Target Ovarian Cancer

What happens next?

A guide for anyone newly diagnosed with ovarian cancer

targetovariancancer.org.uk

Welcome to our guide for anyone newly diagnosed with ovarian cancer.

This guide is for you if you have recently been diagnosed with ovarian cancer. It talks through your practical and emotional needs in the days and months after a diagnosis. It also helps you find more support. This guide has been written with experts in ovarian cancer and its treatment - so you can trust that it's reliable, accurate and up to date.

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

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

Notes from Alison

"I originally trained as a nurse and later switched to research. In 1996 I was awarded a PhD for my work on the psychological aspects of breast cancer. After working as a teaching fellow at the University of Southampton for a number of years, teaching psycho-oncology, I decided to return to nursing. I now work as a psycho-oncology nurse specialist, offering psychological support to people with cancer. I was diagnosed with ovarian cancer in 2001 and my experience of surgery and chemotherapy has given me valuable insight into the impact of the disease."

Dr Alison Farmer

1 What is ovarian cancer?

In this section

- Ovarian cancer starts when a tumour grows in or on the ovaries. These are found in your pelvis (low in the tummy).
- There are different types of ovarian cancer. Epithelial high grade serous ovarian cancer is the most common type.
- Primary peritoneal cancer (PPC) and fallopian tube cancer are treated in the same way as ovarian cancer.

Being diagnosed with ovarian cancer can come as a big shock, even if you had symptoms. You may not have heard of ovarian cancer before and this can make you feel like you are the only one facing this diagnosis. You may also hear people using medical words that you have not heard before. All of this can make it hard to understand what your diagnosis means.

What is cancer?

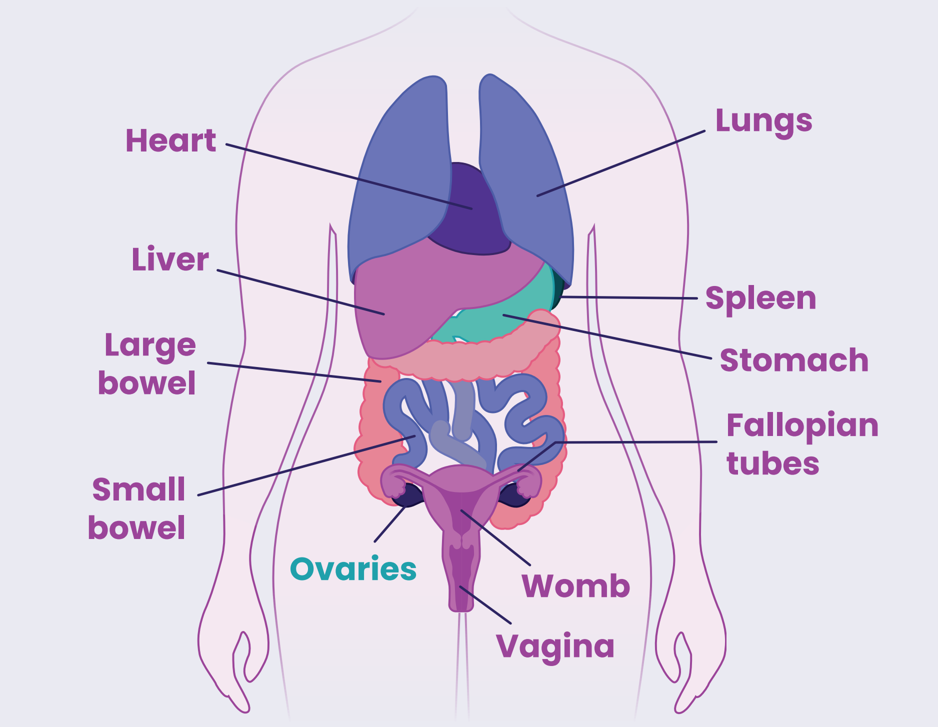
Our bodies are made up of millions of cells. Our body is always replacing old cells with new ones. It does this to keep us healthy and to help if we get hurt, for example if we get a cut or a graze. This process is usually very controlled so that the number of new cells that our body makes is the same as the number that were old and destroyed. But sometimes too many new cells are made. When this happens a group of new cells forms a lump called a **tumour**.

Some tumours are **benign**. This is where a tumour grows but it can't spread.

Others are **cancerous**. This is where a tumour grows out of control and can sometimes spread to other parts of our body. You may also hear the term **malignant** to describe a cancerous tumour.

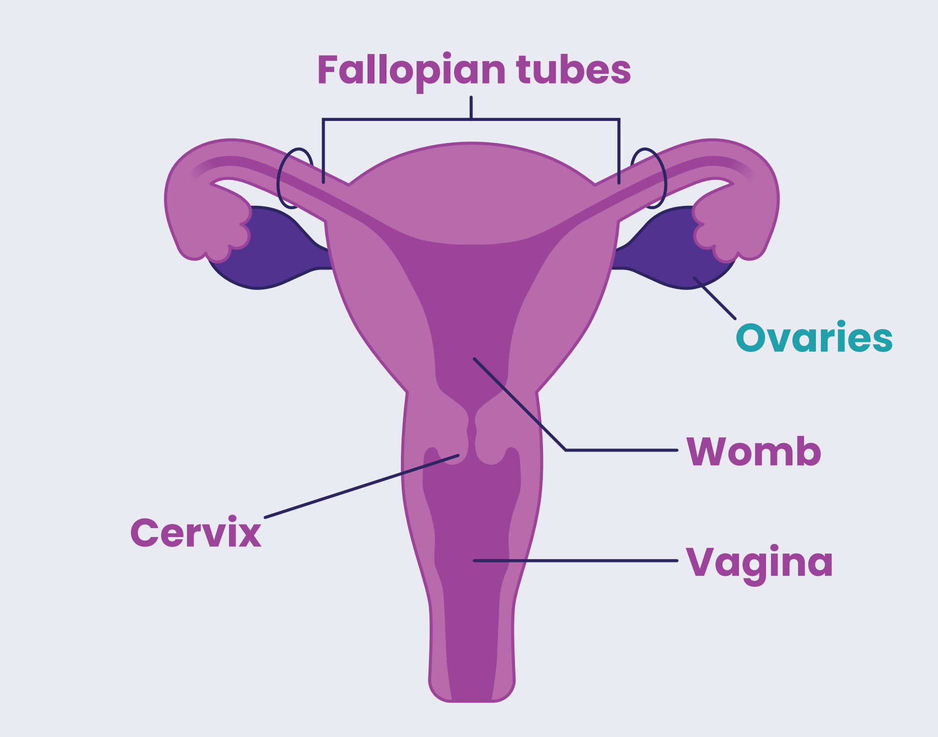
What is ovarian cancer?

Ovarian cancer starts when a tumour grows in or on the ovaries. The ovaries are two small organs each about the size of an almond. They are found in the low area of your tummy called the **pelvis**.



Ovaries make hormones called **oestrogen** and **progesterone**. These hormones help to tell the ovaries when to release an egg through the fallopian tubes and into the womb to prepare for the chance of becoming pregnant. They also control the menstrual cycle (periods).

Hormones are chemical messengers that tell the parts of our body what to do.



There are different types of ovarian tumours. They are named after the types of cell that they come from:

Epithelial ovarian cancer

90 in 100 ovarian tumours start in **epithelial cells**. These are the cells that cover the ovaries or fallopian tubes. The most common type of epithelial ovarian cancer is high grade serous ovarian cancer. Other types include:

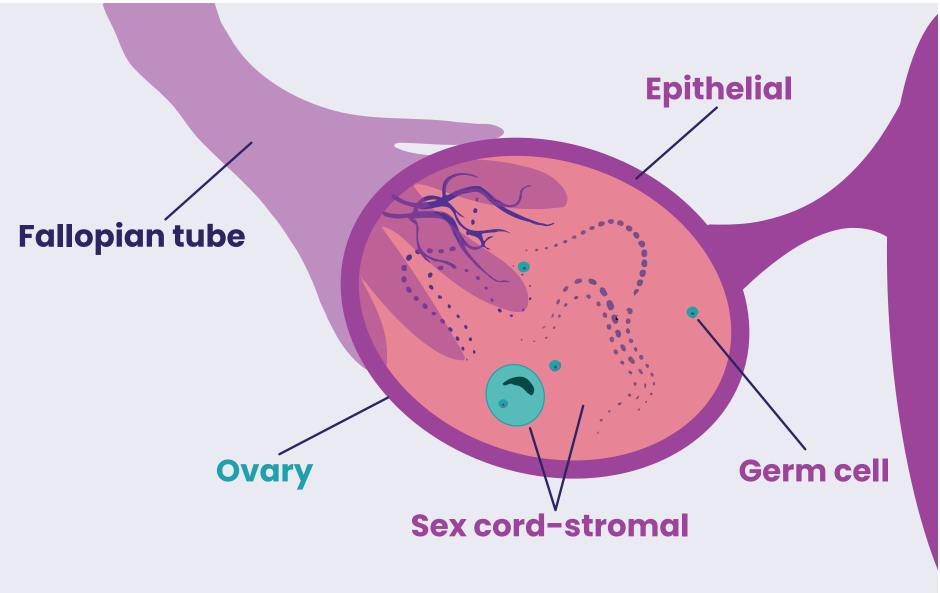
- low grade serous ovarian cancer
- endometrioid ovarian cancer
- clear cell ovarian cancer
- mucinous ovarian cancer.

