MACMILLAN
CANCER SUPPORT

UNDERSTANDING WOMB (ENDOMETRIAL) CANCER

> ‘My consultant put me in touch with the Macmillan nurses at the hospital and they were fantastic. It was so good to know that there would be someone there for you when you needed help and support.’

Anne, who was diagnosed with womb cancer

About this booklet

This booklet is about a type of womb cancer called endometrial cancer. It is for anyone affected by this type of cancer. There is also information for carers, family members and friends.

The booklet explains how womb cancer is diagnosed and treated. It gives information about coping during and after treatment.

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

This booklet does not have information about:

- other types of cancer that start in the womb
- cancer that starts in the lower part of the womb called the cervix.

We have other booklets about this called:

- Understanding cervical cancer
- Understanding soft tissue sarcomas.

See page 120 for details of how to order a free copy.

For more information

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

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

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

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

How to use this booklet

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

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

We have included quotes from people who have had womb cancer and have chosen to share their story with us. This includes Anne, who is on the cover of this booklet. We hope you will find these helpful.

Contents

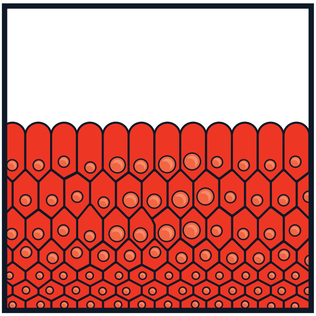
CANCER OF THE WOMB

What is cancer?

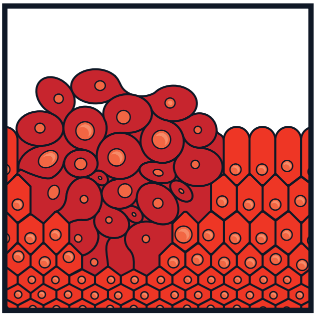
Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop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

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

Normal cells



Cells forming a tumour



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

A lump that is cancer (**malignant**) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or lymphatic system (see page 10). When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a secondary cancer or a **metastasis**.

The womb

The womb (uterus) is a pear-shaped organ where a baby is carried during pregnancy. It is low in the pelvis (the area between the hips) and is supported by the pelvic floor muscles.

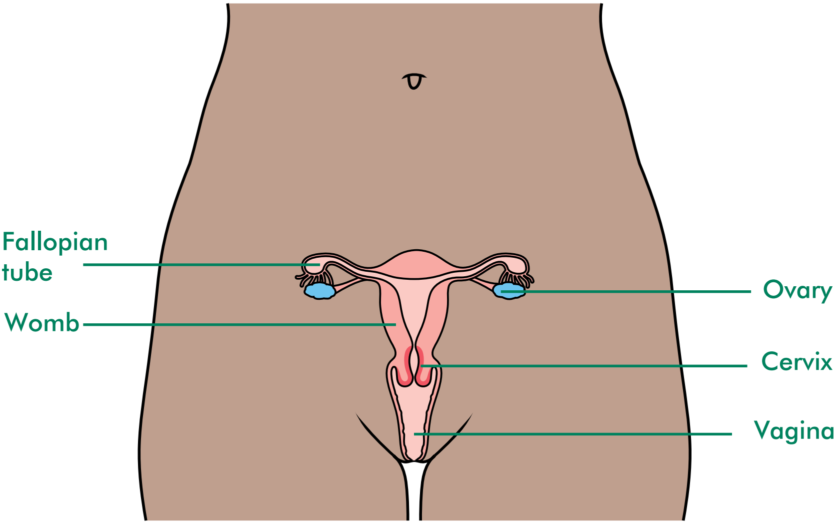
The womb is made up of three layers:

- an outer protective layer
- a middle muscular layer, called the myometrium
- an inner layer, called the lining of the womb or endometrium.

The ovaries are on either side of the womb. They make eggs and the female hormone oestrogen. The fallopian tubes connect the ovaries to the womb.

The lower part of the womb connects to the top of the vagina. This is called the cervix or the neck of the womb. Cancers that start in the cervix behave differently and are treated differently from womb cancer. We can send you more information about cervical cancer. See page 120 for details of how to order a copy.

The womb and reproductive organs



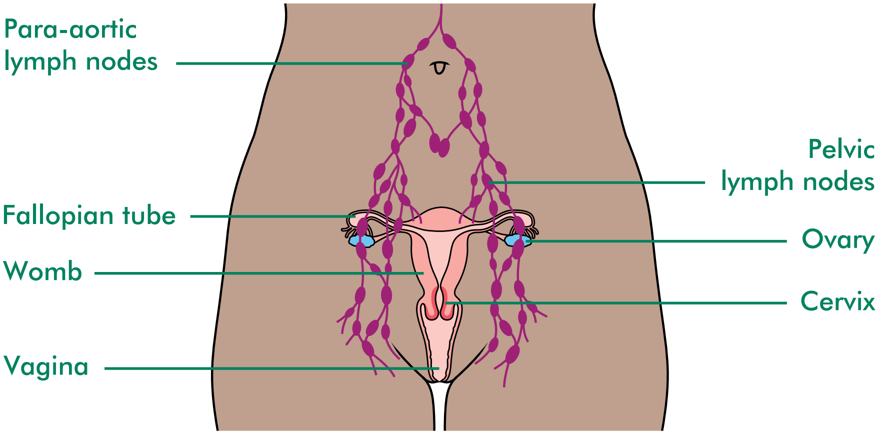
The lymphatic system

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

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

Sometimes cancer can spread through the lymphatic system. If the cancer cells spread outside the womb, they are most likely to go to lymph nodes in the pelvis (the area between your hips). They may sometimes go to the lymph nodes in the tummy (abdomen).

Lymph nodes in the abdomen and pelvis



About womb cancer

In the UK, about 9,200 women are diagnosed with womb cancer each year. Womb cancer is rare in women under 40 and becomes more common after the age of 55.

Endometrial cancers

Most womb cancers start in glandular cells found in the lining of the womb (the endometrium). They are called endometrial cancers. They are usually diagnosed early and treated successfully. This booklet is about endometrial cancers.

Other types of womb cancer

Some cancers start in the supporting tissues of the womb or in the muscle layer of the womb (the myometrium). These are called soft tissue sarcomas. The most common type of sarcoma of the womb is leiomyosarcoma.

We can send you more information about soft tissue sarcomas. See page 120 for details on how to order a free copy.

Risk factors and causes

There are certain things that can increase the risk of developing womb cancer. These are called risk factors. Having a risk factor does not mean you will get cancer. And not having a risk factor does not mean that you will not get it. Most risk factors for womb cancer are linked to how much oestrogen the lining of the womb is exposed to over a woman's lifetime.

Age

The risk of womb cancer increases with age.

Hormonal factors

Before the menopause, the ovaries produce the hormones oestrogen and progesterone. These help to control your periods. After the menopause, the ovaries no longer produce hormones. But women still produce some oestrogen in their body fat and adrenal glands.

The risk of womb cancer can be affected by:

- exposure to oestrogen
- how this is balanced with progesterone.

When there is too much oestrogen without progesterone to balance it, the risk of womb cancer increases.

Longer exposure to oestrogen can increase your risk of womb cancer. This may be influenced by the following factors:

- Starting your periods early (before the age of 12).
- Having a late menopause (after the age of 55).
- Having longer periods.
- Having irregular periods.
- Having hormone replacement therapy (HRT).
- Taking oestrogen-only HRT or a type of HRT called tibilone (Livial®). Oestrogen-only HRT is usually only given to women who have had an operation to remove their womb.
- Not having children, or being unable to have children. Oestrogen in the body is low during pregnancy, and the level of progesterone is high.

Weight and physical activity

Being overweight is an important risk factor for womb cancer. After the menopause, body fat is the main source of oestrogen. Women who are overweight may have a high level of oestrogen. At least 1 in 3 womb cancers (33%) may be caused by being very overweight (obese). There is also evidence that being less physically active can increase the risk of womb cancer.

Genetic factors (family history)

A small number of womb cancers (fewer than 5 in 100 or less than 5%) are caused by gene changes that are passed on in a family. If there are several close relatives on the same side of the family with bowel, breast, ovarian or womb cancer, there may be a genetic link. Close relatives include parents, children, sisters and brothers.

If you are worried about a family history of cancer, speak to your cancer doctor or GP. They can decide if you should be referred to a family cancer clinic.

There are some genetic conditions that can increase the risk of womb cancer. Women with Lynch syndrome, also known as hereditary non-polyposis colorectal cancer (HNPCC), have an altered gene that increases the risk of bowel cancer and womb cancer. Women with this gene have a 30 to 60% risk of developing womb cancer over their lifetime. They are screened for bowel cancer and womb cancer. And they may be advised to have a hysterectomy (operation to remove the womb) if they no longer want to be able to get pregnant.

