MACMILLAN
CANCER SUPPORT

# Understanding womb (endometrial) cancer

> "I phoned Macmillan's helpline to find out more information about my cancer. They helped me get the information I needed."

Anne, diagnosed with womb cancer

# About this booklet

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

The booklet explains how womb cancer is diagnosed and treated. It also has information about looking after yourself and getting support.

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 sarcoma**.

Page 126 has details of how to order a free copy.

## How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

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

On pages 131 to 140, there are details of other organisations that can help.

## Quotes

In this booklet, we have included quotes from people who have had womb cancer, which you may find helpful. This includes Anne, who is on the cover of this booklet. Some are from our Online Community (**macmillan.org.uk/community**). The others are from people who have chosen to share their story with us. To share your experience, visit **macmillan.org.uk/shareyourstory**

## For more information

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

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

If you are deaf or hard of hearing, call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

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

# Contents

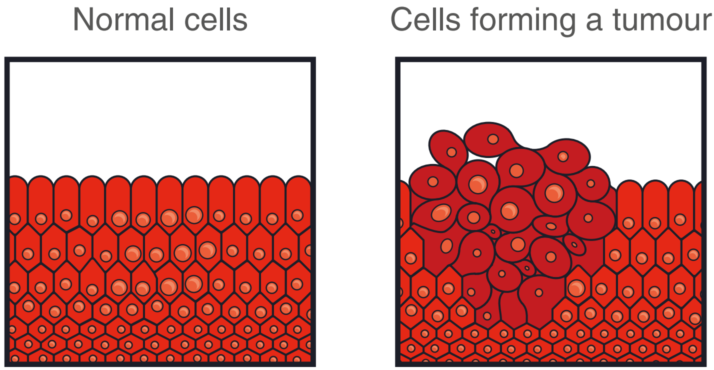
# WOMB CANCER

# What is cancer?

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

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

## Abnormal cells forming a tumour



Normal cells

Cells forming a tumour

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

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

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

Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system (page 10). When these cancer cells reach another part of the body, they may grow and form another tumour. This is called a secondary cancer or a metastasis.

# 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.

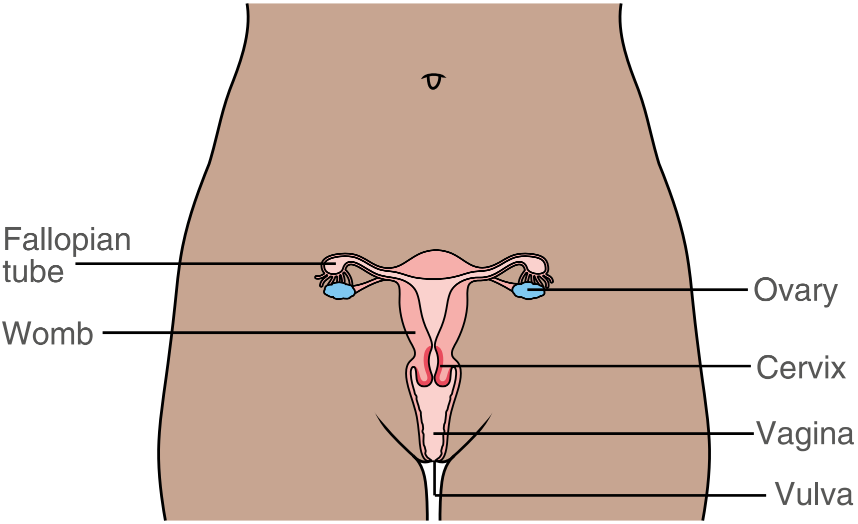
The womb is made up of 3 layers:

- 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 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 have more information in our booklet **Understanding cervical cancer** (page 126).

## The womb and reproductive organs



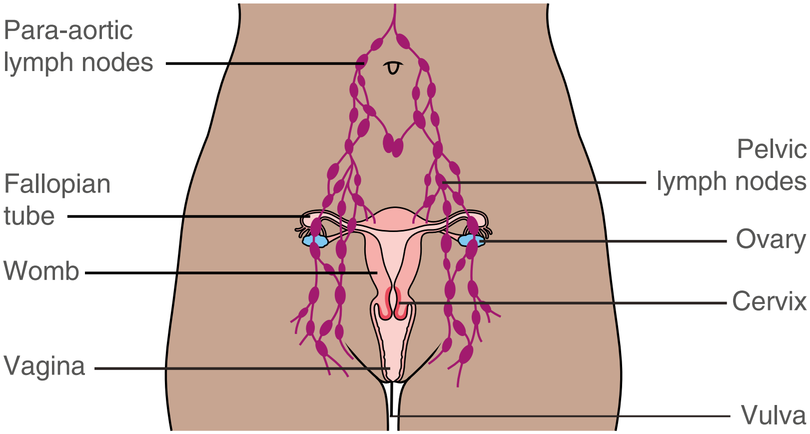
# The lymphatic system

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

Lymph nodes are sometimes called lymph glands. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, 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 9,400 women are diagnosed with womb cancer each year. Womb cancer is rare in women aged under 40 and becomes more common after the age of 55.

Womb cancer can affect anyone who has a womb. This includes women, transgender (trans) men and people assigned female at birth.

## Endometrial cancers

Most womb cancers start in glandular cells found in the lining of the womb (the endometrium). These are called endometrial cancers. They are usually diagnosed early and treated successfully. This information 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 have more information you may find useful in our booklet **Understanding soft tissue sarcoma** (page 126).

# 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 in your 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 the body still produces some oestrogen in body fat and the adrenal glands. The risk of womb cancer can be affected by exposure to oestrogen and 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 from:

- 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 some types of hormone replacement therapy (HRT), for example oestrogen-only HRT
- 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

At least 1 in 3 womb cancers (33%) may be caused by being very overweight (obese). This may be linked to the fact that body fat is the main source of oestrogen after the menopause.

Being more physically active may reduce the risk of womb cancer.

## Genetic factors (family history)

A small number of womb cancers are caused by gene changes that are passed on in a family. This affects less than 5 in 100 women (5%). There may be a genetic link if there are several close relatives on the same side of the family with the following cancers:

- bowel
- breast
- ovarian
- womb.

Close relatives include parents, children, sisters and brothers.

If you are worried about a family history of cancer, speak to your cancer doctor, specialist nurse 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.

## Lynch syndrome

Lynch syndrome is also called hereditary non-polyposis colorectal cancer (HNPCC). This condition increases the risk of bowel cancer and womb cancer. Lynch syndrome means there is a 3 to 6 in 10 risk (30 to 60%) of developing womb cancer over your lifetime if you have a womb. Regular screening for bowel cancer and womb cancer may help reduce the risk. Some people are advised to have a hysterectomy (operation to remove the womb) if they no longer want to be able to get pregnant.

## Cowden syndrome

Cowden syndrome is a rare genetic condition. It increases the 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. This may include changes in the womb lining (endometrial hyperplasia) or polyps. 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. Endometrial hyperplasia can be managed with 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. PCOS may cause:

- fertility problems
- infrequent periods
- no periods
- weight gain or diabetes.

## 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 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 contact your GP about it. Other conditions that affect the womb, such as fibroids, can also cause unusual vaginal bleeding.

