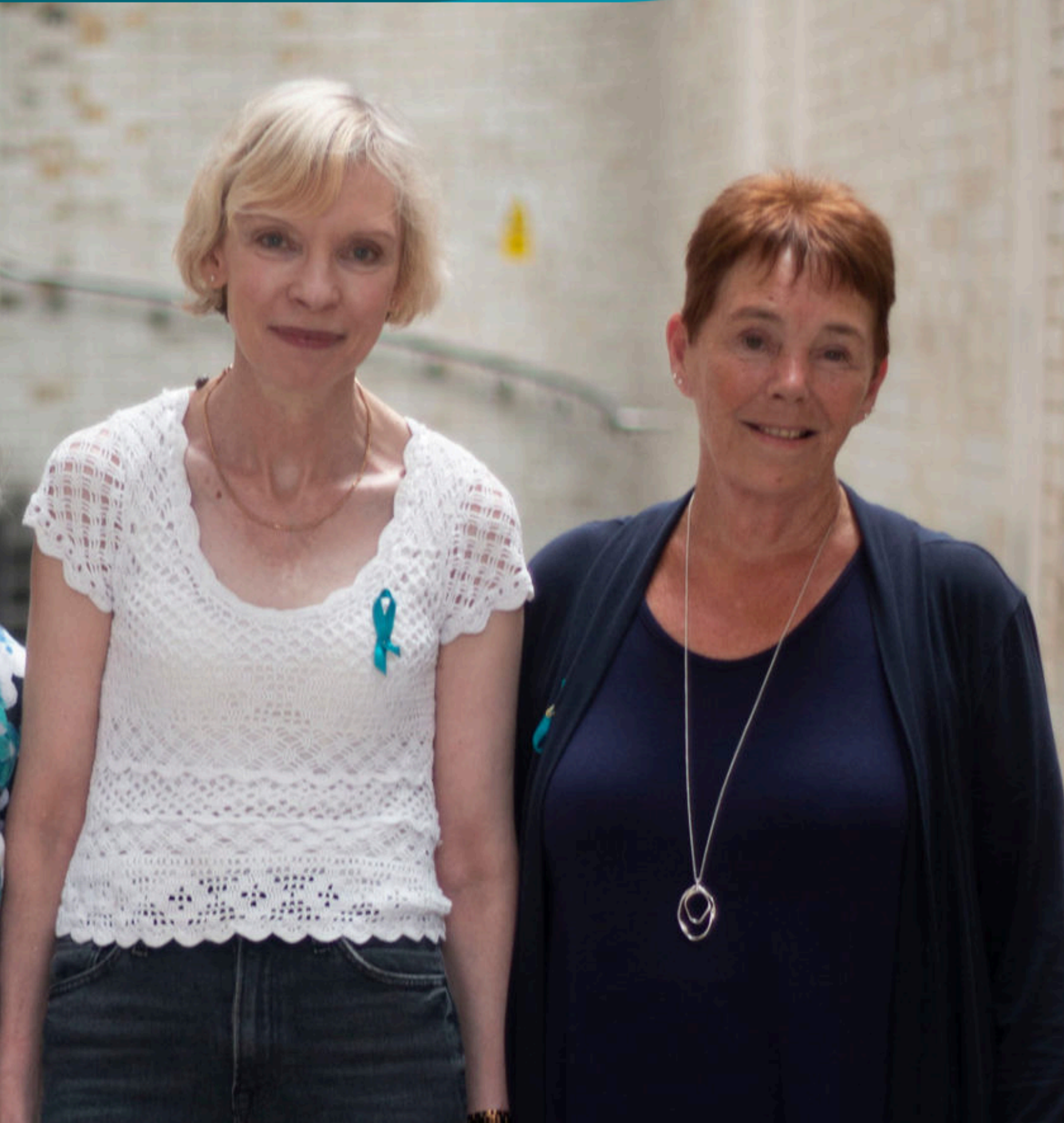
ovacome..
ovarian cancer

What happens if you are diagnosed



Ovacome is a national charity providing support and information to anyone affected by ovarian cancer. We run a free telephone and email support line and work to raise awareness and give a voice to all those affected by ovarian cancer.

This booklet is part of a series giving clinical information about ovarian cancer. It gives an overview of what happens when you are diagnosed.

