WE ARE MACMILLAN. CANCER SUPPORT

A practical guide to tests and treatments

UNDERSTANDING CHEMOTHERAPY

> ‘For many people, chemotherapy is a bit of a shock. For me, I welcomed each round as it was helping me to feel more like me again.’
>
> **Kate**

About this booklet

This booklet is about chemotherapy. It is for anyone who is having chemotherapy treatment for cancer. There is also information for carers, family members and friends.

The booklet explains how chemotherapy works and how it is given. There is also information about common side effects, how they can be treated and what you can do to manage them.

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

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**, Monday to Friday, 9am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use. If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

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

How to use this booklet

The booklet is split into sections to help you find what you need. You 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.

In this booklet, we have included quotes from people who have had chemotherapy. We hope you find these helpful. Some are from **healthtalk.org** The others are from people who have shared their stories with us. This includes Kate, who is on the cover of this booklet. To share your experience, visit **macmillan.org.uk/shareyourstory**

There are sections at the back of the booklet called **Your chemotherapy** and **Questions you could ask about chemotherapy** that you may find useful (see pages 124 to 127).

Contents

WHAT IS CHEMOTHERAPY?

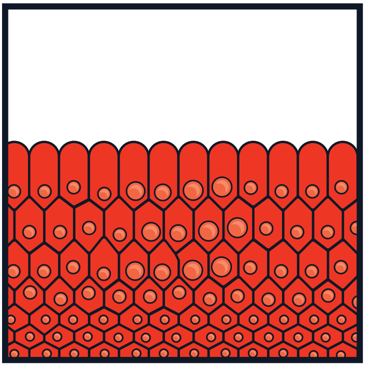
What is cancer?

To understand how chemotherapy treats cancer, it helps to know what cancer is.

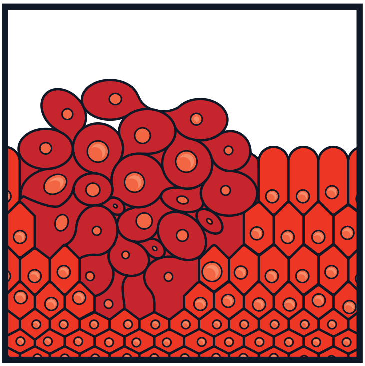
Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop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

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

Normal cells



Cells forming a tumour



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

A lump that is cancer (**malignant**) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or lymphatic system.

When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a **secondary cancer** or a **metastasis**.

Your data and the cancer registry

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

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

The lymphatic system

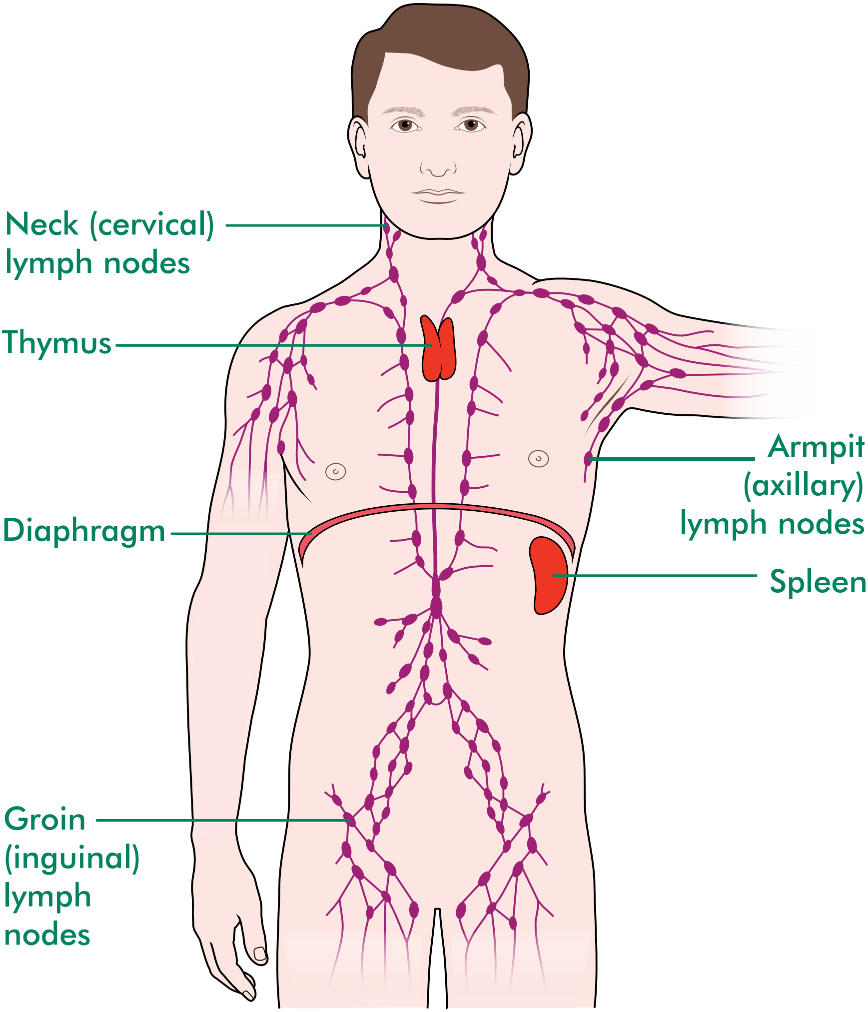
The lymphatic system helps to protect us from infection and disease. It also drains lymph fluid from the tissues of the body before returning it to the blood.

The lymphatic system is made up of organs such as the bone marrow, thymus and the spleen. It also has fine tubes called lymphatic vessels that connect to groups of lymph nodes throughout the body.

Lymph nodes (sometimes called lymph glands) are small and bean-shaped. They filter bacteria (germs) and disease from the lymph fluid.

One of the first places a cancer may spread to is nearby lymph nodes. Your doctor may remove some lymph nodes during surgery to check them for cancer cells. If they contain cancer cells, your doctor may talk to you about treatment with chemotherapy to help reduce the risk of the cancer coming back.

The lymphatic system



Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. Cytotoxic means toxic to cells. Cytotoxic chemotherapy drugs disrupt the way cancer cells grow and divide but they also affect normal cells.

Sometimes chemotherapy is used alone to treat some types of cancer. But often it's used with other treatments such as surgery, radiotherapy, hormonal therapy, or other anti-cancer drugs such as targeted therapies.

> 'The "chemo" word is scary. But it's just medicine. I had 3 cycles, and whilst it wasn't fun, it wasn't unbearable. The overriding memory was boredom and some tiredness.'
>
> **Mark**

Chemotherapy drugs

Not all cancers are treated with the same chemotherapy drugs, or in the same way. You may have one chemotherapy drug or a combination of different drugs. There are many different chemotherapy drugs and new drugs are being developed all the time.

Research that has already been done will help your cancer specialist decide on the most effective drugs to treat the type of cancer you have. You may be invited to take part in a research trial.

Other anti-cancer drugs

Other anti-cancer drugs are used to treat cancer, but they are not usually known as chemotherapy. For example, drugs called targeted therapies are directed at certain parts of the cancer cells and work differently to chemotherapy. These drugs can be given on their own or in combination with chemotherapy drugs.

We have information about:

- individual and combinations of chemotherapy drugs
- other anti-cancer drugs, such as targeted therapies.

To get information on targeted therapies or chemotherapy drugs, call us on **0808 808 00 00** or visit our website at **macmillan.org.uk**

How chemotherapy drugs work

Chemotherapy drugs work by stopping cancer cells dividing and growing. Different drugs affect the cancer cells in different ways. When a combination of drugs is used, each drug is chosen for its different effects.

Most chemotherapy drugs are carried in the blood. This means they can reach cancer cells anywhere in the body. But chemotherapy can be given in different ways (see pages 33 to 50). The way you have chemotherapy depends on:

- the type of cancer you have
- the chemotherapy drugs being used.

Chemotherapy drugs also affect some of the healthy cells in your body. These healthy cells can usually recover from damage caused by chemotherapy. But cancer cells cannot recover and they eventually die.

Side effects

Because chemotherapy drugs can affect some of the healthy cells in your body, this can cause side effects. Most side effects will go away after treatment finishes.

Healthy cells in certain parts of the body are more sensitive to chemotherapy drugs. For example, this includes cells in the bone marrow (which makes blood cells) and the digestive system.

This is why certain side effects are more common, such as being at risk of infection or feeling sick. We have more information about the side effects of chemotherapy and how they can be reduced and managed (see pages 53 to 84).

Monitoring the effects on the cancer

During treatment, your cancer doctor may want to find out how the cancer is responding to the chemotherapy drugs. This can be done in different ways:

- If your doctor can see or feel the cancer, they will be able to tell if it is responding to chemotherapy by doing a physical examination.
- If the cancer can be seen on a scan, you may have another scan after a few cycles of chemotherapy to see if the cancer is getting smaller. If you are having chemotherapy to reduce the risk of cancer coming back after surgery (adjuvant chemotherapy), you will not usually need scans to check if it is working.
- With some cancers, blood tests can be used to check if treatment is working. These cancers release proteins into the blood (called tumour markers) that can be measured with a blood test. If the tumour markers are reducing, it usually means the chemotherapy is working.

If results show the cancer has not responded well enough, your doctor may decide to change your treatment to different chemotherapy drugs.

When chemotherapy is used

Having chemotherapy depends on different factors. These include the type of cancer, the risk of it coming back, if it has spread and your general health.

Chemotherapy can be used:

- as a main treatment for cancers such as lymphomas and leukaemias
- before surgery or radiotherapy, to shrink a cancer (neo-adjuvant chemotherapy)
- after surgery or radiotherapy, to reduce the risk of cancer coming back by treating any remaining cells (adjuvant chemotherapy)
- at the same time as radiotherapy, to make it work better (chemoradiation)
- to treat cancer that has spread into surrounding areas (locally advanced cancer) or to other parts of the body (advanced or metastatic cancer) – this may cure certain cancers, but more often the aim is to shrink and control a cancer to try to prolong life, and to relieve symptoms (palliative chemotherapy).

Your cancer doctor or chemotherapy specialist nurse will explain why chemotherapy is being advised for you.

Planning chemotherapy

Your treatment is planned by your cancer doctor (oncologist). This doctor is an expert in treating people with chemotherapy, and other cancer treatments and drugs. Other health professionals are also involved in your care. You may see a chemotherapy specialist nurse and a pharmacist, who can give you information and support.

Your cancer doctor or specialist nurse will explain the:

- aims of your chemotherapy
- possible side effects
- benefits and disadvantages.

Giving your consent

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

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

If you don't understand what you've been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it's not unusual to need repeated explanations. It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment (see pages 122 to 124).

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

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

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

We have a booklet called **Making treatment decisions** that you may find helpful – see page 112 to order a copy.

Research – clinical trials

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

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

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

Our booklet **Understanding cancer research trials (clinical trials)** describes clinical trials in more detail – see page 112.

Your course of chemotherapy

Chemotherapy is usually given as several sessions of treatment, with rest periods in between the sessions. The rest period allows your body to recover from the side effects. It also allows the number of healthy cells in your blood to go back to normal. Chemotherapy and the rest period make up a cycle of your treatment. Your cancer doctor will explain the number of cycles you need to treat the cancer. After your first cycle, you will have a better idea of what to expect, and how much you may or may not be able to do. The complete course of all the cycles of chemotherapy you need may take several months.

