Understanding cancer of the ovary, fallopian tube or peritoneum

> “Macmillan's information centre staff were very helpful. They provided information and a listening ear. They also organised alternative therapy and relaxation classes.”

Pavitter, diagnosed with ovarian cancer

About this booklet

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

The booklet explains about cancer that starts in the ovary, fallopian tube or peritoneum. It explains how the cancer is diagnosed and treated and how certain symptoms are managed. It also has information about:

- the different feelings you may have
- looking after your well-being
- getting support.

This booklet does not have information about a rare cancer that can spread to the peritoneum called pseudomyxoma peritonei (PMP). We have information on our website about PMP (see page 120).

We hope this booklet helps you deal with some of the questions or feelings you may have.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not 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.

On pages 125 to 133, there are details of other organisations that can help.

Quotes

In this booklet, we have included quotes from people who have had cancer of the ovary, fallopian tube or peritoneum, which you may find helpful. This includes Pavitter, who is on the cover of this booklet. These are from people who have chosen to share their story with us. To share your experience, visit **macmillan.org.uk/shareyourstory**

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**.

Help us improve our information. Scan the QR code below to tell us what you think.

Contents

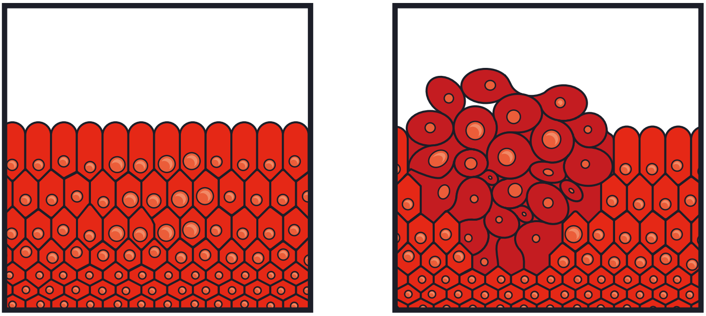
CANCER OF THE OVARY, FALLOPIAN TUBE OR PERITONEUM

What is cancer?

Cells are tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old, damaged or no longer needed. When this happens, the cell gets a signal from the body to stop working and die.

Sometimes these signals can go wrong, and the cell becomes abnormal. The abnormal cell may keep dividing to make more and more abnormal cells. These can form a lump, called a tumour.

Cells forming a tumour



Normal cells

Cells forming a tumour

Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample of cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

A tumour that is not cancer (a benign tumour) may grow, but it cannot spread to anywhere else in the body. It usually only causes problems if it grows and presses on nearby organs.

A tumour that is cancer (a malignant tumour) can grow into nearby tissue.

Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system. When these cancer cells reach another part of the body, they may grow and form another tumour. This is called a secondary cancer or a metastasis.

Some types of cancer start from blood cells. Abnormal cells can build up in the blood, and sometimes the bone marrow. This is where blood cells are made. These types of cancer are sometimes called blood cancers.

The ovaries, fallopian tubes and peritoneum

The ovaries

The ovaries are 2 small, oval-shaped organs in the pelvis (the lower area between the hips). They are on either side of the womb (uterus), close to the ends of the fallopian tubes (see page 11). The ovaries are part of the reproductive system.

Each month, one of the ovaries produces an egg. The ovaries also produce the hormones oestrogen and progesterone. These help to control the reproductive system. As you get older, the ovaries make less of these hormones. They eventually stop releasing eggs each month and your periods stop. This is called the menopause. It usually happens naturally between the ages of 45 and 55. It means you cannot get pregnant anymore.

The fallopian tubes

The fallopian tubes are 2 fine tubes that link the ovaries to either side of the womb. The egg released by an ovary travels 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.

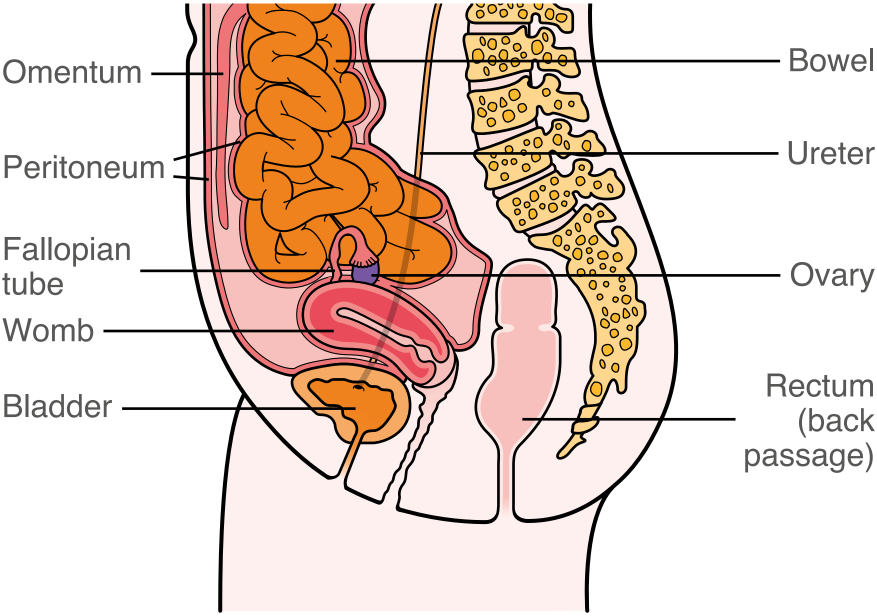
Ovarian cancer can affect anyone who has ovaries and fallopian tubes. This includes women, transgender (trans) men and people assigned female at birth.

Organs close to the ovaries and fallopian tubes

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

- the womb
- lymph nodes in the pelvis
- the bladder
- the ureters – tubes that drain pee (urine) from the kidneys to the bladder
- the back passage (rectum)
- part of the bowel.

Side view of an ovary and surrounding structures



The peritoneum

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

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 2 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.

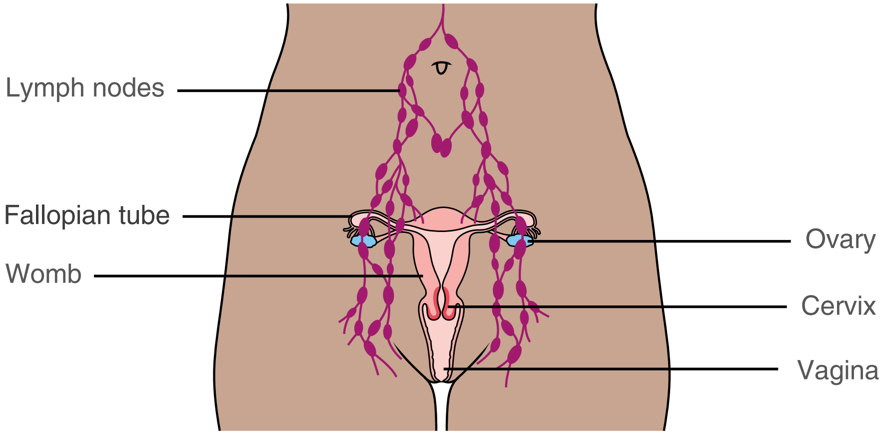
The lymphatic system

The lymphatic system helps protect us from infection and disease. It is made up of fine tubes called lymphatic vessels. These vessels connect to groups of small lymph nodes throughout the body. The lymphatic system drains lymph fluid from the tissues of the body before returning it to the blood.

Lymph nodes are sometimes called lymph glands. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, some lymph nodes may 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 spread to the lymph nodes in the pelvis or tummy.

Lymph nodes in the abdomen and pelvis



About cancer of the ovary, fallopian tube or peritoneum

About 7,400 women are diagnosed with cancer of the ovary (ovarian cancer) each year in the UK.

The surface of the ovaries, fallopian tubes and peritoneum are very close together. The tissue that covers the ovary is called epithelial tissue or the epithelium. It is made up of the same cells that line the peritoneal cavity. Sometimes it may not be clear which of these areas a cancer started in. Doctors now think most ovarian cancers start in the cells at the end of the fallopian tube and travel to the ovaries or the peritoneum.

Doctors often group cancers of the ovary, fallopian tube or peritoneum (primary peritoneal cancer) together because they are so similar. These cancers:

- cause the same symptoms
- have similar risk factors
- are treated in the same way.

Ovarian cancer can affect anyone who has ovaries and fallopian tubes. This includes women, transgender (trans) men and people assigned female at birth.

Types of ovarian cancer

There are different types of cancer that can start in the ovary, fallopian tube or peritoneum.

Epithelial ovarian cancers

The most common type of cancer to start in the ovary, fallopian tube or peritoneum is called epithelial ovarian cancer. It starts in epithelial cells, and there are different sub-types.

Serous cancer

Serous cancers are the most common type of epithelial ovarian cancer. At least 8 in 10 of all ovarian cancers (80%) are serous cancers. They are usually high grade. This means they can grow more quickly. Doctors think most high-grade serous ovarian and peritoneal tumours start at the very end of the fallopian tube. The cancer cells then spread to the ovaries and peritoneum.

A small number of serous cancers are slow growing (low grade).

Other types of epithelial ovarian cancer

The following types of epithelial ovarian cancer are much less common. They are more likely to be diagnosed at an earlier stage:

- clear cell (12% of cases)
- endometrioid (11% of cases)
- mucinous (3% of cases).