▶ Sex cord-stromal ovarian cancer

About 5 in 100 ovarian tumours start in **sex cord** or **stromal cells**. These are cells in the core (centre) of the ovaries. Granulosa cell tumours are the most common type of sex cord and stromal tumours.

▶ Germ cell ovarian cancer

Around 5 in 100 ovarian tumours come from **germ cells**. These are the cells in the ovaries that develop into eggs.



There are also rare types of ovarian cancer. These include sarcomas, which start in the **connective tissue** in the ovaries. Connective tissue joins or separates organs in the body.

If you have had a hysterectomy in the past, where your womb and cervix were removed but you kept your ovaries, you can still get ovarian cancer. If you have had your ovaries removed, it is also still possible to get ovarian cancer as it can affect your fallopian tubes or peritoneum.

What about primary peritoneal cancer?

Primary peritoneal cancer starts in the **peritoneum**. This is a thin sheet of tissue that covers the organs in your tummy.

Primary peritoneal cancer is treated in the same way as ovarian cancer. This is because it acts the same way and responds to the same treatment as ovarian cancer.

What about fallopian tube cancer?

Fallopian tubes link the ovaries to the womb. Fallopian tube cancer is when a tumour grows in the fallopian tube.

Like primary peritoneal cancer, fallopian tube cancer is treated in the same way as ovarian cancer.

The information in this guide is for all types of ovarian cancer, primary peritoneal cancer and fallopian tube cancer.

2 Your diagnosis

In this section

- You will have a medical team looking after your treatment and care. This may include an oncologist, a surgeon and a gynae-oncology clinical nurse specialist (CNS).
- Telling people about your diagnosis can be difficult. How you tell them and when you tell them is your choice.
- How children react to the news can depend on their age. Whatever their age, there is support available.

When you are first diagnosed with ovarian cancer you may be given lots of information all at once. This can make it difficult to hear and understand everything you are told. You may feel shocked, frightened and upset. You may feel quite numb, and you may not be able to take in everything that is going on around you. You may feel that you have a lot of questions about what happens next.

As a start, it is helpful to know 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 treatment team. This is called a **multi-disciplinary team (MDT)**. It will involve all the people caring for you. The main hospital staff you will come across will be:

Oncologists

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

- A **gynaecological oncology surgeon** who will do your operation. They have had extra training to operate on those with ovarian cancer. In this guide we call this person a **surgeon**.

- A **clinical or medical oncologist** who organises chemotherapy. Medical oncologists also organise hormonal treatments and treatments such as PARP inhibitors (see the **Treatment** section of this guide). Clinical oncologists focus more on radiotherapy but also organise chemotherapy. In this guide we call this person an **oncologist**.

Gynae-oncology clinical nurse specialist (CNS)

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

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

Chemotherapy nurse

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

Other health professionals

Other people who may be involved in the MDT are:

- **radiologists** - who do scans like x-rays and CT scans
- **psychologists** - who help your mental health during and after a cancer diagnosis
- **pathologists** – who look at the cells in a laboratory to see if they are cancerous and to find out what type of cancer it is
- **anaesthetists** – who choose the right anaesthetic for you when you have surgery. This stops you from feeling pain during the operation. They also help you to prepare and recover from surgery
- **dietitians** - who give advice about what to eat and drink

- **physiotherapists** - who help you with movement and exercise
- **occupational therapists** – who help you cope with daily tasks that are difficult because of illness.

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

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

You should be told who the main person looking after your care and treatment is. This is usually a CNS. You should be given contact details for them 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. You may have different key contacts for different parts of your treatment. If you are not sure who they are, or how to contact them, ask someone in your treatment team to write down the details for you.

> “The specialist nurses were brilliant. They were always there to help me, hold my hand and tell me that I was going to be OK.”
> **Anita**

Telling family and friends

Who you tell about your diagnosis, when you tell them, and how you tell them is up to you. If you need to take a few hours, a few days, or longer to think about this, that's OK.

It can help to be as truthful as possible about your diagnosis from the start and have an open conversation with family members or friends about how you are both feeling. This can create a mutual understanding about how you talk about your diagnosis with each other going forward and reduce any extra burden on you.

It is not unusual for family or friends to cry or become very quiet. This can be hard for you to cope with. It might feel as though people are avoiding you or they don't seem to speak to you in the same way as before. Often people are worried about saying the wrong thing or upsetting you. They may simply need reminding that you are 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. If you want to tell people yourself, it's important to do it in a way that is most comfortable for you. This may be face to face, particularly if you have a really close relationship, or over the phone or email for wider friends and family.

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 with our support line. Call **020 7923 5475** to speak to our specialist nurses.

Macmillan has more information to help you tell people about your diagnosis. They also have information about emotional support for family and friends. Search **talking about cancer** and **supporting someone** at **macmillan.org.uk**

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

Telling children

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

Teenagers may ask for more information. They may need a little more time to work through their feelings and think about the questions they 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. What you have been told about your diagnosis will have an impact on how you feel about what you want to say.

Take things one step at a time with your children, family and 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 has more information to help you talk to children and teenagers and to help your understand their reaction. Search **talking about cancer** at **macmillan.org.uk**

There are also organisations that offer practical support for looking after children when an adult has cancer. Some can directly support children to help them cope. You can find more details about these in the **Help for you** section at the end of this guide.

> “I had a lot of help from my family and friends. Them knowing what I was about to go through and what it meant helped me a lot. They were a huge support to me and I wouldn’t have got through it without them.”
>
> **Anita**

Notes from Alison

“You might have been expecting your diagnosis or it might have been a complete shock. Either way, it’s never easy. 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 is the fact you have a diagnosis of cancer that is distressing. You may be feeling a range of emotions from sadness to anxiety, or perhaps hopelessness and fear. It is also common to feel angry. The anger might be directed at your doctor, your family, or even at yourself.

You may feel focused on trying to understand why you got cancer. Unfortunately it is not always possible to know why some people get cancer and this can be frustrating.

We are all individuals and cope with a diagnosis of cancer in different ways. Some people see cancer as a challenge to overcome. Others would rather not talk or think about it. Some people find a diagnosis of cancer can cause low mood (depression). All these emotions are normal and understandable, particularly just after diagnosis.

At the time of diagnosis support from close friends and family can be invaluable. However, whilst some relationships get stronger, some people won’t know what to say and may avoid you, which can be hurtful. Others may tell you to “stay positive”. This is meant well but can be very tiring and frustrating. Remember, it is 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 **Help for you** section of this guide explains different ways you can find this support.”

3 Making decisions about your treatment

In this section

- Using the list of questions in this section can help you to make treatment choices that are right for you.
- Taking in information at this time can be difficult. Find tips in this section to help you understand.
- If you are still not sure about treatment options after speaking to your treatment team then you can ask for a second opinion from another oncologist or surgeon.

Some people like to talk about all the treatment choices there might be. Others prefer to ask their treatment team to recommend an option. Whatever suits you, it is really important for you to take some time to make sure you have the information you need. This is so that you can make decisions that are right for you.

Share your thoughts

It can help to share your thoughts on the questions below 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 decisions?
    - Do you prefer to take some time to take the information in before deciding?
    - Do you need to talk it through with anyone before deciding?
    - What is the aim 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

Key decisions about treatment options include:

- whether or not to have treatment
- what type of treatment to have
- where to have your treatment
- when to have surgery and/or chemotherapy.

Good to know

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

- What treatment options do I have?
- How will certain treatments help me and how effective are they?
- Does the treatment have any risks now and in the future?
- What are the side effects? How might the treatment affect me physically, emotionally and sexually?
- How long do these side effects last?
- What might help me to reduce, control or recover from these side effects?
- How will treatment affect my life and health in general?
- Will I be able to go on holiday?
- Can I continue to work?
- If I stop working, when will I be able to go back to work?
- Where can I be treated?
- Would a different cancer centre offer me other treatment options?
- Is it possible to take part in a clinical trial (a research project) at this centre or any other centre?

Top tips to help you get the information you need

Sometimes it can be hard to take information in when you are first diagnosed. Here are some things you can do to help:

1. Before your appointment write down any questions you have. Write down the answers to these questions in your appointment.

2. Taking a family member or friend to your appointments can help if you find it difficult to take everything in. Talk to them before your appointment about what you would like to know from the oncologist.

