

Information for you

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Ovarian cancer

Who is this information for?

This information is for you if you have ovarian cancer or want to know more about it. It tells you about the most common form of ovarian cancer, the stages and grades of cancer, and the treatment you may be offered. It may be helpful if you are a partner, friend or relative of someone with ovarian cancer.

Being diagnosed with ovarian cancer will be a worrying and distressing time for you and your family. The team of healthcare professionals looking after you will support you and give you information that you might find helpful. This leaflet is to complement the support you will get.

What is ovarian cancer and how common is it?

Cancer is a disease of cells in the body. Normally cells grow and multiply in an orderly way, with new cells made only when they are needed. When someone has cancer, this process goes wrong and cancer cells grow and multiply too quickly. As they multiply and grow, the cancer cells damage healthy tissue.

In ovarian cancer, the cancer cells come from the ovary. This is called a primary ovarian cancer. However, in some instances these cells are thought to come from the fallopian tubes that are close to your ovaries. Sometimes the cells can spread beyond the ovary to the womb, abdomen and lungs. The cells then grow in these new sites as secondary tumours. When cancer spreads like this, it is called metastasis.

In the UK, ovarian cancer is the fifth most common cancer in women, with over 6500 women diagnosed each year. The majority of cases occur in women who have gone through the menopause and are usually aged over 50, but younger women can also be affected. The earlier the disease is found and treated, the better the survival rate.

There are several types of ovarian cancer. The most common type is epithelial ovarian cancer, which develops from the surface layer of cells in the ovary. This cancer type is rare in young women and is usually found in women who have been through the menopause.

The following information relates to epithelial ovarian cancer.

What causes ovarian cancer?

In most cases, the reason why ovarian cancer develops is unknown. However, there are factors that can affect the risk of ovarian cancer developing:

- The risk increases with age. More than 8 out of 10 cases occur in women over the age of 50.
- Being overweight or obese increases the risk.
- If the number of eggs a woman releases (ovulation) during her lifetime is reduced, her risk of getting ovarian cancer is lower. Factors that reduce the number of times a woman ovulates include taking the oral contraceptive pill, being pregnant or breastfeeding. The risk increases slightly in women who have not had children and who have a late menopause.
- A family history of ovarian or breast cancer increases the risk. This can be the result of a faulty gene. The most common faulty genes are *BRCA1* and *BRCA2*. About 1 in 10 ovarian cancers may be caused by a faulty gene. If you are concerned that you or your family may be at increased risk, talk to your specialist team or your GP who can refer you to a genetic counselling clinic for advice and testing.

What symptoms might I have?

Most women have very few symptoms but you may experience one or more of the following:

- lower abdominal pain or pelvic pain
- pain during sex
- pain related to your bowels
- a feeling that you want to pass urine urgently and more frequently
- a change in appetite or feeling full quickly
- a distended (swollen) abdomen.

How is it diagnosed?

Ovarian cancer may be suspected if an ovary appears abnormal on an ultrasound scan. Abnormal blood tests such as high levels of a protein called CA125 can make it more likely that it is malignant.

You are likely to be offered a CT scan (computed tomography scan) of your abdomen and pelvis. Sometimes you may be advised to have a biopsy (the taking of a small sample of tissue for examination). This may be done with you awake in the X-ray department or as a keyhole operation with a general anaesthetic.

If your abdomen is swollen with fluid (called ascites) you may be advised to have this drained. This is usually done under ultrasound guidance. The removed fluid may be checked for cancer cells.

If cancer is confirmed, you will be referred to a specialist gynaecology cancer centre to plan treatment.

What are the stages and grades of the disease?

The stage of a cancer tells you how far the cancer has spread. Doctors divide ovarian cancer into four stages. The stage can only be confirmed by having surgery.

Stage 1 – only affecting one or both of the ovaries

Stage 2 – has spread outside the ovaries but not outside the pelvis

Stage 3 – has spread outside the pelvis to the lining of the abdomen and bowel

Stage 4 – has spread to other parts of the body such as liver, spleen, lungs

Cancer cells are graded according to how they look under a microscope. The cancer can be low grade (slow-growing in appearance), moderate grade (more abnormal than low grade) or high grade (fast-growing in appearance).

The stage and grade of disease will help your specialist team decide on the best type of treatment for you.

What are the treatment options?

Treatment options include surgery, chemotherapy and occasionally radiotherapy.