Borderline ovarian tumours

Borderline ovarian tumours are made up of abnormal epithelial cells. But these cells are not true cancers. Borderline tumours grow slowly. They are not invasive. This means they may spread to nearby tissue but do not grow in these tissues. They can also spread to other parts of the body.

Non-epithelial ovarian cancers

These cancers make up about 1 in 10 (10%) of all ovarian cancers. They usually start in cells specific to the ovaries. There are different types, including sex cord-stromal tumours and germ cell tumours. Germ cell tumours usually affect younger women.

This information is about epithelial ovarian cancer. We have separate information about germ cell tumours on our website (see page 120).

> **‘I visited A&E with extreme pain and was admitted. Diagnoses were varied, including having a kidney stone. And then I was moved to the gynae ward.’**
>
> **Pavitter, diagnosed with ovarian cancer**

Risk factors and causes

Doctors do not know what causes cancer to start in the ovary. But there are some risk factors that may increase the chances of it developing.

Doctors know less about the risk factors for fallopian tube and primary peritoneal cancers because these cancers are less common. But doctors think they are generally the same as the risk factors for epithelial ovarian cancer.

Having a risk factor does not mean you will get cancer. And if you do not have any risk factors, this does not mean you will not get cancer.

Age

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

Hormonal factors

Doctors think the number of times an ovary releases an egg (ovulates) may be linked to ovarian cancer risk. This is because there is evidence that having children, breastfeeding, and taking the contraceptive pill reduce the risk of ovarian cancer.

Hormone replacement therapy (HRT)

Taking HRT after the menopause slightly increases the risk of ovarian cancer. About 4 in 100 cases (4%) may be linked to taking HRT. But doctors think this is only for serous and endometrioid ovarian cancers.

Breast cancer

If you have had breast cancer, you may be more likely to develop ovarian cancer. This may be because these cancer types share the same risk factors. But doctors think it may be because both cancers can be caused by the same cancer genes (see page 17).

Other conditions

Some other conditions can increase your risk of developing ovarian cancer.

Diabetes

Having diabetes may increase the risk of developing ovarian cancer.

Endometriosis

Endometriosis is a non-cancerous condition. With this condition, cells similar to the cells that line the womb are found in areas outside the womb. Having endometriosis may slightly increase the risk of endometrioid and clear cell ovarian cancers (see pages 13 to 14). These types of ovarian cancer are often diagnosed earlier.

Lifestyle factors

There are also some lifestyle factors that can increase your risk of developing ovarian cancer.

Weight

Being overweight (obese) may increase the risk of some ovarian cancers.

Smoking

Smoking cigarettes may slightly increase the risk of developing 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.

Family history of ovarian cancer

Having a family history of ovarian cancer can increase your risk of developing it. If your mother or sister has had ovarian cancer, your risk may be up to 3 times higher. If they were diagnosed at a young age, your risk may be higher.

We have more information for people who are worried about a family history of ovarian cancer in our booklet **Cancer and genetics – how cancer sometimes runs in families** (see page 120). 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

Around 5 to 15 out of 100 ovarian cancers (5 to 15%) are thought to be caused by a change (mutation) in a gene that is passed on in the family. Genes contain our genetic information, which is passed on from our parents. Some cancers, such as ovarian, breast, bowel and womb cancers, may affect several people in the same family. They may develop at a younger age.

BRCA1 and BRCA2

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

If you have a mutation in the BRCA1 gene, your risk of developing ovarian cancer is up to 65% higher. With BRCA2, it is up to 35% higher.

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.

Rare genetic conditions

Lynch syndrome and Peutz-Jeghers syndrome are both rare genetic conditions that affect some families. They can increase the risk of some cancers, including ovarian cancer.


ONE DAY at a time

Symptoms

Cancer of the ovary, fallopian tube or peritoneum usually causes symptoms that are similar to common non-cancerous conditions. This can make it difficult to diagnose early.

If you have any of these symptoms or get these symptoms regularly, your GP should offer you cancer tests:

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

Other symptoms may include:

- a change in your normal bowel function (diarrhoea or constipation)
- weight loss for no obvious reason
- unexplained or extreme tiredness (fatigue)
- vaginal bleeding after the menopause.

If you are aged 50 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 function. But it does not usually start after the age of 50.

Transgender (trans) men

If you are a trans man and have not had surgery to remove the womb, ovaries and fallopian tubes, you are still at risk of ovarian cancer.

If you are worried about ovarian cancer, have any of the symptoms, or have a family history, talk to your GP.

The LGBT Foundation can give you confidential advice and support (see page 131). You can also talk to one of our cancer support specialists on **0808 808 00 00**, 7 days a week, 8am to 8pm.

> **‘I had lost a lot of weight rather quickly and also my tummy had started to swell up. But I didn’t think I had cancer.’**
>
> **Louise**

DIAGNOSING CANCER OF THE OVARY, FALLOPIAN TUBE OR PERITONEUM

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 and do an internal (vaginal) examination (see page 26) to check for any lumps or swelling.

After examining you, your GP will usually arrange for you to have the following tests:

- A blood test, to check a protein called CA125 – The levels of this protein may be higher if you have ovarian cancer.
- An ultrasound scan – This uses sound waves to produce a picture of the organs in the pelvis. You have this if your CA125 levels are raised (35 IU/ml or above).

If the ultrasound results show any abnormal areas, your GP will arrange for you to see a specialist doctor within 2 weeks. This will be a gynaecologist, who treats problems with the female reproductive system.

If your CA125 and ultrasound results are normal, but your symptoms continue or get worse, your GP can refer you to see a specialist.

If your GP finds a lump in your pelvis or fluid in your tummy (ascites), they will refer you to a specialist straight away.

Some people are diagnosed with cancer after being admitted to hospital with a symptom that is making them very unwell.

At the hospital

The specialist doctor will ask about:

- your general health
- any previous health problems
- if you have any history of cancer in your family.

They will do another internal examination. Your GP usually does a CA125 blood test and an ultrasound scan. But if you have not had these, the specialist doctor will arrange for you to have them.

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

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

If the results show there may be a cancer, your doctor will arrange further tests, such as a CT scan (see page 28). The results help your doctors diagnose the cancer and plan your treatment.

You will usually also meet a specialist nurse. They can give you advice and support. Your doctor or nurse will explain which tests you need.

Tests

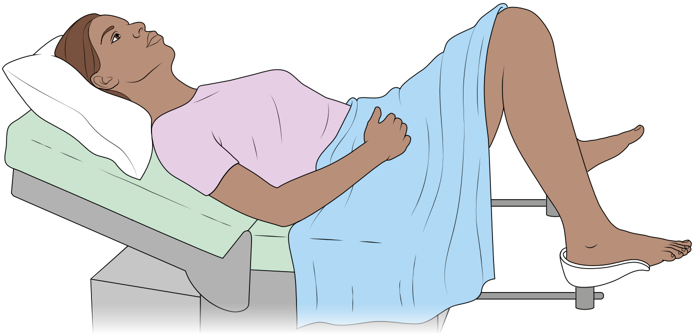
Internal (vaginal) examination

Your doctor will do an internal examination to check for any lumps or swelling in the ovaries or womb. This takes about 5 minutes. It should not be painful, but it may be uncomfortable.

When you are ready, you undress from the waist down. You then lie on your back on an examination couch. Some clinics have couches with foot or leg supports that you can rest your legs up on. You will be asked to lie with your knees bent and apart.

The doctor places 1 or 2 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 to check that your cervix looks normal.

Having an internal examination



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

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 levels may be higher if you have ovarian cancer. CA125 can also be raised due to non-cancerous conditions and other types of cancer.

In early ovarian cancer, CA125 levels may be normal.

Ultrasound scan

An ultrasound scan uses sound waves to create a picture of the organs in the pelvis and tummy area. 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 either a pelvic ultrasound or a vaginal ultrasound. Or you may have them together:

- **Pelvic ultrasound** – You will be asked to drink plenty of fluids before this scan so that your bladder is full. The person doing the scan will spread a gel onto your tummy. They will then gently press a small, hand-held device that produces sound waves against your skin.
- **Vaginal ultrasound** – The person doing the scan will gently put a small ultrasound probe into the vagina. The probe is about the size of a tampon. It produces the sound waves. Although this scan sounds uncomfortable, you may find it easier than a pelvic ultrasound, as you do not need to have a full bladder.

CT scan

A CT scan makes a three-dimensional (3D) picture of the inside of the body using x-rays taken by the CT scanner. It uses a small amount of radiation. This is very unlikely to harm you. It will not harm anyone you come into contact with.

You will get an appointment letter telling you if you need to do anything before the scan. You may be asked not to eat or drink for a few hours before the scan. If this is a problem for you, call the number on your appointment letter.

You have the scan at the hospital. The person who works the scanner is called a radiographer. They help you prepare for the scan. You may have a drink or injection of a dye. This is called a contrast. It helps show certain areas of the body more clearly. The contrast may make you feel hot all over for a few minutes. It is important to let your doctor know if you are allergic to iodine or have asthma. This is because you could have a more serious reaction.

The scan takes 5 to 10 minutes, but you may be in the department for longer. You will lie very still on a narrow bed. The bed moves slowly back and forward through the donut-shaped scanner.

Removing fluid from the tummy

Sometimes a build-up of fluid can cause swelling or bloating in the tummy. This is called ascites. It can be caused by cancer and some 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 gives you an injection of local anaesthetic to numb the area. They will then 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 tummy, it can be uncomfortable. Your doctor may remove it. This is called ascitic drainage.