It suggests questions for you to ask to help yourself, has useful links to further information and shares the experiences of Ovacome members living with an ovarian cancer diagnosis.

Trusted Information Creator

Patient Information Forum

What happens if you are diagnosed

What if my GP thinks I have ovarian cancer?

If your GP thinks you may have ovarian cancer, they might take a blood test to measure your CA125 level. This is a protein that can be raised if ovarian cancer is present. But it can also be raised because of other, less serious, conditions.

Normally, CA125 is less than 35 units in a millilitre (one thousandth of a litre) of blood. A level of 35 or more means that ovarian cancer could be a possible diagnosis. However, having your period, ovarian cysts, endometriosis, or fibroids are just some of the conditions that can also cause your CA125 level to rise.

If the level is raised, or you still have symptoms and the cause has not been found, your GP may ask for an ultrasound scan of your abdomen and pelvis.

This may be a transvaginal scan, when a small ultrasound probe is placed in the vagina to look at your womb and ovaries. If you are not comfortable with this, you can ask for an abdominal scan. You don’t have to give a reason.

If the ultrasound scan shows any abnormalities that affect your ovaries and could be ovarian cancer, then your GP should refer you to a specialist gynaecological oncologist. This is a gynaecologist who is also trained to treat people who have, or may have, cancer.

Mary says: "I had an emergency appointment with my GP who thought I probably had an unsettled stomach. She said it was probably a good idea to do a CA125 test. The test came back at 1,255."

Your first hospital appointment

Your specialist should tell you what will happen next and how a diagnosis will be made. This may mean having an MRI or CT scan. If you haven't had a CA125 test and an ultrasound, these will be done too. Your specialist may request a biopsy.

See more information about tests for ovarian cancer here:
https://www.ovacome.org.uk/tests-for-ovarian-cancer-booklet

You may have experienced bowel symptoms for some while, which have been seen as irritable bowel syndrome (IBS).

IBS is a condition that starts in the 20s and 30s when ovarian cancer is rare. If it starts when you are older, perhaps in your 50s, the symptoms could be those of ovarian cancer pressing on the bowel. It is important then to see your doctor.

You may have a build-up of fluid in your abdomen that makes you look bloated. This is called ascites. It is made by the cancer and can cause the bowel symptoms. Your doctor may want to take a sample to check for cancer cells. The ascites can be drained. This is usually done as an outpatient day case.

Your results will be reviewed by the team of clinical staff who will oversee your care. This is the multidisciplinary team (MDT) which includes staff from different specialisms:

- Gynaecological cancer surgeons.
- Oncologists, who can prescribe chemotherapy.
- Radiologists, who will look at your scans.
- Pathologists, who examine your biopsy samples to make sure your diagnosis is correct.

Your second appointment

You will get a second appointment when your doctors will discuss with you the results of the MDT meeting. Your doctors will explain your diagnosis and recommend a treatment plan.

This may be the point when you meet your cancer nurse specialist (CNS) who will be an important contact for you.

If your tests show that you could have ovarian cancer, your MDT may advise you to have surgery. This will be to remove the cancer and confirm the diagnosis.

Barbara says: "I had the dreaded call … the scan had shown ovarian cancer…I was devastated. The hardest part was telling my husband, family, and close friends – all utterly shocked."

Your tests may have shown that your cancer is at a very early stage and has not spread. This could mean it can be treated with surgery only.

See more information about the staging and grading of ovarian cancer here: https://www.ovacome.org.uk/stages-of-ovarian-cancer-booklet

If your cancer is in your pelvis (the area between your hips) and has not spread further, then you may need surgery first with chemotherapy afterwards.

If your scans have shown that the cancer has spread from your pelvis into your abdomen, your MDT may recommend that you have chemotherapy before your operation. This is to shrink the tumour and make it easier to remove. Then, after your operation, when you have recovered, you can have more chemotherapy.

Having chemotherapy first, then surgery, then more chemotherapy, is called interval surgery.

Your specialist will tell you about the risks and benefits of the treatments the MDT has recommended. This should include information about possible side effects. You should be given time to think about your choices and what is best for you. You should be told where you can find services to support you.

Jenny says: "Learning it was cancer was a shock. But at the same time, feeling part of the team that was dealing with it really helped. My role was to listen, ask questions, turn up and drink plenty of water!"

