inconclusive, even when several family members are affected. If the test shows a mutation or is inconclusive you will be supported by an expert genetic counsellor to understand the results and what this could mean for you and your family.

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

There are a number of things to think about if you find out you have a mutation in your BRCA1 or BRCA2 genes. Firstly, there is the impact on you - it may have some implications for the treatment of your ovarian cancer. Over the last few years new drugs (PARP inhibitors) have been developed that target ovarian cancer specifically and work by stopping cancer cells repairing themselves (so they die). You may be eligible for treatment with these drugs. Ask your oncologist about whether this type of treatment might be suitable for you.

The result will also have an impact on your risk of developing other cancers. People with ovarian cancer who have a mutation in the BRCA1 or BRCA2 gene also have an increased risk of developing breast cancer in comparison to the general population. An increased risk does not mean that you will definitely develop breast cancer and there are a number of ways you can reduce the risk, such as having regular breast screening (checks), medications or considering risk-reducing surgery. You'll be offered information and support to help you decide the best option for you.

There could also be an impact on family members who may have inherited the gene mutation, which could put them at increased risk of developing ovarian and breast cancer.

What are the implications for other family members?

If you have a BRCA1 or BRCA2 gene mutation, other members of your family may also have it (including your mother or father, siblings, aunts, uncles and cousins, depending on the side of the family the mutation is passed down). Children of someone with a BRCA gene mutation have a 50 per cent chance of inheriting it and therefore being at increased risk. They also have a 50 per cent chance of having inherited a normal copy of the gene from the parent with the gene mutation.

Adults in your family can choose to have a genetic test to find out if they have inherited the same mutated gene. This is called 'predictive testing'. It does not mean that they have cancer or are going to develop it. If your family members are found to be at increased risk, they will need support to make decisions about what to do with that knowledge. Women with a BRCA gene mutation have an increased risk of developing breast and ovarian cancer. Men may have an increased risk of developing prostate cancer and breast cancer. There may also be a small increased risk of pancreatic cancer for people who carry BRCA2 gene mutations.

You can download or order our guide *Genetic testing and hereditary ovarian cancer* at targetovariancancer.org.uk/guides or by calling 020 7923 5475.

"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



7

Back to everyday life after treatment

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Although you will be told about the practicalities of what happens next from your hospital when treatment has finished, going back to everyday life can be challenging. You may find that normal life no longer feels 'normal' and it may take time for you to process all that has happened. Feelings of isolation can surface at this time and you may feel alone. You can contact your CNS between hospital appointments if there are things you feel you want to discuss, including any psychological (mental health) issues that you may be experiencing.

“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

You can also contact Target Ovarian Cancer’s support line by calling **020 7923 5475**. Our specialist nurses are available Monday to Friday, 9am–5.30pm, to provide confidential advice and support about any aspect of ovarian cancer, including any practical or emotional concerns that you that you or your loved ones might have.

Finding a new routine

An ovarian cancer diagnosis can change things. Going home and trying to get back into a routine might be difficult. It can take time to get back to your usual energy levels. Some people will experience fatigue, which can mean they feel exhausted most of the time. This might be caused by your treatment, as well as feeling drained emotionally. It will get better, but it takes time. Be realistic and find a pace you can cope with. Creating a new routine to help plan out the day might help to give you a sense of normality again. It can be daunting at first and everyone will have different expectations about what they want their life to be like after a cancer diagnosis. Some people may want to use a diary or day planner to help focus, while others may just want to take each day as it comes. Some people talk about finding ‘a new normal’ (finding a routine that works for you now).

Now is the time for you to accept help with some of the practical things. Try to think about people in your life that may be able to cook for you, run

errands or help with everyday things. Perhaps your local community is good at supporting each other, or your family and friends are close by? You might have to ask for help, which can feel hard, but many people will be happy to be able to do something practical. Not everyone has a large group of people who are able to help, but there might be volunteers or organisations you can contact through your hospital or council who may be able to offer some support.

It is common to have days when you feel tearful and miserable. After cancer treatment life can feel different and learning to accept that and carry on everyday life can be hard. Sometimes you may need emotional support help from friends, family and professionals, and perhaps from friendships made through cancer experiences. You should be able to contact your CNS or key worker if you feel like you need their support during this time, or have a look at the section of this guide called **Who 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 a stoma (an opening through your tummy to bring the end of your bowel through the skin), you may have experienced menopause as a result of your surgery, have gained or lost weight or be facing temporary hair loss. Your CNS or key worker will continue to support you to help you get used to this new way of life, and meeting others who have experienced these things can be helpful too. You may also find it helpful to contact some of the organisations listed in the **Who might help?** section of this guide for support with your specific concerns.

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 people 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 also find life after your diagnosis hard to deal with. Friends may want to be supportive but may

be very busy with their own families and careers. 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 can provide support for family, friends and carers, so ask them to get in touch, or talk to your CNS about what other support may be available in your area.

“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 people, making arrangements to socialise with friends may feel daunting. 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, or their own experiences. 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 frightening as it is a reminder that any of us can develop a serious illness at any time in our lives.