We have more information about draining fluid from the tummy (see pages 82 to 83).

Having a CT scan

Biopsy

If your first treatment is surgery, you have biopsies taken during the operation. If your doctor thinks you need chemotherapy first, you usually have a biopsy before treatment. This means removing a small sample (biopsy) from the lump or abnormal area. If your scan or blood tests results are not typical of ovarian cancer, you may have a biopsy first. This is so your doctor can be certain of the diagnosis before surgery.

The biopsy is looked at under a microscope to check for cancer cells. The results of your biopsy also tell your doctor about the type, stage and grade of the cancer (pages 34 to 37).

Image-guided fine needle biopsy

A doctor (radiologist) or nurse numbs your skin using a local anaesthetic injection. They may also give you a sedative to help you relax. The doctor passes a fine needle through the skin, using a CT or ultrasound scan to guide them to the right place. They remove a small sample of tissue or cells from the abnormal area with the needle. Sometimes they take a biopsy through the vagina, using an ultrasound scan to guide them to the area.

You usually stay in hospital for a few hours after this test. But sometimes you need to stay overnight.

Laparoscopy (keyhole surgery) biopsy

A laparoscopy is sometimes called keyhole surgery. You have it under a general anaesthetic. The surgeon makes 3 or 4 small cuts about 1cm long in your lower tummy area. They pump some gas into the tummy to lift up the tummy wall so they can see the organs clearly. After this, they put a thin tube called a laparoscope through one of the cuts. This has a tiny camera on the end. It allows the surgeon to examine the area carefully and take biopsies.

You can usually go home the same day after a laparoscopy. But you may have discomfort in your neck or shoulder for 1 or 2 days afterwards. Walking about may help with the discomfort. You may have cramps or painful wind. Sipping peppermint water and moving around can help reduce these effects.

Laparotomy

Sometimes you have an operation called a laparotomy to get a biopsy. The surgeon uses 1 larger cut to open the tummy and look inside. If they find a cancer, they may remove it. This is only done if you and your doctor have discussed it and you have agreed (consented) – to it before the operation (see page 49).

Genetic testing

Your doctor and nurse may talk to you about having a blood test for genetic testing. This is to find out if you have a change (mutation) in the BRCA genes (see page 18) that can cause ovarian cancer. This helps your doctor decide whether certain targeted therapy drugs could be helpful treatments for you.

We have more information about cancer and genetic changes on our website (see page 120).

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 a support organisation (see pages 125 to 133) can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**, 7 days a week, 8am to 8pm.

> ‘When I was diagnosed, I was scared, angry and confused. And to a certain extent, I felt relieved. I finally had a reason for all the symptoms I was feeling, and a plan of action for what needed to be done.’
>
> **Laura, diagnosed**
> **with ovarian cancer**

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 (see page 133). 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.

Staging and grading

Knowing the stage and grade of the cancer helps your doctors plan the best treatment for you.

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 test results, such as your CT scan (see page 28), to decide the stage of the cancer.

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

Stage 1

This is early cancer.

Stage 1a

The cancer is only in 1 ovary or fallopian tube (see page 9).

Stage 1b

The cancer is in both ovaries or both fallopian tubes.

Stage 1c

The cancer is in 1 or both ovaries or fallopian tubes.
1 or more of the following has also happened:

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

Stage 2

The cancer is in 1 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 1 or both ovaries or fallopian tubes, or in the peritoneum. It has also spread to:

- the lymph nodes at the back of the tummy (retroperitoneal nodes) – see page 11
- the peritoneum outside the pelvis.

Stage 3a1

The cancer has spread to the lymph nodes in the tummy.

Stage 3a2

Very small amounts of cancer have spread to the peritoneum, outside the pelvis. There may also be cancer in the lymph nodes in the tummy.

Stage 3b

There are areas of cancer on the peritoneum, outside the pelvis. These areas are less than 2cm in diameter. There may also be cancer in the lymph nodes in the tummy.

Stage 3c

There are areas of cancer on the peritoneum, outside the pelvis, that are larger than 2cm in diameter. There may also be cancer in the lymph nodes in the tummy. The cancer may have spread to the capsule surrounding the liver and spleen, but not inside these organs.

Stage 4

The cancer has spread to other parts of the body outside the tummy.

Stage 4a

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

Stage 4b

The cancer has spread to the inside of the liver or spleen. Or the cancer has spread to lymph nodes or organs outside the tummy, such as the lungs.

Grading

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

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

- **Low grade or well differentiated (grade 1)** – The cancer cells look very like 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 usually grow more quickly.

Most epithelial ovarian cancers are high-grade serous (see page 13).

Doctors do not stage or grade borderline tumours. This is because they are made up of abnormal cells rather than cancer cells.

TREATING CANCER OF THE OVARY, FALLOPIAN TUBE OR PERITONEUM

Treatment overview

The main treatments for cancer that starts in the ovary, fallopian tube or peritoneum are surgery, chemotherapy and targeted therapies.

Depending on the stage of the cancer (see pages 34 to 37), the aim of treatment may be to cure the cancer or to control it for as long as possible. Your specialist doctor and nurse will explain the aim of treatment to you.

Sometimes other treatments such as hormonal therapy (see page 81) or radiotherapy (see page 80) are used to improve symptoms. Your specialist doctor may also talk to you about taking part in a clinical trial to research newer treatments (see pages 86 to 87).

The treatment you have will depend on:

- the type of cancer you have
- its stage and grade
- your general health
- your personal preferences.

Cancer treatments can cause an early menopause (see page 97) and affect your fertility (ability to get pregnant) – see page 98. If you still want to be able to get pregnant, talk to your specialist doctor before treatment starts.

We have more information about fertility and cancer treatment and about coping with the menopause (see page 120).

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 these tumours rarely come back.

Rarely, borderline tumours spread and behave more like a low-grade cancer (see page 37). If this happens, you may not need more treatment. But you may have chemotherapy Ovacome (see page 125) has more detailed information about borderline ovarian tumours.

Treating stage 1 cancer

Some stage 1 cancers in the ovary or fallopian tube (see page 35) can be cured with surgery alone. Depending on the stage and grade of the cancer, you may have surgery to remove only the affected ovary and fallopian tube. This means you can still get pregnant in the future.

If the cancer is stage 1c or high grade, your doctor may advise you to have chemotherapy after surgery. This is to reduce the risk of the cancer coming back.

Treating stage 2 to 4 cancer

You will usually have surgery and chemotherapy or chemotherapy on its own. You may also have treatment with a targeted therapy drug.

Surgery

You usually have surgery to remove as much of the cancer as possible. If the cancer has spread to other areas in the pelvis, you may need more surgery. Sometimes you have chemotherapy before surgery to shrink the cancer and make it easier to remove.

Chemotherapy

You have chemotherapy to:

- shrink the cancer before surgery
- treat any remaining cancer cells that cannot be seen during surgery
- shrink any cancer that could not be removed during surgery.

If you have chemotherapy before surgery, you have a scan mid-way through the course of chemotherapy treatment. If the cancer has shrunk enough, you have surgery before having more chemotherapy. If not, you finish the whole course of chemotherapy.

Sometimes chemotherapy may be the only treatment you have. This is usually when it is not possible to remove the cancer or if you are not well enough for surgery.

Targeted therapy drugs

You may have targeted therapy drugs (see pages 76 to 79) after chemotherapy to keep the cancer under control. Drugs called PARP inhibitors are often used. You take them as tablets for as long as they are working for you. This is called maintenance treatment.

You may have a drug called bevacizumab (Avastin®) as a drip, along with chemotherapy or on its own. You may also have it with a PARP inhibitor drug.

Having chemotherapy

Treating cancer that comes back

If cancer comes back, it can usually be treated again with more chemotherapy, targeted therapies and sometimes more surgery.

You may have several courses of chemotherapy and targeted treatments spaced over several years. This can help to keep the cancer under control and improve any symptoms. Sometimes you can have hormonal therapy if you do not want further chemotherapy, or want to delay it.

Treating symptoms of advanced cancer

Sometimes ovarian cancer may cause some discomfort or pain. It may also cause fluid to gather in the tummy (see pages 82 to 83), and bowel problems. But these symptoms can be treated and controlled. For example, you may have radiotherapy to reduce pain or bleeding in the pelvis. If you have fluid in the tummy (ascites), your doctor can drain it away to make you feel more comfortable.

Your specialist doctor and nurse will help to make sure your symptoms are controlled. This is called supportive or palliative care. You may see a specialist palliative care doctor or nurse for expert help with your symptoms.

We have more information in our booklet **Coping with advanced cancer** (see page 120).

How your treatment is planned

After your test results, you and your doctor start to talk about your treatment. Your doctor usually meets with other specialists to get their opinions too.

Multidisciplinary team (MDT) meeting

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT).

The MDT look at national treatment guidelines or the latest evidence for the type of cancer you have. If you have any treatment preferences, your doctor will tell them about this.

The MDT will usually include the following professionals:

- 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 specialist nurse – A nurse who offers support, information and advice if you have a gynaecological cancer.
- A radiologist – A doctor who analyses x-rays and scans to diagnose problems.
- A pathologist – A doctor who looks at cells or body tissue under a microscope to diagnose cancer.