3. Your treatment team might use medical words that are difficult to understand. Keep asking if you do not understand what they are telling you. Or ask them to explain it another way.

4. Your CNS can help to make sure that your views are heard in decisions about your treatment. Let them know how you feel and what is affecting your decision making. This may include things that are going on outside the hospital, at home or at work.

> “Before I had surgery I had a lot of help from my family and friends, and they did all the research because mentally I wasn’t able to understand it all. It helped a lot that they knew what I was about to go through and what it meant.”
>
> **Anita**

Second opinions

After talking to your treatment team about your options you may still feel unsure 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 or surgeon about your diagnosis and treatment options. Your CNS, hospital doctor or GP should be able to tell you how to do this.

Notes from Alison

“Doctors used to tell patients what treatment they were going to have without asking their opinion. These days doctors are likely to talk to you about treatment options 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 is important to tell the doctors and nurses how you would like to make decisions. Your feelings might change over time so do not be afraid to let your team know if you would like to be more or less involved.

There are different types of ovarian cancer. To understand your treatment options it is helpful to have information from your treatment team about your diagnosis. This includes 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/whatisovariancancer**”

Our interactive stages tool helps you to understand the different stages of ovarian cancer. Access the tool by scanning this code with your phone camera or by visiting **targetovariancancer.org.uk/stages**

4 Treatment

In this section

- Treatment for ovarian cancer is usually chemotherapy and surgery, depending on the stage, grade and type of the cancer. It may also include other treatments such as maintenance therapies.
- Treatment for ovarian cancer can cause early menopause and fertility issues.
- You may get side effects from chemotherapy, but these can be managed by your treatment team.
- Beyond the standard treatment for ovarian cancer, you may be able to access other drugs.

It is common to treat ovarian cancer with surgery and chemotherapy. Your treatment will depend on the type of ovarian cancer you have. For example, low grade serous ovarian cancer responds less well to chemotherapy than high grade serous so you may be treated using other drugs. It will also depend on 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
- some chemotherapy before surgery and some afterwards. This is called **neoadjuvant chemotherapy**. You may have this if your treatment team do not think it will be possible to remove all of the tumour during surgery before shrinking it with chemotherapy. After three or four cycles of chemotherapy, if your scans show that the cancer has shrunk, then you may be able to have surgery.

For some women surgery is not considered the best option for treating the cancer. This may be if you have a medical condition that means 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 other organs in your body. In these cases your team may advise that you have chemotherapy on its own.

If the cancer is diagnosed at a very early stage it may be treated just by surgery.

Your oncologist or surgeon will talk to you about what treatments are available, based on your own needs. Your diagnosis will have been talked about at an MDT meeting but your treatment team will also listen to what you want to do. It is important that you feel comfortable and confident to tell your medical team how you feel before and during your treatment. It is also important to ask them any questions you have. They will be able to talk you through things 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 the cancer. This is known as **supportive care**. Target Ovarian Cancer has a guide called *My care, my future* which has been written for anyone living with incurable ovarian cancer. Download or order your free copy at **targetovariancancer.org.uk/guides** or by calling **020 7923 5475**

> “When my treatment team said they were going to do chemotherapy before surgery I remember being disappointed that we weren’t going to get rid of those big tumours to begin with. But actually, they were doing the chemotherapy first to give me the best possible chance with the surgery. I had to adjust to that because I think when you’re first diagnosed you just want it out. So you have to trust your treatment team to do that multidisciplinary team meeting and come up with the very best treatment for you in your situation.”
>
> **Sarah**

Surgery

Surgery is done to take out as much of the cancer as possible. If you have any questions, worries or fears about your surgery, talk about them with your surgeon. You can also talk to the nurses about how you are feeling. If you think of questions later you can ask your CNS about anything you did not understand.

Preparing at home

It is important to be as fit and healthy as possible for surgery. Eating a well-balanced diet that includes lots of fruit and vegetables and staying active can help with this. You could try short walks, gardening or doing some exercises in your home.

Some NHS hospitals offer **prehabilitation** programmes. These offer support and advice to help you physically and mentally prepare for cancer treatment.

It is also useful to plan ahead before surgery. Make sure that there is plenty of food in the house so that you do not need to worry about going to the shops after. You may also want to consider making sure that everything you might need in the house is within easy reach of your bedroom. Or 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.

> “My surgeon told me to eat as much protein as possible because that will help with healing. I started to eat chicken and fish and walked the dog as much as I could. And I think that helped physically, but also mentally, just to clear my mind.”
>
> **Linda**

Before your surgery

At the hospital you will be examined and given some tests to check that you are well enough to have surgery. Your surgeon will tell you what will happen during the operation. It is often difficult for the surgeon to know exactly how much surgery you will need until they begin to operate, so they may talk to you about the different possibilities and options.

What happens during surgery?

Surgery normally includes removing:

- the womb (uterus)
- the neck of the womb (cervix)
- both ovaries and fallopian tubes (called a **salpingo-oophorectomy**)
- the omentum (a sheet of fat that hangs within the tummy).

You may have lymph nodes removed as well. These are small structures that are part of your immune system and contain white blood cells. They help your body fight infection and disease.

If the ovarian cancer has spread further, you may need surgery on other areas in your body. This may include removing parts of the:

- bowel (an organ that is part of the digestive system and breaks down food)
- diaphragm (a muscle that helps with breathing)
- liver (an organ that helps to absorb nutrients from food and break down toxic substances)
- peritoneum (a large, thin, flexible sheet of tissue that covers the organs inside your tummy)
- spleen (an organ in the upper left side of your tummy that makes up part of your immune system).

If you have been diagnosed with early-stage ovarian cancer and the cancer is only in one of your ovaries or fallopian tubes, your surgeon may be able to leave your other unaffected ovary and fallopian tube if you are hoping to have children in future. This is called **fertility-sparing surgery**.

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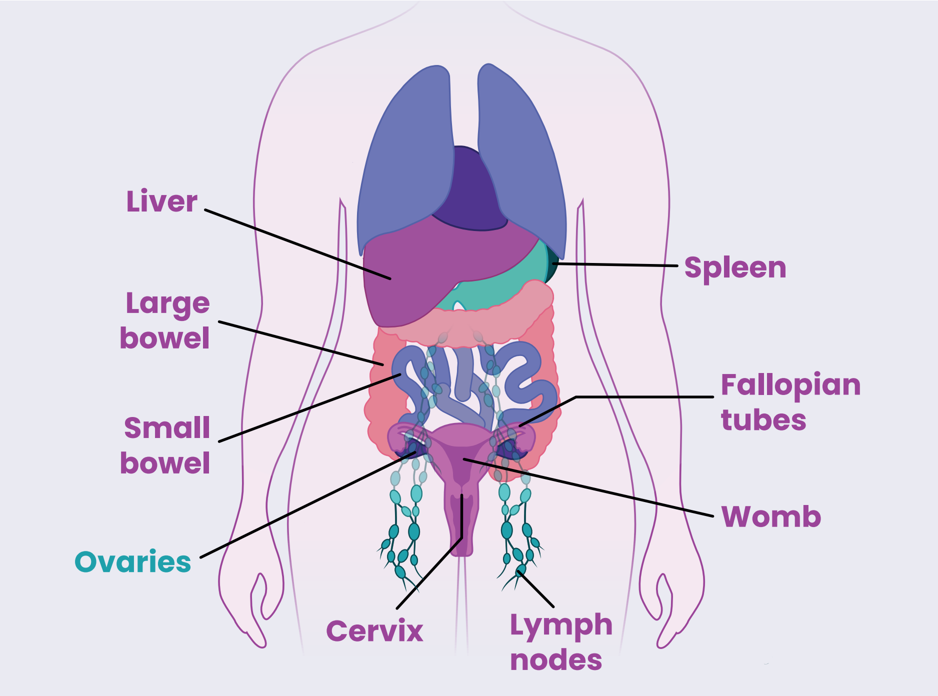

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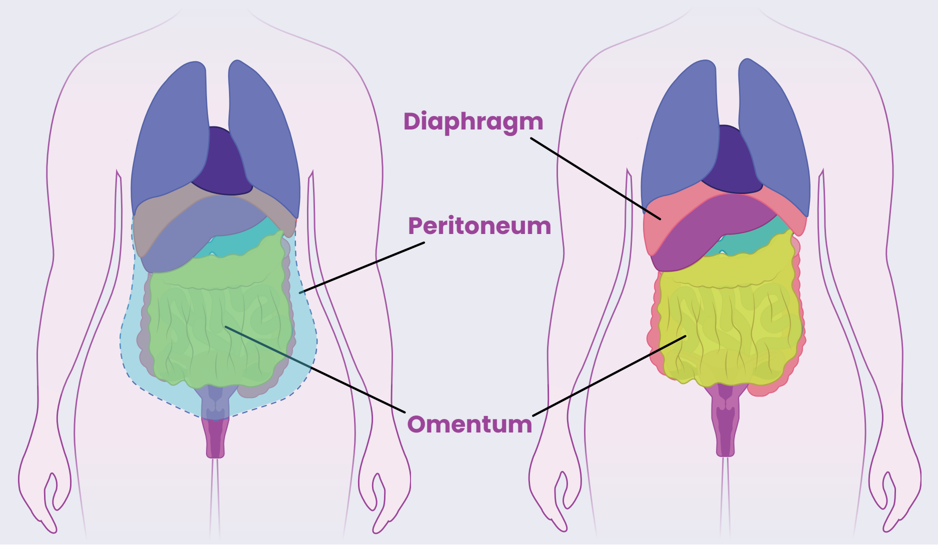

Surgery will also confirm the type (e.g. epithelial), subtype (e.g high grade serous), stage and grade of the cancer. This is not possible to do just through scans.