If you are having surgery only, or surgery followed by chemotherapy, you will be given a date for your admission to hospital for your operation. You will usually be asked to come to a pre-surgery assessment to check your health. This will be a few days before your surgery.

Having surgery first – and questions to ask…

If you are having surgery only, or surgery followed by chemotherapy, you will be given a date for your admission to hospital for your operation. You will usually be asked to come to a pre-surgery assessment to check your health. This will be a few days before your surgery.

You might want to ask these questions:

If I need surgery, what will be removed?

Can all the cancer be taken away?

Do I need other tests before my surgery?

What are the risks?

Can my fertility be preserved?

Will the surgery cause an early menopause?

What will happen after the operation?

Will I be offered genetic testing for a changed BRCA gene and Lynch syndrome?

How long will I be in hospital?

Can my friends and family visit me?

How soon can I get back to my usual activities?

When will I get the results of my surgery?

Who can I ask if I have questions before I go into hospital?

See more information about chemotherapy here:
ovacome.org.uk/chemotherapy-booklet

The Ovacome support team is here to help you talk through questions and plan for meetings with your team. Details of how to contact us are at the end of this booklet.

Having chemotherapy before surgery

If you have been advised to have chemotherapy to shrink the tumour before your operation, your team will usually need to take a biopsy (sample) from the tumour. This is to check that ovarian cancer is the correct diagnosis. It may have been done already.

The biopsy is often done by a radiologist, using scans to find the best place to take the sample. You will have a local anaesthetic to numb the area. It can take at least a week for the sample to be tested and another week for it to be examined and reported on by a histopathologist.

If your biopsy confirms that you have ovarian cancer, your surgeon will refer you to an oncologist who will plan your chemotherapy.

You are likely to be advised to have three or four cycles of chemotherapy before surgery, one every three weeks for nine weeks.

Each cycle is given over a day in hospital as an outpatient.

Another option may be to use a smaller dose of chemotherapy every week for nine to twelve weeks before your operation.

See more information about chemotherapy and potential side effects here:
https://www.ovacome.org.uk/chemotherapy-booklet

You can find information about diet and nutrition, including during chemotherapy, here:
https://www.ovacome.org.uk/diet-and-nutrition

Questions to ask...

What choices do I have for my chemotherapy treatment?

How will I know it is working?

Will I get side effects, and how long will they last?

What help can I have to manage side effects?

Who do I contact if I feel unwell at home?

Can someone come with me to the appointments?

How can I help myself during treatment?

Can I carry on working?

Who can I ask if I have any questions?

Sue says "I was terrified of chemotherapy! I asked my sister to come and hold my hand when I had my first treatment in case something awful happened, because I felt safer with her there.

"But it wasn't as bad as I expected. It wasn't very nice in the first week after treatment, like a dose of flu with added extras. But I survived it, and recovered each time, ready for the next treatment."

Your operation

When you have finished the three cycles of chemotherapy, you will be reviewed. You may have another scan to see how much the tumour has shrunk. If it has reduced enough to make successful surgery possible then your operation will be arranged. You can have a short break between the chemotherapy and surgery to allow you to recover.

The operation will aim to take out as much of the cancer as possible. This can mean it will remove your ovaries (occasionally an unaffected ovary can be left), fallopian tubes, womb, cervix, and omentum (a layer of tissue across the abdomen). It may be necessary to remove parts of the bowel too.

After your surgery you may be in hospital for three to four days and then continue your recovery at home. If you have needed more extensive surgery, you may need to stay in hospital for seven days or more.

Mary says: "The surgeon came to see me the morning after the operation and said he couldn't be more pleased. Almost all the tumours had disappeared and even the ones that remained had reduced in size (after chemotherapy). I had a bit of trouble with nausea and vomiting and felt weak, but I made a good recovery and was discharged a week later."

Chemotherapy after surgery

If you had chemotherapy before your operation, you will need a further two or three cycles afterwards so that you have six cycles in total. You can start these once you are fit enough after surgery.

If you had your surgery first, to be followed by chemotherapy, you are likely to be offered a cycle (dose) of chemotherapy every three weeks for six cycles, which lasts for a total of 18 weeks.

If any of the cancer remains after surgery, your doctor may suggest adding bevacizumab (Avastin) to your chemotherapy and continuing it after the chemotherapy has been completed. This is a targeted treatment that can reduce the tumour's blood supply. Using it can delay a recurrence of the cancer.