The MDT may also include the following healthcare professionals:

- dietitians
- physiotherapists
- occupational therapists
- radiographers
- psychologists
- counsellors.

Talking about your treatment plan

After the MDT meeting, you will usually see your specialist doctor and nurse. They will talk to you about your treatment plan. It can help to write down your questions before you see them. You may want to ask a family member or friend to come with you. They can help remember what is said and talk with you about it afterwards. You need to know as much as possible before you can make any treatment decisions.

Your specialist doctor should explain:

- the aim of the treatment – whether it is to cure the cancer or control it
- the benefits of the treatment
- the disadvantages of the treatment – for example, the risks and side effects
- any other treatments that may be available
- what may happen if you do not have the treatment.

Cancer treatments can be complex. It can also be hard to concentrate on what you are being told if you are feeling anxious. If the doctor says something you do not understand, ask them to explain it again.

Most people worry about the side effects of treatment. Your doctor or nurse will explain how side effects can be controlled and what you can do to manage them. They can also tell you if your treatment is likely to cause any late effects and how these can be managed.

You may need more than one meeting with your doctor or nurse to talk about your treatment plan.

Making treatment decisions

You and your doctor can decide together on the best treatment plan for you. Your doctor is an expert in the best treatments. But you know your preferences and what is important to you. You can decide how involved you want to be in your treatment plan.

Sometimes doctors need to review a treatment plan. This may be when more information about the cancer becomes available – for example, when the doctor knows the results of surgery to remove the cancer. It may mean making more decisions with your doctor.

Decisions about advanced cancer

For advanced cancer, the aim of treatment is to control the cancer, help you live for longer and improve symptoms.

This can mean you have different treatments depending on when you need them. You may have long periods in between treatments when you feel well and can continue with everyday life. You may have ongoing treatment to control the cancer. This is sometimes called maintenance treatment.

Your doctor can often give you an idea about how well a treatment will work. You may decide to have one treatment instead of another because:

- the side effects are different
- it means you will spend less time at the hospital.

We have more information about making treatment decisions on our website. Visit **macmillan.org.uk/making**

You may need to have a treatment for a while to see if it is helping. Doctors will try to avoid you having unnecessary side effects from a treatment that is not working well.

If it becomes difficult to control the cancer, you may decide not to have further treatment. Your doctor and nurse will support you and make sure your symptoms are managed.

We have more information about coping with advanced cancer on our website. Visit **macmillan.org.uk/advanced**

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan.

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken (verbal) agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

Second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your specialist doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your specialist doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website. Visit **macmillan.org.uk/second-opinion**

Surgery

Surgery is one of the main treatments for cancer of the ovary, fallopian tube or peritoneum. You have surgery to remove the cancer. But it also helps doctors to:

- diagnose the type of cancer (see pages 13 to 14)
- find out more about its stage (see pages 34 to 37).

You usually have surgery to remove the following:

- the ovaries
- the fallopian tubes
- the womb
- the omentum
- lymph nodes.

If the cancer has spread to other areas in the pelvis, you may need more surgery. Sometimes you have chemotherapy before surgery (see page 65) to shrink the cancer and make surgery easier. If the cancer comes back, it may be possible to have more surgery.

If you have a very early-stage cancer and want children, it may be possible to have only the affected ovary and fallopian tube removed. This is called fertility-sparing surgery (see page 54).

A surgeon called a gynaecological oncologist will do your surgery (operation). Before you have surgery, your surgeon and nurse will talk it over with you and answer any questions. It is important you understand what your operation may involve.

Surgery to remove the cancer

The surgeon aims to remove all the cancer or as much of it as possible. During the operation, they usually remove:

- the ovaries and fallopian tubes (bilateral salpingo-oophorectomy)
- the womb and cervix (total hysterectomy)
- the omentum (omentectomy).

The surgeon will also check how far the cancer has spread. This is important because it tells them more about the stage of the cancer. During surgery, they:

- take samples of tissue (biopsies) from other areas nearby
- remove some lymph nodes in the tummy and pelvis
- put fluid into the tummy and collect it to test for cancer cells – this is called abdominal or peritoneal washing.

You may also need surgery to other areas to remove as much of the cancer as possible. This depends on where the cancer has spread in the pelvis.

Removing as much of the cancer as possible

Many cancers of the ovary, fallopian tube or peritoneum have spread when they are diagnosed. If the cancer has spread to other areas in the pelvis or tummy, it may not be possible to remove it all. Your surgeon will try to remove as much of the cancer as they can. Doctors sometimes call this debulking or cytoreductive surgery.

Removing part of the bowel

If the cancer has spread to the bowel, you may also need a section of bowel removed. If possible, the surgeon removes the affected piece of bowel and joins the 2 remaining pieces together. This is called a bowel re-join.

Sometimes the surgeon cannot safely join the remaining pieces of bowel together. Instead, they bring the upper end of the bowel out onto the skin of the tummy. This is called a stoma. After the operation, you wear a bag over the stoma to collect stools (poo). A stoma can be temporary to protect the bowel re-join. Or it may be permanent if a safe bowel re-join is not possible.

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

We have more information about having a stoma on our website (see page 120).

Surgery to protect your fertility

If you have very early ovarian cancer, it may be possible to have surgery that means you can still get pregnant. This is usually possible if the cancer is stage 1a and is not high grade (see pages 34 to 37).

The surgeon only removes the affected ovary and fallopian tube. They leave the other ovary, other fallopian tube and the womb. During the operation, the surgeon checks the other ovary and may take biopsies from it.

If any biopsies, lymph nodes or fluid removed from the pelvis show the cancer has spread, you will need another operation. This is usually to remove the womb, remaining ovary and remaining fallopian tube. You may find this difficult to cope with if you were hoping to have a pregnancy. Your specialist nurse will give you lots of support. They may be able to refer you to a counsellor for further emotional support.

Before your operation

Your doctor and nurse will talk to you about preparing for your operation. Some hospitals may provide support to help you to get fitter. They may have a programme to help you to exercise, stop smoking, eat well and cut down on alcohol. This is sometimes called prehabilitation or enhanced recovery.

If you smoke, it is important to stop or cut down before your operation. This will reduce your risk of chest problems and help your wound to heal after the operation.

There are NHS services to help you stop smoking. Look on the NHS website for the country where you live. Your GP can also prescribe nicotine replacement therapy.

You will usually go to a pre-assessment clinic a few days or weeks before the operation. You will have tests to check your fitness for surgery. This includes blood tests and sometimes an echocardiogram (ECG) to check your heart or chest x-ray to check your lungs.

Your doctor and nurse will explain the operation to you. Make sure you discuss any questions or concerns about the operation with them.

You will also see the doctor who gives the anaesthetic (anaesthetist). They will talk to you about the anaesthetic. They will also explain how any pain will be controlled after surgery.

You will usually be admitted to hospital on the day of your operation or the day before.

Your nurse will give you elastic stockings (TED stockings) to wear during and after the operation. These prevent blood clots forming in your legs.

You may also be given something to drink to help clear your bowel before the operation. Sometimes a doctor or nurse will draw marks on your tummy in case you need a stoma (see page 53).

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 helps prevent chest infections and blood clots. A physiotherapist or nurse will show you how to do these exercises.

You may have regular injections of a blood-thinning drug to reduce the risk of blood clots. If you need them after you go home, your nurse will teach you, or someone you live with, how to give the injection. Or they can arrange for a district nurse to do this.

Drips and drains

After your operation, 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 may have a drainage tube in your wound or tummy to drain extra fluid into a small bottle. This is usually removed after a few days.

Urinary catheter

You will have a tube (catheter) to drain urine from your bladder. It may be taken out the day after your operation or a few days later. This depends on the type of surgery you have. If you go home with the catheter, it can be removed at a follow-up appointment or by a district nurse.

Pain

It is normal to have some pain or discomfort for a few days after surgery. But this can be controlled with painkillers. If the painkillers are not working, it is important to tell your doctor or nurse as soon as possible. They may change the dose or give you different painkillers.

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

- By injection into a muscle. This is done by a nurse.
- An epidural. This is a small, thin tube in your back that goes into the space around your spinal cord. An epidural gives you continuous pain relief via a pump. You will not be able to walk around if you have an epidural in place.
- 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 safe as it is set so that you cannot give yourself too much painkiller.

As pain starts to improve, 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. They can change the dose or give you a different painkiller.

Your wound

The clips or stitches in your wound are usually removed after you go home. A practice nurse at your GP surgery can do this. Some stitches are absorbed by the body and do not need to be removed.

Wound infections can be a complication of surgery. If a wound is infected, it may:

- feel hot to touch
- look red
- look swollen
- leak fluid or pus (discharge)
- make you feel unwell
- cause you to have a fever or high temperature.

Tell your nurse or specialist doctor straight away if you get any of these symptoms, even after you go home. If you cannot talk to your hospital team, contact your GP or call the **NHS urgent advice number** on **111**.

Wind and constipation

You may have difficulty emptying your bowels (constipation) for a few days after the operation. You may also have uncomfortable wind.

Tell the nurses if you have these symptoms. 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.

Going home

When you go home will depend on the operation you have and how quickly you recover. You are usually in hospital for up to 1 week. If you have surgery for a very early-stage cancer, you may only be in hospital for a few days.

You will have a follow-up appointment with your surgeon and a nurse at a clinic. This will be arranged for you before you go home or soon after. If you live a distance from the hospital, you may have this appointment over the phone.