How it felt for me

“I was due to go into surgery at about 5pm. We were delayed a bit but everyone was lovely and told me what was going on. They were very clear about what was going to happen. I was taken down to the operating theatre, they did an epidural and you feel your legs starting to go numb. And then before you know, you wake up and you’re in recovery.”

Sarah

“I was really scared going down to the operating theatre but my team were excellent and they reassured me that I was going to be OK. I had a surgeon who was very funny and so that helped. It took the anxiety away a bit.”

Anita

Creation of a stoma

The operation may include surgery on the bowel. Most of the time 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 (tummy) and bring the end of the bowel through it. This is called the creation of a **stoma** or **ostomy**.

You can read more about the different types of stomas and how to manage them at **targetovariancancer.org.uk/stoma** You can also download or order our free guide, *Ovarian cancer and stomas*, at **targetovariancancer.org.uk/guides** or by calling **020 7923 5475**

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. Listen to your body as you slowly do more 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 pain medication so that you are as comfortable as possible. After surgery it is common to feel tired 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 about how you feel.

You will be given blood thinning injections for 28 days after surgery. These help to reduce the risk of blood clots. You will also be given 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 more 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
- moving your toes when you are sitting or lying down.

How it felt for me

“I sat down with my wife and went through all the people who needed to be told that I was coming out of surgery - those who would be happy for a text and those who I really wanted her to ring - so that I was completely relaxed and so that everyone who needed to know knew that I was OK.”

Sarah

“Your body is amazing. Take that time to rest and recover and try not to lift anything. That was really hard for me because I have my daughter who wanted cuddles and your natural reaction is to want to pick them up. But I just used to sit down. She used to come to me for cuddles, so that was good.”

Linda

Early menopause

The menopause is when your periods stop because oestrogen and progesterone hormones in your body reduce. This generally happens naturally when a woman is aged 45 to 55. If you have not gone through the menopause and you have had – or are having – surgery to remove both your ovaries, you will experience an early menopause.

In a natural menopause the hormone levels slowly reduce. Removing the ovaries during surgery causes a sudden loss of hormones. You may experience lots of symptoms because of this. These can include:

- hot flushes (suddenly feeling hot or cold in your face, neck and chest)
- vaginal dryness (when you feel dry and itchy in and around the vagina)
- loss of interest in sex
- changes to your mood
- trouble sleeping.

Your oncologist or CNS will be able to talk to you about how these symptoms can be managed.

Hormone replacement therapy (HRT) may be an option for you depending on the type of ovarian cancer you have. HRT is a medication used to help with symptoms of the menopause. Talk to your oncologist to see if this is something you may be able to have.

You may want to try something other than HRT to help you with your menopausal symptoms. These include:

- non-hormone medications from your doctor
- complementary therapies (like acupuncture or aromatherapy)
- cognitive behavioural therapy (CBT)

- 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 to show whether other treatments help but before trying anything you should ask your doctor or pharmacist to make sure that they are safe for you and will not affect any other medications that you are taking.

Making a decision about HRT or other treatments can be difficult. You should talk to 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.

Having children

Surgery may mean that you will not be able to become pregnant naturally. If the cancer has been caught early and only involves one of your ovaries it may be possible for you to keep your womb and 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 how much was removed during surgery and your individual circumstances. Whether you are hoping to start a family or have more children in the future, there may be an option to see a fertility doctor for advice and information before starting any treatment.

Freezing your eggs

If treatment does not need to start straight away, you may want to think about freezing your eggs or using your eggs and your partner's sperm to make and freeze embryos. This is where your eggs can be collected, frozen and used later if you want to become pregnant in the future.

They can also be used for surrogacy. This 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 and you are still well after treatment has finished, you may consider having IVF. This is where an egg and sperm are combined to make an embryo outside of the body. This embryo is then placed in the womb. IVF can be done with your own frozen eggs or embryos (if this was an option for you) or a donor egg. Speak to your CNS about getting a referral to a specialist fertility service.

Find out more about IVF at the Human Fertilisation and Embryology Authority (HFEA) who regulate and license fertility clinics: **hfea.gov.uk**

Surrogacy, fostering and adoption

If you have had a hysterectomy with both your ovaries and womb removed, you may want to think about other options for having a child. This could be through surrogacy, fostering or adoption:

- Surrogacy is when someone carries and gives birth to a baby for another person or couple.
- Fostering is when you look after a child who cannot live with their parents or family for a certain amount of time.
- Adoption is when you permanently become a legal parent for a child.

There is more information about these options on our website: **targetovariancancer.org.uk/youngerwomen**

For more information on surrogacy visit Surrogacy UK: **surrogacyuk.org**

For more information on fostering and adoption visit the CoramBAAF Adoption and Fostering Academy: **corambaaf.org.uk**

Notes from Alison

“Many young women find the thought 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 is important to share those feelings rather than bottle them up.

Research has shown that younger women may find that any feelings of anxiety and depression last longer than older women. Many women need a great deal of support and may benefit from professional counselling (see our **Help for you** section in this guide). 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.”

Chemotherapy

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

Some people feel more anxious about chemotherapy than surgery. This is because a lot of blood tests are needed and drips are put into veins in the arm. These drips are called **intravenous infusions**. 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. This should make you more comfortable.

What chemotherapy will you have?

Your oncologist will decide with you which chemotherapy drugs you will have. It is likely you will get a combination of drugs, one of which is a **platinum-based** chemotherapy. This mix of drugs is usually a drug called **carboplatin** (but sometimes cisplatin) and a drug called **paclitaxel** (most commonly called Taxol®). Sometimes carboplatin will be given on its own. This may be if you are not well enough to cope with the side effects of both drugs, or if you were diagnosed at an early stage.

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 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.

Sometimes your oncologist may need to delay your next chemotherapy session for a week or two. This can happen if your blood counts have not recovered (increased enough) or if you have really bad side effects from the last cycle of chemotherapy.

What happens when you have chemotherapy treatment?

It is likely you will have chemotherapy at your local hospital or cancer centre. At the hospital you will have some blood samples 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 able to settle yourself in a comfy chair. The nurse will place a **cannula** into one of the veins in your hand or arm and attach a drip so the drugs can enter your bloodstream. A cannula is a small tube like a needle.

The drugs are given over several hours. It might feel a bit uncomfortable as the cannula goes in but should not be uncomfortable after this. If it does hurt or feel uncomfortable during treatment let the chemotherapy nurse know.

If you are having carboplatin and paclitaxel then the nurse will give you the paclitaxel first and then carboplatin afterwards.

If it is difficult for you to have a cannula put into a vein in your hand or arm, you may have a central line put in that stays in place throughout your treatment. A central line is a tube that is placed in a large blood vessel in your chest. It means you will not need a cannula put in your hand or arm for each chemotherapy treatment. There are three types of central line; a PICC line (inserted through a vein in the arm), a portacath and a Hickman line (inserted through the chest).

Macmillan has more information about central lines. Search the terms **central lines**, **PICC lines** and **portacaths** at **macmillan.org.uk**

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, a good book, or watching something on your phone or tablet can also help to pass the time.

How it felt for me

"I actually used to find chemotherapy days quite relaxing. I got a nice comfortable reclining chair. I would have a sleep and watch things on my tablet. It's nowhere near as bad as I imagined it to be."
Linda

"It was a long day, but we got through it on the ward. I met a whole bunch of other people who were in a similar position. I actually found that my chemo days over time became a place where I felt really safe and really comfortable and where, actually, having cancer was the norm."
Sarah

Will you have any side effects?

It is common to get some side effects from chemotherapy. These can usually be easily treated. It is rare for side effects to be severe. Usually, side effects do not start straight away. When you see the list of all the possible side effects it can be worrying. Remember it is unlikely that you will experience all of them, they should be mild and your treatment team can help.

Your oncologist and the chemotherapy nurses will check you very closely during 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 effects of chemotherapy is that it reduces the number of white blood cells in your blood. 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 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, ask them.

