

**MACMILLAN**  
CANCER SUPPORT

# UNDERSTANDING CANCER OF THE OVARY, FALLOPIAN TUBE AND PERITONEUM





● I was given a lot of support when I was diagnosed, which was great because I was struggling to process anything. I was in so much shock. I just heard it as “the big C” and I broke down. ●

# About this booklet

**This booklet is about cancer that starts in the ovary, fallopian tube, or peritoneum.**

It is for anyone affected by these types of cancer. There is also information for carers, family members and friends.

The booklet explains how these cancers are diagnosed and treated. It gives information about coping during and after treatment.

We hope it helps you deal with some of the questions or feelings you may have. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

This booklet does not have information about

- cancer that spreads into these areas from somewhere else in the body such as the bowel, stomach or pseudomyxoma peritonei (PMP).
- peritoneal mesothelioma, a different type of cancer that starts in the peritoneum.

We have other booklets about this called:

- Understanding colon cancer
- Understanding stomach cancer
- Understanding mesothelioma.

We also have information on our website about pseudomyxoma peritonei (PMP).

## For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

## How to use this booklet

The booklet is split into sections to help you find what you need. You don't have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

We have included quotes from people who have had cancer of the ovary, fallopian tube or peritoneum, which you may find helpful. These include quotes from Diane, who is on the cover of this booklet.

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# CANCER OF THE OVARY, FALLOPIAN TUBE OR PERITONEUM

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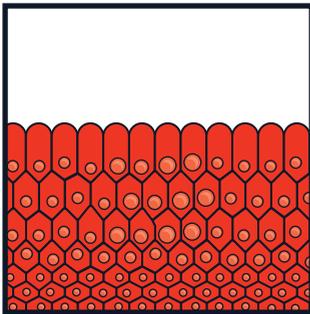
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# What is cancer?

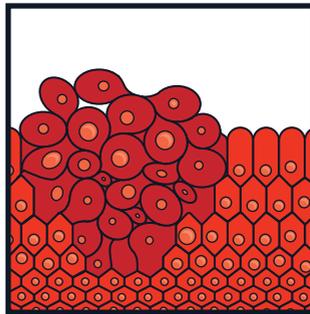
Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop growing. When a cell is no longer needed or can't be repaired, it gets a signal to stop working and die.

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing making more and more abnormal cells. These eventually form a lump (**tumour**). Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a **biopsy**. The doctors examine the sample under a microscope to look for cancer cells.

Normal cells



Cells forming a tumour



A lump that is not cancerous (**benign**) may grow but cannot spread to anywhere else in the body. It usually only causes problems if it puts pressure on nearby organs.

A lump that is cancer (**malignant**) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or lymphatic system (see pages 12 to 13). When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a secondary cancer or a **metastasis**.

# The ovaries, fallopian tubes and peritoneum

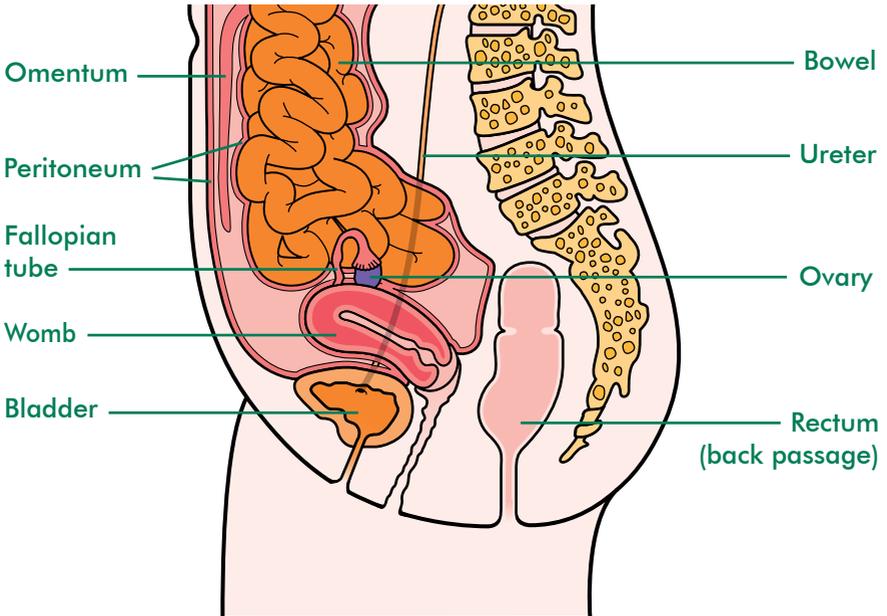
## The ovaries and fallopian tubes

The ovaries are two small, oval-shaped organs in the pelvis. The pelvis is the area between the hips in the lower part of the tummy. The ovaries are part of the female reproductive system. This is the system involved in making eggs, having sex, carrying a baby and giving birth. It also includes the fallopian tubes, womb (uterus), cervix and vagina (see diagram on opposite page).

The fallopian tubes are two fine tubes that link the ovaries to either side of the womb. Normally, from puberty to menopause, one of the ovaries releases an egg once a month. The egg passes down the fallopian tube to the womb. If the egg is not fertilised by a sperm, it passes out of the womb as part of the monthly period.

The ovaries also produce the female hormones oestrogen and progesterone. These help control the reproductive system. As you get older, the ovaries make less of these hormones. The ovaries stop releasing eggs each month and periods stop. This is known as the menopause. It means you cannot get pregnant anymore. It usually happens naturally between your mid-40s and mid-50s.

## The ovaries and surrounding structures



## Organs close to the ovaries and fallopian tubes

There are several organs close to the ovaries and fallopian tubes. These include:

- the bladder
- the ureters – tubes which drain urine from the kidneys to the bladder
- the back passage (rectum)
- part of the bowel
- groups of lymph nodes (see pages 12 to 13)
- the womb (uterus).

## The peritoneum

A layer of tissue supports the ovaries and fallopian tubes. This tissue is called the peritoneum.

In men and women, the inner layer of the peritoneum covers the surface of all the organs in the tummy (abdomen), such as the stomach, liver and bowel. The outer layer lines the wall of the abdomen. Between the two layers is a small amount of fluid. This lets the layers move easily against each other.

The peritoneum helps protect the organs in the abdomen and keep them in place. A section of the inner layer forms an extra flap of tissue that hangs down from the stomach, in front of the bowel. This flap is called the omentum.

# About cancer of the ovary, fallopian tube or peritoneum

About 20 women a day are diagnosed with cancer of the ovary (ovarian cancer) in the UK. That is about 7,000 a year.

It is rarer for cancer to start in the fallopian tube or peritoneum (primary peritoneal cancer). Primary peritoneal cancer can affect men as well as women, although this is very rare.

The surface of the ovaries, fallopian tubes and peritoneum are all close together in the body. This means that sometimes it is not clear which of these areas a cancer has started in.

Cancers that start in an ovary, fallopian tube or the peritoneum:

- often cause the same symptoms
- are diagnosed using the same tests
- are treated using the same treatments.

We have separate information about cancer that spreads into these areas from somewhere else in the body. This includes bowel cancer, stomach cancer, pseudomyxoma peritonei (PMP) and some types of sarcoma. We also have information about peritoneal mesothelioma, a different type of cancer that starts in the peritoneum. Call us on **0808 808 00 00** for more details.

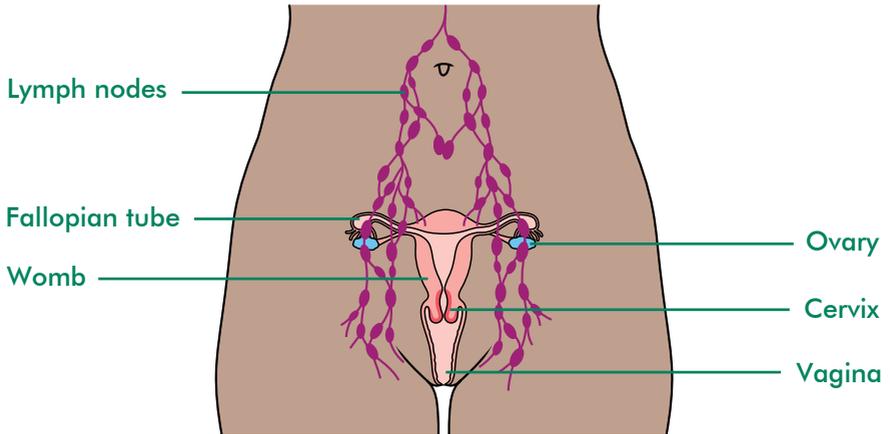
# The lymphatic system

The lymphatic system (see diagram on opposite page) helps to protect us from infection and disease. It also drains lymph fluid from the tissues of the body before returning it to the blood. The lymphatic system is made up of fine tubes called lymphatic vessels that connect to groups of lymph nodes throughout the body.

Lymph nodes (sometimes called lymph glands) are small and bean-shaped. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, lymph nodes often swell as they fight the infection.

Sometimes cancer can spread through the lymphatic system. Cancer that starts in the ovaries, fallopian tubes or peritoneum is most likely to go to the lymph nodes in the pelvis (the area between your hips) or abdomen (tummy).

## Lymph nodes in the abdomen and pelvis



## Risk factors and causes

We do not know what causes cancer to start in the ovary, fallopian tube or peritoneum. But we know some of the risk factors that may increase the chances of it developing.

We know less about the risk factors for fallopian tube and primary peritoneal cancer because these cancers are less common. But they are likely to be similar to the risk factors for ovarian cancer.

Having a risk factor does not mean you will definitely get cancer. Equally, if you don't have any risk factors, this does not mean you will not get cancer.

## Age

These cancers are rare in people under the age of 30. The risk increases with age. More than half (50%) of ovarian cancers occur in women over the age of 65.

## Hormonal factors

Doctors think the number of times an ovary releases an egg (ovulates) may be linked to ovarian cancer risk. These cancers are more common in women who have ovulated more times. For example, women who:

- have never given birth
- give birth for the first time after the age of 35
- start their periods young
- have a later menopause.

Factors that reduce ovulation may help lower the risk of ovarian cancer. For example, taking the contraceptive pill, having more pregnancies and breastfeeding.

## Hormone replacement therapy (HRT)

Taking HRT after the menopause slightly increases the risk of developing ovarian cancer. About 1% of cases may be linked to taking HRT.

## Medical conditions

### Breast cancer

Women who have had breast cancer may be more likely to develop ovarian cancer. This may be because these cancers have some risk factors in common.

### Endometriosis

Endometriosis is a condition where the lining of the womb grows outside the womb. Having this condition slightly increases the risk of ovarian cancer.

### Diabetes

Having diabetes may slightly increase the risk of developing ovarian cancer.

## Lifestyle factors

### Smoking

Smoking cigarettes increases your risk of a less common type of ovarian cancer called mucinous cancer. But it does not affect your risk of the most common type of ovarian cancer.

## Weight and height

There is limited evidence that being overweight (obese) or taller may increase the risk of ovarian cancer.