# DIAGNOSING WOMB CANCER

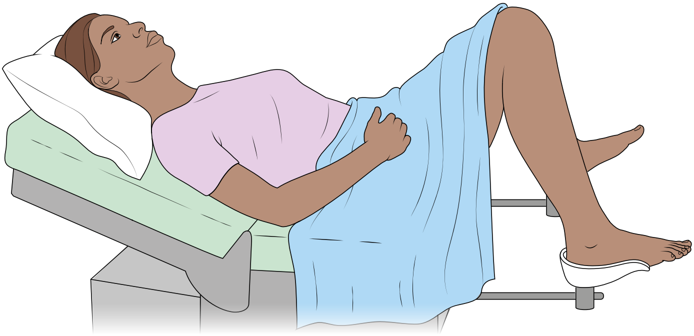
# How womb cancer is diagnosed

You usually start by meeting with your GP, who will ask you about your symptoms.

Your GP may do an internal 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 this, tell the nurse or doctor. They can answer any questions you have.

The doctor does the internal examination by gently putting 1 or 2 fingers of their hand into the vagina. They will be wearing gloves. They then feel around the vagina. While they are doing this, they may put their other hand flat on the tummy area (lower abdomen) and press down.

## Having an internal examination



Your GP may do a blood test and ask you to give a sample of your pee (urine). They may arrange for you to have an ultrasound scan of the womb (page 22). Or they may refer you directly to a gynaecologist. This is a doctor who treats problems with the female reproductive system.

You will be referred urgently (within 2 weeks) for a clinic appointment if you have:

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

## At the hospital

The gynaecologist will ask about your general health and any other medical problems you have. They will also ask 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 examination. If you have not had one recently, you may also have a cervical smear test. This is to check the cervix for any abnormal changes. After this, they will explain any more tests you may need. We have more information about smear tests in our booklet **Understanding cervical screening** (page 126).

# Tests

## Blood tests

You may have blood tests to check:

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

## Trans-vaginal ultrasound scan

This scan uses sound waves to make up a picture of the inside of the 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 the vagina. The test can be 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

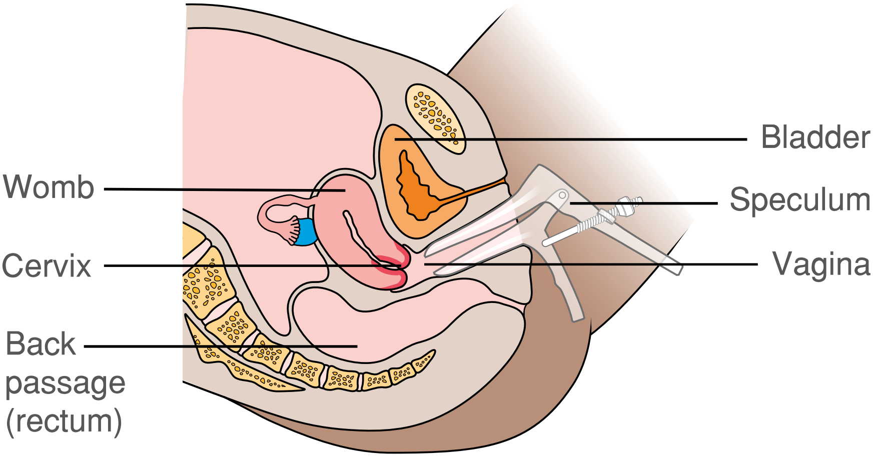
If the ultrasound showed any abnormal areas in the womb lining, your doctor may suggest having a biopsy. This involves taking a sample of cells or tissue from your womb lining. A doctor will then look at the sample under a microscope. If there are cancer cells present, the biopsy results usually show 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 do not usually need an anaesthetic. But some people may have it at another time, with a local or general anaesthetic. Your doctor or nurse gently puts an instrument called a speculum into the vagina to keep it open. They carefully pass a fine tube through the cervix into the 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 uses a thin, flexible tube with a light on the end (hysteroscope). They gently pass it through the vagina and cervix, into the womb.

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

During the hysteroscopy, pictures of the inside of the womb show up on a screen. The doctor or nurse puts 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 and a small number of people may find it painful. If you are worried about the test, talk to your doctor about what they can do to make it as comfortable as possible. Some people may choose to have it done under a general anaesthetic.

After the test, you will have some vaginal bleeding and period-like cramps for a couple of days. Taking 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)

You have this test under a general anaesthetic. It is usually done as an outpatient. The surgeon gently 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 you are diagnosed with womb cancer, you may have further tests. These show the position of the cancer and whether it has spread from where it started. This is called staging (pages 32 to 34). The results of these tests help you and your doctor make decisions about your treatment.

## CT scan

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

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

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

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

# Having a CT scan

## MRI scan

An MRI scan uses magnetism to build up a detailed picture of areas of your body.

The scanner is a powerful magnet. You will be asked to complete and sign a checklist to make sure it is safe for you. The checklist asks about any metal implants you may have, such as a pacemaker or surgical clips. You should also tell your doctor if you have ever worked with metal or in the metal industry. Tiny fragments of metal can sometimes lodge in the body.

You have the scan in the x-ray department at the hospital. A person called a radiographer works the scanner. They may give you an injection of a dye, called a contrast. It helps show certain areas of the body more clearly.

During the test, you need to lie very still on a bed inside a long cylinder (tube). If you are worried about feeling claustrophobic, you may be able to have a sedative to help you relax. Talk to your GP or doctor about this before the scan.

The scan takes 15 to 90 minutes. It is painless but you may find it uncomfortable to lie still for that long. After the scan is finished you can usually go home.

## Chest x-ray

This uses x-rays to take a picture of your chest. It may be done to:

- check your general health
- look at your lungs and heart
- look for changes to the lungs that may be caused by cancer.

Having a chest x-ray is not painful. It only takes a few minutes. It uses a small amount of radiation, which is very unlikely to harm you.

## Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or a support organisation can also provide support (pages 131 to 140). You may find it helpful to talk to one of our cancer support specialists on **0808 808 00 00** (7 days a week, 8am to 8pm).

> **'I felt numb. My Macmillan nurse Linda talked to me and my partner about everything and gave me a pack of information.'**
>
> **Laura**

# 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.

## 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 usually grow more quickly. They include:

- serous endometrial carcinoma
- carcinosarcoma
- clear cell carcinoma
- grade 3 endometrioid cancers
- 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 helps you and your doctor make decisions about your treatment.

The exact stage of the cancer is usually confirmed after surgery (if you have this). We have more information about surgery (pages 47 to 62).

Womb cancer is divided into 4 main stages.

## Stage 1

The cancer is contained in the womb. About 3 out of 4 womb cancers (75%) are diagnosed at stage 1.

Stage 1 can be divided into:

- **stage 1A** – the cancer is only in the lining of the womb, or has grown less than halfway into the muscle
- **stage 1B** – the cancer has grown halfway or more 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 or the ovaries and fallopian tubes, or both
- **stage 3B** – the cancer has spread into the vagina or into the tissues around the womb (parametrium), or both
- **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 4 can be divided into:

- **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.

## How cancer stages are described

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. Womb cancer can be graded as:

- **grade 1 or low-grade or well differentiated** – the cancer cells look like normal cells, 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, some information about you, your diagnosis and your treatment is collected in a cancer registry.

The information is used to help understand cancer in the UK better. This is important for planning and improving health and care services. It can be used to ensure that people living with cancer get the best possible care and support.