How often you have chemotherapy, how it is given, and how long your course takes depends on:

- the type of cancer you have
- the chemotherapy drugs you are having
- how the cancer responds to the drugs
- how the side effects are affecting you (see pages 53 to 85).

Sometimes treatment involves having chemotherapy in more than one way (see pages 33 to 50). For example, you may have chemotherapy into a vein (intravenous) and also take chemotherapy tablets.

Chemotherapy is sometimes given continuously by an infusion pump for several days or several weeks. If you are having chemotherapy as tablets or capsules, you may have them daily for several weeks or months before a rest period.

Changes to your treatment plan

If your chemotherapy treatment plan needs to be changed, your cancer doctor or nurse will explain why.

It may be because of the effects of the chemotherapy on your body, or the effects on the cancer. Sometimes changes can be made to suit your personal circumstances. Depending on the reason, your doctor may:

- delay your chemotherapy for a short while
- reduce the dose
- give you a different chemotherapy drug.

Delaying your chemotherapy

The most common reason for delaying chemotherapy is a low number of white blood cells (neutrophils). This is not unusual, so try not to worry too much about it. When your white blood cells are back to a healthy level, you can start your next cycle of chemotherapy.

You may also be able to delay chemotherapy if you have a special social occasion coming up. Depending on the type of cancer, a small delay in your treatment is not usually a problem. Your cancer doctor or specialist nurse can tell you if this is advisable.

Effects on your body

Chemotherapy can affect organs, such as the bone marrow, lungs, kidneys and liver. You will have regular tests to monitor this. Some drugs can affect the nerves in your feet and hands (known as peripheral neuropathy) and other drugs may affect your hearing.

Sometimes your doctor may need to reduce the dose of the drug or change your chemotherapy drug to a different one.

Effects on the cancer

Your doctor may arrange x-rays, scans, blood tests or a physical examination during treatment. This is to check the effects of chemotherapy on the cancer (see pages 12 to 14).

If the test results show that chemotherapy is not having enough effect on the cancer, your doctor may talk to you about having different treatment.

HAVING CHEMOTHERAPY

Preparing for chemotherapy

Having information about the chemotherapy treatment and its side effects can help you get organised and feel more in control. There are things you can do to help you feel prepared.

Getting organised

Your fertility

Some chemotherapy drugs affect your fertility (the ability to get pregnant or father a child). If this is a concern for you, it is very important to talk to your cancer doctor before treatment starts. Sometimes your fertility can be preserved by storing sperm or storing eggs before chemotherapy begins (see pages 81 to 83).

Getting a wig

If the chemotherapy drugs cause hair loss or thinning, you might decide to have a wig fitted (see pages 60 to 63). You can have the wig fitted before your hair falls out. This means you can match it to your own colour and style.

Dental checks

Your doctor or nurse may advise you to have a dental check-up before starting chemotherapy. If your teeth or dentures are in good condition, this reduces the risk of possible problems with your mouth during treatment.

Taking other drugs, vitamins or supplements

Always tell your cancer doctor about any prescription and other drugs, vitamins or supplements you are taking or plan to take. Some drugs may interact with chemotherapy drugs and make treatment less effective.

Work or education

Before starting chemotherapy, it is a good idea to think about your work or education (see pages 100 to 101). This means you can make arrangements for time off during treatment.

Help at home

Chemotherapy makes you tired, so you may need help with day-to-day tasks. Although it can be hard to ask for help, family and friends are usually keen to do whatever they can. If you live alone or are caring for someone else, you can ask to talk to the hospital social worker about getting help.

Help with children

If you have children, you may need help with taking and picking them up from school or clubs. Family and friends usually want to help, so accept their offers or ask for any help you need. It is also useful to know who you can contact at short notice to look after your children. We have more information about childcare when you have cancer (see page 112).

Tests and scans

Your cancer doctor or specialist nurse will talk to you about any tests, scans or check-ups you need before chemotherapy begins.

Scans and x-rays

Some chemotherapy drugs can affect organs, such as the heart or the kidneys. You may need tests to measure how well these organs are working before you have chemotherapy. For example, if you are having drugs that can affect the heart, you may have an electrocardiogram (ECG). This measures how well your heart is working. Or you may have an echocardiogram (ECHO), which uses soundwaves to create a picture of the heart.

Some people may need further scans or x-rays to find out more about the extent of the cancer (its stage) before chemotherapy.

Height and weight

A nurse will check your height and weight. Your cancer doctor and pharmacist use this information to work out the right dose of chemotherapy for you.

Blood tests

You will have a blood test before each cycle of chemotherapy. To save time, sometimes your blood may be checked 1 to 2 days before chemotherapy. This can be done:

- at the hospital where you are having chemotherapy
- by your GP or practice nurse
- at a hospital closer to your home.

The results will be ready for you when you go to have your chemotherapy.

Pregnancy test

Women may have a pregnancy test before starting treatment.

Having a blood test

Where chemotherapy is given

Usually chemotherapy is given in a chemotherapy day unit or outpatient clinic. But depending on the type of chemotherapy, some people may stay in hospital to have it.

Chemotherapy in a day unit

Chemotherapy drugs into a vein (intravenous) are usually given to you by nurses in a chemotherapy day unit. They take blood samples, give you your chemotherapy and monitor you for side effects. They also provide information and support for you and your family.

The nurses try to make sure the unit has a calm atmosphere and the environment is comfortable. There are normally recliner chairs and some beds if you need to rest. A relative or friend can usually stay with you during your treatment. There may be volunteers who can give you drinks or snacks when you need them. Some units also have complementary therapists, who provide therapies such as massage and reflexology (see page 107).

> ‘I thought the unit would be full of doom, gloom and really ill patients. It’s anything but that. The nurses were amazing – they explained everything and put us at ease.’
>
> **Lynn**

Having the chemotherapy drugs may take from half an hour to a few hours. But you may also have to wait:

- for blood test results
- for your chemotherapy drugs to be made up and checked by the pharmacy
- to see your cancer doctor.

The nurses will try to make sure you do not have to wait too long.

You can take some things with you to help pass the time and feel more comfortable, such as:

- a soft, cosy blanket or slippers
- an MP3 player with relaxing music or relaxation techniques
- a newspaper, some magazines, a book or an e-reader
- snacks in case you get hungry
- playing cards or some knitting.

> ‘My husband always planned something nice after chemotherapy. That way we had the bad and the good. It distracted me.’
>
> **Beverley**

After you have had your chemotherapy, the nurses may give you drugs to take at home or a prescription for the hospital pharmacy. This may include anti-sickness drugs, steroids or any chemotherapy tablets you need to take. Your nurse or pharmacist will explain these to you.

Chemotherapy in hospital

Some chemotherapy treatments are more complicated or take longer. This may mean you need to stay in hospital to have your treatment. Your cancer doctor or specialist nurse will explain more about this.

Chemotherapy at home

Sometimes, specialist chemotherapy nurses visit people at home to give intravenous chemotherapy. If you are having chemotherapy through a pump, the nurses can come and disconnect the pump when it is finished. This means you do not have to come back to the hospital.

This service is only available in some parts of the UK, and only with certain chemotherapy treatments. Your cancer doctor can tell you more about this.

How to contact the hospital

You will be given phone numbers to contact the hospital if you:

- have a temperature
- feel unwell
- need advice on side effects.

This should include out-of-hours contact details for evenings, during the night or the weekend. Some cancer centres have a 24-hour number you can call at any time for advice. In Scotland, you may be given the number of the Cancer Treatment Helpline.

It is very important to keep the numbers somewhere safe and to follow the contact advice you have been given by the chemotherapy nurse or cancer doctor. You could save the numbers in:

- your phone
- your **My Organiser** – see page 112 to order a copy
- the ‘Your chemotherapy’ section (see pages 124 to 125).

> ‘The nurses were always prepared to answer the phone 24 hours a day, if you had side effects that you didn’t understand or couldn’t cope with. They were really helpful.’
>
> **Rob**

HOW CHEMOTHERAPY IS GIVEN

Ways of having chemotherapy

Chemotherapy can be given in different ways depending on the type of cancer you have and your treatment plan. Your chemotherapy nurse will explain what is involved.

Chemotherapy can be given:

- by injection or a drip directly into a vein (intravenous chemotherapy)
- by mouth as tablets or capsules (oral chemotherapy)
- by injection into a muscle (intramuscular) or under the skin (subcutaneous)
- by injection into the fluid around the spine and brain (intrathecal chemotherapy)
- directly into a body cavity, for example the bladder (intracavitary)
- directly to the skin as a cream for some skin cancers.

Chemotherapy into a vein

Chemotherapy given into a vein (intravenous) goes directly into your blood and is carried to all areas of your body.

It can be given through:

- a cannula – a short, thin tube put into a vein in your arm or the back of your hand
- a central line – a long, thin tube inserted into a vein in your chest (see pages 37 to 38)
- a PICC line (peripherally inserted central venous catheter) put into a vein in the arm and threaded through to a vein in the chest (see pages 39 to 40)
- an implantable port (portacath) put into a vein, with an opening (port) under the skin on your chest or arm (see pages 40 to 41).

When your cannula, line or port is in place, the chemotherapy drugs can be given into it by injection, as a drip or through a pump.

Your nurse will check that the cannula, line or port is working properly before giving you the chemotherapy.

Cannula

Having a cannula put in can be a bit uncomfortable or painful, but it should not take long. When it is in place, it should not be painful.

The cannula is put into a vein in the back of your hand or lower arm. Your nurse will place a see-through dressing over it to make sure it stays in place. The cannula is removed before you go home.

If you feel any discomfort or stinging, or notice redness or swelling around the cannula or along your arm during or after chemotherapy, tell your nurse or doctor straight away.

Central lines, PICC lines and implantable ports

Lines and ports are used to take blood samples as well as to give you chemotherapy. You can go home with the line or port in. It can be left in until you have finished your course of chemotherapy. This means you will not need a cannula or needles put into the veins in your arm every time you have chemotherapy or blood tests. You can also have antibiotics, fluids or a blood transfusion through your line or port.

Your specialist nurse will explain how the line or port will be put in. Once it is in place, the nurses will show you how to look after it (see page 42).

When your course of treatment is over, the line or port will be taken out. A doctor or nurse will do this for you, usually in the outpatients department.

Many people will not need to have a line or port. It depends on the type of cancer you have or the chemotherapy treatment you are having. They can also be used if there are problems with the veins in your arm, or if you are very anxious about having needles put in.

Central line

A central line is a long, thin, hollow tube that is put into a vein in your chest. Central lines are sometimes called skin-tunnelled central venous catheters. But you may hear them called by brand names, such as Hickman® or Groshong® lines.

How it is put in

A specialist nurse or doctor will put in your central line at the hospital. You will usually have it done under a local anaesthetic, but sometimes a general anaesthetic is used. Before the procedure, your neck will be checked for a suitable vein using a small ultrasound machine.

The doctor or nurse makes a small cut in the skin near your collarbone. They will gently thread the tip of the line into a large vein just above your heart.

The other end of the line is tunnelled under the skin to reach the site where it comes out of your body (exit site). You will have a chest x-ray to make sure it is in the right position.