Women with a rare genetic condition called Cowden syndrome have an increased risk of non-cancerous tumours and also some cancers. This includes womb cancer, but the increase in risk is small.

Tamoxifen

Tamoxifen is a hormonal drug used to treat breast cancer. It can slightly increase the risk of pre-cancerous changes in the womb. Rarely, it can cause womb cancer. But there are very clear benefits of taking tamoxifen that far outweigh this risk. Always tell your doctor if you are taking tamoxifen and have any unusual vaginal bleeding.

Other medical conditions

Some other medical conditions may cause an increased risk of pre-cancerous changes in the womb or womb cancer.

Thickening of the womb lining

Thickening of the lining of the womb is called endometrial hyperplasia. Symptoms include heavy periods and bleeding between periods or after the menopause. When it is diagnosed, women have treatment or regular check-ups.

Diabetes

Diabetes increases the risk of womb cancer. There may also be a separate link between womb cancer and insulin, a hormone that regulates blood sugar.

Polycystic ovary syndrome (PCOS)

PCOS is a condition where cysts grow on the ovaries. Women with PCOS may:

- have fertility problems, infrequent periods or no periods
- be very overweight or diabetic.

These are all linked with womb cancer risk.

Uncommon ovarian cancers

Some types of ovarian cancers called granulosa and theca cell tumours can produce oestrogen. This increases the risk of pre-cancerous changes and rarely can cause womb cancer.

Symptoms

Usually the first sign of womb cancer is unusual vaginal bleeding. For example, this could be:

- bleeding after the menopause (this is the most common symptom)
- bleeding in between periods
- heavier periods than usual (if you have not been through the menopause)
- a bloody or pink and watery vaginal discharge.

Less common symptoms are pain or discomfort in the pelvic area, or pain during sex.

If you have any unusual vaginal bleeding, always see your GP about it. Other conditions that affect the womb, such as fibroids, can also cause unusual vaginal bleeding.

DIAGNOSING CANCER OF THE WOMB

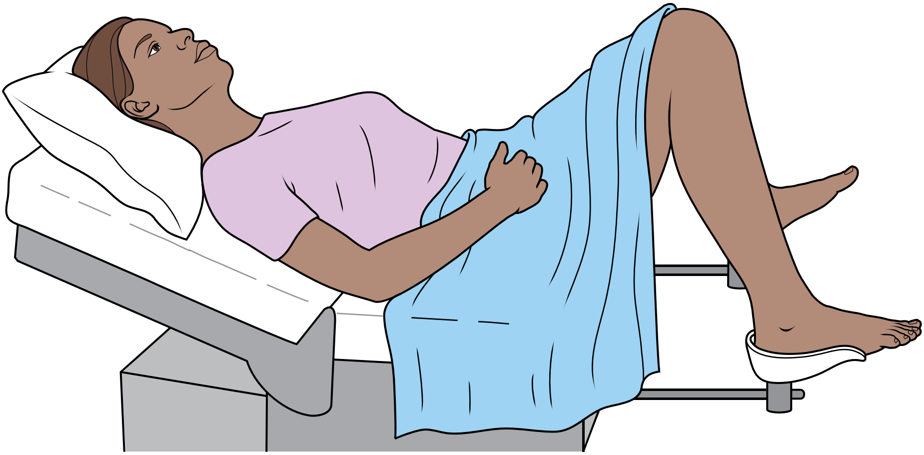
Being diagnosed with womb cancer

You usually begin by seeing your GP, who will ask you about your symptoms.

Your GP may do an internal vaginal examination to feel for anything unusual in the pelvis. You will have a nurse with you during your examination. An internal examination should not be painful, but it may be uncomfortable. If you have questions or worries about having an internal examination, let the nurse or doctor know. They can answer any questions you have and explain ways they can make it easier for you.

The doctor does the internal examination by gently putting two fingers of their gloved hand into the vagina and feeling all around it. While they are doing this, they may put their other hand flat on the lower abdomen (tummy area) and press down. You might have a blood test. Your GP may also ask you to give a sample of your wee (urine) for testing.

Having an internal examination



Your GP may arrange for you to have an ultrasound scan (see page 22) of your womb. Or they may refer you directly to a gynaecologist. This is a doctor who specialises in treating conditions of a woman's reproductive system.

You may be referred urgently (within two weeks) for a clinic appointment if you have:

- vaginal bleeding after the menopause
- a lump in the pelvis that your GP can feel
- ongoing vaginal bleeding in between your periods.

At the hospital

The gynaecologist will ask about your general health, any other medical problems you have, and whether you have any close relatives with womb or bowel cancer. You may also meet a gynaecology specialist nurse. They can give you information and support.

The gynaecologist will examine you and do an internal pelvic examination. You may also have a smear test if you have not had one recently. After this, they will explain any more tests you need to have.

Tests

Blood tests

You may have blood tests to check:

- your general health
- the number of blood cells in your blood (blood count)
- how well your kidneys and liver are working.

Trans-vaginal ultrasound

This uses soundwaves to make up a picture of the inside of your womb. It shows how thick the lining of the womb is. The person doing the scan gently places a small probe with a rounded end into your vagina. The test can be a little uncomfortable, but should not be painful. It only takes a few minutes. If it is not possible to do the scan through the vagina, it can be done by passing a small device over the tummy (abdomen).

Biopsy

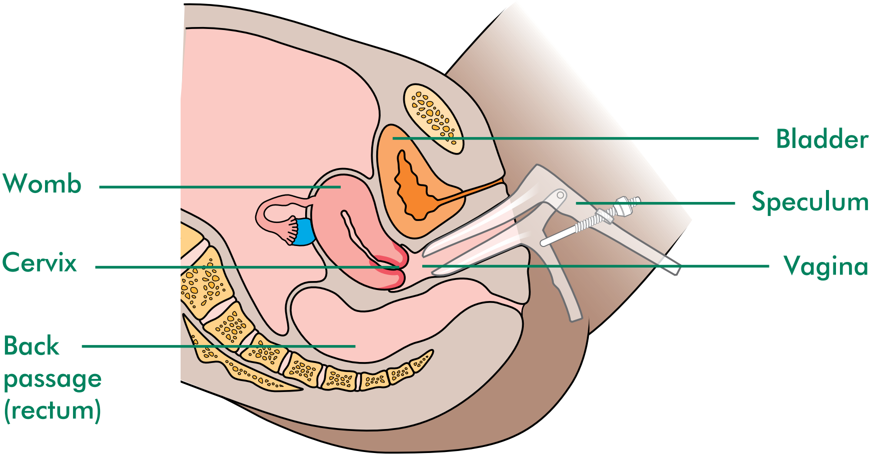
This involves taking a sample of cells or tissue from your womb lining. A doctor will then look at the sample under a microscope. If there are cancer cells present, the biopsy results will usually show what type of womb cancer it is. Biopsies can be taken in different ways, including by aspiration or during a hysteroscopy.

Aspiration biopsy

This can often be done at your clinic appointment. You will not usually need an anaesthetic. But some people may have it at another time, with a local or general anaesthetic. Your doctor or nurse will gently put an instrument called a speculum into your vagina to keep it open. They carefully pass a fine tube (called a pipelle) through the cervix into your womb.

They then draw some cells from the womb lining into the tube, using gentle suction. You might feel some period-like cramps while it is being done, but they usually wear off in a few minutes. After the test, you may have light bleeding and some mild period-like discomfort for a couple of days.

Having an aspiration biopsy



Outpatient hysteroscopy

You can have this test in an outpatient clinic. Your doctor or nurse will pass a very thin, flexible tube with a light on the end (hysteroscope) through the vagina and cervix into your womb.

They may put a speculum in your vagina first, and inject a small amount of anaesthetic into the cervix. This helps open the cervix a little and allows the hysteroscope into your womb. They may advise you to take some painkillers an hour before the test.

During the hysteroscopy, pictures of the inside of your womb will show up on a screen. The doctor or nurse will put some clear fluid or air into the hysteroscope to allow them to get a better picture. They will take a sample of tissue (biopsy) from the womb lining.

This test may be uncomfortable, but it should not be painful. If you are worried about the test, talk to your doctor about what they can do to make it as comfortable as possible.

After the test, you will have some vaginal bleeding and period-like cramps for a couple of days. Taking non-steroidal anti-inflammatory painkillers, such as ibuprofen, can help with cramps. You can check with your doctor that these drugs are suitable for you.

Hysteroscopy dilatation and curettage (D&C)

This is done under a general anaesthetic. The surgeon stretches (dilates) the cervix to open it and uses a hysteroscope to examine the womb. They then use a small instrument, called a curette, to carefully remove tissue from the womb lining. Afterwards, you may have period-like pains and some vaginal bleeding for a couple of days.