If this is your experience, you could try attending a local support centre, group, or course. You may not have thought this would suit you, but lots of people tell us it can be really helpful. 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 through 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

If you feel you would prefer to talk to other people online, there are lots of support forums and groups that might help. Target Ovarian

Cancer has two private Facebook groups where you can connect with others.

- The **Ovarian Cancer Community** is open to everyone affected by ovarian cancer, including family and friends, and is a place to come together, share experiences and advice, access our digital events and hear from clinicians.
- If you've received a diagnosis of ovarian cancer, we'd also encourage you to join our **In Touch** Facebook group. In Touch is a safe and understanding group created by Target Ovarian Cancer, just for women living with and beyond ovarian cancer, to stay in touch with other women wherever you are in the UK.

You can find these through targetovariancancer.org.uk/facebookgroup or by searching directly on Facebook. There are also other groups listed in the **Who might help?** chapter of this guide.



"Talk about it. It's likely that someone else has had the same experience as you."
Julia

Relationships with your partner

Relationships with partners may also be affected, and these changes might be both positive and negative. You might find that your relationship is stronger as you and your partner come to terms with your diagnosis together. But in other cases your partner may not know what to say and may be feeling many of the emotions you are, particularly if they feel you may not be able to have the same life you had planned to have together.

HOW YOU MIGHT FEEL



Finishing treatment can be frightening and you may feel vulnerable: the emotional and physical side effects don't go away overnight. It's normal to still feel many of the same 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, try to tell them how you feel and what you want from them. Let them know you're the same person that you were before you had cancer.

Sex and intimacy

With a 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 restart your sex life, particularly if you have had major surgery. For some people though, having sex during this time can help them feel cared for, loved and secure. You may just want a cuddle at this time. Physical contact with a partner can release chemicals in your brain and make you feel good, so whether it's a cuddle, a kiss or more it might help you to manage stress.

For some people, being sexual 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 treatment. You may have to reassure your partner that you want to try having sex or touching each other sexually. Sex can help you feel connected to your partner and give 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 those with a partner. We can make ourselves feel good by touching our bodies and loving ourselves. There is nothing wrong with masturbation at any time of 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 and nurses examine you, touching yourself may be comforting and help you reconnect with your body. Getting to know your body again is important as it may feel different if you have had surgery.

If there is a problem

Sometimes people have difficulties having sex again. This happens to lots of women and your CNS or key worker will be happy to speak to you about any concerns that you might have. Sometimes talking about it or taking a little bit of time is all that is needed. Some people like to talk to a sex therapist (this is usually a psychologist who is specially trained to help with issues to do with sex). There should be a psychosexual counsellor (sex therapist) available in your area through your local NHS. 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 many people's lives. It can 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 vaginal moisturiser or lubricant. Your CNS will be able to give you more guidance about this, and you should be able to find a variety of lubricants quite easily on the shelves of the larger chemists.

Whatever your problem - talk about it. It's worth it.

If you would like to find out more, Target Ovarian Cancer has produced a mini guide, *Ovarian cancer, sex and intimacy*, which you can download or order at targetovariancancer.org.uk/guides or by calling **020 7923 5475**.

Getting back to work

Working through cancer treatment or returning to work after treatment is a very personal decision. You might have to return to work for financial reasons. Perhaps working also 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. If you are going to lots of appointments and it is having an impact on your energy, telling them could make it easier for them to understand your situation and support you.

Ask your 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 might 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

"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

plan to support you through this time can help you feel more in control. It is very important that any plan is what works best for you. It can be 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 if you would like to. 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.

Your rights

Everyone living with or beyond cancer is protected under the Equality 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, as long as they know (or should reasonably know) that you have or have had cancer. This might include changing some of your duties, agreeing different working hours, and allowing time off for appointments.

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.



"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

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 colleagues are making unreasonable demands of you, you can get advice from these organisations:

- Citizens Advice – citizensadvice.org.uk
- Advisory, Conciliation and Arbitration Service (ACAS) for free employment advice – acas.org.uk or **0300 123 1100**.
- 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