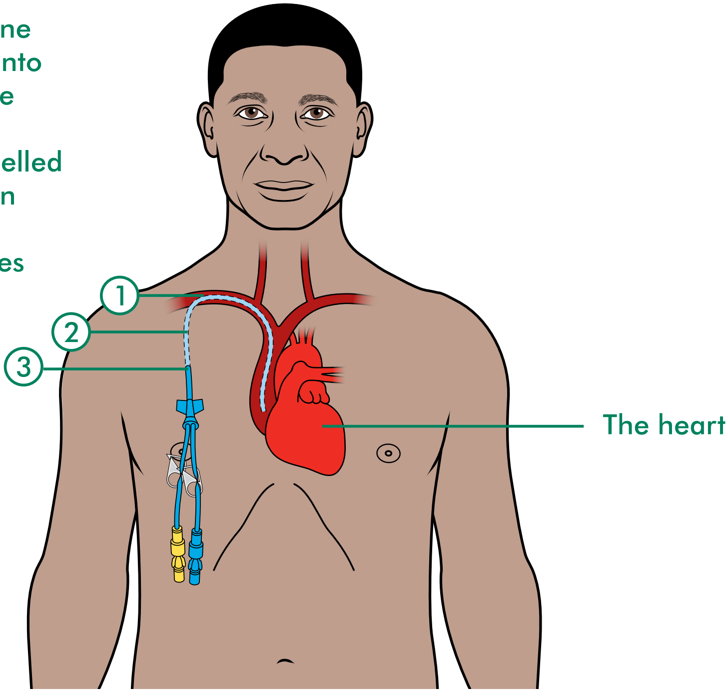
Around the central line, there is a small cuff you can feel just under the skin. The tissue under your skin grows around this cuff over about 3 weeks and holds the line in place. Until this happens, you will have a stitch holding the line in place.

A central line

① Central line inserted into chest here

② Line tunnelled under skin

③ Line comes out here



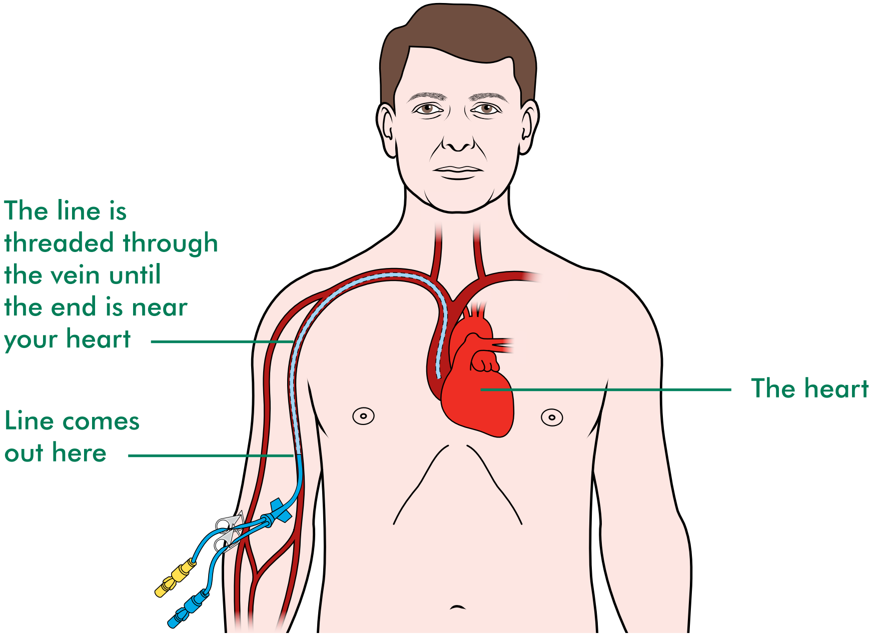
We have more information about central lines on our website. We also have an animation about having a central line put in. You can watch it at **macmillan.org.uk/havingacentralline**

PICC (peripherally inserted central venous catheter line)

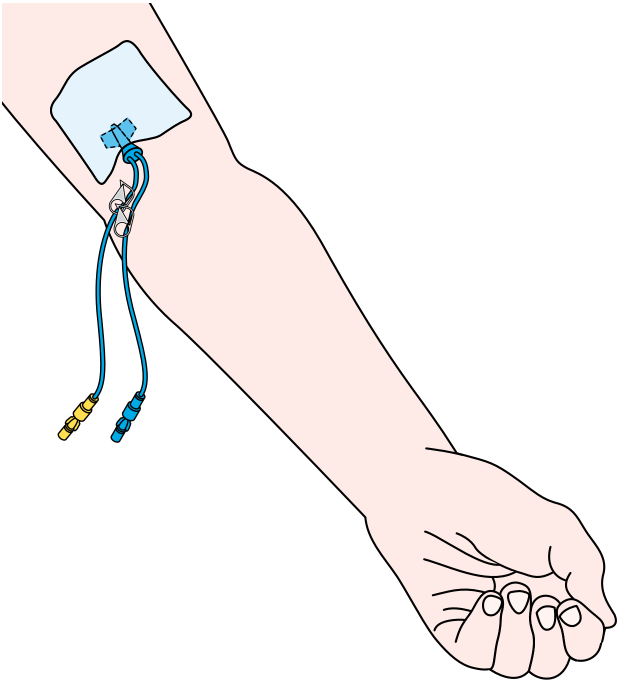
A PICC line is a long, thin, hollow tube that your doctor or nurse puts into a vein above your elbow.

Your doctor or nurse will give you a local anaesthetic to numb the area before the line is put in. Then they will gently thread the line along the vein until the tip sits in a large vein in your chest. The end of the line comes out above the bend of your elbow. Once it is in place, the PICC line is taped firmly to your arm to prevent it being pulled out of the vein.

A PICC line



The end of the PICC line comes out above the bend of the elbow



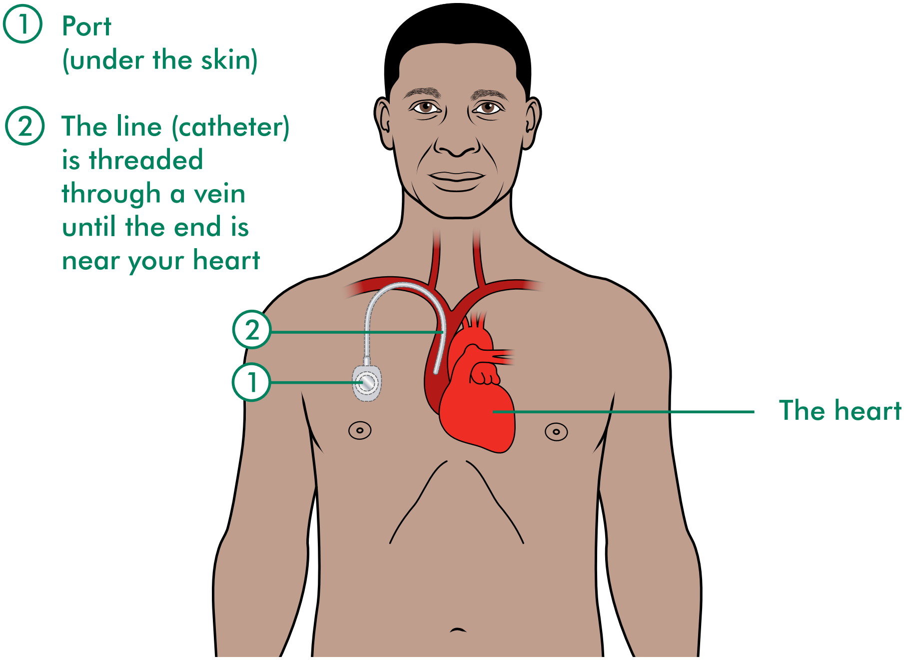
We have more information about PICC lines on our website. We also have an animation about having a PICC line put in. You can watch it at **macmillan.org.uk/havingapiccline**

Implantable port (portacath)

An implantable port is a thin, soft, silicone tube with a small reservoir (port) at the end. It can be put in under a general or local anaesthetic. The tube is inserted into a vein until its tip sits just above your heart and the port lies under the skin on your upper chest. Once it is in place, you can feel and see the port as a small bump underneath the skin of your chest, but nothing shows on the outside of your body.

To use the portacath, a special needle called a Huber needle is passed through your skin into the port. Your nurse can give medicines into the vein or take blood. The skin over the port can be numbed with an anaesthetic cream first so you do not feel any discomfort. We have more information about implantable ports on our website.

An implantable port



Looking after your line or port

Before you go home, the nurses will show you how to look after your line or port. If you find this difficult, your nurse can show a family member or friend how to do it or arrange for a district nurse to visit you. The main things you need to do are:

- clean the area around the line to reduce the risk of infection
- keep the area dry when you have a shower or bath – your nurse may give you waterproof dressings to use
- phone the number you have been given for advice if you think there is a problem with your line or port.

What to look out for

Most people will not have any serious problems with their line or port, but possible problems can include blockage and infection. Your nurse will talk to you about this.

Your hospital nurse will arrange for you to have your line or port flushed regularly at the hospital or day unit, or by a district nurse. A small amount of fluid is flushed into the line using a syringe to keep it working and stop it from getting blocked.

Phone the contact number you have been given straight away if you have:

- soreness, redness or darkening of the skin around the line or port
- fluid leaking from the skin around the line or port
- swelling of your arm, chest, neck or shoulder
- pain in your chest, arm or neck
- feeling shivery or unwell after your line or port has been flushed
- a high temperature – most hospitals say that a temperature above 37.5°C is high, but the cancer doctors and nurses at your hospital will advise you on this.

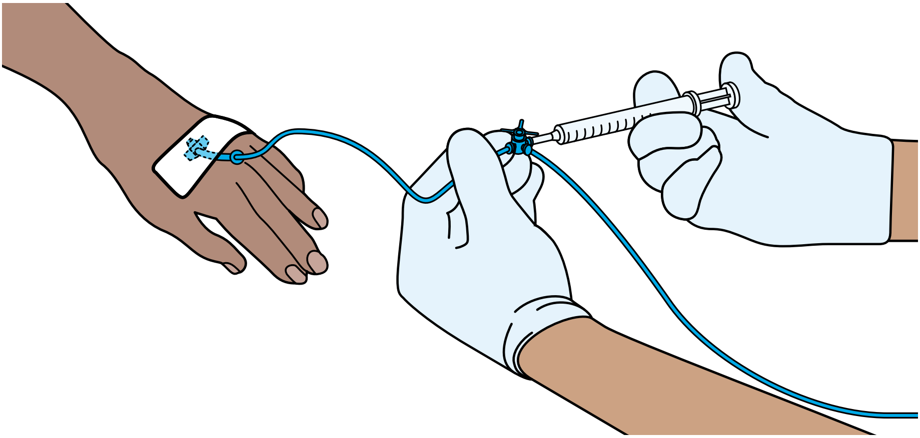
Having intravenous chemotherapy

Chemotherapy drugs given into a vein (intravenously) can be delivered in different ways. Your chemotherapy nurse will wear gloves and a plastic apron while giving you chemotherapy. This is just a precaution to protect them from any spillage of the drugs.