Good to know

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 give you a list of things to look out for (for example a rash or raised temperature).

As treatment continues you may get used to the side effects more and you can plan your normal activities around them. For example, some people can feel very tired for a certain number of days after chemotherapy and so do not plan any trips or activities on those days. But if you are badly affected get in touch with your hospital as they will be able to help you.

It can be useful to keep a diary of your side effects so that you know what to expect and when in between chemotherapy sessions. This can help you to:

- speak to your oncologist about which side effects you have had and how strong they have been so that they can best help you manage them

- prepare anything you need at home to help you manage them
- plan any activities around how you are feeling.

You can use the **chemotherapy side effects tracker** at the end of this guide to keep track of any side effects.

Common side effects of chemotherapy can include:

Tiredness and fatigue

It is very common to feel really 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 gentle activities instead. This may be reading or watching television.

Research shows that one of the best things for fatigue is to keep active. It is important to get a good balance between resting and staying active. Even a gentle walk around the block, when you feel able, can help to give you an energy boost.

Hair loss

It is rare for platinum chemotherapy to cause hair loss. But 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 **scalp cooling**. This is a cold hat that you wear while having chemotherapy to help reduce hair loss. Having this against your scalp reduces the blood flow to the skin on your scalp and hair. This 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. However, they can work really well, and you can ask for support to make it work for you.

You may also want 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. You may prefer to wear head scarves or hats. Your CNS will be able to help you find information about this as well.

> “The biggest thing for me was knowing that I was going to lose my hair. My hair was really long and it was always on top of my head, but it was there. I got my hairdresser round and she cut it into a bob. I think that was probably the most upset I was because even though I had cut my hair before, this time didn’t feel like it was my choice. But I wanted to take control of the situation and that’s what I did. I think that really helped.”
>
> **Linda**

Feeling or being sick (vomiting)

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

Changes in taste

You may find that food and drink tastes different 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 the case as there are simple tips that can help.

You might also find it helpful to read Target Ovarian Cancer’s information sheet, *Ovarian cancer, diet and nutrition*, available from **targetovariancancer.org.uk/guides**

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 called **peripheral**

neuropathy. This can be frustrating but there are some medications and complementary therapies that may help with this. Complementary therapies are treatments that can be used alongside medical treatments such as surgery and chemotherapy.

You can read Target Ovarian Cancer's information sheet, *Ovarian cancer and complementary therapies*, available from **targetovariancancer.org.uk/guides**

Concentration

You may experience something called **chemo brain** or **chemo fog**. This is when you can't think as clearly after chemotherapy as you were able to before treatment. This is usually temporary but may last a while after chemotherapy.

Find out more about this by searching **chemo brain** at **cancerresearchuk.org**

Effects on your blood

White blood cells are found in your blood and fight infection in your body. Chemotherapy can reduce the number of white blood cells in your blood. This can increase the risk of infection. Your white blood cells are lowest one to two weeks after each chemotherapy session.

Contact your treatment team straight away if you suddenly feel unwell or you have a fever (a body temperature above 37.5°C/99.5°F).

Red blood cells are found in your blood and carry oxygen around the body. Chemotherapy can reduce the number of red blood cells in your blood. A low number of red blood cells is called **anaemia**. Symptoms include pale skin, feeling tired or having no energy, feel breathless and feeling dizzy. Speak to your treatment team if you have these symptoms.

Platelets help your blood to clot and stop bleeding when you have an injury. Chemotherapy can reduce the number of platelets in your blood. This can increase bleeding or bruising.

Speak to your treatment team if you have bleeding gums, nosebleeds, blood when you go to the toilet or little red or purple spots on your skin that look like a rash.

Other side effects

Other side effects may include:

- **changes to your skin** – it may slightly change colour or become more dry. It may also be more sensitive to the sun
- **changes to your nails** – they may become weaker or fall out but will grow out after treatment has finished
- **changes to your hearing** – you may have some hearing loss or get ringing in your ears. This is called **tinnitus**
- **diarrhoea or constipation** – your poo may become more watery, you may poo less often or it may become harder to poo
- **sore mouth** – your mouth or throat may feel sore and you may get mouth ulcers. These are small sores on your gums, tongue or the inside of your cheek.

Read more about other chemotherapy side effects at **nhs.uk/conditions/chemotherapy** or by searching **chemotherapy side effects** at **macmillan.org.uk**

> “I had built up in my mind that I would feel nauseous, I would look dreadful, that I would feel awful. Actually, I was sent home with an armoury of tablets for any possible side effects and I felt very much in control. Yes, I had days when I felt tired and I had days where I felt less well, but overall I felt way better than I expected.”
>
> **Sarah**

Top tips from our community

Our community share what helped them manage the side effects of chemotherapy.

1. A neck fan! It sits around your neck and cools any hot flushes from the chemo or menopause but keeps your hands free so you can get on with things. **Ellie**

2. Ginger biscuits dunked in black tea helped when I felt sick. I couldn't eat them dry as I kept getting mouth ulcers so dunking them in the tea made them soft. **Debbie**

3. I started drinking prune juice on the day of my chemotherapy. Then I drank it every day for about five days after. That helped me with the constipation. Not sure I could stomach it now, but at the time it really helped me! **Linda**

4. For me it was going outside, getting fresh air and doing some walking. There are days where you don't feel like it or you're very sleepy, but when you can, doing what you can in order to just keep everything moving, that was really positive. **Sarah**

5. Be prepared and plan ahead. The first week I'd have everything ready to cope with being poorly. The second week I'd start to feel slightly normal where I could go into the living room and enjoy the company of my family. The third week I could make plans to meet friends, family for meals of just a little chat and a coffee. **Anita**

6. Don't scour the internet for information about ovarian cancer and treatment. There's so much information out there, which may be out of date or incorrect, and that can be scary. Stick to trusted sites like Target Ovarian Cancer, NHS UK, Cancer Research UK, and Macmillan. **Dot**

Radiotherapy

Radiotherapy involves using radiation to treat cancer. This produces beams of high energy to kill cancer cells. 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 search **radiotherapy** at **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 drugs to help treat the cancer. The way drugs are approved for use in the NHS is different across the UK which means that there can be some differences in which drugs are available depending on where you live.

PARP inhibitors

PARP inhibitors are a type of **targeted therapy**. You may hear them called **maintenance treatments**. They stop the cancer cells fixing themselves, so the cells die. They aim to stop or delay the cancer coming back.

At the time of this guide's publication (February 2024), there are three PARP inhibitors available on the NHS in the UK: niraparib, olaparib, and rucaparib. These are available as a maintenance treatment to women with stage 3 or 4 high-grade epithelial ovarian cancer, fallopian tube cancer or primary peritoneal cancer who have responded to platinum-based chemotherapy.

Which of these you can access and at what stage of your treatment depends on:

- where you are being treated in the UK
- whether you have a BRCA variant. This is an alteration in the BRCA1 or BRCA2 gene. This alteration can be in the cells of your body and passed down through families (a **germline variant**) or it can develop in the cells in the tumour (a **somatic variant**), which isn't passed down to other family members
- whether your tumour tests positive for homologous recombination deficiency (HRD)
- your personal situation, for example your overall health.

PARP inhibitors are given as a tablet and can be taken at home.

If you have responded well to platinum-based chemotherapy you may benefit from a PARP inhibitor. Platinum-based chemotherapy usually includes carboplatin or cisplatin and may be given with paclitaxel as well. If you have a BRCA variant or your tumour tests positive for HRD, the benefit of taking a PARP inhibitor may be greater.

Why does having a BRCA variant or being HRD positive affect how well PARP inhibitors work?

Like our healthy cells, the DNA within tumour cells is also always repairing itself. One way of repairing the DNA is through a process called **homologous recombination**. If you have a BRCA1 or BRCA2 gene variant, your tumour can't use this repair process because of **homologous recombination deficiency** (HRD). Some people without the BRCA1 or BRCA2 gene variant will also have a tumour with HRD.

HRD means that the cancer cells have a harder time repairing themselves. The PARP inhibitors block a second DNA repair pathway which means that the cancer cells are even less likely to be able to repair themselves.

As part of your treatment plan you should be offered testing to find out if you have a BRCA variant and/or if your tumour is HRD positive.

Find out more about gene variants, HRD and testing for these in the next two sections of this guide.

If you have been diagnosed with stage 3 or 4 high-grade epithelial ovarian cancer, you may be able to access PARP inhibitors after you've finished chemotherapy. Find out which PARP inhibitor you can access by scanning this code with your phone or by visiting **targetovariancancer.org.uk/drugs**

Bevacizumab

Bevacizumab is another type of targeted therapy. You might also hear it called Avastin®. At the time of this guide's publication (February 2024) it is currently available to some women with advanced ovarian cancer in the UK.