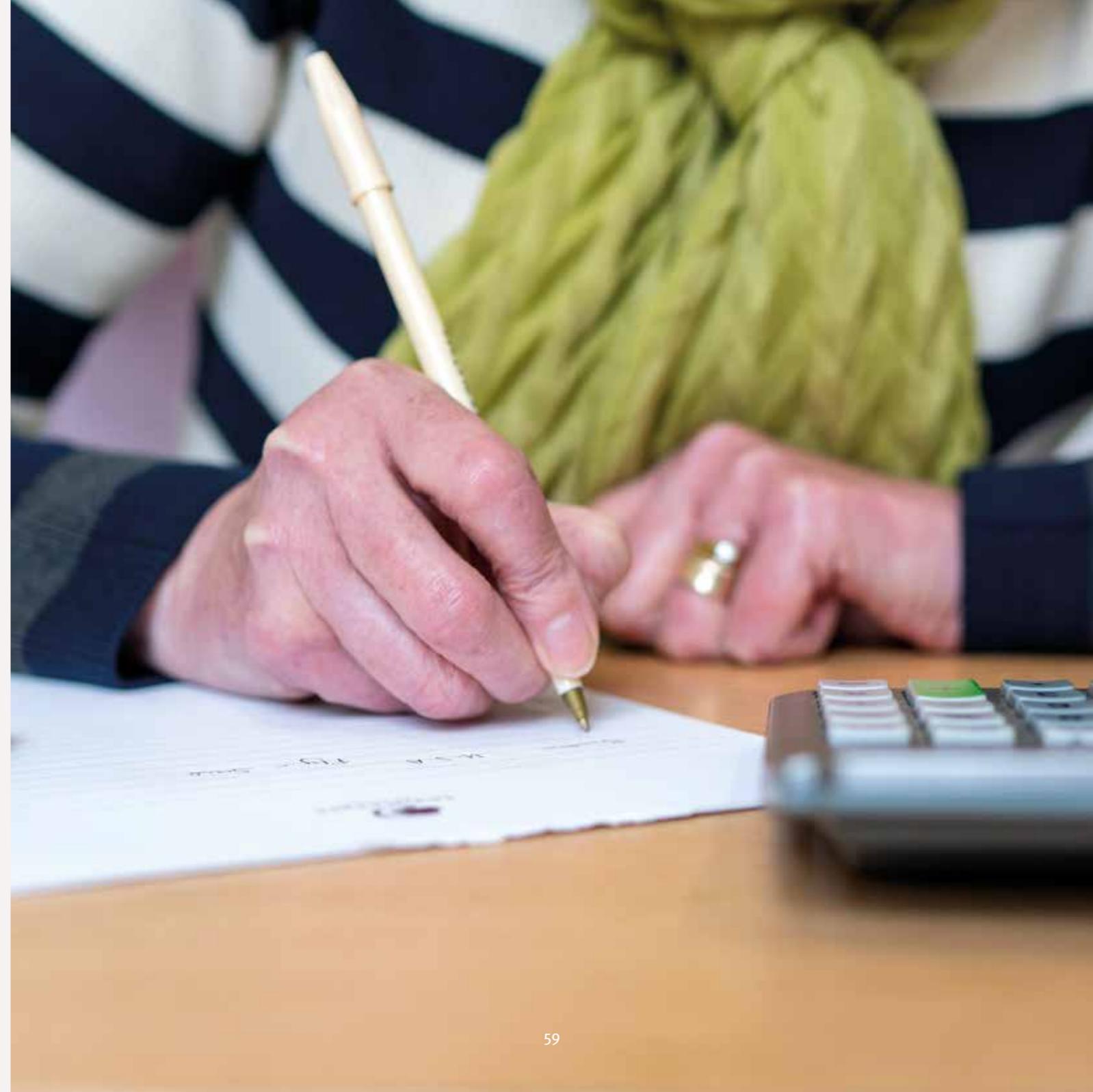
Financial help

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.

How do I find out more?

- Target Ovarian Cancer has a useful booklet called *Ovarian cancer and your finances* that you can download or order at targetovariancancer.org.uk/guides or by calling **020 7923 5745**.
- Macmillan has a benefits helpline staffed by trained advisers that can be reached on **0808 808 0000** or at macmillan.org.uk. Macmillan benefit advisers also visit some hospitals so speak to your CNS if you would like to book an appointment.





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Taking care of yourself

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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 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 medical 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 let your CNS and oncologist know about any therapies you're thinking about trying. Most hospitals have links with a local cancer support centre which might offer a range of therapies 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?

- Target Ovarian Cancer has a useful booklet, *Ovarian cancer and complementary therapies* that you can download or order at targetovariancancer.org.uk/guides or by calling **020 7923 5475**.
- Cancer Research UK has very thorough information about a range of therapies on its website. Search 'complementary therapy' on cancerresearchuk.org

Physical activity

Being more active can help you with some of the side effects that you may experience, such as tiredness, 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 gentle exercise little and often, perhaps 10 minutes every day, and gradually build up the amount that you do.

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

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

"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! Jarvis is a special dog and a fabulous handful and distraction at times"

Sarah

Your local gym or leisure centre may also offer classes or a reduced membership rate.

Give it a go and find out what exercise you enjoy and that feels right for you. Ask for help from your CNS or oncologist if you are not sure how much and what exercise you should do.

How do I find out more?

Macmillan has more information on physical activity. Visit macmillan.org.uk and search for 'physical activity' or call **0808 808 0000**.



Diet and nutrition

Many people with ovarian cancer find themselves wondering whether their diet is linked to their diagnosis and they may feel that they have to make big changes to their eating habits. You may be wondering whether a change in diet could make a difference to how you feel or how your cancer acts. There is no evidence to suggest that what you do or don't eat will impact on how your cancer behaves.

The most important thing for you is being as healthy as possible. This means eating foods that are made up of things that help your body to repair and maintain itself and to give you the energy you need. A balanced diet involves eating a mixture of:

Protein

(beans, pulses, fish and meat)

Starchy carbohydrates

(high fibre bread, potatoes, rice and pasta)

A small amount of fats

(unsaturated oils and spreads)

Some dairy or alternatives (soya, oat, coconut)

(milk, yoghurt, cheese)

Lots of fruit and vegetables

It's not uncommon for women to feel that they can't eat as much as they used to, or that their tastes have changed. If you are having problems, try eating little and often rather than full portions at mealtimes, and choose foods high in protein, vitamins and minerals.