At this appointment, the surgeon will check your wound is healing and that you are recovering well. They will also explain the results of your operation and tell you more about the stage of the cancer. They will tell you about any further treatment you may need. If you have any problems before your appointment, you can always phone them for advice.

> **‘I had support from community nurses, who visited my home to change my dressings and provide aftercare.’**
>
> **Pavitter, diagnosed with ovarian cancer**

Vaginal bleeding

You may have some light vaginal bleeding or a red-brown discharge for up to 6 weeks after surgery.

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

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

If you cannot get through to your surgeon or specialist nurse, contact your GP or call the **NHS urgent advice** number on **111**.

For 6 weeks after your operation, you should avoid:

- having sex
- placing anything in your vagina – including tampons
- swimming.

This will reduce the risk of infection and help your wounds to heal.

Menopause

If you were still having periods, surgery will bring on the menopause and you will not be able to get pregnant. If you have surgery to protect your fertility, this will not bring on the menopause.

Your surgeon or nurse will explain what to expect before you have surgery. We have more information about managing the symptoms of the menopause on our website (see page 120).

Sex

After 6 weeks, your wounds are likely to have healed. This means you should be able to have sex again. But it may take longer than this for your energy levels and sex drive to improve.

If you have any questions or concerns, you can talk to your specialist nurse.

You may also find it helpful to contact one of the support organisations we list on pages 125 to 133. Or you can call the Macmillan Support Line on **0808 808 00 00**, 7 days a week, 8am to 8pm.

Physical activity

After surgery, you will need to take things easy for a few weeks. It can take 3 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.

You may want to 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 have and how quickly you recover. You need to feel comfortable wearing a seatbelt. You also need to be able to do an emergency stop if necessary. Ask your nurse or doctor for advice. Some insurance companies have guidelines about this. 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 give our cancer support specialists a call.

Chemotherapy

When you have chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. It is one of the main treatments for cancer of the ovary, fallopian tube or peritoneum.

You may have chemotherapy:

- after surgery – to reduce the risk of the cancer coming back (adjuvant chemotherapy)
- before surgery – to shrink the cancer to make the operation more effective (neo-adjuvant chemotherapy)
- to treat any cancer that cannot be removed during surgery
- as your main treatment – if your doctors think surgery is not the best option for you, or if you are not well enough to have a big operation.

Chemotherapy after surgery

You usually have chemotherapy when you have recovered from your operation. You usually start it about 4 weeks after surgery. But it may start up to 12 weeks after.

If you have stage 1 ovarian cancer (see page 35), you may also have chemotherapy after surgery. Your specialist doctor will talk to you about this. They may ask you to think about having chemotherapy if the cancer was either:

- grade 3 (see page 37)
- stage 1c (see page 35).

> **‘I had both chemotherapy and radical debulking surgery. I feel like I am getting stronger each day, both physically and mentally. I have days where I don’t feel like that at all, but I know that is a normal part of this journey.’**
>
> **Laura, diagnosed with ovarian cancer**

Chemotherapy before surgery

If you have chemotherapy before surgery, you usually have it every 3 weeks for 3 treatment cycles.

After 3 treatment cycles, you will have a CT scan (see page 28) or MRI scan to check how well the chemotherapy has worked. Your doctors will tell you if the cancer has shrunk enough for you to have surgery.

If you have surgery, you will usually have 3 more cycles of chemotherapy after you have recovered from the operation. If you do not have surgery, you will still have another 3 cycles of chemotherapy. You will have 6 cycles in total.

Chemotherapy drugs for ovarian cancer

You usually have chemotherapy drugs called carboplatin and paclitaxel (Taxol®).

If you are not well enough to cope with the side effects of the 2 drugs, you may have carboplatin on its own.

If you have early-stage ovarian cancer, you may sometimes have carboplatin on its own.

Sometimes you have chemotherapy and a targeted therapy drug called bevacizumab (Avastin®) – see page 77.

Other chemotherapy drugs you may have 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 on our website. Visit **macmillan.org.uk/cancer-information-and-support/treatments-and-drugs**

Treating ovarian cancer that comes back

If the cancer comes back, it can usually be controlled by more chemotherapy. If your first treatment with a platinum drug (carboplatin or cisplatin) worked well, you may have the same drug again. But you may have it with other drugs such as liposomal doxorubicin or gemcitabine.

If the cancer comes back soon after treatment has finished, you will have different drugs. For example, you may have liposomal doxorubicin by itself.

Having chemotherapy

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

You have chemotherapy as 1 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 are 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. If you are having a single drug on its own, you may have it every 4 weeks. Your specialist doctor or nurse will explain what to expect. Most courses of chemotherapy have 6 cycles.

We have more information about having chemotherapy on our website (see page 120).

Side effects

Chemotherapy drugs may cause side effects. But these can usually be controlled with medicines and will usually go away after treatment has finished. Not all drugs cause the same side effects for each person. Some people have very few side effects. Your specialist doctor or nurse will explain what to expect.

Risk of infection

This treatment 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 sometimes called neutropenia.

An infection can be very serious when the number of white blood cells is low. It is important to get any infection treated as soon as possible. Contact the hospital straight away on the 24-hour contact number you have 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
- your temperature goes below 36°C (96.8°F).

Symptoms of an infection include:

- feeling shivery and shaking
- a sore throat
- a cough
- breathlessness
- diarrhoea
- needing to pass urine (pee) a lot, or discomfort when you pass urine.

It is important to follow any specific advice your cancer treatment 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 treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time, until your cell count increases.

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.

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.

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.

Feeling tired

Feeling tired is a common side effect. It is often worse towards the end of treatment and for some weeks after it has finished. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy. If you feel sleepy, do not drive or operate machinery.

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.

> **What I do find hard is losing my eyebrows and eyelashes. My family and friends tell me that there is nothing to be ashamed of.**
> **But I find it difficult to deal with.**
>
> **Samantha**

Sore and red palms of hands and soles of feet

You may get sore and red palms of hands and soles of feet. The skin may also begin to peel. This is called palmar-plantar or hand-foot syndrome. It usually gets better after treatment ends.

Tell your doctor or nurse about any changes to your hands or feet. They can give you advice and prescribe creams to improve any symptoms you have. It can help to:

- keep your hands and feet cool
- moisturise your hands and feet regularly
- avoid tight-fitting socks, shoes and gloves.

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.

> ‘Chemotherapy and steroids treatment caused my sugar levels to go up and caused stress. Other effects were sickness, painful joints, fatigue and weight gain.’
>
> **Pavitter, diagnosed with ovarian cancer**

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.

Sore mouth and throat

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

If your mouth or throat 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 and throat.

Loss of appetite

This treatment can affect your appetite. Don't worry if you do not eat much for a day or two. But if your appetite does not come back after a few days, or if you are losing weight, tell your nurse or dietitian. They can give you advice. They may give you food or drink supplements. Or they may suggest changes to your diet or eating habits to help.

Blood clot risk

Cancer and some cancer treatments can increase the risk of a blood clot. Symptoms of a blood clot include:

- throbbing pain, redness or swelling in a leg or arm
- suddenly feeling breathless or coughing
- sharp chest pain, which may be worse when you cough or take a deep breath.

If you have any of these symptoms, contact the hospital straight away on the 24-hour contact number you have been given. If you cannot get through to your doctor, call the **NHS urgent advice** number on **111**.

A blood clot is serious, but it can be treated with drugs that thin the blood (anticoagulants). Your doctor or nurse can give you more information.

We have more information about blood clots on our website. Visit **macmillan.org.uk/blood-clots**

Targeted therapies

There are different types of targeted therapy drug. Each type targets something in or around the cancer cell that is helping it grow and survive.

Your specialist doctor and nurse will explain which targeted treatment is most suitable for you. You may have targeted therapy drugs for as long as they are keeping the cancer away or controlling it.

Newer targeted therapy drugs are becoming available to treat ovarian, fallopian tube or peritoneal cancer. You may have targeted therapy as part of a clinical trial (see pages 86 to 87).

Some of these drugs may only be available in some situations. Your specialist doctor can tell you if a drug is suitable for you. If a drug is not available to you on the NHS, there may be different ways you can have it. Your specialist doctor can give you advice.

We have more information about what to do if a treatment is not available on our website. Visit **macmillan.org.uk/options**

Bevacizumab (Avastin®)

You may have bevacizumab (Avastin®) if the cancer has spread further in the pelvis. You usually have it every 3 weeks along with chemotherapy. Your nurse will give it into a vein as an infusion (drip).

You carry on having bevacizumab when the chemotherapy has stopped. You may continue to have it for 1 year or longer if it is working for you. This is called maintenance treatment. Sometimes you may have bevacizumab along with a drug called olaparib as maintenance treatment.

You may also have bevacizumab if the cancer comes back.

PARP inhibitor drugs

These drugs block a protein called PARP which helps damaged cells to repair themselves. Without the PARP protein, the cancer cells may become too damaged to survive.

You start taking PARP inhibitor drugs several weeks after chemotherapy has finished. You take them for as long as they are working for you. This is a type of maintenance treatment. You take them as tablets or capsules every day.

Niraparib (Zejula®)

You may start niraparib after your first course of chemotherapy finishes if the chemotherapy has worked well.

You may also have niraparib if the cancer comes back and further chemotherapy has been helpful.