Hospitals automatically send information to the cancer registry. There are strict rules about how the information is stored, accessed and used. Information about health is sensitive, so by law it has to be kept under the highest levels of security.

If you have any questions, talk to your doctor or nurse. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out (page 140).

# TREATING WOMB CANCER

# Treatment overview

## Surgery

The main treatment for womb cancer is an operation to remove the womb, cervix, fallopian tubes and ovaries (pages 47 to 62). This is sometimes the only treatment needed to cure the cancer.

If you cannot have a general anaesthetic for health reasons, you may be offered radiotherapy (pages 63 to 75) or hormonal therapy (pages 87 to 89) instead of surgery.

If the cancer has spread but is still in the pelvic area, you may still be offered 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 called adjuvant treatment.

The stage and grade of the cancer helps your specialist decide if you need further treatment (pages 32 to 34).

People with stage 2 or stage 3 cancer, or a high-grade tumour (grade 3), are usually advised to have further treatment.

The most common adjuvant treatment is a type of internal radiotherapy called vaginal brachytherapy (page 66), and external beam radiotherapy (pages 67) to the pelvic area. You may be offered chemotherapy (pages 76 to 86) as well as radiotherapy. Or you may have chemotherapy on its own instead of radiotherapy. You may also be invited to take part in a clinical trial (pages 91 to 93).

## Advanced cancer

Chemotherapy (pages 76 to 86) or hormonal therapy (pages 87 to 89) are used to treat cancer that has spread to other parts of the body, such as the liver or lungs. This is called palliative treatment.

The aim of treatment is usually to help:

- shrink and control the cancer
- relieve symptoms.

Radiotherapy is sometimes given to help control bleeding (pages 63 to 75).

There are newer treatments called targeted therapy and immunotherapy drugs (page 90) that may help to control the cancer. Your cancer doctor will discuss if these may be suitable for you. These treatments may be offered as part of a clinical trial (pages 91 to 93).

A small number of people may have an operation or targeted radiotherapy (called stereotactic radiotherapy) to treat cancer that has spread. But this is not common. It can only be done if the cancer is small and only in one part of the body. Your cancer doctor will explain more about this if it is suitable for you.

# 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 early-stage, low-grade endometrioid cancer (pages 30 to 31), it may sometimes be possible to have fertility-sparing treatment. This may involve having hormonal therapy instead of surgery. This is not standard treatment, so it is important to discuss the risks and benefits with your cancer specialist before making any decisions.

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. We have more information in our booklet **Cancer and fertility** (page 126).

> **‘I went for an MRI scan and then saw a gynae oncologist to discuss preserving my fertility.’**
>
> **Lexie**

## How your treatment is planned

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

## Multidisciplinary team (MDT) meeting

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

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

The MDT will usually include the following professionals:

- Gynaecological oncologist – a surgeon who specialises in gynaecological cancers.
- Medical oncologist – a doctor who uses chemotherapy and other anti-cancer drugs to treat people with cancer.
- Clinical oncologist – a doctor who uses radiotherapy, chemotherapy and other anti-cancer drugs to treat people with cancer.
- Gynae-oncology nurse specialist – a nurse who specialises in gynaecological cancers.
- Radiologist – a doctor who looks at scans and x-rays to diagnose problems.
- Pathologist – a doctor who looks at cells or body tissue under a microscope to diagnose cancer.

Depending on the type of cancer you have, the MDT may also include:

- a dietitian – someone who gives information and advice about food and food supplements
- a physiotherapist – someone who gives advice about exercise and mobility
- an occupational therapist (OT) – someone who gives information, support and aids to help people with tasks such as washing and dressing
- a psychologist – someone who gives advice about managing feelings and behaviours
- a counsellor – someone who is trained to listen to people's problems and help them find ways to cope.

## Talking about your treatment plan

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

Your specialist doctor should explain:

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

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

## The benefits and disadvantages of treatment

Many people are worried about having cancer treatments 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 people with womb cancer have surgery with the aim of curing the cancer. You may also have additional treatments to reduce the risk of the cancer coming back.

If the cancer is advanced and has spread to other parts of the body, treatment may only be able to control it. This can help improve symptoms and your quality of life. But for some people in this situation, the treatment may 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 to have the treatment may not be difficult. But if a cure is not possible and the treatment is to control the cancer for a period of time, it may be more difficult to decide.

Making decisions about treatment in these situations is always difficult. You may need to discuss in detail with your doctor whether you wish to have treatment. Tell your doctor or nurse if you feel you need more time to decide. If you choose not to have the treatment, you can still have supportive (palliative) care, with medicines to control any symptoms.

## Second opinion

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

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

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

We have more information about getting a second opinion at **macmillan.org.uk/second-opinion**

# Giving your permission (consent)

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

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

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

# Surgery

Surgery is the main treatment for womb cancer. A surgeon experienced in treating gynaecological cancers will do the operation.

After the operation, they can tell you more about the stage of the cancer (pages 32 to 34). It can take about 2 to 3 weeks for the stage to be confirmed.

## Surgery to remove the womb (hysterectomy)

The surgeon usually removes:

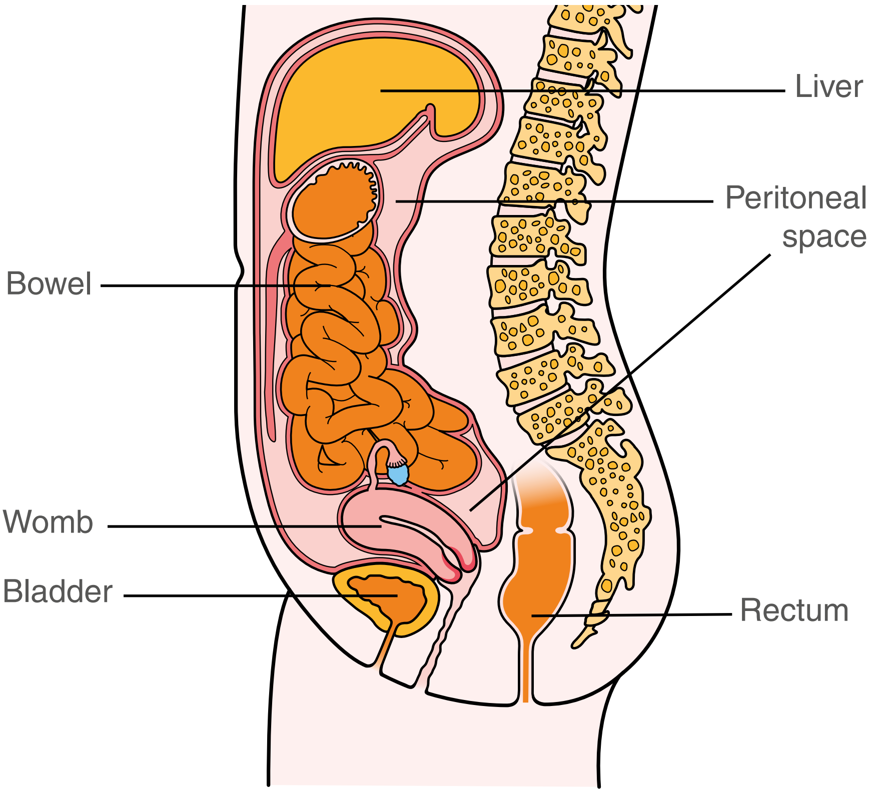
- the womb and the cervix – this is called a total hysterectomy
- the fallopian tubes and both ovaries – this is called a bilateral salpingo-oophorectomy or BSO.