As an injection

The chemotherapy drugs are injected directly into a vein through your cannula or central line over a few minutes. Sometimes, a bag of clear fluid is attached to plastic tubing and connected to the cannula or line in your vein first (called a drip or infusion). The drug is injected into a connection or tap on the plastic tubing and flushed into your vein with fluid from the bag.

Chemotherapy being given by injection into a cannula



A drip through a pump

The chemotherapy drugs are dissolved in a bag of fluid and given to you as a drip that runs through an infusion pump. The nurses set the pump to give you a controlled amount of chemotherapy over a fixed time. This can be from 10 minutes to several hours, depending on the chemotherapy you are having.

A drip on its own

Sometimes chemotherapy is given through a drip without a pump. The nurses set the rate and check it regularly to make sure it is at the right speed.

Through a small pump

Some types of chemotherapy are given over a few days and are set up at the hospital so you can go home with it. The chemotherapy is in a small pump which your nurse connects to your central or PICC line. The pump is small enough to be carried in a bag or belt holster.

You, and sometimes a family member or friend, will be taught how to look after it. Some pumps are battery-operated, so you need to be careful not to get them wet when you are washing. There are also disposable pumps that are operated by a balloon mechanism or spring control.

When the infusion is finished, there may some fluid left in the pump. Some pumps need to be overfilled to get the correct dose, so this may be normal. Your nurse or pharmacist can tell you if you should expect this.

You usually come back to the hospital to have the pump disconnected. Sometimes, a district nurse will do this for you at home. Your chemotherapy nurse or pharmacist will explain how to look after the pump and what to do if there is a problem.

If a chemotherapy drug leaks

If a drug leaks into the area around the vein while being given, this is called extravasation. This is uncommon but can happen if a cannula moves and is not in the correct position in the vein. Extravasation rarely happens with a lines or ports. Your nurse will be very careful to prevent extravasation when giving your chemotherapy.

Some chemotherapy drugs can damage the tissues, so it is very important that extravasation is dealt with straight away. If you notice any swelling, pain, stinging or redness during your chemotherapy, tell your nurse immediately. If you develop any of these problems after you go home, contact the hospital straight away.

Other ways of having chemotherapy

There are other ways you can have chemotherapy, apart from into a vein (intravenously). Your chemotherapy nurse or cancer doctor will explain more about this.

By mouth (oral chemotherapy)

Some chemotherapy drugs can be taken by mouth (orally) as tablets or capsules. This is just as effective as other types of chemotherapy. The drug is absorbed into your blood and carried around your body, just like intravenous chemotherapy. You may have all your treatment as oral chemotherapy, or you may have it in some other ways as well.

You will be told when to take your chemotherapy tablets or capsules. Your nurse or pharmacist may give you other instructions, such as whether or not to take them with food, or any food or drinks to avoid.

It is very important to:

- read the labels on the drug boxes before you leave the hospital and speak to your nurse, doctor or pharmacist if any instructions are unclear
- take your drugs exactly as prescribed, because not taking them at the right times can affect how well treatment works
- contact your nurse or doctor at the hospital straight away for advice if you cannot take your medicines for any reason, are sick after taking them, or have forgotten to take a dose.

Chemotherapy by mouth can cause side effects, just like chemotherapy into a vein. It is important to know what they are. You also need to know how to store your drugs safely. You can read more about having chemotherapy at home on page 50.

Injection into a muscle or skin

Some chemotherapy drugs are given by injection into a muscle in the leg or buttock (intramuscular). This might feel a bit painful or uncomfortable for a short time.

Some drugs are given by injection under the skin (subcutaneous) using a very fine needle.

Injection into the spinal fluid (intrathecal)

In some leukaemias, lymphomas or brain tumours, cancer cells can pass into the fluid that surrounds and protects the brain and spinal cord (cerebrospinal fluid or CSF).

Intrathecal chemotherapy can be used to prevent this from happening, or to destroy any cancer cells in the CSF. Only certain chemotherapy drugs can be given in this way. Chemotherapy into a vein or by mouth cannot reach these cancer cells.

The doctor numbs an area of skin over your spine with local anaesthetic. After a few minutes, they gently insert a needle between two of the spinal bones into the CSF. This is called a lumbar puncture. Your doctor then injects intrathecal chemotherapy through the needle into the CSF.

Having a lumbar puncture is not usually painful, although some people may find it uncomfortable. Your cancer doctor and nurse will explain it to you so you will know what to expect. They will make sure you are comfortable and you can have a relative or friend with you.

The most common side effect of a lumbar puncture is a headache. To help prevent this, you will be advised to drink plenty of fluids and lie flat afterwards. This may be from 1 hour to a few hours, depending on how you feel.

We have information about intrathecal chemotherapy and lumbar punctures on our website (**macmillan.org.uk**).

Into a body space (intracavitary)

Chemotherapy drugs can be given into a space (cavity) in the body. This can cause irritation or inflammation in the area the drugs are given, but it does not usually cause side effects in other parts of the body.

A fine tube (catheter) is usually inserted into the body cavity and chemotherapy is put in through this tube. It may be drained out again after a set period of time. Chemotherapy can be given into the following places:

- **Into the bladder (intravesical)** – This is used to treat early bladder cancer. Liquid chemotherapy drugs are given directly into the bladder through a catheter, which is removed when it is over.
- **Into the abdominal cavity (intraperitoneal chemotherapy)** – This is very occasionally used to treat ovarian cancer or mesothelioma in the abdomen (peritoneal mesothelioma).
- **Between the 2 layers of the pleura (tissue that covers the outside of the lungs)** – Chemotherapy is sometimes put in between the 2 layers of the pleura to treat cancer cells that have spread there.
- **Into a limb (isolated limb perfusion)** – Chemotherapy is very occasionally given directly into the blood vessels in a limb. This is to treat a skin cancer called melanoma that has come back.

We have more information about these other ways of having chemotherapy (see page 112).

Chemotherapy creams

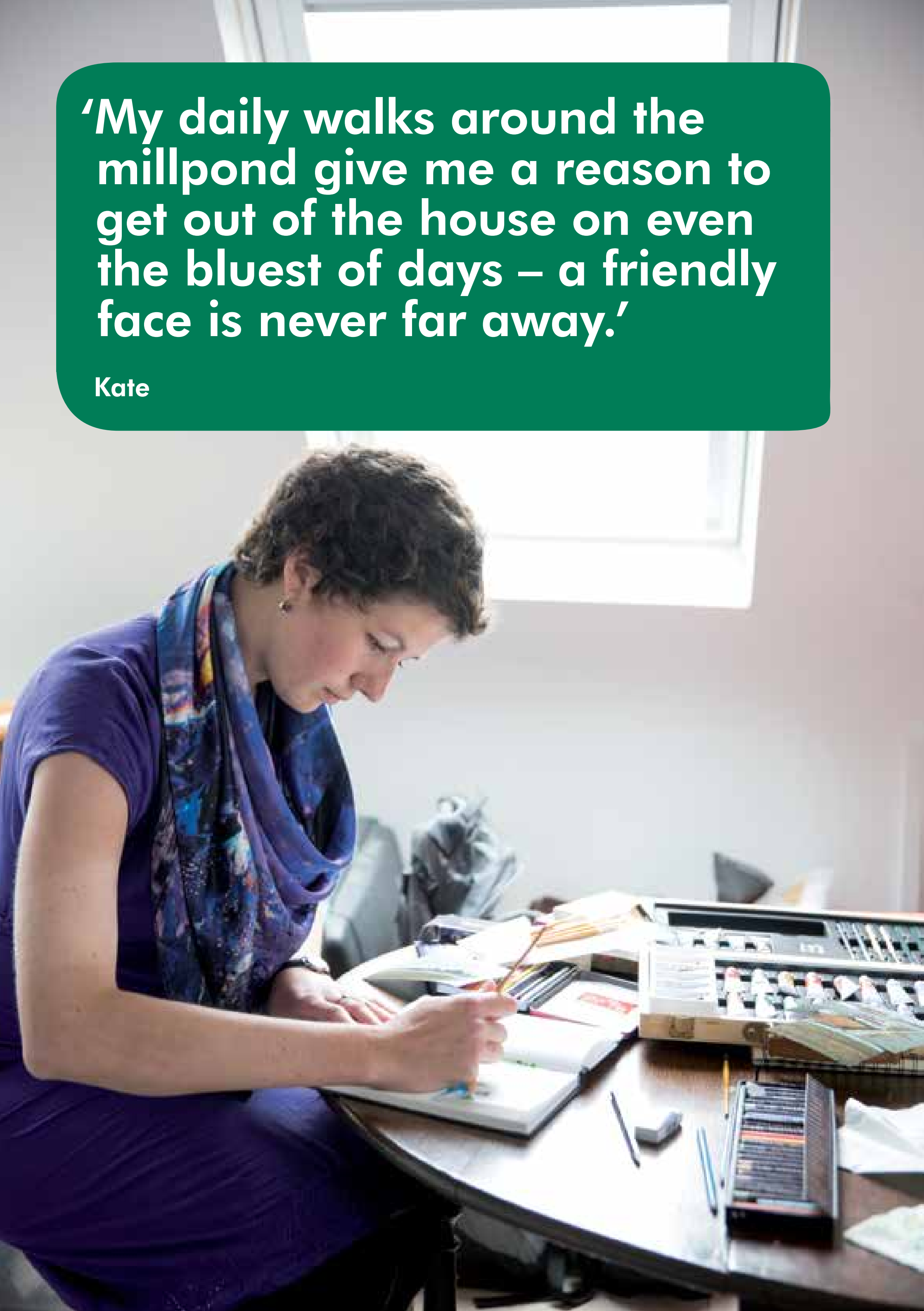
Chemotherapy creams are used to treat some types of skin cancer. You put a thin layer of the cream on the affected skin and cover the area with a dressing. Your specialist nurse or pharmacist will show you how to do this and will explain how often you need to apply the cream. Although the cream can irritate the skin in the area or make it sore, it will not cause side effects in other parts of the body.

Chemotherapy at home

If you are having chemotherapy at home as tablets or through a pump, there are certain things to remember:

- Chemotherapy tablets, capsules or injections may need to be stored in a particular way, such as in the fridge. Always follow the instructions given by your nurse or pharmacist.
- Other people in your household should avoid direct contact with your chemotherapy drugs and avoid picking them up with bare hands.
- All drugs must be stored out of the reach of children, as they could cause serious harm if taken by accident.
- If you are having intravenous chemotherapy by pump and you notice the drug leaking from the pump or tube, you should close the clamps on the pump, wrap it in a plastic bag and wash your hands. Some hospitals provide a spill or leakage kit, which includes instructions on what to do if your pump leaks. You should then contact the nurse or doctor at the hospital straight away.
- If you feel unwell at any time of the day or night, use the contact numbers you have been given to get advice.


The Leopard



> ‘My daily walks around the millpond give me a reason to get out of the house on even the bluest of days – a friendly face is never far away.’
>
> **Kate**

SIDE EFFECTS OF CHEMOTHERAPY

Possible side effects

The side effects you get will depend on the chemotherapy drugs you are having. Different drugs cause different side effects. You may get some of the side effects mentioned, but you are very unlikely to get all of them.

Some side effects are mild and easily treated. Your doctor, nurse or pharmacist may prescribe drugs to help control them. It is very important to take the drugs exactly as instructed. This means they will be more likely to work for you. Other side effects can be harder to manage, but can often be reduced or helped in some way. Your nurse will give you advice about this.