Further tests

If womb cancer is diagnosed, you will usually have further tests. These find out more about the position of the cancer and whether it has spread from where it started. This is called staging (see pages 30 to 32). The results of these tests will help you and your doctor make decisions about your treatment.

CT scan

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10 to 30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan.

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

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

MRI scan

This test uses magnetism to build up a detailed picture of areas of your body. The scanner is a powerful magnet so you may be asked to complete and sign a checklist to make sure it's safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins, etc. You should also tell your doctor if you've ever worked with metal or in the metal industry as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body, it's likely that you won't be able to have an MRI scan. In this situation, another type of scan can be used. Before the scan, you'll be asked to remove any metal belongings including jewellery.

Some people are given an injection of dye into a vein in the arm, which doesn't usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly. During the test, you'll lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It's painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It's also noisy, but you'll be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.

Chest x-ray

This uses x-rays to take a picture of your chest, to check your lungs and heart.

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or one of the organisations listed on pages 125 to 132 can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

> ‘Waiting for the results was really hard. I tried to keep myself focused on other things so as not to let my mind get too carried away with negative thoughts.’
>
> **Anne**

Types of endometrial womb cancer

Most womb cancers develop from cells in the lining of the womb. They are called endometrial cancers. The lining of the womb is called the endometrium.

There are different types of endometrial cancer:

- endometrioid cancer
- serous endometrial carcinoma (also called uterine serous carcinoma)
- carcinosarcoma (these cancers are not sarcomas, despite their name)
- clear cell carcinoma
- mucinous carcinoma
- mixed cell endometrial cancer.

About 3 out of 4 womb cancers (75%) are endometrioid cancers. They are usually grade 1 or grade 2 and are diagnosed at an early stage (see pages 30 to 32).

Type 1 and type 2 endometrial cancer

Some doctors describe endometrial cancers as type 1 or type 2.

Type 1 cancers

These cancers are slow growing and are usually diagnosed at an early stage. They include grade 1 and grade 2 endometrioid cancers and all mucinous cancers.

Type 2 cancers

These cancers are always high-grade (grade 3) and tend to grow more quickly. They include serous endometrial carcinoma, carcinosarcoma, clear cell carcinoma, grade 3 endometrioid cancers and mixed cell endometrial cancers.

Staging and grading

Staging

The stage of the womb cancer describes:

- how far the cancer has grown
- if it has spread from where it started.

Knowing the stage of the cancer is important. It affects the decisions you and your doctor will make about treatment. The exact stage of the cancer is usually confirmed after surgery (if you have this). See pages 42 to 55 for more information about surgery.

Womb cancer is divided into four main stages.

Stage 1

The cancer is contained in the womb. About 3 out of 4 women (75%) have stage 1 cancer when they are diagnosed.

Stage 1 can be divided into:

- **Stage 1A** – The cancer is only in the lining of the womb, or has grown no more than halfway into the muscle.
- **Stage 1B** – The cancer has grown more than halfway into the muscle wall.

Stage 2

The cancer has spread to the cervix (the neck of the womb).

Stage 3

The cancer has spread outside the womb but has not spread beyond the pelvis.

Stage 3 can be divided into:

- **Stage 3A** – The cancer has spread to the outer surface of the womb and/or the ovaries and fallopian tubes.
- **Stage 3B** – The cancer has spread into the vagina and/or into the tissues around the womb (parametrium).
- **Stage 3C** – The cancer has spread to pelvic lymph nodes or to lymph nodes in the tummy (abdomen).

Stage 4

The cancer has spread to other organs in the body:

- **Stage 4A** – The cancer has spread into the bowel or bladder.
- **Stage 4B** – The cancer has spread to other organs such as the lungs, liver or bones.

Terms for cancer stages

Your doctor or nurse may use some of the following terms to describe the cancer:

- **Early-stage womb cancer** – This usually means stage 1 and stage 2 womb cancers.
- **Locally advanced womb cancer** – This usually means stage 3 and stage 4A womb cancers.
- **Advanced, metastatic or secondary womb cancer** – This usually means stage 4B womb cancer.
- **Recurrent cancer** – This means a cancer that has come back after treatment. It is not usually given a stage.

Grading

Grading is about how the cancer cells look under the microscope compared with normal cells. The grade helps your doctor to decide about your treatment.

Grade 1 or low-grade or well differentiated – The cancer cells look similar to normal cells and usually grow slowly and are less likely to spread.

Grade 2 or moderate-or intermediate-grade – The cancer cells look more abnormal and are slightly faster growing.

Grade 3 or high-grade or poorly differentiated – The cancer cells look very different from normal cells and may grow more quickly.

Your data and the cancer registry

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

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

> ‘I felt very reassured that the multidisciplinary team were making the right decisions about my treatment.’
>
> **Anne**

TREATING CANCER OF THE WOMB

Treatment overview

Surgery

The main treatment for womb cancer is an operation to remove the womb, cervix, fallopian tubes and ovaries. This is the only treatment many women need to cure the cancer. Women who cannot have a general anaesthetic for health reasons may have radiotherapy or hormonal therapy instead of surgery.

If the cancer has spread but is still in the pelvic area, you will usually have an operation to remove as much of it as possible. This can make any treatment you have after surgery more effective.

Other treatments

After surgery, your doctor may advise you to have other treatments to reduce the risk of the cancer coming back. This is known as adjuvant treatment.

The stage and grade (see pages 31 to 33) of the cancer helps your specialist decide if you need further treatment. Women who have stage 2 or stage 3 cancer are almost always advised to have further treatment.

The most common adjuvant treatment is radiotherapy to the pelvic area. A few women have chemotherapy to as well as radiotherapy. Sometimes you may have chemotherapy on its own instead of radiotherapy. You may also be invited to take part in a clinical trial.

Advanced cancer

Chemotherapy or hormonal therapy is used to treat cancer that has spread to other parts of the body, such as the liver or lungs. This is known as palliative treatment.

The aim of treatment can be to help to:

- shrink and control the cancer
- relieve symptoms.

A small proportion of people may have an operation to remove cancer that has spread. But this is uncommon and can only be done if the cancer is small and confined to one part of the body.

Fertility

If you are of child-bearing age and want to have children in the future, it is important to talk to your doctor before you start treatment. For some younger women with early-stage, low-grade endometrioid cancer (see pages 28 to 29), it may be possible to have fertility-sparing treatment. This may involve having hormonal therapy instead of a hysterectomy. This is not standard treatment, so it is important to discuss the risks and benefits with your cancer specialist before making a decision about it.

If fertility-sparing treatment is not possible for you, your hospital doctor can refer you to a fertility specialist before your surgery. They will be able to discuss possible options for fertility with you.

How treatment is planned

In all NHS hospitals, a team of specialists will meet to discuss your treatment options. Your cancer doctor will then talk to you about them. Together you can decide what is best in your situation. The team of experts are called the multidisciplinary team (MDT). They will include:

- a surgeon who specialises in gynaecological cancer surgery (gynaecological oncologist)
- a medical oncologist (chemotherapy specialist)
- a clinical oncologist (radiotherapy and chemotherapy specialist)
- a gynae-oncology specialist nurse
- radiologists who analyse the x-rays and scans
- pathologists who advise on the type of womb cancer.

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

The MDT will look at many factors when planning your treatment options. These will include:

- your general health
- the type and size of the tumour
- whether the cancer has begun to spread.

The benefits and disadvantages of treatment

Many people are frightened at the idea of having cancer treatments, particularly because of the possible side effects. But these can usually be controlled with medicines. You might have treatment for different reasons, and the potential benefits will depend on your situation.

Most women with womb cancer have surgery with the aim of curing the cancer. You may also be given additional treatments to reduce the risk of it coming back.

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

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

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

Our booklet **Making treatment decisions** has more information. See page 120 for details on how to order a free copy.

Second opinion

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

Giving your consent

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

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

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

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

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

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

> **'Making decisions about treatment was so hard. My advice is to talk about it as much as you can, and ask all your questions no matter how silly you think they are.'**
>
> **Trish**

Surgery

Surgery is the main treatment for womb cancer. A surgeon who is experienced in treating gynaecological cancers will do the operation. After the operation, they can tell you more about the stage of the cancer (see pages 30 to 32). It can take about two weeks for the stage to be confirmed.