Depending on the stage, grade and type of womb cancer, your surgeon may also recommend removing:

- lymph nodes close to the womb (pelvic nodes) – page 10
- lymph nodes higher up in the abdomen (para-aortic nodes)
- the omentum – a layer of fat and tissue covering the organs in the front of the tummy area (abdomen).

They then check these for cancer cells. Before the operation, your surgeon will talk to you about the surgery. They will explain the benefits and disadvantages, including the side effects and what to expect (pages 48 to 62). Ask them any questions you have.

## The womb and organs in the abdomen



## Early menopause

If you are still having regular periods, after having a hysterectomy and your ovaries removed, you will start the menopause. This can cause menopausal symptoms (pages 98 to 99).

Sometimes it may be an option not to have your ovaries removed. This will prevent an early menopause. This is usually only possible for if you have a low-grade, early-stage cancer (pages 32 to 34).

## 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 and reduce side effects of further treatment such as radiotherapy. Your GP can give you advice and support.

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 electrocardiogram (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 are usually admitted to hospital on the morning of your operation. You will be given elastic stockings (TED stockings) to wear during and after the operation. These help 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.

Your doctor or nurse may give you information about diet and exercise before surgery. Or they may make 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.

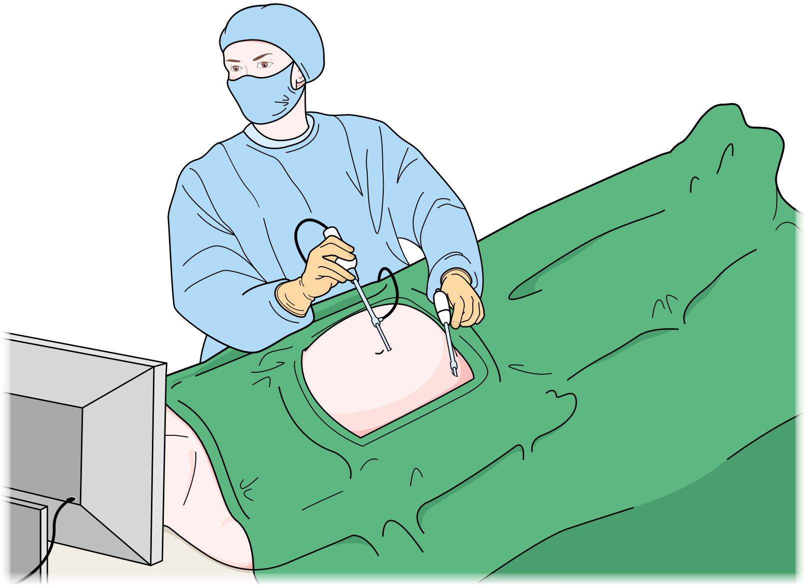
# Having a hysterectomy

A hysterectomy can be done in different ways:

- Laparoscopic surgery – the surgeon operates through small cuts in the tummy (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 in the tummy. Afterwards, you have a wound that goes across your tummy just above the hips, or that goes down from the belly button to just above the hips. Before the operation, your surgeon will discuss with you which cut they will make.
- 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.

## Having laparoscopic surgery



# What else may be done during the surgery

During your operation, the surgeon will check nearby organs and lymph nodes to find out more about the stage of the cancer (pages 32 to 34).

## Removing lymph nodes

The surgeon may remove lymph nodes close to the womb (pelvic nodes) and higher up in the abdomen (para-aortic nodes) – page 10. This is so they can be checked for cancer cells. How many lymph nodes need to removed depends on the stage, grade and type of womb cancer.

If the womb cancer is early, small and low grade, you may not need to have any lymph nodes removed.

Sometimes your surgeon will talk to you about removing only 1 or 2 lymph nodes closest to the cancer to check for cancer cells. This is called a sentinel lymph node biopsy. It may help decide if more treatment is needed.

If scans show the cancer has spread further, they may recommend removing more lymph nodes during the surgery.

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. This is to try and 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 has spread throughout the pelvis, you may have surgery. The surgery will remove the bladder and the bowel, as well as the womb. This is a major operation called pelvic exenteration.

If the cancer has spread to the liver or lungs, surgery is not usually possible. Sometimes you may be able to have an operation to remove a secondary tumour, but this is rare. This is only possible if it is contained in one area, and there are no signs of cancer elsewhere in the body.

# After your operation

## Recovery

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

Your nurses will encourage you to start moving around as soon as possible. This helps with your recovery. While you are in bed, it is important to move your legs regularly and do deep-breathing exercises. This helps prevent chest infections and blood clots. A physiotherapist may show you how to do these exercises. Your nurse may also give you daily injections of a blood-thinning drug to reduce the risk of blood clots. If you have had lymph nodes removed from your pelvis, they will encourage you 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. Your nurse usually takes this out when you are eating and drinking normally.

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

You will have a tube (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. This can be controlled with painkillers.

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

- By mouth (orally).
- As an injection.
- Through an epidural. This is a small, thin tube in your back that goes into the space around your spinal cord. It gives 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.
- Through a thin tube called a rectus catheter that your surgeon places in your tummy. You may have this kind of catheter if you have the cut downwards from your belly button to your tummy.
- As a combination of some of the above.

It is important to tell your doctor or nurse if the pain is not controlled. They can change your painkillers.

> **‘I went home with painkillers which I found helpful for the first couple of weeks. I also listened to my body – when the pain got more intense I would rest for a while.’**
>
> **Anne, diagnosed with womb cancer**

## Your wound

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

Sometimes people can develop an infection in their wound. 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.

## Constipation

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

## Low mood

It is common to feel upset after the operation. This is often a reaction to:

- the diagnosis of cancer
- having the operation
- being away from your usual support network.

These feelings usually begin to improve, or you may continue to feel this way. Tell your doctor or specialist nurse if you are not feeling better or if you begin to feel very low. You may need extra help and support.

Some hospitals have local support groups for people who have gynaecological cancers. You may find a support group helpful. Ask your nurse specialist if there is one in your hospital or local area.

You may want to talk about your feelings with an organisation that specialises in womb cancer. You could also join an online support group such as our Online Community (page 129). You can chat with other people who have womb cancer. Or you can just read the posts or blogs other people have written.

## Going home

If you have laparoscopic or robotic surgery, you can usually go home later that day or the day after. 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 your recovery, and how to care for your wounds. How quickly you recover will depend on the operation you had. It is important not to do too much for a while. Try to get plenty of rest, do gentle exercise and eat well. If you have any problems, it is important to contact your doctor or specialist nurse.

> **‘I knew I was going to be out of action for at least 6 weeks. So I was planning for that – making sure I had food in the freezer and lifts for my children to school and back.’**
>
> **Daloni**

## Follow-up appointment

You will be given an appointment to come back to the outpatient clinic to meet with the surgeon. You may also meet with your specialist nurse. Sometimes you may have it as a telephone appointment.

Your surgeon or nurse will check how you are recovering. They will explain the results of the operation and tell you if you need further treatment.