## Family history of cancer

If you have a family history of ovarian cancer, you may have a higher risk of developing it yourself. Your risk may be about three times higher if you have one close relative with ovarian cancer. If you have two or more close relatives with ovarian cancer or certain other types of cancer, your risk may be higher than this.

We have more information for people who are worried about a family history of ovarian cancer. Call us on **0808 808 00 00** for more details. Your GP can also give you information and support. If they think your family might have a higher risk of cancer, they may arrange for you to see a genetics specialist.

## Inherited genetic conditions

All cells in the body contain genes. These genes are the instructions your cells need to work. Genes affect the way your body grows, functions and looks. Sometimes a gene is damaged or develops a fault (mutation). Changes like this can be linked to a higher risk of certain health problems.

Genes are passed from parent to child. Half of the genes in your cells are identical to some of your father's genes and half are identical to some of your mother's. This means gene mutations can be passed on from parent to child.

A small number of cancers that start in the ovaries, fallopian tubes or peritoneum are linked to a gene mutation. If a family has a gene mutation linked to ovarian cancer, there may be a pattern of cancer in that family. Several people in the family may be affected by ovarian cancer or related cancers, such as breast, bowel or womb cancer. They may also develop these types of cancer at an unusually young age.

## **BRCA1 and BRCA2**

The most commonly affected genes are called BRCA1 and BRCA2. People who have a mutation in one of these genes have a higher risk of ovarian, fallopian, primary peritoneal and some other types of cancer.

Families from all ethnic backgrounds can be affected by a gene mutation linked to cancer. But families from an Ashkenazi Jewish background have a particularly high risk of having BRCA1 or BRCA2 mutations.

## **Lynch syndrome**

This is a rare genetic condition that affects some families. It increases the risk of several types of cancer, including ovarian cancer.

We have more information about BRCA1, BRCA2 and Lynch syndrome on our website – visit [macmillan.org.uk](http://macmillan.org.uk)

'I have talked to my daughters. They want to be tested. Had I known that I carried the gene, I think I would have been a lot more determined with my doctors.'

**Karen**

# Symptoms

Cancer of the ovary, fallopian tube or peritoneum often causes symptoms that are similar to other more common and less serious conditions. This can make it difficult to diagnose early, before the cancer has spread.

If you have any of these symptoms for no reason, or you get these symptoms regularly (especially more than 12 times a month), your GP should offer you cancer tests:

- a long-lasting bloated or swollen tummy
- loss of appetite
- feeling full quickly when you eat
- pain in the lower tummy area or back
- passing urine more often than usual
- passing urine more urgently (feeling like you can't hold on).

Other symptoms may include:

- a change in your normal bowel habit (diarrhoea or constipation)
- weight gain or weight loss
- unexplained or extreme tiredness (fatigue)
- vaginal bleeding after your menopause.

If you are 50 years or older and develop symptoms of irritable bowel syndrome (IBS) for the first time, you should also have tests. IBS can cause bloating and changes in bowel habit, but it does not usually start after the age of 50.

**'I was told that I had ovarian cancer. In hindsight, I had shown some other symptoms. I was feeling bloated and I had diarrhoea and loss of appetite.'**

**Diane**



# DIAGNOSING CANCER OF THE OVARY, FALLOPIAN TUBE OR PERITONEUM

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# How cancer of the ovary, fallopian tube or peritoneum is diagnosed

You usually start by seeing your GP. Your GP will ask about your symptoms (see pages 20 to 21) and do an internal (vaginal) examination to check for any lumps or swellings.

They will also arrange for you to have:

- a blood test called a CA125 test
- an ultrasound scan to look at your ovaries.

There is more information about having an internal examination and tests on pages 26 to 32.

If your GP is worried about cancer, they will arrange for you to see a specialist doctor within two weeks. This specialist is usually a gynaecologist (a doctor who treats female reproductive system problems).

Some people are admitted directly to hospital if they have a symptom that is making them very unwell.

## At the hospital

The specialist doctor will ask you about your general health, any previous health problems, and whether you have any history of cancer in your family. They will do an internal (vaginal) examination again. If you have not already had a CA125 blood test and ultrasound, they will usually arrange for you to have these tests.

The doctor may use the results of these tests to check your Risk of Malignancy Index (RMI) score. This is a system that checks how likely it is that your symptoms are caused by cancer. It takes into account:

- whether you have gone through the menopause
- the level of CA125 in your blood
- the results of your ultrasound.

They may also organise further tests, such as a CT scan (see page 28). These tests help your team diagnose the cancer and plan your treatment.

You may also meet a nurse specialist. They can give you advice and support. Your doctor or nurse will explain any tests you need. If you have questions or need more information, just ask.

## Tests

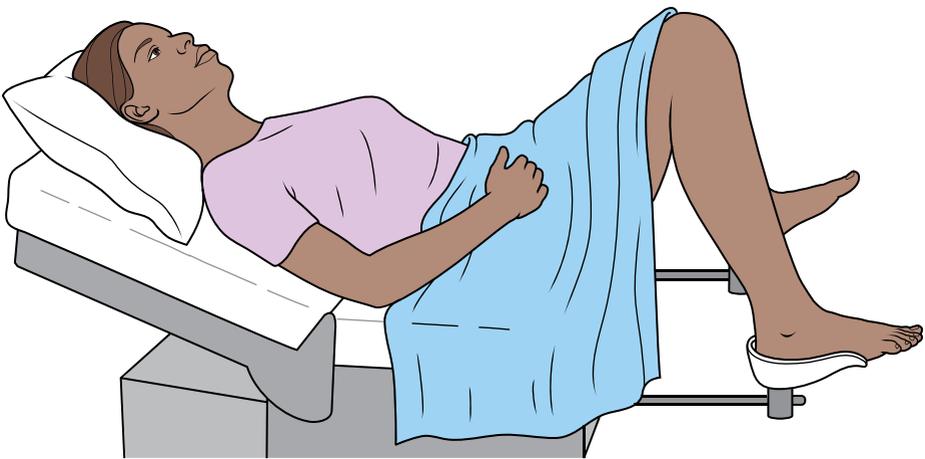
### Internal (vaginal) examination

Your doctor will do an internal examination to check for any lumps or swelling in the ovaries or womb. It takes about five minutes. It should not be painful, but may be uncomfortable.

You lie on a couch with your feet drawn up and knees apart. The doctor places one or two gloved fingers into your vagina and gently presses on your lower tummy with their other hand. They may put an instrument called a speculum into your vagina. They use this to hold the vagina walls apart, so they can check that your cervix looks normal.

If you have questions or worries about having an internal examination, tell the nurse or doctor. They can answer any questions you have and explain ways they can make it easier for you.

### Having an internal examination



## CA125 blood test

This blood test checks for raised levels of a protein called CA125. It is normal to have some CA125 in the blood, but the level may be higher in women with ovarian cancer. The level of CA125 can also be raised by non-cancerous conditions and by other types of cancer.

In early ovarian cancer, CA125 levels may be normal.

## Ultrasound scan

An ultrasound scan uses sound waves to build up a picture of the organs inside the abdomen (tummy area) and the pelvis. A computer converts the sound waves into pictures that you can see on a screen.

You have the scan in the hospital scanning department. The person doing the scan will explain more about it and help you lie down comfortably on your back.

You may have a:

- **Pelvic ultrasound** – You will be asked to drink plenty before this test so that your bladder is full. They spread a gel on to your abdomen and gently press a small hand-held device against your skin. This produces the sound waves.
- **Vaginal ultrasound** – They gently put a small ultrasound probe into your vagina. The probe is about the size of a tampon and produces the sound waves. Although this scan sounds uncomfortable, some people find it easier than a pelvic ultrasound, as you do not need a full bladder.

## CT scan

A CT scan takes a series of x-rays, which build up a 3D picture of the inside of the body. The scan takes 10 to 30 minutes and is painless.

It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan.

You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. It's important to let your doctor know if you are allergic to iodine or have asthma, because you could have a more serious reaction to the injection.

You'll probably be able to go home as soon as the scan is over.

## Removing fluid from the abdomen

Sometimes swelling or bloating in the tummy is caused by a build-up of fluid. This is called **ascites**. It can be caused by cancer or by other non-cancerous conditions. If you have ascites, your doctor may want to take a sample of this fluid to check for cancer cells.

The doctor injects some local anaesthetic into the skin on your tummy (abdomen) to make it numb. They gently pass a small needle through the skin and collect some fluid in a syringe. The fluid is sent to the laboratory to be examined.

If you have a lot of fluid in your abdomen, it can be uncomfortable, so your doctor may remove it (called ascitic drainage). We have more information about ascitic drainage. Visit [macmillan.org.uk](http://macmillan.org.uk) to find out more.

## Having a CT scan



## Biopsy

This is when the doctor removes a small sample (biopsy) from the lump or abnormal area. The sample is then sent to the laboratory and looked at under a microscope. This test checks that the abnormal area is cancer. It also finds out more about the type (see page 33) and grade (see page 38) of the cancer.

If your first treatment is likely to be surgery to remove a tumour (see pages 51 to 62), biopsies are often taken during your operation. Sometimes a biopsy is needed before any treatment starts, to check that your symptoms are definitely caused by cancer and not by another condition. For example, you may have this test if your doctor thinks you need chemotherapy as your first treatment.

If you need a biopsy before treatment, this will usually be an image guided biopsy. Less often, some people have surgery to look inside the abdomen and collect samples.

### Image guided biopsy

Your doctor numbs your skin using a local anaesthetic injection. You may also have a sedative to help you relax. The doctor passes a needle through the skin, using a CT or ultrasound scan to guide them to the right place. They collect a small sample from the abnormal area with the needle.

You will usually stay in hospital for a few hours after this test, and sometimes overnight.

### Surgery to take biopsies

This is usually done with an operation called a laparoscopy (or keyhole surgery). You have a general anaesthetic. You can usually go home later the same day or the next day.

The surgeon makes three or four small cuts in the lower abdomen. The cuts are about 1cm long. The surgeon pumps some gas into the abdomen to lift up the tummy wall, so the organs can be seen clearly. The surgeon then puts a thin tube with a tiny camera on the end into the abdomen. This is called a laparoscope. They examine the area carefully and take biopsies.

You may have discomfort in your neck or shoulder after the operation. This will go away after a day or two. Walking about may help. Some people have cramps or painful wind in the tummy. Taking sips of peppermint water and moving around can help.

Sometimes an operation called a laparotomy is done instead. The surgeon uses one larger cut to open the abdomen and look inside. If cancer is found, they may then operate to remove the cancer. This is only done if you and your doctor have discussed it and you have agreed (consented) to it before the operation.

We have more information about having surgery and what to expect – see pages 51 to 62.

## Genetic testing

Your doctor may talk with you about having a blood test to look for genetic changes (see pages 18 to 19) that are linked to cancer. This is only done if you have certain types of cancer, such as high-grade serous or endometrioid cancer.

Knowing about any genetic changes helps your doctor plan your treatment.

We have more information about cancer and genetic changes. Visit [macmillan.org.uk](https://www.macmillan.org.uk) or call us on **0808 808 00 00** to find out more.

## Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or one of the organisations listed on pages 115 to 120 can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

'As soon as I was diagnosed, I was able to say "I have ovarian cancer". I think you have got to be able to admit it to yourself and not be afraid of it. It is just part of the journey.'

Clara

# Types of ovarian, fallopian tube and peritoneal cancer

The most common cancer to start in the ovary, fallopian tube or peritoneum is called epithelial cancer.

The different types of epithelial cancer are:

- serous
- mucinous
- endometrioid
- clear cell.

High-grade (see page 38) serous cancer is the most common type.

## Germ cell ovarian tumours

This rare type of ovarian tumour starts in the cells that produce eggs. It usually affects younger women and may be treated differently to epithelial cancer. We have separate information about germ cell ovarian tumours. Visit [macmillan.org.uk](http://macmillan.org.uk) to read more.

## Borderline ovarian tumours

Borderline ovarian tumours are made up of abnormal epithelial cells, but they are not true cancers. They usually grow slowly and are unlikely to spread. They can sometimes behave more like a low-grade cancer (see page 38), but this is rare.



# Staging and grading

## Staging

The stage of a cancer describes where the cancer has been found and other places it has spread to. Knowing the stage helps your doctors plan the best treatment for you.

Your doctor will not usually know the exact stage of the cancer until it has been removed with surgery. If you have not had surgery, they can use the results of your tests to decide the stage of the cancer.

Doctors use the FIGO staging system to stage cancer of the ovary, fallopian tube and peritoneum. This uses numbers and letters to describe different stages.

You may find the diagram on page 9 helps you understand this section.

## Stage 1

This is early cancer.

### Stage 1a

The cancer is only in one ovary or fallopian tube.

### Stage 1b

The cancer is in both ovaries or fallopian tubes.

### Stage 1c

The cancer is in one or both ovaries or fallopian tubes with any of the following:

- The tissue surrounding the ovary (capsule) or fallopian tube has broken, which may have let cancer cells leak into the abdomen or pelvis.
- There are cancer cells on the surface of the ovaries or fallopian tubes.
- There are cancer cells in the fluid in the abdomen or pelvis.

## Stage 2

The cancer is in one or both ovaries or fallopian tubes and has grown into nearby areas inside the pelvis.

Or the cancer has started in the peritoneum but only affects areas inside the pelvis.

### Stage 2a

There is cancer on the womb, fallopian tubes or ovaries.

### Stage 2b

There is cancer on other structures in the pelvis, such as the bowel or bladder.

## Stage 3

The cancer is in one or both ovaries or fallopian tubes or started in the peritoneum. And it has spread to:

- the peritoneum outside the pelvis
- the lymph nodes in the abdomen and/or pelvis.

### Stage 3a1

The cancer has spread to the lymph nodes in the abdomen and/or pelvis.

### Stage 3a2

Very tiny amounts of cancer have spread to the peritoneum outside the pelvis. There may also be cancer in the lymph nodes in the abdomen and/or pelvis.

### Stage 3b

There are areas of cancer on the peritoneum outside the pelvis. These areas are less than 2cm. There may also be cancer in the lymph nodes in the abdomen and/or pelvis.

### Stage 3c

There are areas of cancer on the peritoneum outside the pelvis that are larger than 2cm. There may also be cancer in the lymph nodes in the abdomen and/or pelvis. There may be cancer cells on the surface of the liver and spleen but not inside these organs.

## Stage 4

The cancer has spread outside the abdomen.

### Stage 4a

The cancer has caused a build up of fluid in the lining of the lungs (called the pleura). This is called a pleural effusion.

### Stage 4b

The cancer has spread to the inside of the liver or spleen, or to lymph nodes or organs outside the abdomen.

## Grading

Grading describes how the cancer cells look under the microscope compared with normal cells. Knowing the grade helps your doctor plan your treatment.

This is how ovarian, fallopian tube and primary peritoneal cancers are graded:

- **Borderline tumours** (see page 33) are made up of abnormal cells rather than cancer cells.
- **Low-grade or well-differentiated (grade 1)** – The cancer cells look similar to normal cells. They usually grow slowly and are less likely to spread.
- **Moderate or intermediate-grade (grade 2)** – The cancer cells look more abnormal. They are slightly faster-growing.
- **High-grade or poorly-differentiated (grade 3)** – The cancer cells look very different from normal cells. They may grow more quickly.

# Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out. You can find more information at [macmillan.org.uk/cancerregistry](https://www.macmillan.org.uk/cancerregistry)



Having chemotherapy

# TREATING CANCER OF THE OVARY, FALLOPIAN TUBE OR PERITONEUM

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# Treatment overview

The main treatments for cancer that starts in the ovary, fallopian tube or peritoneum are surgery and chemotherapy. Sometimes other treatments are also used, such as radiotherapy or targeted therapies. Your cancer doctor may also talk with you about taking part in a clinical trial to research newer treatments.

The treatment you have is based on:

- the type of cancer you have (see page 33)
- its stage and grade (see pages 35 to 38)
- where it is
- your general health
- your personal preferences.

Cancer treatments can cause early menopause (see page 88) and affect your fertility (ability to get pregnant). If you still want to be able to get pregnant, talk to your cancer doctor before treatment starts. We have more information about fertility and cancer treatment. Visit [be.macmillan.org.uk](https://www.be.macmillan.org.uk) to order a free copy.

## Treating borderline ovarian tumours

Most borderline tumours are found at an early stage and can often be cured with surgery. No further treatment is needed and the tumour rarely comes back.

Sometimes, cells from these tumours spread and attach to nearby areas, such as the peritoneum. These are called non-invasive implants. They do not usually cause problems and often do not need to be treated. Instead, the doctor may monitor them at regular check-ups.

Rarely, borderline tumours spread and behave more like a low-grade cancer. Again, this may not need more treatment. Areas of spread may develop so slowly that you have no symptoms. But sometimes chemotherapy is used.

Ovacome has more detailed information about borderline ovarian tumours. See page 115 for contact details.

## Treating stage 1 cancer

Some stage 1 cancers in the ovary or fallopian tubes can be cured with surgery alone.

Your doctor may advise you have chemotherapy after surgery to reduce the risk of the cancer coming back. This includes stage 1 cancers that are:

- high-grade (see page 38)
- stage 1c (see page 36).

## Treating stage 2 to 4 cancer

These stages of cancer are usually treated with surgery and chemotherapy, or with chemotherapy on its own. Treatment may cure the cancer or keep it under control for as long as possible. Your cancer doctor or nurse will explain what to expect.

Surgery is used to remove as much of the cancer as possible. After this, you have chemotherapy to:

- treat cancer cells that cannot be seen during surgery – they can only be seen under a microscope
- shrink any cancer that could not be removed during the operation.

Some people also have chemotherapy before surgery. This helps shrink the cancer so that the operation is easier to do and more likely to be effective.

Chemotherapy may be the main treatment if it is not possible to remove the cancer or if you are not well enough for surgery. The aim is to shrink the cancer, help to control it and relieve symptoms.

## Treating cancer that comes back

If cancer comes back, it can usually be treated again with more chemotherapy, targeted therapies and sometimes more surgery. Some people will have several courses of chemotherapy or other treatments spaced over a few years. This is used to keep the cancer under control for a time and improve any symptoms.

## Treating advanced cancer

If the cancer is very advanced, some people may decide to stop treatment or not have treatment. Your cancer doctor and nurse will support you and help you control any symptoms. This is known as supportive or palliative care. You may see a specialist palliative care doctor or nurse for expert help with your symptoms.

We have more information about coping with advanced cancer. You can order a free copy at **[be.macmillan.org.uk](https://www.be.macmillan.org.uk)** If you have questions or want to talk about this, call our cancer support specialists on **0808 808 00 00**.

## How treatment is planned

You should be treated by a specialist gynaecological cancer team. These teams are based in larger cancer centres, so you may have to travel for your treatment. They will meet to discuss and decide the best treatment for you. They will consider your own wishes too.

This multidisciplinary team (MDT) will include:

- a **gynaecological oncologist** – a surgeon who specialises in gynaecological cancers
- **oncologists** – doctors who specialise in cancer treatments such as radiotherapy, chemotherapy and targeted therapy drugs
- a **gynae-oncology nurse specialist**
- a **radiologist** – a doctor who analyses x-rays and scans
- a **pathologist** – a doctor who examines cancer cells under a microscope and advises on the type and extent of the cancer.

It may also include other healthcare professionals, such as a dietitian, physiotherapist, occupational therapist, radiographer, psychologist or counsellor.

After the team has met, your specialist will discuss your treatment options with you. You can ask questions about anything you don't understand or are worried about. You should also be given a telephone number for your specialist nurse or key worker who you can contact if you have any questions when you get home.

You can also talk to our cancer support specialists on **0808 808 00 00**.



## Giving your consent

Before you have any treatment, your doctor will explain its aims. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent, and before you are asked to sign the form you should be given full information about:

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you don't understand what you've been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it's not unusual to need repeated explanations. It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

People sometimes feel that hospital staff are too busy to answer their questions, but it's important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

You can always ask for more time if you feel that you can't make a decision when your treatment is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you don't have it. It's essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You don't have to give a reason for not wanting treatment, but it can help to let the staff know your concerns so they can give you the best advice.

## The benefits and disadvantages of treatment

Many people are frightened at the idea of having cancer treatments, particularly because of the side effects that can occur. However, these can usually be controlled with medicines. Treatment can be given for different reasons and the potential benefits will vary depending upon your individual situation.

If the cancer is advanced and has spread to other parts of the body, treatment may only be able to control it, improving symptoms and quality of life. However, for some people in this situation the treatment will have no effect on the cancer and they will get the side effects without any of the benefit.

If you've been offered treatment that aims to cure the cancer, deciding whether to accept it may not be difficult. However, if a cure is not possible and the purpose of treatment is to control the cancer for a period of time, it may be more difficult to decide whether to go ahead.

Making decisions about treatment in these circumstances is always difficult, and you may need to discuss in detail with your doctor whether you wish to have treatment. If you choose not to have it, you can still be given supportive (palliative) care, with medicines to control any symptoms.

## Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion. Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

# Surgery

Surgery is one of the main treatments for cancer of the ovary, fallopian tube or peritoneum. It is also sometimes used to diagnose the cancer and to find out more about the type and stage of the cancer. A surgeon called a gynaecological oncologist will do your operation.

The type of surgery you have may depend on:

- the stage of the cancer
- the areas affected by cancer
- whether you want to be able to get pregnant in the future.

Before you have surgery, your surgeon and nurse will explain what to expect and answer any questions you have. It may help to look at the diagram on page 9 when reading this section.

## Types of surgery

### **Surgery to remove the ovaries and womb**

The aim of this operation is to remove all of the cancer.

The surgeon usually removes:

- the ovaries and fallopian tubes (called a bilateral salpingo-oophorectomy or BSO)
- the womb and cervix (called a total abdominal hysterectomy or TAH)
- the omentum (called an omentectomy).

During the operation, the surgeon:

- takes samples (biopsies) from other areas nearby
- may remove some of the lymph nodes in the abdomen and pelvis
- puts fluid into the abdomen and collects it again (called abdominal or peritoneal washing).