The treatment you will be offered will depend on the stage and grade of the cancer, your general health and your own wishes. You should be advised on the benefits, risks, side effects and likely success rate of treatment options. There is a good chance of successful treatment if your cancer is diagnosed at an early stage.

The team caring for you may use the word 'remission', which means there is no sign of cancer returning after treatment has ended. The more advanced the cancer is at the time of diagnosis, the less likely you will go into remission, but treatment can often shrink the cancer and relieve symptoms. New forms of treatment for ovarian cancer are being developed. Your specialist team will be able to discuss the best treatment option for your individual circumstances.

Surgery

Most women will require surgery. The type of surgery will depend on the cancer stage and grade and on your wishes. Surgery usually involves removing both ovaries and the fallopian tubes (called a bilateral salpingo-oophorectomy), the womb and cervix (called a total hysterectomy) and the layer of fatty tissue in the abdomen known as the omentum (called an omentectomy). Biopsies and some lymph nodes may also be taken from your abdomen and pelvis. This helps to give an accurate idea of the stage the cancer has reached and to decide whether you need further treatment.

If the cancer has spread to other areas of your pelvis or abdomen, your surgeon will remove as much of the cancer as safely possible. The less cancer left in your body after surgery, the more likely chemotherapy is to work.

If the cancer is at an early stage and you wish to become pregnant, you may only need to have the affected ovary and tube removed. Your specialist team will discuss with you the benefits and risks of this form of surgery and they will also discuss the possibility of egg or embryo freezing before treatment.

Surgery may not always be possible because of where the cancer is or if you are not well enough for an operation. If this is the case, your specialist team may recommend chemotherapy to shrink the tumour and relieve symptoms.

Chemotherapy

Chemotherapy treats cancer by using anti-cancer (cytotoxic) drugs to kill cancer cells. Ovarian cancer is usually very sensitive to chemotherapy. It is usually given after surgery. Sometimes it may be given before surgery, usually to help shrink the tumour and to make it easier to remove. This is called neoadjuvant chemotherapy.

There are a number of different anti-cancer drugs and different treatment plans. You may have a single drug or a combination of drugs. The choice of drug and how and when it is given depends on the stage and grade of your cancer and your general health. You are most likely to have either a platinum-containing drug (carboplatin) on its own or in combination with another anti-cancer drug called paclitaxel.

You will usually be given the chemotherapy through a drip in your arm over several hours in hospital. Most women have the treatment as an outpatient. A session of chemotherapy is followed by a period of rest to allow your body to recover. This is known as a cycle and often takes 3 weeks. Most women have six cycles of chemotherapy.

There are some side effects of chemotherapy. These will depend on the drugs you have, the dose and your individual reaction to the drug.

The main side effects of chemotherapy are caused by its effect on the healthy cells in your body. Side effects may include nausea and vomiting, loss of appetite, tiredness, a sore mouth, hair loss, numbness or tingling in the hands and feet, and an increased risk of getting infections. Often these side effects can be well controlled with medication.

Radiotherapy

Radiotherapy is a treatment that uses high-energy radiation beams to target rapidly growing cancer cells. Radiotherapy is not often used in the treatment of ovarian cancer but your specialist team may recommend it in some circumstances such as for shrinking a secondary tumour and/or for treatment of pain.

Supportive care

You may not be well enough to have the treatment/s described above or you may decide against anti-cancer treatment. If so, you should discuss your wishes with your healthcare professionals. You will be offered treatment to relieve symptoms. This is known as supportive or palliative care.

How will I know whether the treatment is working?

As well as clinical follow-up by your doctor, the following may be helpful to monitor your response to treatment:

- CA125 blood test – in response to treatment, the level of CA125 will gradually fall and return to a normal value
- imaging scans such as chest X-rays or CT or MRI (magnetic resonance imaging) scans – these techniques will look for signs of cancer in your pelvis, abdomen and chest.

What are the treatment options if the cancer returns?

Cancer can return after treatment. If this happens, you are likely to be offered another course of chemotherapy. There are a number of anti-cancer drugs that can be used. Your specialist will recommend the drug or drug combination that is best for you. This will depend on the type of ovarian cancer, the drugs you had before and how well they worked, how long you were in remission and what side effects you had. You may be advised to have carboplatin again, usually in combination with another drug such as gemcitabine.