If you have to eat a different diet because of your treatment or having a stoma, you can ask your CNS, key worker or a dietitian (a qualified health professional who works with people with special dietary needs due to health conditions) for support with this.

How do I find out more?

- Target Ovarian Cancer has a useful booklet called *Ovarian cancer, diet and nutrition* that you can download or order at targetovariancancer.org.uk/guides or by calling **020 7923 5475**.
- The World Cancer Research Fund is the leading authority on the links between diet and cancer and produces a report called *Diet, Nutrition, Physical Activity and Cancer: A Global Perspective*. You can also download their booklet *Eat Well During Cancer* for recipe ideas and tips to manage side-effects of treatment from wcrf-uk.org

When you suffer from chemotherapy side effects

If you are experiencing side effects of chemotherapy (for example feeling sick, being sick or 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 that eating cold foods help you to avoid cooking smells, which can sometimes cause people to feel sick. Eating slowly and sitting in an upright position may also help, and you may find it best to eat at certain times of day (for example, not late at night). Nourishing drinks such as fruit smoothies and milkshakes can help you build up and maintain your weight if you're finding it hard to eat. Ask your CNS or a dietitian if you have any concerns or want to know more about whether certain foods or nutritional supplements may be right for you.

How do I find out more?

- Maggie's has lots of helpful information about eating well with cancer and their local centres can also offer support: maggies.org
- Penny Brohn UK has information on healthy eating: pennybrohn.org.uk/resources
- Macmillan has lots of information about maintaining a healthy lifestyle including a selection of simple recipes. Search 'healthy eating' at macmillan.org.uk

"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

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 chance that the cancer might return (recur) but we don't know who will have a recurrence and who will not. The chance of recurrence (the cancer coming back) will depend on a combination of things, including your tumour stage at diagnosis (how much cancer there is and how far it has spread) and your response to surgery and chemotherapy treatment.

It's normal to feel worried about your cancer coming back. No one can take these feelings away. You might worry about every ache and pain being a sign that the cancer is back. Many people go through this and for most, time allows them to learn to put this worry to the back of their mind 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.

"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

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 **Who might help?** section of this guide for further support.

Symptoms

If your cancer does come back, your symptoms may or may not be the same as the first time.

Symptoms may include:

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

However, other symptoms not listed above may develop so it's important to tell your CNS or GP about **anything persistent and unusual for you**, even if it's a slight change, so that you can get checked out quickly. You know your body best. Don't be afraid to flag any concerns that you have, as it's always better to get them checked.

Target Ovarian Cancer's guide, *Back here again*, has more information if your ovarian cancer has come back (recurred). You can download or order this at targetovariancancer.org.uk/guides or by calling **020 7923 5475**.



HOW YOU MIGHT FEEL

The emotions you experienced when you were told that you had cancer will not go away overnight. You may need some help to come to terms with your diagnosis. If you look for help this is not because you are 'weak' or a 'failure'; it 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 they 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 a few minutes each 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 (forecast for the future) is uncertain, to search for new treatments and 'miracle cures'. If you are tempted to try a treatment please discuss this with your doctor first. Some alternative treatments may be very expensive and have no evidence that they work.

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.





Target Ovarian Cancer has co-produced with other charities an information guide for *Younger women with ovarian cancer* that you can download or order at targetovariancancer.org.uk/guides or by calling **020 7923 5475**.

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Younger women



There are a number of issues relevant to younger women who are diagnosed with ovarian cancer. Perhaps you have young children or care for an elderly relative, have a demanding job 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.



“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

Whether you're hoping to start a family or have more children in the future, there may be an opportunity to see a fertility doctor for advice and information before starting any treatment.

Most women with ovarian cancer will have surgery that includes a hysterectomy with both their ovaries and womb removed, meaning they will not be able to become pregnant naturally. If your cancer has been caught early and only involves one of your ovaries it may be possible for you to keep your womb (uterus) and possibly the unaffected ovary. However, there is also a chance that the one remaining ovary becomes affected by chemotherapy and may stop working. There may be options for you to consider, depending on the extent of your surgery and your individual circumstances.

Freezing your eggs

If treatment doesn't need to start straight away, you may want to consider freezing your eggs. This is where your ovaries are stimulated (encouraged) to produce more eggs than usual so that they can be collected and frozen for use if you want to become pregnant in the future or use a surrogate to have a child (surrogacy is when a woman carries and gives birth to a baby for another person or couple). You can read more about this on the Human Fertilisation and Embryology Authority (HFEA) website: hfea.gov.uk

In vitro fertilisation (IVF)

If you have kept your womb (uterus) and are still well two years after treatment has finished, you can consider a pregnancy either with your own frozen eggs (if this was an option for you) or a donor egg through IVF. This is where an egg and sperm are combined to make an embryo outside of the body and then placed in the uterus. Speak to your 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