## Blood-thinning injections

Your nurse may give you daily blood-thinning injections to take home. They will show you how to inject yourself. If you are not able to inject yourself, they will show a family member or friend how to. Or they will arrange for a district nurse to do it for you.

## Vaginal care

After a hysterectomy, you may have some vaginal discharge for up to 6 weeks. This is usually a reddish-brown colour. Contact your doctor straight away if the discharge:

- becomes bright red
- is heavy
- smells unpleasant
- contains clots (lumps).

Your doctor or nurse will advise you to shower daily. They will also advise you that for the first 6 weeks after surgery, you should not:

- have penetrative sex
- put anything inside the vagina (such as tampons).

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.

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

If you have a laparoscopic hysterectomy, your surgeon or nurse may recommend waiting longer before having penetrative sex. This may be up to 12 weeks. This is because the wound at the top of the vagina can take longer to heal.

## Physical activity

You doctor or nurse will advise you 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 gentle exercise every day, such as walking. You can slowly increase how much you do. It will help you build up your energy levels and feel better.

We have more information in our booklet **Physical activity and cancer** (page 126).

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

**Anne, diagnosed with womb cancer**

## Driving

You may 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 drive. Some insurance companies have guidelines about this. It is best to contact your insurer to check you are covered to drive.

# Possible long-term complications

Most people do not have any long-term complications after surgery. But having other treatments as well as surgery may increase the risk of problems.

If you had your 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. We have more information in our booklet **Understanding lymphoedema** that you may find useful (page 126).

# 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. You can also talk to your specialist nurse, our you can call our cancer support specialists on **0808 808 00 00** to talk.

# Radiotherapy

Radiotherapy treats cancer by using high-energy x-rays. It destroys cancer cells in the area where the radiotherapy is given.

Radiotherapy may be given internally or externally, or as a combination of both. Sometimes you have radiotherapy with chemotherapy (pages 76 to 86). This is called chemoradiation. Your cancer specialist will discuss your treatments with you.

## When radiotherapy is used

You may have radiotherapy:

- after surgery, to reduce the risk of the cancer coming back (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 after surgery

Your cancer specialist may talk to you about having radiotherapy after surgery (pages 47 to 62). 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 (pages 32 to 34).

Some people with early stage cancer may not need radiotherapy. But your doctor may suggest having radiotherapy if you have a slightly higher risk of the cancer coming back. This can help to reduce your risk. Most people with stage 2 or 3 womb cancer are advised to have radiotherapy after surgery.

Your specialist will explain 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, you may have external beam radiotherapy to shrink the cancer or to control the symptoms. For example, you may have this treatment if the cancer has spread in the pelvic area, or to other parts of your body such as the bones. This is called palliative radiotherapy. It is planned carefully so that you have as few side effects as possible.

## Planning your radiotherapy treatment

You will have a hospital appointment to plan your treatment. You will usually have a CT scan of the area to be treated (page 26). During the scan, you need to lie in the position that you will be in for your radiotherapy treatment.

Your radiotherapy team use information from this scan to plan:

- the dose of radiotherapy
- the area to be treated.

If you are having external radiotherapy, you may have some small, permanent markings made on your skin (like tattoos). The marks are about the size of a pinpoint. They help the radiographer make sure you are in the correct position for each session of radiotherapy. These marks will only be made with your permission. If you are worried about them, talk to your radiographer.

# Internal radiotherapy (brachytherapy)

Internal radiotherapy is also called brachytherapy. It gives a high dose of radiotherapy directly to the top of the vagina (where the womb was before surgery to remove it). It also gives a high dose 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 usually have it as an outpatient.

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

After the applicators are in place, they are connected to the brachytherapy machine. The machine is operated by a radiographer or physics technician. It places a radioactive capsule (source) into the applicators. The machine then gives the planned dose of radiation. When the treatment is finished, the radioactive source goes back into the machine. The nurses will then take out the applicators and you can go home.

If you still have a womb, you 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 a general anaesthetic or sometimes a spinal anaesthetic. Your doctor or nurse can explain more about how it is given.

There are different ways of giving internal radiotherapy. It can be given over several sessions or one longer session. Your cancer doctor and nurse specialist will explain about your treatment, and what to expect.

# External radiotherapy

External radiotherapy uses a machine 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.

Your radiotherapy is planned by your clinical oncologist and a technical team. They will plan your treatment, so it does as little harm as possible to normal cells.

## Treatment sessions

Your radiographer will explain what you will experience. The radiotherapy machine will move around you, but it does not touch you. The treatment is painless. Once you are comfortable in the correct position, they will ask you to keep as still as possible. They will leave the room for a few minutes while you have your treatment. There will be a camera so they can see you and hear you if you need to talk to them.

## 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. Sometimes you may notice the side effects get a little worse for a short time after finishing treatment, before they start to get better.

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. The NHS has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live.

If you are having only internal radiotherapy, it is not common to get side effects. You may feel some discomfort when the tube is placed into the vagina. But your doctor or nurse will use some gel to numb the area. The treatment only affects a very small area in the top of the vagina. This means is not likely to cause any long-term side effects, for example to your bladder or bowel. But you may notice some effects to the vagina and your sex life after treatment.

External radiotherapy causes more side effects than internal radiotherapy.

Your doctor, nurse or radiographer will explain what to expect. Tell them about any side effects you have during or after treatment. There are often things that can help.

## Skin reactions

The skin in the area that is treated may:

- redden
- darken
- feel sore or itchy.

Your radiographer or specialist nurse will give you advice on taking care of your skin. If your skin becomes sore or itchy or changes colour, tell them straight away. They can give you advice and treatments if needed.

Skin reactions should get better within 4 weeks of treatment finishing.

During your treatment, you are usually advised to:

- wear loose-fitting clothes made from natural fibres, such as cotton
- wash your skin gently with mild, unperfumed soap and water and gently pat it dry
- avoid rubbing the skin
- avoid wet shaving
- avoid hair-removing creams or products, including wax
- follow your radiotherapy team's advice about using moisturisers
- protect the treated area from the sun.

## Pubic hair

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

## Tiredness

Radiotherapy often makes people feel tired. Tiredness may get worse as treatment goes on. If you are having radiotherapy alongside other treatments, such as surgery or chemotherapy, you may feel more tired. But there are things you can do to help, such as:

- get plenty of rest
- do some gentle exercise, such as short walks
- eat a healthy diet and drink plenty of fluids
- ask others for help with everyday jobs.

After treatment finishes, you may continue to feel tired for weeks or months. If it does not get better, tell your cancer doctor or specialist nurse.

We have more information in our booklet **Coping with fatigue (tiredness)** – page 126.

> **Fatigue is something I struggle with. Some days I'm fine and productive but others I have difficulty concentrating. I've learned to accept that there will be days when I can't do as much as I want to do.**
>
> **Laura**

## Bowel changes

Radiotherapy to the pelvis may irritate the bowel. It can 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 few 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 (pee) more often and causes a burning feeling when you pass urine. Your doctor can give you medicines to help. Drinking at least 2 litres (3½) of fluid a day will also help.

Your doctor may ask you to give a urine sample. This is to check you do not have a urine infection.

## Vaginal discharge

You may have a small amount of 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.

# Possible late effects of radiotherapy

Radiotherapy to the pelvic area can sometimes cause problems months or years after treatment. These are called late effects. Some of these may be permanent, but 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 checked, as they may not be caused by radiotherapy.