Olaparib (Lynparza®)

Olaparib stops the PARP protein from helping cancer cells repair a faulty BRCA gene or a certain type of DNA damage.

You may have olaparib after your first course of chemotherapy if:

- you have a faulty BRCA1 or BRCA2 gene
- chemotherapy has worked well.

You may also have olaparib with bevacizumab as maintenance treatment. You have these after your first course of chemotherapy if:

- tests show the cancer cells are unable to repair a certain type of DNA damage
- chemotherapy has worked well.

If you did not have olaparib during your first treatment, you may have it if the cancer comes back and is responding to further chemotherapy.

Rucaparib (Rubraca®)

Rucaparib is another PARP inhibitor similar to niraparib. You usually only have rucaparib if the cancer comes back and chemotherapy has worked well. Depending on your situation, you may have rucaparib instead of chemotherapy.

Side effects

Your specialist doctor or nurse will explain the side effects of the drug you are having. They will explain how some side effects can be controlled or managed. Always tell them about your side effects, especially if they do not improve or get worse.

Some common side effects of targeted therapy drugs are:

- increased risk of infection, anaemia and bleeding – this is due to a reduced number of blood cells
- tiredness
- feeling sick
- high blood pressure.

Rarely, you may have an allergic reaction when you have bevacizumab. This is more likely with the first or second drip, so you have these more slowly. The nurses will monitor you closely.

We have more information about targeted therapy drugs and their side effects on our website. Visit **macmillan.org.uk/treatments-and-drugs**

Radiotherapy

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

It is not often used to treat cancer of the ovary, fallopian tube or peritoneum. But it can be used to control symptoms in the pelvic area, such as bleeding, pain or discomfort. This is called palliative radiotherapy.

You have radiotherapy in the hospital radiotherapy department. You may have a course of palliative radiotherapy 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 doctors or nurse will talk about this with you in detail.

We have more information about radiotherapy in our booklet **Understanding radiotherapy** (see page 120).

You may have stereotactic ablative radiotherapy (SABR). This type of radiotherapy targets certain cancers. You may have it if the cancer has spread to only 1 other part of the body – for example, to a lymph node or to the lung or brain.

We have more information about SABR on our website. Visit **macmillan.org.uk/sabr**

Hormonal therapy

Hormones help control how cells grow and what they do in the body. Some hormones may encourage cancer cells to grow.

You may have hormonal therapy for ovarian, fallopian tube or peritoneal cancer. But it is not a main treatment. The drugs you may have are often used to treat breast cancer. They block or change the level of hormones such as oestrogen. This may help to slow the growth of the cancer. Tests on the cancer cells can tell if they have receptors (proteins) for oestrogen.

You may have hormonal therapy if the cancer comes back and you do not want more chemotherapy or want to delay it for a while. You usually have it for low-grade cancers which grow more slowly.

The hormonal therapy drugs you may have include:

- tamoxifen – this blocks oestrogen from reaching the cancer cells
- letrozole – this reduces the amount of oestrogen in the body.

These drugs can cause menopausal symptoms such as hot flushes and vaginal dryness. Letrozole can cause joint pain. Your nurse will explain the different side effects and how they can be managed.

We have more information about these drugs and their side effects on our website. Visit **macmillan.org.uk/treatments-and-drugs**

Managing the symptoms of advanced cancer

For advanced cancer, treatments such as chemotherapy or surgery will usually improve any symptoms you have. If you have ongoing symptoms, there are also other ways these can be controlled.

We have more information about managing symptoms of advanced cancer on our website (see page 120). These symptoms include feeling sick, tiredness, pain and breathlessness.

We have included some information here about specific symptoms that may be linked with advanced ovarian cancer.

Fluid build-up in the tummy

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 2 layers of the peritoneum (see opposite). This is called ascites. The fluid can be drained to make you feel more comfortable.

Having the fluid drained

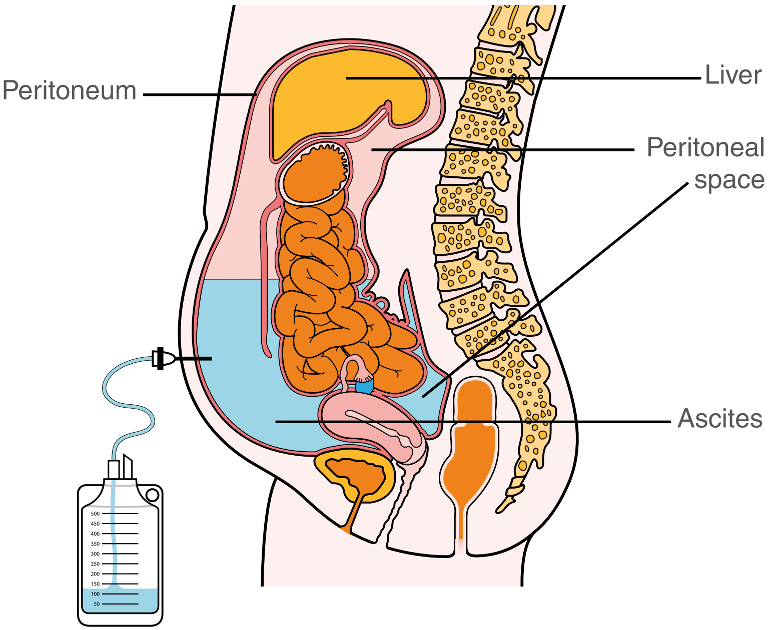
If there is only a small amount of fluid, you may have it drained in the outpatient clinic. But you may have a short stay in hospital if there is more fluid to drain.

The doctor gives you an injection of local anaesthetic to numb the area. They make a small cut in the skin of your tummy and insert a thin tube. This drains the fluid from your tummy into a drainage bag. The tube is covered with a dressing. The doctor may use a few stitches to hold it in place.

While the tube is in place, a nurse will check how much fluid is draining. They also check your blood pressure regularly. If your blood pressure drops, they may stop or slow the draining. You may only need to keep the drain in for a few hours. But depending on how much fluid there is, it can stay in for a few days.

If the fluid builds up again, your doctor can arrange for you to have it drained. This can be done when you need it. You may have a permanent drain put in if you need to have fluid drained regularly. Your doctor can tell you more about this.

Fluid being drained from the tummy (ascitic drainage)



Blocked bowel

If the cancer is growing close to the bowel, it may put pressure on the bowel. This may gradually narrow the bowel so the contents cannot easily pass through. This is called a blocked bowel or a bowel obstruction.

Sometimes a blocked bowel happens because surgery to the abdomen has caused tissues to stick together. These are called adhesions.

A blocked bowel can cause symptoms such as:

- tummy pain
- bloating
- feeling sick
- vomiting large amounts
- constipation
- diarrhoea.

Treatments for the cancer may improve a bowel obstruction. Or you may need an operation to remove the blocked section of bowel. This may mean you have a temporary or permanent stoma after surgery (see page 53). Your specialist doctor and nurse will talk this over with you before the operation.

Sometimes a blocked bowel is managed by having fluids through a drip for a time. Your doctor may suggest artificial nutritional support. This is when nutrients are delivered into your body through a tube, either into the gut or into a vein. This is also called artificial feeding. You may have it when you are not able to eat or drink in the usual way.

Fluid in the lungs

If cancer cells spread to the lining of the lungs (pleura), it can cause fluid to build up. This is called a pleural effusion. It can make you breathless. Your doctor can treat this by passing a narrow tube into your chest to drain off the fluid. This usually improves your breathing straight away. If it comes back, the fluid can usually be drained again. It may be possible to have a special catheter put in that allows you to drain the fluid into a bottle while you are at home.

Clinical trials

Clinical trials are medical research studies involving people. Doctors may use cancer clinical trials to:

- test new treatments to see if they work better than current treatments
- find which treatments have fewer side effects
- find new ways to combine treatments to see if they work better
- test new cancer drugs to find out more about them and their side effects
- improve the way treatments are given to try to reduce side effects.

Results from clinical trials can improve cancer treatments and help people live longer. Trials can also look at improving things like diagnosis and symptom management.

Taking part in a trial

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask them if there are any trials suitable for you.

Usually, cancer clinical trials happen in several hospitals around the country. You may have to travel to take part in a trial.

A research nurse or doctor will give you information about the trial. It is important to understand what is involved before you agree (consent) to take part (see page 49). You can ask the research nurse or doctor any questions you have. They will also explain the possible benefits and any possible risks of the trial. Clinical trials are designed to be as safe as possible. The researchers will monitor you closely during and after the trial.

If you decide not to take part in a trial, your cancer doctor and specialist nurse will respect your decision. You do not have to give a reason for not taking part. Your decision will not change your care. Your cancer doctor will give you the standard treatment for the type and stage of cancer you have.

We have more information about cancer clinical trials on our website. Visit **macmillan.org.uk/clinical-trials**

Giving blood and tissue samples

During your diagnosis and treatment doctors often take blood samples. They may also take a small piece of tissue or a sample of cells. These tissue samples are called biopsies. The samples can be looked at under a microscope. Your cancer doctor may ask your permission to store and use these blood or tissue samples for cancer research. This will only happen after they have done all the tests you need.

Your samples can only be stored for research if you give your consent. Your cancer doctor can answer any questions you have.

Your name is removed from the samples before they are stored. This means you cannot be identified.