You may be offered other drugs that are maintenance therapies. These can prevent or delay the cancer coming back. They include PARP inhibitors such as olaparib, niraparib, or rucaparib. They act on the cancer's DNA to stop it repairing itself.

See more information about targeted therapies here:
https://www.ovacome.org.uk/targeted-therapies-booklet

Lynne says: "I got through it all with wonderful support from my family, friends and medical staff. The cancer support centre in the hospital grounds was always there with a cuppa and a friendly face to talk to."

At the end of your treatment

At the end of your chemotherapy or maintenance therapy, you may have a scan and then a programme of regular follow-up appointments.

These may be face to face or using the telephone or online. You will be asked about your health and then have a blood test. If you develop further symptoms, you may have a scan.

Some people find follow-up appointments make them anxious. It can be hard to adjust when you have longer between appointments, so you are monitored less often. You may feel uncertain about your health and have a lot of questions.

You can still speak to your clinical nurse specialist (CNS) or call the Ovacome free support line on 0800 008 7054.

You can ask...

How will I be followed up, and for how long?

What further investigations may be done?

What should I be looking out for?

Who can I contact between appointments?

How long will it take to recover?

Can I use HRT (Hormone Replacement Therapy)?

What local support is available for me?

Finding help

When you are told you have cancer, you may feel frightened, alone, and angry. This is understandable, but these feelings can sometimes overwhelm you and stop you carrying out your usual activities.

You may blame yourself for having ovarian cancer. But remember that its symptoms can be non-specific so the cancer is hard to detect, and diagnosis can take time. Your illness is not your fault.

Sometimes people develop depression about their diagnosis or during their treatment, causing poor sleep, tiredness, loss of appetite, tearfulness, and sadness. If this happens to you, it is important to know that help is available.

Your GP or clinical nurse specialist (CNS) should be able to put you in touch with a counsellor trained to listen and understand your thoughts and feelings.

You may want to help yourself by using relaxation, complementary therapies such as reflexology, and massage. Do check with your medical team before starting a new therapy, diet, or supplement.

See more information here:

https://www.ovacome.org.uk/getting-support-booklet

https://www.ovacome.org.uk/complementary-therapies-booklet

https://www.ovacome.org.uk/coping-with-anxiety-booklet

Family and other people

The people around you may respond in different ways to your diagnosis. You may find that other people avoid talking about your illness and treatment. Sometimes this includes family members too. They may try to be cheerful, sometimes because they don't know what to say and are afraid of upsetting you.

You can respond by saying how you feel and ask to talk. Or you can say that things are hard right now, and you don't want to talk at the moment.

People may urge you to stay strong and positive, but you should not feel guilty if you can't do this all the time.

See more information about talking to other people: https://www.ovacome.org.uk/talking-to-your-friends-and-family-booklet

Support groups

No matter how close your friends and family are to you, it can be helpful to talk to people going through similar experiences. It can be reassuring to speak to someone who has also had cancer treatment. It can be a chance to talk through some of your worries that you don't want to mention to your family or friends in case you upset them.

Ovacome offers a range of support groups. There is information on the Ovacome website including our support groups and events and a list of local support groups. Ovacome has a lively online community that you can join here: https://www.ovacome.org.uk/forum

See more information about Ovacome support services and ways to get in touch: https://www.ovacome.org.uk/Pages/Category/support-services

Samixa says: "I am very happy to say that more than 12 years after presenting to my GP, I am feeling stronger mentally and physically and have accepted that my life will never be the same as before my ovarian cancer. I have learnt to let go of the small stuff and enjoy the precious time I have been given since my diagnosis."

We welcome your feedback on this booklet. Please email ovacome@ovacome.org.uk or call 0800 008 7054. If you would like to discuss anything about ovarian cancer, please phone our support line on 0800 008 7054 Monday to Friday between 10am and 5pm. You can also visit our website at www.ovacome.org.uk. This is one of a series of information booklets produced by Ovacome. You can see them here: ovacome.org.uk/information.

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Disclaimer

Version 4.3 | Date last updated May 2024 | Date for review May 2027

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Support line: 0800 008 7054
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Ovacome is a charity. We receive no government funding and most of our funding is provided by our community of supporters. We want to continue providing free support and information to people when they need it most. If you can, then please help us by making a donation. You can **scan the QR code** to the right or visit **www.ovacome.org.uk/donate.**

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