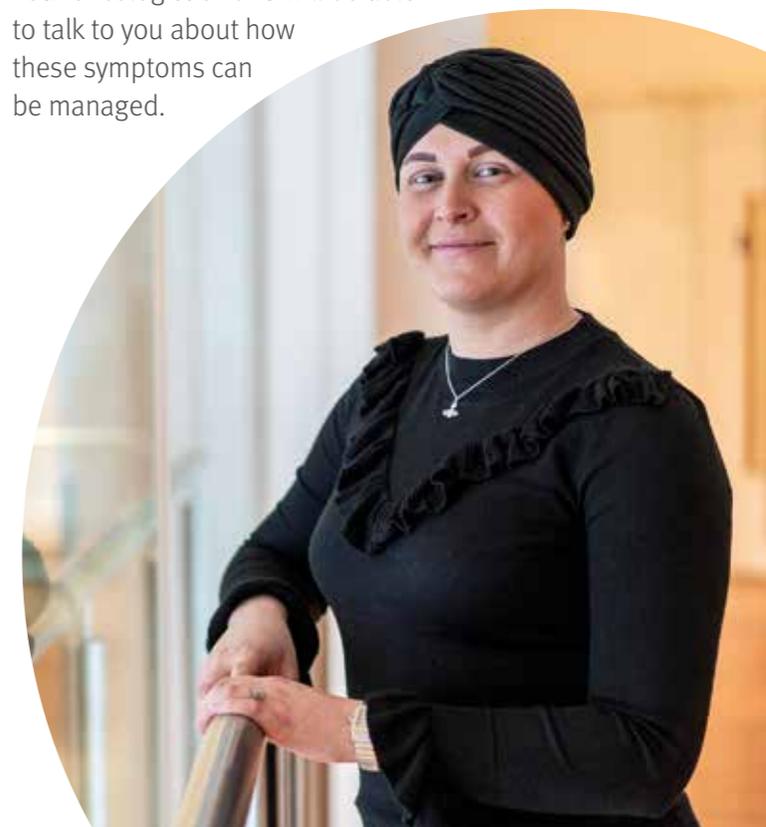
Surrogacy

If you have had a hysterectomy with both your ovaries and uterus (womb) removed, you may want to consider other options for having a child, such as surrogacy (when a woman carries and gives birth to a baby for another person or couple) or adoption (when you legally take on parental responsibility for a child that is not your biological child). There is more information about these options in our guide for *Younger women with ovarian cancer* 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 not be able to become pregnant using your own eggs and you will also experience an early menopause. The menopause is a reduction of the hormones called oestrogen and progesterone 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 loss of hormones and some people experience lots of symptoms as a result. You may experience hot flushes, vaginal dryness, mood swings, feeling tearful 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 people hormone replacement therapy (HRT) may be an option. HRT is a treatment used to help with symptoms of the menopause by replacing the hormones that are at lower levels because of menopause. There have not been many clinical trials of HRT after a diagnosis of ovarian cancer. Available evidence suggests that HRT use after treatment for ovarian cancer is safe and does not increase the risk of the cancer coming back for most women. There are some rare types of ovarian cancer when you will be advised not to take HRT but your medical team will give you more information based on your individual circumstances.

Some people prefer alternatives to HRT to help them with their menopausal symptoms. These include non-hormone medications from your doctor, complementary therapies (like acupuncture or aromatherapy), cognitive behavioural therapy (CBT) and herbal and dietary supplements, lots of which are available online or over the counter. There are also a number of creams and gels that can help with vaginal dryness if this is the main problem. There is not a lot of evidence for the effectiveness of the alternatives to HRT but before trying anything you should ask your doctor or pharmacist to make sure that they won't interfere with any other medications that you are taking.

Making a decision about HRT or its alternatives can be difficult, and you should discuss this with your oncologist or CNS to weigh up the benefits and risks involved. If you choose to try HRT, you may need to try different types and 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 may 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's 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 **Who 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.





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Who might help?

It may take time to adjust after cancer treatment. It's fine if you have days when you feel upset. But if these become 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 CNS or key worker. They are qualified to provide 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 there are lots of ways to get support. These can include talking to a professional or simply chatting to someone on the phone or an online forum.



Target Ovarian Cancer

If you're worried about anything you've read in this guide or would like more information, get in touch with our support line. You can call us about anything to do with ovarian cancer. Our specialist nurses are here to listen. Call **020 7923 5475** (Monday – Friday, 9am – 5.30pm) or visit **targetovariancancer.org.uk/supportline**

Our website **targetovariancancer.org.uk** brings you insights from women who have had a diagnosis of ovarian cancer and how they feel in our stories section.

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

Facebook groups

Join our private Ovarian Cancer Community on Facebook, a group for **anyone affected by ovarian cancer** (including loved ones) to connect, share experiences and support one another. Keep in touch with Target Ovarian

“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

Cancer and experience our digital events together with your family and friends. Hear from clinicians and our specialist nurses to learn more about ovarian cancer. To join visit **facebook.com/groups/ovariancancercommunity** You can also join our private Facebook group, In Touch, which is a safe space **just for women with a diagnosis**, to talk to others and share experiences. To join visit **facebook.com/groups/intouchtargetovariancancer**

Support events

Target Ovarian Cancer runs a programme of free digital and face-to-face events across the UK to support people living with and beyond ovarian cancer. They offer an opportunity to meet others and provide support and information. You can find out more at **targetovariancancer.org.uk/supportevents**



“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/supportgroups** to find a group near you.