Targeted therapies

These are new types of cancer treatment. By targeting a particular part of the tumour cell, these drugs may cause less damage to healthy cells than more traditional chemotherapy. The benefits of drugs that stop the formation of new blood vessels, such as bevacizumab, used in combination with other chemotherapy drugs are still being tested. If your specialist recommends bevacizumab, he or she will explain why as well as discuss the possible side effects.

If you have developed ovarian cancer due to a faulty *BRCA1* or *BRCA2* gene, you may be treated with drugs called PARP inhibitors. These drugs target tumour cells while sparing normal cells. The benefits of these drugs are still being assessed and tested.

If you are asked to take part in a clinical trial on the treatment of ovarian cancer, you will be given written and verbal information so you can make an informed decision on whether or not to take part. If you do not wish to take part or if you withdraw from the trial at any stage, this will not affect the quality of the care you will receive.

Follow-up after treatment

Your specialist team will advise you to have regular hospital follow-ups after treatment. For the first couple of years you will have follow-up appointments every 2–3 months. If all remains well, the visits will then become less frequent and you may only be seen once or twice a year for up to 5 years.

It is important to attend these follow-up visits even if you are feeling well, as cancer can return even when you have no symptoms. Should you get symptoms or be worried about anything, contact your GP or your specialist team as soon as possible. Do not wait until your next appointment.

At your follow-up visit, the doctor will ask you how you are feeling and whether you have any symptoms or are suffering from side effects of treatment. He or she will usually examine you. You may also have blood tests, scans or X-rays to see how your cancer has responded to treatment.

Support during and after treatment

Coping with cancer can be emotionally challenging. Your specialist team and your GP will help and support both you and your family. You should be offered contact details for a key worker who is often a clinical nurse specialist. Don't be afraid to ask questions, to talk about your feelings and to ask for help. You may find it beneficial to see a trained counsellor. You may also find it helpful to talk to someone else who has also had ovarian cancer and treatment.

If your ovaries have been removed before your menopause, you may want to consider hormone replacement therapy (HRT). You should talk to your specialist team about this.

The following organisations will be able to offer support:

Ovarian Cancer Action

8–12 Camden High Street
London NW1 0JH
020 7380 1730

www.ovarian.org.uk

Target Ovarian Cancer

2 Angel Gate
London EC1V 2PT
020 7923 5470

www.targetovarian.org.uk

Macmillan Cancer Support

89 Albert Embankment
London SE1 7UQ
0808 808 0000

www.macmillan.org.uk

Making a decision

Shared Decision Making

If you are asked to make a choice, you may have lots of questions that you want to ask. You may also want to talk over your options with your family or friends. It can help to write a list of the questions you want answered and take it to your appointment.



Ask 3 Questions

To begin with, try to make sure you get the answers to three key questions if you are asked to make a choice about your healthcare.

1. What are my options?
2. What are the pros and cons of each option for me?
3. How do I get support to help me make a decision that is right for me?

These resources have been adapted with kind permission from the MAGIC Programme, supported by the Health Foundation

* Ask 3 Questions is based on Shepherd HL, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial. Patient Education and Counselling, 2011;84: 379-85



<http://www.advancingqualityalliance.nhs.uk/SDM/>

Sources and acknowledgements

This information has been developed by the RCOG Patient Information Committee. It is based on the NICE 2011 Clinical Guideline *Ovarian Cancer: Recognition and Initial Management*, which you can find online at: www.nice.org.uk/guidance/cg122, and the RCOG Scientific Impact Paper No. 12 *Targeted Therapies for the Management of Ovarian Cancer* (September 2013), which you can find online at: www.rcog.org.uk/en/guidelines-research-services/guidelines/sip12. The guideline contains a full list of the sources of evidence we have used.

This leaflet was reviewed before publication by women attending clinics in Cambridge, Kirkcaldy, London, Manchester and Newcastle upon Tyne, and by the RCOG Women's Voices Involvement Panel.

The RCOG produces guidelines as an educational aid to good clinical practice. They present recognised methods and techniques of clinical practice, based on published evidence, for consideration by obstetricians and gynaecologists and other relevant health professionals. This means that RCOG guidelines are unlike protocols or guidelines issued by employers, as they are not intended to be prescriptive directions defining a single course of management.

A glossary of all medical terms is available on the RCOG website at: www.rcog.org.uk/en/patients/medical-terms.