After the operation, everything that the surgeon removed is sent to the laboratory and carefully examined. This gives more information about the type and stage of the cancer. This information helps your team decide if you are likely to need further treatment.

If you are still having periods, this surgery will bring on your menopause and you will not be able to get pregnant. Your surgeon or nurse will explain what to expect before you have surgery. Ask them for advice if you are worried about your fertility.

## Fertility-sparing surgery

Some women choose to have surgery that protects their fertility (ability to get pregnant). This may be possible if cancer or a borderline tumour is only affecting one ovary or fallopian tube.

The surgeon only removes the affected ovary and fallopian tube. They leave the other ovary, fallopian tube and the womb. This means you may still be able to get pregnant in the future.

During the operation, the surgeon checks the other ovary and may take a sample from it. They will also take washings and samples (biopsies) from other nearby areas. They may remove some lymph nodes from the pelvis or abdomen.

If the washings, biopsies or lymph nodes show the cancer has spread, you may need a second operation. This usually involves removing the womb, omentum and remaining ovary and fallopian tube.

## Removing as much of the cancer as possible

When cancer has spread to other areas in the pelvis or abdomen, it is not always possible to remove it all. Instead, the surgeon aims to remove as much of the cancer as they can. This is called debulking or cytoreductive surgery. It helps keep the cancer under control and may improve any symptoms you have.

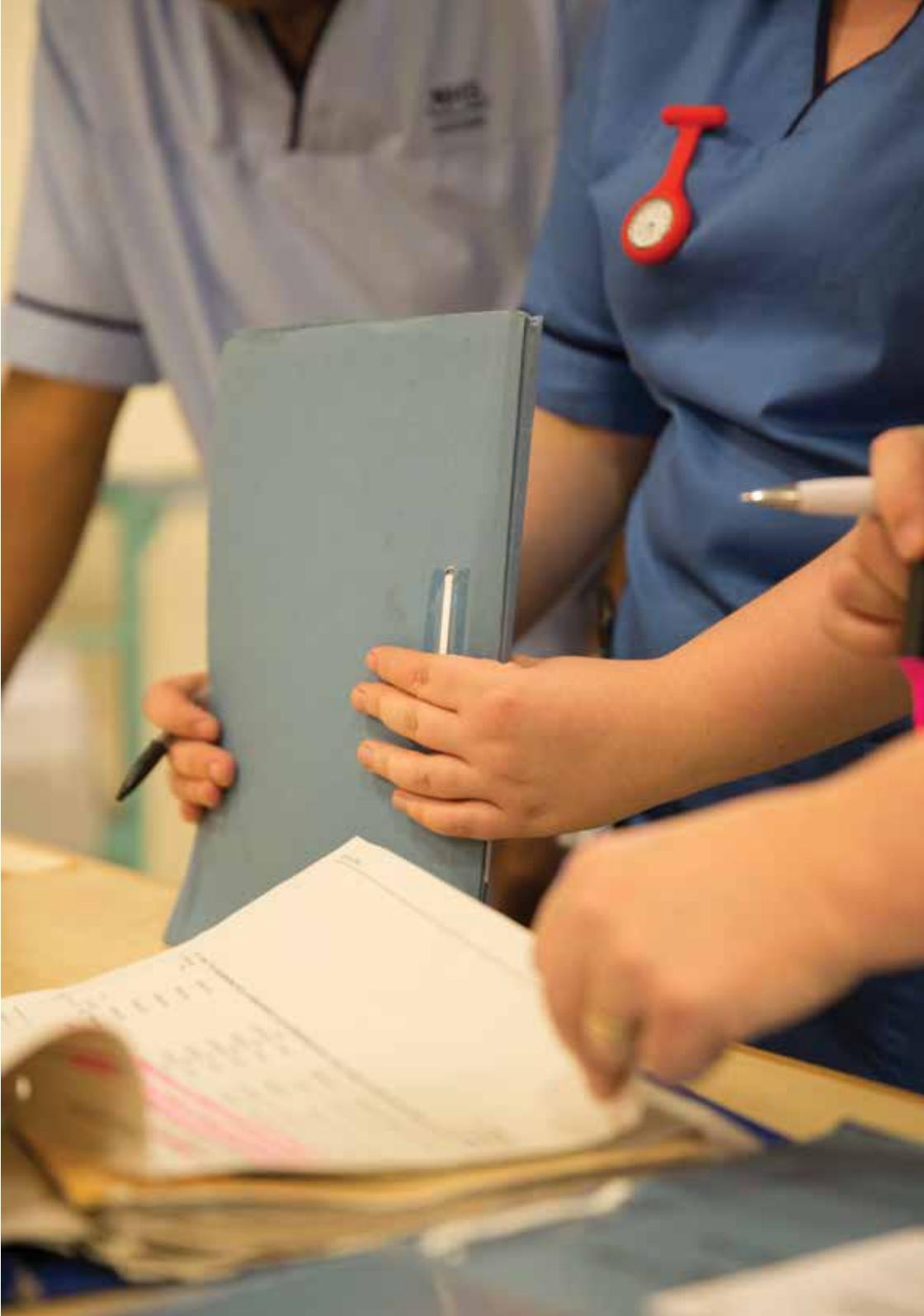
## Removing part of the bowel

If the cancer has spread to the outside of the bowel, you may also need a section of bowel removed. If possible, the surgeon removes the affected piece of bowel and joins the two remaining pieces together.

Rarely, the surgeon cannot safely join the bowel back together. Instead, they bring the upper end of the bowel out onto the skin of the abdomen. This is called a stoma. After the surgery, you wear a bag over the stoma to collect poo (stools).

If you are likely to need part of your bowel removed, your surgeon will talk to you about this before your surgery. If you need a stoma, your hospital team and a stoma nurse will give you support and advice.

We have more about stomas in our information on bowel cancer. See page 110 for details on how to order it.



## Before your operation

If you smoke, try to give up or cut down before your operation. This will help reduce your risk of chest problems and will help your wound to heal after the operation. Your GP can help you if you want to give up smoking.

You will usually go to a pre-assessment clinic a few days or weeks before the operation. You will have tests to check you are fit for surgery, such as blood tests and an echocardiogram (ECG) to check your heart.

A member of the surgical team and a specialist nurse will explain the operation to you. Make sure you discuss any questions or concerns that you have about the operation with them.

You will also see the doctor who will give you your anaesthetic (the anaesthetist). They will talk to you about the anaesthetic and explain how your pain will be controlled after the operation.

You will usually be admitted to hospital on the day of your operation. Sometimes, you may be admitted the day before. Your doctor or nurse will tell you when you need to arrive at hospital.

You will be given elastic stockings (TED stockings) to wear during and after the operation. These prevent blood clots forming in your legs.

## After your operation

How quickly you recover will depend on the type of operation you have. You will be encouraged to start moving around as soon as possible. While you are in bed, it is important to move your legs regularly and do deep breathing exercises. This is to help prevent chest infections and blood clots. A physiotherapist will show you how to do these exercises. You may also have regular injections of a blood thinning drug to help reduce the risk of blood clots. You may need to continue the injections after you go home. Your nurse will teach you or a relative how to give the injections, or arrange for a district nurse to visit you at home.

### Back on the ward

You will be given fluids into a vein in your hand or arm. This is called a drip or intravenous infusion. This will be taken out as soon as you are eating and drinking normally.

You will usually have a tube (catheter) to drain urine from your bladder. It is usually taken out a few days after your surgery, but sometimes it may need to stay in for longer.

You may have a drainage tube from your wound to drain fluid into a small bottle. This is usually removed after a few days.

## Pain

It is normal to have some pain or discomfort for a few days after surgery. But this can be controlled with painkillers. It is important to let your doctor or nurse know as soon as possible if the pain is not controlled, so that they can change your painkillers.

Immediately after your operation you may have strong painkillers. You may be given painkillers through one of the following straight after your operation:

- By injection into a muscle – The nurses will do this for you.
- An epidural – This is a small, thin tube in your back that goes into the space around your spinal cord. An epidural will give you continuous pain relief.
- A patient-controlled analgesia pump (PCA pump) – The pump is attached to a fine tube (cannula), in a vein in your arm. You control the pump using a handset that you press when you need more of the painkiller. It is fine to press the handset whenever you have pain. The pump is designed so that you cannot give yourself too much painkiller.

When you no longer need strong painkillers, you will be given milder painkillers as tablets. You may be given a supply to take home. Tell your nurse or doctor if you are still in pain, so they can adjust the dose or give you a different painkiller.

## Wind and constipation

Some women have difficulty opening their bowels or have uncomfortable wind for a few days after the operation.

Tell the nurses if you have this. They can give you medicines to relieve discomfort and constipation. Constipation and wind usually get better once you are moving around more. Drinking plenty of fluids and eating high-fibre foods can also help.

## Your wound

The surgeon will close your wound using clips, stitches or sometimes skin glue. Clips or stitches are usually removed after you go home. A practice nurse at your GP surgery can do this. Some stitches, called dissolving stitches, can be absorbed by the body and do not need to be removed.

Wound infections can be a complication of the surgery. Signs of wound infection include:

- heat
- redness
- swelling
- discharge (fluid or pus coming from the wound)
- feeling unwell
- a fever or high temperature.

Tell your nurse or doctor if you get any of these symptoms, even after you go home. If you can't talk to your hospital team, tell your GP or out of hours service.

## Going home

You may be able to go home three to seven days after your operation. It will depend on the operation you had and how quickly you recover.

Before you go home, you will be given an appointment to see the surgeon and nurse at an outpatient clinic. They will check your wound is healing and that you are recovering well.

They will also tell you more about the results of your operation and any further treatment you might need. You can ask questions and discuss any problems or worries at this appointment. But if you have any difficulties or worries before this, you can always phone them for advice.

See pages 82 to 89 for more information about what to expect after treatment.

## Vaginal bleeding

You may have some light vaginal bleeding or red-brown discharge for up to six weeks after surgery.

Tell your surgeon or specialist nurse straight away if the discharge:

- becomes bright red
- is heavy
- smells unpleasant
- contains clots.

You should not have sex or place anything in your vagina (such as tampons) for about six weeks after your surgery. You should also avoid swimming. This reduces the risk of infection and helps your wounds heal.

## Sex

After six weeks, your wounds are likely to be healed and you can have sex again. But it may take longer than this for your energy levels and sex drive to return.

If you have any worries or concerns, you can talk to your specialist nurse. You may also find it helpful to contact one of the support organisations listed on pages 115 to 120. Or call the Macmillan Support Line on **0808 808 00 00**.

## Physical activity

You will be recovering for some time after you go home, so take things easy for a few weeks. It can take three months or more to fully recover. It may take longer if you have chemotherapy as well.

For about 12 weeks, avoid any activity that:

- makes you breathless
- involves heavy lifting, pushing, pulling or stretching.

Your physiotherapist or nurse will give you advice about physical activity.

Build up your energy levels gradually. Taking regular walks is a good way of doing this. You can increase the amount you do as you feel able.