Most side effects stop or slowly go away when chemotherapy finishes. The side effects can be unpleasant, but the benefits of chemotherapy usually outweigh this.

If you are having a single drug, you may not have as many side effects as someone having a combination of drugs. People having high doses of chemotherapy may have more complex side effects.

Your cancer doctor and nurse specialist will explain the side effects that your chemotherapy is likely to cause. The main areas of your body that may be affected by chemotherapy are areas where new cells are being quickly made and replaced. This includes the:

- bone marrow (where blood cells are made)
- hair follicles (where hair grows from)
- digestive system
- lining of your mouth.

Your bone marrow and blood

Chemotherapy can reduce the number of blood cells made by the bone marrow. Bone marrow is a spongy material that’s found in the middle of your bones. It makes special cells called stem cells which develop into the different types of blood cells:

- white blood cells, which fight and prevent infection
- red blood cells, which carry oxygen to all parts of the body
- platelets, which help the blood to clot and prevent bleeding and bruising.

You’ll have regular blood samples taken to check the number of these cells in your blood (called a full blood count).

Risk of infection

If you have a low number of white blood cells, you are more likely to get an infection. The main white blood cells that fight infection are called neutrophils. When they are low, you are neutropenic.

Your resistance to infection is usually lowest 7 to 14 days after chemotherapy. The number of your white blood cells will then increase steadily and usually return to normal before your next cycle of chemotherapy is due.

Infection

Developing an infection when you have a low number of white blood cells can sometimes be a serious complication of chemotherapy.

Although this may sound scary, most people do not have any serious problems with infection. Some chemotherapy treatments are more likely than others to reduce the number of your white blood cells. Your doctor may prescribe you antibiotics and other medicines to take during chemotherapy to prevent an infection. These are called prophylactic drugs.

Even a mild infection can delay your chemotherapy treatment. Your doctor may wait until the infection has gone and for your blood cell levels to go back up before you continue with treatment.

Your chemotherapy nurse will talk to you about infection and show you how to check your temperature.

You can have an infection without having a high temperature. Drugs such as paracetamol lower your temperature, so they can hide or mask an infection.

Always contact the hospital on the 24-hour contact numbers you have been given and speak to a nurse or doctor if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have any symptoms of an infection such as a cold, sore throat, cough, passing urine frequently (urine infection), diarrhoea or feeling shivery and shaking.

Chemotherapy units usually have a policy they follow when someone with low white blood cells has an infection. This is to make sure you get treatment with antibiotics straight away to prevent any complications.

Some people may have to stay in hospital to have antibiotics given into a vein (intravenously). After a few days, you can usually have them as capsules or tablets to take at home.

G-CSF

After chemotherapy, your nurse may give you injections of a drug called G-CSF under the skin. This encourages the bone marrow to make more white blood cells and reduces the risk of infection.

We have more information about G-CSF on our website (**macmillan.org.uk**).

Here are some tips for avoiding infection:

- Keep clean and always wash your hands thoroughly after using the toilet or before preparing food.
- Stay away from crowded places and from people who you know have an infection, such as a cold.
- Make sure your food is thoroughly cooked, and ask your nurse if there are any foods you should avoid.

We have more information about avoiding infection when your immunity is low on our website (**macmillan.org.uk**).

Anaemia (reduced number of red blood cells)

If chemotherapy reduces the number of red blood cells in your blood, you may become very tired and feel you have no energy. You may also become breathless and feel dizzy and light-headed. These symptoms happen because the red blood cells contain haemoglobin, which carries oxygen around the body.

If your haemoglobin is low, you may be offered a blood transfusion. After this, you will have more energy and feel less short of breath.

In certain situations, doctors may prescribe a drug called erythropoietin to treat anaemia. It is given as an injection under the skin. But it is more common to have a blood transfusion for anaemia.

We have more information about blood transfusions and erythropoietin on our website (**macmillan.org.uk**).

Increased bleeding and bruising

If the number of platelets in your blood is reduced, you may notice you bruise easily or bleed more than usual from minor cuts or grazes.

Tell your hospital doctor or nurse about this and contact them straight away if you have:

- nosebleeds
- bleeding gums
- tiny red or purple spots on the skin (petechiae) that sometimes cluster to make a rash.

Here are some tips for avoiding injury:

- Wear protective gloves when doing work around the house or in the garden.
- Be careful to avoid bumping into things or tripping.
- Use a soft toothbrush to protect your gums from bleeding and do not floss.

Some people may need a platelet transfusion. This is given by drip (infusion). The platelets will start working immediately to prevent bruising and bleeding.

We have more information about platelet transfusions on our website **macmillan.org.uk**

Your hair

Your doctor or specialist nurse will tell you if the chemotherapy is likely to cause hair loss. Knowing what to expect gives you time to prepare and find ways of coping.

Some drugs do not make your hair fall out, but can make it thinner. You might notice your hair becomes dry and brittle and breaks easily. Looking after the condition of your hair can make it less likely to break off.

Here are some tips for looking after your hair:

- Use gentle hair products.
- Pat hair dry after washing it and gently brush with a wide-toothed comb.
- Avoid using hairdryers, straighteners, tongs or curlers.
- Do not perm or colour your hair if it is brittle or your scalp is dry – if you do want to do this, make sure you get professional advice first.
- If you want to colour your hair, use a mild, vegetable-based colourant and test a strand of your hair first. You can also ask your hairdresser for advice.

Scalp cooling

Some people having certain types of chemotherapy may be able to prevent hair loss by using a cold cap. This works by temporarily reducing the blood-flow and the amount of the drug reaching the scalp. But the cold cap only works with certain drugs and types of cancer and does not always prevent hair loss. You can ask your doctor or nurse whether using one would be helpful for you.

‘I decided to take back control. My hairdresser kindly shaved my head and I intended to wear a wig or scarves. But actually I spent about 3 or 4 months being totally bald and really happy.’

Kate

Losing your hair

Some chemotherapy drugs cause all or most of your hair to fall out, which can be very upsetting. There are lots of ways you can cover up, if you choose to, such as using wigs, hats, turbans, scarves or bandanas. We have more information about coping with hair loss on our website (**macmillan.org.uk**).

Hair loss usually starts within a few weeks of starting chemotherapy or, very occasionally, within a few days. You usually notice your hair coming out more when you brush, comb or wash it, and you may find hair on your pillow in the mornings.

You may lose underarm, body and pubic hair as well. Some chemotherapy drugs also make the eyelashes and eyebrows fall out.

Here are some tips for coping with hair loss:

- Cutting your hair short before chemotherapy can stop the weight of long hair pulling on the scalp, which can make hair fall out earlier.
- Wearing a hairnet, soft cap or turban at night stops your hair becoming tangled and helps to collect loose hair.
- You can ask your own hairdresser to cut and style your wig for you.

Your hair will usually grow back over a few months after you have finished treatment. It will be very fine at first and may be a slightly different colour or texture than before. You will probably have a full head of hair after 3 to 6 months. To begin with, you should try to look after the condition of your hair.

Wigs

If you are choosing a wig, here are some tips:

- Match the wig to the volume and colour of your natural hair.
- Get the wig fitted before you lose your hair so you can get used to wearing the wig.
- Get a wig with an adjustable size.

Think about whether you want to try a different hair style from the one you have.

There are different options for paying for your wig:

- NHS wigs are free in Scotland and Wales, and for people of a certain age or on a low income in England.
- Health Service wigs are free in Northern Ireland.
- If you are not entitled to a free wig, you can get one from the NHS at a subsidised price.
- You may want to buy a wig privately. You should not have to pay VAT on your wig if your hair loss is caused by cancer.

We have more information and helpful advice about this in our booklet **Coping with hair loss** (see page 112).

> ‘I thought a wig was a thing you put on your head and was all hot and horrible. But there was lots of choice and the hairdresser was brilliant. She cut and styled it to suit me.’
>
> **Medha**

Your digestive system

Your digestive system (stomach and bowels) can be affected in different ways by chemotherapy.

Feeling sick (nausea)

Some chemotherapy drugs can make you feel sick (nauseous), or be sick (vomit). Not all drugs cause sickness and many people have no sickness at all. There are very effective treatments to prevent and control sickness.

We have more information about controlling sickness and vomiting below and on our website (**macmillan.org.uk**).

Anti-sickness drugs

If your chemotherapy is known to cause sickness, you will be given anti-sickness (anti-emetic) drugs by injection or tablets before your chemotherapy. You will also be given tablets to take at home afterwards. Take these regularly, even if you do not feel sick, and exactly as your doctor has prescribed them. It is easier to prevent sickness than to treat it once it has started.

> ‘Don’t stop taking the anti-sickness treatment, as that makes a big difference. You take so much medication, which takes a bit of getting used to, but take it all is my advice!’
>
> **Jazz**

Contact your doctor or nurse at the hospital if:

- the anti-sickness drugs do not stop you feeling or being sick – other drugs can be prescribed
- if you are being sick and are not able to drink enough fluids
- the anti-sickness drugs make you constipated.

If you cannot keep down tablets, your doctor can prescribe injections or suppositories to take until the sickness is controlled.

Try to have a small meal a few hours before chemotherapy but not just before it. If you are managing to eat well in between treatments, do not worry if you cannot eat much for a couple of days after chemotherapy.

Here are some tips to help with feeling sick:

- Try eating dry food, such as toast or crackers, first thing in the morning.
- Ginger can help reduce feeling of sickness – try crystallised ginger, ginger tea or ginger biscuits.
- Try sipping a fizzy drink, for example mineral water, ginger beer or ale, lemonade or soda water. Sip it slowly through a straw.
- Avoid fried, fatty foods or foods with a strong smell.
- Eat cold food if the smell of cooking bothers you.
- If possible, let someone else cook or prepare food for you.

Some complementary therapies such as acupuncture may help, but ask your cancer doctor first. Some people find Sea-bands® helpful. They use acupressure to help relieve nausea. You can buy them in a chemist.

Diarrhoea

Some chemotherapy drugs can cause diarrhoea, usually in the first few days. Tell your nurse or doctor if this happens. They can prescribe medicine to help.

Make sure you drink plenty of liquid to replace fluid you are losing with diarrhoea. Try to drink 2 litres (3½ pints) a day. It can also help to avoid:

- alcohol
- caffeine
- milk products
- high-fat foods
- high-fibre foods.

Sometimes, diarrhoea can be more severe. It is important to contact the hospital if this happens. If you have more than 4 to 6 episodes of diarrhoea a day, contact the hospital on the telephone numbers you have been given and speak to a doctor or nurse.

Constipation

Some chemotherapy drugs, anti-sickness drugs and painkillers can cause constipation.

Tell your nurse or doctor if this happens, so they can prescribe drugs to prevent or treat it.

Try to eat more fibre (cereals, raw vegetables and fruits) and drink plenty of liquid. Gentle exercise, such as short walks, can help to improve constipation.

Loss of appetite

Chemotherapy can affect your appetite. If you have a poor appetite, try to eat little amounts as often as possible. Keep snacks such as nuts, grated cheese or dried fruit handy to eat whenever you can.

It is important to try to eat well during your treatment. If you are having problems, ask your nurse for advice. You can also ask to see a dietitian.