Bevacizumab (Avastin®) targets and attacks a protein in the body that helps cancer cells develop a new blood supply. It stops this blood supply which is needed for the cancer cells to grow.

It is given through a drip into the vein at the same time as chemotherapy and also continues after chemotherapy has finished. When chemotherapy has finished your oncologist will give you up to a total of 18 doses of bevacizumab with one dose (cycle) every three weeks. Ask your oncologist whether bevacizumab may be an option for you.

If your tumour tests positive for HRD, you may be advised to have a PARP inhibitor alone or you may be able to access bevacizumab with olaparib (a PARP inhibitor) after chemotherapy has finished. If you have it with olaparib, your oncologist will talk to you about how long treatment will continue for and why. If your tumour tests negative for HRD you may be advised to have either a PARP inhibitor or bevacizumab alone.

Letrozole and anastrozole

Letrozole or anastrozole are types of **hormone therapies** that may be used instead of chemotherapy if you have certain types of ovarian cancer, such as low-grade serous ovarian cancer. They may also be used after chemotherapy, as a maintenance treatment.

Good to know

Access to different drugs through the NHS may change. The information above is up to date as of February 2024. Go to **targetovariancancer.org.uk/drugs** or call **020 7923 5475** and speak to one of our specialist nurses for the most up to date information about ovarian cancer drugs.

Clinical trials

Clinical trials are research studies that look at potential new drugs, new ways of giving treatment or different types of treatments.

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

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

You might not always know which group you are in, but you will be closely monitored no matter which treatment you have. This may include more regular tests and checkups during or after treatment.

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

Not all cancer centres take part 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 am I suitable for at my treatment centre?
- If you are 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 work?
- What is the control group, and how does it compare to treatment I would get if I did not join?
- 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 that involve completing surveys or being interviewed. These may include studies about your wellbeing.

Remember, it is your decision whether to join a clinical trial or a research study.

You can search all live UK trials for ovarian cancer on our website: **targetovariancancer.org.uk/clinicaltrials**

Notes from Alison

“For many of us a variety of treatments lie ahead and sometimes in different orders. 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 ability to become pregnant.

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 many different chemotherapy drugs and we do not all react to them in the same way. The doctors and nurses will tell you what side effects to expect, but each person will react slightly differently so be sure to let them know how you feel throughout your treatment.

If you are told you are going to lose your hair you may feel very upset. Having no hair constantly reminds us of our cancer and makes us feel different. You may want to prepare for losing your hair by getting a short haircut and perhaps buying scarves, hats or a wig. This can be an emotional experience and you may feel particularly vulnerable at this time. You may wake up one morning to find much of your hair on the pillow or in the shower tray. At this point many people shave their hair off. My husband shaved my head, burst out laughing and said, “You look like Alf Garnett but I still fancy you!” Laughter can sometimes come at the most unexpected times.

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 is understandable.

It may also be tempting to downplay side effects of treatment 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 are unusually tired, or have other side effects, do speak to the doctors and nurses about it as there may well be something they can do to help."

5 Family history, genetic testing and hereditary ovarian cancer

In this section

- Up to 2 in 10 cases of ovarian cancer happen because of a genetic variant. This is most commonly a variation in the BRCA1 or BRCA2 gene, which can be passed down through families and can increase the risk of some cancers.
- Most women with ovarian cancer can access testing for genetic variants.
- Whether or not you have a genetic variant can impact which treatments you can access after surgery and chemotherapy.

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.

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 2 in 10 cases of ovarian cancer happen because of a genetic variant. This is an alteration (or change) in one or more of your genes that increases the risk of ovarian cancer.

This variant 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 variation in a gene than others. Variants are more common in high grade serous ovarian cancer. They are uncommon in mucinous or germ cell ovarian cancer.

Hereditary ovarian cancer is ovarian cancer that has developed because of a gene variant that has been passed on through one generation of a family to the next. It is most commonly caused by a variation in either the BRCA1 or BRCA2 genes. These genes help to repair breaks in DNA that happen when cells divide. If a BRCA gene is not working because it has a variation then this increases the chance of cancer developing. That is because it cannot repair the damaged cells which can build up to make a tumour. Some variants in other genes can also increase the risk of ovarian cancer and scientists are learning more about these other genes.

Variations in genes such as BRCA1 or BRCA2 can happen in both men and women in any family so a gene variant 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 about five times more likely to have a BRCA1 or BRCA2 gene variant. This means they are more at risk of developing hereditary ovarian cancer than the general population in the UK.

Should I be tested?

In the UK, most women diagnosed with ovarian cancer should be offered genetic testing for variations in the BRCA1 and BRCA2 genes. This should be offered even if you have no family history of ovarian cancer.

There are two ways that you may be able to access genetic testing in your area. You may be offered genetic testing that is done in the same place as your treatment. Or you may be sent to a specialist genetic service.

It is important that you talk about genetic testing with your treatment team or a **genetic counsellor**. This is a professional who is trained to talk to you about the risks and benefits of genetic testing.

You may not be able to have genetic testing due to the type of ovarian cancer you have. However, it is important to talk about genetic testing with your oncologist or a genetic counsellor to find out if it is right for you.

The test may find variations in either the BRCA1 or BRCA2 genes. Or it may be inconclusive, even when several family members are affected. An inconclusive result means the test found a gene variant but it is not known what effect it may have (i.e. if it increases the risk of cancer in future). You may hear this called a **variant of unknown significance**. If the test shows that there is a gene variant or is inconclusive you will be supported by a genetic counsellor to understand the results and what this could mean for you and your family.

What does it mean if I do have a BRCA1 or BRCA2 gene variant?

There are a number of things to think about if you find out you have a BRCA1 or BRCA2 gene variant. Firstly, there is the impact on you. It may affect which treatments are recommended for you (see the **Treatment** section of this guide).

The result will also have an impact on your risk of developing other cancers. If you have a BRCA1 or BRCA2 gene variant you also have an increased risk of developing breast cancer. 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. This includes having regular breast screening (checks), medications or considering surgery to reduce the risk. You will 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 variant.

What does it mean for my family members if I have a BRCA gene variant?

If you have a BRCA1 or BRCA2 gene variant, other members of your family may also have it. This includes your mother or father, siblings, aunts, uncles and cousins, depending on the side of the family the variant is passed down.

Children of someone with a BRCA gene variant have a 1 in 2 chance of inheriting it. If they have inherited it they are more at risk of developing some cancers such as breast, ovarian, prostate or pancreatic cancer. They also have a 1 in 2 chance of having a normal BRCA gene with no variant. In that case they have a similar chance of developing ovarian or breast cancer as the general population.

If you have a BRCA variant or a variant in other genes linked to ovarian cancer then close (first degree) relatives can choose to have a genetic test. This is to find out if they have inherited the same gene variant. It is called **predictive testing**. Close relatives include your adult siblings, children and your parents.

If they have inherited the gene variant, it does not mean that they have cancer or are going to develop it but their risk of developing certain cancers is higher. If your family members do have a gene variant, they will need support to make decisions about what to do.

Some other gene variants can increase the risk of ovarian cancer and some other cancers. These include RAD51C, RAD51D, BRIP1, PALB2, MLH1, MSH2 and MSH6 genes. You may be tested for these. For more detailed information:

- Visit **targetovariancancer.org.uk/genetics**
- Download or order our guide *Genetic testing and hereditary ovarian cancer* at **targetovariancancer.org.uk/guides** or by calling **020 7923 5475**

6 Homologous recombination deficiency (HRD)

What is homologous recombination deficiency and how do I get tested for it?

If you have recently been diagnosed with stage 3 or 4 high grade ovarian, fallopian tube or primary peritoneal cancer you should be offered testing for homologous recombination deficiency (HRD).

We all have DNA in our cells. DNA tells the cells how to work and behave. Our DNA is always being damaged and repairing itself. This process is called **homologous recombination**. When our body can't repair our DNA, this is called **homologous recombination deficiency**. It means that if your tumour tests positive for HRD, the cancer cells have a harder time repairing themselves.

A sample of your tumour is needed to test for HRD. This can be taken during surgery or through a biopsy. A biopsy involves taking a small sample of body (tumour) tissue so that it can be examined under a microscope.

This type of testing is called **somatic testing**. This means it only picks up gene variants in the tumour. It doesn't show if there are gene variants in the germline cells (the ones that are passed down through families). Some people may only have a variant in the tumour, while others may have it in both the tumour and germline cells. Therefore, a test for a germline BRCA variant should be done separately.

It's useful for your treatment team to understand if your tumour tests positive for HRD, as this will help them decide which treatments may work best for you.

7 After treatment

In this section

- Finding a new routine after treatment can take time. Asking loved ones for help with daily tasks can be a big help.
- Treatment may change your sex life and your body image. There is information and support to help with this.
- There is support available to help you with your finances and work.