## Effects on the vagina

Radiotherapy can make the 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 prevent narrowing. Dilators are tampon-shaped plastic tubes of different sizes, which you use with a lubricant.

Your specialist nurse or doctor will explain the best way to use them.

### Vaginal dryness

Radiotherapy can also cause vaginal dryness. This can feel uncomfortable, particularly during sex. Creams, gels or lubricants can help.

There are lots of products you can try. You can buy them at a pharmacy or online, or your doctor can prescribe them.

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 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. Tell your doctor 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 after sex or after using the vaginal dilators. Bleeding may be caused by:

- vaginal tissue sticking together
- scar tissue causing the vagina to narrow.

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

## Bowel or bladder changes

After radiotherapy, you may develop changes to the bowel or bladder. It is common to have some mild changes, but 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 go to the toilet more often or more urgently than usual, or you may have diarrhoea.

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

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

## 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 straight away
- contacting 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.

If you develop lymphoedema, you can be referred to a lymphoedema specialist to help manage it.

## Changes to the pelvic bones

Radiotherapy can cause thinning of the bones in the pelvis. Often this does not have any symptoms, but is seen on scans. Sometimes it may cause fractures in the pelvis called insufficiency fractures. These can cause pain in the lower back or pelvis. If this happens, your doctor can give you painkillers to help. You may also be referred to a physiotherapist.

# 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 (pages 47 to 62) and radiotherapy (pages 63 to 75). 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:

- at a more advanced stage (stage 3 or stage 4) – pages 32 to 33
- a non-endometrioid type – page 11
- high grade (grade 3) – page 34.

Your cancer doctor 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 doctor 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 one drug, or you may have 2 or 3 drugs together. If you are having adjuvant chemotherapy, you are more likely to have a combination of drugs. Your cancer doctor or specialist nurse will explain more about your treatment.

## Having chemotherapy

You usually have chemotherapy in a chemotherapy day unit and go home after it. The drugs are 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 usually 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. Most cycles are 1 to 3 weeks long. Sometimes it is given every 4 weeks. Your cancer doctor or specialist nurse will explain what to expect. Most courses of chemotherapy are made up of 6 cycles.

## Side effects of chemotherapy

Chemotherapy drugs can cause side effects. But many of these can be controlled with medicines and usually go away when your treatment finishes. If the cancer is causing symptoms, chemotherapy can also make you feel better by relieving them.

Each different chemotherapy drug has different side effects. Your doctor, nurse or pharmacist will explain what to expect. Always tell your doctor or nurse about any side effects you have.

These are some of the main side effects of chemotherapy.

> 'At first, I found chemotherapy a bit daunting. But you get into the swing of treatment and get to know how you are likely to feel.'

**Anne, diagnosed with womb cancer**

## Risk of infection

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

An infection can be very serious when the number of white blood cells is low. It is important to get any infection treated as soon as possible. Contact the hospital straight away on the 24-hour contact number you have if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection
- your temperature goes below 36°C (96.8°F).

Symptoms of an infection include:

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

**It is important to follow any specific advice your cancer treatment team gives you.**

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

## Anaemia (low number of red blood cells)

This treatment can reduce the number of red blood cells in your blood. Red blood cells carry oxygen around the body. If the number of red blood cells is low, this is called anaemia. You may have symptoms such as:

- pale skin
- lack of energy
- feeling breathless
- feeling dizzy and light-headed.

Tell your doctor or nurse if you have these symptoms.

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

This treatment can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot.

If the number of platelets is low, you may bruise or bleed easily. You may have:

- nosebleeds
- bleeding gums
- heavy periods
- blood in your urine (pee) or stools (poo)
- tiny red or purple spots on the skin that may look like a rash.

Tell your doctor if you have any unexplained bruising or bleeding. You may need a drip to give you extra platelets. This is called a platelet transfusion.

## Feeling sick

Your doctor will give you anti-sickness drugs to help prevent or control sickness during treatment. 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 regularly. It is important to drink enough fluids. If you continue to feel sick, or are sick (vomit)more than once in 24 hours, contact the hospital as soon as possible. They will give you advice. Your doctor or nurse may change the anti-sickness drug to one that works better for you.

## Sore mouth

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

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

Sucking ice chips may sometimes help relieve mouth or throat pain. But if you are having radiotherapy to the head or neck, do not suck on ice. It can cause damage.

## Diarrhoea

This treatment may cause diarrhoea. Diarrhoea means passing more stools (poo) than is usual for you, or having watery or loose stools. If you have a stoma, it will be more active than usual.

If you have diarrhoea:

- try to drink at least 2 litres (3½ pints) of fluids each day
- avoid alcohol, caffeine, milk products, high-fat foods and high-fibre foods
- contact the hospital for advice.

## 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 to cover up hair loss if you want to. This includes using wigs, hats, turbans, scarves or bandanas. It is important to cover your head to protect your skin when you are out in the sun.

Hair loss is usually temporary. Your hair will usually grow back after treatment finishes. Rarely, 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. We have more information in our booklet **Coping with hair loss** (page 126).

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

Some chemotherapy drugs may 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. 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 people have an allergic reaction while having some types of chemotherapy drugs. Signs of a reaction can include:

- feeling hot or flushed
- shivering
- itching
- a skin rash
- feeling dizzy
- a headache
- feeling breathless or wheezy
- 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 happens 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 some cancer treatments can increase the risk of a blood clot. Symptoms of a blood clot include:

- throbbing pain, redness or swelling in a leg or arm
- suddenly feeling breathless or coughing
- sharp chest pain, which may be worse when you cough or take a deep breath. If you have any of these symptoms, contact a doctor straight away on the 24-hour contact number you have been given. If you cannot get through to your doctor, call the NHS urgent advice number on **111**.

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

You can help reduce the risk of developing a blood clot by:

- staying active during treatment
- drinking plenty of fluids, especially water.

You may be given anticoagulants to help prevent a clot.

# Hormonal treatment

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

- have advanced womb cancer
- have womb cancer that has come back after treatment (recurrent cancer)
- cannot have surgery (pages 47 to 62) or radiotherapy (pages 63 to 75) because of other health issues.

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

If you are younger and who want to have children in the future, you may be offered hormone therapy instead of a hysterectomy. This is called fertility-sparing treatment. After you have had children, you would then have a hysterectomy (pages 47 to 51).

The main hormonal treatment for womb cancer that has spread or come back is progesterone. You usually have it as a tablet. The most common types of progesterone are:

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

Other hormonal treatments are sometimes used, such as tamoxifen and letrozole (Femara®).

## Side effects

The most common side effects of progesterone are:

- increased appetite
- weight gain
- fluid build-up (for example swollen ankles)
- feeling sick
- a small risk of developing a blood clot.

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. Tell your doctor or nurse if you are having side effects.

## Fertility-sparing treatment

An operation to remove the womb and ovaries (hysterectomy) is usually the standard treatment for womb cancer. But it is sometimes possible to have fertility-sparing treatment instead if you want the chance to have children in future. It is only suitable if you have stage 1, grade 1 womb cancer (pages 32 to 34).

The treatment usually involves taking daily progesterone tablets. Sometimes, progesterone is 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. 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.

# Targeted therapy and immunotherapy

Newer treatments called targeted therapy and immunotherapy may be used to treat womb cancer that has spread. These can help to control the cancer and slow down the growth.