You can add extra energy and protein to your diet with everyday foods or by using food supplements. We have more information about this in our booklet **The building up diet** (see page 112).

Taste changes

You may find that your sense of taste changes, or that the texture of food seems different. This may be due to the cancer, or it can be a temporary change following cancer treatment. You may no longer enjoy certain foods, or find that all foods taste the same. Some people having chemotherapy notice a metallic taste in their mouth. Others find that food has no taste at all.

> ‘Pineapple was a favourite on my ward. Spicy foods were better than bland ones. The worst were things with no taste, such as water.’
>
> **Greg**

Helpful hints – changes to sense of taste

- You might find cold foods taste better than hot foods.
- Sharp-tasting fresh fruit/juices can leave a pleasant taste in the mouth.
- Use seasoning, spices and herbs to flavour cooking.
- Try marinating food or use strong-flavoured sauces.

We have more information about eating problems in our booklet **Eating problems and cancer** (see page 112).

Mouth problems

Chemotherapy can cause different mouth problems, such as a sore mouth, mouth ulcers or infection. Your chemotherapy nurse will explain how to look after your mouth to reduce the risk of problems.

Some chemotherapy drugs can make your mouth sore and you may get mouth ulcers about 5 to 10 days after they are given. Mouth ulcers can become infected or you may develop an infection in your mouth.

The most common mouth infection is called thrush (or candidiasis). It shows as white spots on your mouth and tongue, or your tongue and mouth lining become red and swollen. Thrush is treated with anti-fungal tablets. Some people are prescribed these tablets to prevent thrush.

Always let your doctor or chemotherapy nurse know if you have mouth ulcers, or any problems with your mouth. They can give you mouthwashes, medicines and gels to heal ulcers and clear or prevent any infection.

It is a good idea to see your dentist before you start treatment. Dental treatment may need to be delayed during chemotherapy because of the risk of infection and a sore mouth.

We have more information in our booklet **Mouth care during chemotherapy** (see page 112).

Here are some tips for taking care of your mouth:

- Clean your teeth or dentures gently every morning, evening and after meals using a soft-bristled or children's toothbrush and rinse your mouth regularly with salt water.
- If your toothpaste stings or brushing your teeth makes you feel sick, try using a mouthwash of 1 teaspoon of bicarbonate of soda dissolved in 1 pint (570ml) of warm water.
- If your doctor or nurse gives you a mouthwash, use it as prescribed to prevent soreness.
- Gently use dental tape or floss once a day (unless you have low platelets).
- Keep your lips moist by using Vaseline® or a lip balm.

Here are some tips if your mouth is sore:

- Try to drink at least 3 pints (1½ litres) of fluid a day, including water, tea, weak coffee and soft drinks.
- Avoid hot spices, garlic, onion, vinegar and salty food.
- Add gravies and sauces to your food to keep your mouth moist and make swallowing easier.
- Avoid unmixed alcoholic drinks, such as vodka and whisky, tobacco and acidic drinks such as orange and grapefruit juice.

Tiredness

Some people feel very tired during chemotherapy. This is normal. It can be very frustrating and difficult to cope with, especially for people who normally have a lot of energy. The hardest time may be towards the end of the course of chemotherapy.

Managing tiredness

Try to cut down on things you do not really need to do. Family and friends are often keen to help with things like shopping, household jobs or gardening.

If you have children, ask for help looking after them when you have chemotherapy and for a few days after. Some people may need extra help with childcare – a social worker can usually arrange this for you.

Make sure you get plenty of rest. But try to do some gentle exercise, such as going for short walks, or more if you feel up to it. This will give you more energy and helps to keep some of your muscles working.

Some people carry on working during chemotherapy. Most employers will reduce your hours and change work duties to make things easier for you.

> ‘The tiredness gets to me. I find it very hard to accept that I cannot do what I used to. I try not to let it impact on my day. The occasional nap in the early afternoon helps a lot.’
>
> **Paul**

If you are having difficulty sleeping, we have information about managing sleep problems. Visit **macmillan.org.uk/difficultysleeping**

The tiredness will get easier when chemotherapy is over. But it can be 3 or 4 months until you feel back to normal. Some people find that they still feel tired a year or so afterwards.

We have more information in our booklet **Coping with fatigue**, which has helpful tips on dealing with tiredness during chemotherapy (see page 112).

Skin and nail changes

Your skin

Some drugs can affect your skin. It may become dry or slightly discoloured. Chlorine in swimming pool water can make this worse. Your skin may also be more sensitive to sunlightduring and after treatment.

Tell your cancer doctor or nurse if you develop any skin changes or rashes.

Here are some tips if you have skin changes:

- Avoid wet shaving – an electric razor is less likely to cause cuts.
- Use moisturising cream if your skin is dry or itchy, but check with your nurse before using creams if you are also having radiotherapy.
- If you are out in the sun, wear a high sun protection factor (SPF) sun cream of at least SPF 30.

Nail changes

Your nails may grow more slowly or break more easily. You may notice white lines across your nails, or other changes to their shape or colour. Once the treatment has ended, any changes usually take a few months to grow out.

There are things you can do to look after your nails:

- Keep your nails and hands moisturised.
- Wear gloves to protect your nails when you are doing things in the house or garden.
- Do not use false nails during this treatment. It is fine to wear nail varnish.
- If your toenails are affected, wear well-fitted shoes to cushion them.

Effects on the nerves

Some chemotherapy drugs can affect the nerves in your hands or feet. This can cause tingling or numbness, or a feeling like pins and needles. This is called peripheral neuropathy. You may also find it hard to fasten buttons or do other fiddly tasks.

It is important to tell your doctor if this happens. The dose of the chemotherapy drug may need to be changed if it gets worse. Usually, peripheral neuropathy gradually gets better when chemotherapy is over, but sometimes it is permanent. We have more information about peripheral neuropathy on our website (**macmillan.org.uk**).

Effects on the nervous system

Some drugs can make you feel anxious, restless, dizzy, sleepy or have headaches. If you have any of these, it is important to tell your cancer doctor or nurse. They may be able to prescribe medicines that can help with some of these effects.

Some people find that chemotherapy makes them forgetful or unable to concentrate during or after treatment. Doctors sometimes call this cancer-related cognitive changes (CRCC) but it is sometimes known as chemo brain.

If this happens, it is usually mild. There are useful ways of managing it, such as using lists, post-it notes, calendars and your mobile phone for reminders. Doing some mental exercises, eating well, and getting enough rest can also help.

We have more information about these cognitive changes on our website (**macmillan.org.uk**).

Changes in how your kidneys work

Some chemotherapy drugs can affect how well your kidneys work (kidney function).

Before each treatment, your kidney function will be checked with a blood test. You may be given fluids through a drip (infusion) before and after the treatment. This is to keep your kidneys working normally. The nurses may ask you to drink plenty of fluids. They may also ask you to record what you drink and the amount of urine you pass.

Changes in hearing

Some chemotherapy drugs can affect your hearing. You may have ringing in your ears (tinnitus), and you may not be able to hear some high-pitched sounds. Rarely, your sense of balance may be affected. Any hearing loss and changes in balance may be permanent. Tinnitus usually improves when treatment ends. You may have hearing tests before, during and after treatment with some chemotherapy drugs.

Tell your cancer doctor or nurse if you notice any changes.

Increased risk of blood clots

Cancer can increase your risk of developing a blood clot (thrombosis), and having chemotherapy may increase this risk further. A blood clot may cause symptoms such as pain, redness and swelling in a leg, or breathlessness and chest pain.

Blood clots can be very serious, so it is important to tell your doctor straight away if you have any of these symptoms. But most clots can usually be successfully treated with drugs to thin the blood. Your doctor or nurse can give you more information about blood clots.

Side effects of steroids

Steroids are drugs that are often given with chemotherapy treatment. They are generally only given for short periods of time. Side effects of steroids may include indigestion, increased appetite, feeling more energetic or restless or having difficulty sleeping.

Taking steroids with food can help reduce indigestion. Your doctor may also prescribe drugs to prevent indigestion.

Steroids can make you feel much hungrier than usual and you may gain weight. Your appetite will go back to normal when you stop taking them. If you are worried about gaining weight, talk to your doctor or nurse.

If you are having difficulty sleeping, it can help to take your steroids in the morning with food.

Sometimes, steroids may cause a temporary increase in your blood sugar level. You may have regular blood or urine tests to check this. If you get very thirsty or feel you are passing more urine than usual, tell your doctor.

After finishing a course of steroids, some people feel tired and a bit low in mood, and have aches and pains. This is due to their body adjusting to the changes in steroid levels. It usually gets better within 2 to 3 days. We have more information about steroids on our website (**macmillan.org.uk**).

Effects on sex life and fertility

Having chemotherapy can sometimes affect your sex life. Side effects like tiredness or feeling sick or weak can reduce your sex drive and make having sex difficult. Feeling low or anxious can also affect your sex life. You might have worries about the cancer, how your family is coping or about money.

Usually, there is no medical reason to stop having sex during chemotherapy. But if you have low platelets or a low level of white blood cells, your doctor may advise you to avoid penetrative sex until your blood cell levels improve.

It can help to talk through any concerns about your sex life with your doctor or specialist nurse. They can often reassure you and support you with any problems. It is also important to try to talk about how you feel with your partner. Cuddling, touching and stroking are good ways of showing your feelings even if you do not feel like having sex.

Chemotherapy should not have a long-term effect on your sex life. The side effects usually gradually wear off after your treatment finishes.

We have information in our booklets **Cancer and your sex life – information for men** and **Cancer and your sex life – information for women** (see page 112).

Protecting your partner

If you have sex in the first few days of having chemotherapy, you need to use a condom. This is to protect your partner in case there is any chemotherapy in semen or vaginal fluid.

Cancer cannot be passed on to your partner and sex will not make the cancer worse.

Contraception

It is important to use effective contraception during chemotherapy and for a few months afterwards to avoid a pregnancy. This is because the chemotherapy drugs could harm a developing baby. Your cancer doctor or nurse can give you more advice.

During treatment, it is usually best to use barrier methods of contraception, such as condoms or the cap. Or you could use a coil (use a non-hormonal coil if you have breast cancer). Side effects from chemotherapy, such as sickness and diarrhoea, can make the contraceptive pill less effective.

Pregnancy and chemotherapy

If you know you are pregnant before starting treatment, or become pregnant during treatment, tell your cancer doctor or nurse straight away. They will talk things over carefully with you and your partner. They will explain the possible risks and benefits of having chemotherapy during pregnancy.

It is sometimes possible to delay chemotherapy until after a baby is born, or to have it later in the pregnancy. This depends on the type of cancer, its stage, the drugs you need, and how many months pregnant you are. Your cancer doctor and nurse will explain the different options in your situation.

This can be a difficult and distressing time, especially if you need to make decisions about continuing with the pregnancy. You will need time to think about the information you have been given and to talk about it with your partner and family. Your cancer team will help to support you. If you need more specialised help, they can refer you to a counsellor. You can also talk to our cancer support specialists on **0808 808 00 00**.

We have more information in our booklet **Cancer and pregnancy** (see page 112).

Breastfeeding and chemotherapy

Breastfeeding during chemotherapy is not advised. This is because the drugs could be passed to your baby through breast milk. You may be able to express extra milk before chemotherapy starts and freeze it to use later.