Surgery to remove the womb (hysterectomy)

The surgeon usually removes:

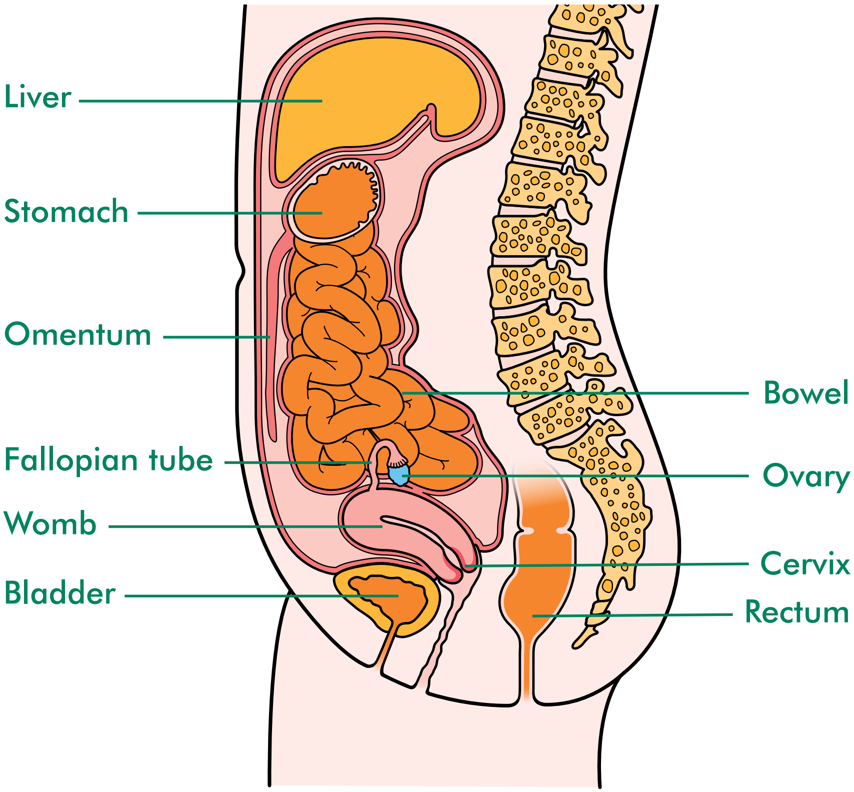
- the womb and the cervix (called a total hysterectomy)
- the fallopian tubes and both ovaries (called a bilateral salpingo-oophorectomy or BSO).

If you have a type 2 cancer (see pages 28 to 29), your surgeon may also remove:

- lymph nodes (see page 10) close to the womb (pelvic nodes)
- lymph nodes higher up in the abdomen (para-aortic nodes)
- the omentum – a layer of fat and tissue at the front of the abdomen, which covers the organs in the tummy area (see diagram on the opposite page).

They then check these for cancer cells. Before the operation, your surgeon will talk to you about the possible benefits and disadvantages of removing the lymph nodes and possibly the omentum.

The female organs



Early menopause

If you are still having regular periods, a hysterectomy and removing the ovaries will end this and the menopause will start. This can cause menopausal symptoms (see pages 92 to 93).

Some women may be offered the option to not have their ovaries removed, to prevent an early menopause. This is usually only possible for women who have a low-grade, early-stage cancer.

How the operation is done

A hysterectomy can be done in different ways.

- Laparoscopic surgery – the surgeon operates through small cuts in the abdomen. They use small surgical instruments and a thin telescope with a video camera on the end (laparoscope). The laparoscope lets the surgeon see inside the body.
- Abdominal surgery – the surgeon makes one cut (incision) in the tummy (abdomen). Afterwards, you have a wound that goes across your tummy close to the bikini line or that goes down from the belly button to the bikini line.
- Robotic surgery. This is like laparoscopic surgery, but the laparoscope and instruments are attached to robotic arms. The surgeon controls the robotic arms.
- Vaginal surgery – the surgeon operates through a cut at the top of the vagina. The surgeon may combine this with laparoscopic surgery.

Your surgeon will talk to you about the most suitable type of surgery for you.

What else may be done

During your operation, the surgeon will check organs nearby to find out more about the stage of the cancer.

Removing lymph nodes

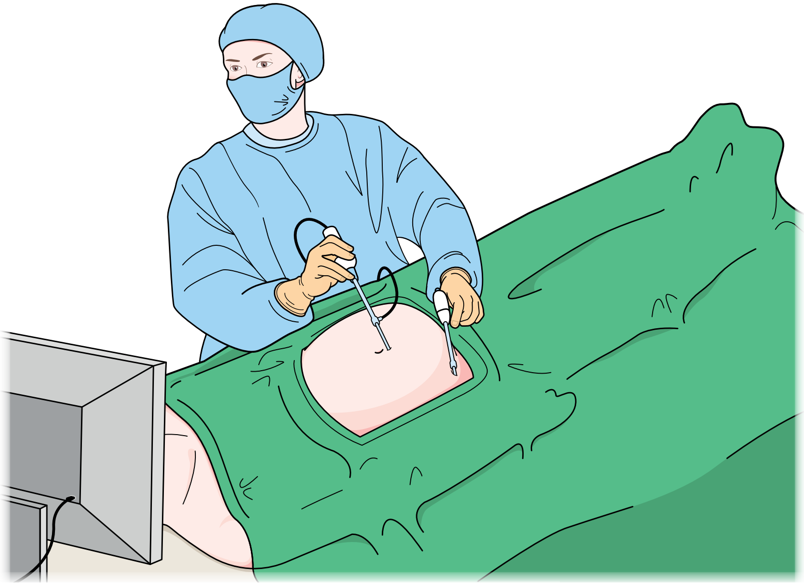
The surgeon may remove lymph nodes close to the womb (pelvic nodes) and higher up in the abdomen (para-aortic nodes). This is so they can be checked for cancer cells. Your surgeon will talk to you about the possible benefits and disadvantages of removing lymph nodes.

If the cancer has spread outside the womb

If the cancer has spread to organs close by, such as the bladder or bowel, you may have an operation to remove as much of the cancer as possible. This helps to control the cancer. It may also make the treatment you have after surgery more effective. Very rarely, if the cancer is widespread in the pelvic area, you may have surgery to remove the bladder and the bowel, as well as the womb. This is a major operation called pelvic exenteration. You can read more on our website – visit **macmillan.org.uk**

If the cancer has spread to the liver or lungs, surgery is not usually possible. Very occasionally, an operation may be done to remove a secondary tumour that is contained in one area. This would only be done if there are no signs of cancer elsewhere in the body.

Having laparoscopic surgery



Before your operation

If you smoke, giving up before your operation will help reduce your risk of chest problems. It will also help your wound to heal after the operation. Your GP can give you advice and support. Our booklet **Giving up smoking** also has more information. See page 120 for details of how to order a free copy.

You will go to a pre-assessment clinic a few days or weeks before the operation. You will have tests to check you are fit for surgery, such as blood tests and an echocardiogram (ECG) to check your heart. A member of the team will explain the operation to you. Make sure you discuss any questions or concerns that you have about the operation with them. You will usually be admitted to hospital on the morning of your operation. You will be given elastic stockings (TED stockings) to wear during and after the operation to prevent blood clots forming in your legs.

Some hospitals follow an enhanced recovery programme.
This aims to:

- reduce the time you spend in hospital
- speed up your recovery
- involve you more in your own care.

For example, your doctor or nurse may give you information about diet and exercise before surgery. Or they may put in place any arrangements needed for you to go home. Your doctor or nurse will tell you if an enhanced recovery programme is suitable for you and if it is available.

> ‘It’s important not to overdo things and to allow yourself time to heal. I took things slowly and followed the advice from health professionals.’
>
> **Daloni**

After your operation

Recovery

How quickly you recover will depend on the type of operation you have and the extent of the surgery.

You will be encouraged to start moving around as soon as possible. While you are in bed, it is important to move your legs regularly and do deep-breathing exercises. This is to help prevent chest infections and blood clots. A physiotherapist may show you how to do these exercises. You may also have daily injections of a blood-thinning drug to reduce the risk of blood clots. If you have had lymph nodes removed from your groin, you will be encouraged to put your feet up when you are sitting. This helps to reduce leg swelling.

Drips and drains

You will have fluids into a vein in your hand or arm. This is called a drip or an intravenous (IV) infusion. A nurse will usually take this out as soon as you are eating and drinking normally.

You may have a drainage tube in your wound or tummy (abdomen) to drain excess fluid into a small bottle. The drain is usually removed after a few days.

You will have a tube (urinary catheter) to drain urine from your bladder. It is usually taken out the day after your surgery.

Pain

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

Immediately after your operation you may have painkillers in one of the following ways:

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

It is important to tell the nurses or doctor if you are still in pain. They can increase the dose or prescribe a different painkiller.

Your wound

The surgeon will close your wound using clips, stitches or skin glue. Some types of stitches can be absorbed by the body and do not need to be removed. If you have clips or stitches that need to be removed after you go home, a practice nurse at your GP surgery can do this.

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

- heat
- redness
- swelling
- fluid coming from wound (especially if it is thick, brown, green or yellow)
- feeling unwell
- a fever or high temperature.