The samples may be used to:

- find out more about the causes of certain cancers
- develop new cancer drugs or treatments.

This type of research takes a long time. The results may not be available for many years.

AFTER YOUR TREATMENT

Follow-up

After your treatment, you will have regular check-ups. These are usually every few months to start with. Your specialist doctor or nurse will ask you how you are recovering from treatment. They will also 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. Sometimes, rather than attending hospital for regular appointments, you may be asked to contact your healthcare team if you have any concerns. They may then arrange for you to see your specialist doctor or advise you to see your GP. With this type of follow-up, you will be given advice on what to look out for. Your nurse or doctor can tell you more about this.

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 (see page 122).

You can also contact another organisation that offers support (see pages 125 to 133).

New 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. Your specialist nurse can give you information on what symptoms to look out for.

Contact your specialist doctor or nurse if you develop new symptoms or if the symptoms you had when you were diagnosed (see page 20) come back. You do not have to wait for your check-up.

CA125 blood tests

You may have CA125 blood tests as part of your follow-up. But these are not always needed. A rising CA125 level may be a sign that cancer has returned. This usually means you need further tests, such as a CT scan (see page 28).

Usually, doctors advise waiting for cancer symptoms to develop before you have more treatment. Starting treatment before you have symptoms does not improve the results of treatment. It also means you have shorter periods of time between treatments and have side effects sooner. But you and your specialist doctor can start to talk about your possible options for further treatment.

Your specialist doctor or nurse can give you more information about CA125 blood tests.

If the cancer comes back

If ovarian, fallopian tube or peritoneal cancer comes back (recurs), it can usually be treated again. The treatment you have will depend on:

- the treatment you had before
- how long it kept the cancer away
- if you had any difficult side effects from previous treatments.

You may have further treatment with chemotherapy, targeted therapy and sometimes surgery. You may have different treatments repeated over many years. Your doctor may also talk to you about having newer treatments in a clinical trial (see pages 86 to 87).

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. Recovery takes time, so do not rush it. 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 needs.

We have more information in our booklet **Healthy eating and cancer** (see page 120).

Be physically active

Being physically active after cancer treatment can:

- increase your energy levels
- help you keep to a healthy weight
- 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. We have more information about keeping active in our booklet **Physical activity and cancer** (see page 120).

Stop smoking

If you smoke, giving up is the healthiest decision you can make. Stopping smoking reduces your risk of heart or lung disease, bone thinning (osteoporosis) and smoking-related cancers. If you want to stop, your GP can give you advice. Stopping smoking can be difficult, but there is lots of support available.

Stick to sensible drinking

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 3 or more days
- try to have several alcohol-free days every week.

A unit of alcohol is half a pint of ordinary-strength beer, lager or cider, 1 small glass (125ml) of wine, or a single measure (25ml) of spirits.

There is more information about alcohol and drinking guidelines at **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 specialist doctor or nurse what is available in your area. We have more information about complementary therapies in our booklet **Cancer and complementary therapies** (see page 120).

Sex, menopause and fertility

Coping with changes to your sex life

Cancer and its treatment can cause physical and emotional changes that affect your sex life. Side effects may mean you feel too unwell or tired for sex. You may also have changes, such as scars or hair loss, that affect your body image and self-esteem.

Usually, difficulties slowly improve after treatment. If you have a partner, it can help to talk openly with them about how you feel. You may both need some time to adjust. We have more information in our booklet **Body image and cancer** (see page 120).

If changes to your sex life are difficult to cope with, there is usually help available. 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 (see page 122).

We have more information in our booklet **Cancer and your sex life** (see page 120).

Coping with early menopause

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

Some of the main effects of the menopause are:

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

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

You may be offered:

- advice and support from your GP or a specialist who treats 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. Sometimes HRT is not advised depending on the type of cancer you have.

Fertility

Fertility problems may occur after radiotherapy or chemotherapy for ovarian cancer. If you have surgery to remove both ovaries and the womb, you will not be able to become pregnant. If you have early-stage ovarian cancer, you may have treatment to preserve your fertility (see page 54). But you may want to talk to your specialist doctor or nurse when you are thinking about trying to get pregnant.

We have more information about cancer and fertility in our booklet **Cancer treatment and fertility – information for women** (see page 120).

‘Initially, after the diagnosis, the fact that you won’t be able to have children seems less important because you are focused on having treatment that will keep you alive. It is when you have finished the treatment and life returns to being more normal that the impact of everything affects you. I think it is something that you just have to come to terms with. But there is no quick-fix solution.’

Louise

YOUR FEELINGS AND RELATIONSHIPS

Your feelings

It is common to have many different emotions when you are told you have cancer. These can be difficult to cope with. We talk about some common feelings here. Partners, family and friends may also have some of the same feelings.

There are lots of different reactions to cancer. You might not have any of the emotions we talk about here. There is no right or wrong way to feel. You will cope with things in your own way.

Talking to family, friends or other people affected by cancer, may help. Or you may get support from your healthcare team.

Shock and denial

You may find it hard to believe that you have cancer when you are first diagnosed. It is common to feel shocked and numb. You may not be able to understand all the information you are given. You may find that you keep asking the same questions. At first, it can be hard to talk about the cancer. Or you might find it hard to think or talk about anything else. Both reactions are normal. Your mind is trying to process what is happening. These feelings usually get easier over time.

Fear and anxiety

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

Sadness and depression

You may feel sad if you have to change your plans because of the cancer, or if your future feels uncertain. Feeling sad is a natural reaction to changes or loss. This feeling may come and go during and after your treatment. For most people, these periods of sadness get better. But for some people, the sadness may continue or get worse. If you think the sadness may be turning into depression, there are things you can do to help.

Avoidance

You may cope by trying not to find out much about the cancer. Or by not talking about it. If you feel like this, tell people that you do not want to talk about it right now. You can also tell your cancer doctor if there are things you do not want to know or talk about yet.

Sometimes, it may be hard to accept that you have cancer. This can stop you making decisions about treatment.
If this happens, it is very important to get help from your healthcare team.

You may feel that your family or friends are avoiding you or avoiding talking about the cancer. This is usually because they are also finding it difficult to cope. They may need support too. Try to tell them how this makes you feel. It may help you, and your family and friends, to talk openly about how you are feeling.

Anger

You may feel angry about your diagnosis. You may also resent other people for being well. These are normal reactions. They are more likely when you feel frightened, stressed or unwell. You may get angry with your family, friends or partner. Tell them you are angry at your illness and not at them. Finding ways to relax can help with anger. This can include talking about or writing down how you feel, doing gentle exercise, having relaxation therapy or meditating.

Guilt and blame

You may feel guilty or blame yourself for the cancer. You may want to find reasons for why it has happened to you. Most of the time, it is impossible to know exactly what causes a cancer. Over time, a combination of different risk factors may cause a cancer. Doctors do not fully understand all these factors yet. Try to focus on looking after yourself and getting the help and support you need.

Feeling alone

You may feel alone or isolated. This could be because you do not think you have support. Family and friends may live far away, be busy, or feel uncomfortable talking about the cancer. Try to tell your family and friends how you feel. This can help them find ways to support you.

You may have times when you want to be alone for a while. But if you find you are avoiding people a lot of the time, try to talk to your doctor or nurse.

If you need more support, you can call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists.

Our website can help you find local support groups.
Visit **macmillan.org.uk/supportgroups**

You can also talk to other people affected by cancer on our Online Community. Visit **macmillan.org.uk/community**

If you need more help

You may find it very difficult to cope with your emotions and may need more help. This does not mean you are failing in any way.

Talk to your doctor or nurse if:

- you feel anxious or worried a lot of the time
- you think you may be depressed.

They can refer you to a specialist doctor, psychologist or counsellor who can help. They may also prescribe medicines to help.

We have more information about coping with the emotional effects of cancer in our booklet **How are you feeling? The emotional effects of cancer** (see page 120).

Coping with your emotions

You may feel that the cancer has taken over your life. This is a common reaction. It can be very hard to cope with. But there are lots of things you can do to help you feel differently:

- You may find it helps to try to keep doing your usual activities.
- You may want to think about what is important to you. This could mean spending time with family, planning a holiday or starting a new hobby.
- You might decide to change your lifestyle. This could be eating healthily, being physically active or trying complementary therapies.
- Making plans can help you feel more in control.
- You might find knowing more about the cancer and your treatment options also helps you cope. It means you can make a plan with your healthcare team.
- Making choices and being active in your own care can help you feel more in control.

If you feel you are not coping well, or need more support, talk to your doctor or nurse.

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You might think it is best to pretend everything is fine. You might not want to worry them. Or you might feel you are letting them down if you admit you are worried or scared.

But not talking to the person with cancer about how you feel may make them feel alone.

You can support the person with cancer by listening and talking with them. Do not feel you have to talk about the cancer. Often it is 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. Visit **macmillan.org.uk/learnzone** to find out more.

We have more information in our booklet **Talking with someone who has cancer** (see page 120).

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers in our booklet **Looking after someone with cancer** (see page 120).

Talking to children about cancer

Deciding what to tell children about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. Children do not always show their feelings, but their behaviour may change at home or at school.

Talking to children about the cancer can:

- help them understand what is going on
- help them feel supported
- prepare them for any changes.

It may also help with some of your own anxiety too. For example, not telling them about hospital appointments may cause extra stress.