Although your treatment team will tell you what happens next, life after treatment can be challenging. You may find that normal life no longer feels 'normal', and it may take time for you to process everything that has happened.

Target Ovarian Cancer's specialist nurses are here to listen. Call **020 7923 5475** or email **support@targetovariancancer.org.uk**

Finding a new routine

Trying to get back into a routine might be difficult. It can take time to get back to your usual energy levels so it is important to find a pace you can cope with. Planning out your day can help you to create a new routine. You may want to use a diary or day planner to help you, or you may just want to take each day as it comes.

During and after treatment is the time for you to accept help from others. 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 family and friends are close by or your local community is good at supporting each other? You might have to ask for help. This can feel hard, but many people will be happy to be able to do something for you.

Not everyone has lots of people around them who are able to help. If you don't, there might be volunteers or organisations you can contact through your hospital or council who may be able to offer some support.

It is normal to have days when you feel upset. Sometimes you may need emotional support from friends, family and professionals, and perhaps from others who have had a similar experience. You should be able to contact your CNS if you feel like you need their support during this time. You can also have a look at **Help for you** section in this guide.

How it felt for me

"I have siblings that live in America and they all took it in turns to spend time with me and be here for me. Mentally, their positive support kept me going and gave me strength. My two sons were taking it in turns to be with me as well and my husband changed his work ethic of travelling and going to clients to staying home with me and working from home, which helped a lot."

Anita

"I've come out of treatment and I've put together a team of people around me to help me to get back to full strength. I have a physical trainer who is helping me to understand how much I could and should be pushing myself to get back to my full strength. I have a coach who is helping me to understand how and when to go back to work. I also have counsellor who I'm working with around the enormity of a diagnosis of ovarian cancer."

Sarah

Identity and body image

Dealing with a changed body image can be difficult after an ovarian cancer diagnosis. You may have scars from surgery or a stoma. You may be going through menopause as a result of your surgery, have gained or lost weight or have lost your hair. Your CNS will continue to support you to help you get used to this new way of life. Meeting others who have been through these things can be helpful too. Take a look at the **Help for you** section of this guide for more support.

Some hospitals have volunteers who can give advice about makeup and head scarves. Look Good Feel Better is a charity that offers body confidence workshops for anyone living with cancer. Visit **lookgoodfeelbetter.co.uk** or ask your CNS about the support that is available in your area.

Relationships with those close to you

Cancer can change how you feel about yourself. It can also have an impact on your relationships. You may find that it brings you closer to the people around you, or your relationships could be more strained. Your friends and family may also find life after your diagnosis hard to deal with. Friends may want to support you but may be very busy with their own families and work.

It can be helpful for your family and friends to get support to cope with your diagnosis. You may feel better to know they are supported. Target Ovarian Cancer can give support for family, friends and carers, so ask them to get in touch with our support line. You can also talk to your CNS about what other support may be in your area.

Resuming your social life

For some people, making arrangements to meet up 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.

> "I said to my friends, you're welcome to text or ring. If I don't feel like it, I won't answer the call, don't take it personally. And I think that helped them to feel that they could approach me."
>
> **Sarah**

If you want to talk to others about what you have been through then support centres can help. They are a place to meet other people who understand what you are going through. Ask your CNS about local support 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**

Target Ovarian Cancer also has two private Facebook groups where you can talk to others online:

- Our Ovarian Cancer Community group is a kind, supportive group for everyone affected by ovarian cancer, including friends and family.
- Our In Touch group is a safe and supportive space only for those with a diagnosis. You can talk honestly and openly about how you are feeling – and find comfort and understanding from others living with and beyond ovarian cancer.

Find these through **targetovariancancer.org.uk/community** or by searching directly on Facebook.

Notes from Alison

“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 are 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 have just been diagnosed. 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.

It may need a bit more time and effort than it did before your treatment. But sex can help you feel connected to your partner and give a boost of pleasure. So if it is something you feel you want, it is worth trying.

On your own

We can make ourselves feel good by touching ourselves. This is called **masturbation**. There is nothing wrong with masturbation at any time of life and when you are living with cancer, this may help you cope. After you have had doctors examining you, touching yourself may be comforting. It can help you connect with your body again. Getting to know your body again is important as it may feel different if you have had surgery.

If there is a problem

Changes to your body can make having sex again more difficult. This is very common. Your CNS will be happy to speak to you about your concerns. You may be able to access more support through the NHS. Your CNS will be able to tell you what's available in your area. There is also support available through private therapists:

- You can find sexual counsellors through the College of Sexual and Relationship Therapists: **cosrt.org.uk**
- You can find sexual counsellors through the Institute of Psychosexual Medicine: **ipm.org.uk**

If you have vaginal dryness or sex hurts after treatment, a vaginal moisturiser or lubricant can help. You should be able to find a range of lubricants in larger chemists. If these don't help then your treatment team may be able to give you vaginal oestrogen. This is a type of hormone replacement therapy. Your CNS will be able to help you with this.

Vaginal dryness is when you have less vaginal fluid. Your vagina may feel more sore or itchy and sex may be uncomfortable.

To read more about sex and intimacy after a diagnosis of ovarian cancer visit **targetovariancancer.org.uk/sexandintimacy**

Getting back to work

Working through cancer treatment or returning to work after treatment is a very personal decision.

You are going to need to take some time off work for treatment. You do not have to tell your work 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. This can make it easier for them to support you. You may want to ask your CNS or oncologist:

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

You may find it difficult to go back to work. Sometimes the mental impact of a diagnosis is not felt fully until you have finished treatment, or a few months later. It is also difficult to know how treatment might affect your ability to work before you start. If you plan to return to work, it is important that you do this at a time that suits you and that you get the support you need from your employer and/or outside of work to do so. It can also

be useful to add some extra time to recover into your work plan.

It is important that your work is flexible as you continue to recover. That is because your needs will change from starting treatment to going back to work and managing any side effects. Your experience will also affect how you feel. 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 work so that they can change things to help.

You may want to talk to someone who is not your 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 your team or manager.

Working with Cancer has more information and support: **workingwithcancer.co.uk**

Your rights

Everyone living with or beyond cancer is protected against unfair treatment at work now and in the future. This is under the Equality Act 2010 in England, Scotland and Wales or the Disability Discrimination Act 1995 in Northern Ireland.

Whether you have symptoms or side effects or not, the law still applies. It also applies when you have finished treatment and have been discharged from hospital. Your work has to make changes to help you work through your treatment or return to work after treatment. This is as long as they know (or should reasonably know) that you have or had cancer. It might include:

- changing some of your duties
- agreeing different working hours
- allowing time off for appointments.

These changes are called **reasonable adjustments**.

This law also protects you from unfair treatment by future employers.

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

If you are self-employed or you work for a small company, it may be up to you to handle the communications and set up a return that works for you.

Citizens Advice can help you understand any rights or support available to you: **citizensadvice.org.uk**

What if there is a problem?

If you feel that your work is 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 workplace 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 more information visit **targetovariancancer.org.uk/workandeducation**

Notes from Alison

"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."

Financial help

There are different types of benefits available to you. These depend on the impact your cancer has had and your current finances. These include benefits if you can't work, help with housing costs or extra costs because of the cancer.

How do I find out more?

- Target Ovarian Cancer has a useful information sheet called *Ovarian cancer and your finances* that you can download at **targetovariancancer.org.uk/guides** or you can read our online information at **targetovariancancer.org.uk/finances**
- 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.

8 Looking after yourself

In this section

- Complementary therapies can be used when going through treatment to help you feel better.
- Physical activity can help with recovery and side effects of treatment. It is important to ease yourself back in gently.
- A balanced diet is important when having treatment for ovarian cancer and there are things you can do to help with any eating problems from treatment.

Complementary therapies

Complementary therapies are treatments carried out by trained therapists. You can use them with the usual (conventional) ovarian cancer treatments (such as surgery and chemotherapy).

There are lots of different complementary therapies. You might want to use some of these with your hospital treatments, to help you relax or to ease side effects.

Complementary therapies should not replace your medical treatment, but they may give you an extra boost. It is important that you use a registered therapist and always let your treatment team know about any therapies you are thinking about trying so they can check they are safe and appropriate for you.

Most hospitals have links with a local cancer support centre. They might offer a range of therapies for free, so it is good to find out about these and check there first.

How do I find out more?

- Read more about ovarian cancer and complementary therapies at **targetovariancancer.org.uk/complementarytherapies**

- Cancer Research UK has more information about a range of therapies. Search **complementary therapies** at **cancerresearchuk.org**

Physical activity

Being more active can help you with side effects such as tiredness. It can improve your mental health too. You may be worried about becoming active, but doing exercise has fewer risks than being inactive.

Start by doing some gentle exercise little and often and slowly build up the amount that you do. Small things you can do include:

- walking up and down your stairs more often
- walking to your local shops instead of taking the car
- raising your legs and moving your arms when watching TV.