Tell your nurse or doctor if you get any of these symptoms, even after you go home.

> ‘If something doesn’t feel right after your operation, go to your doctor immediately. They will be more than happy to help you. It’s better to catch something like an infection early.’
>
> **Joan**

Constipation

If you are having problems emptying your bowels (pooing) after surgery, tell your doctor or nurse. They can give you a laxative to help. See your GP if you have problems after being discharged from hospital.

Low mood

Many women experience low mood about three days after surgery. This may last for 24 to 48 hours. It is a normal reaction to a stressful event such as surgery after being diagnosed with cancer.

Going home

If you have laparoscopic or robotic surgery, you can usually go home later that day or the day after the operation. If you have an abdominal hysterectomy, you can usually go home 2 to 8 days after the operation.

Your nurse will give you advice on looking after yourself so that your wound heals and you recover well. How quickly you recover will depend on the operation you have had. It is important to take things easy for a while. Try to get plenty of rest and eat well. If you are having any problems, it is important to contact your doctor or specialist nurse.

Follow-up appointment

You will be given an appointment to come back to the outpatient clinic to see the surgeon. You may also see your specialist nurse. They will check how you are recovering. Your surgeon will explain the results of the operation and tell you if you need further treatment.

Blood-thinning injections

Some women will be given a supply of daily blood-thinning injections to take home. A nurse will show you how to inject yourself. If you are not able to inject yourself, they will show a relative or friend how to do this. Or they will arrange for a district nurse to do it for you.

Vaginal care

After a hysterectomy, you may have a vaginal discharge for up to six weeks. This is usually reddish-brown in colour. Contact your doctor straight away if the discharge:

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

Your doctor or nurse will advise you to have a shower daily. They will also advise you not to have penetrative sex or put anything in your vagina (such as tampons) for about 6 weeks after your surgery. You should also avoid swimming. This will allow the surgical area to heal properly and reduce the risk of infection.

Sex

After 6 weeks, if your wounds have healed properly, you can usually safely:

- have penetrative sex
- use sex toys inside the vagina
- use fingers inside the vagina.

But you may need more time than this before you feel ready to have sex, especially if you are having other treatment as well.

Physical activity

You will be advised to avoid strenuous physical activity or heavy lifting for about:

- 12 weeks after an abdominal hysterectomy
- 6 weeks after laparoscopic or robotic surgery.

Your physiotherapist or specialist nurse will give you advice about this. Try to do some light exercise every day, such as walking. You can slowly increase this. It will help you build up your energy levels and feel better.

Driving

Some women find it uncomfortable to drive for a few weeks after the surgery. Ask your nurse or doctor for advice on when it will be safe for you to start driving again. Some insurance companies have guidelines about this. It is best to contact your insurer to check you are covered to drive.

> ‘I felt that it was really important to exercise gently after my surgery. I did some walking each day, gradually increasing the amount.’
>
> **Anne**

Possible long-term complications

Most women have no long-term complications after surgery. But having other treatments as well as surgery may increase the risk of problems.

If you have had the pelvic lymph nodes removed, there is a risk of developing swelling (lymphoedema) in one or both legs. This is a build-up of lymph fluid in the tissues. Lymphoedema is not common. But if you have radiotherapy as well as surgery, there is more risk.

Our booklet **Understanding lymphoedema** has more information that you might find useful. See page 120 for details of how to order a free copy.

Getting support

It is not unusual to feel anxious after surgery. You may feel your recovery is taking longer than you expected. Or you may be worried about having further treatment. It is often helpful to talk about your feelings with your family and friends. Your nurse specialist, our cancer support specialists or some organisations (see pages 125 to 132) can also give you support. You can call our cancer support specialists on **0808 808 00 00** to talk, and for information about local support groups.

Radiotherapy

Radiotherapy treats cancer by using high-energy x-rays. These destroy cancer cells, while doing as little harm as possible to normal cells. Radiotherapy may be given internally or externally, or as a combination of both. Some women may have radiotherapy with chemotherapy. This is called chemoradiation.

When radiotherapy is used

You may have radiotherapy:

- after surgery, to reduce the risk of the cancer coming back (called adjuvant radiotherapy)
- instead of surgery, if a general anaesthetic or an operation is not suitable for you
- to try to cure a cancer that has come back after surgery (recurrent cancer)
- to treat cancer that was not completely removed with surgery.

Radiotherapy can be given externally (see pages 58 to 60) or internally (see pages 61 to 62), or as a combination of the two. Your cancer specialist can discuss this treatment in detail with you.

Radiotherapy after surgery

Your cancer specialist may talk to you about having radiotherapy after surgery. This is to reduce the risk of the cancer coming back in the pelvic area. Your specialist team will look at the stage, grade and type of womb cancer you have before discussing this with you.

Many women with stage 1 cancer will not need radiotherapy. But some women have a higher risk of the cancer coming back. In this situation, your doctors may suggest you have radiotherapy to reduce your risk. Most women with stage 2 or 3 womb cancer are recommended to have radiotherapy after surgery.

Your specialist will tell you about the benefits and disadvantages of radiotherapy in your situation. They will explain the side effects you are likely to get and the possible long-term effects.

Radiotherapy to control symptoms

If the cancer has spread in the pelvic area or to other parts of your body, such as the bones, you may have radiotherapy to shrink the cancer or to control the symptoms. This is called palliative radiotherapy. It will be planned to ensure that you have as few side effects as possible.

Having radiotherapy

External radiotherapy

External radiotherapy uses a machine called a linear accelerator. It is like a big x-ray machine, which produces high-energy rays. A radiographer gives you the treatment in the radiotherapy department at the hospital. You have it as an outpatient once a day from Monday to Friday, with a rest at the weekend. Each session of treatment usually takes just a few minutes. A full course may last up to 5 to 6 weeks.

External radiotherapy is painless. It will not make you radioactive. It is safe for you to be around other people, including children and pregnant women.

Planning your radiotherapy

Your radiotherapy will be planned by your clinical oncologist with the support of a technical team. The planning is done to make sure the radiotherapy targets the area accurately and causes as little damage as possible to nearby tissue.

First planning visit

Your first planning visit will take 30 to 60 minutes. The staff in the radiotherapy department will explain what to expect. It is fine to ask as many questions as you need to. The staff will tell you beforehand if you need to prepare in any way. For example, you may be asked to drink plenty of water and to use a small enema. An enema is a liquid that empties the lower part of the bowel. Your team will explain how to use it.

You will usually have a CT scan (see page 25) of the area to be treated. This helps your doctor plan the precise area for your radiotherapy. Before your scan, you may be asked to remove some of your clothes and to wear a gown.

You may have an injection of dye into a vein when you have the CT scan. This allows particular areas of the body to be seen more clearly.

During your scan, you need to lie still on a hard couch. If you feel uncomfortable when the radiographers position you on the couch, let them know. They can make you more comfortable. This is important because, once you are comfortable, they will record the details of your position. You will need to lie in the same position on a similar couch for your treatment.

The information from the scan will be used by your radiotherapy team to work out the precise dose and area of your treatment. It can take up to two weeks to plan your treatment.

The radiographer will make some tiny tattoos on your skin. This may be a little uncomfortable while they are doing it. They will only do it your permission. The tattoos help the radiographers position you at each treatment session to make sure the rays are directed accurately.

Treatment sessions

At the beginning of each session, your radiographer will explain what you will see and hear.

Once you are comfortable, and in the correct position, they will ask you to keep as still as possible. The radiographers will leave the room for a few minutes while you have your treatment. There will be a camera so they can see you from outside the room. There is usually an intercom, so you can talk to them if you have any concerns during your treatment.

The radiotherapy machine does not touch you and the treatment is painless. You may hear a slight buzzing noise from it while you have your treatment.

Once your treatment session has finished, the radiographers will come back and help you off the treatment couch. You will then be able to go home or, if you are staying in hospital, back to the ward.

Internal radiotherapy

Internal radiotherapy is also called brachytherapy. It gives a high dose of radiotherapy directly to the top of the vagina (where the womb was) and to the area close by. You may have internal radiotherapy on its own. Or you may have it at the end of your external radiotherapy treatment. You can usually have it as an outpatient.

The treatment is given by placing hollow tubes, called applicators, into the vagina. The radiotherapy is given through these tubes.

After the applicators are in place, you will probably then have a scan or x-rays to check their position. When it is confirmed that the applicators are in the correct position, they will be connected to the brachytherapy machine. The machine is operated by a radiographer or physics technician. It places a radioactive capsule, called a source, into the applicators. The machine then gives the planned dose of radiation.

Women who still have their womb may have a slightly different type of internal treatment. It involves putting an applicator into the womb as well as the vagina. This is done under general anaesthetic or occasionally a spinal anaesthetic. Your doctor or nurse will explain more about what is involved.