“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.”

Lynette

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

Ruth

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.

Online communities and telephone support

- The Macmillan Cancer Support free support line is available seven days a week, 8am - 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 support at **community.macmillan.org.uk**

- Maggie's provide online cancer support where you can access specialist advisors and meet others through online support groups. Contact your local Maggie's centre for more information: **maggies.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.org.uk**
- 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 by calling **116 123**, free of charge, or by emailing **jo@samaritans.org**

Other professional support

If you feel you would like to have some more professional help dealing with your feelings and improve your mental health, there are plenty of choices available. The best first step would be to ask your CNS, key worker or GP about the services available at your local cancer centre or within your local area.

Many people 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 the **Psychological therapies** section can help you find a registered professional.

"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

"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



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 or anxious than is usual for you.

How can they help?

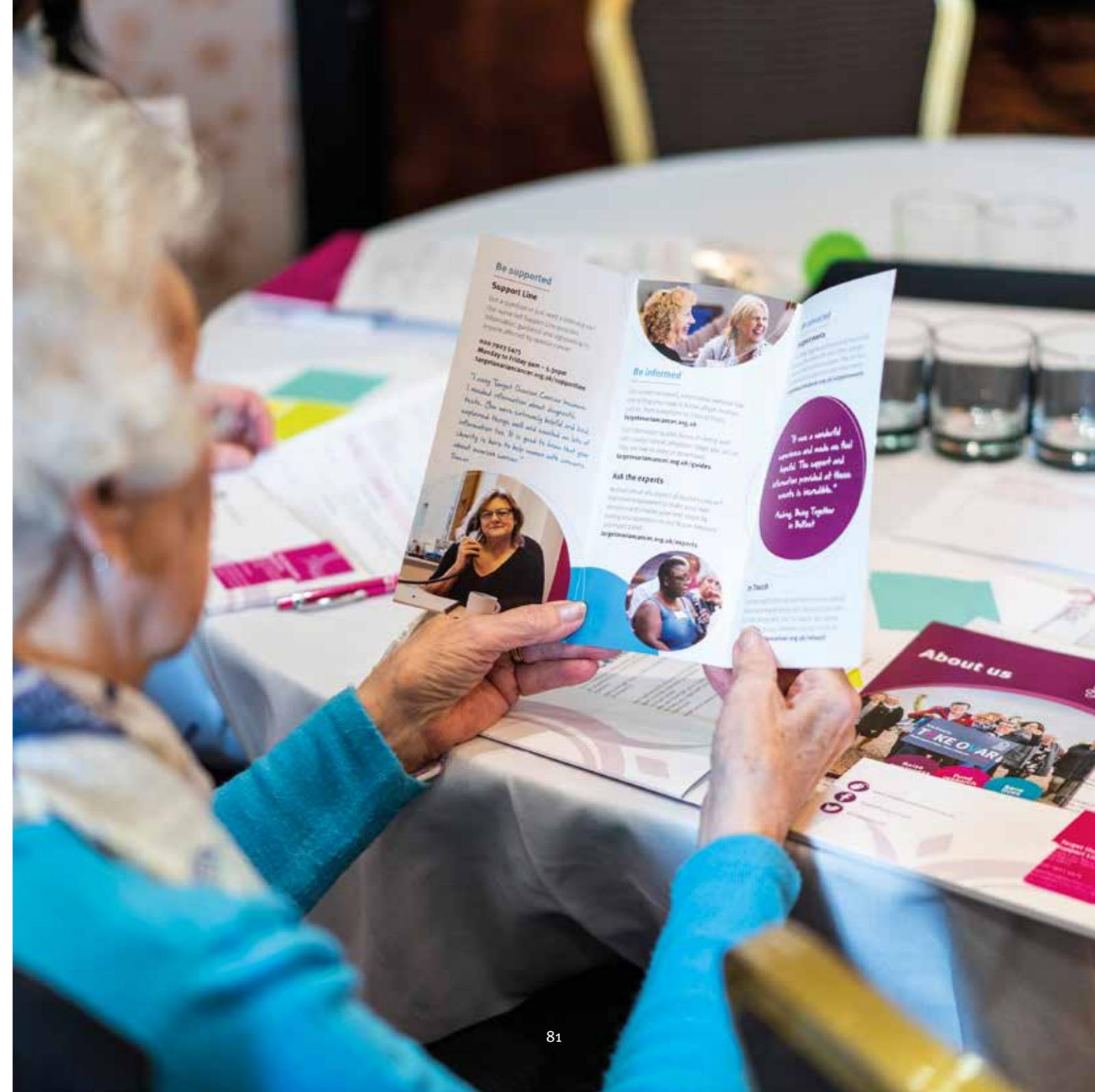
Health professionals who work with people with cancer in the NHS have been trained to understand how cancer may cause difficulties for you emotionally, practically and in relationships. Just getting things off your chest can help. You can discuss the problems you are having and explore difficult feelings 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 hospitals and treatment centres offer referrals to counselling services and many cancer support centres offer free counselling services on-site. Ask your CNS, GP or local

support centre for more information. If you prefer to 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: **bacp.co.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 call **0116 254 9568**.
- **Cognitive behavioural 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 also 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](https://www.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 help avoid repeat 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.