Your doctor will send a sample of the cancer cells taken during a biopsy or surgery to be tested. This helps to check which type of treatment may work best for you. Your cancer doctor or nurse will explain more about your treatment and what to expect. Targeted therapy and immunotherapy may be offered as a clinical trial.

# Clinical trials

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

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

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

## Taking part in a trial

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

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

A research nurse or doctor will give you information about the trial. It is important to understand what is involved before you agree (consent) to take part. You can ask the research nurse or doctor any questions you have.

They will also explain the possible benefits and any possible risks of the trial. Clinical trials are designed to be as safe as possible. The researchers will monitor you closely during and after the trial.

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

We have more information about cancer clinical trials at **macmillan.org.uk/clinicaltrials**

## Giving blood and tissue samples

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

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

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

The samples may be used to:

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

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

# AFTER YOUR TREATMENT

# Follow-up

After your treatment, you will have regular check-ups. They will include an internal examination. These will be every few months at first. Eventually, you may only have them 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 people do not have routine appointments. Instead, they are asked to contact their cancer doctor 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
- any lumps or swellings.

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 contact the Macmillan Support Line on 0**808 808 00 00.**

# Sex after treatment

Womb cancer, its treatments and their side effects may affect your sex life and how you feel about yourself. This often slowly improves after treatment, but for some people, it may take longer. There may be a period of adjustment for you, and for any partners.

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 feel ready to have sex. There is no right or wrong time.

It is common to feel nervous about sex after cancer treatment, but it is completely 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 can help to reassure you and offer advice 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 (page 132).

We have more information about cancer and sex in our booklet **Cancer and your sex life** (page 126).

# Menopausal symptoms

If you have not been through the menopause, a hysterectomy (page 47 to 51) that involves removing the ovaries will cause the menopause straight away. This will also happen if you have radiotherapy without any surgery (pages 47 to 62). This is because radiotherapy stops the ovaries working.

These are some common symptoms of the menopause.

## Hot flushes and sweats

Your doctor may suggest a low dose of an anti-depressant drug 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 how you feel.

## Emotional symptoms

These can include:

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

Talking about your feelings with your family, friends, doctor or nurse can help. Some people find it helps to talk things through with a counsellor. We have lots more information in our booklet **Your feelings after cancer treatment** (page 126).

## Bone thinning

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

## Managing symptoms

Your doctor or specialist nurse can give you advice about 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. Some cancer specialists may prescribe HRT for early-stage womb cancer that is causing troublesome menopausal symptoms. They may do this if other treatments have not worked.

Some organisations give support to people going through the menopause. This includes the Daisy Network (page 131) and the Women's Health Concern (page 132). We have more information on managing symptoms of menopause at **macmillan.org.uk**

# Well-being after treatment

After treatment, you will probably want 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 with some difficult emotions. Recovery takes time, so try not to be hard on yourself. It is not unusual to feel anxious and lonely 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. Your cancer doctor or nurse will explain what to look out for, which can help you manage some of these feelings. It is important to tell them about any concerns or questions you have. You do not need to wait until your follow-up appointments.

These are some of the problems people have after treatment.

## Lifestyle changes

After treatment, you may 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 when you are feeling well enough, 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.

Healthy ways to lose weight include:

- only eating as much food as you need
- eating a balanced diet with lots of fruit and vegetables
- eating less fat and sugar
- being more physically active.

## Eat healthily

Eating a healthy, balanced diet gives you more energy and will help you recover. Try to eat plenty of fruit and vegetables (5 portions a day), cut down on red meat and eat more chicken and fish.

## Be physically active

Being physically active after cancer treatment can:

- increase your energy levels
- help you keep to a healthy weight
- reduce stress and tiredness
- reduce 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 developing some other cancers. It also reduces the risk of bone thinning (osteoporosis) after an early menopause.

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

We have information in our booklet **Physical activity and cancer** that you may find useful (page 126).

## Stop smoking and drink sensibly

If you smoke, stopping is the healthiest decision you can make. It 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.

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

- do not regularly drink more than 14 units in a week
- spread the amount you drink in a week over 3 or more days
- try to have several alcohol-free days every week.

1 unit of alcohol is:

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

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

# YOUR FEELINGS AND RELATIONSHIPS

# Your feelings

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

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

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

## Shock and denial

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

> ‘Being diagnosed with womb cancer came completely out of the blue and I was in denial at first. I would encourage anyone experiencing the emotional impact of cancer to seek help.’

**Sharon, diagnosed
with womb cancer**

## Fear and anxiety

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

## Sadness and depression

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

## Avoidance

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

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

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

## Anger

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

## Guilt and blame

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

## Feeling alone

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

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

If you need more support, you can call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find local support groups. Visit **macmillan.org.uk/supportgroups** You can also talk to other people affected by cancer on our Online Community. Visit **macmillan.org.uk/community**

## If you need more help

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

Talk to your doctor or nurse if:

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

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

We have lots more information in our booklet **How are you feeling? The emotional effects of cancer** (page 126).

# Coping with your emotions

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

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

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

# If you are a family member or friend

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

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

You can support the person with cancer by listening and talking with them. Do not feel you have to talk about the cancer. Often it is enough just to listen and let the person with cancer talk when they are ready.

We have more information in our booklet **Talking with someone who has cancer** which you may find helpful (page 126).

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers in our booklet **Looking after someone with cancer** (page 126).

# Talking to children about cancer

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

Talking to children about the cancer can:

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

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

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

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

## Teenagers

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

Sometimes teenagers may find it hard to talk about a cancer diagnosis. You can encourage them to talk to someone they trust, who can support and listen to them. This might be a grandparent, family friend, teacher or counsellor. They may also find support online.

We have more information in our **Talking to children and teenagers when an adult has cancer** booklet (page 126).

# WORK AND FINANCIAL SUPPORT

# Financial help and benefits

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

## Statutory Sick Pay

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

## Benefits

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

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

### Employment and Support Allowance (ESA)

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

## Universal Credit

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

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

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

## Personal Independence Payment

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

## Attendance Allowance

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

## Special rules

If you are terminally ill, you can apply for some benefits using a fast-track process called special rules. You can apply if your doctor thinks you may be reasonably expected to live for less than 12 months. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 12 months.

## Help for carers

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

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

## Grants

You may be able to get some financial help from other charities – for example, one-off grants. For further information, contact the Macmillan Support Line.

## Insurance

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

If you are thinking about buying insurance or making a claim, one of our money advisers may be able to help. You can call them on **0808 808 00 00**.

We have more information in our booklet T**ravel and cancer** (page 126). Our Online Community forum on T**ravel insurance** may also be helpful. Visit **macmillan.org.uk/travelinsurancegroup**

## More information

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

You can also get information about benefits and other types of financial help from Citizens Advice (pages 135 to 136).

Our booklet **Help with the cost of cancer** has lots more information (page 126).

# Work

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

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

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

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

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

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful (page 126). There is also lots more information at **macmillan.org.uk/work**

## Employment rights

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

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

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

Our booklet **Your rights at work when you are affected by cancer** has more information (page 126).