Internal radiotherapy can be given as high-dose-rate, low-dose-rate or pulsed-dose-rate treatment. These different ways of giving internal radiotherapy all work equally well. The type you have will depend on the system your hospital uses. Your cancer specialist and specialist nurse will explain more, so that you know what to expect.

High-dose-rate treatment

This is the most common way of giving internal radiotherapy to treat womb cancer. You usually have it as an outpatient. Each treatment takes a few minutes. You will usually have 3 or 4 treatments, over 2 to 3 weeks. The applicators are removed after each treatment before you go home.

Low-dose-rate treatment

If you have this treatment, you will usually be in hospital for 12 to 24 hours. But sometimes you may have it over a few days. Your doctor, nurse or radiographer will tell you more about low-dose-rate treatment.

Pulsed-dose-rate treatment

This treatment is given over the same length of time as low-dose-rate treatment. But the radiation dose is given in pulses rather than as a continuous dose. Your doctor, nurse or radiographer will give you more information.

Side effects of radiotherapy

You may develop side effects over the course of your treatment. These usually improve over a few weeks or months after treatment finishes. Your doctor, nurse or radiographer will discuss this with you, so you know what to expect. Let them know about any side effects you have during or after treatment. There are often things that can help.

External radiotherapy causes more side effects than internal radiotherapy. But many women have a combination of both treatments. If you are only having internal treatment, the most common side effects are to the bowel and bladder.

The side effects of radiotherapy are made worse by smoking. If you smoke, stopping smoking will help. If you want help or advice on how to give up, talk to your clinical oncologist, GP or a specialist nurse. There are organisations that offer advice and support to help people stop smoking. Our booklet **Giving up smoking** also has more information – see page 120 for details on how to order a free copy.

Skin changes

The skin in the area being treated sometimes gets dry and irritated. Avoid using perfumed soaps or body wash during treatment, as they could irritate the skin. You will be given advice on looking after your skin. Your doctor can prescribe cream to soothe it if it becomes sore.

You may lose some of your pubic hair. After treatment, it will usually grow back, but it may be thinner than it was before.

Tiredness

Tiredness is a common side effect and may continue for months after treatment is over. During treatment, you will need to rest more than usual, especially if you have to travel a long way for treatment each day. But it is good to do gentle exercise when you feel able to, such as walking. Once your treatment is over, slowly increase your activity and try to balance rest periods with exercise such as walking. This will help build up your energy levels.

Bowel changes

Radiotherapy to the pelvis may irritate the bowel and cause diarrhoea and soreness around the back passage.

Eating a low-fibre diet may help reduce diarrhoea. This means that during treatment and for a couple of weeks after it, you should avoid:

- wholemeal bread and pasta
- raw fruit
- cereals
- vegetables.

If you have diarrhoea, your doctor can prescribe medicine to help control it. Make sure you drink plenty of fluids if you have diarrhoea.

Bladder changes

Radiotherapy can irritate the bladder. This can make you want to pass urine more often and causes a burning feeling when you pass urine. Your doctor can prescribe medicines to reduce these symptoms. Drinking at least two litres (three and a half pints) of fluid a day will also help.

Vaginal discharge

You may have a slight vaginal discharge after treatment has finished. If you are worried about this, or if it continues or becomes heavy, talk to your specialist nurse or cancer doctor.

> **‘It’s important to realise that side effects vary. I had some diarrhoea and some nausea. This was managed with medication.’**
>
> **Daloni**

Possible late effects of radiotherapy

Radiotherapy to the pelvic area can sometimes cause problems months or years after treatment (late effects). These may be permanent. If they happen, there are lots of ways to manage or treat them.

It is always important to tell your GP or cancer doctor about any new symptoms that develop a long time after treatment. They need to be investigated, as they may not be caused by radiotherapy.

Our booklet **Managing the late effects of pelvic radiotherapy in women** has more information. See page 120 for details on how to order a free copy.

Effects on the vagina

Radiotherapy can make your vagina narrower and less stretchy. The vaginal walls may be dry and thin, and can stick together. This can make penetrative sex and internal examinations uncomfortable.

Your hospital team may recommend you use vaginal dilators to help. Dilators are tampon-shaped plastic tubes of different sizes, which you use with a lubricant.

Although dilators are commonly used, there is not strong evidence about how effective they are. Your specialist nurse or doctor will explain the best way to use them.

If your vagina is dry, moisturising creams or lubricants designed to be used in the vagina can help. There are lots of products you can try. You can buy them in chemists or online. Or your doctor can prescribe them.

Vaginal moisturisers work by drawing moisture into the vaginal tissue. You apply them regularly. You can also use lubricants when you have sex to make it feel more comfortable and pleasurable. Lubricants can be water-based, silicone-based or oil-based. You can buy them from chemists, some supermarkets or online.

Vaginal dryness can make you more likely to get infections, such as thrush. Let your doctor know if you have symptoms such as itching or soreness.

Vaginal bleeding

After pelvic radiotherapy, the blood vessels in the lining of the vagina can become fragile. This means they can bleed more easily, especially after sex. Bleeding may also be caused by the vaginal tissue sticking together, or scar tissue causing the vagina to narrow.

If you have any bleeding, always let your cancer doctor or nurse know. They will examine you and explain whether it is likely to be caused by the radiotherapy. If the bleeding is minor, once you know the cause you may find that it does not trouble you much.

Bowel or bladder changes

After radiotherapy, some women may develop changes to the bowel or bladder. It is common to have some mild changes. But it is much less common to have severe side effects that affect your quality of life. If this happens, symptoms may develop months or sometimes years after radiotherapy treatment.

If your bowel is affected, you may have to poo more often or more urgently than usual, or you may have diarrhoea.

If the bladder is affected, you may need to pass urine more often or more urgently than usual.

The blood vessels in the bowel and bladder can become more fragile. This can cause blood in your urine or poo. If you have bleeding, always tell your cancer doctor or GP so that they can check it.

Lymphoedema

Pelvic radiotherapy may increase the risk of swelling in one or both legs. This is called lymphoedema. It is not common. But the risk is higher if you have surgery to remove the lymph nodes as well as radiotherapy. You can reduce the risk of lymphoedema by:

- taking care of the skin on your feet and legs
- avoiding cuts and insect bites on your feet and legs
- treating any cuts, bites or grazes quickly
- seeing your GP straight away if you have any signs of infection in your feet or legs
- doing regular gentle exercise such as walking
- keeping to a healthy weight.

Changes to the pelvic bones

Radiotherapy can cause thinning of the bone in the pelvis. Often, this does not cause any symptoms. But it may be seen on scans. In some women, it may cause fractures in the pelvis called insufficiency fractures. This can cause pain in the lower back or pelvis. If this happens, painkillers and physiotherapy can help.

Having chemotherapy

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. The drugs are carried in the blood and can reach cancer cells anywhere in the body. If you have early-stage womb cancer, you are unlikely to need chemotherapy.

Chemotherapy to reduce the risk of cancer coming back

Chemotherapy is sometimes offered after surgery (see pages 42 to 54) and radiotherapy (see pages 55 to 69). Or, in some situations, you may have chemotherapy after surgery instead of radiotherapy. The aim is to reduce the risk of womb cancer coming back. This is called **adjuvant chemotherapy**.

There may be more risk of the cancer coming back if the cancer is:

- a more advanced stage (stage 3 or stage 4)
- a non-endometrioid type
- high-grade (grade 3).

Your specialist will talk to you about the possible benefits and side effects of chemotherapy. You can then decide if it is right for you.

You may sometimes have chemotherapy before surgery to shrink the cancer before it is removed. This is called **neo-adjuvant chemotherapy**.

Chemotherapy to control cancer and relieve symptoms

You may have chemotherapy to help control cancer and relieve symptoms. This may happen if:

- it is not possible to remove all the cancer with an operation
- the cancer has spread to other parts of the body.

This is sometimes called palliative treatment. Your cancer specialist or specialist nurse will explain what it involves and the likely side effects.

Chemotherapy drugs used

The drugs commonly used to treat womb cancer are:

- carboplatin
- paclitaxel
- docetaxel
- cisplatin
- doxorubicin
- epirubicin
- gemcitabine.

Other drugs may also be used. You may have a combination of two or three drugs, or just one. If you are having adjuvant chemotherapy, you are more likely to have a combination of drugs. Your doctor or specialist nurse will explain more about the chemotherapy treatment to you.

Having chemotherapy

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

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

The length of a cycle depends on the chemotherapy drugs you have. But most cycles are 1 to 3 weeks long. Your cancer doctor or nurse will explain what to expect. Most courses of chemotherapy are made up of 6 cycles.

Our booklet **Understanding chemotherapy** has more details. See page 120 for information on how to order a free copy.