The Mental Health Foundation have more information about the different types of mindfulness, just search 'mindfulness' at [mentalhealth.org.uk](https://www.mentalhealth.org.uk). Or try their mindfulness course at [bemindfulonline.com](https://www.bemindfulonline.com)

You can also search 'mental wellbeing' at [nhs.uk](https://www.nhs.uk) for further information and advice on mental health.

Other sources of support

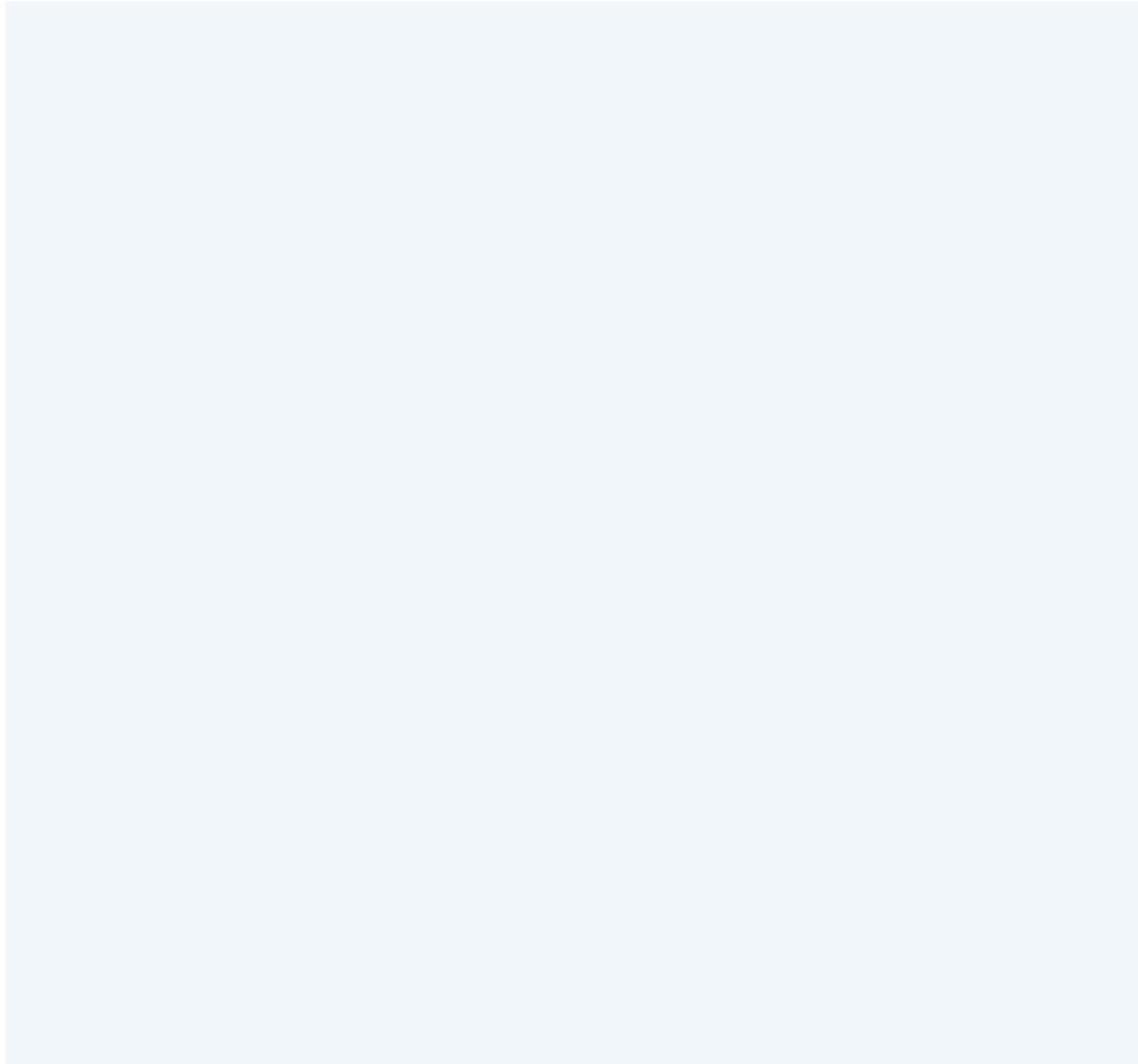
You may feel you need some specific support in particular areas. There is plenty of help available.