During chemotherapy, you may be able to express milk. You cannot keep or use it, but you may be able to express so you are still producing milk when your treatment finishes.

You may be able to start breastfeeding after chemotherapy. But this will depend on whether you are having any other treatment that could interfere with breastfeeding. Your cancer doctor and nurse will tell you about this.

Having chemotherapy will not affect your ability to breastfeed in the future.

Early menopause

In some women, chemotherapy causes an early menopause. This can cause menopausal symptoms like hot flushes, vaginal dryness, anxiety, mood swings and a reduced sex drive (libido). Your periods will stop and you'll start the menopause. Doctors usually say early menopause is before 45.

You may be able to have HRT to replace the hormones your ovaries are no longer producing. It can improve some symptoms of menopause and protect your bones and heart. Early menopause can increase the risk of bone thinning (osteoporosis).

But some cancers, for example breast cancer and womb cancer, depend on hormones to grow so your specialist may not advise HRT. For women with breast cancer we have a fact sheet about managing menopausal symptoms (see page 112).

If you've had early menopause because of chemotherapy, ask your cancer specialist if HRT is suitable for you.

Managing menopausal symptoms

If your doctor does not advise you to take HRT or if you do not want to take it, there are different ways that symptoms can be managed. If your symptoms are affecting your day-to-day life, ask your doctor about other medicines that may help with menopausal symptoms.

Low doses of anti-depressant drugs, or a drug called Clonidine (Catapres®, Dixarit®) which is used to control blood pressure, can reduce hot flushes and sweats. Some women find that using a slow, controlled breathing technique, yoga or acupuncture may help with flushes. Different lubricants or creams can help reduce discomfort from vaginal dryness during sex.

Effects on fertility

Unfortunately, some chemotherapy drugs can cause infertility. Infertility is the inability to become pregnant or to father a child. This may be temporary or permanent, depending on the treatment that you have.

It's important to discuss your infertility risk with your cancer doctor before you start chemotherapy. If you have a partner, it's a good idea to include them at this discussion.

Although chemotherapy can affect fertility, it's still possible for a woman to get pregnant or for a man to get his partner pregnant during chemotherapy. It's important to avoid pregnancy when you're having chemotherapy as the drugs could harm a developing baby.

Effects on women's fertility

Some, but not all, chemotherapy drugs may temporarily or permanently stop your ovaries producing eggs.

Chemotherapy may cause your periods to become irregular or stop for a while (temporary infertility). But after treatment stops the ovaries can start producing eggs again and your periods will return to normal. It may take a few months or up to 2 years for them to come back again. The younger you are, the more likely you are to have periods again and still be fertile after chemotherapy.

If your periods don't come back you won't be able to become pregnant and will have your menopause.

It's important to know if your fertility is likely to be affected before chemotherapy starts. You can then decide if you want to be referred to a fertility specialist. They can discuss possible options to help preserve your fertility, such as storing embryos (fertilised eggs) or eggs, with you.

We have a leaflet **Cancer treatment and fertility – information for women** (see page 112).

Effects on men's fertility

Some chemotherapy drugs have no effect on fertility, but others can slow down or stop you producing sperm. For most men this will be temporary. Any problems with sperm production will not stop you from getting an erection or enjoying sex.

Even if your chances of becoming infertile are low, you may still be advised to store sperm for use in the future. This has to be done before you start chemotherapy. Teenage boys at risk of infertility should also, if possible, have their sperm stored for later years.

You will usually be asked to produce several sperm samples over one or 2 weeks. These will be frozen and stored so they can be used later to try to fertilise an egg and make your partner pregnant.

It can take a few years for your sperm count to go back to normal after chemotherapy. Unfortunately in some men infertility is permanent. Your doctor can check your sperm count after treatment is over.

We have more information about this in our booklet **Cancer treatment and fertility - information for men** (see page 112).

Feelings about infertility

If you had been planning to have children, infertility can be very hard to come to terms with.

You may find it helpful to talk about your feelings with a trained counsellor or therapist who specialises in fertility problems. Your doctor or specialist nurse may be able to arrange this. You can contact the organisations on pages 117 to 121 for more information. Our cancer support specialists on **0808 808 00 00** can also provide support.

Late effects of chemotherapy

Some people may have late effects from chemotherapy. These are side effects you still have 6 months after chemotherapy, or side effects that begin years later. Late effects are not common, and any risk is outweighed by the benefits of chemotherapy.

Your cancer doctor or specialist nurse can explain any possible late effects of your chemotherapy treatment. Different drugs cause different late effects. Some drugs may cause:

- an early menopause (see page 80)
- infertility (see pages 81 to 83)
- peripheral neuropathy (for more information, visit our website at **macmillan.org.uk**)

Effects on the heart or lungs

Some chemotherapy drugs can increase the risk of heart or lung problems later in life. Your doctor can give you more information about this. There are things you can do to help improve your general health.

We have more information on how to improve your general health in our booklets **Healthy eating and cancer**, **Physical activity and cancer** and **Giving up smoking** (see page 112).

We have helpful tips on looking after your heart and how late effects can be monitored and managed in our booklet **Heart health and cancer treatment** (see page 112).

Second cancer

Some chemotherapy drugs can increase the risk of developing some types of cancer or leukaemia later in life. This is rare, and your doctors will consider the small increase in risk of this happening against the benefit of the chemotherapy in treating your cancer.

LIFE DURING CHEMOTHERAPY

Effects on everyday life

Many different areas of your life can be affected by cancer and its treatment. You might find you go through many different emotions. You might also find you need to take a break from work, and need support with your finances.

Even though chemotherapy treatment can cause unpleasant side effects, some people still manage to lead an almost normal life during treatment. But this depends on the type of chemotherapy you are having.

Even if you feel unwell after a cycle of chemotherapy, you might recover quickly. You may have time to do the things you usually do before your next cycle. Also, if you have symptoms that are caused by the cancer, your chemotherapy may make you feel better by relieving them.

Some people are able to go to work during treatment, but may take time off or work shorter hours.

> ‘Listen to your body, do as the professionals advise. Don’t try to be a superhero. Nobody expects you to be – they just want you to be mended.’
>
> **Kenny**

Social life

Depending on how you feel, there is no reason to stop going out or visiting friends if you plan ahead.

If you are going out for the evening, try to rest during the day so you have more energy at night. If you are going out for a meal, take anti-sickness tablets before you go if you need to.

If you have an important social event coming up, ask your cancer doctor if your treatment date can be changed so that you feel as well as possible for the occasion.

Alcohol

For most people, having the occasional drink should not affect your chemotherapy treatment. But it is best to check with your cancer doctor or specialist nurse first.

Vaccinations

Vaccinations can reduce your chance of getting certain infections. If you have had chemotherapy, you may not be able to have some vaccinations as your immune system may be weakened. These include live vaccinations, which use tiny amounts of a live virus or bacteria, such as:

- MMR (the triple vaccine for measles, mumps and rubella)
- BCG (tuberculosis)
- yellow fever
- oral typhoid
- shingles.

If you are going abroad during chemotherapy treatment, it is important to remember that you should not have any live travel vaccines. The vaccinations you may need will depend on where you are going. Before booking a trip, ask your doctor if you need any vaccines and whether it is safe for you to have them.

Holidays and travel insurance

If you are planning a holiday, it is important to speak to your cancer doctor or nurse before you make any plans. Sometimes, people who have cancer can find it difficult to get travel insurance. It is best to look for travel insurance as early as possible. Ideally, you should start looking before booking a holiday.

We have information about travelling and finding travel insurance in our booklet **Travel and cancer** (see page 112).


Portugal
Portugal
EUROPEAN UNION
UNITED KINGDOM OF GREAT BRITAIN AND NORTHERN IRELAND
PASSPORT
Havaianas

Your feelings

You may find that coping with cancer and chemotherapy can sometimes make you feel anxious, frightened or depressed.

Sometimes, these feelings can be caused by things like having to change your daily routine to fit in with chemotherapy. Or it may be something more obvious, such as a particular side effect or the risk of infertility. It is natural to have these feelings during your treatment.

Everyone needs support during difficult times, and having cancer is one of the most stressful situations you are likely to face. It is often helpful to talk about your feelings with your family or close friends.

> ‘As a mother of young children, I struggled when side effects took all my energy. It got a bit easier as I went through, but I was still in shock.’
>
> **Audrey**

You can also talk to your cancer doctor, specialist nurse or a social worker about how you are feeling. It is important to let them know if you are struggling, or if you think you may be depressed. They can arrange more support or refer you to a counsellor or doctor who specialises in emotional problems. They may also prescribe an anti-depressant or anti-anxiety drug for you.

There are things you can do which may make your course of chemotherapy treatment easier to cope with.

People often talk about having a positive attitude. This does not mean being cheerful and happy all the time. When you are coping with a serious illness, it is normal to feel worried and low sometimes. Accepting that you will have days when you do not feel positive is part of coping with cancer.

We have information about coping with your feelings and emotions in our booklet **How are you feeling?** (see page 112).

> ‘The worry when you’re diagnosed with cancer is that you will become a cancer patient and that will be your identity. But actually my friends and family have really made me feel that I am Kate and this is just part of who I am.’
>
> **Kate**

Finding information

Knowing more about the cancer and the side effects of your treatment may help you feel more in control. You may have questions about the effects of chemotherapy on the cancer and your life in general. Getting information and answers to these questions can help to reduce anxiety.

If you do not understand an explanation, keep asking questions until you do. Most doctors and nurses are very willing to answer any questions and to keep you up-to-date on your progress.

Keeping a journal or blog

You may find it helpful to keep a diary, journal or blog (online journal) of your treatment. This can have a practical use, as well as letting you express your feelings. If you record any side effects you have, this will help you to tell your doctor or nurse how things have been for you in between your appointments.

It will also help you to see how things change when different medicines are used. Changes to reduce side effects can often be made by using this kind of information.

You may find it encouraging to look back at your journal to see how you coped during previous difficult times. A private diary also allows you to write down things that you find difficult to talk about. Sometimes, it can be used to help you prepare to speak to someone about a problem. Or you can use it to describe anger or sadness that you feel you cannot express in any other way.

You can create your own blog, chat to people and watch videos on our Online Community (**community.macmillan.org.uk**).

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 and 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 cannot work because of illness or disability. There are different types of ESA:

- Contribution-based ESA may be available if you have paid enough National Insurance.
- Income-related ESA may be available if your income and savings are low, or if you cannot get contribution-based ESA. Income-related ESA is gradually being replaced by a new benefit called Universal Credit.

Personal Independence Payment

This benefit is for people aged between 16 and 64 who have problems moving around and looking after themselves. You must have had these difficulties for at least 3 months and expect them to last for at least 9 months.

Attendance Allowance

This benefit is for people aged 65 or over who have problems looking after themselves because of an illness or disability. This could mean getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months.

Special rules

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

Help for carers

Carer's Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you do not qualify for it, you can apply for Carer's Credit.

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

Macmillan Grants

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

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

How much you get will depend on your situation and needs. The average grant is around £400. A grant from Macmillan would not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

Insurance

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

If you are looking into buying insurance or making a claim, one of our financial advisers can help. Call **0808 808 00 00**.