> ‘I did find the treatment days quite long. I had a couple of drips over several hours. Having a friend with me to pass the time was great.’
>
> **Anne**

Side effects of chemotherapy

Chemotherapy drugs can cause side effects. But many of these can be well controlled with medicines and will usually go away when your treatment is finished. If the cancer is causing symptoms, chemotherapy can also make you feel better by relieving them. Your doctor or nurse will tell you more about what to expect. Always mention any side effects you have. There are usually ways that they can be controlled.

The main side effects of chemotherapy are described here, along with some ways to control or reduce them.

Risk of infection

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

If you have an infection, it is important to treat it as soon as possible. Contact the hospital straight away on the 24-hour contact number you have if:

- your temperature goes over 37.5°C (99.5F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery
- a sore throat
- a cough
- diarrhoea
- needing to pass urine often.

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.

Anaemia (low number of red blood cells)

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

Bruising and bleeding

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

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

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

Feeling sick

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

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

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.

Loss of appetite

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

Sore mouth

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

If your mouth is sore:

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

> **'I wasn't able to do all the active things that I used to do before. I needed to sleep a lot, to rest a lot.'**
>
> **Daloni**

Diarrhoea

If you have diarrhoea, contact the hospital for advice. Try to drink at least two litres (three and a half pints) of fluids every day. It can help to avoid alcohol, caffeine, milk products, high-fat foods and high-fibre foods.

Hair loss

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

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

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

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

Numb or tingling hands or feet (peripheral neuropathy)

Some chemotherapy drugs affect 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.

Allergic reaction

Some chemotherapy drugs may cause an allergic reaction while you are having them. Signs of a reaction can include:

- feeling hot or flushed
- a skin rash
- itching
- shivering
- feeling dizzy
- a headache
- feeling breathless
- swelling of your face or mouth
- pain in your back, tummy or chest.

Your nurse will check you for signs of a reaction during your treatment. If you feel unwell or have any of these signs, tell them straight away. If you do have a reaction, it can be treated quickly.

Sometimes a reaction can happen a few hours after treatment. If you get any signs or feel unwell after you get home, contact the hospital straight away.

Blood clot risk

Cancer and treatment with chemotherapy can increase the risk of a blood clot. Symptoms of a blood clot include:

- pain, redness or swelling in a leg or arm
- breathlessness
- chest pain.

If you have any of these symptoms, contact a doctor straight away.

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

Hormonal treatment

Hormones are made in the body and help control many body functions. The hormones oestrogen and progesterone can affect how cells in the womb lining grow. Your cancer specialist may suggest hormonal therapy if you:

- have advanced womb cancer
- have womb cancer that has come back after treatment (recurrent cancer)
- cannot have surgery or radiotherapy because of other health issues.

The aim of treatment is to try to shrink the cancer and control symptoms.

Some younger women who want to have children in the future may also be offered hormone therapy instead of a hysterectomy. After they have had children, they will then have a hysterectomy.

The main hormonal treatment for advanced or recurrent womb cancer is progesterone. You are most likely to have it as a tablet. Or your GP or practice nurse may give it to you as an injection. The most common types of progesterone are:

- medroxyprogesterone acetate (Provera®)
- megestrol (Megace®).

Other hormonal treatments are sometimes used, such as tamoxifen and letrozole.

Side effects

The most common side effects of progesterone are:

- increased appetite
- weight gain
- fluid build-up (for example swollen ankles)
- feeling sick.

The side effects can be mild and you are not likely to get all of them. They usually get better after 3 to 4 weeks. Let your doctor or nurse know if you are having troublesome side effects.

Fertility-sparing treatment

An operation to remove the womb and ovaries is the standard treatment for most women with womb cancer. But some women may have fertility-sparing treatment instead. This is for women who want the chance to have children in future. It is only suitable for a few women with stage 1, grade 1 womb cancer.

The treatment usually involves taking daily progesterone tablets. Less commonly, progesterone can be given directly into the womb through a hormone-releasing intrauterine device (sometimes called an IUD or coil).

This treatment is only done in a few specialist centres. So you may have to travel further to have it. You will have regular checks during and after treatment. This is because with this type of treatment, there is a higher risk that the cancer may not respond to treatment or may come back. You will need a hysterectomy:

- if the cancer does not respond to hormone treatment
- after you have had children.

Your specialist doctor can explain the possible risks and benefits of fertility-sparing treatment.

Research – clinical trials

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

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

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

Taking part in a trial

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

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

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

Clinical trials are described in more detail in our booklet **Understanding cancer research trials (clinical trials)**. We can send you a free copy. See page 120 for ordering details.

Blood and tumour samples

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

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

AFTER YOUR TREATMENT

Follow-up

After your treatment, you will have regular check-ups. These will include an internal examination. These will be every few months at first. Eventually, you may only be seen once a year. If you have any problems or new symptoms in between appointments, it is important to contact your cancer doctor or specialist nurse as soon as possible.

Some women do not have routine appointments. Instead, they are asked to contact their cancer specialist or nurse if they have new symptoms or are worried about anything. Important symptoms to be aware of are:

- bleeding from the vagina or back passage
- pain in the pelvic area.

If womb cancer comes back in the same area, it can often be treated successfully.

You may feel worried for a while before your appointments. This is natural. It can help to get support from family and friends. You can also call the Macmillan Support Line on **0808 808 00 00** or contact another organisation that offers support – see pages 125 to 132 for contact details.

Sex life

Treatment for womb cancer may affect your sex life and how you feel about yourself sexually. There are things you can do that can help.

Sex after treatment

Womb cancer, its treatments and their side effects may affect your sex life and how you feel about yourself as a woman. This should slowly improve after treatment finishes. But for some women, it may take longer. Try not to think that sex is never going to be important in your life again. There may be a period of adjustment for you, and for your partner if you have one.

Cuddles, kisses and massages are affectionate and sensual ways of showing how much you care for someone, even if you do not feel like having sex. You can wait until you and your partner feel ready. There is no right or wrong time.

It is common to feel nervous about sex after cancer treatment. But it is perfectly safe for both you and your partner. At first, it may help to take more time to relax and for your partner to be very gentle.

Tell your doctor or nurse if you are having problems with your sex life. They may be able to reassure you and offer help and support. If you feel uncomfortable talking to your doctor or nurse, you can call us on **0808 808 00 00**. You may find it helpful to talk to a sex therapist. You can contact a therapist through the College of Sexual and Relationship Therapists – see page 126 for details.

Menopausal symptoms

If you have not been through the menopause, a hysterectomy that involves removing the ovaries (see pages 42 to 54) will cause the menopause straight away.

Women who have radiotherapy (see pages 55 to 69) without any surgery will also have their menopause. This is because radiotherapy stops the ovaries working.

We describe some common symptoms of the menopause here.

Hot flushes and sweats

Low doses of anti-depressant drugs can be prescribed to reduce flushes.

Vaginal dryness

Non-hormonal creams and water-based lubricants help reduce discomfort during sex.

Low sex drive

Vaginal changes can reduce your sex drive. But getting help to manage these changes can improve things for many women.

Emotional symptoms

These can include:

- mood swings
- feeling anxious
- problems with concentration and memory.

Talking about your feelings (see pages 100 to 104) with your family, friends, doctor or nurse can help. Some women find it helps to talk things through with a counsellor.

Bone thinning

An early menopause can increase the risk of bone thinning (osteoporosis).

Your doctor or specialist nurse can give you advice on how to manage symptoms. They can sometimes prescribe drugs to reduce hot flushes.

Hormone replacement therapy (HRT) is not usually advised after womb cancer, because it contains oestrogen. But there is no evidence that it increases the risk of the cancer coming back. Some cancer specialists may prescribe HRT for women who had early-stage womb cancer and who are having troublesome menopausal symptoms. They may do this if other treatments have not worked.

A number of organisations give support to women going through the menopause. This includes the Daisy Network (see page 125).


SHERLOCK HOLMES
WORDS AWAY

Well-being after treatment

After treatment, you will probably be keen to get back to doing the things you did before your cancer diagnosis. But you may still be coping with the side effects of treatment and some difficult emotions (see pages 100 to 104). Recovery takes time, so try not to be hard on yourself. It is not unusual to feel anxious and isolated at this time.

People often worry about the cancer coming back. You may worry that any ache or pain is a sign that it has returned. It is important to talk about any concerns or questions you have with your cancer doctor, specialist nurse or GP. You do not need to wait until your follow-up appointments.

In this section, we discuss some of the problems people face after treatment and things that can be done to help.

Lifestyle changes

After treatment, some women choose to make positive lifestyle changes. Even if you had a healthy lifestyle before being diagnosed with womb cancer, you may now be more focused on making the most of your health.