## Driving

How soon you can drive will depend on the surgery you had and how quickly you recover. You need to feel comfortable wearing a seatbelt. You also need to be able to carry out an emergency stop if necessary. Ask your nurse or doctor for advice. Some insurance companies have guidelines about this. So it is a good idea to contact your insurance company to check before you start driving again.

## Your feelings

Surgery for cancer of the ovary, fallopian tube or peritoneum is usually a major operation. It is natural to feel low or tearful after these types of surgery. You are likely to feel tired. Your body needs time to recover and heal. This can make it harder to cope with the stress of having cancer and the difficult emotions you may be feeling.

As you recover, you may find it is easier to cope. It can help to talk about how you feel and get more support. Talk to your specialist nurse or call our cancer support specialists on **0808 808 00 00**.



# Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. This treatment is often used to treat cancer that starts in the ovaries, fallopian tubes or peritoneum.

You may have chemotherapy:

- after surgery to reduce the risk of the cancer coming back (adjuvant chemotherapy)
- to treat any cancer that cannot be removed during surgery
- before surgery to shrink the cancer and make the operation easier and more effective (neo-adjuvant chemotherapy)
- as a main treatment if surgery is not possible.

If the cancer comes back after your first treatments, it can often be controlled by having chemotherapy again.

## Chemotherapy drugs

A chemotherapy drug called carboplatin is often used. You have it on its own or in combination with the chemotherapy drug paclitaxel (Taxol®).

If the cancer comes back and you need chemotherapy again, you may have different drugs from the first time. It depends how long ago you had your first chemotherapy and your risk of side effects.

Other chemotherapy drugs that are used include:

- cisplatin
- docetaxel (Taxotere®)
- etoposide (VP-16®, Etopophos®, Vepesid®)
- gemcitabine (Gemzar®)
- liposomal doxorubicin (Caelyx®, Myocet®)
- topotecan (Hycamtin®).

We have more information about different chemotherapy drugs and their side effects. Visit [macmillan.org.uk](http://macmillan.org.uk) to find out more.

## Having chemotherapy

You usually have chemotherapy in the chemotherapy day unit and go home after it. The drugs are usually given into a vein (intravenously).

Chemotherapy is given as one or more sessions of treatment. Each session takes a few hours. After the session, you will have a rest period of a few weeks. The chemotherapy session and the rest period is called a cycle of treatment.

The length of a cycle depends on the chemotherapy drugs you have. But most cycles are 1 to 3 weeks long. Your cancer doctor or nurse will explain what to expect. Most courses of chemotherapy are made up of six cycles.

Our booklet Understanding chemotherapy has more information. See page 110 for details of how to order a free copy.

## Chemotherapy before surgery

You usually have three cycles of chemotherapy followed by a CT scan to check how effective treatment has been. Your surgeon will then talk to you about whether an operation is possible.

If you have surgery, you will have three more cycles of chemotherapy after you have recovered from the operation. If you do not have surgery, you will have another three cycles of chemotherapy.

## Side effects

Chemotherapy drugs may cause unpleasant side effects. But these can often be well controlled with medicines and will usually go away once treatment has finished. Not all drugs cause the same side effects, and some people may have very few. Your cancer doctor or nurse will explain what to expect.

The main side effects of chemotherapy are described on the next few pages, as well as some ways to reduce or control them.

## **Risk of infection**

Chemotherapy can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is called neutropenia.

If you have an infection, it is important to treat it as soon as possible. Contact the hospital straight away on the contact number you've been given if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection – these can include feeling shaky, a sore throat, a cough, diarrhoea or needing to pass urine a lot.

It is important to follow any specific advice your chemotherapy team gives you.

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more chemotherapy. If your white blood cell count is low, your doctor may delay your treatment for a short time.

## **Anaemia (low number of red blood cells)**

Chemotherapy can reduce the number of red blood cells in your blood. These cells carry oxygen around the body. If the number of red blood cells is low, you may be tired and breathless. Tell your doctor or nurse if you feel like this. If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

## **Bruising and bleeding**

Chemotherapy can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. Tell your doctor or nurse if you have any bruising or bleeding that you can't explain. This includes:

- nosebleeds
- bleeding gums
- tiny red or purple spots on the skin that may look like a rash.

Some people may need a drip to give them extra platelets. This is called a platelet transfusion.

## **Feeling sick**

You may feel sick in the first few days after chemotherapy. Your doctor will give you anti-sickness drugs to help prevent or control sickness. Take the drugs exactly as your nurse or pharmacist tells you. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluids and eat small amounts often. If you continue to feel sick, or if you vomit more than once in 24 hours, contact the hospital as soon as possible. They will give you advice and may change the anti-sickness drug to one that works better for you.

## **Muscle or joint pain**

You may get pain in your muscles or joints for a few days after chemotherapy. If this happens, tell your doctor so they can give you painkillers. Tell them if the pain does not get better. Having warm baths and taking regular rests may help.

## Hair loss

Some chemotherapy drugs cause hair loss. This can range from hair thinning to losing all your hair including eyelashes and eyebrows. The extent of hair loss depends on what chemotherapy drugs you have. Your doctor or nurse can tell you what to expect.

Scalp cooling is a way of lowering the temperature of your scalp to help reduce hair loss. Your nurse can tell you if this is an option for you.

Your nurse can talk to you about ways to cope with hair loss. There are lots of ways you can cover up, if you choose to, such as using wigs, hats, turbans, scarves or bandanas. It is important to cover your head to protect your scalp when you are out in the sun.

Hair loss is usually temporary, and hair grows back after treatment ends. But rarely, hair loss is permanent. Hair may not grow back or it may be thinner than before. If you are worried about this, talk to your cancer doctor or nurse.

## Numb or tingling hands or feet (peripheral neuropathy)

This treatment affects the nerves, which can cause numb, tingling or painful hands or feet. You may find it hard to fasten buttons or do other fiddly tasks.

Tell your doctor if you have these symptoms. They sometimes need to lower the dose of the drug or delay treatment for a short time. The symptoms usually improve slowly after treatment finishes, but for some people they may never go away. Talk to your doctor if you are worried about this.

## Sore mouth

You may get a sore mouth or mouth ulcers. This can make you more likely to get a mouth infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

If your mouth is sore:

- tell your nurse or doctor – they can give you a mouthwash or medicines to help
- try to drink plenty of fluids
- avoid alcohol, tobacco, and foods that irritate your mouth.

## Loss of appetite

This treatment can affect your appetite. Don't worry if you don't eat much for a day or two. But if your appetite does not come back after a few days, tell your nurse or dietitian. They will give you advice. They may give you food or drink supplements.

# Targeted therapies

Targeted therapies are drugs that use unique features of the cancer to find and treat cancer cells. They are also called biological therapies. These drugs only target the cancer cells, so they have less effect on healthy cells.

## Olaparib

Olaparib (Lynparza®) is a targeted therapy drug used if high-grade (see page 38) serous cancer has come back after other treatments.

This drug is only used if:

- tests show you have a faulty BRCA1 or BRCA2 gene (see pages 18 to 19)
- certain types of chemotherapy drug are controlling the cancer effectively.

You have a course of chemotherapy before you start olaparib. The chemotherapy gets rid of as much of the cancer as possible. You then take olaparib capsules twice a day to stop the cancer growing again. Your cancer doctor or nurse will explain how long you can keep taking olaparib.

We have more information about olaparib and its side effects on our website. Visit [macmillan.org.uk](https://www.macmillan.org.uk) to find out more.

## Bevacizumab

Bevacizumab (Avastin®) is a targeted therapy drug sometimes used to treat advanced cancer. You usually have this drug in combination with chemotherapy and then on its own. Your nurse will give it to you into a vein as an infusion (drip).

We have more information about bevacizumab and its side effects on our website.

Some people may have this drug as part of a cancer research trial (clinical trial) – see pages 77 to 79. But bevacizumab is not widely available through the NHS.

When a drug is not available through the NHS, it may still be possible to access it in some situations. Your cancer doctor can give you advice about this.

We have more information about what you can do if a treatment is not available. Visit [macmillan.org.uk](https://www.macmillan.org.uk) to find out more.

## Having radiotherapy



# Radiotherapy

Radiotherapy treats cancer by using high-energy rays to destroy the cancer cells, while doing as little harm as possible to normal cells.

Radiotherapy is rarely used to treat cancer of the ovary, fallopian tube or peritoneum. It is sometimes used to treat an area of cancer that has come back when other treatments are no longer possible.

It may also be used to control symptoms, such as bleeding, pain or discomfort. This is known as palliative radiotherapy.

Radiotherapy is given in the hospital radiotherapy department. A course of palliative treatment may be given over 1 to 10 daily sessions. Each session lasts a few minutes. The length of your treatment will depend on the type and size of the cancer. Your doctor will discuss this with you in detail.

Our booklet **Understanding radiotherapy** has more details. See page 110 for information on how to order a free copy.

# Ascitic drainage

Cancer that starts in the ovary, fallopian tube or peritoneum can cause a build up of fluid in the tummy area (abdomen). The fluid collects in between the two layers of the peritoneum (see diagram on the opposite page). This is called ascites. If ascites is making you feel uncomfortable, the fluid can be drained. This is called ascitic drainage or paracentesis.

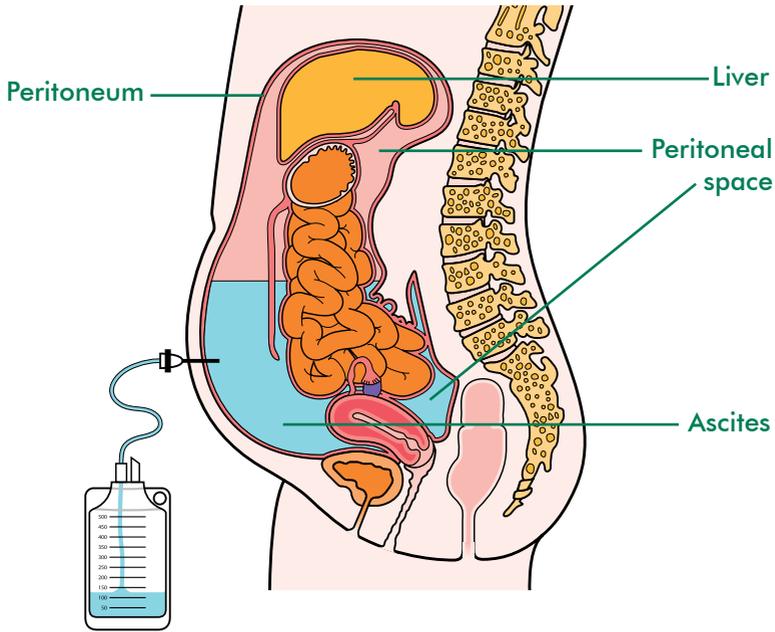
Once you are lying down comfortably, the doctor will clean the skin on your tummy. They will give you an injection of local anaesthetic to numb the area.

The doctor will make a small cut in the skin of your tummy and insert a thin tube. The fluid drains out of your tummy and collects in a drainage bag. The tube is covered with a dressing. Sometimes, the doctor may use a few stitches to hold it in place.