Many cancer centres have gentle exercise classes such as yoga or tai chi. They will be run by people who are trained to work with people who have had cancer treatment. Your local gym or leisure centre may also offer classes or a reduced membership rate.

Target Ovarian Cancer also runs weekly online yoga and relaxation sessions for anyone with a diagnosis: **targetovariancancer.org.uk/digital-events**

Ask for help from your treatment team if you are not sure how much and what exercise you should do.

Macmillan has more information on physical activity. Search **physical activity** at **macmillan.org.uk**

Diet and nutrition

Eating a healthy balanced diet will help your body to repair itself and give you the energy you need through your recovery. There is no evidence to suggest that what you eat will impact on how your cancer behaves.

Food can taste different and you may find you can not eat as much as you used to. Try eating little and often rather than full plates at mealtimes. Drinks such as fruit smoothies and milkshakes can help you build up and maintain your weight if you are finding it hard to eat. Adding a spoonful of nut butter (any type), ice cream and your favourite fruit can help you get some extra calories.

If you have to eat a different diet because of treatment or because you have a stoma, you can ask your CNS or a dietitian for support with this. Dietitians work with people who need a different diet because of a health condition.

If chemotherapy makes you feel sick, be sick or feel less hungry, it can be difficult to eat three large meals each day. You may want to try:

- eating small meals and snacks often
- eating cold foods so that you avoid cooking smells, which can sometimes make people feel sick
- eating slowly and sitting in an upright position
- eating at certain times of day and not late at night.

Ask your CNS if you have any concerns or if you want to know more about whether certain foods or supplements may be right for you. You may also be able to access a dietitian through your local NHS. If you would like to find a dietitian privately then the British Dietetic Association has a database where you can search for dietitians who work with people with cancer (oncology): **bda.uk.com**

How do I find out more?

- Read more about diet and nutrition at **targetovariancancer.org.uk/diet**
- The World Cancer Research Fund is the leading authority on the links between diet and cancer. You can download their booklet *Eat well during cancer* for recipe ideas and tips to manage side effects of treatment from **wcrf-uk.org**

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 but we do not know whose cancer will come back and whose will not. The chance of recurrence (the cancer coming back) will depend on a mix of things. This includes the stage of the cancer when you were diagnosed (how much cancer there is and how far it has spread). It also includes your response to treatment.

It is normal to feel worried about the cancer coming back. You might worry about every ache and pain being a sign that it is back. Many people go through this. Over time you may be able to put this worry to the back of your mind rather than thinking about it all the time, and live life without actively worrying about the cancer returning.

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

> “My worry is I don’t want my fear to stop me from living my life now. I want to enjoy that time with my daughter without that worry in the background. I think once I have finished my last treatment I’ll probably look into some counselling. It’s important to talk about your fears and your anxiety and get given those coping mechanisms.”
>
> **Linda**

Symptoms

If the 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
- tummy or pelvic pain (below your tummy)
- needing to wee more urgently or more often than usual.

However, other symptoms may develop. It is important to tell your CNS or GP about anything persistent and unusual for you so that you can get checked out quickly. This is even if it is a slight change. Do not be afraid to talk to them any concerns that you have, as it is always better to get them checked.

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

Notes from Alison

“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’. 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. Some people want to try counselling. It can help to talk to a non-judgemental 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.

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 mood starts to have a big impact on your life, perhaps affecting your sleep and weight, please talk to your CNS or GP.”

9 Help for you

It may take time to adjust after cancer treatment. It is OK if you have days when you feel upset. But if these happen more 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.

The following services can help if you're experiencing difficult times.

Target Ovarian Cancer

Support line

Need someone to talk to about ovarian cancer?

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

Call us today: **020 7923 5475**

Our support line is open Monday to Friday 9am-5pm, excluding bank holidays.

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

> "I've used the support line a few times when I've been concerned about something or when I feel low and I don't feel it's something I can talk about with my nearest and dearest, because they're going through their own anxiety. I found that really helpful."
> **Sarah**

Facebook groups

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

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

Join us today: **targetovariancancer.org.uk/community**

Support events

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

Register today and we will send you details on how to join us online: **targetovariancancer.org.uk/supportevents**

Website

Our website **targetovariancancer.org.uk** has more information about ovarian cancer as well as stories from women who have had a diagnosis of ovarian cancer. You can also download or order more of our guides for free.

You can 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.

Support groups

Simply being around people who know what you're going through can help. Often groups have members who have had different types of cancers but there may be a group just for those with gynaecological cancers. Your CNS may run a support group locally or you can visit **targetovariancancer.org.uk/supportgroups** to find a group near you.

Support centres

Many hospitals will have a cancer support centre. This may be either their own or a charity-run centre, such as a Macmillan or Maggie's centre. They are usually at the hospital or close to the hospital. These centres can be a great source of comfort and may offer other support services. Many centres around the country run a range of activities and workshops from reflexology, creative writing and walking to coping with fatigue and managing hair loss. You don't have to talk about your experience. It is 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 tell you about the support centres in your area.

Visit **macmillan.org.uk/in-your-area** to find your local Macmillan support centre.

Visit **maggies.org/our-centres** to find your local Maggie's support centre.

Online and telephone support

- The Macmillan 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.
- Maggie's provide cancer support where you can access specialist advisors and meet others through support groups. Contact your local Maggie's centre for more information: **maggies.org**
- The Samaritans are also available 24 hours per day, 365 days a 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**

Psychological therapies

Psychological therapies support your mental health during hard times. They allow you to talk about your thoughts and feelings. They also help you to manage them, especially if you have low mood or feel more nervous or anxious than usual.

How do I find out more?

- Counselling is where you speak to someone about your worries and fears. A counsellor's job is to listen and allow you to talk. Many hospitals can refer to counselling services. Cancer support centres may also offer free counselling. Ask your CNS, GP or local support centre for more information. If you would like private counselling you can find a registered counsellor through the British Association of Counselling and Psychotherapy (BACP). You can call directly on **01455 883 300** or visit their website: **bacp.co.uk**

- Psychological support looks 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. You can either visit their website: **bps.org.uk** or call **0116 254 9568**

- Cognitive behavioural therapy (CBT) looks less at the causes of your feelings and more at what to do about it. It looks at how the way you think can make you feel and act. It then helps to improve your reactions to difficult situations by finding new ways to think about and deal with problems. The more specific a problem the more likely CBT will be able to help. 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 access one through your GP.

- Psychotherapy is like counselling but this time the therapist will try to find out where emotions or problems might be coming from. A therapist will help you to think about what is happening in your life now. They will also look at what has happened to you in the past that might affect how you are feeling and acting. Psychotherapy can help you to understand why you behave in certain ways and how you might change this behaviour. The UK Council for Psychotherapy has a **Find a therapist** service available on their website: **psychotherapy.org.uk**
- Mindfulness helps you focus on the present moment and can be done at home. It is a type of meditation that can help with your wellbeing, stress and anxiety and low mood. Mindfulness and mindfulness-based cognitive therapy is taught by applied psychologists and other registered health professionals. To find out more about mindfulness, search **mindfulness** at **mentalhealth.org.uk**. You can also search **mindfulness** at **nhs.uk** or visit **pennybrohn.org.uk/resources** for mindfulness and relaxation resources.

Search **mental wellbeing** at **nhs.uk** for further information and advice on mental health.

Other sources of support

- The 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**
- Carers Trust works to improve support, services and recognition for anyone living with the challenges of caring for a family member or friend: **carers.org**
- Carers UK gives expert advice, information and support to carers: **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**
- Daisy Network offers information and support to people who have experienced a premature menopause due to a medical condition or treatment: **daisynetwork.org**
- Home Start helps families with young children deal with whatever life throws at them. They can help to look after children or just be someone to talk to: **home-start.org.uk**
- Hope Support Services offers support to anybody age 11 – 25 when a close family member is diagnosed with cancer: **hopesupport.org.uk**
- Penny Brohn UK provides wellbeing information and support for anyone with a diagnosis of cancer: **pennybrohn.org.uk**
- Relate offers counselling, support and information for all relationships: **relate.org.uk**

Notes

Useful contacts

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

Questions I want to ask

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

Chemotherapy side effects tracker

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

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

Week 2 side effects	Week 3 side effects

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

We're open 9am-5pm, Monday-Friday. Call us on 020 7923 5475

Target Ovarian Cancer

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

- ☎ Support line: 020 7923 5475
- @ info@targetovariancancer.org.uk
- targetovariancancer.org.uk
- TargetOvarianCancer
- @TargetOvarian
- @TargetOvarian

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

Disclaimer: We make every effort to ensure that the information we provide is accurate. If you are concerned about your health, you should consult your doctor.

Target Ovarian Cancer cannot accept liability for any loss or damage resulting from any inaccuracy in this information or third party information on websites to which we link.

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