Keep to a healthy weight

If you feel you need to lose weight after your treatment has finished, ask your GP for advice. They can tell you what your ideal weight is.

There is some evidence that keeping to a healthy weight after the menopause may help reduce the risk of womb cancer coming back. It also reduces the risk of some other cancers, heart problems and other illnesses, such as diabetes.

Here are some tips to help you lose weight:

- Only eat as much food as you need.
- Eat a balanced diet with lots of fruit and vegetables.
- Eat less fat and sugar.
- Be more physically active.

Eat healthily

Eating healthily will give you more energy and help you recover. Try to eat plenty of fruit and vegetables (five portions a day). Cut down on red meat and eat more chicken, fish, lentils and beans.

Be physically active

Being physically active:

- helps keep your weight healthy
- reduces stress and tiredness
- reduces the risk of other health conditions.

There is some evidence that doing regular physical activity may help to reduce the risk of womb cancer coming back, and of getting some other cancers. It also reduces the risk of bone thinning (osteoporosis) in women who had an early menopause.

Your GP or cancer specialist may be able to refer you to special exercise groups run by professional trainers.

Our booklet **Physical activity and cancer** has more information. See page 120 for ordering details.

Stop smoking and drink sensibly

If you smoke, giving up is the healthiest decision you can make. Stopping smoking reduces your risk of heart and lung disease, bone thinning (osteoporosis), and smoking-related cancers. If you want to stop, your GP can give you advice. We have more information about giving up smoking – see page 120 for ordering details.

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

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

There is more information about drinking alcohol at **drinkaware.co.uk**

YOUR FEELINGS AND RELATIONSHIPS

Your feelings

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

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

Shock and disbelief

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

Fear and anxiety

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

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

Avoidance

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

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

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

Anger

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

Guilt and blame

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

Feeling alone

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

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

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

If you need more help

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

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

Our booklet **How are you feeling? The emotional effects of cancer** discusses the feelings you may have in more detail, and has suggestions for coping with them.

> 'The Online Community is a place where we can share our experiences. Where nobody judges us.'
>
> **Daloni**

If you are a relative or friend

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

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

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

Our booklet **Talking with someone who has cancer** has more suggestions if you have a friend or relative with cancer.

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

We have more information about supporting someone with cancer at **macmillan.org.uk/carers**

Talking to children

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

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

Teenagers

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

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

What you can do

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

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

Finding ways to cope

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

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

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

Who can help?

Many people are available to help you and your family.

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

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

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

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

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

WORK AND FINANCIAL SUPPORT

Financial help and benefits

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

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

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

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

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

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

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

Help for carers

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

More information

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

We've just listed some benefits here, but there may be others you can get. You can find out about state benefits and apply for them online at **gov.uk** (England, Wales and Scotland) and **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines or Citizens Advice (see page 129).

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

Insurance

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on page 129.

Our booklets **Insurance** and **Travel and cancer** may also be helpful.

Work

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

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

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

Employment rights

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

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful. There's also lots more information at **macmillan.org.uk/work**

> 'I was fortunate to be able to work from home. This helped me feel I was contributing to work and also gave me a sense of normality while having treatment.'
>
> **Anne**

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

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

Online information

All of our information is also available at **macmillan.org.uk/information-and-support** There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

Other formats

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

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

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

Help us improve our information

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

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

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

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 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'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Talk to others

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

Support groups

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

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.

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

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

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

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

Help with work and cancer

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

My Organiser app

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

Other useful organisations

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

Womb cancer support organisations

The Eve Appeal

Tel 020 7605 0100
Email office@eveappeal.org.uk
www.eveappeal.org.uk

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

Womb Cancer Support

Email wcsuk@hotmail.co.uk
www.wombcancersupportuk.weebly.com

Provides support, advice and information to women who have been diagnosed with womb cancer.

Early menopause and women's health support organisations

Daisy Network

Email info@daisynetwork.org.uk
www.daisynetwork.org.uk

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

Women's Health Concern

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

Support with relationships and sexuality

College of Sexual and Relationship Therapists

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 with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

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, including a free helpline, counselling, and links to local support groups.

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 Centres

Tel 0300 123 1801
Email enquiries@maggiescentres.org
www.maggiescentres.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, 9.30am to 5pm)
Email helpline@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

Has mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

General health information

Health and Social Care in Northern Ireland

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

Healthtalk

Email
info@healthtalk.org
www.healthtalk.org
www.healthtalk.org/young-peoples-experiences (site for young people)
Has information about cancer, and videos and audio clips of people's experiences. Also provides advice on topics such as making decisions about health and treatment.

NHS.UK

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

NHS Direct Wales

www.nhsdirect.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline 0800 22 44 88
(Mon to Fri, 8am to 10pm, Sat and Sun, 9am to 5pm)
www.nhsinform.scot
NHS health information site for Scotland.

Patient UK

www.patient.info
Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health and illness-related websites.

Financial or legal advice and information

Benefit Enquiry Line Northern Ireland

Helpline 0800 220 674
(Mon, Tue, Wed and
Fri, 9am to 5pm,
Thu, 10am to 5pm)
Textphone 028 9031 1092
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Citizens Advice

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

England

Helpline 03444 111 444
www.citizensadvice.org.uk

Wales

Helpline 03444 77 2020
www.citizensadvice.org.uk/wales

Scotland

Helpline 0808 800 9060
www.cas.org.uk

Northern Ireland

Helpline 0800 028 1181
www.citizensadvice.org.uk/nireland

Department for Work and Pensions (DWP)

Personal Independence Payment (PIP) Helpline
0345 850 3322
Textphone 0345 601 6677
(Mon to Fri, 8am to 6pm)
Carer's Allowance Unit
Tel 0800 731 4321
Textphone 0800 731 0317
(Mon to Fri, 8am to 6pm)
www.gov.uk/browse/benefits
Manages state benefits in England, Scotland, and Wales. You can apply for benefits and find information online or through its helplines.

GOV.UK

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

The Law Society of Northern Ireland

Tel 028 9023 1614
Email enquiry@lawsoc-ni.org
www.lawsoc-ni.org
Provides details of solicitors in Northern Ireland. You can search a directory of solicitors on the website.

The Law Society of Scotland

Tel 0131 226 7411
Email lawscot@lawscot.org.uk
www.lawscot.org.uk
Provides details of solicitors in Scotland. You can search a database of solicitors on the website.

Support for carers

Carers 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 Wed, 10am to 4pm)
Helpline (Northern Ireland)
028 9043 9843
Email advice@carersuk.org
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with support groups for carers in their area.

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)

Tel 01455 883 300
Email bacp@bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor on the website.

Mind

Helpline 0300 123 3393
(Mon to Fri, 9am to 6pm)
Text 86463
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.

LGBT-specific support

LGBT Foundation

Tel 0345 330 3030
(Mon to Fri, 10am to 10pm)
Email info@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.

Cancer registries

The cancer registry

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

National Cancer Registration and Analysis Service

Tel 020 7654 8000
Email enquiries@phe.gov.uk
www.ncras.nhs.uk
Tel (Ireland) 021 4318 014
www.ncri.ie (Ireland)

Scottish Cancer Registry

Tel 013 1275 7777
Email nss.csd@nhs.net
www.isdscotland.org/health-topics/cancer/scottish-cancer-registry

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel 029 2037 3500
Email general.enquiries@wales.nhs.uk
www.wcisu.wales.nhs.uk

Northern Ireland Cancer Registry

Tel 028 9097 6028
Email nicr@qub.ac.uk
www.qub.ac.uk/nicr

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

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With thanks to: Elly Brockbank, Consultant Gynaecological Oncology Surgeon; Jane Evans, Macmillan Gynaecological Oncology Clinical Nurse Specialist; Tracie Miles, Lead Gynaecology Oncology Nurse Specialist; and Melanie Powell, Consultant Clinical Oncologist. Thanks also to the people affected by cancer who reviewed this edition, and to those who shared their stories.

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

Sources

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

Colombo et al. ESMO-ESGO-ESTRO Consensus Conference on Endometrial Cancer: diagnosis, treatment and follow-up. Annals of Oncology. 27. 2016.
RCOG. Fertility Sparing Treatments in Gynaecological Cancers. 2013.
Sundar et al. BGCS uterine cancer guidelines: Recommendations for practice. European Journal of Obstetrics & Gynecology and Reproductive Biology. 213. (2017).

Can you do something to help?

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

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

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

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Surname

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Postcode

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

Registered with FUNDRAISING REGULATOR

If you'd rather donate online go to macmillan.org.uk/donate

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

27530

This booklet is about a type of womb cancer called endometrial cancer. It is for anyone who has been diagnosed with this type of cancer. There is also information for carers, family members and friends.

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

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

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

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

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Certified member

This organisation has been certified as a producer of reliable health and social care information.
www.theinformationstandard.org

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