We have more information in our booklets **Insurance** and **Travel and cancer** – see page 112 to order a copy. Our Online Community forum **Travel 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 experienced welfare rights advisers and financial guides. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice – see page 120.

Our booklet **Help with the cost of cancer** has lots more information – see page 112 to order a copy.

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 early on. 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 carry on 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 take on too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful (see page 112). There is also lots more information at **macmillan.org.uk/work**

Employment rights

If you have, or have ever had cancer, the law considers you to be disabled. This means you cannot be treated differently (less favourably) than other people at work because of cancer. If you are treated less favourably because of cancer, this is called discrimination.

The law also says your employer has to make reasonable adjustments (changes) to your workplace and their work practices.

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

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 112).

AFTER TREATMENT

Follow-up

After your chemotherapy has finished, you will have regular check-ups and possibly scans or x-rays. This will depend on the type of cancer and the treatments you have had.

Many people find they get very anxious before their appointments. This is natural. It may help to get support from family, friends or from a useful organisation during this time (see pages 117 to 121).

Follow-up appointments are a good opportunity to discuss any problems or worries you have. It may help to make a list of questions beforehand so you do not forget anything important.

If you have any problems, or notice any new symptoms in between your appointments, let your GP, specialist nurse or cancer doctor know as soon as possible. Do not wait until your next scheduled appointment – you can ask for an earlier one.

You may have your follow-up appointments at a nurse-led clinic and only see your cancer specialist if something needs to be checked further. Instead of routine appointments, some people are asked to contact their nurse or cancer specialist if there is anything they are worried about.

Beginning to recover

Coming to the end of your chemotherapy treatment can be a time of mixed emotions. You will probably feel relieved, but may feel anxious or uncertain about the future. Many people find that they feel very emotional at this time, when they had expected to be able to put the cancer and the treatment behind them.

It can take time to rebuild your confidence and to come to terms with what you have been through. It may also take time to recover from treatment. You may feel tired for a while and you might have emotional or physical changes to deal with. It is important to give yourself time to adjust.

You can ask your healthcare team about support or search for organisations or local support groups that may be able to help you.

We have more information about coping with your feelings in our booklet **Your feelings after cancer treatment** (see page 112).

How you can help yourself

When treatment is over, you may want to think about making changes to your lifestyle and find out more about healthy living.

Perhaps you already followed a healthy lifestyle before your treatment, but you may now want to focus more on making the most of your health. There are things you can do to help your body recover. These can also help improve your sense of well-being and lower your risk of getting other illnesses and other cancers.

What you can do

There are some things you can do that will help improve your health:

- Regular physical activity is good for your heart and lungs, and it keeps your bones healthy.
- Keeping to a healthy weight and eating healthily is good for your heart and bones.
- If you smoke, giving up is the best decision you can make for your health. Smoking is a major risk for heart and lung problems and also affects your bone health.

We have more information in the following booklets: **Physical activity and cancer**, **Heart health and cancer treatment**, **Giving up smoking**, **Healthy eating and cancer** and **Managing your weight after cancer treatment** (see page 112).

Complementary therapies

Complementary therapies can help improve people's quality of life and well-being. They can also sometimes help reduce the side effects of chemotherapy. Many people find complementary therapies can help them feel stronger and more able to deal with chemotherapy. Many of these therapies can be used safely alongside conventional treatments and medicines, but it is important to check the particular therapy with your doctor or nurse first.

You may want to try complementary therapies to help you feel less anxious, such as meditation or visualisation. Other therapies may also help, such as gentle massage. Some hospitals offer complementary therapies alongside conventional care. These may include massage, relaxation and aromatherapy.

We have more information in our booklet **Cancer and complementary therapies**, with information on how to contact registered practitioners (see page 112).

How other people can help

There may be times when you want to be alone with your thoughts. At other times, sharing your feelings can be a relief.

Support groups

Support groups can put you in touch with other people having similar treatment. Talking with other people can be a good way of discussing feelings, and you can also pick up some useful coping tips. Our cancer support specialists can give you details of your local support groups – call us on **0808 808 00 00**.

Our booklet **Talking about cancer** has more information (see page 112).

Family and friends

Family and friends often want to help you. But they may find it hard to understand exactly what you are going through. For example, you might feel your family and friends should be helping, but they may wait for you to make the first move. This is often because they are worried they may say the wrong thing, or they think you want to cope alone. They may also be feeling quite emotional themselves.

Good communication is really important. Try to be open and honest about how your treatment is going and how you feel about it. This will help your family and friends understand what is happening. It will also give them the chance to show their love and support.

Our booklet **Talking with someone who has cancer** is for family members and friends of people with cancer. It looks at the difficulties people may have when talking about cancer (see page 112).

> ‘People are afraid to talk about cancer, but that’s the worst thing. I’d rather have it out in the open, because that’s the only way people will become more comfortable.’
>
> **Kate**

FURTHER INFORMATION

About our information

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

Order what you need

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

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

Online information

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

Other formats

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

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

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

Help us improve our information

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

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

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

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

Our free, confidential phone line is open Monday to Friday, 9am to 8pm. Our cancer support specialists can:

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

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

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

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

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

Talk to others

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

Support groups

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

Online Community

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

The Macmillan healthcare team

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

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

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area.

Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

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

My Organiser app

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

Other useful organisations

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

Cancer support organisations

Cancer Black Care

Tel 020 8961 4151
Email
info@cancerblackcare.org.uk
www.cancerblackcare.org.uk
Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

Cancer Focus Northern Ireland

Helpline 0800 783 3339
(Mon to Fri, 9am to 1pm)
Email
nurseline@cancerfocusni.org
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

Cancer Research UK

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

Cancer Support Scotland

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

Daisy Network: Premature Menopause Support Group

Email
daisy@daisynetwork.org.uk
www.daisynetwork.org.uk
A support group for women who have early ovarian failure. They have information about premature menopause and related issues. Also a mailing list for subscribers and details of other helpful groups. Membership fee of £20 a year.

Look Good...Feel Better

Tel 01372 747 500
Email info@lgfb.co.uk
www.lookgoodfeelbetter.co.uk
Holds free skincare and makeup workshops to help with the visible side effects of cancer treatment and aims to boost confidence and well-being.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices
A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's Centres

Tel 0300 123 1801
Email
enquiries@maggiescentres.org
www.maggiescentres.org
Has a network of centres in various 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.

National Cancer Treatment Helpline (Scotland)

Helpline 0800 917 7711
A 24-hour national helpline for assessment and referral of patients feeling unwell after cancer treatment.

Penny Brohn UK

Helpline 0303 3000 118
(Mon to Fri, 9.30am to 5pm)
Email
helpline@pennybrohn.org.uk
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Riprap

www.riprap.org.uk
Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.

Tenovus

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

Financial or legal advice and information

Benefit Enquiry Line Northern Ireland

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

LGBT-specific support

LGBT Foundation

Tel 0345 330 3030
(Mon to Fri, 10am to 10pm, Sat, 10am to 6pm)
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.

Citizens Advice

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

England

Helpline 03444 111 444
www.citizensadvice.org.uk

Scotland

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

Wales

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

Northern Ireland

Helpline 0800 028 1181
www.citizensadvice.co.uk

Civil Legal Advice

Helpline 0345 345 4345
(Mon to Fri, 9am to 8pm, Sat, 9am to 12.30pm)
Minicom 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 isn't your first language.

Department for Work and Pensions (DWP)

Personal Independence Payment (PIP) Helpline
0345 850 3322
Textphone 0345 601 6677
(Mon to Fri, 8am to 6pm)
Carer's Allowance Unit
Tel 0345 608 4321
Textphone 0345 604 5312
(Mon to Thurs, 8.30am to 5pm, Fri, 8.30am to 4.30pm)
www.gov.uk/browse/benefits

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

GOV.UK

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

Personal Finance Society – 'Find an Adviser' service

www.thepfs.org/yourmoney/find-an-adviser
Use the website to find qualified financial advisers in your area of the UK.

Support for carers

Carers Trust

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

Carers UK

Helpline (England, Scotland, Wales)
0808 808 7777
(Mon to Wed, 10am to 4pm)
Helpline (Northern Ireland)
028 9043 9843
Email advice@carersuk.org
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with support groups for carers in their area.

Support for older people

Age UK

Helpline 0800 678 1174
(Daily, 8am to 7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

YOUR NOTES AND QUESTIONS

Your chemotherapy

Drug name	Dose	When do I take it?

Number of cycles planned: ______________________

Dates: ______________________

____

____

____

Treatment will be reviewed on: ______________________

How do I take it? (E.g. injection, liquid, tablet.)	Any special instructions? (E.g. with food/ empty stomach.)	Possible side effects

If there are any problems, contact:

In clinic hours: ______________________

At other times: ______________________

Tell the doctor or nurse:

- Your name ______________________
- Your hospital number ______________________
- Your diagnosis ______________________
- Your chemotherapy treatment ______________________
- Name of your cancer doctor ______________________

Questions you could ask about chemotherapy

Here are some questions that you may want to ask your cancer doctor or specialist nurse.

What are the contact telephone numbers I should use, and who do I contact if I have problems during the night?

How long will my whole course of chemotherapy take?

How many cycles of chemotherapy will I have?

Will I have to stay in hospital?

Can I have the treatment closer to home?

Will I need any tests before or after chemotherapy?

What are the likely side effects of the chemotherapy?

What can I do to help myself or prevent side effects?

Are there any long-term effects I should know about?

Will the chemotherapy drugs affect my fertility?

Any other questions you may have:

Disclaimer

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

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor, Dr Tim Iveson, Consultant Oncologist.

With thanks to: Wendy Anderson, Macmillan Nurse Consultant Chemotherapy; Claire Haslop, Clinical Nurse Specialist; Robin Jones, Clinical Oncologist; Jenny King, Chemotherapy Clinical Nurse Specialist; Catherine Loughran, Pharmacist; and Natalie Singer, Macmillan Advanced Haematology Clinical Nurse Specialist;

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

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

Sources

We have listed a sample of the sources used in the booklet below. If you would like further information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Brighton, D. Wood, M. The Royal Marsden Hospital handbook of cancer chemotherapy. Elsevier Churchill Livingstone. 2005.
Johnson, TM. Long-term care: safe drug handling of oral chemotherapy. The Consultant Pharmacist, Vol. 32 (p. 74-83). 2017.
National Institute for Health and Care Excellence (NICE). Neutropenic sepsis guideline CG151. 2012.
National Institute for Health and Care Excellence (NICE). Venous thromboembolism in adults: diagnosis and management Quality standard [QS29]. 2013.
Perry, MC. The chemotherapy source book (5th ed.). Philadelphia: Lippincott, Williams & Wilkins. 2012.
Scottish Intercollegiate Guidelines Network (SIGN). Long term follow up of survivors of childhood cancer. SIGN guideline. 132. 2013.

Can you do something to help?

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

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

5 WAYS YOU CAN HELP SOMEONE WITH CANCER

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

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

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

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

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

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Email

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I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

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

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

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

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

27530

This booklet is about chemotherapy. It is for anyone who is having chemotherapy or has been offered it as part of their cancer treatment. There is also information for carers, family members and friends.

The booklet explains what chemotherapy is, how it is given and possible side effects. It also has information about emotional, practical and financial issues.

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm, or visit **macmillan.org.uk**

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

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

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