- **British Infertility Counselling Association** is the professional association for infertility counsellors and counselling in the UK and can help you to find help near you: [bica.net](https://www.bica.net)
- **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](https://www.carers.org)
- **Carers UK** gives expert advice, information and support to carers: [carersuk.org](https://www.carersuk.org)
- **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](https://www.cosrt.org.uk)
- **Daisy Network** offers information and support to people who have experienced a premature menopause due to a medical condition or treatment: [daisynetwork.org.uk](https://www.daisynetwork.org.uk)
- **Home Start** help 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](https://www.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](https://www.hopesupport.org.uk)
- **Relate** offers counselling, support and information for all relationships: [relate.org.uk](https://www.relate.org.uk)

Notes

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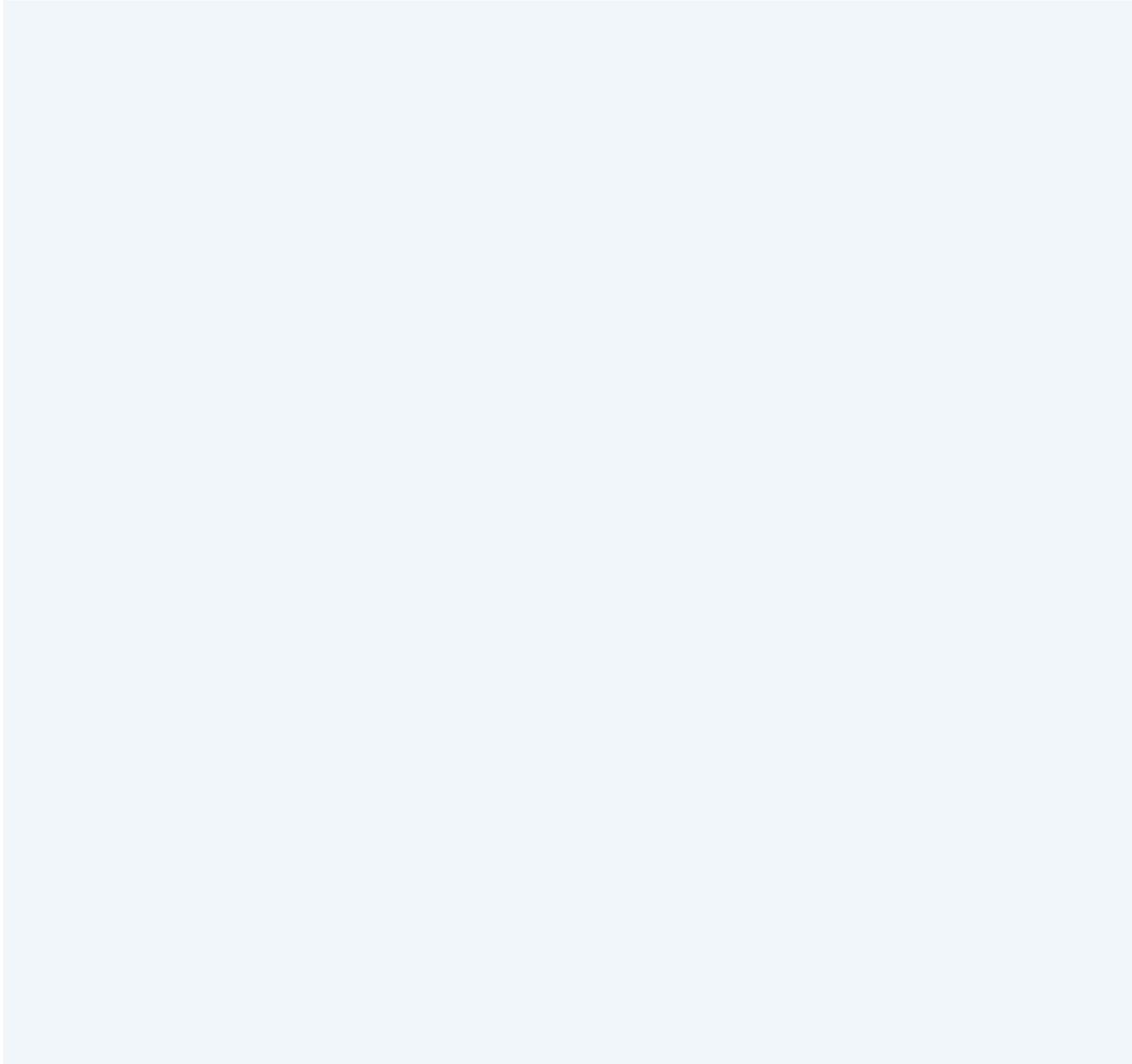
Useful contacts You can use this space to record useful contacts such as your CNS etc.



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.

All our publications and information are subject to an information production system that ensures quality and impartiality. All our publications are 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 for improvement, please get in touch.

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.

Our commitment to diversity, equity and inclusion

Target Ovarian Cancer is committed to embedding equity, diversity and inclusion into every area of the charity. We have embarked on a programme of work to make sure we're reaching and representing everyone who needs us, actively looking at how we can make sure our support reaches everyone affected by ovarian cancer, and that it reflects the communities

we serve. Through this work we are taking time to educate ourselves and think carefully about the needs of, and challenges faced by, people we currently support, and those that we could support.

You can find out more about our immediate plans on our website at targetovariancancer.org.uk/equity and if you'd like any more information please email us at info@targetovariancancer.org.uk

Our nurse-led support line is here for anyone affected by ovarian cancer – if you're worried about symptoms, if you have a diagnosis, or if you're a family member or a friend supporting someone living with ovarian cancer.

We're open from 9am–5.30pm, Monday to Friday.

Call us on **020 7923 5475**



Target Ovarian Cancer
30 Angel Gate, London, EC1V 2PT



Support line: 020 7923 5475



info@targetovariancancer.org.uk



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