How long the tube needs to stay in place depends on how much fluid needs to be drained. While the tube is in place, a nurse will check how much fluid is draining. If there is just a small amount of fluid, you may have it drained off in an outpatient clinic. If there is a large amount of fluid, you may need to have a short stay in hospital. The drain usually only stays in for a few hours, but sometimes it can stay in for a few days if needed.

Fluid can build up again, so you may need to have it drained more than once.

## Fluid being drained from the tummy (ascitic drainage)



## Possible problems

When the fluid is being drained, your blood pressure may drop. Your nurse will check your blood pressure as the fluid drains. They may slow or stop the speed it is draining. A litre of fluid may be drained safely as soon as the drain has been inserted. After this, it will usually be done more slowly.

The tube can become blocked. Changing your position or sitting upright may help clear it, but sometimes the tube may need to be replaced.

The drain can sometimes become infected. Your temperature will be checked regularly, as a high temperature can be a sign of infection.

Once the drain is removed, there may be a bit of leakage from the drain site until the hole heals. You will have a dressing or drainage bag over the area until the leakage has stopped.

# Research – clinical trials

Cancer research trials are carried out to try to find new and better treatments for cancer. Trials that are carried out on patients are known as clinical trials. These may be carried out to:

- test new treatments, such as new chemotherapy drugs or targeted therapies
- look at new combinations of existing treatments, or change the way they are given to make them more effective or reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- find out which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different type of surgery, chemotherapy, hormone therapy, radiotherapy, or other treatment is better than what is already available.

## Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and develop new treatments. You will be carefully monitored during and after the study.

Usually, several hospitals around the country take part in these trials. It's important to bear in mind that some treatments that look promising at first are often later found not to be as good as existing treatments or to have side effects that outweigh the benefits.

If you decide not to take part in a trial, your decision will be respected and you don't have to give a reason. However, it can help to let the staff know your concerns so that they can give you the best advice. There will be no change in the way that you're treated by the hospital staff, and you'll be offered the standard treatment for your situation.

Clinical trials are described in more detail in our booklet **Understanding cancer research trials (clinical trials)**. We can send you a free copy. See page 110 for ordering details.

## Blood and tumour samples

Blood and tumour samples may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you take part in a trial you may also give other samples, which may be frozen and stored for future use when new research techniques become available. Your name will be removed from the samples so you can't be identified.

The research may be carried out at the hospital where you are treated, or at another one. This type of research takes a long time, and results may not be available for many years. The samples will be used to increase knowledge about the causes of cancer and its treatment, which will hopefully improve the outlook for future patients.



# AFTER YOUR TREATMENT

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## Follow-up

After your treatment, you will have regular check-ups. These are usually every few months to start with.

Your cancer doctor and nurse will ask you how you are recovering from treatment. They will ask if you have any new symptoms. If needed, you may have scans or blood tests.

You can talk to your doctor or nurse about any problems or worries at these check-ups. But if you notice new symptoms or have problems between appointments, contact them for advice sooner.

Many people find they get anxious before the appointments. This is natural. It can help to get support from family, friends or your specialist nurse. Or you can speak to our cancer support specialists on **0808 808 00 00**. Some other organisations also offer support – see pages 115 to 120 for details.

‘While I was going through treatment, I had everyone around me. But once the treatment had finished, I did feel alone and down. I am lucky that I could focus on work and get out and about. I also accessed Macmillan counselling services to deal with the emotional impact of cancer.’

**Pavitter**

## CA125 blood test

CA125 blood tests (see page 27) are sometimes done as part of your follow-up, but this is not always needed. A rising CA125 level may be a sign that the cancer has returned. But for most people, it is just as effective to wait for symptoms of cancer to develop and then start treatment again.

Starting treatment before you have symptoms:

- is no more effective at controlling the cancer
- means you will have side effects of treatment sooner.

Your cancer doctor or nurse can give you more information about this.

## Symptoms

After treatment, it can take time to work out what feels normal for you. You may worry that every ache or pain you have is a sign of cancer returning.

If you develop any new symptoms, do not wait for a follow-up appointment. Contact your specialist nurse or see your GP. They can arrange for you to be seen by your cancer doctor if needed.

If cancer comes back (recurrence), it can often be treated with more chemotherapy and sometimes more surgery. Some people will have repeat treatments to manage cancer recurrence over several years.

# Well-being and recovery

After treatment, you may just want to get back to everyday life. But you may still be coping with the side effects of treatment, adjusting to physical changes or dealing with some difficult emotions (see pages 92 to 96). Recovery takes time, so do not rush it and try to be kind to yourself.

Some people choose to make lifestyle changes to improve their health and well-being. Even if you had a healthy lifestyle before cancer, you may be more focused on making the most of your health.

## Eat healthily

A healthy, balanced diet gives you more energy and will help you to recover. Talk to your GP, specialist nurse or a dietitian if you have any special dietary or medical needs. Our booklet **Healthy eating and cancer** has more information. See page 110 for details on how to order a free copy.

## Be physically active

Being physically active after cancer treatment can:

- boost your energy levels
- keep your weight healthy
- reduce stress and fatigue.

It can also reduce your risk of:

- bone thinning, if you have had an early menopause
- health problems such as diabetes, heart disease and some cancers

Your GP or cancer doctor may be able to refer you to an exercise group for people with cancer. Ask them for advice about what is available in your local area.

Our booklet **Physical activity and cancer treatment** has more information. See page 110 for details on how to order a free copy.

'Being physically active made me feel alive and well and it took me to a place that I was familiar with. It helped me forget the trauma that I had experienced. It made me feel normal and gave me something to focus on. I turned a negative into a positive.'

**Donna**

## Stop smoking and stick to sensible drinking

If you smoke, giving up is the healthiest decision you can make. Stopping smoking reduces your risk of heart and lung disease, bone thinning (osteoporosis), and smoking-related cancers. If you want to stop, your GP can give you advice. We can send you more information about giving up smoking.

Alcohol has also been linked to a higher risk of some types of cancer and to weight gain. If you drink alcohol:

- do not regularly drink more than 14 units in a week
- spread the amount you drink in a week over three or more days
- try to have several alcohol-free days every week.

There is more information about drinking alcohol at [drinkaware.co.uk](http://drinkaware.co.uk)

## Complementary therapies

Some people use complementary therapies to help them relax or cope with treatment side effects. Some hospitals or support groups offer therapies such as relaxation or aromatherapy. Ask your cancer doctor or nurse what's available in your area. Our booklet **Cancer and complementary therapies** has more information. See page 110 for details on how to order a free copy.

# Coping with sexual changes

Cancer and cancer treatment can cause physical and emotional changes that may affect your sex life. There is no right or wrong way to feel about having sex after your treatment. But if you are finding a change difficult to cope with, there is often something that can be done to help.

Your specialist nurse can give you advice or arrange expert support if needed. Or you might find it helps to talk to our cancer support specialists on **0808 808 00 00**.

You may find our booklet **Cancer and your sex life – information for women** helpful. See page 110 for details on how to order a free copy.

# Coping with early menopause

If you have not been through the menopause already, your cancer treatment may cause this. Surgery to remove the ovaries will bring on the menopause straight away. Chemotherapy may cause it more gradually.

Some of the main physical effects of the menopause are:

- hot flushes
- vaginal dryness
- lowered sex drive (libido)
- mood changes.

This can be difficult, particularly when you are already coping with cancer. You can have treatment and support to cope with any symptoms and the emotional effects of early menopause. You can also have treatment to protect you from the long-term effects of menopause, such as brittle bones (osteoporosis) and heart disease.

You may be offered:

- advice and support from your GP or a specialist who treats women with early menopause
- treatment and advice to help you cope with symptoms
- hormone replacement therapy (HRT) or a type of hormonal contraceptive to prevent long-term effects.

Your doctor will explain the possible risks and benefits of any treatment to you. Some women cannot take HRT safely because of the type of cancer they have.

# Coping with the symptoms of advanced cancer

Treatments such as chemotherapy or surgery for advanced cancer will often improve any symptoms you have. But if you have ongoing symptoms, there are also other ways these can be controlled. Always tell your cancer doctor or nurse if you have new symptoms or if your symptoms get worse.

Many hospitals have doctors and nurses who are experts in treating pain and other symptoms (palliative care team).

We have more information about coping with advanced cancer and about managing different symptoms of cancer. See page 110 for ordering details.



# YOUR FEELINGS AND RELATIONSHIPS

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# Your feelings

It's common to feel overwhelmed by different feelings when you're told that you have cancer. We talk about some of these here. Partners, family and friends may also have some of the same feelings.

You might have different reactions to the ones we describe here. There is no right or wrong way to feel. You'll cope with things in your own way. Talking to people close to you or other people affected by cancer can often help.

## Shock and disbelief

You may find it hard to believe it when your doctor tells you that you have cancer. It's common to feel shocked and numb. You may not be able to take in much information and find that you keep asking the same questions again and again. At first, you might find it hard to talk to family and friends about the cancer. This usually gets easier as the shock wears off and it becomes more real to you. You may find you can't think or talk about anything but the cancer. This is because your mind is trying to process what you're going through.

## Fear and anxiety

People can be very anxious or frightened about whether treatment will work and what will happen in the future. This uncertainty can be one of the hardest things to cope with. It can help to try to focus on what you can control. You may want to find out more about the cancer, its treatment and how to manage side effects. It can also help to talk about your feelings and to take time to do things that are important to you and that you enjoy.

Doctors often know roughly how many people can benefit from a type of treatment. But they can't be sure what will happen to an individual person. Although they may not be able to answer your questions fully, they can usually talk through any problems with you and give you some guidance.

## Avoidance

Some people cope by not wanting to know very much about the cancer and by not talking about it. If you feel like this, let your family and friends know that you don't want to talk about it right now. You can also tell your doctor if there are things you don't want to know or talk about yet.

Occasionally, this avoidance can be extreme. Some people may not believe that they have cancer. This is sometimes called being in denial. It may stop them making decisions about treatment. If this happens, it's very important for them to get help from their doctor.

Sometimes, avoidance is the other way around. Family and friends may seem to avoid you and the fact that you have cancer. They may not want to talk about it or they might change the subject. This is usually because they are also finding the cancer difficult to cope with, and they may need support too. Try to let them know how this makes you feel and that talking openly with them about your illness will help you.

## Anger

You may feel angry about your illness and sometimes resent other people for being well. These are normal reactions, especially when you feel frightened, stressed, out of control or unwell. You may get angry with the people close to you. Let them know that you are angry at your illness and not at them. Finding ways to help you relax and reduce stress can help with anger. This can include talking about or writing down how you feel, gentle exercise, breathing or relaxation therapy, yoga or meditation.

## Guilt and blame

Some people feel guilty or blame themselves or others for the cancer. You may try to find reasons for why it has happened to you. Most of the time, it's impossible to know exactly what has caused a person's cancer. Over time, several different factors may act together to cause a cancer. Doctors don't fully understand all of these factors yet. Instead, try to focus on looking after yourself and getting the help and support you need.

## Feeling alone

Some people feel alone because they don't have enough support. Family and friends may live far away, have other commitments or feel uncomfortable because of their own fears about cancer. Try to let your family and friends know how you feel and how they could support you more.