> **‘I found it really helpful to have some great work colleagues who I could talk to. They were very supportive and continue to be during my recovery.’**
>
> **Anne, diagnosed with womb cancer**

# FURTHER INFORMATION

# About our information

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

## Order what you need

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

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

## Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

## Other formats

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

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

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

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

## The language we use

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

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

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

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

# Other ways we can help you

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

## Talk to us

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

### Macmillan Support Line

Our support line is made up of specialist teams who can help you with:

- emotional and practical support if you or someone you know has been diagnosed with cancer
- clinical information from our nurses about things like diagnosis and treatments from our nurse specialists
- welfare rights advice, for information about benefits and general money worries.

To contact any of our teams, call the Macmillan Support Line for free on **0808 808 00 00**. Or visit **macmillan.org.uk/support-line** to chat online and find the options and opening times.

### Macmillan Information and Support Centres

Our Information and Support Centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you would like a private chat, most centres have a room where you can speak with someone alone and in confidence.

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

# Talk to others

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

### Support groups

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

### Online Community

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

# The Macmillan healthcare team

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

# Help with money worries

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

## Financial advice

Our expert money advisers on the Macmillan Support Line can help you deal with money worries and recommend other useful organisations that can help.

## Help accessing benefits

You can speak to our money advisers for more information. Call us free on **0808 808 00 00**. Visit **macmillan.org.uk/financialsupport** for more information about benefits.

# Help with work and cancer

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

# Other useful organisations

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

## 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.

### Peaches Womb Cancer Trust

**www.peachestrust.org**
Provides support and information for womb cancer patients. Also raises awareness and funds research into womb cancer.

### 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 **0734 047 1970**

**www.cancerblackcare.org.uk**

Provides support for all those living with and affected by cancer, with an emphasis on Black people and people of colour.

### Cancer Focus Northern Ireland

Helpline **0800 783 3339** (Mon to Fri, 9am to 1pm)

Email **nurseline@cancerfocusni.org**

**www.cancerfocusni.org**

Offers a variety of services to people affected by cancer in Northern Ireland.

### Cancer Research UK

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

### Maggie’s

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

### Penny Brohn UK

Helpline **0303 3000 118** (Mon to Fri, 10am to 2pm)
Email **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** (Mon to Fri, 9am to 5pm, and Sat to Sun, 10am to 1pm)
**www.tenovuscancercare.org.uk**
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online ‘Ask the nurse’ service.

## Counselling

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

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

### UK Council for Psychotherapy (UKCP)

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

## Emotional and mental health support

### Mind

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

### Samaritans

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

## Financial support or legal advice and information

### Advice NI

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

### Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271** (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

### Carer’s Allowance Unit

Tel **0800 731 0297**
Textphone **0800 731 0317** (Mon to Fri, 8am to 6pm)
**www.gov.uk/carers-allowance-unit**
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

### Citizens Advice

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

### England

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

### Scotland

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

### Wales

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

### Civil Legal Advice

Helpline **0345 345 4345** (Mon to Fri, 9am to 8pm, and Sat, 9am to 12.30pm)
Textphone **0345 609 6677**
**www.gov.uk/civil-legal-advice**
Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English is not your first language.

## GOV.UK

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

## Jobs and Benefits Office Enquiry Line Northern Ireland

Helpline **0800 022 4250** (Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)
Textphone **0800 587 1297**
**www.nidirect.gov.uk/money-tax-and-benefits**
Provides information and advice about disability benefits and carers' benefits in Northern Ireland

## Money Advice Scotland

Tel **0141 572 0237**
Email **info@moneyadvicescotland.org.uk**
**www.moneyadvicescotland.org.uk**
Use the website to find qualified financial advisers in Scotland.

## NI Direct

**www.nidirect.gov.uk**
Has information about benefits and public services in Northern Ireland.

## StepChange Debt Charity

Tel **080 0138 1111** (Mon to Fri, 8am to 8pm and Sat, 8am to 4pm)
**www.stepchange.org**
Provides free debt advice through phone, email, the website and online through live chats with advisers.

## Equipment and advice on living with a disability

### British Red Cross

Tel **0344 871 11 11**
Email **contactus@redcross.org.uk**
**www.redcross.org.uk**
Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

### Living Made Easy

Helpline **0300 999 0004** (Mon to Fri, 9am to 5pm)
Email **info@dlf.org.uk**
**www.livingmadeeasy.org.uk**
Provides free, impartial advice about all types of disability equipment and mobility products.

## LGBT-specific support

### LGBT Foundation

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

### OUTpatients (formerly called Live Through This)

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

## Support for carers

### Carers Trust

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

### Carers UK

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

## Cancer registries

The cancer registry is a national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services.

There is a cancer registry in each country in the UK. They are run by the following organisations:

### England – National Disease Registration Service (NDRS)

**www.digital.nhs.uk/ndrs/patients**

### Scotland – Public Health Scotland (PHS)

**www.publichealthscotland.scot/our-areas-of-work/conditions-and-diseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/overview**

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

Tel **0292 010 4278**
**www.phw.nhs.wales/wcisu**

### Northern Ireland – Northern Ireland Cancer Registry (NICR)

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

## Disclaimer

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

## Thanks

This information has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Professor Nick Reed, Consultant Clinical Oncologist.

With thanks to: Jan Dodge, Gynae-Oncology Clinical Nurse Specialist; Sara Elias, Gynae-Oncology Clinical Nurse Specialist; Mr Simon Leeson, Consultant Gynaecologist and Oncologist; Dr Alexandra Taylor, Consultant Clinical Oncologist; and Dr Mark Zahra, Consultant Clinical Oncologist.

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

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

## Sources

Below is a sample of the sources used in our womb (endometrial) cancer information. If you would like further information about the sources we use, please contact us at **informationproductionteam@macmillan.org.uk**

Concin et al. ESGO/ESTRO/ESP guidelines for the management of patients with endometrial carcinoma. International Journal of Clinical Oncology. 2021. Available from www.pubmed.ncbi.nlm.nih.gov/33397713/

Royal College of Radiotherapy: Clinical Oncology. Radiotherapy dose fractionation, third edition. 2019. Available from www.rcr.ac.uk/publication/radiotherapy-dose-fractionation-third-edition

Sundar et al. BGCS uterine cancer guidelines: Recommendations for practice. European Journal of Obstetrics & Gynecology and Reproductive Biology. 2017. Available from www.bgcs.org.uk/wp-content/uploads/2019/05/BGCS-Endometrial-Guidelines-2017.pdf

# Can you do something to help?

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

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

## 5 ways you can help someone with cancer

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

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

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

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

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

**Call us to find out more 0300 1000 200**
**macmillan.org.uk/getinvolved**

## Please fill in your personal details

**Mr/Mrs/Miss/Other**

**Name**

**Surname**

**Address**

**Postcode**

**Phone**

**Email**

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

**Valid from** ☐☐ ☐☐

**Expiry date** ☐☐ ☐☐

**Issue no** ☐☐☐

**Security number** ☐☐☐

Signature

Date / /

## Do not let the taxman keep your money

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

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

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

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

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

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

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REGULATOR

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Freepost RUCY-XGCA-XTHU, Macmillan Cancer Support, PO Box 791, York House, York YO1 0NJ

**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 talks about the signs and symptoms of endometrial cancer. It explains how it is diagnosed and how it may be treated. It also has information about emotional, practical and financial issues.

At Macmillan we know cancer can disrupt your whole life. We'll do whatever it takes to help everyone living with cancer in the UK get the support they need right now, and transform cancer care for the future.

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 Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

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

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