How much you tell children will depend on their age and how mature they are. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Teenagers usually understand what cancer is. Some will want to know more.

Whether they are teenagers or young children, talking about the cancer helps them cope.

Teenagers

It can help to encourage teenagers to ask questions, ask them their opinion and try to give them time to think about what is happening. They may have to, or want to, take on more responsibilities to help – perhaps cooking meals or looking after younger children. This can be hard at a time when they may want more freedom and independence.

Sometimes teenagers may find it hard to talk about a cancer diagnosis. You can encourage them to talk to someone they trust, who can support and listen to them. This might be a grandparent, family friend, teacher or counsellor. They may also find support online. The website **riprap.org.uk** offers information and support for teenagers who have a parent with cancer.

We have more information in our booklet **Talking to children and teenagers when an adult has cancer** (see page 120).

WORK AND FINANCIAL SUPPORT

Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Wales or Scotland, or **nidirect.gov.uk** if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by cancer.

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who have an illness or disability that affects how much they can work. There are different types of ESA, so it is a good idea to speak to a welfare rights adviser to see if you can make a claim.

Universal Credit

Universal Credit (UC) is a benefit for people under State Pension age who are either:

- out of work – for example, because of an illness or because they are caring for someone
- on a low income.

UC can include money for basic living costs, looking after children and housing.

Personal Independence Payment

This benefit is for people aged 16 to State Pension age who have problems moving around or looking after themselves. You must have had these problems for 3 months and expect them to last for at least 9 months, unless you are terminally ill.

Attendance Allowance

This benefit is for people at or over State Pension age who have problems looking after themselves because of an illness or disability. This could mean problems getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months, unless you are terminally ill.

Special rules

If you are terminally ill, you can apply for some benefits using a fast-track process called special rules. You can apply if your doctor thinks you may be reasonably expected to live for less than 6 months. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

Help for carers

Carer’s Allowance is a weekly benefit to help people who look after someone with a lot of care needs. If you do not qualify for it, you may still be able to apply for Carer’s Credit.

Carer’s Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

Macmillan Grants

Macmillan Grants are small, mostly one-off payments to help people with the extra costs cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. A grant from Macmillan does not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on **0808 808 00 00**.

We have more information in our booklet **Travel and cancer**. Our Online Community forum on **Travel insurance** may also be helpful.

More information

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice or Advice NI (see page 130).

Our booklet **Help with the cost of cancer** has lots more information (see page 120).

Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager soon after you are diagnosed. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others keep working, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to do too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

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 120). There is also lots more information at **macmillan.org.uk/work**

Employment rights

If you have, or have ever had, cancer, the law considers this as a disability. This means you cannot be treated less favourably than people who do not have cancer because you have cancer, or for reasons connected to the cancer. That would be discrimination.

The law also says your employer must make reasonable adjustments (changes) to your workplace and their work practices to help you stay at work or return to work.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 120).

> **‘During the chemo, my 12-month work contract finished, and I found myself unemployed. But thanks to the Macmillan website, I found all the information I needed to get help to claim benefits.’**
>
> **Nicola, diagnosed with ovarian cancer**

FURTHER INFORMATION

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 booklets or leaflets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring 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 would 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**.

The language we use

We want everyone affected by cancer to feel our information is written for them.

We try to make sure our information is as clear as possible. We use plain English, avoid jargon, explain any medical words, use illustrations to explain text, and make sure important points are highlighted clearly.

We use gender-inclusive language and talk to our readers as ‘you’ so that everyone feels included. Where clinically necessary we use the terms ‘men’ and ‘women’ or ‘male’ and ‘female’. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected. Our aims are for our information to be as clear and relevant as possible for everyone.

You can read more about how we produce our information at **macmillan.org.uk/ourinfo**

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are 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, 8am 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**

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 would 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** 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 is 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**

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**

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.

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have 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** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you are 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**

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

Ovarian cancer support organisations

Eve Appeal

Helpline **0808 802 0019**
Email **nurse@eveappeal.org.uk**
www.eveappeal.org.uk
Information and support for anyone affected by gynaecological cancers. Also provides information about cervical screening and for trans, non-binary and intersex people.

Ovacome

Tel **0800 008 7054**
Email **hello@ovacome.org.uk**
www.ovacome.org.uk
Information and support for anyone affected by ovarian cancer, including patients, families, friends, carers and health professionals.

Ovarian Cancer Action

Tel **020 7380 1730**
Email **info@ovarian.org.uk**
www.ovarian.org.uk
Information and support for anyone affected by ovarian cancer.

Target Ovarian Cancer

Tel **020 7923 5475**
Email **support@targetovariancancer.org.uk**
www.targetovariancancer.org.uk
Working to improve early diagnosis, fund life-saving research and provide much-needed support to women with ovarian cancer. You can speak to specialist nurses on their support line.

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.

Support with relationships and sexuality

College of Sexual and Relationship Therapists

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.

General cancer support organisations

Cancer Black Care

Tel **020 8961 4151**
www.cancerblackcare.org.uk
Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

Cancer Focus Northern Ireland

Helpline **0800 783 3339** (Mon to Fri, 9am to 1pm)
Email **nurseline@cancerfocusni.org**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline **0808 800 4040** (Mon to Fri, 9am to 5pm)
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Cancer Support Scotland

Tel **0800 652 4531** (Mon to Fri, 9am to 5pm)
Email **info@cancersupportscotland.org**
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Maggie’s

Tel **0300 123 1801**
Email **enquiries@maggies.org**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 3000 118** (Mon to Fri, 10am to 2pm)
Email **info@pennybrohn.org.uk**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

Helpline **0808 808 1010** (Daily, 8am to 8pm)
Email **info@tenovuscancercare.org.uk**
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online ‘Ask the nurse’ service.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300** (Mon to Fri, 10am to 4pm)
Email **bacp@bacp.co.uk**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their ‘How to find a therapist’ page.

UK Council for Psychotherapy (UKCP)

Tel **020 7014 9955**
Email **info@ukcp.org.uk**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

Helpline **0300 123 3393** (Mon to Fri, 9am to 6pm)
Email **info@mind.org.uk**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **116 123**
Email **jo@samaritans.org**
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
Provides advice on a variety of issues including financial, legal, housing and employment issues.

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 by contacting:

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

Support for older people

Age UK

Helpline **0800 678 1602** (Daily, 8am to 7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030** (Mon to Fri, 9am to 9pm)
Email **helpline@lgbt.foundation**
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Live Through This

www.livethroughthis.co.uk
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. LTT runs a peer support group with Maggie's Barts.

Support for carers

Carers Trust

Tel **0300 772 9600** (Mon to Fri, 9am to 5pm)
Email **info@carers.org**
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline (England, Scotland, Wales) **0808 808 7777** (Mon to Fri, 9am to 6pm)
Helpline (Northern Ireland) **028 9043 9843**
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

Cancer registries

The cancer registry

The cancer registry is 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 (England)

digital.nhs.uk/ndrs/patients

Scottish Cancer Registry and Intelligence Service (SCRIS)

Tel **0345 646 0238**
beta.isdscotland.org/topics/scottish-cancer-registry-and-intelligence-service-scris

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 010 4278**
phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu/

Northern Ireland Cancer Registry

Tel **0289 097 6028**
www.qub.ac.uk/research-centres/nicr

Your notes and questions

Your notes and questions

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 Chief Medical Editor, Prof Tim Iveson, Consultant Medical Oncologist.

With thanks to: Ms Christine Ang, Consultant Gynaecological Oncologist; Lynn Buckley, Macmillan Gynae-oncological Clinical Nurse Specialist; Nellie Kumaralingam, Advanced Nurse Practitioner; Helen Manderville, Gynae-oncological Clinical Nurse Specialist; Dr Shibani Nicum, Consultant Medical Oncologist; Claire Paterson, Macmillan Gynae-oncological Clinical Nurse Specialist; Rae Roan, Gynaecological Clinical Nurse Specialist; and Dr Alexander Taylor, Consultant Clinical Oncologist.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

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

Sources

Below is a sample of the sources used in our ovarian cancer information. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Ledermann, Raja, Fotopoulou et al. Newly diagnosed and relapsed epithelial ovarian carcinoma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. Annals of Oncology. 2013. Volume 24, Supplement 6. Updated online 2020. Available from **www.esmo.org/guidelines** [last accessed July 2021].

National Institute for Health and Care Excellence (NICE) Clinical Guideline ovarian cancer: recognition and initial management of ovarian cancer. 2011. Available from **www.nice.org.uk/guidance**

Scottish Intercollegiate Guidelines Network (SIGN). Management of epithelial ovarian cancer. Scottish Intercollegiate Guidelines Network (SIGN). 2013, revised 2018. Available from **www.sign.ac.uk**

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are 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 are here 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.

5 ways you can help someone with cancer

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

Please fill in your personal details

Mr/Mrs/Miss/Other

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Surname

Address

Postcode

Phone

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Please accept my gift of £
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I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
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Issue no ☐☐☐

Security number ☐☐☐

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Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

☐ I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

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 would rather donate online go to **macmillan.org.uk/donate**

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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

MACMILLAN
CANCER SUPPORT

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

The booklet talks about the signs and symptoms of cancer of the ovary, fallopian tube or peritoneum. It explains how it is diagnosed and how it may be treated. It also has information about emotional, practical and financial issues.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

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.

Trusted Information Creator

Patient Information Forum