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find out about local support groups – visit **[macmillan.org.uk/supportgroups](https://www.macmillan.org.uk/supportgroups)** You can also talk to other people going through the same thing on our Online Community at **[macmillan.org.uk/community](https://www.macmillan.org.uk/community)**

It's normal to have times when you want to be left alone to sort out your feelings. But if you find you're avoiding people a lot of the time, then try to talk to your doctor or nurse.

## If you need more help

These feelings can be very difficult to cope with and sometimes people need more help. This happens to lots of people and doesn't mean you're not coping.

If you feel anxious, panicky or sad a lot of the time, or think you may be depressed, talk to your doctor or nurse. They can refer you to a doctor or counsellor who can help. They may also prescribe medicine to help with anxiety or an antidepressant drug.

Our booklet **How are you feeling? The emotional effects of cancer** discusses the feelings you may have in more detail, and has suggestions for coping with them. See page 110 to find out how to order a free copy.

# If you are a relative or friend

Some people find it hard to talk about cancer or share their feelings. You might think it's best to pretend everything is fine, and carry on as normal. You might not want to worry the person with cancer, or you might feel you're letting them down if you admit to being afraid. Unfortunately, denying strong emotions can make it even harder to talk, and may lead to the person with cancer feeling very isolated.

Partners, relatives and friends can help by listening carefully to what the person with cancer wants to say. It may be best not to rush into talking about the illness. Often it's enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking, to help friends and family support their loved ones affected by cancer. Visit [macmillan.org.uk/learnzone](https://www.macmillan.org.uk/learnzone) to find out more.

Our booklet **Talking to someone who has cancer** has more suggestions if you have a friend or relative with cancer. See page 110 for details on how to order a free copy.

If you're looking after a family member or friend with cancer, you may find our booklet **Looking after someone with cancer** helpful. It's based on carers' experiences and has lots of practical tips and information.

We have more information about supporting someone with cancer at [macmillan.org.uk/carers](https://www.macmillan.org.uk/carers)



# Talking to children

Deciding what to tell your children or grandchildren about your cancer is difficult. An open, honest approach is usually best. Even very young children can sense when something is wrong, and their fears can sometimes be worse than the reality.

How much you tell your children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information, and gradually tell them more to build up a picture of your illness.

## Teenagers

Teenagers can have an especially hard time. At a stage when they want more freedom, they may be asked to take on new responsibilities and they may feel over-burdened. It's important that they can go on with their normal lives as much as possible and still get the support they need.

If they find it hard to talk to you, you could encourage them to talk to someone close who can support and listen to them, such as a grandparent, family friend, teacher or counsellor. They may also find it useful to look at the website [riprap.org.uk](http://riprap.org.uk) which has been developed especially for teenagers who have a parent with cancer.

Our booklet **Talking to children and teenagers when an adult has cancer** has more information. See page 110 for details on how to order a copy.

# What you can do

One of the hardest things to cope with can be the feeling that the cancer and its treatment have taken over your life. This is a common feeling, but there are lots of things you can do.

There may be days when you feel too tired to even think about what could help. You'll have good and bad days, but if you're overwhelmed by these feelings, let your doctor or nurse know. It may be that you have depression, and this is treatable so they should be able to help.

## Finding ways to cope

You may find it helps to try to carry on with life as normally as possible, by staying in contact with friends and keeping up your usual activities. Or you may want to decide on new priorities in your life. This could mean spending more time with family, going on the holiday you've dreamed about or taking up a new hobby. Just thinking about these things and making plans can help you realise that you still have choices.

Some people want to improve their general health by eating a more healthy diet, by getting fitter or by finding a relaxing complementary therapy.

Understanding about the cancer and its treatment helps many people cope. It means they can discuss plans for treatment, tests and check-ups with their doctors and nurses. Being involved in these choices can help give you back control of your life.

# Who can help?

Many people are available to help you and your family.

District nurses work closely with GPs and make regular visits to patients and their families at home if needed.

The hospital social worker can give you information about social services and benefits you may be able to claim. These may include meals on wheels, a home helper or money to help with hospital transport fares. The social worker may also be able to arrange childcare for you during and after treatment.

In many areas of the country, there are also specialist nurses called palliative care nurses. They are experienced in assessing and treating symptoms of advanced cancer. Palliative care nurses are sometimes known as Macmillan nurses. However, many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you're at a clinic or in hospital.

Marie Curie nurses help care for people approaching the end of their lives in their own homes. Your GP or hospital specialist nurse can usually arrange a visit by a palliative care or Marie Curie nurse.

There's also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.



# WORK AND FINANCIAL SUPPORT

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# Financial help and benefits

If you are struggling to cope with the financial effects of cancer, help is available.

If you cannot work because you are ill, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks of sickness. If you qualify for it, they cannot pay you less.

Before your Statutory Sick Pay ends, or if you do not qualify for it, check whether you can get Employment and Support Allowance (ESA). This benefit is for people who cannot work because they are ill or disabled. There are two different types of ESA:

- contribution-based (contributory) – you can get this if you have paid enough national insurance
- income-related (means tested) – you can get this if you don't qualify for contribution based ESA or if your income is low.

ESA is gradually being replaced by a new benefit called Universal Credit. This benefit is for people below retirement age who are out of work or on a low income.

Personal Independence Payment (PIP) is a new benefit for people aged between 16 and 64. It is for people who have problems moving around and looking after themselves. You must have had these difficulties for at least three months and expect them to last for at least nine months. PIP replaces an older benefit called Disability Living Allowance (DLA) for adults.

Attendance Allowance (AA) is for people aged 65 or over who have problems looking after themselves. You may qualify if you have problems with personal care, for example getting out of bed, having a bath or dressing yourself. You don't need to have a carer, but you must have had these problems for at least six months. If you are terminally ill, and may be expected to live for less than six months, you can apply for PIP, DLA or AA under the special rules. It does not have to be certain and it does not matter if you live longer than six months. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

## Help for carers

Carer's Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you don't qualify for it, you can apply for Carer's Credit. This helps you to build up qualifying years for a State Pension.

## More information

The benefits system can be hard to understand, so it's a good idea to talk to an experienced welfare rights adviser. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**.

We've just listed some benefits here, but there may be others you can get. You can find out about state benefits and apply for them online at **gov.uk** (England, Wales and Scotland) and **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines or Citizens Advice (see pages 118 to 119).

Our booklet **Help with the cost of cancer** has more detailed information. You might also find our video at **macmillan.org.uk/gettingfinancialhelp** useful.

## Insurance

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on pages 118 to 119.

Our booklets **Insurance** and **Getting travel insurance** may also be helpful.

# Work

You may need to take time off work during your treatment and for a while afterwards. It can be hard to judge the best time to go back to work, and this will depend mainly on the type of work you do and how much your income is affected. It's important to do what's right for you.

Getting back into your normal routine can be very helpful, and you may want to go back to work as soon as possible. It can be helpful to talk to your employer about the situation – it may be possible for you to work part-time or job share.

On the other hand, it can take a long time to recover fully from cancer treatment, and it may be many months before you feel ready to return to work. It's important not to take on too much, too soon. Your consultant, GP or specialist nurse can help you decide when and if you should go back to work.

## Employment rights

The Equality Act 2010 protects anyone who has, or has had, cancer. Even if a person who had cancer in the past has been successfully treated and is now cured, they are still covered by the act. This means their employer must not discriminate against them for any reason, including their past cancer. The Disability Discrimination Act protects people in Northern Ireland.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful. See page 110 for details on how to order a free copy. There's also lots more information at [macmillan.org.uk/work](http://macmillan.org.uk/work)



# FURTHER INFORMATION

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# About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

## Order what you need

You may want to order more leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets on different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer and information for carers, family and friends.

## Online information

All of our information is also available at **macmillan.org.uk/information-and-support**

There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

## Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**

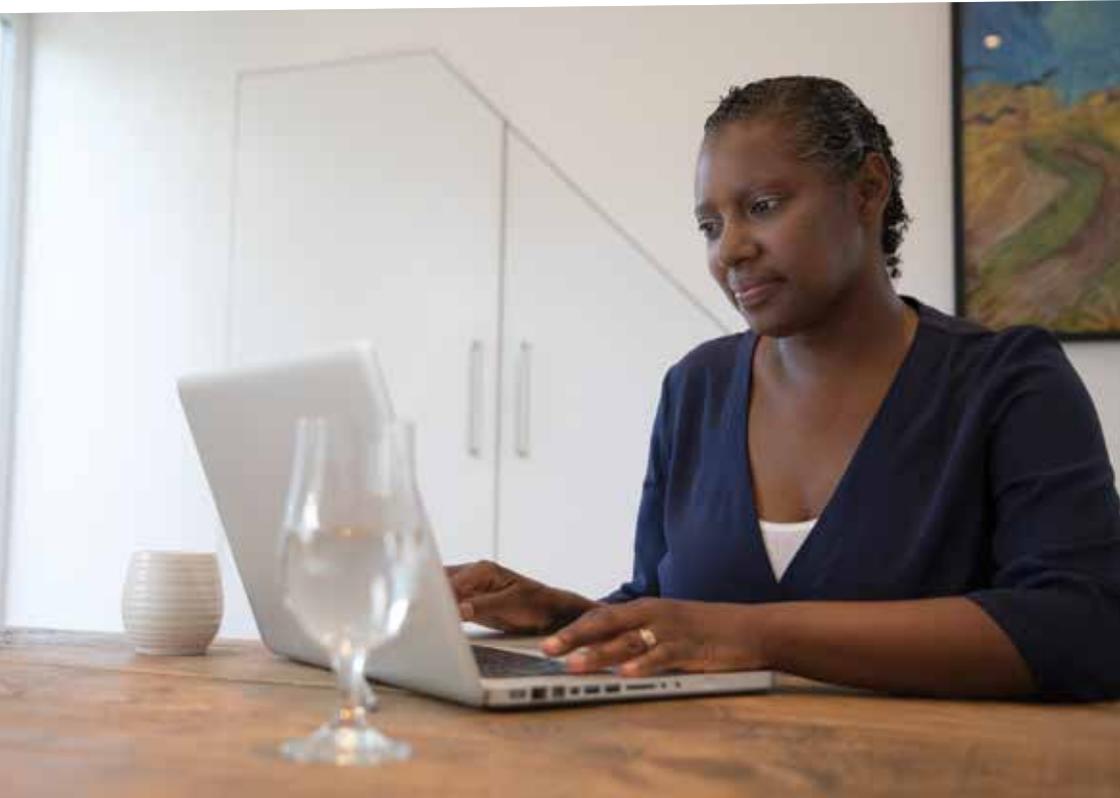
If you'd like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

## Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email [reviewing@macmillan.org.uk](mailto:reviewing@macmillan.org.uk). You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



# Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you.

## Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

### Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8 am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **[macmillan.org.uk/talktous](https://www.macmillan.org.uk/talktous)**

### Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **[macmillan.org.uk/informationcentres](https://www.macmillan.org.uk/informationcentres)** or call us on **0808 808 00 00**.

## Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That's why we help to bring people together in their communities and online.

## Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting [macmillan.org.uk/selfhelpandsupport](https://www.macmillan.org.uk/selfhelpandsupport)

## Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

## The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

Mal

## Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

### Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

### Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

### Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit **[macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport)** to find out more about how we can help you with your finances.

## Help with work and cancer

Whether you're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **[macmillan.org.uk/work](https://www.macmillan.org.uk/work)**

### My Organiser app

Our free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

# Other useful organisations

There are lots of other organisations that can give you information or support.

## Ovarian cancer support organisations

### The Eve Appeal

**Tel** 020 7605 0100

**Email** [office@eveappeal.org.uk](mailto:office@eveappeal.org.uk)

**[www.eveappeal.org.uk](http://www.eveappeal.org.uk)**

UK national charity raising awareness and funding research into the five gynaecological cancers – ovarian, womb, cervical, vaginal and vulval.

### Ovacome

**Support line** 0800 008 7054

**Email** [hello@ovacome.org.uk](mailto:hello@ovacome.org.uk)

**[www.ovacome.org.uk](http://www.ovacome.org.uk)**

National support group for everyone involved with ovarian cancer, including patients, families, friends, carers and health professionals. The Ovacome Support Line offers information and emotional support.

### Ovarian Cancer Action

**Tel** 0207 380 1730

**Email** [info@ovarian.org.uk](mailto:info@ovarian.org.uk)

**[www.ovarian.org.uk](http://www.ovarian.org.uk)**

Raises awareness of ovarian cancer and funds research into ovarian cancer. Offers a helpline for women who are concerned they have symptoms that might be caused by ovarian cancer.

### Target Ovarian Cancer

#### Target Ovarian Cancer

**Support line** 020 7923 5475

**Email** [support@](mailto:support@targetovariancancer.org.uk)

[targetovariancancer.org.uk](http://targetovariancancer.org.uk)

**[www.targetovariancancer.org.uk](http://www.targetovariancancer.org.uk)**

Dedicated to improving the survival and quality of life of women with ovarian cancer.

## Early menopause and women's health support organisations

### Daisy Network

**Email** info@

daisynetwork.org.uk

**www.daisynetwork.org.uk**

A support group for women who have early ovarian failure. The website gives information about premature menopause and related issues. It also has a mailing list for subscribers and details of other helpful groups.

### Women's Health Concern

**www.womens-health-concern.org**

Provides help and advice to women on gynaecological, urological and sexual health conditions. Offers information by email, Telephone advisory service, in print and online. Has a wide range of fact sheets and an email advice service. The charity depends on private donations and grants. They ask for a minimum donation of £10 to cover the costs of this service.

## Support with relationships and sexuality

### College of Sexual and Relationship Therapists

**Tel** 020 8543 2707

**Email** info@cosrt.org.uk

**www.cosrt.org.uk**

A national specialist charity for sex and relationship therapy. Has a list of qualified practitioners and clinics providing sex or relationship therapy in the UK.

## Counselling and emotional support

### British Association for Counselling and Psychotherapy (BACP)

**Tel** 01455 883 300

**Email** bacp@bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

## General cancer support organisations

### Cancer Focus

#### Northern Ireland

**Helpline** 0800 783 3339

(Mon to Fri, 9am to 1pm)

**Email** [nurseline@cancerfocusni.org](mailto:nurseline@cancerfocusni.org)

[cancerfocusni.org](http://cancerfocusni.org)

**[www.cancerfocusni.org](http://www.cancerfocusni.org)**

Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling, and links to local support groups.

### Cancer Support Scotland

**Tel** 0800 652 4531

(Mon to Fri, 9am to 5pm)

**Email** [info@cancersupportscotland.org](mailto:info@cancersupportscotland.org)

[cancersupportscotland.org](http://cancersupportscotland.org)

**[www.cancersupportscotland.org](http://www.cancersupportscotland.org)**

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

## General health information

### Health and Social Care in Northern Ireland

**[www.hscni.net](http://www.hscni.net)**

Provides information about health and social care services in Northern Ireland.

### Healthtalk

#### Email

[info@healthtalk.org](mailto:info@healthtalk.org)

**[www.healthtalk.org](http://www.healthtalk.org)**

**[www.healthtalk.org/](http://www.healthtalk.org/)**

**[young-peoples-experiences](http://www.healthtalk.org/young-peoples-experiences)**  
**(site for young people)**

Has information about cancer, and videos and audio clips of people's experiences. Also provides advice on topics such as making decisions about health and treatment.

### NHS Choices

**[www.nhs.uk](http://www.nhs.uk)**

The UK's biggest health information website. Has service information for England.

### **NHS Direct Wales**

**[www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)**

NHS health information site for Wales.

### **NHS Inform**

**Helpline** 0800 22 44 88

(Daily, 8am to 10pm)

**[www.nhsinform.scot](http://www.nhsinform.scot)**

NHS health information site for Scotland.

### **Patient UK**

**[www.patient.info](http://www.patient.info)**

Provides people in the UK with information about health and disease.

Includes evidence-based information leaflets on a wide variety of medical and health topics.

Also reviews and links to many health and illness-related websites.

### **Financial or legal advice and information**

#### **Benefit Enquiry Line Northern Ireland**

**Helpline** 0800 220 674

(Mon, Tues, Wed and Fri, 9am to 5pm, Thurs, 10am to 5pm)

**Textphone** 028 9031 1092

**[www.nidirect.gov.uk/money-tax-and-benefits](http://www.nidirect.gov.uk/money-tax-and-benefits)**

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

#### **Citizens Advice**

Provides advice on a variety of issues including financial, legal, housing, and employment issues. Use their online webchat or find details for your local office in the phone book or by contacting:

#### **England**

**Helpline** 03444 111 444

**[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)**

#### **Wales**

**Helpline** 03444 77 2020

**[www.citizensadvice.org.uk/wales](http://www.citizensadvice.org.uk/wales)**

**Scotland**

**Helpline** 0808 800 9060  
**www.citizensadvice.org.uk/scotland**

**Northern Ireland**

**Helpline** 0800 028 1181  
**www.citizensadvice.co.uk**

**Department for Work  
 and Pensions (DWP)  
 Personal Independence  
 Payment (PIP) Helpline**

0345 850 3322  
**Textphone** 0345 601 6677  
 (Mon to Fri, 8am to 6pm)  
**Carer's Allowance Unit**  
**Tel** 0345 608 4321

**Textphone** 0345 604 5312  
 (Mon to Thurs, 8.30am to 5pm,  
 Fri, 8.30am to 4.30pm)  
**www.gov.uk/browse/benefits**

Manages state benefits in England, Scotland, and Wales. You can apply for benefits and find information online or through its helplines.

**GOV.UK**

**www.gov.uk**  
 Has information about social security benefits and public services in England, Scotland, and Wales.

**The Law Society of  
 Northern Ireland**

**Tel** 028 9023 1614  
**Email** enquiry@lawsoc-ni.org  
**www.lawsoc-ni.org**

Provides details of solicitors in Northern Ireland. You can search a directory of solicitors on the website.

**The Law Society of Scotland**

**Tel** 0131 226 7411  
**Email** lawscot@lawscot.org.uk  
**www.lawscot.org.uk**

Provides details of solicitors in Scotland. You can search a database of solicitors on the website.

**Support for carers****Carers UK**

**Helpline  
 (England, Scotland, Wales)**  
 0808 808 7777  
 (Mon to Wed, 10am to 4pm)  
**Helpline (Northern Ireland)**  
 028 9043 9843

**Email** advice@carersuk.org  
**www.carersuk.org**

Offers information and support to carers across the UK. Has an online forum and can put people in contact with support groups for carers in their area.

## Cancer registries

### The cancer registry

A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

### National Cancer Registration and Analysis Service

**Tel** 020 7654 8000

**Email** [enquiries@phe.gov.uk](mailto:enquiries@phe.gov.uk)

**[www.ncras.nhs.uk](http://www.ncras.nhs.uk)**

**Tel (Ireland)** 021 4318 014

**[www.ncri.ie](http://www.ncri.ie) (Ireland)**

### Scottish Cancer Registry

**Tel** 013 1275 7777

**Email** [nss.csd@nhs.net](mailto:nss.csd@nhs.net)

**[www.isdscotland.org/](http://www.isdscotland.org/Health-Topics/Cancer/Scottish-Cancer-Registry)**

**[Health-Topics/Cancer/](http://www.isdscotland.org/Health-Topics/Cancer/Scottish-Cancer-Registry)**

**[Scottish-Cancer-Registry](http://www.isdscotland.org/Health-Topics/Cancer/Scottish-Cancer-Registry)**

### Welsh Cancer Intelligence and Surveillance Unit (WCISU)

**Tel** 029 2037 3500

### Email

[general.enquiries@wales.nhs.uk](mailto:general.enquiries@wales.nhs.uk)

**[www.wcisu.wales.nhs.uk](http://www.wcisu.wales.nhs.uk)**

### Northern Ireland Cancer Registry

**Tel** 028 9097 6028

**Email** [nicr@qub.ac.uk](mailto:nicr@qub.ac.uk)

**[www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr)**



## Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

## Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor, Professor David Luesley, Professor of Gynaecological Oncology.

With thanks to: Jane Evans, Macmillan nurse; Michelle Ferguson, Consultant medical oncologist; Raj Naik, Gynaecological Oncologist; Claire Parkinson, Macmillan gynaecology clinical nurse specialist; and Rae Roan, Clinical nurse specialist. Thanks also to the people affected by cancer who reviewed this edition, and to those who shared their stories.

## Sources

We've listed a sample of the sources used in the publication below. If you'd like further information about the sources we use, please contact us at **bookletfeedback@macmillan.org.uk**

Fotopoulou et al. British Gynaecological Cancer Society (BGCS) epithelial ovarian/ fallopian tube/ primary peritoneal cancer guidelines: recommendations for practice. *European journal of obstetrics, gynecology, and reproductive biology*. 2017. 213.  
National Institute for Health and Care Excellence. Ovarian cancer: recognition and initial management. Clinical guideline [CG122]. April 2011. <https://www.nice.org.uk/Guidance/CG122> (accessed June 2017).

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

# Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we're there to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.



## **Share your cancer experience**

Support people living with cancer by telling your story, online, in the media or face to face.

## **Campaign for change**

We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

## **Help someone in your community**

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

## **Raise money**

Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

## **Give money**

Big or small, every penny helps. To make a one-off donation see over.

**Call us to find out more**

**0300 1000 200**

**[macmillan.org.uk/getinvolved](http://macmillan.org.uk/getinvolved)**

**This booklet is about cancer of the ovary, fallopian tube and peritoneum. It is for anyone who has been diagnosed with one of these types of cancer. There is also information for carers, family members and friends.**

**The booklet explains the signs and symptoms of these cancers, and how they are diagnosed and treated. It also has information about emotional, practical and financial issues.**

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

**MACMILLAN  
CANCER SUPPORT**  
**RIGHT THERE WITH YOU**

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Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604).  
Also operating in Northern Ireland.



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Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box.

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.



If you'd rather donate online go to [macmillan.org.uk/donate](https://macmillan.org.uk/donate)

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